LIFESTYLE PERSPECTIVES OF PERSONS WITH DISABILITIES
IN A PERSON-CENTERED SUPPORT PARADIGM

by

PAUL HECTOR MALETTE

B. Comm., University of Windsor, 1979
M.A., University of British Columbia, 1991

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF EDUCATION

in

THE FACULTY OF GRADUATE STUDIES

(Department of Educational Psychology and Special Education)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

September 1996

© Paul Hector Malette 1996
In presenting this thesis in partial fulfilment of the requirements for an advanced
degree at the University of British Columbia, I agree that the Library shall make it
freely available for reference and study. I further agree that permission for extensive
copying of this thesis for scholarly purposes may be granted by the head of my
department or by his or her representatives. It is understood that copying or
publication of this thesis for financial gain shall not be allowed without my written
permission.

Department of Educational Psychology and Special Education

The University of British Columbia
Vancouver, Canada

Date Sept 27, 1996
LIST OF TABLES

Table 1: Nature of Data Collected........................................................................................................44
Table 2: Lisa’s Activity Schedule (March 1996)..................................................................................149
Table 3: Responsive Support Characteristics of Victory Housing and CSB ...........................211
ABSTRACT

This study is a qualitative investigation of a person-centered support option called micro boards. A micro board is a small non profit society comprised of family and friends who assist persons with disabilities to develop individualized housing and support options. Defining features of the micro board project include direct funding to individuals with disabilities to secure housing and support options, freedom to choose where and with whom to live, and autonomy in hiring and defining the nature of personal care and support.

Three persons with severe disabilities were the primary focus of this study. These individuals required extensive supports in all aspects of daily living including feeding, dressing, and mobility. They resided in three separate subsidized or cooperative living arrangements in a large urban centre in the Province of British Columbia. Two organizations central to the micro board project were also a focus of study.

The study period was eighteen months. Qualitative techniques were employed to collect and analyze data regarding lifestyle quality in the micro board project, and organizational assumptions and characteristics inherent in this support paradigm.

Results indicated that all three participants with disabilities experienced positive lifestyle gains as a result of the micro board project. Direct funding and the freedom to choose accommodation and individualized support structures were identified as axial to lifestyle quality. Participants also experienced increased community participation and expanding networks of social support as a result of the micro board project.

An analysis of the characteristics and themes embedded in the multiple case studies identified five responsive organizational characteristics which contributed to the
development of the micro board project, and assisted in the achievement of a quality life in the community for the three participants in this study: willingness to change; inclusion of persons with disabilities and their families in organizational policy; small, flexible support structures; collaborative planning; and a holistic view of support grounded in social justice.

These results are discussed in relation to previous research done in this area. Inferences are made about how factors such as lifestyle planning, empowerment, personal perceptions of disability, and responsive support systems influenced lifestyle quality. Parallels are drawn to related health care fields, and a restructuring of disability support is explored. Limitations of the research are identified, and potential areas for further research are suggested.

Advisor

Sally Rogow
TABLE OF CONTENTS

ABSTRACT ................................................................................................................................. ii
TABLE OF CONTENTS ........................................................................................................ iv
LIST OF TABLES ................................................................................................................... viii
LIST OF FIGURES ................................................................................................................ ix

CHAPTER I: INTRODUCTION .............................................................................................. 1
  Background of the Problem ............................................................................................... 1
  Statement of the Problem ............................................................................................... 4
  Rationale .......................................................................................................................... 4
  Purpose of the Study ....................................................................................................... 5
  Definition of Terms ......................................................................................................... 5

CHAPTER II: REVIEW OF THE LITERATURE .................................................................. 7
  Segregation and Institutionalization (1950s-1960s) ......................................................... 7
  Deinstitutionalization and the Least Restrictive Environment (LRE) (1970s-1980s) ... 8
    Validation Research: Institutional vs. Community Living .......................................... 10
    Lifestyle Outcomes in the Continuum Model ................................................................. 12
    Planning Procedures and Assumptions in the Continuum Model ............................... 15
    The Emergence of Lifestyle Planning Procedures ....................................................... 16
  Full Inclusion and Person-Centered Supports; Real Jobs and Real Homes ................. 21
    Key Service Elements of a Person-Centered Approach ............................................... 21
    Organizational Characteristics Associated with a Person-Centered Paradigm ........... 23
    Personal Perspectives of Person-Centered Supports ................................................... 25
  Summary of Review ......................................................................................................... 28

CHAPTER III: THE PRESENT STUDY ............................................................................. 31
  Statement of the Problem ............................................................................................... 31
  The Ethnographic Context of the Study ........................................................................... 34
    Setting ........................................................................................................................... 34
    Selection of Participants ............................................................................................. 35
    Jason ............................................................................................................................. 36
    Lisa ............................................................................................................................... 37
    Sarah .............................................................................................................................. 38
  Research Methodology and Design .............................................................................. 40
    Data Gathering and Theoretical Framework ............................................................... 41
    Participant Observation ............................................................................................... 43
    Interviews .................................................................................................................... 45
    Permanent Products ................................................................................................... 46
    Data Analysis and Validity .......................................................................................... 47
    Validation ..................................................................................................................... 47
TABLE OF CONTENTS, Continued:

CHAPTER IV: THE CHANGING ROLE OF THE VICTORY HOUSING SOCIETY .............................................. 49
  Introduction ........................................................................................................................................ 49
  The Role of Victory Housing ............................................................................................................. 50
  Examining Values and Organizational Change .................................................................................. 51
  Evolution of the Micro Board Concept .............................................................................................. 53
  Defining Characteristics of Victory Housing ...................................................................................... 56
  Summary ........................................................................................................................................... 72

CHAPTER V: "GRASS ROOTS DEVELOPMENT": THE COMMUNITY SERVICES BRANCH MINISTRY OF HEALTH ......................................................................................................................... 74
  Introduction ........................................................................................................................................ 74
  Organizational Description .................................................................................................................. 74
  History ............................................................................................................................................. 75
  Defining Characteristics of CSB .......................................................................................................... 76
  The Micro Board Pilot Project ............................................................................................................ 79
  Summary ........................................................................................................................................... 85

CHAPTER VI: "WELL BEING" JASON'S STORY ................................................................. 87
  Personal Profile ................................................................................................................................. 87
  Jason’s Personal History .................................................................................................................... 89
    Family Life ..................................................................................................................................... 89
    Introduction to the Handicapped Continuum in Education ............................................................. 90
    The Continuum Model of Adult Services: Living the Handicapped Culture .................................. 94
    Breaking Free of the Continuum .................................................................................................... 96
  Jason’s Apartment and Neighborhood ............................................................................................... 101
  Jason’s Support Network .................................................................................................................. 103
  Merging of Formal and Informal Support Structures ........................................................................ 117
  Quality of Life .................................................................................................................................. 119
    Choice .......................................................................................................................................... 120
    Competence ................................................................................................................................... 122
    Community Participation and Community Presence ...................................................................... 122

CHAPTER VII: “CHANGE” LISA'S STORY ................................................................. 125
  Personal Profile ................................................................................................................................. 125
  Lisa’s Personal History ...................................................................................................................... 127
    Family Life ................................................................................................................................... 127
    Introduction to the Handicapped Continuum of Education and the Residential
    Continuum ..................................................................................................................................... 129
    Breaking Free of the Handicapped Continuum ............................................................................. 132
  Lisa’s Home and Neighborhood (January, 1996) ............................................................................. 140
  Present Support Situation .................................................................................................................. 141
TABLE OF CONTENTS, Continued:

<table>
<thead>
<tr>
<th>Chapter Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifestyle</td>
<td>148</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>154</td>
</tr>
<tr>
<td>CHAPTER VIII: “IT’S ABOUT RELATIONSHIPS” SARAH</td>
<td>159</td>
</tr>
<tr>
<td>Personal Profile</td>
<td>159</td>
</tr>
<tr>
<td>Personal History</td>
<td>161</td>
</tr>
<tr>
<td>Family Life</td>
<td>161</td>
</tr>
<tr>
<td>The Handicapped Continuum of Education</td>
<td>162</td>
</tr>
<tr>
<td>Entering the Continuum of Residential Services</td>
<td>165</td>
</tr>
<tr>
<td>Life in a Hospital</td>
<td>166</td>
</tr>
<tr>
<td>Return Home</td>
<td>167</td>
</tr>
<tr>
<td>Sarah’s Present Situation</td>
<td>177</td>
</tr>
<tr>
<td>Sarah’s Formal Support Network</td>
<td>188</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>192</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>200</td>
</tr>
<tr>
<td>Community Presence</td>
<td>201</td>
</tr>
<tr>
<td>Respect</td>
<td>201</td>
</tr>
<tr>
<td>Competence</td>
<td>202</td>
</tr>
<tr>
<td>Community Presence</td>
<td>202</td>
</tr>
<tr>
<td>Choice</td>
<td>204</td>
</tr>
<tr>
<td>Conclusions</td>
<td>204</td>
</tr>
<tr>
<td>CHAPTER IX: PEOPLE AND ORGANIZATIONS</td>
<td>206</td>
</tr>
<tr>
<td>Enabling Organizational Characteristics</td>
<td>206</td>
</tr>
<tr>
<td>Willingness to Change</td>
<td>207</td>
</tr>
<tr>
<td>Strong Value Base and Philosophy Statement Developed with</td>
<td>207</td>
</tr>
<tr>
<td>Persons with Disabilities and their Families</td>
<td>207</td>
</tr>
<tr>
<td>Small, Flexible, and Creative Support Structures based on Personal Need,</td>
<td>208</td>
</tr>
<tr>
<td>Rather than Organizational Policy and Procedures:</td>
<td>208</td>
</tr>
<tr>
<td>Collaborative, Non Hierarchical Planning and Implementation Strategies</td>
<td>210</td>
</tr>
<tr>
<td>Social Justice and Equality</td>
<td>210</td>
</tr>
<tr>
<td>Personal Characteristics and Family Support</td>
<td>212</td>
</tr>
<tr>
<td>Freedom to Choose Accommodation and Formal Support Structure</td>
<td>214</td>
</tr>
<tr>
<td>Choice</td>
<td>219</td>
</tr>
<tr>
<td>Respect</td>
<td>220</td>
</tr>
<tr>
<td>Competence</td>
<td>220</td>
</tr>
<tr>
<td>Community Presence and Participation</td>
<td>220</td>
</tr>
<tr>
<td>Limitations</td>
<td>221</td>
</tr>
</tbody>
</table>
TABLE OF CONTENTS, Continued:

<table>
<thead>
<tr>
<th>Chapter/Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHAPTER X: DISCUSSION</td>
<td>224</td>
</tr>
<tr>
<td>The Disability System and Persons with Severe Disabilities</td>
<td>224</td>
</tr>
<tr>
<td>The Nature of Disability</td>
<td>225</td>
</tr>
<tr>
<td>Support Structures</td>
<td>226</td>
</tr>
<tr>
<td>Lifestyle Planning Tools</td>
<td>230</td>
</tr>
<tr>
<td>The Nature of Organizations in a Person Centered Paradigm</td>
<td>231</td>
</tr>
<tr>
<td>People, Relationships, and Community</td>
<td>234</td>
</tr>
<tr>
<td>Implications for Future Research</td>
<td>237</td>
</tr>
<tr>
<td>Conclusion</td>
<td>238</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>240</td>
</tr>
<tr>
<td>APPENDICES</td>
<td>255</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>The Residential Continuum</td>
<td>9</td>
</tr>
<tr>
<td>Figure 2</td>
<td>Continuum Model of Supports vs. Person Centered Paradigm</td>
<td>29</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Organizational and Support Framework of the Study's Three Micro Boards</td>
<td>41</td>
</tr>
<tr>
<td>Figure 4</td>
<td>Jason's Support Network</td>
<td>104</td>
</tr>
<tr>
<td>Figure 5</td>
<td>Lisa's Support Network</td>
<td>144</td>
</tr>
</tbody>
</table>
To my father, who taught me about family, relationships, and strength in the face of adversity. Claude, Je me souviens.
ACKNOWLEDGMENTS

The author wishes to express his sincere appreciation to the participants in this study for welcoming me into their world and sharing their stories. I also wish to thank my thesis committee members, Dr. Allison and Dr. McKellin for their assistance in preparing this manuscript. I am particularly grateful to my advisor, Dr. Rogow. Thank you Sally for being a friend and mentor. Finally, my love and thanks to Alicia for her patience, encouragement, and personal sacrifice. I promise I will put the computer away for awhile.
CHAPTER I
INTRODUCTION

Background of the Problem

The principle of normalization proposed by Wolfensberger (1972) substantively influenced where persons with disabilities should live, learn, work, and recreate. The principle of normalization is defined as: “Utilization of means which are as culturally normative as possible, in order to establish and or maintain personal characteristics which are as culturally normative as possible” (p. 28). This principle, combined with the efforts of others such as Blatt (1969), Dunn (1968), Dybwad (1964), and Lilly (1970), led to widespread objection to segregated placements such as institutions, special schools, and special classes (Stainback, Stainback & Bunch, 1989, p.8).

However, persons with severe disabilities did not leave institutions to live and work with the nondisabled population. An intermediate step developed in the late 1960s and early 1970s described as the Least Restrictive Environment (LRE) was introduced. The LRE principle interpreted normalization to mean the maximum integration feasible. The LRE implied that some individuals were in need of restrictive placements, and could not, or were not ready to live and work in the general community.

The LRE principle is defined in terms of a continuum consisting of an ordered sequence of placements that vary according to degree of restrictiveness. The residential continuum of services is typically represented as a straight line running from the most to the least restrictive alternative. The most restrictive placements are also the most segregated within this continuum model (Taylor, 1988; Hitzing, 1980; Schalock, 1983).
The primary assumptions of the continuum model are: (1) every person with a developmental disability can be located somewhere along this continuum based on the severity of their disability; (2) if and when a person develops additional requisite skills, he or she can move to a less restrictive placement, or may be required to move to a more restrictive placement if problems occur; (3) housing options are generally owned and operated by human service agencies rather than people with disabilities; (4) these facilities tend to have licensing restrictions not typically found in "regular homes" in the community; and (5) housing is linked to a particular service (e.g. different types of residential facilities offer varying degrees of service, such as behavior management, life skills emphasis, etc.); (Racino, Walker, Oconnor & Taylor, 1993, p.1). This continuum model is the structural and procedural framework for service design in several, diverse human service fields, including mental health (Randolph, Laux, & Carling, 1987; Shoultz, 1988), developmental disabilities, and aging (Gelfand, 1988; Hoggs & Moss, 1990).

Research and practice during the past twenty five years have evolved from the continuum and facility based service models. Research has focused on facilities such as community residences, group homes, intermediate care facilities (ICFs/MR), and semi-independent apartment living programs. The predominant focus of study has been group home living. Group homes have been studied according to a myriad of variables; such as size (Baroff, 1980; Landesman-Dwyer, 1981; Landesman-Dwyer, Berkson, & Romer, 1979); normalization and quality of life factors (Eyman, Demaine, & Lei, 1979; Hill, Rotegard, & Bruininks, 1984); staff attitudes and practices (Lakin, Bruininks, & Hill, 1986); and changes in adaptive and maladaptive behavior after placement from institutions (Conroy & Bradley, 1985; Gollay, Freedman, Wyngarrden, & Kurtz, 1978; Seltzer, 1981). Further, a considerable
volume of literature has emerged on the financing, administration (Gelman, 1988; Janicki, Mayeda, & Epple, 1983), and staffing (George & Baumeister, 1981; Jacobson & Janicki, 1984; Levy, Levy, Freeman, Feinman, & Samowitz, 1988) of community residential facilities (Racino et al., 1993; Nisbet, Clark, & Covert, 1991).

As noted by Taylor (1988), the LRE principle was forward looking for its time. Prior to the continuum model, persons with severe disabilities were excluded from schools, were warehoused in institutions, or were offered no services at all. The continuum model provided the framework for most research studies in the 1970s. However, in the 1980s, the assumptions of the continuum model were questioned (Galloway, 1980; Hitzing, 1987; Taylor, 1988; Taylor, Racino, Knoll, & Lutfiyya, 1987). Taylor (1988) illustrated that the continuum model is characterized by conceptual and programmatic flaws as it sanctions infringements on people's rights, supports the primacy of professional decision making, and directs attention to physical settings rather than the services and supports that people need to be included in their communities.

Today, the disability field is moving away from the continuum model of residential facilities to more flexible and individualized approaches referred to as "non facility based," "person-centered," or a "housing and support" approach for adults (Racino et al., 1993 p.3).

Community living for persons with disabilities is rapidly changing, and encompasses the following key principles and assumptions (Racino et al., 1993).

1. Everyone needs and deserves a home.
2. Housing should be based on an individual's choice and preferences.
3. The provision of services should be dictated by an individual's needs and circumstances, not by a facility or program.
4. Needed services should be provided regardless of where an individual may live.

5. Adequate supports should be available to allow individuals to live in integrated, individualized housing situations (Covert, 1990; Ostroff & Racino, 1991).

Statement of the Problem

Although the disability field is beginning to examine creative housing and support approaches for persons with disabilities, there has been very little research on these emerging practices. Both in research and practice, the disability field is just beginning to examine these new strategies to see how or if they have a positive impact on the lives of people with disabilities (Racino et al., 1993, p.5)

To date, quantitative, cross condition analyses and analyses of community placement variables have dominated the research agenda. Nisbet et al. (1991) suggest that; as the field of disabilities moves closer to the goals and values of full community inclusion and equal rights for persons with disabilities, research agendas need to shift from comparative perspectives to ones that are life enhancing and descriptive, focusing on the experiences of people with disabilities regarding communities, social networks, empowerment, and facilitative relationships (Nisbet et al., 1991, p.137).

Rationale

The state of the art in community living represents a radical departure from facility based models. A myriad of new variables and research questions have emerged. As Nisbet et al. (1991) suggest, the move to more inclusive supports for people with disabilities requires research methodologies which attempt to understand life in the community from the perspective of persons with disabilities, and to capture their impressions of lifestyle quality. In the context of inclusive supports for persons with disabilities, ethnographic research
strategies such as interviews and participant observation techniques (Bogdan & Biklen, 1982) are needed (Nisbet et al., 1991).

Knoll & Olsen (1988) provided the following cogent rationale for qualitative studies in inclusive settings: “A qualitative study can contribute an analysis of how people interact with the community, how staff relate to people in this type of setting, and of issues in individualized planning which can inform any effort to assure that people with severe disabilities are being integrated into the community” (Knoll & Olsen, 1988, p.14).

**Purpose of the Study**

The purpose of this study is three fold: (1) to identify defining characteristics and assumptions of an innovative housing and support concept known as micro boards; (2) to identify from the perspectives of three persons with severe disabilities, important quality of life factors inherent to their micro board situations; and (3) to identify formal and informal supports associated with micro boards that encourage and foster and/or discourage and hinder the quality of life of the studies three participants.

**Definition of Terms**

Persons with severe disabilities: These people include individuals of all ages who require extensive ongoing support in more than one major life activity in order to participate in integrated community settings, and to enjoy a quality of life that is available to citizens with fewer or no disabilities. Support may be required for life activities such as mobility, communication, self-care, and learning as necessary for independent living, employment, and self-sufficiency. (Document 1.1, Definition of the People TASH serves, Revised November 1986 in Meyer, L.; Peck C.A., & Brown, L.,1991).
Micro boards: “A micro board is a small group of committed family and friends that join together with a person to create a small non profit society that will address the person’s support needs in an empowering and customized fashion” (Victory Housing Society, 1990).

Formal Supports: Formal supports include schools, training programs, employment services, hospitals, and other agencies with staff who are paid to monitor and support a persons well being (O’Brien, 1987).

Informal Supports: include family members, friends, neighbors, and fellow members of church and other voluntary associations to which a person belongs (O’Brien, 1987).

Well Connected: Well connected is a term used to describe persons who are participating members of their community, and who have a mix of family, friends, community members, and paid supports comprising their social networks.
CHAPTER II
REVIEW OF THE LITERATURE

This review examines the evolution of person-centered housing options for persons with severe disabilities. Historically, residential options for these individuals have been tied to the values, assumptions, and empiricism of the disability field and society in general. During the past four decades, three distinct social policy directions can be identified which have influenced housing and support options for persons with severe disabilities: (1) segregation and institutionalization; (2) deinstitutionalization and the Least Restrictive Environment (LRE); and (3) full inclusion and person-centered supports; "real jobs" and "real homes."

Each policy direction has a set of values and assumptions which effect research and practice. Nisbet et al. (1991), and Racino et al. (1993), have provided the field with authoritative analyses of community living for persons with severe disabilities. Their historical perspectives form the basis of this review. Salient research associated with each policy direction is examined, and specific implications for person-centered housing and support are illustrated.

Segregation and Institutionalization (1950s-1960s)

In North America, during the 1950s and 1960s, disability was largely considered a medical problem and a medical condition. The language and labels present in the literature reflect the values and assumptions of the time. Persons with severe disabilities were labeled cripples, shut ins, retardates, imbeciles, vegetables, autistics, and mongoloids.
The prevailing assumptions of the institutionalization era were that persons with disabilities were uneducable and needed to be protected from society. Also, it was assumed that society needed to be protected from persons with disabilities, as they were purported to possess criminal tendencies because of their genetic makeup (Davies, 1930).

In the 1950s and 1960s, the primary housing option for persons with severe disabilities was large state run institutions (White, Lakin, Hill, Wright, & Bruininks, 1988; Stainback et al., 1989). Blatt and Kaplan (1966) published a now famous photographic essay on institutions for the “mentally retarded.” This essay chronicled atrocious conditions at these facilities. They found dehumanizing staff attitudes, appalling living conditions, and lives of misery and pain. Other researchers examined state institutions and found similar conditions. They characterized the worst facilities as barren, unsanitary, and abusive. The “best” institutions were characterized as impersonal, regimented, and intrusive (Bogdan & Taylor, 1982; Taylor, 1978; Wolfensberger, 1975).

In the late 1960s and early 1970s, it became evident that the values and assumptions driving segregation and institutions were untenable. Further, persons with disabilities did not need to be protected from society, as they were more likely to be abused in state run institutions than in the general community. Lastly, more and more educators were demonstrating increasing success in providing educative programs for persons with severe disabilities previously labeled “uneducable” (Dussault, 1989).

**Deinstitutionalization and the Least Restrictive Environment (LRE) (1970s-1980s)**

In the early 1970s, a process of deinstitutionalization began as the public realized that institutional residences for persons with severe disabilities were barbarous and dehumanizing (Nisbet et al., 1991). The principle of normalization (Wolfensberger, 1972) guided the
integration of people with severe disabilities into communities that they were once excluded from. However, families, legislators, researchers, and service agencies struggled with the interpretation of normalization, and the design of supports for people with disabilities.

The wisdom of the time was that small group homes of six or eight people could, through decorating and arranging, be like all of the other houses in the community; in essence a home (Nisbet et al., 1991, p.115). Group homes did not, however, constitute the only residential options for persons with disabilities. Given that the disability population consisted of persons with severe, moderate, and mild disabilities, a continuum of residential services called the LRE was deemed to be most appropriate.

The residential continuum of services is frequently represented as a straight line running from the most to the least restrictive placements (see Figure 1) (Hitzing, 1980; Schalock, 1983). The most restrictive settings, which are also the most segregated, are

<table>
<thead>
<tr>
<th>Nursing Homes and Private Institutions</th>
<th>Group Homes</th>
<th>Semi-Independent Living</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Institution</td>
<td>Community ICFs/MR</td>
<td>Foster Care</td>
</tr>
</tbody>
</table>

Figure 1
The Residential Continuum

intended to provide the most intensive services, and typically have access to the greatest financial resources. The least restrictive settings, which are the most integrated, provide the least intensive services and usually have access to the least financial resources. Within the continuum model, persons with severe disabilities tend to be placed in the most restrictive
settings and persons with mild disabilities tend to be placed in the least restrictive settings 
(Nisbet et al., 1991; Racino et al., 1993)

Although specific steps in the continuum vary in different provinces and states 
throughout Canada and the United States, the continuum model as practiced in North 
America is based on the following assumptions:

(1) community living arrangements are generally agency 
owned, operated, and/or licensed facilities; (2) housing and 
services are linked together (e.g., different types of facilities 
offer varying degrees of services); (3) people with disabilities 
are expected to make the transition to less restrictive settings or 
placements as they acquire additional skills, or to move to more 
restrictive settings if “problems” occur; and (4) perceived 
severity of a disability determines the type of facility in which 
an individual will be placed (Racino et al., 1993, p.1).

The continuum model created a hierarchy of placements based on the notion that 
some people were not ready for, or could not lead regular lives in homes of their choosing in 
the community. Integration was conditional within the continuum model. Despite a tenuous 
set of inferences, and a lack of empirical evidence to support the efficacy of the continuum, 
massive new bureaucracies and a new disability culture were created within mainstream 
society in the early 1970s. It was assumed that the continuum model would effectively 
integrate persons with disabilities into the general community.

Validation Research: Institutional vs. Community Living

Nisbet et al. (1991) illustrated that the primary research agenda in the 1970s and early 
1980s was to validate the success of small- group living arrangements in comparison to the 
dehumanizing institutions for persons with severe disabilities. Predominant research 
variables included “size, resident composition, location, staff training, cost, property values, 
neighborhood responses, and ‘client’ interactions and progress” (Nisbet et al., 1991, p.115).
Cost was a dominant issue in the era of deinstitutionalization and community living. Numerous studies were conducted that compared the costs of community residential facilities (Baker, Seltzer, & Seltzer, 1977; Heal & Daniels, 1978; O'Connor, 1976; O'Connor & Morris, 1978; Templeman, Gage, & Fredericks, 1982). Similarly, studies were conducted that compared the cost of public institutions with that of community residential facilities (Mayeda & Wai, 1975; Minnesota Developmental Disabilities Planning, 1982; Nihira, 1979; Wieck & Bruininks, 1980). In all of these studies, the cost of community living arrangements was less than the cost of institutional care (Nisbet et al., 1991, p. 121).

Changes in skill development and adaptive behavior as a result of deinstitutionalization were other areas that dominated the research agenda. Conroy and Bradley (1985) conducted a longitudinal study that measured numerous variables including the change in skill acquisition and adaptive behavior of residents as a result of community versus institutional placement. Individuals who left the institution were placed in community living arrangements (CLAs) that housed an average of three people, and typically no more than six. Adaptive behavioral data were collected on 176 people who resided at the institution from 1978 to 1980, and who then lived in CLAs in 1983 and 1984. While in the institution, the individuals demonstrated no gains in adaptive behavior, whereas there was a significant increase in adaptive behavior after placement in the community (Nisbet et al., 1991, p. 119).

Sokol-Kessler, Conroy, Feinstein, Lemanowicz, and McGurin (1983) collected behavioral data on 713 residents of public institutions in 1978 and 1980. The same data were collected on individuals living in the community. These individuals were matched on adaptive behavior measures. Residents of institutions made no significant developmental
progress over a 2-year period. Conversely, individuals residing in the community made significant progress in the reduction of maladaptive behavior (Nisbet et al., 1991, p.119).

Larson and Lakin (1989) examined 16 studies of persons with disabilities who had left institutions and were living in community residences which housed fewer than 15 people. All of the studies reported improvement in adaptive skills as a result of living in the community. Thirteen studies reported significant improvement in adaptive skills, or improvement in the self-care/domestic domain (Nisbet et al., 1991, p.123).

The continuum model was increasingly scrutinized with evidence that persons with the most severe disabilities could successfully be placed in the community; its values, assumptions, and procedures were examined regarding lifestyle outcomes for the individuals served.

**Lifestyle Outcomes in the Continuum Model**

Wolfensberger (1980) argued that most human services do not support desirable futures for people who depend on them. He asserted that the continuum model often mirrors the unconscious patterns of devaluation in the community, and services within the continuum create layers of devaluing messages--images and symbols which reinforce cultural stereotypes and dehumanizing roles for people with handicaps (Mount, 1987).

Flynn (1980) used the “Program Analysis of Service Systems” (PASS) evaluation tool designed by Wolfensberger (1975) to assess programs throughout the United States, and found persons with disabilities were physically and socially isolated. He further found that many persons with disabilities were subjected to dehumanizing conditions and humiliating processes, such as behavior modification programs that primarily relied on aversive methods of control. Other observers also found that many services promote existing patterns of
segregation, devaluation, and stigmatization, often contributing to the problem instead of improving the lives of persons with disabilities in the larger community (Mount, 1987).

Kishi, Teelucksingh, Zollers, Park-Lee, and Meyer (1988) conducted a life-choice survey and used a protocol developed by Meyer, St. Peter, and Park-Lee (1986). Forty-two adults without mental handicaps and twenty-four adults with mental handicaps participated in the study. They found that persons living in group homes generally lacked choices about essential matters of living when compared to their nondisabled peers, and persons identified as the most handicapped in each home had more limited choices than did those ranked as the least handicapped (Nisbet et al., 1991, p. 125).

Kendrick (1987) examined and compared the social lives of people living in group homes and people living in supported apartments. Interviews, observations, and examinations of the daily schedules of the residents were conducted. He reported that persons in supported living arrangements were more isolated and participated less frequently in community activities than did persons living in group homes. The study illustrated that setting alone, independent of other factors such as friendship, supports, and location, does not facilitate community integration and positive lifestyles for persons with disabilities. (Nisbet et al., 1991, p. 127).

The nature of staff roles, interactions, and relationships in the continuum was also studied. Bercovici (1981) found that residential staff discouraged persons with disabilities from maintaining relationships with friends. Janicki (1981) observed that staff members typically interacted with residents in oppositional ways that controlled their behavior. Staff in general lacked sufficient training and were unclear of their roles (Backus, 1983), (Nisbet et al., 1991, p. 126).
Bellamy, Rhodes, Bourbeau, and Mank (1982) studied the outcomes of traditional day service programs that are based on a four step sheltered workshop continuum. This traditional continuum includes three segregated environments (a day activity center, a work activity center, a sheltered workshop and a non-segregated environment in competitive employment). The assumption is that a person will matriculate through the continuum to competitive employment. The study concluded that persons with disabilities do not matriculate through the continuum to competitive employment. At the current rate of progress, people with disabilities would actually require 47 to 56 years to move through the continuum to competitive employment. Contrary to the explicit matriculation assumption of the continuum model, the longer a person stays in such programs, the fewer the chances of obtaining a job in the competitive sector. Braddock, Hemp, and Fujiura (1986) confirmed that persons with severe disabilities are similarly trapped in the most restrictive ends of the residential continuum. These authors illustrated that the readiness notion which girds the continuum does not support the goals of integration for persons with disabilities.

Taylor (1988) found that the continuum model constitutes a “readiness trap,” and is rife with philosophical and empirical flaws. He characterized these flaws as: (1) The continuum legitimates restrictive environments and confuses segregation and integration with the intensity of services needed to support a person with disabilities; (2) The continuum model supports the primacy of professional decision making, and sanctions infringements on people’s rights as they must show “readiness” to live in less restrictive settings and gain greater autonomy in their lives; and (3) the model directs attention to physical settings rather than to services and supports that are required for integration.
As the assumptions and practices of the continuum were examined, so were the
assumptions and practices of planning processes associated with the continuum model.
Concepts such as full inclusion, community presence, participation and choice making were

Planning Procedures and Assumptions in the Continuum Model

Mount (1987) investigated the values, assumptions, procedures, and efficacy of the
Individual Program Plan (IPP), and its relationship to the structure and assumptions of the
continuum model. The IPP is the primary planning tool used to develop services and
residential and vocational placements for persons with disabilities within the continuum
model. She noted four major components of the IPP process: (a) assessment, (b) planning, (c)
delivery of services, and (d) evaluation of services by an interdisciplinary team. In her
evaluation, she identified a number of areas in the IPP process which did not lead to fulfilled
and meaningful lifestyles for persons with disabilities.

The IPP focuses on the deficits of an individual, and planning is centered on the
amelioration of these deficits (Hammill & Bartel, 1975; Salvia & Ysseldyke, 1985). These
deficits are identified by assessments which employ standardized tests supporting the primacy
of professional decision making (Gardner, 1980; Mount, 1987). The interdisciplinary make
up of the team, and the primacy of professional decision making, tends to result in poorly
coordinated plans, and isolated services (Gardner, 1980). Hermary (1987) reported that there
was confusion and lack of communication among and between family members, staff, and
professionals working on IPP teams regarding individual roles and responsibility.

Mount (1987) organized the assumptions of the IPP process into three categories: (1)
locus of the problem, (2) desirable outcomes, (3) decision making and the role of the expert.
She concluded that the IPP is a blueprint planning tool designed to fit environments, service systems, and people which are stable, predictable, and under the control of some authority.

The assumption that the locus of the problem rests with the individual, i.e., they have a problem that needs to be fixed is the foundation of the IPP, and is reflected by the use of standardized tests and assessments inherent in the process. The deficits of the person are framed as the “problem,” and consequent goals and strategies for change are related to these deficits. In this context, the IPP process becomes a tool which justifies and reinforces patterns of discrimination, segregation, and devaluation in the lives of persons with disabilities. The contemporary human service system operates with closed-system notions for persons with disabilities. The goal of “fixing people up” to fit artificial environments associated is opposed to goals that are related to valued life outcomes within the larger community (Mount, 1987).

Lastly, Mount asserts that the composition and the process of the IPP team reflect the assumption that human service professionals should have the most authority and influence in the design of personal plans. The IPP process assigns authority and control to professionals who assume responsibility for designing, implementing, and monitoring the future of persons with disabilities. Mount characterized the contemporary human service system as “closed,” replacing community roles and relationships with goals and outcomes which have little to do with participation in the general community (Mount, 1987).

The Emergence of Lifestyle Planning Procedures

In the late 1980s and early 1990s four alternatives to deficiency-based planning procedures emerged in the literature. New planning tools include “Lifestyle Planning” (O’Brien, 1987), “Lifestyle Development Process” (LDP) (Malette, Mirenda, Kandborg, Jones, Bunz, & Rogow, 1992), “Personal Futures Planning” (PFP) (Mount, 1987; Mount &

Building on the work of Bolles (1984) (career and life/work planning for the nondisabled population), O’Brien (1987) described a planning process called “Lifestyle Planning” which systematically guides family members, friends, and service providers through three planning activities: (a) statement of a desirable future for the individual; (b) delineation of the activities and supports necessary to ensure that goal; and (c) acceptance of responsibility for use of available opportunities, or development of needed activities and community supports such as securing job opportunities in the general community, and the utilization of friends and neighbors as teachers.

This type of planning makes explicit the role of formal and informal resource systems and is based on the notion that cooperative efforts by family members, friends, and service providers are necessary if a quality lifestyle is to be achieved for the individual with a disability (O’Brien, 1987). Community presence, choice, competence, respect, and community participation are quality of life criteria. Further, these quality of life criteria represent a reformulation of the principle of normalization (O’Brien, 1987; Mount & Zwernick, 1988).

Planning for quality of life outcomes involves a series of meetings. The first planning meeting includes key people who most influence the individual’s quality of life. The individual’s current lifestyle is reviewed prior to the planning meeting in order to identify the person’s present relationship to family, community, people, places and activities. The central issues addressed at the planning meeting include: (a) quality of the person’s present life experiences, (b) changes needed to improve experiences, (c) concerns and
opportunities for improvement of lifestyle, and (d) removal of critical barriers to lifestyle improvement (O’Brien, 1987).

O’Brien’s work represented a substantial departure from the IPP process. Lifestyle planning is person-centered and focuses on the strengths of the individual rather than their deficits. Secondly, Lifestyle Planning explicitly states that formal (professional paid supports) are not sufficient to create a quality life for the focus individual and that informal supports (friends, neighbors, and family members) are necessary to achieve this goal, and that these individuals are valued and equal members of the planning process. Lastly, in Lifestyle Planning, valued outcomes are related to quality of life rather than the amelioration of deficits.

Building on the concept of Lifestyle Planning, Mount (1987) developed “Personal Futures Planning” (PFP). The five essential lifestyle outcomes and accomplishments developed by O’Brien (1987) provide a framework for desired outcomes in the PFP process. She reviewed the effectiveness of this procedure with six persons with mental disabilities who were in transition from high school to adult life, and compared the results of the PFP planning process with the IPP documents of six additional people who were the control group.

Mount found that after one year the IPP process did not produce change in the lives of the individuals in a control group, in contrast with the PFP process which was reported to result in major life changes. Staff in the PFP process maintained rich visions of the future and learned to manage change for the individuals for whom they were responsible.

Two primary differences were noted between the PFP process and the IPP process. First, the PFP process developed services based on the informed choices, strengths, and needs
of individuals, rather than on the needs of the service delivery system. Second, the PFP process enhanced the abilities of ordinary citizens, co-workers, and neighbors to provide skill teaching and help individuals to form relationships and participate more fully in their communities.

Vandercook et al. (1989) described a futures planning process designed primarily for the education system. The "McGill Action Planning System" (MAPS) focuses on the inclusion, participation, and learning of students with disabilities in integrated school settings. The desired outcome of the MAPS process is the full inclusion of persons with severe disabilities in community life including regular age-appropriate classes. Relationships are cited as markers of quality of life as well as enhancers of social and cognitive development (Lewis, 1982).

Four assumptions guide the MAPS process: (a) integration, (b) individualization, (c) teamwork and collaboration, and (d) flexibility. MAPS involves a planning meeting and a planning team. The planning team consists of the individual, family members, friends, and regular and special educators or supports. The inclusion of nondisabled peers in the planning process is a unique component of MAPS.

Malette et al. (1992) reported on the efficacy of a fourth lifestyle planning tool called "The Lifestyle Development Process" (LDP). The LDP is a five step procedure that incorporates the values and many of the procedures of Personal Futures Planning and Lifestyle Planning. In addition, supports based on current "best practices" in the fields of behavioral, communication, and instructional strategies are utilized where needed. The LDP incorporates outcome measures to evaluate changes in the focus person's social and activity patterns, and to evaluate the effectiveness of various technical supports.
Four persons with severe disabilities and challenging behavior were participants. These individuals resided in four communities in the Province of British Columbia. All four individuals engaged in a greater number of preferred, integrated activities during the mid-and posttests than at baseline. Their social networks and program quality scores also showed various degrees of improvement. The behavior problems that were reported at the referral stage were substantially reduced at the posttest for all individuals. Two of the participants required substantial “social/political consultation” (p.417) (Gallessich, 1985) and negotiations based on “games theory” (Zagare, 1984) in which “win-win” solutions are the ultimate goal. These strategies were necessary to achieve quality of life outcomes as two participants experienced highly restrictive settings, resistant formal support systems, and program plans based on their deficits rather than their strengths.

Lifestyle planning tools are based on vastly different assumptions and procedures than the traditional planning procedures associated with the continuum model. Typical planning tools are based on the assumption that specialists and professionals are most knowledgeable regarding the needs of people with disabilities. Further, the roles of professionals are to identify problems, and define treatment.

Lifestyle planning tools are based on the assumption that persons with disabilities, their family, and friends are key decision makers. Coordinated efforts between formal and informal supports are necessary components of successful planning and implementation. Planning focuses on the strengths and capacities of the individuals.

It has become increasingly apparent that a merging of lifestyle planning tools with responsive systems are needed if people with disabilities are to be included in their
communities. As a result, innovative, person-centered approaches to supporting people with disabilities in the community began to emerge in the mid to late 1980s (Racino et al., 1993).

**Full Inclusion and Person-Centered Supports; Real Jobs and Real Homes**

Racino et al. (1993) describe that a person-centered approach to housing is an attempt to allow persons with severe disabilities to have a home of their own, as opposed to a home like facility such as a group home. In the literature, home has a variety of meanings, but is primarily viewed as a physical site. These include; a place of housework, recreation, leisure, learning, convalescence and death (Racino et al., 1993, p.11).

Taylor, Bogdan, and Racino, (1991) and Racino et al. (1993) have studied organizations throughout North America who are attempting to integrate persons with disabilities in their communities. Racino et al. (1993) noted that there are several factors that are prominent in a person-centered support paradigm. These include: a personal commitment to an individual (e.g. Shoultz, 1991); standing by and with people (Racino, 1991); listening and respecting the person’s perspective, inclusive of the person’s cultural heritage, taking direction from the person with a disability; and recognizing and respecting the person’s individuality and humanity (Taylor & Bogdan, 1989; Racino et al., 1993, p.12).

**Key Service Elements of a Person-Centered Approach**

Racino (1988) identified the key service elements of a person-centered housing and support approach. These include the separation of housing and support; leasing, home, and cooperative ownership; individualized and flexible supports; close ties among individualized assessment, planning, and funding; and choice and self-determination.

A person-centered approach separates housing and support services, therefore enabling people to obtain necessary supports wherever they live. This allows for, but does not
ensure, choice by the individual with a disability in several areas, including with whom and where they will live (Johnson, 1985; O'Brien & Lyle, 1986; Taylor et al., 1987; Racino et al., 1993).

In contrast to the continuum model of supports, where a person is expected to conform to the norms and rules of a particular setting, a person-centered housing approach extends the roles and rights of people with disabilities to those of tenants, homeowners, and cooperative members. A person-centered approach challenges the exclusion of persons with disabilities from these options. In a person-centered approach, support is characterized as more individualized and flexible. Support strategies vary for each individual and reflect a unique combination of services, adaptations, goods and assistance from paid staff, neighbors, families, and friends to enable people to live in homes of their choosing. Responsive agencies build this flexibility into their service and organizational design (Racino et al., 1993, p.4).

A person-centered housing approach utilizes community oriented assessments (see Brost & Johnson, 1982) for the purpose of informed lifestyle planning with people with disabilities. Person-centered residential options challenge the primacy of professional decision making, and design funding arrangements to meet the unique needs and desires of people with disabilities. Choice in all aspects of a person's life is central to a person-centered approach to housing (Racino et al., 1993, p.5).

Racino et al. (1993) summarized the key concepts and assumptions that gird a person-centered approach to housing. A person-centered approach is not viewed as a new program or model, no new or distinct housing models for persons with disabilities are needed. Persons with disabilities have the same need as the nondisabled population with regard to a safe,
valued life space. The issue of individualized supports applies to children as well as adults and their families (Racino & Taylor, 1993).

A person-centered approach to housing implies a change in how people with disabilities are viewed as well as a change in the relationships between people with disabilities and the organizations supporting them. Given that the assumptions and procedures of the continuum model remain pervasive in North America, changing this model will take time and will occur at different rates for different organizations and different individuals. These fundamental changes cannot be imposed or required, rather they must be addressed in many ways, including the shifting of power and control to the hands of people with disabilities (Racino & Taylor, 1993).

The substantive changes implied by a person-centered approach suggest new relationships between the world of disability and local communities. This may manifest itself through new participation in housing associations, or greater involvement with ordinary community members (Racino & Taylor, 1993).

When support services are separated from housing, the power is shifted to an equitable balance between person and agency. As this shift occurs, staff roles, organizational roles, and the relationship of the general community to disability organizations change. Support is pursued across all life domains such as work and recreation instead of sheltered work programs, and special recreation programs (Racino & Taylor, 1993).

Organizational Characteristics Associated with a Person-Centered Paradigm

Taylor et al. (1991) studied 40 organizations in 21 states that were attempting to integrate people with developmental disabilities, including those with severe disabilities in the general community. Qualitative research methods were used, which employed open ended
and nondirective interviews, observations of people, homes, and settings, and written documents. They found that responsive organizations were characterized by a number of attributes that made them successful.

Responsive organizations were characterized by their clearly stated philosophy or belief system that guided the work of the organizations. The specifics of the philosophy may vary from organization to organization, but is grounded in a pervasive and fundamental respect for people with disabilities. Persons with disabilities are not viewed merely as “clients” or “consumers,” but as people who are entitled to respect, and who have their own unique traits and contributions (Taylor et al., 1991, p. 254).

As part of the change process, many organizations undergo evaluation or self-study as they examine the dilemmas and issues they are confronting. These organizations do not rigidly adhere to specific models, programs, or approaches, but adapt what they can learn from others to fit their own situations (Taylor et al., 1991, p. 255). Being responsive to people with disabilities and their families is made explicit in outlined procedures. Responsive agencies also tend to be either decentralized or small, and have administrators who are deeply involved in the spirit of the organization. Decisions are made by friends and staff who are close to people with disabilities and their families (Rucker, 1987; Taylor et al., 1991, p. 256).

Many agencies providing services to people with disabilities present the values and assumptions of inclusion in their philosophy statements and mission statements, but practice policies of segregation. In contrast, responsive agencies are more concerned with “doing good” rather than “looking good,” and do not confuse the difference between what appears on paper and what actually happens in the lives of people (Taylor et al., 1991, p. 252). Such agencies do not define themselves in terms of narrow service categories, and take an
advocacy role which transcends service boundaries. This transcendence brings the organizations into the larger community domain, and addresses community issues such as housing and poverty (Taylor et al., 1991, p. 257).

Central to a person-centered approach is the focus on the needs of people with disabilities, and giving people a voice in their own destiny. What is needed in future research are perspectives from persons with disabilities (Nisbet et al, 1991; Bruininks, Meyers, Sigford, and Lakin; Williams & Shoutz, 1982). The Center on Human Policy has published several personal perspectives from persons with disabilities, family members, and support staff in person-centered housing and support situations.

Personal Perspectives of Person-Centered Supports

Michael Kennedy (1993) described his personal experiences as he moved from institutional settings, to an apartment in the continuum model, and finally to a home of his own. Michael is a man in his thirties who has cerebral palsy. He was forced to spend 15 years of his life in institutions as services were not available to assist his family when he was growing up. Michael describes his life in institutional care as devalued and abusive. He was placed under ice cold showers for up to one hour for reporting abuse by staff members, and was hung upside down in a doorway by his ankles as punishment for an altercation with another resident.

In 1982, following fifteen years in institutional settings, Michael moved to a supported apartment program run by a private, nonprofit agency. This supported apartment was part of the continuum model, where living arrangements and decisions were mostly agency controlled. Initially, Michael reported that the program was much better than life in the institution. However, over time, he began to feel restricted in his growth and controlled
by a bureaucracy. After five years in a supported apartment program, Michael moved into a house of his own.

Michael reported numerous differences between living in his own home with roommates and living in state run, or agency owned facilities. He considered it important to be trusted, to have his own home, and be responsible for paying his share of his living expenses. Previously, he had not been trusted with responsibilities. For the first time in Michael's life, his mother, who lived more than 200 miles away, could stay at his house and feel comfortable. Michael was enabled to take control of his own life, no decisions were made without consulting him. Michael reported that he regained the ability to choose what he would wear, what he would eat, when to take a bath, and where to go in the community. He felt like a person again. He shared a home with friends and was not a client of a program, despite the fact that his roommates were technically listed as "careproviders." Central to his new relationship was that Michael and his roommates were not constrained by rigid role structures, and friendship grew out of mutual respect.

Michael also found that old habits were hard to break. For fifteen years, he had lived in situations where decisions were made for him. The opportunity for choice and control of his own affairs, by themselves, were not sufficiently empowering. For two years, Michael asked for permission to do things in his own home until his "roommate" helped him to break the pattern of total dependence. Michael stated that it was difficult to break the habit of not trusting people and explained to his roommate, "It's not you, it's just that for a lot of years, I could not trust people, and you get into a pattern and you don't trust. Not that I want to be that way. It's a pattern, a habit I got into" (p.215).
Judith E. Heumann (1993) described her life experiences. Judith has polio and grew up in Brooklyn, New York. Her parents were advised to place her in an institution at the age of two, but they refused, and kept her at home. She was educated in segregated facilities, but was integrated in her community.

Judith worked at the Center for Independent Living (CIL) in Berkley, California (1975-1982), and is a leader of the independent living movement. She noted that the key assumption to be adopted by any service or helping system is that there are no real differences between the hopes and needs of disabled people and their peers. Support systems for people with disabilities need to be more user friendly. Cash subsidies and entitlement systems should be directed to a person with a disability, not organizations (Heumann, 1993).

Heumann cautions against prepackaged training programs, or state regulated credentials. When training programs exist, the individuals who need the service and their advocates must be significantly involved in the training. She suggests that the day that people with disabilities are able to receive adequate funding for the hiring of personal assistants will constitute another landmark in the disability movement. In achieving this landmark, she suggests that workers need to be paid adequate wages with real benefits and value their work.

On the issue of integration, Heumann challenges several of the assumptions of the disability movement. She reports that a common assumption made by the disability field is that the most important lifestyle aspect for disabled people is to spend time with nondisabled people. Heumann stated that forced integration doesn’t work. Persons with disabilities should have the right to choose the people they are most comfortable with, who have similar interests, and who share the experiences encountered as a disabled person. The goal of integration is for people with disabilities to be equal, integrated members of the community,
free to choose a range of associations with disabled and nondisabled persons (Heumann, 1993).

Summary of Review

Housing and support options for persons with disabilities have evolved during the past four decades. In the 1950s and 1960s persons with disabilities, particularly persons with severe disabilities, were mostly housed in institutions. Few options existed for persons with disabilities and their families to receive support in their home communities.

By the late 1960s and early 1970s, persons with disabilities, their families, and advocacy groups challenged the assumptions behind segregation and institutionalization. However, persons with disabilities did not leave institutions to join the nondisabled population in real jobs, and real homes in the community. Instead, a continuum of supports was created such as nursing homes, intermediate care facilities, group homes, semi-independent, and independent living programs. The continuum model was predicated on the assumption that persons with disabilities need specialized treatment or “fixing” prior to achieving full community status. The assumption was that each person with a disability could be placed somewhere along the continuum based on the severity of their problem. The more severe the problem, the more restrictive the environment. The goal of treatment and placement along the continuum was to ameliorate deficits and prepare the person with a disability for the next step on the continuum.

Characterized by a top down planning model known as the IPP, placement along the continuum is determined by a group of professionals using standardized tests and other assessment instruments. The list of deficits are reported, and a set of goals are developed. Many research studies were directed to validate that persons with disabilities could live in the
community at costs similar to the institution, and were able to acquire more skills than they could in the institution. With positive results, research agendas moved to studies of group homes, and began to explore the effects of size, resident composition, and locations of group homes.

In the mid to late 1980s, the assumptions of the continuum model were increasingly questioned, and the efficacy of the model was examined. In the late 1980s and 1990s new approaches to supporting persons with disabilities in the community began to develop. These approaches are referred to as “non facility based approaches,” or “person-centered approaches” (Racino et al., 1993). This approach assumes that all persons regardless of degree of disability have the right to a home of their own, control of their own destiny, and a quality life in the community, and recognizes that all persons regardless of degree of disability can be supported in the community. The nature of support requires a balance of formal and informal supports, and planning should focus on the strengths and capacities of the individual (Racino et al., 1993). Figure 2 contrasts the assumptions of the continuum model, and a person-centered paradigm. Despite increasing interest in innovative housing and

<table>
<thead>
<tr>
<th>Continuum Model of Supports</th>
<th>Person Centered Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Top down planning dominated by professionals</td>
<td>Collaborative lifestyle planning with Friends, neighbours and person with disability</td>
</tr>
<tr>
<td>Focus on deficits</td>
<td>Focus on Strengths and capacities</td>
</tr>
<tr>
<td>Placement on a continuum of handicapped services based on deficit profile</td>
<td>A home in the community based on personal preferences and needs</td>
</tr>
<tr>
<td>Outcomes are measured in terms of amelioration of deficits</td>
<td>Outcome is a quality life in the community</td>
</tr>
<tr>
<td>Continuum of supports: Institutions Nursing homes Group Homes Independent Living</td>
<td></td>
</tr>
</tbody>
</table>

Figure 2
Continuum Model of Supports vs. Person Centered Paradigm
support structures for persons with disabilities, there is limited research on these practices and strategies. In North America, the continuum model continues to dominate service delivery for persons with disabilities (Racino et al., 1993).

Nisbet et al. (1991) suggest that studies are needed which are descriptive and rich in detail regarding the successful inclusion of persons with disabilities. Ethnographic research strategies such as interviews and participant observation techniques (Bogdan & Biklen, 1982) that attempt to capture community lifestyles, events, and interactions appear more appropriate given the directions of the field and the needs of persons with disabilities and their families” (Nisbet et al., 1991, p.116).

The present study is a qualitative analysis of a person-centered approach called micro boards. The study focuses on the experiences of three people with physical disabilities and their individual micro boards. The goal is to understand life in the community from the point of view of the participants, and how they describe and value their lives. The methodology of the present study is described in the following chapter.
CHAPTER III
THE PRESENT STUDY

Statement of the Problem

This study is a qualitative investigation of a person-centered housing and support approach known as micro boards. “A micro board is a small group of committed family and friends that join together with a person to create a small non profit society that will address the person’s support needs in an empowering and customized fashion” (Victory Housing Society, 1990). Specifically, the study was directed to the following questions.

1. What are the defining characteristics of micro boards?
2. What are the values and assumptions inherent in this approach?
3. How did the micro board project evolve?
4. What formal and informal support systems are inherent in this approach?
5. What is the nature of these formal and informal supports?
6. How do these informal and formal support systems influence the quality of life of the focus person?
7. What are the implications of this approach within the generic health care system?

The micro board concept was developed by David Wetherow and Faye Buchanan in Winnipeg, Manitoba, in the mid 1980’s. According to Wetherow (1995):

Our idea when we set up the first micro board pilot project in the mid 1980s, was to simply try out the idea of creating a circle of friends and family around a single person and to direct the financial resources to where they really belong - in the hands of the consumer and the family (Transition News, Mss, Bulletin #2, February, 1995, pg. 1)
Specific principles that guide micro boards include the following:

1. Micro board members must have a personal relationship with the person for whom the board is established.

2. All people are assumed to have the capacity for self determination and this capacity will be acknowledged and respected.

3. All decisions made by a micro board will demonstrate regard for the person’s safety, comfort, and dignity.

4. The more complex a person’s needs are, the more important it is that services are customized and individualized to support those needs.

5. Micro boards must have access to money based on detailed proposals they develop to outline support services.

6. All services developed and/or contracted are based on the person’s need, not availability of service.

7. Micro boards will only negotiate contracts with people and/or agencies able to demonstrate a concrete ability to provide services as identified and in an individualized fashion

8. The person and/or agency that provides a home for a person should not be the same person and/or agency that provides direct service support.
Specific functions of micro board members include:

1. To get to know the person and establish a personal relationship (friendship) with the person.

2. To act as sponsors to the community ensuring the person participates in community activities with micro board members (i.e. family functions, social events, etc.)

3. To ensure the person has the opportunity to both receive and give from and to their community as well as with other individuals in their networks.

Once the above three functions are developed, the following functions are to occur:

4. To identify and request funds for services.

5. To identify and negotiate services with service providers.

6. To monitor services

7. To honor legal requirements of the Societies Act. A minimum of (5) board members must sit on the board. However, with any more than 7 or 8 people on a micro board it can become too bureaucratic and unwieldy. This could destroy the intent of the micro board process. (Victory Housing Guiding Principles and Functions, 1995)

The principles and functions of micro boards embrace the fundamental tenets of a person-centered approach, and are specific with regard to intent. Enabling principles include the following: (1) supports are customized and individualized to the needs of the individual, regardless of degree of disability; (2) a person with a disability and their friends and family are key decision makers in a bottom up planning structure, versus a professionalized and bureaucratized, top down planning structure; (3) home and supports are separated, as a person
or agency that provides a home should not be the same person or agency that provides direct service support; and (4) the goals of support are self determination, safety, comfort, dignity, respect, community presence, and community participation.

The goals of this study are to examine how these principles and functions translate to lifestyle outcomes for the individuals served, and to explore the philosophical, procedural, and support assumptions of micro boards in relation to the emerging paradigm of person-centered supports.

The Ethnographic Context of the Study

Setting

The study took place in the metropolitan district of the city of Vancouver, and the nearby city of Richmond. Vancouver and Richmond are situated on the West Coast of British Columbia. Both communities are in the southwestern area of the Coast, and are approximately 40 kilometers north of the Washington state border.

Metropolitan Vancouver has a population of over 1.5 million people. The city of Vancouver is bounded by the Pacific Ocean and the Coast Mountain Range. It is a scenic, cosmopolitan city and is home to one of the busiest ports in North America. The economy is diverse, supporting a range of service industries, resource industries, tourist industries and import/export companies capitalizing on the Pacific Rim trade. The three main industries are forestry, tourism, and mines and minerals. The demographics of the population reflects the influences of Pacific Rim trade, and burgeoning Asian immigration.

It has been estimated that the average family household income in Vancouver is $50,723.00. The average monthly shelter cost in Metropolitan Vancouver is $739.00. The city offers a range of subsidized housing projects that are not “ghettoized,” but are scattered
throughout various “desirable” districts within the city. Vancouver’s mission statement is “to create a great city of communities which cares about its people, its environment and the opportunities to live, work, and prosper” (The City of Vancouver, 1995).

Richmond is separated from Vancouver by the Fraser River. The distance from Richmond’s city hall to Vancouver’s city hall is approximately 10 kilometers. Richmond has been described as a “bedroom community” of Vancouver and shares many of the city’s demographic characteristics. The majority of Richmond’s population are between the ages of thirty and forty years old. Richmond has a growing Asian population of mostly Chinese origin. The population of Richmond is just over 130,000 people, and the lifestyle is more suburban than urban. The core of the city contains shopping centers, food outlets, small industry, and hotels. On the outskirts of Richmond, there is a mix of farms, fishing boats, and other marine activities.

Richmond is more of a family oriented community than Metro Vancouver. The municipality mirrors the general trend of shrinking household size, and an increase in the number of one person households, and households without children. Richmond is experiencing rapid growth, and over 1,200 new housing units are created each year. These are comprised of single family dwellings, duplexes, townhouses, and apartments. There is some subsidized housing which is wheelchair accessible.

**Selection of Participants**

Participants in this study are Lisa, Jason, and Sarah (pseudonyms). They are a diverse group of young adults who live in subsidized and cooperative housing projects in Vancouver and Richmond. Lisa, Jason, and Sarah have cerebral palsy, and require 12 to 24 hour supports in order to manage daily living tasks, and to connect with the communities in which they live.
Lisa, Jason, and Sarah were identified for the study via a "reputational approach" often used in qualitative research (Taylor & Bogdan, 1984). The key informant for the present study was Lynn Percy (pseudonym), whom I knew through my professional work. Lynn has been facilitating the implementation of micro boards throughout the Province of British Columbia for the past five years.

Since there are few examples of persons with severe disabilities who are living in their own homes, and who are well connected members of their community, it was necessary to conduct a search for participants. A "purposeful sampling" technique (Taylor & Bogdan, 1984) was employed to locate people with severe disabilities who: (a) were well connected members of their community, and (b) lived in homes of their choosing. Rather than select a random sample of people served in the micro board project, the goal was to examine the lives of people who met the above criteria.

Lynn suggested I contact Lisa, Jason, and Sarah, three of the first participants of British Columbia’s micro board project. I conducted telephone inquiries and personally spoke with Lisa, Jason, Sarah, and members of their micro boards. (See Appendix A for descriptions of the study and letters of consent).

Jason

Jason is a bright twenty seven year old man with a diverse set of interests. Some of these interests include hockey (Edmonton Oilers), soccer, wheelchair boccia ball, computer games, the ballet, parasailing, horseback riding, and restaurants (Greek, East Indian, and Oriental). As a career, Jason is considering becoming an accessibility consultant, or a model.

Jason lives in a cooperative housing complex in the south section of Vancouver. He has a three bedroom apartment in this complex. The complex is approximately six kilometers
from the downtown core of Vancouver, and is situated one block from the main artery of the
city. He is close to shops, restaurants, services, and recreational facilities and has his own van
for transportation.

Jason’s micro board consists of his brother Jim, his sister in law Kate, his aunt Cyndy,
his friend Simon, and his ex-wife’s mother, Eileen (pseudonyms). Jason joined the micro
board pilot project in 1991.

Jason has cerebral palsy and requires an extensive network of supports to meet his
daily needs. He receives 12 hours of daily support, and has a team of five people who provide
this support. Jason has interviewed and hired each person. Jason requires assistance with
virtually all of his daily routines including bathing, eating, and dressing. Primarily, he uses
speech to communicate, and his written communications are facilitated with the use of a
computer and a head stick.

Lisa

Lisa is a calm, sociable, twenty six year old woman, who enjoys wheelchair soccer,
crafts, Earl’s restaurant, Michael Jackson, Madonna, seeing her mom, and shopping. Her
dream is to be reunited with her birth mother, whom she has recently located.

Lisa lives in a new, two bedroom apartment in a cooperative housing complex in
Richmond. There are approximately 120 units in her building. The building is wheelchair
accessible, and she lives on the third floor. Lisa moved to her new home after separating from
her husband, Jason. She chose the apartment from a list of available options that were
wheelchair accessible.
Lisa lives approximately 10 kilometers from the downtown core of Vancouver. She does not have her own transportation and is reliant on public transit, which has limited wheelchair accessibility, or a specialty bus service for the disabled, which is “unreliable.”

Lisa’s micro board is comprised of her foster mother Eileen, her birth mother, Vivian, and her friends, Craig, Lisa, and Tony (pseudonyms).

Lisa has cerebral palsy and requires assistance with eating, bathing, cooking, cleaning, shopping, etc. These support needs necessitate 24 hour care. Lisa uses an electric wheelchair with a joy stick, and is a competent driver. Lisa’s support network, in her home, is comprised of five people. Lisa has control over whom she hires in her home. For her day time supports she contracts with an agency.

Lisa communicates primarily by pointing to letters of the alphabet pasted to a lap tray attached to her wheelchair. She uses her left index finger to spell requests, responses, information sharing, joke telling, and expressions of feelings and emotions. Although she has a speech output augmentative and alternative communication device, she does not routinely use it.

Sarah

Sarah is a gentle, patient, 25 year old woman who loves life. She is part of a close and caring family whom she sees often. Sarah enjoys fashionable clothes, and is a fan of basketball, baseball, football, and hockey. Presently, Sarah lives in her own apartment in a subsidized housing project on the south side of Vancouver. Sarah has lived in this apartment since she was thirteen years old. Sarah and her mother moved to this apartment in 1983. Her mother has since moved to a small town in the southwestern region of British Columbia. Sarah now shares the apartment with a roommate, who provides support. The apartment is
situated in a residential area with abundant park land nearby. Sarah is approximately one mile from most amenities, and has her own van for transportation.

Sarah’s micro board is comprised of her mother Pat, her brother Al, her sister-in-law Karen, her sister Alicia, and her friends Nita, and Sharon (pseudonyms). Sarah’s micro board came about in 1991 through the efforts of her mother. Sarah was one of the first participants in the micro board pilot project.

Sarah has complex medical needs and requires 24 hour care. She has cerebral palsy-spastic quadriplegia, epilepsy, scoliosis, reflux esophagitis, and two pins and a metal plate in her left hip. Further, her vision is impaired by nystagmus and exotropia, and she has osteoporosis.

As a result of these medical complications, Sarah requires assistance in all aspects of her daily routine; including positioning, feeding, dressing, eating, and personal hygiene. Her daily medication regime consists of Carbamazepine (500mg. daily), Losec (20mg breakfast), Glysennid (24 mg supper), and a Stresstab (breakfast).

Sarah is non-verbal, and responds to questions with a head nod or head shake (yes/no). Sarah uses vocalizations and body gestures to communicate emotions of discomfort, anxiety, and pleasure. Sarah and her support network also use photographs for scheduling and choice making.

Sarah’s paid supports are comprised of a network of six people. This network provides twenty four hour care, and is hired by Sarah and her micro board. They do not work for an outside agency, and there is a distinction between day supports and residential supports.
Research Methodology and Design

The overall research strategy of this study is to: (a) examine the defining characteristics of micro boards; (b) identify and explore the formal and informal supports associated with the micro board project; (c) discover how they came to be; and (e) examine how they influence the quality of life of the people served. The main goal of the present study is to provide a qualitative perspective of the life style quality of Lisa, Jason, and Sarah within the socio-political context of a government funded pilot project.

A person-centered approach to housing and support involves a complex interrelationship of value based procedures, responsive organizational variables, and individual or person-centered variables. Micro boards, which are the basis of investigation of the present study, represent this complex framework.

The lines of formal and informal supports in the micro board approach become somewhat blurred but it is clear that there are complex organizational interactions: (1) there is a governmental funding source (the Community Services Branch (CSB), Ministry of Health); (2) there is a non profit organization that assists individuals and their families and friends to develop micro boards (Victory Housing); (3) individual micro boards are technically non profit agencies; and (4) individuals and their micro boards may purchase services from an outside agency to provide support. Figure 3 illustrates the organizational and support framework involved in this study.

A technique similar to that of Mehan, Hertweck, and Meihls (1986) was employed. This is a micro-macro technique that serves as the basis for the research design of this study. A focus on the daily lives and interactions of the participants allowed the most salient features to emerge. To avoid editing out the larger socio-political and organizational issues
 involv...e of the lives of Lisa, Jason, and Sarah and their perceptions of lifestyle quality; (2) develop parameters of support and perceptions of organizational variables from the perspective of participants and their micro boards; (3) examine the organizational characteristics of formal support systems (Victory Housing, Community Services Branch); and (4) examine and analyze these variables and characteristics in the context of the emerging theory of person-centered approaches to housing and support.

Data Gathering and Theoretical Framework

Hammersley and Atkinson (1983) suggest that design and data collection in ethnographic research should follow a reflexive approach that operates throughout every
stage of a project. A reflexive approach implies that the course of ethnography cannot be pre-
determined, however this does not eliminate the need for pre-fieldwork preparation nor does
it suggest that a researcher’s behavior in the field need be haphazard, merely adjusting to
events by taking the “line of least resistance.”

They suggest a design and strategy that begins with “foreshadowed problems”
grounded in the theory being developed. These foreshadowed problems serve as a starting
point and framework from which a systematic data collection procedure evolves. The process
remains reflexive through all stages of the research, and contributes to the development of an
emerging theory, or a description of phenomena under investigation.

This reflexive approach has been employed by Taylor et al. (1991) in preliminary
studies of responsive organizations, which contributed to the emerging concept of person-
centered approaches to housing and support.

The methodology is both structured and open-ended. It is
structured in the sense that site visits are intended to yield
information about integration and are based on a general site
visit guide. It is open-ended in the sense that specific research
procedures depend on the place we are visiting. A flexible
approach enables us to pursue lines of inquiry as suggested by
what we are learning at the site. Our assumption is that we
cannot anticipate exactly what might be learned at an
organization before we spend time there (p.6).

The methodology and data collection procedures of the present study are both
structured and open-ended. A person-centered approach, as described by Racino et al. (1993)
and Taylor et al. (1991), has a range of distinguishing characteristics: (1) values and
philosophy; (2) structure and nature of organizations; (3) nature of relationships between
formal and informal supports; and (4) focus on a quality of life of the individual. These four
themes or foreshadowed problems comprised the structured component of inquiry in the present study. Following is a description of data collection procedures and their purpose.

**Participant Observation**

The writer was a participant observer. This method involves the collection of detailed notes written during or immediately after each scheduled observation or informal discussion to reconstruct and describe the observed experiences as accurately as possible. A rotating schedule of observations across contexts (see Table 1) was employed to record and describe important aspects of the participants daily lives and interactions with the community and formal and informal support systems (Salisbury, Palombaro, & Hollowood, 1993).

Borg and Gall (1989) identified three different levels of participation in the participant observer method: (1) In complete participation, the individual becomes a full member of the group and the role of the observer is concealed; (2) the observer’s role may be somewhat open but the observer functions primarily as a participant, keeping observational activities as unobtrusive as possible; (3) the researcher may function primarily as an observer, but may participate enough to gain rapport with the group and develop a better understanding of the group’s functions and relationships.

My role in the present study varied depending on the context. When interacting with Lisa, Jason, Sarah, and their supports, the author primarily functioned as participant observer, who shared in the conversation, and sometimes assisted Sarah, Jason, or Lisa. Over time the author was included more and more in day to day interactions and functions.
Table 1
Nature of Data Collected

<table>
<thead>
<tr>
<th>Type of Data</th>
<th>Collected By</th>
<th>Duration/Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant observations</td>
<td>Researcher/Author</td>
<td>rotating schedules monthly/bi-weekly over 18 months</td>
</tr>
<tr>
<td>community activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>home visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>micro board meetings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>parties and family events</td>
<td></td>
<td></td>
</tr>
<tr>
<td>budget meetings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>educational settings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>recreational activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interviews</td>
<td>Researcher/Author</td>
<td>52 hrs of taped transcripts over 18 month study period</td>
</tr>
<tr>
<td>Sarah, Jason, Lisa</td>
<td></td>
<td></td>
</tr>
<tr>
<td>micro board members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>paid supports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>family members</td>
<td></td>
<td></td>
</tr>
<tr>
<td>funding and monitoring agency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>micro board support agency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>therapeutic supports</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Products</td>
<td>Researcher/Author</td>
<td>As available Approximately 50 pieces of data</td>
</tr>
<tr>
<td>philosophy statements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>monitoring tools</td>
<td></td>
<td></td>
</tr>
<tr>
<td>government briefs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>minutes, micro board meetings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>lifestyle planning tools</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the context of micro board meetings, and meetings with persons from the Community Services Branch, the author functioned more as an observer, but did fully participate over time in Sarah’s micro board meetings. The author's role was flexible, depending on the context, and in all situations rapport was gained with the individuals. The author was able to observe and gain understanding of the functions and relationships of various formal and informal support systems.

Guiding principles for observations were O’Brien’s (1987) five essential support outcomes which constitute a quality of life; community presence, choice, competence,
respect, and community participation. O'Brien (1987) defined each outcome as follows: 
(1) community presence is the sharing of the ordinary places that define community life;
(2) choice is the experience of autonomy both in small, everyday matters (e.g., what to eat and or what to wear) and in large, life enhancing contexts and situations (e.g., where to live, with whom to live); (3) competence is the opportunity to perform functional and meaningful activities with whatever level or type of assistance that is required; (4) respect is having a valued place among a network of people and valued roles in community life; and (5) community participation is the experience of being part of a growing network of personal relationships, that includes close friends.

Interviews

Semi-structured and unstructured interviews occurred throughout the 18 month research period. Participants were interviewed including their support staff, micro board members, friends, family members, neighbours, members of Victory Housing and members of the Community Services Branch. Interviews ranged from one to four hour sessions (determined by participants). Semi-structured interviews were audio taped, transcribed verbatim, and incorporated into the chronological data base.

Spradley’s (1979) parameters of the ethnographic interview were followed. He described the ethnographic interview as a series of friendly conversations in which the investigator gradually introduces new ethnographic elements in order to gain the information sought. Initially, the interviews with Lisa, Jason, Sarah, and their support staff were unstructured and were typically embedded in natural activities during participant observations to ensure that rapport was developed (See appendix b for samples of interview blocks).
The interview goals with Lisa, Sarah, and Jason were to: (1) develop framework of personal background, including biological, educational, medical, and residential history; (2) elicit their self perception of disability and contrast with other descriptions of disability; and (3) elicit their perceptions of quality of life.

The interview goals with micro boards, Victory Housing, and CSB were more intentional, directional, and structured, as interviews constituted the primary data gathering technique for this group. The goal was to develop an understanding of the underlying values, purpose, history, and structure of these organizations. The author was known to members of the Community Services Branch and Victory Housing, and had an understanding of the workings of each of these organizations before the study began.

Permanent Products

Written materials from individual micro boards as well as materials from the Community Services Branch and Victory Housing were collected over 18 months. At the micro board level; copies of planning tools, daily logs, daily schedules, monitoring tools, newsletters, and personal reflections were included in the data base as additional indices of organizational features and descriptors of lifestyle. This information was dated, the source and context were identified, and it was entered into the chronology for that week and month.

Materials collected from the Community Services Branch included philosophy statements, monitoring tools, and newsletters. These materials provided the framework for semi-structured interviews regarding the process of operationalizing the goals stated in printed philosophical statements of the branch.

Materials collected from Victory Housing included the guiding principles and functions of the organization, a review of micro boards commissioned by Victory Housing,
and various newsletters. These materials were also dated, the context was noted, and they were entered in the chronology for that week and month. These written materials provided a framework to evaluate and link the goals and mission of the organization with the lifestyle outcomes of Jason, Lisa, and Sarah.

**Data Analysis and Validity**

The main purpose of the data analysis was to identify themes and issues that were grounded in the data being collected, and to contrast and compare these with the emerging themes and assumptions characterizing responsive organizations in a person-centered paradigm of support. Rotating schedules of observation, coupled with ongoing interview schedules, provided the opportunity to discuss trends, affirm perceptions, and evaluate the data (Taylor & Bogdan, 1984).

All fieldnotes, permanent products, and interviews were sorted and transcribed in chronological order. Final data analyses involved the identification, coding, and categorizing of primary patterns in the data. These patterns were then cross referenced with relevant literature regarding the emerging characteristics of a person-centered approach to housing. Finally, meetings were held with the participants, micro board members, and members of Victory Housing and the Community Services Branch in which the emergent themes of the research and supporting evidence were shared.

**Validation**

Triangulation and multiple methods were employed to validate the data and process of analysis. Triangulation is a strategy of using several different kinds of data-collection instruments such as direct observation, interviews, and content analysis to explore a problem or issue (Borg & Gall, 1989). First, triangulation of data sources was employed. I reviewed
the written philosophy statements, and principles and functions of micro board organizations.

I then interviewed individual members about their perceptions of roles and procedures.

Finally, I observed how these procedures actually occurred in the lives of Jason, Lisa, and Sarah, and solicited their perceptions.

Second, analytic triangulation was employed. Although I sorted the data into categories and themes, these themes were reviewed by those being studied and were affirmed, revised, and finally validated by these members. This “member check” (Salisbury, Palomburo, & Hollowood, 1993, p. 78) served to reduce the potential bias that might arise from my perspective alone, and served to further assure that the findings reflected the perceptions and experiences of the studies participants.

Third, as patterns seemed to emerge from the interviews and observations, these emergent themes were considered in the context of the continuum model and person-centered approaches to community living. Through this process of triangulation, consistency and congruency in practice and procedure were identified. Lastly, the period of observation and the differing levels of immersion in the micro board approach contributed to greater assurance that in depth collection of evidence would be possible, and that data would be accurately interpreted.
CHAPTER IV
THE CHANGING ROLE OF THE VICTORY HOUSING SOCIETY

Introduction

For clarity of presentation, and temporal integrity, the results of this study reflect the chronological evolution of the micro board concept in British Columbia. This chronology involves two organizations; Victory Housing, and the Community Services Branch (CSB). The evolution of the micro board concept was instrumental in changing the lives of Jason, Lisa, and Sarah. They were three of the first four participants in a pilot project with Victory Housing and CSB. Prior to the pilot project, Lisa, Jason, and Sarah, were either about to enter, or were being served by traditional services. Their residential options were hospitals or group homes. Organizational characteristics of Victory Housing and the Community Services Branch are examined in the next two chapters. The influences of these formal supports on the lives of Lisa, Jason, and Sarah are explored in chapters VI, VII, and VIII.

There is a complex interaction of person centered variables and organizational variables that led to the development of the micro board project in British Columbia, and the inclusion of Lisa, Jason, and Sarah. This chapter describes: (a) the role and function of Victory Housing in the micro board project; (b) the history of Victory housing; (c) the emergence of a person-centered perspective at Victory Housing; (d) the development of principles and functions guiding the micro board project, and (e) the relationship of Victory’s practices to the emerging paradigm of person-centered supports and responsive organizations.
The Role of Victory Housing

Victory Housing is a small, non profit organization partially funded by the Ministry of Health. The role of Victory Housing is to assist individuals with disabilities and their family and friends to develop micro boards. This facilitative role is multi-faceted. The primary goal is to support the growth and development of individual micro boards so that they are ready to enter into a contract with CSB.

This support role includes the following functions: (1) disseminating information, easing anxiety, and fostering relationships; (2) assisting individuals and their support network to build a vision of a quality life in the community; (3) assisting in the logistics of developing a micro board, including budgeting, hiring staff, setting up a payroll etc.; and (4) public education, training of government personnel, and advocacy with government on behalf of micro boards (Women’s Research Centre, 1994).

Victory Housing does not negotiate with the government on behalf of micro boards. The goal is to assist micro boards to become autonomous in their negotiations and functioning. Procedurally, this is very individualized and reflective of the needs of each individual and their emerging micro board. A Victory Housing board member explained the flexible role of Victory Housing, and the importance of autonomy in the micro board project:

In some instances we have continued to be involved for an extended period of time, but basically it’s up to the micro board then to decide to what extent we are to be involved. We try to provide support to them as they need it, but once they’re set up, they operate independently, and call on us when they need us.

Structurally, Victory Housing resembles that of many non profit societies. There are a total of seven board members. Two staff members function as facilitators, one administrator, and a co-ordinator assist the facilitators. Facilitators interact directly with individual micro
boards, and assist with the planning of a quality life in the community, and the logistics of setting up a micro board. To date, Victory Housing has assisted over thirty individuals to develop micro boards throughout the province of British Columbia. The values and practices of the organization reflect the elements of a person-centered approach and responsive support systems.

Victory Housing has been in existence since the early 1980s. Originally it was part of a larger society that provided a traditional continuum of vocational and residential facilities and supports. These facilities included sheltered workshops, day activity centers, group homes, semi-independent living, and independent living facilities. Its name originates from its early days as an organization that provided housing, and owned a number of group homes and apartments.

In the mid 1980s, the British Columbia Association for Community Living (previously the British Columbia Association for the Mentally Retarded) took over Victory Housing, as the previous continuum based service agency was unable to maintain it. The British Columbia Association for Community Living sold the group homes to other non-profit societies; it maintained five bachelor apartments for people who had been labeled mentally handicapped.

**Examining Values and Organizational Change**

The Board of Directors of Victory began to examine what was happening in the lives of people receiving support. This reflection contributed to the emergence of a person-centered paradigm of support at Victory Housing. A previous president of Victory Housing explained how the organization examined its mission regarding choice, empowerment, and the separation of housing and support.
I guess it was in 86, 87 that I got involved with Victory. Things had sort of stabilized enough and we were looking at what was going on in the lives of the tenants that we had. And realized, because of this landlord tenant relationship, there were real barriers to what we could actually do in terms of support to people.

That, (inflection) and what was coming from the individuals themselves, they didn’t want the support coming from their landlord. And we began to realize that it was a difficult position for us to be in as well. We were having to look at evicting someone for non payment of rent. It was very difficult if we were also involved with them in some way.

But I think the board at that time... were much more interested in looking at how to support people to live lives in the way that they wanted to. So we began exploring a number of things. We spent some time looking at, whether or not we should get into developing co-op housing, where we could look at making sure that people were more integrated. And through that process, we had to realize more and more clearly that what we were really interested in was not more physical structures, but what we could do to support people to have maximum amount of control over their lives.

... That also coincided with what was happening in terms of deinstitutionalization. Where it was becoming clearer that some of the people with the highest needs and some of the people most at risk of never getting into the community were the people who were left in institutions. So we wanted to look at what we could do.

At the time that Victory Housing was administered by the British Columbia Association for Community Living, and the continuum model was entrenched as the program model; members of the board began to examine their mission. The process of moving from a continuum based model to a person-centered approach was both a bottom up and top down phenomena. People with disabilities who depended on Victory were recognizing that the landlord tenant relationship had serious flaws, as did the Victory board members.
A senior board member of Victory Housing described how the organizational mission changed from service provision to facilitating community inclusion.

We were looking beyond just being service providers. We were already clear about, you know, wanting to look at ways of empowering people and stuff. What we figured out was that we didn’t just want to develop housing, that we were looking at how to put (empowerment) into practice, so that people were much more involved in their communities. That people had greater control, and people having communities of support around them.

Evolution of the Micro Board Concept

Following a convergence of the notions of empowerment and the separation of housing and support, Victory turned to the innovative work of David Wetherow and Faye Buchanan. David and Faye were members of the Association for Community Living in Winnipeg, Manitoba. Their roles as members of a team within the Association for Community Living included education, advocacy, service development, family support, and demonstrations aimed at showing government innovative strategies to support people with disabilities in their communities (Ministry of Social Service, 1995). The micro board concept was developed and piloted in Winnipeg, Manitoba, in the mid 1980’s. The project developed from a strong values base and was specific with regard to intent.

The author had the opportunity to interview David and Faye about the evolution of the micro board concept. David and Faye presently facilitate a governmental steering committee in which Jason (study participant) participates. Following is an excerpt from that transcript:

(Scene: Jason’s living room in his apartment, David and Faye have come to discuss personal and business issues with Jason. I happened to be present at the time. After approximately 45 minutes, the conversation turned to micro boards.)

(14) Interviewer: Am I correct in saying that the micro board was a concept that you developed in Manitoba?
(15) Faye: Yeah, it all started from moving forward from the family model. We were looking at the least amount of structure that would allow the government of Manitoba at that time to fund people. Our intention in the long run was to get the funding directly to people, to get income to people so that they would have control over it. At that time, in Manitoba, there was no vehicle for that, so the micro board was sort of the smallest vehicle, and the least restrictive vehicle that would allow the government to funnel the money through with the least amount of bureaucracy.

(16) David: It still had points on it, legally it’s a small non profit society.

(17) David: We started a couple of those in Manitoba and Lynn Percy (Victory Housing), and people from CSB figured out a way to get a substantial number of those happening in B.C.

Faye: Yeah, so Manitoba was the seed and B.C. really took the idea and ran with it.

In 1989, Victory Housing participated in a workshop with David Wetherow and developed a set of guiding principles and functions that are contrary to the “medical model.” The medical model is implicit in the continuum model of supports as persons (a) are diagnosed and assessed by a team of professionals, (b) are subsequently labeled (e.g., Jim is a behavior problem, Jim has severe cerebral palsy, etc.), and (c) based on the severity of perceived disability are placed in a specialized facility.

The daily living circumstances in the continuum model tend to be “highly professionalized” and “medicalized” (Mount, 1987). Professional decision making is supreme, and a team of specialists determines if and when a person is ready for a home of their own, and a life in the community.

In contrast, the micro board concept consists of a small group of committed family and friends who link up to create a small non profit society and develop support networks that foster quality of life. The structure of support is not highly professionalized or
bureaucratized. Rather, supports are highly individualized, relatively unencumbered by bureaucracy; the individual and their circle of friends and family are empowered to customize their support needs (Victory Housing Society, 1995).

Victory Housing adopted several specific principles and functions to guide the development of support structures. First, all persons are assumed to have the capacity for self determination and this capacity must be acknowledged and respected (Victory Housing, 1995). This assumption or principle is nonexclusionary. In Victory's conceptualization of support, all persons regardless of disability have the right and ability to develop a life of their own in communities of their choosing.

A second defining principle is the separation of housing and support. “The person and or agency that provides a home for a person should not be the same person and/or agency that provides direct service support” (Victory Housing, 1995). Racino et al. (1993) adopted the separation of housing and support as a key service element of a person-centered paradigm. By separating housing and support, people with disabilities are not required to move away from family neighborhoods or friends in order to receive services. Victory Housing’s guiding principles and assumptions are explicit regarding the nature of supports in a micro board.

The more complex a person’s needs are, the more important it is that the services are customized and individualized to support those needs. Micro boards must have access to money, based on detailed proposals they develop to outline support services. All services developed and / or contracted are based on the person’s need, not availability of service. Micro Boards will only negotiate contracts with people and / or agencies able to demonstrate a concrete ability to provide services as identified and in an individualized fashion (Victory Housing Society, 1995, p.2)
Defining Characteristics of Victory Housing

Congruent with a person-centered paradigm of support; Victory Housing includes persons with disabilities in organizational decision making and evaluation. A Victory board member, who once lived in a group home, and who has his own individualized funding and supports, provided his perspective on quality of life and the micro board concept.

For me an important part of my quality of life is control, and controlling where my destiny is going to go and what I want to do. And I think with what Victory is doing... providing the support for the individual to look at where they want to go,... is a great facilitation system when you first start dealing with wanting to become a micro board.

It's a real big picture of "where am I going to go with my life?" "what do I want to do?" And it's okay to dream a bit of what you want to do. And I think what's really exciting about this process, is that someone can dream. They can actually decide where they're going to go and before, you know, they're stuck in their homes and there's no support, no services, in a lot of cases, or the support that they were getting was really abusive.

Prior to the micro board project, Victory board members provided support regarding tenant liaison, and assisting persons with disabilities when appliances malfunctioned etc. A senior board member described how the organization strives to maintain close relationships with persons receiving support.

... I don’t know whether to call it a value, but certainly belief, and it’s one of my fears as we grow and expand and get more staff is to maintain the sense of intimacy and the sense of connection that I think our smallness has allowed us. And a sense of involvement so that the board isn’t really removed. And I think that is a real challenge.

Victory board members have not developed a detailed policy or procedural manual, and emphasized that a micro board is not a model that can be broken into a step by step process that fits all persons. Victory does not adhere to a prescriptive or formula approach to
developing micro boards and supporting people. Defining characteristic of Victory as an
organization is its commitment to ensuring that valued life outcomes are accruing to the
people they support. Choice and control of major and minor life decisions by persons with
disabilities was viewed as a dominant, positive achievement of the micro board project.
Mutuality is important; It is not just what the micro board gives to the person, but what the
person with a disability is able to give to their communities.

A Victory Housing board member, who had had no prior experience in the disability
field, and a prospective board member who witnessed the workings of micro boards
described how micro boards assist persons to lead lives of quality in the community, and how
their own involvement has enriched their lives.

(38) Interviewer: ... From your personal perspectives what do
you see as the mission and values which drive Victory? and I
guess maybe I will just go around the table.

(41) Board member: Boy, sure, start with me (laughter).
Otherwise I would just echo what everyone else said probably.
The biggest thing for me has been the involvement, albeit
limited, at the micro board conference and seeing the micro
boards and talking to them about their perception of the
difference this has made in their individual lives...

...And for someone who is not involved in continuing care, or
this field, to hear people talk about it with an almost rhapsodic
tone to their voice about how much it has improved their son or
daughter’s or friend’s life has been quite amazing. Because as
someone not involved in that I wouldn’t have believed it could
have done that much.... mostly by what people have said in
terms of the difference it has made to them. ... It’s been quite
profound... It’s the choice that has been incorporated into their
lives and the fact that they can now take some control and
almost have to take control.... I think it’s a fundamental tenet of
what we hope to provide.

Steve (pseudonym), the first person interviewed provided an outsider’s perspective on
support issues. Prior to his involvement in the micro board project, he had few encounters
with persons with significant disabilities and support needs. Steve described how his involvement with Victory Housing has enriched his world view.

(44) Interviewer: So prior to this (serving on the board of Victory Housing) you didn’t really have a lot of knowledge about how typical services were set up and some of those models?

(45) S: Zip literally.

(46) Interviewer: Would you say from a personal perspective that you were unaware of the impact that choice and control could have on someone’s quality of life?

(47) S: Yeah, I mean again speaking strictly personally, I didn’t realize that a lot of these people existed, because you just didn’t see them. I mean where would you see them? Unless you wandered through hospitals or care facilities where they might have been or might still be. You know, you don’t see them in the malls or out on the street, I mean it was just a complete eye opening to a world I hadn’t seen before.

(53) Interviewer: ...How has this impacted on you; being part of this process.

(54) S: Well it’s certainly opened my eyes, and I hope broadened my mind a little if only through the repeated beatings I’ve taken(laughter), as to just what really goes on in the world. However global that may sound. But just the fact that so much more goes on than your daily life, and there’s a lot of other people involved, the more you find out about them, the more you learn.

(55) Interviewer: One of the things that struck me as I’ve been spending time with different micro boards and groups of people I’ve been struck by each individual and some of the very intense interactions. Initially, I interpreted this to mean that sitting on a board was a bit of a burden... From your perspective what do you get from this process?

(56) S: Well there’s days like that when you know you’ve gotta do something, and for a period of time you feel like it’s a burden. But, you know you come to a meeting like it’s an Amway meeting or something (laughter). (inflection)You come to a meeting and you hear something, or you go to the conference, or D phones with an issue about something and it
brings it home. What it is that you’re doing, and the difference that’s being made.

And it’s not that individually I’m causing a big difference to happen, I’m just part of a cog in a wheel that’s turning, and together we seem to be making a difference as a group... Due to the functioning of the board and especially the staff, it just made an incredible difference.

(57) Board member: So do you think and feel differently about people with disabilities now than when you first started with us?

(58) S: Yeah well, Yeah I think so. I hope so. I don’t know that I could articulate it very well...but certainly there’s more awareness, there’s certainly more understanding, there’s certainly a lot more empathy...But awareness really of what they face. And what’s going on in their minds as well as my own.

Jim (pseudonym), who is a prospective board member, attended a Victory board meeting. Jim is an attendant for one of the Victory board members, and has worked in both continuum models and person-centered support systems. Jim described his perceptions of lifestyle quality in these divergent support paradigms, and discussed how communities are enriched when persons with disabilities are included.

Two other individuals that were supported by Victory, and who were friends of Pat’s (pseudonym), actually one of them at one time lived in the same group home, was able to move out, get married, do all kinds of things, that just simply were ... I mean it was the same staff at the group home that I was working with who were saying it was impossible for Pat to move out. So wherever you went these various characters, maliciously or otherwise, were simply saying none of these things are possible.

Well, while Pat and I were making something possible, Victory was doing the same thing with much more difficult cases. And then, within that, Pat became involved (with Victory board of directors) and helps people who were deemed to be impossible to move, persons who were stuck in a (hospital). (These are the folks who people were saying) “we’re not going to let any of these people out.”

59
Well they’re out in their own place. Prior to that they were stuck in a hospital at the mercy of the place. You’ve been in hospitals, you know what that’s like. Well that’s what their lives were like and organized. It’s hard to put into words, it’s just the difference between life and death. It’s just an unbelievable difference, and those people (persons who have moved from hospital settings to their own homes) ... I consider it a privilege to know them, and a privilege that they’re making that contribution. And prior to this point, they were actually buried. So it’s not only an individual privilege for me to be involved with them, but it’s actually enriching that whole fabric (of the community).

Victory has a diverse board comprised of persons with disabilities, advocates, and community members who were not previously connected to the disability field. Each person has an individual perspective on the meaning of their work. One of the board members is a parent of a son with disabilities, and has experienced the traditional continuum of services as well as the micro board concept. This board member refuted the notion that micro boards place more stress and responsibility on families than traditional support structures, and stated that:

(Micro boards)... It’s reunited brothers and sisters. It’s brought families together again that have been really quite isolated... It’s allowed them an opportunity to come together to begin to not only reconnect with each other, but to talk about it. And to come to terms with some of the things they may have felt around growing up around a brother or sister, or had a disability, and to be able to resolve some of those issues.

And to move back towards balance in peoples lives. I mean we see husbands and wives that actually have relationships with one another now. And you know it’s really quite exciting to see, that they have these lives and they can go back to their hobbies. And once the micro board is done and facilitated, then brothers and sisters have a role again, and they can be a brother and sister again, even though they’re on a micro board. And the nieces and nephews are also involved, they see this as a natural extension of dropping in, and you know, just hanging out.
Victory’s first facilitator, Lynn Percy (presently functioning as coordinator), has done much of the pioneer work in developing the micro board concept. She assisted Jason, Lisa, and Sarah in developing their micro boards. Lynn was interviewed regarding: (a) her perceptions of Victory Housing; (b) her personal value base; (c) her relationship with the Community Services Branch; (d) her role as a facilitator; (e) her involvement with Jason, Lisa, and Sarah, and (f) her role as a coordinator.

Interview: Lynn Percy, coordinator, Victory Housing
Date: October 1995
Place: Lynn’s office
Present: Lynn, interviewer

Interviewer: When you think about Victory as an organization, what key concepts or descriptors come to mind that describe the spirit of the organization and the people there?

Lynn: It is non hierarchical. I think that is one of the key things. I feel like my role in many ways from board member to staff hasn’t changed. Having worked for a lot of traditional agencies, I don’t feel, I mean I’m accountable to the board but the board is also accountable to me. It’s a mutual kind of thing. I don’t feel like I have to take orders, it’s a consensus approach. It’s based on our relationships too... It’s interesting when we get a board member how long it takes for that person to feel a part of things, because it really is based on the relationships we have with each other. I mean some of the board members are friends of mine, and others I wouldn’t call friends, but we certainly hold each other in high regard, and respect each other’s perspectives... It really is collaborative.

And we’ve gone through phases where that’s been challenged, and it’s really really been a struggle for us. Where there’s been someone who’s come in with a different bent on things that’s made it look hierarchical, and we’ve all really rebelled against it. And I think that is probably the single most significant difference from other agencies that I have worked for. And we know each other, I’ve been on boards where I’ve vaguely known the president, but I know these people intimately.

Interviewer: What do you think is Victory’s fundamental value base, above and beyond the philosophy statement?
Lynn: Our philosophy statement is what we believe. There truly is a belief that all people should have the opportunity to direct their lives. That's absolutely fundamental. Everyone on the board even the people that haven't come from anywhere near this field hold that true.

Interviewer: ... Where did you develop your value base?

Lynn: Probably from my family. I come from an incredibly eclectic ethnic and religious background. You name the race and religion, and I'll name the relative. I'm not kidding, I mean that's for real, I have great uncles that are African American. I have relatives that are Orthodox Jews, you name it and they're in my family. So I grew up believing that everybody was equal and of value.

I also grew up in a neighborhood where there was a number of kids with disabilities. One of my best friends was deaf, and through him I learned how to lip read. And as a little kid you don't put value on that, it was just a cool skill to learn. It never occurred to me that there was something wrong with him because he was deaf until we got to school and he disappeared. And there was a number of kids that had mental challenges in the community and we just all played together. So it was never an issue when I was a kid. So suddenly when I hit the school system and got hit in the face with the fact that it is to everyone else, and that always seemed really weird to me. And I couldn't get it, so I started volunteering when I was thirteen trying to figure out how come? And never did get it, it always felt weird to me. And the more I got into the field and started linking up with other like minded people I went “ahh,” so I'm not nuts, I'm not alone in this, there are a lot of people who think that this is weird.

Lynn: The other thing about Victory which is really critical is that I think we can fight with each other, it is has been safe enough to argue...We have had some real knock down drag em out fights and gone out for dinner afterwards. We recognize that we are discussing our values and things that we believe passionately, and people get that the world’s not going to end if you argue about it. And that's a healthy process. And I've really appreciated that, I've never worked for another organization where it has felt safe enough to do that.

Interviewer: Can you describe your relationship with the Community Services Branch?
Lynn: ... I think it was a magic moment in history ... it really was (partnership between Victory Housing and the Community Services Branch). There were so many committed people from both organizations that came together to create this project. And I think about the people in that organization (CSB), and I’ve been the antithesis of bureaucracy, and there’s people in that organization I trust my life with. I would trust my child’s life with them, and there’s not a lot of people in government I would say that about. There are people there that I hold in incredible regard. They’re amazing, an incredible group.

Interviewer: After Lisa, Jason, and Sarah were referred to you, you had to take all of the principles and put them into practice. How did you conceptualize what you had to do?

Lynn: That’s a good question. To use an overworked phrase, I made the path by walking. I mean I didn’t know what I was doing. There was lots of times that I would say to people, “okay that’s what you need, no problem we’ll go out and get it.” And then I would go home and figure it out, sometimes through the night, how they were going to get it. So a lot of it was by the seat of my pants through the first year. I had the concept down, the philosophy and intent, so I knew there had to be the relationships.

With Lisa and Jason it was really clear that there were people who really loved them, and that they trusted, and they knew who they wanted on the board. So with them it was much more getting into the meat and potatoes of it. Okay, “so you are sure that these are the people that you want,” and it was evident that those relationships were strong. So it was just a matter of getting those people together, explaining the concept, and carrying on.

Likewise with Sarah, it took a little longer. More of my focus was on Pat, and recognizing that Pat had been through a lot, where she didn’t trust a lot of people. So a lot of my time went into winning Pat’s trust, and spending the time with Pat. You know going over the idea...and trusting me enough to figure out “okay, who can we include in this.” And then proceeded from there.

Interviewer: How important is lifestyle planning to this process?

Lynn: It’s critical to it, but you have to have the relationships first. So once we have those relationships and they are really
clear and strong, then I conceptualize it as two streams of activities start to happen, and it all stems from a Mapping session, or Lifestyle planning. I give them options, here’s a bunch of ways that we can plan. Which one makes sense to you? Jason chose a lifestyle plan first time, and then a MAPS session. From that planning, we get a clearer picture what that person wants out of life. And from there, we start to do what I call the pragmatics as well as the vision stuff side by side.

“Okay, so this is the lifestyle that you want, so this means this is the kind of place you’re going to want to live, so let’s start looking for it, let’s start planning a budget around it.” Based on what you say you need, we’ve got to figure out what that’s going to cost. And start working on the budget and letting the government know what we need.

Interviewer: Can you describe the present configuration of facilitators and your role as coordinator.

Lynn: We have two new facilitators, and I am the coordinator. I’m still developing boards, because my personal belief is, I have a terror of administration, I hate it, and the further that you get away from the actual process, the less likely I’m going to understand what’s going on. So one of the deals I cut with the board is that I will coordinate this, and supervise these two people, but I will continue to do boards myself.

Also a lot of my role has been helping with the interpersonal stuff within boards. There is a critical point where boards are either made or broken. So far, any of the boards that we’ve been directly involved with, we’ve come in at that point and helped them negotiate through the interpersonal side... and that’s solidified them and they’ve carried on. Almost all of the boards that I am aware of have reached that point...within six months to a year where things are getting real tense, people are starting to feel real uncomfortable around each other, and a couple of people want to punch each other out. And they sort of need some help, and invariably that’s where I will hear from them again. What we usually do is go back to the vision “Why did you get involved in this in the first place? Who are we here for? What’s this all about?” And then help them from there.

Usually the bedrock underneath what they’re fighting about is identical. They’ve just come up with different ideas about how to address it. And so, often, at that point my job is to help them learn communication skills as a team. And recognize that this isn’t unhealthy, or this isn’t abnormal, this is what everybody seems to go through. If they can work their way through that,
then they have a healthier way of arguing with one another, and they feel safer in that. And they seem to take off like gang busters from then on.

Interviewer: In talking to other people, what worries them is that much of the work rests with you, and would Victory and the micro board project be what it is without you?

Lynn: Yeah, and this isn’t like I think I am wonderful. I’m not. I’ve heard that from people, and started to look at it and go “why would it be that way?” And I think their right, and that’s why we’ve looked at hiring facilitators, because we started with the mentoring and that wasn’t working...One of the things I recognized, I just happened to have at that particular time a unique set of skills that fit the job. Because I had the vision and I also had the pragmatic skills, like how to set up services because that’s what I’d done. So I understood systems and had worked within them. I had worked for Continuing Care and I’d done project work for Social Services. So I understood the system as well as how to set up services on top of the value base. I recognize now that that was a unique set of skills when we came into it. What I’m trying to do is try to impart those skills on other people. That’s why we’ve hired the two people that we’ve hired. I see it as piling skills on top of the values base.

Interviewer: Can you describe the characteristics that people require to be as successful as you were.

Lynn: Yup, the values. Some of the pragmatic skills like how to develop a budget, how to set up services, like literally how to hire staff, how to train staff, cause often times we do that for the boards. Understanding the politics. Diplomacy, tenacity, and advocacy. I never take no for an answer.

Interviewer: In terms of monitoring do you acquiesce to CSB.

Lynn: Absolutely. I have called CSB to monitor certain things.

Interviewer: When you look at quality in life, what types of things are you looking for.

Lynn: I go on gut reaction. I know it’s one of things that I irritate my board with, because I haven’t been able to give them tangibles of what it is. I’m working on it. But it’s what I’ve had all throughout my work in this field. If I walk into a house and go “God I don’t want to be here.” I know that’s the place I
should be spending my time. If I walk into somebody’s home like Jason’s and go “Ahh, I would like to spend the afternoon here,” I know there’s not a lot to worry about. It’s a gut reaction. I’m basing it on feelings I’m getting from the individual and that’s where I start. “So how does this person feel in this environment? Is their comfort level clearly stated, and is it okay?” And then the interactions between them and the people that are in the environment with them. And finally the general environment, what does the place look like? But that’s the last thing. And what I’ve learned over the years is that I’m seldom wrong. If I go into a place and I want to hang out, then I know they don’t really need me there.

Interviewer: Is a micro board dependent on a strong circle of supports to make it work.

Lynn: Yeah, I think so, there’s only one board that has fallen apart and the time wasn’t spent on developing those relationships. People keep asking “who are they good for?” And people are looking for a set of circumstances around the person, like a type of disability that it’s good for. And that’s irrelevant. I mean this could work for anybody, regardless of where they come from that need some sort of support. But what I think is critical is someone that’s willing to take some responsibility… To be a serious risk taker. Because at certain points they are taking risks, and if people want to play it safe, then micro boards aren’t the place to do it. Because you’re taking the responsibility, as a board member you’re saying “I will be accountable, and I want to make a commitment.”

One of Victory’s facilitators has a daughter with severe disabilities, who provided her insights on support issues from the point of view of both parent and facilitator. She related her perspectives concerning, (a) her role as a facilitator, (b) her impressions of the micro board project, (c) her personal values, and (d) her relationship with Lynn Percy.

Interview: J, Facilitator, Victory Housing
Date: August 19, 1995

Interviewer: What do you see as your role as the facilitator

J: I see my role as to help families and their friends. Whoever it is that has come together around an individual, to guide them through a process of developing their own service for this person. I see my role more as a teaching role, so that I would
help them through the process, they learn how to do it. Eventually they won’t need me. They may occasionally give me calls, and ask “how do we work around this issue or that issue?” But eventually you work yourself out of a position. I always come from the position that these are the people that know the individual. ... So I definitely rely on the people that come around the person as a circle to know what this person needs. If they can’t speak for themselves they (circle of supports) must know the person’s needs intimately. And I rely on them to do that, that’s part of their job being part of a micro board. And then I help them move through the process. I show them all of the steps, and they learn the steps as we go.

Interviewer: I am searching for the themes and issues that are the defining characteristics of the people and the spirit of Victory and the micro board project. What do you see as central to the micro board concept?

J: (emphatically) Individualization. It is just so different for every family group and their micro board, because every person is so different. And you can’t take what you learned from one, and automatically put it on another.

Interviewer: What other characteristics do you see as being important in your role as a facilitator?

J: ... Part of my role is to be non judgmental in how people choose to support a person. Together they work out with a person how they want to be supported. And it is so different from one family group to another. So it is important to always remain non judgmental in how people choose to do the things that they do.

Interviewer: As a facilitator then, the job description is not really clear.

J: No (laughs). Because each micro board requires something different. They all come with such different sets of skills. So you don’t know when you go in what it is you’re going to do with this family...It may be relationship building...or they may need a whole lot of support around setting up employment agreements and job descriptions. So it is very different from one to another.

Interviewer: One of the roles of the facilitator is helping with vision planning.
J: Absolutely, that’s what I spent eight hours doing yesterday was a MAPS process.

Interviewer: Do you see that aspect of your job, building the vision with people, as a critical piece?

J: I see it is one of the most important. Some people have a very clear vision of what they would like to see happen and others have no vision. And they need to work really hard on “how does this person want to live?” So again, each time it is very different. And I think what people don’t understand the most is that it is the relationship between board members and the person that takes the longest, and is often the more difficult to work with. You’re working with a number of people all who are doing many different things in their lives, this is only one part of it, but it is very intense. And it takes a lot of fairly focused work on the part of the facilitator to make sure that people can come together to do this.

Interviewer: Do you do a MAPS session with every person?

J: There are different planning processes. I let people choose what suits their needs. I use PATH and Personal Futures Planning, but they all have to go through a planning process, whatever they may choose.

Interviewer: But all of your planning tools are vision planning tools which focus on the strengths and capacities of the individual?

J: Yep, that’s it.

Interviewer: How did you come to be associated with Victory.

J: We had a project that happened to be here in the Comox Valley that I worked really hard with our parent group to get, which was called “building bridges.” And that is where I met Lynn, and got to know her. She told me about the micro board project, and I applied for the job, because it made so much sense to me as a parent. You know I have a daughter (with a disability) who would be served by CSB. And when I thought about how I wanted her to live, I didn’t have a clear vision. And the more I learned about visioning processes, and realized that what I wanted for her could never happen in standard service.
So I was hooked, I thought this (micro boards) is what would really make a difference in my daughter’s life, and I realized what an incredible difference this would make to so many peoples lives. Not that this process is for everyone, certainly for a lot of families it is. But for a lot of families it’s an incredible amount of work and they would just not be interested...For those that are interested, it is just such a relief to know that a person can live the way they need to live in order to survive. Because some people will just not survive in institutional type settings, and even in group home type institutional settings.

Interviewer: The micro board project appears to be characterized by connections and like minded people crossing paths.

J: It is. And it’s really phenomenal. The building bridges project was one way for me to find out about micro boards...It’s amazing to see how many people around the province we’ve connected with.

Interviewer: Do you see a common thread in people that makes micro boards work.

J: I guess the common thread I see is the incredible respect for people with disabilities, and their choices. And that’s regardless of a level of disability, or a level of communication ability. I think it’s just a profound respect for their choices and honoring their choices. I find it just filled me with such joy to see that, and often it’s not seen (in traditional support programs).

Interviewer: There appears to be a common value base among the people that I have spoken with in the micro board project. And this value base has come from a variety of sources. In your connections with people do you see a common thread or commonality that goes beyond viewing people with disabilities to a broader vision of how people want society to look?

J: I do, and it would be interesting to do a PATH with these people to see where all of their common views came from. But I guess the majority of people all seem to believe in social justice. For me, it’s a justice issue. It’s just amazing how many people believe in social justice and equality at the heart of their being, and many of them try to live it in their work.

Interviewer: One of the persons in the study has labeled it as “talking the talk, and walking the walk.”
J: Yeah, and I think many people believe in social justice and equality, but the system stops them from doing it. The system stops them from walking the walk and talking the talk. Yet here’s a group that’s found a way to do it, and it’s worked, and I think all of us need to work harder at dismantling the system that prevents us from doing it.

Interviewer: How did you develop your personal value base?

J: I guess because my daughter is severely disabled that I’ve been lucky to find people wherever I’ve lived, and I’ve lived from one side of Canada to the other,... who had a vision that shared it with me, and then I realized, “that is what I was looking for.” And all of her life, the last nineteen years, I’ve found people who’ve been able to help me be creative and innovative in developing service, and I’ve always been attracted to people who’ve done things differently and were outspoken in what they did. So I’ve just been very very lucky. Here I was lucky enough to find Lynn Percy and Victory and knew a good thing when I saw it (laughs).

Interviewer: Lynn’s name comes up everywhere I go, is it difficult working in the shadow of Lynn Percy?

J: No, no, because I always look to her for confirmation. “Have I really got it down? is the philosophy right? am I coming from the heart?” She always brings me back to reality. And I can always check “is what I’m doing in the right spirit of things?” She always challenges what we’re doing, and I really value that. She has no qualms about doing that, she is very forthright, and I like that.

Interviewer: What personal attributes do you see as being important to the facilitator role.

J: I think that you have to have a personal vision, and personal values that support this program... If you don’t, I don’t think that you can do it. You have to be open and honest with yourself and others, you have to be non judgmental. Willing to learn. There’s a lot of learning as you go along, and being able to question what you do, and learn from your mistakes. We’ve all learned not to take no for an answer, and try another way.

Interviewer: From your perspective, what do you see as the defining characteristics of Victory as an organization.
J: Honest, and caring, and that's always surprising because I
don't expect that from a board of directors (laughs). I guess
really, just a very caring attitude that you don't often get from
the regular service delivery system. They do care about people,
and they're relationship oriented.

Interviewer: You have an interesting perspective as a parent of
a daughter with severe disabilities. You have contacts with
both Victory Housing and CSB. What characteristics come to
mind when you think of CSB.

J: Pretty open and innovative. Open to change and doing things
differently. They attempt to make things as unbureaucratic as
they can be, which is really really nice. At least from where I
am, they seem to have a much more laid back perspective than
the other agencies that I've had to deal with. And again, really
interested in the personal relationships, they certainly need to
know about the money and where everything is going, that
doesn't take a second seat to anything else, but they still are
interested in the relationships, and how people are choosing to
live and really want to know, "is this person's wishes being
respected?"

Interviewer: Have you seen any down sides to the micro board
project or things that need to change to improve the concept?

J: I haven't really seen any down sides. There's always times
when it's been hard work for the people that are doing it. They
always seem to go through crises that from the outside look
like they're having a real hard time. And we shouldn't put
families through this kind of process because it's so hard for
them, and there's so much for them to do. And other people
may see those crises as were asking too much of families, and I
don't think so. But the people that are in it always see the light
at the end of the tunnel...Micro boards do change peoples lives
and relationships will change between parents, siblings, and the
people receiving support.

Interviewer: Some of the criticism of the micro board project
has been that micro boards change the fundamental structure of
families in a negative way.

J: When you have a person with severe multiple disabilities in
your family your family structure is very different than what it
is for many other families. Usually the mother takes on many
roles that I personally don't see anybody else of my friends
doing. I take on an incredible amount of roles in advocacy,
medicine, in research and all kinds of areas that I have to do in order to be able to help my daughter. Micro board work isn’t really any different. I have to handle all kinds of finances, whether she has a micro board or not. Just to be able to get her equipment, when she was younger to access the “At Home Program” and use it’s money. It doesn’t matter whether it’s a micro board or not, I’m doing the same work I did before. I’m a coordinator. I coordinate tons of things for my daughter. The micro board actually helps me, and allows me to be more of a parent than I was before. Because now the work load is shared. The hard part is that other people may know my daughter and make recommendations for what she wants to do that I don’t see, because she’s my daughter, and I only see her in that role. Other people see her as a young woman who wants to make choices in her life, and they want her to make decisions that a young woman would make. But for me she’s still my daughter. ...I don’t see that my role as a parent changes at all. I’m still doing tons of coordinating. What’s changed is that my work load will eventually be lighter. She’ll have more friends, more connections, she will be safer, and more like my other kids in that other people give her input.

...She’s allowed to talk to other people that know her and that understand her, they help her explore things that as a parent I might not encourage her to do. I don’t take my other kids drinking or to their first bar, but other people can help my daughter experience things that as a parent I wouldn’t do. But it’s a challenge. I think it’s more normal, I think a micro board helps a family to become more normal.

**Summary**

Presently, 90,000 people with developmental disabilities reside in public institutions in North America. In many states and provinces, deinstitutionalization has meant the creation of smaller institutional settings within the general community. Many people with disabilities have simply been transferred to nursing homes, intermediate care facilities, and group homes (Taylor et al., 1991).
The micro board concept represents a complex interplay of grounded theory, values, innovation, and practical experience. Faye Buchanan and David Wetherow describe the theoretical assumptions and values underpinning the micro board concept as follows.

We sort of came out of the same training, you know Wolfensberger, John Vanier, John McKnight, John O’Brien. There were a few teachers, and then I think there were people who’s lives were affected, and we started working away at that. We were looking at not congregating, and valuing the gifts that people with disabilities bring to their communities...and along with that were the concepts of individualization and listening to families.

Characteristics congruent with a person-centered paradigm are evident in Victory Housing, and define the spirit of the organization. These include (1) a strong sense of mission and purpose that values and respects all persons, and is focused on the quality of life of people most at risk to leading devalued lives; (2) the organization and individual people are open to change and self evaluation; (3) creativity, flexibility, and individualization permeate practices and procedures; (4) valued outcomes concern the lives of the people served; and (5) people in the organization have a strong sense of purpose, and persevere when confronted with attitudinal, knowledge, or opportunity barriers that arise in the human service system and general community.

Another organization which was central to the implementation of the micro board concept in British Columbia is the Community Services Branch of the Ministry of Health. A description of this organization is presented in the next chapter.
CHAPTER V

“GRASS ROOTS DEVELOPMENT”

THE COMMUNITY SERVICES BRANCH

MINISTRY OF HEALTH

Introduction

The Community Services Branch (CSB) provided information about the type of support that they were encouraging. The author was interested in (a) the history of the branch; (b) the evolution of its values and priorities; (c) the organizational characteristics of the branch, and (d) the relation of the branch to responsive organizations. The author participated in and observed budget meetings, and was given access to multiple sources of information such as monitoring tools, interview questions etc.

Organizational Description

CSB is an anomaly in the human service field. Typically, governmental funding agencies have a very broad mandate, and are characterized by a fairly rigid and complex bureaucratic structure. CSB in contrast is: (a) small; (b) driven by a philosophy and mission that was developed in consultation with families, advocates, and consumers; and (c) is flexible and creative. CSB plays a central role in the lives of Sarah, Jason, and Lisa. They provide the funds for the micro board pilot project.

CSB serves people with complex physical and health care needs throughout the province. Two senior members guide the work of thirteen service coordinators, who assist human service agencies and micro boards to plan, coordinate, and monitor quality supports for persons with disabilities.
The philosophy statement of CSB has seven guiding principles which are reflective of responsive organizations and a person-centered paradigm of support. These include (a) the right of individuals with a handicap to determine their own personal goals, and access to community services; (b) recognition of family and friends as key support persons, (c) planning and implementation of support structures are directed to a quality life in the community; and (d) a commitment to provide services that respect the human dignity of individuals with handicaps (Philosophy Statement, CSB, 1988).

The philosophy statement of CSB was presented to and adopted by the Ministry of Health in 1986. The evolution of person-centered supports at CSB was similar to the adoption of the micro board concept by Victory Housing; involving a complex interaction of values, personal experiences, multiple points of view, fortuitous political timing, and emerging theory.

History

British Columbia, in the mid to late 1980s, embraced the notion of deinstitutionalization. There was a commitment to closing the institutional facilities in the province. In his throne speech of 1981, Premier Bill Vander Zalm declared that institutions in the province of British Columbia would be closed in ten years. The continuum model was to be the vehicle for deinstitutionalization, and the assumptions and procedures associated with the continuum influenced decision making. Some fifty people were considered to have such extensive health care needs that it was assumed that they would need to remain in institutional care. Families and advocacy groups in the province rallied together and lobbied for the placement of these individuals in the community. These efforts resulted in the creation of CSB.
A member of the Branch stated; ... “the vision was created by those families... Peter and Mitch, and Andre (members of the government), they were out there meeting with groups of families. This Branch had an advisory committee that was made up families and service providers...It was grass roots developed.”

A senior member of the Community Services Branch stated that during its inception the Branch received support from people in higher echelons of government, “support for the Branch went all the way to the top, the minister of Social Services and Housing was also the minister for Health, he had encompassing ability there and said ‘yes okay we can do this through the Ministry of Health, we will set up a division that will support people with multiple disabilities’… So we had a man in a very powerful position that really understands.”

The people hired for the Branch shared the philosophy of person-centered supports. Disability advocates were hired to specifically guide the principles and practices of the Branch. A senior member stated, “they were hired specifically for their views of the world, and they were our consciences often ... trying to have this Branch be different and do different things. ... So we were hired knowing that this was the philosophy statement.”

**Defining Characteristics of CSB**

The Branch is small and relatively autonomous. A key to success or failure rests with the people working there. The Regional Manager and Regional Coordinator were hired to carry out the philosophy of the Branch. They have first hand knowledge of disability issues. The Regional Manager is a foster parent to a son with disabilities, and the Regional Coordinator has a disability. The Regional Manager discussed his value base and how his experiences as a foster parent contributed to his conceptualization of support.

Myself, our family has fostered a child for the last number of years, so we’ve gained some insights by having someone with a disability live with us. And we’ve learned from some
experiences what might be good and what might not be good. I’m not sure, I guess some of the values comes from your own beliefs, and I’m not quite sure how you develop those values. I don’t think I can pin it to my upbringing or anything (laughter).

... one of the things about values that are meaningful is that you’re not prepared to compromise them. You won’t overlook them. If there are issues that are important, and that you value in terms of a quality of life, then you deal with them and bring them forward.

The Regional Coordinator described how her experiences growing up with a disability led to her value base and conceptualization of support.

I think my values base came from growing up with a disability ... having my own disability and being in that service system sort of all of my life. I think it probably comes from that end of things, having that experience ... How it is to be done to, and people think because you don’t walk well that you don’t think well either, you know those kinds of things.

Empowerment, choice, control, and inclusive communities are pervasive goals for members of CSB. The following excerpt provided by one of CSB’s outspoken service coordinators illustrates this point. At the time of her entry to the disability field she was working as a flight attendant, and had little prior experience with people with disabilities.

One night she was in a piano bar and ran into an old friend of hers who happened to be playing that evening. They began discussing careers and he felt that her values and skills would be perfect for the disability field, and he gave her the name of a contact person. She was hired as a supervisor of a group home. She describes how disparate her world view was to the culture of her first job in the disability field.

L: Funny you know I didn’t really know that I thought particularly differently until I started supervising in a four person group home... I’ll never forget, it was like my second week there or something, and I was having a conversation with one of the staff.... One of the guys that lived there, he really had I was told very good number skills. So I was wondering why
was I doing the budgets and not him? And I was talking to a staff person about choices and things like that, and why was it that no one had choices around here? ...It seemed really weird to me... Why is it like this?

Well, she got really angry at me and sort of stuck her finger in my nose and said: “If you keep giving them choices, and talking about this, before you know it he’s going to be running the place” (voice elevated). And I said “well yes, why not you know?” But I didn’t understand that until I got in the group home, and then really started to get it a bit, about the very different thinking... and we kept hitting head on, and head on, and head on.

Despite the strong personal commitment of the members of the Branch and an enabling philosophy statement, the service design initially followed the continuum model. Four bed group homes were developed, however the individuals administering the Branch soon realized that traditional models of support did not meet the needs of many people. The Branch began exploring more individualized notions of support.

CSB and Victory Housing united and developed a pilot project involving the micro board concept. A number of factors contributed to the ability of CSB to join with Victory Housing to develop the pilot project. A person previously employed by Victory Housing, with first hand knowledge of the micro board concept was hired by CSB, which itself was small and relatively autonomous. The Branch had liaisons in the higher echelons of government who shared a commitment to integration. They adopted a “bottom up” planning model which was unencumbered by bureaucratic processes dictating policies and procedures. The values inherent in the micro board approach were congruent with the philosophies and values of the members of CSB. A key person in the development of the micro board project was a former member of Victory Housing who joined CSB. The Regional Manager described this members role in the facilitation of the project.
...Steven was on the board of Victory but eventually he came over to the Branch. So he became an employee of the Branch and was connected in terms of being able to help facilitate the pilot project, but he also came with the grounding of being a member with Victory.

With the approval of directors higher in the bureaucracy, the pilot project was facilitated. Senior members of CSB described how the small autonomous nature of the Branch contributed to the development of the micro board project.

Our Branch was so small and so different than anything else that was happening in health, that no one really understood what we were doing. They gave us a few million dollars compared to so many billion. It was sort of see no evil, you know, it was sort of their approach (larger ministry).

The Branch has never also had a policy manual. We’ve never had anything that’s sort of guided our work other than our philosophy statement. We don’t have a book that we can pull up and say this is how to do this situation. The closest that we’ve gotten is some guidelines around our children’s program. But we don’t have any structure that’s written that tells us how to do our jobs, so it has allowed us to be quite flexible, and creative...

The Micro Board Pilot Project

In 1989/1990 CSB entered into a pilot project with Victory Housing. The original contract with Victory was to develop three micro boards to the point that they were ready to enter into a contract with the Branch. This contract has since expanded, and CSB has funded Victory Housing to develop a handbook and support the recruitment and training of more facilitators, as Victory has moved from the pilot project stage to supporting roughly thirty micro boards throughout the province.

CSB has three primary support roles in the micro board project: (1) funding Victory Housing to support the development of micro boards; (2) funding individual micro boards
and developing contracts for support; and (3) monitoring of supports and quality of life via a
service coordinator.

A micro board is registered as a non profit agency and negotiates with CSB regarding
housing and support dollars. Once budgets and supports are negotiated, monitoring of
supports is facilitated by a service coordinator. The regional manager of CSB characterized
the role of the service coordinator.

What we’re hoping is to support the service providers to
develop a circle of supports. We try to bring them back to the
question, what are you going to do to help support this person
to build these circles?

... (We monitor) around the intentionality or the understanding
of that staff team to sort of create those friendships around the
individual. We monitor from our own physical presence, we
monitor via schedules and contracts, we have professional
supports that feed back to us, and we have the Quality Lifestyle
Plan and that monitoring tool.

CSB originally supported 50 or so people moving from institutions to group homes in
the community. Presently, they support a range of individuals and practices, which include
micro boards, and have developed procedures regarding personal planning, monitoring, and
the provision of supports. O’Brien’s (1987) lifestyle accomplishments (choice, competence,
community presence, community participation and respect) serve as a guide to planning. The
guiding principles provided by CSB are:

1. The person and his/her family have the right to receive quality service.
2. The Branch's work will respect the privacy of the person’s and family’s interests and
   support needs.
3. The Branch will promote the building of increasingly competent communities by
developing, supporting and relying upon local expertise wherever possible.
4. The Branch will promote and adopt a comprehensive, integrated approach to
   planning.
5. The Branch’s staff will ensure that the person receiving support is central to all
   planning and documentation and that the person is supported to play a lead role in
determining the direction of his/her life.
6. Individuals/families must be supported to make informed choices. These choices may include non-participation in the Branch’s various forms of planning. This does not, however, absolve the service provider or Branch staff of their responsibility to ensure that people have dynamic yet safe lives in the community (CSB Monitoring tool).

Although CSB does not impose specific planning procedures on micro boards or agencies providing support, the assumption is that the plan “clearly identifies the goals, dreams, needs, and desires that lead to a fulfilling and dynamic life for that person” (Community Services Branch, Ministry of Health, p.2).

Several outcomes associated with a person centered paradigm of support are reflected in the monitoring categories and expectations set out in CSB documents. These include: (1) health and safety; (2) personal power and choice; (3) personal value and positive recognition by self and others; (4) a range of experiences which help the person participate in community life; (5) good relationships with friends and relatives; and (6) ability to choose daily activities and pursue personal goals (CSB, 1994). Appendix C provides a sample of CSB’s monitoring tool.

Racino et al. (1993) observed that quality of life markers can be present in print but not practiced. Two aspects of CSB practice were of particular interest: (1) The organizational conceptualization of lifestyle quality; and (2) personal perspectives of members of CSB. Members of CSB described how they monitored lifestyle quality and aspects which they deemed to be important. Fundamentally, they are striving for support agencies to “honour personal expectations, and get to the bottom of who the person is and what the person wants.” They do not define quality of life, but rather define the process by which it can be determined what individuals and their supports define as quality of life.

Service coordinators at CSB attempt to become involved in peoples lives, attending parties, going out for lunch etc. Monitoring of lifestyle quality is ongoing and has both formal
and informal components. The regional coordinator of CSB summarized how the Branch attempts to evaluate lifestyle quality from a holistic perspective.

Most monitoring tools use domains and areas or whatever and we’ve got that too, but I think one of the important things is... the major issue is the personal satisfaction. Like the person’s expectations for what they want in their life, all of that is trying to get them to define their own quality of life. But for me and the bureaucratic situation that I sit in, it’s the inter-connectedness of all of this which means a lot to me.

I think too often these things have been looked at in isolation. They’ll talk about community involvement, and they’ll talk about personal relationships, and they’ll talk about a person’s home, but they’ll talk about them all in separation from each other. And really it’s the inter-connectedness of all of that where life really happens. And that’s what I like about some of the stuff that we’re doing, is we look at that inter-connectedness. It’s when people get this inter-connectedness that people start seeing what quality of life is all about.

Individual members of the Branch differ in what they consider quality of life outcomes, but as a group they share a common framework. Choice, self determination, respect and relationships are considered important markers of quality of life. A senior member of CSB referenced her perceptions of lifestyle quality to persons receiving support from the Branch.

(Lifestyle quality) ... it’s the feeling that you have something that is important to give, and that you are valued, and that this world isn’t just going to chug along exactly the same way if you’re not in it. It’s not even what I have finalized, but that it is my presence that is important.

It is difficult to define but my sense of beingness is an important attribute. And of course that is very much how I value people who have disabilities. I think the world is richer, you know the society is only as strong as it treats its weakest members. And it’s not a very strong society if we don’t have a place for people who need more support than we may need.
The purpose of lifestyle planning tools is to search for capacities in individuals, and to assist in the attainment of a quality life in the community. Secondly, the parameters of a quality of life in the community include choice, respect, community presence, and community participation (O'Brien, 1987). Technically, facilitators at Victory Housing and service coordinators from CSB are paid supports and are part of a formal support structure. To be effective they needed to develop relationships with the people they support, these relationship may be professional as well as personal.

CSB senior members discussed their views concerning the positive elements of the micro board approach, and components that need to improve:

Interviewer: What types of issues have been problematic with the micro boards?

Regional Manager: ... The good intentions of the micro boards sometimes don’t bring the administrative where with all, or ability to set up the contract and manage some of the other aspects of the agreement with government.

If there has been a struggle it hasn’t been so much, perhaps, with the good intentions of the micro boards regarding the service they want to provide for the people that they are involved with. But, we’ve certainly been able to identify and be concerned about their lack of understanding around the contract and their agreement. One of the things is that we are learning that we need to help and encourage competencies around the contract end as well as around the support end. We’ve identified it, but we haven’t been that supportive in making it happen. We usually just throw it back to the micro boards to make that happen. We need to work to make that happen.

Regional Coordinator: We need to get the administrative end in order because the bureaucratic function of government very much looks at fiscal competency. It is still an experiment in the broader government purview, and a micro scope will be turned on it. And in some ways to discredit it. So we need to get it together.

We have been the buffer for the downfalls, and have figured out where to get the money because we have been so
committed to the project. But I can’t say for sure that that would continue if we weren’t here, and we may not be. And that worries me.

Interviewer: What are your personal beliefs about micro boards in terms of giving people more self determination, more choice, more control.

Regional Coordinator: None of that is in question, because we value it. However, in a few cases we have had situations with certain families where the control issues have been difficult, where we’ve seen that the person has lost more self determination by being under the influence of their family.

Service Coordinator: You know I go into both group homes and agency settings. I mean I sit down with the micro boards and it’s real life stuff. And I go into many group homes and you are into some of the weirdest things. And you spend most of your time talking about the impact that those things have for the people, and 90% of your time trying to minimize that stuff and make it less weird.

Interviewer: You have an interesting perspective. You monitor programs in a wide variety of homes and you see the good, the bad, and the ugly of the group home scenario....

Regional Coordinator: Mainly the bad and the ugly. We’re really quite down on group homes right now... I mean we’re really quite down on them... You know they always talk about the next generation dismantling the previous generations good ideas. Well I think people are going to spend the next generation dismantling group homes.

Service Coordinator: You know the most ridiculous thing is that I sit down in group homes, and I have to get people to commit in writing that they are going to take a person to the store, and get the flowers that they want for the center piece. Because it doesn’t happen, month after month unless I do that.

Regional Coordinator: Don’t forget we set up group homes, even though we had our values statement. We are talking about the things that we have done.

Regional Manager: By comparison to most other things, micro boards are still closer to any other service that we’ve supported, in terms of giving people more choice and control in their lives. Even looking at individuals supported by larger
society's who might live by themselves, and be seen as having a contract around themselves. There is not all the intentionality around supporting that individual that there is surrounding the micro board.

**Summary**

CSB is a formal support system which funds, coordinates services, and monitors group homes and other support arrangements throughout the province. They are funding approximately 30 micro boards throughout the province.

The philosophy statement that guides the Branch has several points which are central to a person-centered paradigm of support. These include: (a) the right to self determination and choice in all aspects of daily living; (b) a focus on quality of life and lifestyle outcomes; and (c) a commitment to include people with handicaps in the general community.

The organization is small, and is unencumbered by an entrenched bureaucracy. Administrative leaders are able to exercise more flexibility when they develop contracts. Service coordinators try to be present in peoples lives, and develop a relationship based on respect and understanding. They assist the person and their support network to develop processes to examine quality of life, rather than defining what it is, or is not.

The Branch discovered that the group home model did not meet the needs of many people, and were willing to support innovative projects. There is a cohesive commitment to the people that they support. As one service coordinator states: “I never have to start with values. You know that’s a given when I talk to Cyndy and Dave. I Just have to explain the issue and then I get support around that, ...I don’t think it is like that everywhere.”

Both Victory Housing and CSB shared a commitment to create better lives for the people that they were supporting. Victory provided the concept and facilitation and CSB provided the funding base and monitoring functions. This convergence created a vehicle for
Lisa, Jason, and Sarah to explore their own individuality and autonomy. A senior member of CSB reflected on this convergence:

I wished it all laid in us but I'm glad to say it doesn't. Because Sarah and her family, Lisa and Jason demanded of the service system a different way of doing things. Their lives, their expectations, what they wanted from life, how they wanted their lives. And they said “We’re not taking what you’re offering us, we want something different.” Yes we are people with values and all this kind of stuff, but we also work with people who say “I got a way I want my life to be, and I’m going to make sure you know about that and I’m not going to take second best.”

Victory Housing and CSB provided the participants of this study, Lisa, Jason, and Sarah with person-centered alternatives to traditional supports. The effects of this person-centered approach on the lives of the three participants in this study are explored in the following chapters.
CHAPTER VI

"WELL BEING"

JASON’S STORY

Personal Profile

Jason (pseudonym) is a bright, friendly, twenty seven year old man. In his words: “I would say I am outgoing. I like to play a lot of practical jokes. I don’t take any guff. I don’t see myself as being disabled. I see buildings as disabled. The barriers are in society.”

Jason’s friends and family describe him as “laid back, mischievous, curious, slightly reckless, and free spirited.” Jason said of himself, “I’m fairly free spirited.” He has a broad range of interests which include hockey, soccer, wheelchair boccia, ballet, swimming, computer games, walks, restaurants (Orestes, Italian, East Indian, and Oriental) parasailing, sailing, horseback riding, movies, TV, “and almost any kind of music except country and western.”

The author met Jason in September 1994, when Jason and Lisa were married and living together, and asked them if they were willing to participate in the present study. Jason has cerebral palsy-spastic quadriplegia with athetoid movements. As a result, his arms may rotate in a jerky circular motion, and his speech is initially difficult to understand. Jason was presented with a written description of the study (see appendix a) and asked, “is this easy or hard to understand?” Jason replied, “Easy.”

The residential facilities with which I had been familiar were uniformly well decorated, clean, but sterile. In contrast, Jason’s apartment was a little messy, had a few dents in the walls, but it seemed like a home. Pictures of his family and friends decorated the walls,
and sat on the book shelves. There were personal papers and a computer in his study. Jason also has a pet dog. When I interviewed him, he was in his wheelchair in the middle of his living room wearing a T-shirt depicting his favorite band, “U2.” During the course of the next eighteen months I accompanied Jason to activities in the community and visited with him at his apartment. It was easy to develop a friendly relationship with him; he has a very relaxed manner, and his support structure is informal and consists of people who are close in age. His relationship to them is non hierarchical. When visiting Jason at his home and in the community, I had the sense that Jason was “hanging out” with his peer group, rather than receiving service from his staff.

Jason’s speech is clearer when he is relaxed, and at first I had some difficulty understanding him, but this problem disappeared after several visits. Jason stated, “I’m best after one beer.” In natural and relaxed conversation, a ten second interval between utterances may be present. Speaking for Jason takes considerable physical effort, which makes it difficult for him to communicate with new communication partners. Stress may cause long intervals between utterances. If his communication partner is having difficulty understanding him, Jason spells the misunderstood words.

During the eighteen month study period, Jason talked about his life history, his perceptions of the role of the micro board, his perceptions of quality of life in the micro board project, and reflected on his future. Jason has a supportive family, and is valued as a contributing family member. His mother, Hanna (pseudonym), and brother Jim (pseudonym), provided details of Jason’s life and talked about their impressions of lifestyle quality in the micro board project. This chapter examines (a) Jason’s personal history and experiences in
the handicapped continuum; (b) Jason’s inclusion in the micro board project; (c) Jason’s present lifestyle and support network; and (d) Jason’s impressions of quality of life.

**Jason’s Personal History**

Jason attended segregated classes during his school years, and lived in a group home prior to his involvement in the micro board project. His history reflects the effects of segregation on his self image and autonomy. Jason described the key events in his life from birth to his present situation. His comments were recorded on chart paper. Throughout the study, Jason had access to the recorded documents, notes, and charts which listed major life events.

**Family Life**

Jason was born in Halifax, Nova Scotia, on April 20, 1968, and is the youngest of five children. He does not remember much of Halifax, but he does remember the inclusive nature of his immediate family. The notion of family elicits strong positive images for Jason. Photographs of Jason as a young child show him smiling and involved in family functions. According to Jason’s brother, Jim, “he used to get sent to bed if he didn’t eat his dinner. He had the same rules as everyone else.”

Jason’s brother described some of the relatives reaction to Jason’s birth. “When Jason was born we had relatives that said forget about him... put him in an institution, it’s the best thing that you can do... I was seven years old. I will never forget that, and I have never forgiven those relatives.” Jason recalled his grandfather’s negative attitude toward disability, and the supportive and inclusive nature of his mother.

_{My grandpa told my mum to put me away, and forget about me, and forget she ever had me. Of course she didn’t listen. She was really mad until he died. I found out when I was eight. When I found out, I changed my mind about my grandfather. I didn’t know what to do. I liked him but I didn’t like him._

89
The attitudes of several of Jason’s relatives were hurtful, and he recalls them to this
day, however the strong support of his mother, brother, and sisters allowed him to maintain a
positive self image, and facilitated his inclusion in family life and community activities from
an early age.

*Introduction to the Handicapped Continuum in Education*

In 1972, Jason and his family moved to Edmonton, Alberta. It was in Edmonton that
he first experienced segregation. Jason was schooled in a hospital setting of 200 people.
Some students lived at the hospital. Jason, due to the support of his family, was able to
reside at home, and came to the hospital school on a bus. He was not able to attend the same
school as his brothers and sisters. This time is significant for Jason, as he was an included
and valued member of his family, but segregation in education for persons with disabilities
was the norm. Jason described his first encounter with the handicapped continuum of
educational supports for children with disabilities.

I felt it wasn’t fair... It was really sterile. It was by a mall. We
hung out at the mall a lot. One part of the school was like a jail
for juvenile delinquents. We weren’t allowed to go to that
section. Most of the kids in the school were my age, some kids
lived at the hospital and came to class on stretchers.

One of the teachers at my brother and sisters school wanted me
to go to a regular elementary school. It was right in the
neighborhood where we lived. It was two blocks away, but the
government said “no.” I remember Mrs. Rude (Laughing), and
she was, and Mr. Good. I didn’t like them.

Although Jason had painful memories of the segregated school, he had fond
memories of the relationships he developed with the friends he made at the school.

It was okay for awhile (segregated school), but I wouldn’t want
to go there for a long time. And I did, I was there for twelve
years. I did get to do a lot of things like going to camp. I met
Fiona at camp. She was my first girlfriend... I also met Monica (friend) while I was at Glenrose...

Jason’s closest relationship was with his brother Jim, and it was through this relationship that Jason was included in typical community activities. From Jason’s perspective, Jim was his brother and his best friend. “I would do lots of stuff with my brother, he was like my best friend, we went to Klondike days, hockey games, football games... I got into a hockey game for free. One of Jim’s friends, Simon’s dad, got me into a lot of games.”

Jason and his mother moved to Vancouver in 1985. Although he was excited by the prospect of moving to the West Coast, he felt a sense of loss in terms of leaving his girlfriend and other family members. Jason’s mother was first interviewed on April 25, 1995, when she came to Vancouver for Jason’s birthday. Hanna described the events leading up to the move to Vancouver and her rationale for leaving Edmonton.

It was becoming more and more difficult in Edmonton. I was doing most of the supports, and it was so cold that winter (1985). It was awful. I was shoveling snow for six months. I would shovel a path to get Jason’s wheelchair to and from the door in the morning, and then I would have to do it again in the afternoon.

I guess too, was the fact that I was leaving something behind that wasn’t great ... a broken marriage. So I decided I was going to take Jason and make a start in Vancouver.

Although Jason had always wanted to move to the West Coast, he found the abrupt nature of the move to be stressful. His relationship with his girlfriend and sister were an important part of his life, and leaving them to start a new life with his mother was difficult.

... I couldn’t believe it. My mom had always said jokingly that she was going to move while I was at camp. Before I went to camp I found out that we were moving. (We) didn’t even go to the house, she just picked me up and we left. I felt sad. I left my girlfriend behind, and my sister was pregnant.
Jason found the West Coast to be more inclusive than Alberta. “I couldn’t believe the difference. The attitudes of the people are so different, Alberta’s full of rednecks.” Jason and Hanna found an apartment in a central area of Vancouver. Jason was sixteen at the time, and technically only adults were allowed in the building. After Hanna explained that Jason had a disability, they were permitted to reside in the building. Hanna worked as a nurse at a nearby hospital. From Jason’s perspective, his living space and neighborhood were well suited to his preferences.

I really liked the neighborhood,... and the building was pretty accessible. There was a little step down at the entrance. It was by Max’s Deli. I would get whatever I wanted. I liked everything. We always went walking around Broadway, False Creek, and Granville Island.

Jason was required to undergo an extensive assessment to determine his school placement. He attended a special class at a rehabilitation center as part of the assessment which took two months. According to Jason, “It was hell, but I liked the teacher.”

The assessment procedure was stressful, physically taxing, and emotionally draining. His future was in the hands of professionals who did not know him. He was enrolled in a segregated program at a secondary school. At various times, there were from seven to thirteen adolescents with disabilities in the class, and students were able to attend other classes at the school. At first, Jason was fearful of these classes. He explained, “I was afraid of change.” But he soon began to enjoy the lifestyle and culture of the high school, and related; “I remember, I really liked it...the independence.”

While at the secondary school, Jason became acquainted with Lisa (his future bride), who was attending another class for students with disabilities. Jason also met Pat, with whom he is currently working in a disability advocacy group. Presently, Jason and Pat play
wheelchair boccia ball together. Jason enjoyed the semi-integrated program and made several friends. Jason stated, “They helped me raise money to go to New York for my operation, through the car wash. They kept the money for me until I went. It was better than Edmonton.”

Jason’s most influential contacts with the disability culture and the continuum model occurred in 1987, when he turned nineteen. Prior to this, Jason was supported by his mother and personal care attendants. His mother found these responsibilities to be difficult at times, especially when she needed to cover for attendant care if there was a scheduling problem. Jason described one such occurrence. “An attendant forgot to get me for my grad pictures...The building superintendent had to call my mother at work...Mom had to come home and rescue me.... I got them done.”

The supports available to Jason and his mother were not ideal, but they allowed Jason to be supported at home. In British Columbia, when a person with a disability turns nineteen, they enter the adult service system. In Jason’s case, as he reached nineteen, his physical size necessitated more extensive care. Without flexible and individualized supports, it became impossible for Hanna to manage.

Jason and Hanna were confronted with limited options; they could either choose a group home or a hospital setting. Hanna described this juncture: “It was very tough to admit I couldn’t be everything to my child. It was scary...I felt I had to be on top of things.” For Jason, the arbitrary nature of leaving his mother’s home and entering the adult service system was terrifying. Upon entering the adult service system, he lost autonomy regarding residential options. He was first presented with a hospital setting as a place of residence. Jason discussed his reaction to this restrictive option.

I did not want to leave my mom’s house. It’s like they were telling me where to live. I had to choose between the lesser of two evils... I toured Y (hospital setting) and was encouraged by
staff not to go there. I wouldn’t have my own room. I didn’t like it at all. It reminded me of Glenrose,... it was like an institution, there was noise, crying, and it was overcrowded.

The only option to living at a hospital was a group home. Group homes, from the exterior, appear to be homes much like the others in the community. When this physical appearance is combined with a philosophy statement promoting inclusion and individualization, they promise a good option for families of persons with disabilities. Hanna visited the group home available to Jason and noted, “The philosophy was wonderful. It seemed like a family group. I was generally pleased, but there was not as much control as the philosophy had stated. Some of the staff you wouldn’t choose to work with your kid.”

The Continuum Model of Adult Services: Living the Handicapped Culture

Jason’s impressions of life in the group home were explicit. Jason felt a loss of personal identity and autonomy, experienced physical and sexual abuse, and experienced a loss of mission and purpose to his life. Jason describes this juncture.

I moved in on my 19th birthday at noon. I will never forget that birthday. I cried, I didn’t want to leave my mom’s house...Get up, watch TV, eat, watch TV, that’s what we did. I lost my independence. I couldn’t do what I wanted....So, I lost interest.

...In a word, living in a group home was hell. But I did make some friends there. In the group home I had more freedom than a lot of the people I knew (friends in other group homes). I could choose when I got up and what I could eat, the staff tried to make it more regimented, but we wouldn’t let it happen. There was one person, Cheryl, that was good, she broke a lot of the rules for us....She really did not care about the rules and thought that they were stupid.

Jason experienced physical, sexual, and emotional abuse while living in a group home. He described his encounters with abuse in the group home.

I know all about abuse. There was a person that tried to sexually assault me in the shower. I brought it up to people and
no one did anything about it. Finally, the person was fired for being late.

I experienced everything. ...I was punched in the stomach. ...One guy took money from me. There were 64 people in four years that took care of me. I didn’t like it at all... There was only one person that was good and she couldn’t take it anymore. She didn’t like working in the home. So, she quit.

In 1989, Jason’s mother returned to Edmonton. His brother, Jim, moved to Vancouver to be closer to Jason (1988). Jim and Hanna provided Jason with support and stability during difficult times. Jim described the effects of group home living on his brother.

When Jason moved into the group home it was shocking. I was living in Calgary at the time...He had just moved in, and I had come out to visit him .... At the time it sounded like a good deal, I mean the options presented to him were Y Hospital or a group home.

We had seen Y Hospital, and the way the group home was described sounded pretty good. But then I remember visiting him a few months after he was in there. He was a completely different person. Didn’t talk...I would walk into the room and it was like walking into somebody who had been in a closet for three days.

After about an hour or so he would click out of it and we would joke around and I would see the old Jason again...Time and time again I would go visit him ... I moved out here largely because I wanted to be with Jason. I felt like if I didn’t call and say “let’s go to a movie,” then he wasn’t going to do anything. And I think that was pretty much the truth. My worst fears at the time were pretty much true.

...It was terrifying...He had some program loaded into the computer ... it was like a pinball machine...he couldn’t play it but he would hit a button and the ball would bounce around the screen for as long as you wanted to watch it. And he would just watch it and watch it. I would try to talk to him and he was just mesmerized by this thing. And I thought, “this is scary.”

He just changed in the time that he was in a group home ... He became institutionalized. Before that he had a lot of ambition... When he was 18 he was very eager to get on with his school, but I think it was delayed three times. He was accepted into a
program some place, but they didn’t have anyone who could take him to the bathroom, so that kept him out for two years, maybe three. After you’ve been through that for a couple of years, it’s pretty easy to sit and watch the TV all day.

I think the time he was there too, was probably the worst time for someone to be in it. You know to be eighteen, nineteen years old. It was just...he should of been out beating the world and instead he was stuck in there for three or four years.

Jason’s choices were severely limited in the group home. He had to share the limited resources and supports with five other people. His choices mostly involved basic daily living issues, such as when to get up and what to eat. Jason said, “I would say we had to fight for our rights.”

He was unable to engage in personalized, preferred activities on a regular basis. The times that he did access the community were mostly with his brother, or Cheryl, a preferred staff person. Although he wanted to return to school, the organization could not figure out how to provide him with support to access the washroom. As a result, Jason “was starting to give up.” Jason reported that the group home was not valued or viewed in a positive way by the neighbors. According to Jason, “we were not respected by the neighbors, we were seen as a nuisance because the Handi Dart (handicapped transport) blocked the alley.”

Breaking Free of the Continuum

Jason’s life up to and including the four years that he spent in a group home can be described as bi-cultural. His life with his brothers, sisters, and parents was inclusive, and Jason developed a strong relationship with his brother, whom he considers his best friend. Jason and Jim accessed the community together, and Jim, being seven years older, helped Jason with the traditional rights of passage in adolescence. According to Jason’s mother, “Jim never coddled Jason, he pushed him and so did we.”
In Jason’s early adult years he began to lose his personal identity and desire, but he was well connected with persons with disabilities. It was within the continuum model that Jason met Lisa, and the micro board option was explored. It was Lisa who learned about the micro board concept from one of her roommates. She contacted a person at CSB, and initiated the project.

Jason’s reflections of this time consist of loss of motivation, and how influential Lisa was in changing the course of their lives. He explained,

I would have taken the initiative but it would have been a lot later (micro boards). I would never believe it now that Lisa got it going. It’s real funny, she was a lot more outgoing then...Lisa initiated going out together... She was pushing for the micro board and getting married... But I proposed to her...Lisa contacted Lynn (Facilitator, Victory Housing). I contacted Jim in Europe, and told him he was on the micro board. We got married on July 20th, and moved to North Van in August 1991.

Several support structures assisted Jason to move out of the group home. First, he had Lisa’s support; it was she who took the initiative to engage Jason in a relationship that led to marriage. Second, he had the support of members of Victory Housing, and members of CSB. Third, he had the support of his brother Jim. Jim explained how these support structures came together to create Jason’s micro board, and his initial, skeptical reaction.

I was in Turkey and I got this letter from Jason. This letter said, “Dear Jim if you’re standing up you had better sit down because I’m finally getting that operation (operation for his spasms). Now, if you’re sitting down you’d better lie down because I’m getting married.” And there was a Polaroid shot of him parasailing over Okanagan Lake, and on the back was written, “ha, ha, here’s something that you’ve never done” ...

Initially when they announced they were going to get married it sent a panic into the service system. The initial reaction was that they can get married, but they can’t live together. That was the initial reaction.

So we got back and he told us that this woman is going to help him move out, and that they were going to get control over the
money and get a micro board. And that woman was Lynn. He had met Lynn through Lisa.

I said, “yeah, yeah, yeah, I’ve heard this before.” Over the years Jason has been promised the moon, and this has happened again and again and again. This is after a series of disappointments, you know people promising him that he could go to school and this and that.

A few months later I met Lynn, and she explained to me what was going to happen. I was the last one to get up to speed with it. I thought it made perfect sense, but it will never happen. My first impression was, “who was going to give us a hundred thousand dollars to get things running?” Once I figured out Lynn was for real; I’m the biggest booster now. I am now on the board of Victory.

Several factors appear to have influenced Jason’s life as he moved through the traditional disability system to the point of entering into the micro board pilot project. Jason’s inclusive family supports gave him a referent, and a normative culture to measure against life in the disability continuum. Jason did not think of himself as disabled but his experiences with the restrictiveness of the adult service system diminished his personal ambition. However, he still had the support of family and friends and the support of Victory Housing and CSB.

Lynn Percy played a central role as a facilitator from Victory Housing. According to Jason, “she has done a lot for me, I consider her a friend.” Jim is more effusive, “Lynn is amazing. She knows how to play the game. She is just unbelievable. She knows what’s available, she’s got the contacts and she’s got the chutzpah. She was very key to getting this involved (micro board) for Jason and Lisa.”

Jason and Lisa’s first choice of residence in the micro board project did not meet their expectations. They thought that they would enjoy the quietude of North Vancouver, which is nestled beneath the Coast Mountains, and is less urban than Vancouver. But, they found
themselves isolated, and too dependent on an inadequate bus system. As they were renters in the general housing market, they were free to choose another residence. They chose an apartment in a southern part of Vancouver, which is Jason's present residence.

After living together, Jason and Lisa found they were not as well suited to one another as they had thought. Prior to their marriage, they lived in separate group homes and the differences in their personal preferences, mannerisms, and ambitions did not fully emerge until they began living together. In March 1995, they separated and Lisa moved to Richmond. The micro board gave them the opportunity to experience life together, and it also allowed them to establish their own living arrangements when they separated.

A summary of the key events in Jason's life illustrates his impressions of life in the handicapped continuum, and life in the community with his family and friends.

### Summary of Key Events In Jason's Life

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1968</td>
<td>Birth</td>
</tr>
<tr>
<td></td>
<td>Hanna-mom</td>
</tr>
<tr>
<td></td>
<td>Len-dad</td>
</tr>
<tr>
<td></td>
<td>Jim-oldest brother</td>
</tr>
<tr>
<td></td>
<td>Cathy, Carol, Jan-Sisters</td>
</tr>
<tr>
<td></td>
<td>Stayed in Halifax until I was 4 (1972), did not remember much of Halifax.</td>
</tr>
<tr>
<td>1972</td>
<td>MOVED TO EDMONTON</td>
</tr>
<tr>
<td></td>
<td>Fondest memory of Edmonton was going to London, England,</td>
</tr>
<tr>
<td></td>
<td>Went with my school</td>
</tr>
<tr>
<td></td>
<td>I went to school in a hospital (Glenrose) 200 people</td>
</tr>
<tr>
<td></td>
<td>It was really sterile</td>
</tr>
<tr>
<td></td>
<td>It was by a mall</td>
</tr>
<tr>
<td></td>
<td>We hung out in the mall a lot</td>
</tr>
<tr>
<td></td>
<td>Met Fiona at camp</td>
</tr>
<tr>
<td></td>
<td>Hung out with my family, we were a tight family</td>
</tr>
<tr>
<td>1981</td>
<td>DAD AND JIM LEAVE HOME</td>
</tr>
<tr>
<td></td>
<td>Dad leaves house</td>
</tr>
<tr>
<td></td>
<td>Jim moves around.</td>
</tr>
</tbody>
</table>
Summary, Continued:

1984  
SISTER GETS MARRIED  
Cathy gets married, New Years Eve, 1984  
Carol is at Red Deer College  
Jan, me, and mom still at home.  
I always had a lot of people around me, I was alone  
My grandfather died right after my sister got married  
I didn’t get to go to the funeral, my mom didn’t want to take me out of school, it made me upset  

1985  
MOVE TO VANCOUVER WITH MY MOM  
Mom and I move to Vancouver  
I couldn’t believe it  
Moved to 13th and Oak (adult building)  
I really liked the neighborhood  
Attendants took care of me while my mom was at work  

ASSESSMENT AT Z AND J.O. HIGH SCHOOL  
Went to Z for assessment to decide where I went to school  
It was hell but I liked the teacher  
Enrolled in separate class at J.O. High School  
I was afraid of change at first  
I really liked the independence.  
John Oliver was a lot better than Edmonton  
I went from grade seven to grade eleven in english, in one year  
I had a better teacher  
I did a little better in math than in Edmonton  

1985  
MET LISA AT J.O.  
Lisa’s idea to start going out  
I didn’t want to go out with Lisa  
She always phoned  

1987  
MOVE INTO A GROUP HOME  
Moved into a group home on my 19th birthday  
I will never forget that birthday  
I cried, I did not want to leave my mom’s house  
In a word it was hell.  

1990  
FIND OUT ABOUT MICRO BOARDS  
Lisa finds out about Micro-Boards from S in C House  
I propose to Lisa  
Hook up with Lynn Percy and tell Jim he is on the micro board.
Summary, Continued:

1991  GET MARRIED AND MOVE INTO OUR OWN APARTMENT  
      Married on July 20th  
      Moved to North Vancouver with Lisa in August  
      Too isolated  

1993  MOVE TO MARPOLE  
      It was much better, I like the area  

1995  SEPARATION  
      Lisa and I separate  
      It was pretty tense, we were fighting a lot  
      Things are better now  
      It's home  

1995  START GOING OUT WITH KATE  
      I am really happy  
      Happier than I've been in years  

1996  BACK TO SCHOOL  
      I took English and biology  
      Now I am in math and biology  
      I'm finally getting my grade 12  

**Jason's Apartment and Neighborhood**

Jason now lives in a subsidized housing cooperative in the south section of Vancouver. Jason chose the apartment, and is simply another member of the cooperative. He is one block from the main artery of the city, and is approximately six kilometers from downtown. His apartment is close to shops, restaurants, coffee houses, banks, and various bars. Most of the streets have “indents” for wheelchairs, and Jason is able to access most places in his community. According to Jason, “it's not barrier free, but it's not bad.”

All persons in Jason’s building are renters, however, they are an autonomous unit and share in the running of the cooperative. Initially, Jason was on the board of directors but has since opted out, “It was a bit of a joke, it was really unorganized.” Jason’s building is
slightly unkempt, but not rundown. There are approximately thirty units in the building and there is an attempt to build a sense of community within the cooperative. Residents have potluck dinners, bingo nights, etc. Recently, the cooperative built a courtyard that seems to attract more people, and serves as a social arena. Jason does not socialize extensively with members of the co-op, but this interaction is available to him if he so desires. The atmosphere is congenial and inclusive. Jason occasionally visits with Jim, another man who used to be the president.

Jason lives on the second floor, which he accesses via an elevator. He can exit the building alone as there is a button positioned specifically for wheelchairs which automatically opens the door. He requires assistance to enter the building as it necessitates using a key, a fine motor activity Jason is unable to negotiate. According to Jason, "a remote would be nice."

Jason has a three bedroom apartment designed for a person in a wheelchair, which has long hallways and an open kitchen (approximately 8' x 10'). The Canadian Mortgage and Housing Company provided Jason with funds to enlarge the bathroom so that he could access it with his wheelchair. Jason said, "I got one of the last grants to do that sort of thing, just before the 1994 budget."

He spends most of his time in the large living room where pictures of his family are prominently displayed. His stereo unit and television are central, and he enjoys these leisure activities. According to Jason, "I am a night owl, Letterman is my favorite night time show."

His apartment is comfortable but not extravagant. Some of the furnishings were funded through CSB. Others were supplied by family and friends, and personal purchases. He
has a balcony where he keeps his barbecue, and serves as the smoking area for visitors and staff. Jason does not smoke.

Jason’s bedroom contains his extensive hat collection, which he has obtained from his trips to different places in North America. He also has a television set and phone that Jason operates from his bed. “My remote is actually a garage opener that has been rigged by the Kinsmen.” The second bedroom is occupied by Jason’s roommate, Tyson (pseudonym), who is seldom home, and minimally involved in Jason’s life. The third bedroom serves as Jason’s study, and the place where his support staff do their administrative duties. The study is cluttered as Jason is adamant that he doesn’t want his place to be sterile and “institutional.” Jason rates cleaning as “sixth on the list of ten things that are important.”

Jason’s computer is sophisticated, and loaded with a number of computer games. His brother is looking into a voice activated system. Presently, Jason uses a head stick to access the computer.

Extensive renovations were not necessary, other than a new drain and shower in the washroom. Various technologies are present, but they are relatively unobtrusive. These include adapted knobs for his telephone and intercom, a switch beside his bed to alert his neighbor and ambulance in case of an overnight emergency, his battery operated wheelchair, and a head stick for his computer.

**Jason’s Support Network**

Jason’s support network consists of an array of formal and informal supports. Jason’s informal supports are: (1) his micro board, which is made up of his brother Jim, his sister in law Kate, his aunt Sam, his friend Simon, and Jason; (2) members of his family including his mother Hanna, his father Len, and his sisters Cathy, Carol, and Jan; (3) his friend Pat, who is
a member of Victory Housing; (4) Tim, a volunteer at Boccia ball; and (5) his cousins Paula
and Dianne.

Jason’s closest ties are with his brother Jim. According to Jason, “I don’t know what
I would do without him, he has been there since day one.” Jason and Jim have regular phone
contact and may get together for dinner or a beer approximately once per week. Jason
maintains regular phone contact with his mother (once per week), sisters (once per month,
and father (once per month). His mother lives approximately 1,000 miles from Vancouver,
and Jason often visits at Christmas. Jason’s micro board meets approximately three times per
year. Jason’s micro board assists him with lifestyle planning (MAPS), hiring staff, and
negotiating with CSB. Jason said, “they help me get money, that’s a bit over my head. I try to
use the lifestyle planning tools, it’s important.”

Jason’s formal supports are comprised of: (1) a facilitator from Victory Housing,
who assists him in the set up and management of his micro board; (2) members of CSB, who
fund and monitor his micro board; (3) community care personnel, which includes his doctor,
dentist, physiotherapist, and wheelchair mechanic; and (4) five daily living supports who
come to his home. Figure 5 depicts Jason support network.

<table>
<thead>
<tr>
<th>Micro board</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jason</td>
</tr>
<tr>
<td>Brother (Jim), Sister-in law (Kate), Aunt (Sam), friend (Simon)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family and Friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother (Hanna), Father (Len), Sisters (Cathy, Carol and Jan), Pat (friend), Tim (friend), Cousins (Paula and Dianne)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Formal Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitator (Victory Housing), CSB Members (funding and monitoring), Community Care Personnel (doctor, dentist, physiotherapist, wheelchair mechanic) Five daily living supports</td>
</tr>
</tbody>
</table>

Figure 4
Jason’s Support Network
An innovative feature of Jason’s formal support network is that all of Jason’s staff are hired by him. He does not contract with an agency, and there is no differentiation between vocational and housing supports. According to Jason, “I think they are a joke, (differentiation of day and vocational supports).” Jason receives 12 hours of support per day. Jason said, “sixteen or seventeen would be perfect.” He hires the people that he feels are best suited for the job. His daily agenda is therefore set by him, rather than by an agency. The supports are tailored to meet Jason’s needs, rather than Jason having to “fit” into the structure or schedule of a support agency. Jason recalled his initial negotiations with CSB regarding the utilization of more traditional day supports, “They tried to get me into a more formal support structure, and I said ‘no way.’” Jason does not have any overnight support. If there is an emergency, Jason uses a call switch located beside his bed, and an ambulance and a neighbor in his building are alerted. His neighbor is paid a small fee to provide this on call service. Andrew (support staff) remarked, “She’s earned her money, one night Jason woke her up when his covers fell off in the middle of the night.” Jason laughed and said, “She said, ‘you should have underwear on.’”

Other innovative features of his support network include supports and services that are community based rather than facility based. One such service is Jason’s mobile wheelchair mechanic. Jason’s mechanic has a disability and understands the lifestyle needs of his clients. If there is a problem, Jason calls his mechanic and the mechanic comes to the apartment. The problem is often fixed on the spot without sending the chair to a shop, or out of town for servicing. Jason said, “he is the only one that is mobile in the Lower Mainland.”
Jason also requires the services of a physiotherapist and an occupational therapist in the following areas: (a) assist in the design of technical aids in his apartment; (b) assessment, prescription, fitting, and follow up regarding seating, positioning, and mobility in his power and manual wheelchairs; (c) in conjunction with Jason, training staff in physical handling, transfers, body mechanics, and lifting techniques; (d) design and monitor, range of motion and stretching exercises (movement program); and (e) consultation regarding eating and feeding. Jason’s therapy needs are supplied by a community based organization.

... Community Therapists (pseudonym) are dynamic community based rehabilitation consultants with a strong commitment to helping people achieve their full potential in natural settings.

...Community Therapists is committed to meeting the ongoing needs of our clients - to enhance their lives in terms of health, safety and independence. All of our interventions are based on individualized assessment. We work with each person’s support network including family, friends, teachers and caregivers, to carry out clear therapy objectives within the natural rhythm of a day. We are flexible in arranging therapy sessions that suit each client’s daily schedule. (Community Therapists Ltd., 1994).

One of the founders of Community Therapists described how the organization is attempting to develop supports from a community living model, rather than a facility based rehabilitation model.

... We’re working kind of outside the system. We pride ourselves on the fact that we’re trying some new approaches outside of the traditional models of rehabilitation and care...Our whole way of practice is developed around the community living model which is quite unusual for the therapy world.

Jason stated, “I really like them.”
The following section describes Jason’s activity schedule and a typical day in his life. Jason typically rises between 9:30 and 10:30 a.m. A support person arrives at 10:00 a.m. and waits until Jason calls for assistance. In Jason’s words, “I just say, 'hey Atanas or Andrew I want to get up.’” When Jason calls, the support person enters his room and helps him out of bed. Jason sleeps in a regular king sized bed.

Jason and his physiotherapist have developed a lifting and transferring technique, which his support workers have learned. Before Jason is transferred to his wheelchair, he chooses his own clothes, and a support person assists him with dressing, which takes approximately five minutes. Jason is a casual dresser and usually wears a t-shirt and shorts in the summer, and a shirt and pants when the weather is cooler.

Jason chooses his own menus. His preferred foods for breakfast include waffles, French toast, pancakes, or oatmeal. These choices may be limited to the culinary skills of the support person. Jason decides what to eat, but he does not participate in the cooking of the meal. His kitchen, as previously described, is small and Jason’s physical disabilities prevent him from cooking for himself.

Jason will either watch TV, listen to music, or converse with his support person while breakfast is cooking. Because he is unable to feed himself, he requires a support person to feed him. He drinks with a straw and a cup holder attached to his wheelchair. It takes Jason approximately one half hour to eat. After breakfast, Jason attends to his own hygiene needs with his support person, who helps him wash his face and brush his teeth. Jason requires support in all aspects of the hygiene routine.

After breakfast, Jason and his support person decide what to do until late afternoon. A board mounted on a wall of his living room lists the days of the week and selected activities.
The board can be wiped clean with a cloth. Important appointments are placed on the board, but Jason does not always use it, "I usually keep my schedule in my head." Jason is not rigid about his day, and states, "I like it loose, I hate formal."

During the study, Jason enrolled at a local college, but he dropped out in March 1995 claiming that "the courses were too hard." He returned to the college program in September 1996. Between March 1995, and September 1996, Jason was unemployed and not attending school.

Jason’s work with the provincial steering committee on disability issues takes up a considerable amount of his time. He travels by ferry to Victoria, British Columbia, to the monthly meetings of this group. Jason described his role on the Realignement Steering Committee “as one of guide to the government, to the Ministries of Social Services and Health. Since I’m a consumer, I believe I’m there to help them do their jobs better... I don’t think the government should be telling me what I’m going to get after the fact.” (Ministry of Social Services, 1995).

Jason’s weekly schedule is fairly full, and typical of other twenty seven year olds living on their own. His days are usually spent taking care of daily living needs as required, such as banking, shopping, paying bills, recycling etc. Once these chores are completed, Jason and his supports may choose to go to a movie, take a walk in Queen Elizabeth Park, have lunch at a restaurant, coffee downtown, or a beer at a local pub etc.

Jason determines his own daily schedule. However, he is fiscally restricted in the things that he can do. As he is not working, his discretionary income is limited. Jason stated, “it’s minute.” According to Jason, “Vancouver is pretty accessible,” and is very leisure oriented. Public parks and gardens are abundant, the downtown area is lively, and a sea wall
circumscribes much of the city. There are a number of preferred places which Jason may access that are free. Following is an excerpt from my notes of a typical afternoon for Jason, in May, 1995.

Jason, Michelle (support person), and I leave for recycling about 1:00 p.m. Jason was a little slow moving today. He was just finishing his breakfast when I arrived. There are about four boxes of recycling materials. Michelle and I take two each. Jason is in his electric wheelchair. He operates it with a head switch. It takes a fair bit of concentration, so he is unencumbered with recycling materials.

Patty (Jason’s dog) stays in the apartment while we are out. Jason usually likes to lead in his wheelchair. Jason needs someone to open the door of his apartment. Once in the hallway, Jason leads the way. His elevator is small and it takes some maneuvering for Jason to position his chair. The buttons are accessible for Jason, but difficult to operate due to his spasticity. Michelle operates the elevator for Jason. Once on the main floor, there is a wheelchair accessible button which automatically opens the door. Apparently the button does not always work. Michelle opens the door and Jason motors ahead. His van is parked about a block away.

There are indents in the sidewalk and Jason is able to drive up to his van. His van is a 1993 customized Ford van with wheelchair lift and an extended roof. Jason has placed two stickers of his favorite hockey teams (Edmonton Oilers, and Vancouver Canucks) on the bumper.

Jason’s lift is situated in the back of his van and is easily operated with one support person. Jason simply drives onto the lift, is locked in, and is lifted into his van. Once in his van, his wheelchair is secured to a bolted track in the floor. Jason’s van, similar to his apartment, is personalized and somewhat “littered” with his stuff (cups, audio tapes, papers, etc.).

Michelle drives the van and Jason gives her directions. Their relationship is reciprocal and friendly. Jason, Michelle and I joke on the way to the recycling depot. Michelle is directive but respectful in her communication style. She has a physical presence. She is about six feet tall, drives a Suzuki 850 motorcycle, has a stud stapled to her lower lip, and usually wears “Doc Marten” boots and black pants. She has a dry delivery and sense of humor that Jason appreciates. Michelle
requested that she be referred to as “Bubbles” in the present study.

The recycling depot has a number of receptacles for various materials such as cardboard, metal, glass etc. The depot is not accessible for a person in a wheelchair. Jason remains in the van as Michelle and I deposit materials in the various bins and return to the van.

Michelle asks Jason: “what do you want to do now.” Jason decides to go to Queen Elizabeth Park in Vancouver. It is a beautiful sunny day and many of the flowers and exotic plants are in bloom.

On the drive to the park the banter is loose and friendly. According to Michelle, “I’ve connected with Jason, we get along well.” A three way conversation continues. Jason is very much the center. Michelle locates free parking that is not “Handicapped Parking.” Jason has to climb a curb with Michelle’s help.

They have a syncopated routine. Michelle tilts Jason’s chair over the curb and Jason drives onto the sidewalk. They have similar styles. Michelle in her “Docs” and Jason in his scuffed up boots, T- shirt, and banged up wheelchair. Jason seems to enjoy the freedom of his power chair and takes us down various steep paths. He swerves onto the grass every once in awhile and looks out of control. Jason and Michelle are relaxed however, and he gets back on track. Michelle jokes that “Jason’s rig is the Buick of wheelchairs.” Have discovered that the sports model of wheelchairs is a brand called the “quickie.” Jason’s wheelchair is by no means quick, but it is heavy and stable.

Very pleasant stroll through the park. Rhododendrons, tulips, daffodils and numerous other plants in bloom. The park is reasonably accessible, although there are several rock gardens that Jason is unable to access. He is assertive in his driving. He confidently moves through crowds. Impressive considering that he controls his chair with head movements.

After buying ice cream, we head back to the van. Jason ventures off of the sidewalk and down a fairly steep, grassy hill. I joke that Jason is “off roading,” in his Buick. He laughs and seems to enjoy challenging himself in his chair. Return home and Atanas and Patty greet us.
Jason has arranged his staffing in such a way that two different persons provide support on a daily basis. On the day described above, Michelle provided support from 9:30 a.m. until 3:30 p.m. and Atanas provided support from 3:30 p.m. to 10:30 p.m. This is the normal staffing schedule during the week. On weekends, Bob lives with him from Friday evening until Monday morning.

One of Jason’s preferred activities is to identify bus routes that are accessible. British Columbia is attempting to make its public transit system more inclusive and there are some wheelchair accessible buses. Presently, the buses are insufficient to meet Jason’s daily scheduling needs in Greater Vancouver. Jason uses the bus system approximately twice each month to “hang out” downtown, and venture out on his own in his power chair. As a matter of preference, Jason is more active during the afternoons and evenings.

On August 11, 1995, I accompanied Jason to a local restaurant within walking distance of his apartment. Jason says, “We’ll walk there,” or, “I want to go for a walk,” not, “I’ll wheel there.” We left his apartment to have lunch at approximately 1:30 p.m. The morning was rather busy as Jason’s wheelchair mechanic and physiotherapist had both booked appointments with him. His support person (Wendy) took Patty (the dog) for a walk, and Jason and I proceeded to the restaurant. Jason’s power chair was in for repairs, and I assisted him in his manual chair, which he cannot maneuver alone. He is unable to grasp or push the wheels of the manual chair. Jason directed me to the restaurant which was approximately five blocks from his apartment. Navigating through his neighborhood afforded insight into Jason’s mobility and accessibility issues as the following notes describe.

Jason and I are alone and heading to “Cravings” restaurant. I don’t know where I am going. Jason gives directions but it is sometimes hard to understand. The street noise is loud and I am behind Jason, pushing. Granville street is a little frightening. Four lanes of traffic. There are indents in the sidewalk for
wheelchairs. Crossing is tentative. I am nervous. Jason seems very vulnerable in his chair at bumper level. I wait to make sure that all of the cars have stopped. Constantly looking to make sure it is safe. Jason seems pretty relaxed. According to Jason, “it’s the most dangerous street I have to cross even with lights.” He seems to trust me. Safely cross Granville and head down 73rd.

73rd is much quieter, more relaxed. Big chestnut trees line the street. I comment to Jason that he “must trust the people pushing his chair.” He responds, “yeah.” I then asked him if I was pushing too fast, or too slow. His response, “too slow.” Jason likes speed. We are moving at a good pace and start talking about accessibility. Contrasted Edmonton with Vancouver. Jason says that Edmonton was more accessible but the attitudes of the people were not as inclusive. His term “Edmonton was full of rednecks.”

Not all of the indents in the sidewalk have the same slope or lip. Some are more difficult than others. On several I had to push with force to get the chair over the lip. On the street adjacent to the restaurant, the sidewalk ended and there was no indent to return to the street. It was a virtual dead end for someone in a wheelchair. Jason comments that it happens all of the time. Able bodied city engineers design from the wrong perspective. They need to consult people with disabilities.

Ease Jason off of the curb. Once again I realize how trusting Jason must be. He is tilted at a twenty degree angle and totally reliant on my dexterity and strength. I am nervous, he is not. We walk down the street as we have run out of sidewalk. The street is wide and not busy. The restaurant is hidden in a small industrial complex. It has a screened in porch adjacent to the parking lot. Access is from the parking lot. There’s no indent for wheelchairs. Once again I have to tilt Jason to get on the sidewalk.

The entrance is tight and the tables are very close together on the porch. I ask him if he wants to eat inside or out. Jason chooses inside. Jason comments that the door should open “in” and not “out” to make it more accessible. Waitress greets us and smiles at Jason. They seem to know each other. Waitress asks Jason where he would like to sit. Jason chooses inside, and waitress seats us in an aisle seat. Jason orders a Coke and a spicy Mexican pasta. Waitress smiles and says, “good choice.” Jason appears to be a valued regular customer.
Several issues appeared noteworthy as I accompanied Jason to “Cravings.” Most sidewalks in Jason’s neighborhood were wheelchair accessible, but were inconsistent such as the wheelchair accessible sidewalk that ended in an abandoned lot. Jason was undaunted by these obstacles and seems to relish the challenge of overcoming them. At “Cravings” restaurant Jason was a “preferred” customer, and the waitress addressed Jason, rather than me.

This connectedness was evident when I accompanied Jason and Michelle to the bank. Although Michelle physically performed much of the interaction, the teller directed attention to Jason, commenting that he (Jason) had a new haircut, and asked him about the upcoming weekend etc.

Jason’s schedule in the micro board project is spontaneous. For example, when I accompanied Jason from his bank one Friday evening, he suddenly decided he wanted to go to a local pub for a beer. He had a bad cold. The interaction between Jason and Michelle regarding this decision is indicative of the respectful, and humorous style that characterizes the relationship with Michelle.

Jason: Let’s go to the Fram (acronym for local bar).

Michelle: You know beer is not a good idea when you have a cold.

Jason: nods

Michelle: Paul, tell Jason it’s not a good idea to drink when you have a cold.

Paul: Jason it’s not a good idea to drink when you have a cold.

Jason: (laughs) I know.

Michelle: All right then, maybe we should go home first and change your shirt.

Jason: Yeah.
The above interaction represents a very different picture from the formal support relationships that often prevail in the disability culture, where adults are often told what they may do. The interactions and rule structures are often child-like and undignified. In contrast, Michelle informed Jason that his choice may make his cold worse, but she did not tell him he could not go to the pub. Jason’s choice was respected.

Jason’s schedule, lifestyle, and home are highly personalized. One evening Jason, Atanas, and I were sitting in Jason’s study talking about a sense of home and the contrast between Jason’s present situation and his life in a group home. Atanas had worked in group home settings. Jason and Atanas provided the following contrasts and impressions of life with a micro board versus life in the continuum model.

Atanas: ...I’ve worked in group homes....They haven’t been as homey as this place, they have this hospital type feel to it.

Jason: “Yeah, they’re ugly.”

Atanas: Yeah there isn’t that personal touch, say pictures on the wall of family, you know, maybe a little bit of a mess, you know plants and stuff. A couple of houses that I’ve been (agency run) of other disabled people, I mean they’ll have a couple of couches and a coffee table, the walls don’t have any personal stuff...it doesn’t feel like anybody’s home.

The difference with Jason’s place is that his family is involved and his staff are much more involved in his life and there isn’t a split between house staff and day program staff like there is in agency run places...I’ve been in those situations when you get inter-agency agendas removed from the people actually living there...there are constant feelings of bad blood. People who are not necessarily personally involved infiltrate the process.

A defining feature of Jason’s life with a micro board is the freedom to make his own daily schedule. This freedom is implicit in the micro board concept, as is the notion that
Jason is the person in control. Jason has hired a group of support workers who share his interests, and who are comfortable with Jason’s “laid back” loose schedule. According to Jason, “I don’t like the word staff, these are my friends.”

During eighteen months, I participated in a wide range of activities with Jason that included evenings at the ballet, movies downtown, coffee in his neighborhood, walks in the park, dining out, sojourns to his local pub, banking, and hanging out at his apartment. Jason’s apartment was “his place” and his paid supports, were more like friends than formal workers or programmers. Michelle, Atanas, Bob, and Andrew often chose to stay with Jason several hours after their shifts were technically finished. As Bob states, “I think we are more part of a family that Jason used to have....This is the first job that I have developed relationships with people outside of my work.”

Jason’s apartment serves as a social gathering place. I have stopped by on several occasions with a pack of Jason’s favorite beer and “shot the breeze” with whomever was there that day. The conversation was often eclectic, and very funny. According to Jason, his supports need to have “a sense of humor...be interesting...and a little bit crazy.”

Jason’s primary contact with the disability culture occurs on weekends when he plays wheelchair boccia ball. Two of his friends with disabilities, Pat, and Monique also compete in wheelchair boccia. I accompanied Jason to a boccia ball tournament and noted the competitive atmosphere. It was very similar to the quiet but intense boccia ball played by nondisabled persons in many parks around Vancouver. The atmosphere was inclusive and friendly. Nondisabled support persons and disabled athletes mingled and conversed freely.
Jason’s supports are crucial to his community participation, and provide assistance in routines, social support, and share humor and friendship. There is an inter-dependence or mutuality in their relationships. Andrew (support worker) described this relationship.

This is my first job where I’ve developed relationships with the people I work with...I’ve known Jason since I was thirteen. Basically I’ve known him for nine years. When I first started working with him, I hadn’t been in touch with him for awhile. Basically, I came in looking at it like it was a support job. You know, home care, cooking, and those kinds of things, and then quickly it turned into a friendship.

And basically my responsibility’s are doing laundry and stuff like that but friendship grew and that’s the reason I’ve been working here for two years while I’ve been going to school, because it’s a stress free job. I have a situation where I’m really good friends with my boss. And I think this kind of situation wouldn’t be able to happen in a group home...I work at Y Hospital as well, and you become acquainted with the people that you work with, but it’s not the same kind of thing as here. Let’s say if I’m working and were doing something fun it’s not uncommon to call up Atanas and say “hey why don’t you come along,” and vice versa. It’s turned into a network of friends, who happen to work with Jason.

Atanas (support worker) commented that the blurring of formal and informal support roles in Jason’s situations is at times difficult.

I got this job through Andrew. We were friends before this. We go for beers after work and stuff...We are all open and straightforward people...When I started working here, I had never worked with people with disabilities, so I was a little nervous at first, but Jason and I became friends pretty quick. Relationship as far as work goes, if I can criticize, this melting of the line between friends and staff can become a little difficult because Jason doesn’t go out of his way to make other friends.

In this type of relationship, it’s easier for us just to do things like cooking, and shopping. I’ve been conscience of not doing those things until Jason tells me to do it, to give Jason more control. It’s easy for us to just take over and run the house. If Jason is to have more independence that way, that’s what he should be doing. But I consider myself and Jason as friends for sure. That is fine but sometimes it hampers Jason from
developing other friends. I would maintain my relationship with Jason if I move if he wanted it. It would be a lot different socially because now we are paid to be here. To not work here would be easier, it would be just Jason, “how’s it going,” we wouldn’t have that employer, employee relationship.

Merging of Formal and Informal Support Structures

As David Wetherow suggested, the micro board concept represents a unique social structure. The process is highly individualized and the focus person and their support structure are free to define their roles and relationships. The interaction of various supports created the opportunity for Jason to develop a micro board, and achieve an autonomous lifestyle.

In Jason’s conceptualization of support, the relationship with members of CSB is friendly but formal. The regional manager, and regional coordinator are the persons with whom Jason and his micro board negotiate a contract. He also has a service coordinator from CSB who’s role is to monitor program quality.

Jason’s emerging self reliance is strongly supported by his micro board and his support staff. The role of his service coordinator is minimized. Jason’s closest ties are with the regional manager and regional coordinator, with whom he meets annually. Recently, Jason and his brother, Jim, renegotiated his contract; Lisa and Jason had separated and required individual contracts. Jim described a recent budget meeting held with CSB: “I just negotiated the newest budget with Jason. Because Jason and Lisa are split now. I was nervous going into the meeting... They were very supportive and said it was very reasonable.”

Lynn, a facilitator from Victory Housing, assisted Jason to become involved with the micro board project. The relationship with Lynn, from Jason’s perspective, has both formal and informal dimensions. In Jason’s words, “she is a friend, and she helps me a lot.” Lynn
described her relationship with Jason, and how her role as a facilitator in the micro board project has enriched her social circle.

...I met Jason through Lisa (Jason’s ex wife). But I was planning for both of them all along, because they were planning on getting married...The relationship evolved naturally...Jason is my friend. I go hang out at Jason’s place and he comes to my house for dinner. I care deeply for a lot of the other people I work with but they are not my friends.

I’m not friends with every person. I figure out where my work ends and my friendships begin. Some of the people that I am involved with I truly love and I will always be there for them.

Since Jason joined the micro board project, his relationship with his brother has changed, and Jason is becoming more independent. Jim described their present relationship.

Jason used to be like a clone of me. But now we’ve kind of grown apart. You know, now, I consider him a peace love hippie. We’ve kind of grown in another direction and I think that has a lot to do with the friends he’s made on his own, which I think is great.

Although Jason and Jim see each other less, their relationship remains close.

According to Jason: “I rely on Jim the most, he has been there since day one, I don’t know what I would do without him.” Jim is similarly emotive:

Jason was the best man at my wedding... They told us that he was going to be such a burden... I have never seen him as a burden. He has always added more to any environment than he has ever taken from. No one has ever bought that “put him away he will be such a burden bullshit.”

Most of Jason’s family (Hanna, Len, Carol, and Jan) live outside of British Columbia, and his contact is primarily by phone and E-mail. His aunt, and cousins live on the outskirts of Vancouver, and he visits them for dinner approximately once per month. He may visit his mother and sisters in Edmonton, Alberta, at Christmas. Throughout Jason’s life, his
relationship with his mother and sisters has been close and he maintains contact. However, Jason does not rely on his mother and sisters for support, as he once did.

Recently, Jason visited his father in Nova Scotia. Since Jason’s involvement with the micro board project he has established more contact with his father. According to Jason, “I’m more respected now, He (Len) would never call me at the group home, he shows interest now.”

Jason’s life in the micro board project consists of an intricate interface of family, friends, and paid supports. The roles and relationships within Jason’s support network evolved naturally and were not constrained by a rigid, prescribed support model. Jason does not have a job description for his paid supports. It is negotiated. According to Jason, “I don’t like it formal, if somebody prefers doing laundry then they do laundry.” A common theme throughout Jason’s support structure is a desire to honor and support him in his quest for a quality life in the community.

Quality of Life

According to Jason, “Health and well being, friends, and shelter” are important markers of a quality of life. Throughout the course of the study, Jason and I discussed quality of life issues from his perspective, and referenced it to respect, choice, competence, community presence, and community participation, (O’Brien, 1987). According to Jason:

Respect is most important to me...Here (micro boards) I am respected. I have more say with the government. I don’t think that I got asked in the group home... I’m getting respect in restaurants, at the bar at the local video place...I’m getting my self respect back...If you don’t respect anyone, then they won’t respect you. I really believe that.

Mutuality and reciprocity permeate the support relationship that Jason has with Atanas, Michelle, Andrew, Lisa, and Bob. Following is a typical interaction between Jason
and his supports. Respect is shown by the way supports interact with Jason when a change in schedule is required; elements are carefully explained.

Okay Jason we've got to juggle the schedule a little bit, because it's going to be a crazy day. I'm going to pick you up tomorrow, otherwise Jill would have insanity time. Umm Jill is sleeping over at Lisa's. I'm going to come pick you up, then we'll go over to Lisa's to pick up Jill and she'll take you to the meeting... I'll meet you back here with Jill's car, okay, if that's cool?

According to Bob (Jason's weekend support person), "Jason is holding his head high, he is looking at people, and he is respecting others as well, before he would bump into people with his chair or run over their toes, now he is careful,...he looks people in the eye, and says 'excuse me.'"

Lastly, an element of care and support that is very important to Jason is bathing and personal hygiene. In Jason's words "What's most important is that people are gentle and respectful. It is good now. I don't have (64) people taking care of me. These are my friends (present paid supports)."

Choice

The second most important marker of a quality life for Jason is choice and independence. In his present situation, Jason is able to choose: (a) where he wants to live; (b) with whom he wants to live; (c) the content of his apartment; (d) the members of his micro board; and (e) the structure and people that comprise his paid support network.

Jason expressed the following vocational and residential desires:

I want to be an accessibility consultant ... I'm also thinking about becoming a model. Lisa's friend, Vicki, runs an agency for people with disabilities. I would like to move out of Marpole (present residential area) and move to Kitsilano (vibrant neighborhood closer to the downtown core of Vancouver). My dream is a house. I would like to have
ownership. I'm still searching for what I want, but I'm feeling stronger about (it).

Jason and his supports report that he is taking much greater control over personal decisions in his life. There is also the realization that Jason requires support to become more assertive in this regard. According to Jason:

I don’t really do enough as the boss...Sometimes, I get lazy...I really like it (my life), but I know it could be better...if I had a job, and I had more say about what’s happening. I need to be more assertive. I find I am passive, not in everything ...but at times I am too passive...Then I don’t get to do what I want, when I want. Someone else will decide.

I am getting more choice and control than I had before. I’m learning how to use it. I’m not a number. I have preferences ... The most important choices to me are where I want to go, what I want to do, what I want to eat, what time I go to bed, and what time I get up. I have these choices now (in the micro board).

Jason’s mother, Hanna, described Jason’s needs:

Jason has to work on it (choice and control). Jason needs to get more assertive. It’s very easy to get institutionalized. I wish I taught (Jason) to be on (his) own. I just never thought he would be here one day (apartment of his own). I never saw it as a possibility. It has to come from him. He has to get off his butt and do it himself and tell people what he wants. People are willing to help, but Jason has to say jump.

Jason’s brother, Jim, attributes Jason’s passivity to his time spent in a group home, and commented that Jason is beginning to take greater control of his life.

...I had been bugging him for years to be more assertive...You know I think he tends to rely on his staff too much ...and most of his staff are all too eager to do it... Jason would be happy to go someplace if a staff member suggests; “why don’t you go to a movie.” It always has to come from someone else... I’ve always thought that that was a result of his years in the group home...But he is working on it. Recently, he had to fire one of his staff members and he was quite proud of himself.
Competence

Jason’s activity schedule is increasingly self directed, functional, and socially relevant to him. His power wheelchair and his increased competence with this technical aid has greatly enhanced his quality of life. Jason’s brother, Jim, is active in his pursuit of technical supports such as a voice activated computer that will strengthen Jason’s ability to participate more fully in all aspects of his life. Also, through Community Therapists, Jason receives support and assistance with technical aids for daily living, such as adapted toothbrushes, palm switches for his TV, etc.

Community Participation and Community Presence

As I examined and shared aspects of Jason’s life with a micro board, I realized that he is well connected in his community and has a balance of paid supports, family, friends, and community members in his life.

Hiring staff remains a challenge for Jason and his micro board. During the summer, Atanas and Andrew were engaged in other activities and Jason needed to hire some part time staff. Atanas recommended a friend of his, Wendy, whom he thought would work well with Jason. This utilization of personal connections and matching of preferences created a mutually beneficial relationship for Wendy and Jason. Wendy described her experiences supporting Jason:

Jason is just so much fun to be with, I mean it really is an equal relationship, which is really quite unique for a work situation for me anyway... A lot of the time I can’t believe I’m actually getting paid to do this because Jason is so much fun to be with. I mean I’m going into nursing and a twelve hour shift in the hospital is just brutal, but I mean spending a 12 hour shift with Jason is like spending it with a friend. I can’t say that we’re close friends or anything because I just started, but if I were working for Jason for any length of time, that’s how it would go, there’s no doubt about it. Or I probably wouldn’t stay.
Jason commented on meeting people and making personal connections:

I don’t really go anywhere (to meet people), it just happens. I like to have fun, talk to people. I look for people that have a sense of humor, that are intelligent, and interesting. Some friends I have met through my brother, others I have met at school, or in the group home, others I have met through the micro board. It just happens. You make connections.

(Life is) much better now. I am treated as an equal. A lot of my staff don’t see it as a job...That’s a good thing.

Jason summed up his impressions of lifestyle quality in the micro board project.

With the micro board I feel I am the key decision maker. Respect and choice are most important to me. I get to say what happens here. I get to make choices. I am more respected now, and I have more respect for myself. I like it a lot better than a group home. I can do whatever I want, whenever I want to, as part of the community. So now I travel with my brother Jim all over the place, even into the States, to tell people about micro boards and what they can do.

I’m feeling stronger about what I want. I’m still searching but I’m getting there. My dream is to have a house. I would like to have ownership... I would like to be a disability consultant. I don’t see myself as disabled. I see buildings as disabled.

Jason’s mother, Hanna, conceptualizes Jason’s life in the following way: “Jason’s life is far better than any I could picture. I never saw it as a possibility. I never expected an individualized system like this. It was beyond my belief of reality that any government would be so giving.”

Jason’s desire to be a participating member of the general culture has driven him to assume risk and search for equal status and a quality life in the community. His strength, humor, and flexibility have helped him to attract and maintain a group of supports who share his interests, appreciate his individuality, and view him as their friend. Jason’s close family ties have been critical in helping him with the transition from the handicapped culture to the
culture of the general community. Finally, the enabling and empowering structure of the people and policies at Victory Housing and CSB have reduced many of the systemic barriers to a quality life in the community.
CHAPTER VII

“CHANGE”

LISA’S STORY

Personal Profile

Lisa is an active, twenty seven year old woman. According to Lisa, “(I like to do) a lot of different things.” Lisa prefers indoor activities. Several of Lisa’s favorite activities include, “soccer, crafts, Earl’s restaurant, seeing mom, and shopping at the mall.” Lisa also enjoys music and television.

I met Lisa in September 1994, when Jason and Lisa were married and living together in South Vancouver. Lisa is a social person with an infectious laugh. She was eager to participate in the study and we established a friendly relationship. At our first meeting in Lisa and Jason’s apartment, she deftly wheeled up to me in her power chair, nudging Jason out of the way. I noted the sparkle in her blue eyes and her youthful exuberance. She struck me as younger than twenty seven.

During the course of this study, Lisa experienced several major life changes. She separated from Jason in March 1995, and moved into her own apartment in Richmond, B.C. This was Lisa’s first experience living on her own, and she developed a new micro board and support structure. These were daunting challenges for Lisa. Prior to the micro board project, she had lived in group homes for nine years. She was not used to assuming this level of responsibility in her life. I was able to observe and document her emotional struggles, her strong desire for an active life in the community, and her ultimate success in developing a support structure and lifestyle suited to her strengths and preferences.
Lisa has cerebral palsy and receives 24 hour support. She is able to feed herself independently, but requires support for all other daily living needs. She is adept with her electric wheelchair, which she controls with a joy stick mounted on the armrest of her chair. Lisa’s communication is multi-modal; she uses speech, gestures, manual signs, Picture Communication Symbols, and spells words by pointing to letters of the alphabet pasted to a lap tray on her power wheelchair. Lisa’s speech consists of one or two word utterances. Lisa’s fine motor control enables her to type with her left index finger. Her literacy skills are emerging. The following unedited article was excerpted from her college newspaper (Emerging Voices, Speech Assisted Reading and Writing Students of Capilano College, 1994), and illustrates her written communication skills.

**My Life About Of My Adopted Family Story**

I will be to see all my adopted family in December for Christmas Day. My brother, Lloyd maybe will be coming down to visit his family for my mom, Mary happy to see him at her home. I will be to see two first time from my brother, Lloyd in Calgary. Big reunion for my adopted family. I am very happy and excited for last time about I was baby 18 months old because all my adopted family to see me. (Lisa, 1994).

Lisa’s foster mother, Eileen (pseudonym), stated that Lisa’s receptive language skills are superior to her expressive skills.

Some people would say that Lisa is borderline mentally handicapped and maybe perhaps that is true, or perhaps a learning disability in some of those areas as well. Verbally she’s certainly bright enough and her auditory channels are fine and she assimilates information really well and can tell it back to you really well, I know when the kids were watching TV I noticed that her reactions were always as fast as everyone else’s. Whether it was sad, happy, giggly whatever, she was always in there with the other kids. And other things she picked up in school really, really well.
Lisa initiated and confirmed impressions of her life history, her perceptions of the role of the micro board, and reflected on her future. Her foster mother and paid supports contributed to Lisa’s life history and served as interpreters and facilitators if Lisa was unable to express herself. The following sections describe (a) Lisa’s personal history, including her family life, life in group home settings, and her marriage to Jason; (b) the formulation of Lisa’s micro board, (c) Lisa’s present support network, (d) Lisa’s present lifestyle, and (e) Lisa’s perceptions and the perceptions of her support structure regarding lifestyle quality in the micro board project.

**Lisa’s Personal History**

Lisa has lived in foster homes, hospital settings, and group homes. She attended segregated schools and segregated classes during her school years, which are reflective of past practices in the disability field. I asked Lisa to describe key events in her life, from birth to her present situation with a micro board. Two primary strategies were used to facilitate this process: (1) questions were directed to Lisa verbally; and (2) pictures and Likert type responses were utilized to enhance the saliency of difficult questions. Lisa’s responses were recorded on chart paper. Throughout the study, Lisa had access to the recorded documents and chart which listed major life events.

**Family Life**

Lisa was born in West Vancouver, British Columbia, on March 15, 1969. Her mother was very young, and was unable to care for Lisa. Shortly after birth, Lisa was adopted. She traced her natural mother and father through the Adopted Children’s Foundation. Vivian (pseudonym, natural mother) presently resides in Vernon, British Columbia, and is a member of Lisa’s micro board.
Lisa was adopted by a family in Burnaby, B.C. Mary and Mike (pseudonyms) had two sons named Larry and Richard (pseudonyms). A medical examination conducted when Lisa was six months old declared her to be a “very healthy baby.” Lisa had a serious case of chicken pox when she was approximately seven months old, and was ill for two months. This illness is believed to have caused cerebral palsy. When Mike and Mary were informed of Lisa’s medical condition, they placed her with the Ministry of Social Services. Lisa resided in a children’s hospital for two years until the ministry found appropriate foster parents.

In 1972, Lisa moved in with her foster parents, Eileen and Jim, and their sons Rick, and Sacha (pseudonyms). Lisa lived with Eileen and Jim until she was thirteen. Lisa spoke highly of Eileen and recalled her fondest memories, “(I) liked the trips, Disneyland, Pluto. (I) Met Craig at Eileen’s. Eileen baby-sat Craig.” Craig presently resides in the same building as Lisa and is a member of her micro board. Eileen described Lisa’s childhood and her relationship with Craig.

I requested another foster child, I had another child already and Lisa was the one they came up with. I went to see her and fell in love with her right away. We tried to normalize her life as much as possible. Tried to keep her doing as many sports activities or taking her along to sports activities to gymnastics started her off with motor soccer, took her down to special events at G.F. Strong (rehabilitation facility), tried to keep life as normal as possible in terms of scheduling. She was in Guides at school, crafts and things... We took her to things at the community centre as well. She even went so far as to take baby sitting courses at the local community centre when she became interested in kids.

She was very interested in eating out in restaurants. That’s probably where she gets her interest in Earl’s. Lisa really liked to be around my son and his friends and the children that we baby sat, who were around the same age as herself. They were good companions for her. It was really noticeable when she was getting into the thirteen, fourteen year old stage, she liked all the things that quote unquote “normal teenagers” liked. Especially boys with nice eyes. She liked to go to movies, she
liked to go camping, I think I backpacked her until she was about five. And then after that she was too heavy, so we were based in one spot, and we had a campsite down at Black Mountain Ranch where she enjoyed swimming and Sauna’s and lying in the sun.

Craig went to G.F. Strong with Lisa and he lived in Richmond. He got off the bus at the same time as Lisa, and his mother asked if I could look after Craig until she came home from work, and I was certainly pleased to do that. That’s how she and Craig met. And there was a little romance there between the ages of ten and thirteen and then they both became interested in different people.

Introduction to the Handicapped Continuum of Education and the Residential Continuum

Lisa received her schooling at a rehabilitation centre until the age of fifteen. According to Lisa, “I don’t remember much. (We did) some reading and writing.” Segregation was the norm for persons with severe physical disabilities when Lisa entered the school system (1974). “All of the kids (with severe physical disabilities) were bussed down to a rehabilitation centre. So she was not in an integrated system until after she went to the group home, and then she attended and graduated from a secondary school.”

Lisa had hoped to become proficient at reading and writing, and laments the fact that reading and writing were not emphasized more during her childhood and adolescence. Eileen stated that the rehabilitation centre did try to teach Lisa to read and write, but that academic subjects suffered, given that much of the focus at the centre was on physiotherapy, occupational therapy, swimming, etc.

In 1983 Lisa moved into an adolescent group home with four other persons with disabilities. Lisa enjoyed the social aspects of living with peers her own age, and the relationships she had with some of her staff. Her negative recollections involved certain staff members whom she described as “mean.”
According to Eileen, the primary factor which led to Lisa’s move to an adolescent group was the lack of community based supports necessary to maintain Lisa at home. She confirmed Lisa’s impressions of the group home.

... I didn’t really like the staff at X House. I thought that in some ways that they didn’t buy into the philosophy of what normalization could be for these kids. I thought that they alienated the family a little bit. I never felt welcome there. I sort of bowed out and Lisa was enjoying the aspects of her life with other youngsters, getting on with her life, the sports, and mobility and doing things for herself, like a kitchen which was set up for wheelchairs etc. So in many ways she was happy there, but she and I identified the same problems. So there was a lot there that I had a problem with. There were two mean spirited staff members that I could not get along with.

Lisa attended a segregated class in a local high school while residing in the group home. The class was comprised of other persons with disabilities. Lisa and her classmates attended some classes with nondisabled peers. Lisa recalls, “I met Jason there (positive recollection), It was okay, but, (school) didn’t help me to learn how to read.”

Typically, persons with extensive support needs are required to move from their adolescent home to an adult group home at the age of nineteen. By the age of nineteen, Lisa had resided in a hospital setting, two family settings, and a group home. The majority of her schooling was provided in a rehabilitation centre with other children with severe physical disabilities. A consistent theme which arose for Lisa was the nature of her support staff. She talked extensively about the “staff” in her life. Her most positive recollections involved “nice staff,” and these relationships appeared as important or more important than her relationship with her peers. Lisa had both positive and negative relationships with persons providing support. Her negative perceptions of the adult group home involved “mean staff” and her
positive recollections involved the friendships she developed with other persons with disabilities. She described her time in an adult group home.

(I was) upset (sticks tongue out). (Y House) was bad. I didn’t like Y. No way. Staff. They mean. Bad staff. Didn’t know how to help. C was mean, A was mean, made us go to bed at 8:00. (There were) 2 good staff. Lisa was there (later hired by Lisa). Helped. Helped to go out. (Lisa was) unhappy for me. Patty and Shelly (roommates) became my friends. I (began) dating Jason while I was at Y House.

In July 1991, Lisa married Jason while they were living in separate group homes. At this time, the concept of marriage was not common among residents of government run facilities. Lisa and Jason received support from their families, but the disability support system was not prepared to facilitate this type of relationship. Jason’s brother, Jim, explained systemic barriers to marriage.

When Lisa and Jason announced that they were going to get married, the reaction was like one of panic from the service providers... An initial reaction was that they can get married but they can’t live together... They (service providers) tried to paint a rosy picture of what it would be like to live apart.

Regarding marriage, Eileen recognized that Lisa and Jason had very different interests, but she supported the marriage, and felt it was important that Lisa be given the opportunity to experience an intimate relationship.

I don’t really know how Lisa and Jason met, it was kind of kept hush hush at the time. But I think Lisa saw Jason at John Oliver (high school) and really liked him, sent him a valentine, and they started interacting together and then there was a love affair. By the time she got to Y (adult group home), Jason had given her an engagement ring. At X (adolescent group home) they were the most vehement that marriage was not going to happen, and that this was a ridiculous idea. So that was another fight I had on my hands, allowing Lisa to make her own decisions. Initially no one knew what to do, or how to facilitate it... The marriage and the wedding and living together.
Lisa was the assertive partner regarding marriage and the pursuit of a micro board. According to Jason, “Lisa initiated going out together, she was pushing for the micro board and getting married. Lisa contacted Lynn (facilitator, Victory Housing).” Lisa was inspired by one of her roommates at the group home. The roommate was setting up a micro board with Lynn of Victory Housing. Lisa was intrigued by this option and contacted CSB. CSB connected Lisa with Lynn Percy, and planning began in 1991 for Lisa and Jason’s micro board. Lynn of Victory Housing described her role.

With Lisa and Jason it was really clear that there were people who really loved them and that they trusted and they knew who they wanted on the board. So with them it was much more getting into the meat and potatoes of it. “Okay so you are sure that these are the people that you want,” and it was evident that those relationships were strong. So it was just a matter of getting those people together explaining the concept and carrying on.

The micro board was formed in 1992, and Lisa and Jason moved into an apartment in North Vancouver. Lisa and Jason thought that they would enjoy the quietude and beauty of this setting, but they soon discovered the inconvenience. Lisa noted, “I didn’t like it. (We had to) bus everywhere.” Without their own transportation and total dependence on wheelchair accessible, public transit, they felt isolated and constrained. They moved to South Vancouver (Jason’s present apartment), which Lisa noted “was better, (we could) get out more.”

Lisa and Jason’s personal interests are different. Lisa enjoys shopping and mainstream pop culture, while Jason is cerebral, and has eclectic interests. In March 1995, Jason and Lisa separated, realizing that in many ways they were not compatible. Lisa informed me of the separation on February 10, 1995, and appeared to be excited about the prospect of having her
own apartment and developing a life of her own. My fieldnotes captured Lisa’s naïve notions of separation and life on her own.

Date: February 10, 1995
Time: 11:00 a.m.
Setting: Lisa and Jason’s apartment

Activity: Getting ready to exit for movie (“The Quick and the Dead”)

Participants: Lisa, Jason, Michelle (support person), Trish (support person), Researcher.

I had set up the time by phone. Originally I was going to talk to both Jason and Lisa. They were going to the movies at 1:00 p.m. I invited myself along. Brought the computer this time. Entered the apartment. Greeted by two dogs. ...

I start talking to Lisa and show her the computer. She shows great interest in the computer and I demonstrate how to use it. Lisa and I typed the following on the laptop.

Interviewer: Hi Lisa. How are you today?
Lisa: I am moving at Richmond... in March 1 ... I wants small computer, I getting more money

Interviewer: You can buy one at the Future Shop on Broadway and Hemlock.

Lisa: pink paint (Lisa wants to paint her apartment pink). I will be big party 301 - 7460 mofat rd rich v6y-3s1 (Lisa invited me to her birthday party at her new apartment)

Interviewer: what can I bring.

Lisa: dessert chocolate bar mint...

Prior to the micro board project, neither Lisa or Jason had the opportunity to fully express their individuality. They were participants in the “group” culture of the handicapped
continuum. As they began to express their individuality, they realized how different they were. I recorded the differences in Lisa and Jason’s preferences and mannerisms.

(Excerpt: Fieldnotes, February 10, 1995:

Trish tells Lisa that she needs to get ready to go to the bank before the movie. I thank Lisa and see what Jason is up to. He is writing a letter on his computer (expressing how much he likes his place and wants to stay). His office is cramped as it has his computer and Lisa’s computer side by side. He has a new computer but the printer isn’t working. We try to get it going with no luck. Jason uses a helmet and a pointer to type with. He is more fluent than I with the printer control window in “Windows.” After much trying we turn the computer off and leave for the movie.

Jason has picked the movie (“The Quick and the Dead”). He and I smile at each other. Although I have developed more rapport with Lisa, Jason and I are beginning to hit it off. Michelle wheels Jason out of the office and bumps into Lisa. Lisa looks somewhat peeved and Michelle apologizes saying, “sorry Lisa but Jason and I are in a hurry.” Michelle has a rougher style than Trish. Michelle and Jason leave, laughing. They have a good rapport, and similar styles. Lisa wheels into the office and shakes her head. Lisa enjoys things clean and tidy. Jason has left the office in disarray. Lisa spells out, “Jason is a slob.”

I drove alone to the movie. The movie had begun when I entered. I spotted Jason up at the very front row. He was in the aisle seated in his power chair. Michelle and her friend were beside him. Lisa joined us with Trish about ten minutes into the movie. Jason is laughing at the picture. Michelle offers him a drink every once in a while. The movie house is reasonably accessible. There is an elevator that Jason and Lisa use. The movie is fairly violent. Jason enjoys some of the gallows humor. Lisa appears disinterested and uncomfortable with the content.

Eileen was not surprised when Lisa and Jason separated, given their differing interests and personalities, but she felt it was important that Lisa be given the opportunity to reach her own decisions and conclusions.
It took her a little while but she quickly realized that she and Jason were very different. In a way it was kind of predictable... Jason had different interests. He wanted to go to the pubs and the girly shows. But they had the right to experience that relationship and they have the right to split up, and if they meet someone else they have the right to make the same mistakes all over again, just as we all have (laughs).

Lisa moved into her own apartment in March 1995, a bright two bedroom suite in a newly built housing co-operative in Richmond, British Columbia. Lisa chose the apartment from a list of wheelchair accessible apartments. Lisa required considerable support during this transition. Lynn Percy of Victory Housing and Eileen, her foster mother, were out of town on other business. The regional coordinator of CSB explained CSB’s perspective.

...That was pretty heavy duty when Lisa and Jason decided to go their own ways. We had to figure out, okay, how are we going to do this, and we had to form a micro board around Lisa and there are struggles....It was difficult to figure out who was in charge. Lynn (facilitator from Victory Housing) was on vacation, Jim was out of the country (president of Jason’s Support Society). Here again is the commitment...John (service coordinator, CSB) stepped in and helped... You know those (issues) are all tough, but that’s real. Like this is good, this is good, if we’re going to be struggling about anything this is good stuff.

Initially, Lisa and Jason maintained the same micro board and shared some support staff. The technical aspects of developing separate micro boards, finding new accommodations and furnishings, and hiring a new circle of supports was daunting for Lisa. Lisa described her feelings. “It doesn’t work anymore. (Points to Picture Communication Symbol) I am frustrated. (I need) help, people don’t ask me enough. I don’t know how. I miss Bob.”(June, 1995).

In March 1995, Lisa had the support of Bob, a support person at Lisa and Jason’s apartment with whom she had developed a good rapport. Bob offered to live with Lisa for
several months to ease the transition, and was her roommate until May 1995. He assumed a mentoring role, easing Lisa’s transition to a life on her own. He explained:

...Lisa was scared to move out. She has lived much of her life in group homes... She went from no control to potential for maximum control. (My role) was to show her how to live with a roommate. I set her up to carry out responsibilities. Getting to know about her house. Basically that’s what I was there for.

...(When I first started living with Lisa) she threw a plate, she didn’t like the skin of the chicken being on. Lisa was regressing when she moved into her new place. She refused to participate, you know learned helplessness, she said she can’t do menu planning and talked of moving back to a group home...I’ve known her for two years...She needs a push. I put my foot down. She can shriek when she doesn’t get her way. She inherited that from the group home. She wants to be a good roommate, but doesn’t know how because of where she’s lived.

Initially, Lisa shared daily supports with Jason. Jason’s supports were well suited to his personality and interests. He was not a “clean freak” and enjoyed a loose schedule and flexible supports. Lisa is fastidious about her apartment, and enjoys a more structured, predictable schedule. According to Lisa: “I’m the boss, (but) it’s hard to tell people what to do. Fred and Sue (pseudonyms for staff shared by Lisa and Jason) don’t keep the place clean. (They) are lazy. They just sit around and watch TV”

In the summer of 1995, Lisa assumed more control of her life, her support network assisted her to develop her micro board, hire new staff, and set up her apartment. In August 1995, Lisa observed, gesturing with her thumbs up, “I like the apartment, I get to choose my own stuff. The apartment is bigger, don’t bump into walls anymore. Donna and Philip (support staff) are helping me. I like them.”

Donna (support person), Philip (support person), and Eileen (foster mother) were instrumental in easing Lisa’s transition to a life on her own. Donna had just graduated from
high school and shared many of the issues confronting Lisa. They were very well matched in terms of personal interests and life experiences. Lisa and Donna discussed their relationship.

Date: August 14, 1995
Scene: Sitting around Lisa's Kitchen table
Participants: Lisa, Researcher and Donna

Interviewer: How do you see your relationship with Lisa?

Donna: I can talk about anything with Lisa. I really consider her a friend.

Lisa: Laughs

Donna: I could tell her about a guy that I like, or if a song reminds me of something, or we'll talk about the eighties, and how much we hate the eighties or something like that (laughter).

Interviewer: So, do you see it more as hanging out than a job?

Donna: Yea, I see us more as hanging out. I've had jobs where I've had to clock in and you're only talked to when you have to do something. This is not a typical nine to five job. This is more about being with Lisa and helping her out.

Lisa: yeah

Interviewer: It seems that you two share quite a bit in common.

Lisa: Vocalizes MMM, shakes head in approval

Donna: Yeah we like Michael Jackson, Amy Grant (Laughs)

Lisa: (laughing loudly)

Interviewer: I guess Lisa, this is really the first apartment of your own?

Lisa: Yeah

Donna: Yeah, it's like you're out living on your own for the first time without having to live with anyone. It's kind of like it's a great big sleep over for the whole summer.
Interviewer: Lisa, would you rather have a roommate or live alone?

Lisa: (I want) a roommate.

Interviewer: So what kinds of things do you do together.

Donna: Watch movies, listen to music, talk a bit. Basically what friends do.

Philip was a steady, formal support for Lisa during her transition. He discussed Lisa’s growth and adjustment during her period of “flux” (March 1995-August 1995).

This is her first opportunity to do it on her own as a young lady out in the world. When she broke away from the group homes with Jason, she started to get more choice and control. She has come a long way from then. But the development through the micro board to here is where she is totally in control.

I’ve really noticed a drastic development change since Lisa has moved out of Jason’s and come out here...In terms of independence. Now when a staff member gives her a hard time, when it’s not called for, it’s taken care of immediately. Lisa will get up and defend herself. It was just starting to come out at (Jason’s), but it would take three or four months to get resolved. Now, it is resolved immediately and the staff person is gone if need be. Lisa has expressed her concerns and two staff have left. It’s been a good learning experience.

Several factors appear to have influenced Lisa’s life as she moved through the disability system to a place and a life of her own in the general community. Lisa is an enterprising individual with a desire for an active, autonomous lifestyle. Consequently, she initiated contact with CSB and Victory Housing. The enabling practices and procedures of these organizations allowed Lisa to experience marriage, and life in the community with Jason. As Lisa and Jason realized that their interests were very different, they chose to separate. The effects of segregation and life in the handicapped continuum appear to have limited Lisa’s abilities to exert full choice and control in her life. At first, she found the
freedom of choice and control in her new apartment to be daunting, and turned to her foster mother Eileen, and her support workers who assisted her to achieve her present life style. The key events in Lisa’s life as she described them, follow.

Summary of Key Events in Lisa’s Life

1969  BIRTH
Born in West Vancouver
Vivian-mom, Greg-dad
Vivian young, split with Greg
Adopted by Mary and Mike
Move to Burnaby

1970  MOVED TO SUNNYHILL HOSPITAL
Mary and Mike find out I have C.P.
Move to Sunnyhill Hospital

1972  MOVE TO EILEEN AND JIM’S HOUSE (FOSTER PARENTS)
Eileen-foster mom
Jim-foster dad
Rob-foster brother
Liked going away on trips, Disneyland, Pluto
Met Craig, Eileen baby-sat Craig
Went to school at G.F. Strong until I was 10
I don’t remember much of school at G.F. Strong

1983  MOVE TO X HOUSE (GROUP HOME) AND JOHN OLIVER HIGH SCHOOL
It was okay
Liked the nice staff, I miss them
Didn’t like mean worker, Debbie M
Went to John Oliver High School until 1989
It was okay, didn’t help me to learn how to read
Met Jason and Kelly at John Oliver

1988  MOVED TO Y HOUSE (ADULT GROUP HOME)
Upset, Y was bad, didn’t like Y
Bad staff, they (were) mean, didn’t know how to help
Made us go to bed at 8:00
Two good staff, Lisa was one of them
Lisa helped me, helped to go out, (she) unhappy for me
Friends, Shelly and Patty lived at Y
Met Jason at Y and began dating

1991  MARRIED JASON
Summary, Continued:

1992
FORMED MICROBOARD
Moved to North Vancouver
didn't like it
(Take) bus everywhere, isolated

1993
MOVED TO SOUTH VANCOUVER
Better, get out more
Attend Douglas and Capilano College
Enter SARAW program

1995
SEPARATE FROM JASON AND MOVE TO RICHMOND
Like apartment
Choose my own stuff
(City of Richmond) okay, don’t like it now.

1996
PURCHASES HER OWN APARTMENT WITH THE ASSISTANCE OF
COMMUNITY SERVICES BRANCH
Wow

Lisa’s Home and Neighborhood (January, 1996)

Lisa prefers clean, bright living spaces, and her apartment reflects her preferences.
CSB provided the funding for housing and furnishings and Lisa chose the location and the content of her apartment.

Lisa has an apartment in a cooperative, a new building situated in a quiet residential area which includes a mix of single family dwellings, townhouses, condominiums, and cooperative housing. She is approximately four kilometers from the commercial hub of Richmond. The cooperative is comprised of three buildings which house 120 suites. Lisa lives on the third floor and accesses her building with a remote switch attached to her wheelchair lap tray. The main entrance to her building is open and spacious providing easy access for her wheelchair. The elevator is small, and it is difficult for Lisa to maneuver her electric wheelchair in this space. Buttons for various floors are accessible, and Lisa is able to
enter and exit her floor and building independently. Opening the door to her apartment requires assistance.

There is a large bright living area, and a large kitchen. There are no adaptations in the kitchen for cooking. According to Philip, “it is too dangerous for Lisa to be cooking as her reaction time is too slow with hot foods and cooking elements.” Lisa remarked, “I don’t like cooking and shopping.” The light switches are positioned at wheelchair level, and the washroom is large and accessible with both manual and power wheelchairs. The sink is positioned at wheelchair level and has adapted faucets. The bathtub is not adapted, and is difficult for Lisa to manage alone.

Lisa is proud of her furnishings and has furnished her apartment to suit her personal preferences. She loves animals and has a cat named Mekey. Pictures of cats adorn the walls of the eating area and living room. There is a large desk in her main living area which supports a computer equipped with adaptive, voice synthesized technology. Above the computer is a large calendar which contains Lisa’s daily schedule and menu. A rose colored couch in the living room was chosen by Lisa along with a new television and stereo system prominently displayed in an entertainment unit. A large balcony with sliding glass doors is adjacent to the living area. Lisa’s bedroom is furnished with a double bed, a desk, and posters of her favorite sports teams. The second bedroom is used by the overnight staff person.

Present Support Situation

Lisa’s support network consists of both formal and informal supports. The informal supports are (1) her micro board which consists of her foster mother, Eileen, her friends, Craig, Lisa, Cyndy, and Eileen’s friend Tony; (2) her boyfriend Craig Y, her friend Shelly, and (3) her birth mother Vivian. During an interview conducted on April 10, 1996, Lisa
described her informal support situation as “good, it is better now, they help me.” Lisa is reliant on her micro board for support, particularly the support of her foster mother, Eileen.

Eileen explained the role of the micro board in Lisa’s life.

My personal role is as chair person and my philosophies remain the same. I want Lisa to be as autonomous and independent as possible and I want Lisa’s life to be as exciting and momentous a life as is possible and I would like to support her in that. And to support the board to do that, and I see the board’s role as similar, to facilitate Lisa to do all of those things and to ensure that Lisa is informed about new things on the horizon and to assist her in areas such as home ownership, and traveling to San Diego with her motor soccer. I see my role as a facilitator and not so much of a doer, seeing as we have a paid staff and a paid supervisor and I delegate a lot of the responsibility to that person.

Eileen described the strengths of Lisa’s micro board.

I think we are all young at heart and young in mind and we can help Lisa to have things that she wants out of life and I think career choices are down the road but we can help advise her on that. And as long as we stay young at heart we can help her to have a happy productive life. I think we are also very caring and we have Lisa’s best interests at heart. I think that everyone on the micro board loves Lisa and I think that that love is reciprocated. As a micro board we see Lisa as a big part of it... of course she is a member of her own micro board. She is able to help with the decision making and in some cases she is the decision maker and it gives her a lot of autonomy.

Although Eileen supports the autonomy afforded Lisa in the micro board project, the intense level of support required by Lisa is stressful and at times compromising. Eileen discussed her personal views regarding the micro board concept.

... I was very excited by the concept of Lisa living in the community with her husband and having staff to look after her. It’s the micro board thing, sometimes I just don’t think that with volunteers... they tend not to work as well as they might and I think our micro board has not worked as well as it should have. So we ran into some money problems and various other things.
...As kids become young adults etc. I think that there should be some agency that overlooks them rather than micro boards. But the micro board is functioning reasonably well and I think everyone has Lisa’s well being at heart.

... I guess after twenty year of fostering I was getting a little bit tired of being the public servant. I don’t mind doing things for Lisa, but I am getting a little tired of doing these services...I am the chair of Lisa’s micro board and we’ve got that set up and we have a treasurer and an accounting system set up in the computer and we’re taking responsibility for our responsibilities and I think we are meeting our responsibilities. But it is still a bit of a drag, I’m working shifts now, and it’s difficult getting the rest of the committee together because some people want to meet on Sunday’s and some people want Thursday’s. So it is difficult to get a full committee together...We take a look at where Lisa is in her life and where she is going. Every month I expect the accounting to be done. I am finding it a bit of a responsibility and I did actually say that if Lisa didn’t get into her new apartment that I was thinking of not being on her committee next year.

Lisa’s formal support network consists of (1) members of CSB who fund and monitor her micro board, (2) a facilitator from Victory Housing who assists with the set up and management of her micro board, (3) five home support staff (hired by Lisa and her micro board), (4) four daily support staff (contract with community support agency), and (5) community care personnel which includes her physician, dentist, physiotherapist, occupational therapist, seating specialist, and orthopedic specialist. Figure 5 illustrates Lisa’s support structure.

It has taken Lisa eighteen months to develop home care staff with whom she feels comfortable. She has identified that she requires assistance to adjust to life on her own, and has developed a support network who understand this need. Lisa described her present home support situation.
Micro board
Lisa
foster mother (Eileen), friends (Craig, Lisa, Cyndy, and Tony)

Family and Friends
boyfriend (Chris Y), friend (Shelly), birth mother (Vivian)

Formal Supports
CSB (funding and monitoring), Victory Housing (facilitator), five home support staff
Four daily support staff (rotating schedules)
Community care personnel (physician, dentist, physiotherapist, occupational therapist,
seating specialist, and orthopedic specialist)

Figure 5
Lisa’s Support Network

It’s great now. I have nice staff. I need help, they help me. (I want) people to look me in the eyes. (I need people) to respect me. (I like) the apartment clean. (I had to) fire Donna,, she was doing her homework and not helping. Chris (support person) is strong, that’s good.

During the course of this study it became apparent that Lisa had concerns about the appearance of her apartment and aspects of her personal care. Eileen and several other support members have described Lisa as somewhat naïve and in an emergent phase regarding personal autonomy and managing her home life. Consequently, she requires support staff who are patient, respectful of her needs, and have a good work ethic. According to Eileen, “she is very clear that this is her home,...and she is getting better at taking control and finding the supports she is most comfortable with.” Chris, a home support worker, described Lisa’s home supports.

You’ve got to do your job, niceness doesn’t quite cut it (Laughs)...Yeah she’s got quite a good team now... things are more stable than they’ve ever been since she’s lived here...And all of the house staff get along with each other as well, because we’re all so similar...We all joke the same way, treat Lisa the same way.
She’s into the swing of hiring and firing now. She’s much more clear on her rights as to saying “I don’t like this person, they’re not treating me the way I want to be treated, and they’re not doing the job I want them to do, and I want them gone.”

Most of the times Lisa will give a gentle reminder to not forget something. She doesn’t kick our butts unless we don’t listen to her the first time, but Lisa very rarely gets mad at us. The only person that doesn’t listen is Fred (overnight support person) and he’s getting the boot.

... (The relationship) It’s a mutual kind of thing just spending time with each other. Everyone has a good sense of humor... Her house staff are her staff and close supports.

... Everybody’s pretty easy going. You’ve got to have a lot of patience and just let certain things roll off your back. A sense of humor seems to be the biggest thing, just to be able to laugh at your own mistakes...and keep everything light hearted and only be serious when it really warrants it.

Lisa and her micro board contract with a community support agency, Daily Life, to provide daily supports. It is a formal support organization funded by the Ministry of Social Services which provides community-based support to adults with disabilities living in the community, or who are in the process of moving from hospitals and institutions to the community. Daily Life is an alternative form of support to traditional centre-based programs. The goal of the organization is community inclusion, and supports individuals to be actively involved in their communities. They provide one to one support to individuals (Daily Life, 1988).

Lisa does not hire her daily support staff, but she is consulted regarding her cohort. She has contracted with Daily Life for the past five years and her present support structure consists of four persons. According to Lisa, “I like them, they’re good, If I need help, I go to Eileen (foster mother) and DL (Daily Life). I like Betty, she is funny.”
Lisa requires and demands supports who recognize that she is in a transition phase from group home living to life on her own. Lisa is particularly close to Betty, one of her daily support persons. Betty is considered her friend and teacher. Betty described her relationship with Lisa.

Generally at Daily Life we focus on personal care needs and we try and focus on ensuring that Lisa’s social and emotional needs are being met. And there’s a real community focus at DL. That wherever possible, let’s get out there, and most of the people that we support do want that, and that’s why this program works for them, and why they choose it. So we get to do all the “out there” stuff.

My interpretation of the goal is to assist people in finding their place in community. So that the ideal situation is that we can back off, that we’re not needed, and that service providers aren’t needed any more.

I come from a professional background. I was a teacher for eleven years. So I am professional, and within this position, I’m still trying to figure out where the line is. The boundary line of professional and friendship. And I think a lot of people at DL struggle with that, because of the nature of our work and what we want to do. We choose to go into this field with this focus. I don’t want to go to work in a group home. I don’t want to spend my day doing maintenance, personal care, you know maybe two or three people that I’m assisting. I don’t want to do that.

So I think most of us choose DL so that we can have the one to one. And you can build up a strong relationship and you can really be there for that person. “What do want to do with your life, how can I help you?” And in doing that, it’s so diverse, like the things that you do with your day, it’s hardly ever the same thing day to day. So I’m still trying to figure out where the two things meet. Where the friendship and the fun stuff meets the professionalism. And my relationships are different with different people that I support. Where I come from, it is very professional. On the outside, everything appears the same, but it’s not that way here.
As I interviewed Betty and observed her interacting with Lisa I noted that there was a mutual bond and respect. Betty discussed her personal philosophy of support.

...I believe that everyone has a strong life inside of them. And if you’re properly supported all sorts of magical things can happen. For anyone, I mean anyone.

...(Those beliefs came) from being a misunderstood whacked around child. Yeah, I think I developed them on my own, and I had a couple of teachers in grade school who were able to feed my flame, despite bad things happening around me, and they were able to say “It’s okay to keep that spark going, there’s good stuff in there.” And that’s what I brought to my teaching, let’s find the place of magic in every person, because it’s there. And so many people don’t see it.

John, a service coordinator with CSB, has also been involved in the development and monitoring of Lisa’s micro board. Lisa turns to John when she needs help with housing and support issues. John is currently looking into home ownership in a condominium complex that is suited to Lisa’s preferences and needs (proximity to wheelchair accessible transportation and her friends).

Lisa’s support workers for physiotherapy and occupational therapy come to Lisa’s home and accommodate her community lifestyle and schedule. Similarly, Lisa accesses community based supports for her other health care needs. There is continuity among her formal and informal supports; all members view their role as supporting Lisa to achieve a quality life in the community. Patience, respect, and a sense of humour are the elements which Lisa requires from her support structure. According to Lisa, “It needs work (support structure), but it is good now...They help me.”

Eileen provided her perspective of Lisa’s formal and informal support structure:

It is a very good relationship. Lynn has been extremely supportive, she is very knowledgeable, she’s very willing, and she’s very understanding and she makes herself available whenever she can. CSB, I haven’t had a lot to do with them but
they have been right there whenever we have needed them. We
definitely share a common philosophy with CSB and Victory
and at the staffing level I think it’s going quite well for her. She
has staff who care for her and care about her.

Lifestyle

Lisa typically rises at approximately 9:00 a.m. Her overnight staff leaves at 9:30 a.m.,
which is the time that her support person from Daily Life arrives. Betty (support person) and
Lisa described a typical morning.

Betty: Lisa usually tries to schedule things so that she can have
a relaxing morning. Rushing things is not a go, if possible.

Lisa: Afraid to choke on my food if I feel rushed.

Betty: Yeah just too much stress on you and your body if you
feel rushed. So we try to schedule things, when I arrive at 9:30,
check in, personal grooming and leave by 10:30 or 11:00,
arrange for transportation which is usually the bus and then
head out. On days when Lisa hasn’t made any commitments,
we make a list and decide what is most important.

Lisa enjoys an active schedule, which includes a mix of recreational activities, house
maintenance, literacy skills, and social engagements. Although she is free to choose her daily
schedule, Lisa stated, “I need help planning my days.” Betty observed,

Planning is something that Lisa and I have started working on.
How can Lisa get the most of her days? Cause it’s easy for us
to just kind of go spend time talking and catching up and
suddenly hours of past. And because Lisa is living out in
Richmond you need to consider traveling time to get to most of
the places that Lisa wants to be. So, we’re trying to find a way
that works for Lisa to get the most of her time. So the way
we’ve started to do that is get out a piece of paper and outline
all of the things that Lisa would like to do, addressing an
envelope, to going into town to meet a friend for lunch, and
then prioritize them, “what's the most important” and fit at
least those most important things into the day... I help Lisa
with, or witness Lisa setting her schedule up. If I see something
I may say “that might be a hard day for you,” and I suggest
considering several possibilities.
Lisa’s activity schedule for the month of March 1996 is illustrated in table 2.

Table 2
Lisa’s Activity Schedule (March 1996)

<table>
<thead>
<tr>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit Shelly</td>
</tr>
<tr>
<td>Neurological centre social function</td>
</tr>
<tr>
<td>Testing for college entry program (literacy)</td>
</tr>
<tr>
<td>Meetings,</td>
</tr>
<tr>
<td>Testing for reading,</td>
</tr>
<tr>
<td>Craig’s for supper,</td>
</tr>
<tr>
<td>DL meeting,</td>
</tr>
<tr>
<td>Meeting with John, Philip and Karen.</td>
</tr>
<tr>
<td>Dancing at the Yale Pub</td>
</tr>
<tr>
<td>Free theater,</td>
</tr>
<tr>
<td>Lunch at the bread garden</td>
</tr>
<tr>
<td>Motion specialist (wheelchair)</td>
</tr>
<tr>
<td>Dinner with Craig H.</td>
</tr>
<tr>
<td>Ford Orthotics (braces for her legs)</td>
</tr>
<tr>
<td>Neurological centre for a social function</td>
</tr>
<tr>
<td>Surprise party for L’s birthday :</td>
</tr>
<tr>
<td>Victoria to see Dad and Grandma</td>
</tr>
<tr>
<td>Workshop</td>
</tr>
<tr>
<td>Dinner with Craig</td>
</tr>
<tr>
<td>Dinner with Paul</td>
</tr>
</tbody>
</table>

During the course of the study, Lisa attended a community college literacy program designed for persons with physical disabilities. The college was approximately twelve kilometers from her home, and it took Lisa two hours to travel to the campus. Lisa relies on the public transit system. I accompanied Lisa to her class and recorded my impressions of the pedagogical approach, access accommodations and barriers at the college, and the insights of her classmates concerning segregated schooling.

I met Lisa in the college cafeteria at approximately 10:15 a.m. Verdant campus, ferns, large fir trees, park like setting. Many walkways and outdoor seating arrangements, which are not accessible by wheelchair.
Lisa is drinking coffee in the cafeteria, joking with Vanessa (support person Daily Life). Lisa and I head to class, Vanessa stays behind. Lisa leads the way in her power wheelchair. Class is accessible by ramp and power operated door. Lisa accesses building with ease. Introduce myself to Jim, one of the instructors. Jim directs me to a computer and explains how to access public communications supplied by students in the program. There are about ten computers in the class and six other students including Lisa.

Lisa is seated beside me, Jim is providing direct instruction. Her computer has adaptive, voice synthesised technology. Lisa is working on word recognition and dictionary skills. My computer has a range of topics generated by students. One topic of interest “My life in school.” Access several perspectives concerning schooling in the handicapped continuum. Recorded several accounts from the screen.

S.C. wrote, “I don’t want pity. I want understanding and friendship. I would like to be accepted as a normal human being.”

J.T. wrote, “We spent time being bored by looking at our cubicles. Quiet as mice. I felt angry in such a small space. I wanted to move to another classroom, where there was sunlight. I would always think about going on field trips, to see the arts, film, music, plays, things we never ever went to see.”

Class ends after approximately one and a half hours. Lisa and I return to cafeteria for lunch. Approximately 200 students in cafeteria. Lisa and I sit with Vanessa and five of Lisa’s peers with physical disabilities. Several others have support workers with them. Friendly and relaxed cohort. Lisa leaves after lunch. It will take her two and a half hours to get home. In all she may travel upwards of five hours to attend one class.

As I read various anecdotes from persons with disabilities in Lisa’s class, I found that others agreed with Lisa’s perceptions of her segregated school days. They felt that they were not given the opportunity to develop their academic potential, and did not have opportunities to experience the breadth of activities available to their nondisabled peers.
Daily Life provides support to Lisa four days per week. The schedule is designed to support Lisa’s needs, and Daily Life staff focus primarily on recreation and leisure activities. Lisa’s home support staff typically relieve Daily Life staff at 4:30 p.m. An attempt is made to make the staff change a smooth transition within the context of Lisa’s daily schedule. I was present for one such transition and observed how support is provided.

Scene: Seated in Lisa’s kitchen area, Betty (daily support person, Daily Life), Lisa, and Paul (interviewer) discussing Lisa’s daily support model. Telephone rings and Chris (residential support person) inquires about Lisa’s schedule. 

Betty: Hi Lisa’s house. Hang on I’ll just check with Lisa. Chris is wondering if you’d like to meet up with her at the mall and do your shopping for the weekend. Do you like that idea?

Lisa: Yeah.

Betty: Okay so we’ll head over later to get to the post office and then meet up with Chris.

Lisa: Okay

I also observed how transitions were made between different staff members and how this affected the flow of Lisa’s day.

Approximately 1:00 p.m. Lisa and Betty prepare to meet Chris at nearby shopping mall. Lisa is in her power wheelchair and Betty assists her with hygiene before exiting apartment. As we exit apartment, Lisa and several neighbors exchange greetings. Friendly, cooperative atmosphere to building. Shopping mall approximately four blocks from Lisa’s apartment. Route is very accessible. Area is relatively new and equipped with indents in the sidewalk for wheelchairs. Lisa navigates to mall with ease. Lisa and Betty converse and cavort as if they were friends.

Meet Chris at bus stop adjacent to shopping mall. Transition is smooth and friendly. Betty’s shift is over and she exits the scene. Chris and Lisa head to mall to shop for Easter weekend. Lisa is hosting a small dinner party. I offer to buy Lisa lunch. I ask Lisa where she would like to eat. Lisa spells “greek.” Chris interprets, “Oh you want to go to the Greek take out place?” Lisa vocalizes “yes.”
Proceed to take out restaurant. I ask Lisa what she would like. Lisa frowns and spells “pit” and pauses with ponderous look. Chris interprets. “Do you want Pita bread?” Lisa nods her head. Chris states, “They have great Pita and Homous here, Lisa likes that.” Lisa nods. Chris then asks, “Do you want Homous or Tsatziki?” Lisa vocalizes “Homous.” Purchase lunch and sit with Chris and Lisa. Chris and Lisa are planning their weekend together. Chris supports Lisa on Tuesday’s (4:30 p.m. to 9:30 p.m.), Thursday’s (2:00 p.m. to 9:30 p.m.), and one weekend per month. Conversation and planning is friendly. Chris has a relaxed style and is patient as she helps Lisa eat her meal. Chris offers Lisa choices for her daily schedule and suggests activities for the weekend. Lisa spells “hair.” Chris responds, “we can get your hair done if you want. Do you want to shop for the weekend first.” Lisa vocalizes “yeah.” Chris turns to me. “Lisa is having friends over for an Easter dinner.” Lisa smiles and nods. Finish lunch and Chris and Lisa head to hairdresser discussing plans for the evening, Chris suggests some movies and Lisa agrees.

Lisa prefers to be active between the hours of 11: a.m. and 5:00 p.m. According to Chris, “Lisa’s (attitude is), ‘let’s get out in the sunshine, let’s go do something’...Lisa wants to live.” Her evening schedule is typically relaxed, and she spends most week night evenings at home. Her friend, Craig H, lives in her building and visits for dinner several times a month. Recently she met an old friend of hers, whom she met while living in the hospital. Lisa describes Craig Y as her “boyfriend” and the relationship is platonic. Lisa and Chris discussed their relationship.

C: She’s known Craig Y since she was little from J (Hospital). He’s at S House now (Group Home).

Lisa: We used to go out all the time.

C: Yeah now you get out all the time, she’s going out with Craig and having dates regularly. We go out with either Fred or J.T. Craig invited her out and gave her a card, He went to the Valentine’s social that Daily Life put on and he asked her if she’d like to be his girlfriend. We’re going out to the Irish Rovers on the tenth.
Chris described a typical evening at Lisa’s apartment. “Usually Lisa’s pretty beat after a full day with Daily Life. We usually just hang out and relax after dinner. We’ll watch TV or a movie, usually there are chores to be done, and we assist Lisa getting ready for bed, taking a bath, all of that stuff.”

On weekends, Lisa enjoys a loose schedule and rises at her leisure. Philip (support staff) described a typical weekend:

(On weekends) We get up whenever we feel like. The times that we have had to get anywhere, we’re pushing it at about an hour to get ready... Lisa has her wheelchair soccer and we might need to take care of things around the apartment, visit friends, but generally it’s pretty relaxed.

It started as an employer, employee relationship and turned into a friendship. Some times I see Lisa more away from work than I do at work... I will always consider this a job, I just happen to be working for a friend.

Lisa’s wheelchair soccer team is comprised of a diverse group of individuals with physical disabilities. She does not socialize with her team other than practices and games, but this recreational outlet is one of her preferred activities. She has traveled to several tournaments throughout North America with her team. I observed the team while attending a practice, and noted that some of the team members still live in hospital settings.

Lisa and her team are assembling outside of the recreational centre. Warm spring day. Team is a diverse and congenial group. The coach is an attractive women in her late twenties, early thirties. She runs a modeling agency for persons with disabilities, and is in a wheelchair. Youngest member of the team is approximately fourteen years old, and is with his father. Bill arrives with a friend, who is an assistant to the team. Her name is Spring and she is effusive, talking and hugging everyone. Her movements are ataxic, but she is able to walk.

Bill has cerebral palsy and resides in a hospital setting. He requires 24 hour support, but does not have close contact with his family and has been in the disability system for many years. Spring lives in the community and acts as an advocate for Bill.
Spring is upset, as Bill’s money and bus pass have gone missing in the hospital. It appears that the other team members live autonomous lives in the community and are concerned about Bill’s restricted lifestyle. Spring states to Lisa and Bob (Lisa’s support person) “We’ve got to get him (Bill) out of there.” I have been to several practices, and talked to Bill. His speech is slurred but he is a bright, funny young man. Observing Lisa’s team, I realized how different Bill’s life must be. Lisa and her team mates go back to their homes after practice, and Bill returns to a hospital ward. I now understand how different Lisa’s situation is from many people with severe disabilities.

**Quality of Life**

Lisa discussed three issues which she considers most important to her quality of life. Respect is paramount. She stated, “(I want) people to look me in the eyes.” Lisa is also attempting to develop a relationship with her birth mother and father. All of her life she has wondered about her birth parents, and recently located them through an adoption agency.

Eileen stated,

Lisa has never understood why she was adopted, and I have expected throughout the years that at some point she would make the choice to trace her birth mum. That was totally her own initiative. When she told me that she wanted to trace her birth mum, I asked her if she was sure and explained to her that some of these things don’t always work out really well, but she said, “yes she was sure” so I got the forms for her,... and it took her over a year to actually fill them out.

Lisa wants to be present in her community and experience a range of activities. Lisa’s support network feel that Lisa is learning to live on her own, but she still requires extensive supports in this regard. Lisa’s autonomy is a central goal of her micro board. According to Lisa, “it is much better now, people are helping.” Lisa has become more assertive regarding her desire for respect, autonomy in her life, and a place in her community. Recently, she had two roommates who were not respectful of her home and needs, and she asked them to leave.
In her words, (rolls her eyes) (Last roommate) (She always) “got mad at me. (vocalizes)

Didn’t ask me. Accident, glue.” Chris added,

Oh yeah, Lisa knocked glue on the floor and she got mad. It was an accident... Yeah she used to get mad and treat Lisa like a child, like an errant six year old, “why did you do that and you should do this, and you should do that, and this is how you should talk to people (exasperated look).”

She seemed like the perfect person from the beginning...But after awhile, she just swooped around and tried to run it like it was her house when in fact, it’s Lisa’s house.

...She tried to act like the mum around the house rather than asking Lisa what she wanted, she would tell Lisa what she thought Lisa should want!... Very nice at first but she had her own agenda and it clashed with the agenda of what Lisa, the staff and micro board wanted.

Lisa describes her apartment as “her home,” and she is the “boss.” Her support structure encourages and respects Lisa’s need for choice and control. Lisa has choice and control in both daily living matters and life defining matters (with whom to live, where to live, what type of career to pursue). Choices in daily living matters include; the furnishings in her apartment, what to eat, what to wear, when to rise, when to go to bed, and activities in her daily schedule.

Throughout the study, Lisa has expressed a desire to move from Richmond to an adjacent suburb, Burnaby, where her friends live. Burnaby is closer to wheelchair accessible transportation (Sky Train). John, who is a service coordinator with the Community Services Branch, explored home ownership options for Lisa, and placed her on a waiting list to purchase a one bedroom apartment in a new complex in Burnaby. Lisa will be moving into her new apartment in May 1996. In her words, “wow.”
Members of the Community Services Branch have been exploring home ownership options for persons with severe disabilities. A number of suites have been purchased for persons with disabilities, and the building is staffed with an over night person to perform routine checks on those who require 24 hour care. This creative home ownership and staffing model gives people more independence regarding their living situations, and reduces costs for those who need 24 hr. support.

Lisa feels that she is supported and is being “helped.” Eileen observed, “(the micro board) We facilitate Lisa’s quality of life by listening to Lisa, by being available to Lisa, and by anticipating her needs and by guiding her to make good choices and becoming autonomous in her life. And allowing her to make a few mistakes but not radical ones (laughs).”

Specific goals for Lisa are to become a more competent communicator and advance her literacy skills. Lisa stated, “I can spell now, and communicate better. (I had my) first picture communication system when I was five. Slow down, hard to listen (when) people talk fast.” Lisa is learning to plan her own menus. Her support staff developed a cook book with pictures to assist this process. Lisa is also learning to manage her bank account.

Lisa expressed, “I need to get out more.” Lisa’s monthly activity schedule is reflective of her personal preferences and desires. Lisa enjoys being active in her community, on a daily basis she is either shopping, visiting parks, eating at restaurants, visiting friends, paying bills, etc. She is also hoping to pursue a volunteer job with “Big Sisters,” which has not yet occurred.

During the course of this study Lisa’s support network has coalesced. When Lisa was living with Jason, her formal support network was more reflective of Jason’s personal
preferences than hers. Initially, when she moved into her own apartment, she felt isolated and anxious, in her words, “it doesn’t work anymore, I am frustrated, I need help.” Since this time, Lisa has developed an extensive formal and informal support network.

In terms of formal supports, Lisa and her micro board have identified a relationship which is best suited to her personality and station in life. She requires and has supports who: (a) respect her individuality; (b) are patient; (c) understand her need for a clean well kept apartment; and (d) have a sense of humor. Some of her formal supports consider Lisa their friend and vice versa. Presently, Lisa describes the support from her micro board and friendship circle as “great.” She is developing a relationship with Craig Y, and is becoming more involved in his circle of friends. Her closest ties remain with Eileen, her foster mother, and staff at Daily Life. If she requires emotional or daily living support she is comfortable in accessing either her formal or informal support structure. John of Community Services Branch and Lynn Percy of Victory Housing have supported Lisa in fiscal and home management issues, and Lisa has turned to them for support on several occasions during this study. Eileen described Lisa’s relationship with these formal support agencies.

“I think she is a lucky young woman, and I think City Club (new apartment complex) will be a positive in her life and I think the people at CSB and Victory are all great people to have around her. Eileen commented on Lisa’s daily support staff and residential staff. “She has come a long way taking control in her life. Since we’ve had our own by-laws things are rolling more smoothly. We are also doing hiring and firing and getting that sorted out. Also getting our interview questions together and other things. Presently, she has a really good group of staff who care about her and understand her.”

Various members of Lisa’s support network reported that Lisa is shedding aspects of learned helplessness and dysfunctional relationships inherited from years in the “handicapped continuum.” These impressions were confirmed in interviews with Lisa and her support
network. When asked about her present quality of life, she said, “everything is good now, it needs work, but it is better.” Eileen reported,

I am just delighted that she has the opportunity to get into City Club, and that they (CSB) are looking into the opportunity to buy into one of the apartments. She wanted to be close to the Sky Train, and this is one of the things that is very important.

For my quality of life I need to expedite. I want efficient meetings. Anything that is formalized I want out of the way, and let’s get on with life and living and loving. And I think for Lisa the same. Let’s keep issues as low key as possible. And deal with problems when they are emergent. Deal with them and not let them become emergencies. Keep life as peaceful as possible. Lisa should have as much peace of mind as possible. Continue to encourage her to be an autonomous adult, who can live and love and go on with her life.

...I find in very many ways the micro board can do that for her. I just don’t see her life going wrong in the next little while. Touch wood. I think her life is in a positive path at the moment.
CHAPTER VIII

“IT’S ABOUT RELATIONSHIPS”

SARAH

Personal Profile

Sarah is an inspiring 25 year old woman. Her friends and family describe her as:

gentle, part of a close and caring family, caring and accepting of others, usually soft spoken, tolerant of others, teaches others, peaceful, has a wild side, good sense of humor, definite taste in music, but able to appreciate many types of music, likes watching sports, has a wonderful laugh,...is strong, persevering, long suffering, patient, good taste with fashion, loves her family, loves children, likes a lot of physical contact (hugs, kisses, hands held), loves life!!” (Excerpted, MAPS session, January 24, 1993, p.6).

I met Sarah in September 1994, when I attended a micro board meeting at her apartment, and explained the study. Sarah was on the couch, surrounded by her family. Pictures of her family adorned the shelves, and her apartment had a sense of “home.” Sarah does not speak, however, during the eighteen month study period, I was able to understand her non verbal communication, and became increasingly involved in her life as the study progressed.

Sarah has an active life in her community and has the support of a close and caring family and formal support structure. She is very expressive when her family visits, and seems to cherish these times the most. She has experienced a great deal of change in her life, and is familiar with the handicapped continuum of supports.
Sarah has multiple disabilities including; cerebral palsy-spastic quadriplegia, epilepsy (mild grand mal seizures almost daily), scoliosis (Harrington rods and spinal fusion), reflux esophagitis, a metal plate and two pins in her hip, nystagmus, exotropia, and osteoporosis. Sarah’s daily seizure medications are 500 mg of carbamezepine, 20 mg of Losec, and 24mg of Glyssenid. Sarah requires twenty four hour support which includes feeding, bathing, dressing, cooking, mobility, community access, and monitoring of medical status.

She is non-verbal and responds to questions with a head nod or head shake to indicate “yes,” and “no.” Nita, a micro board member, stated: “At one time we took some data on Sarah’s “yes,” “no” response, and found that she responded clearly to questions about 50% of the time.” Although Sarah’s “yes,” “no” response is not always clear or reliable, she uses consistent vocalizations, facial expressions, and gestures to express her feelings of contentment and discomfort. According to Sarah’s support network, “When Sarah is happy, she is smiling, her tongue is out and slightly curled, and her left leg may be kicking slightly. If she is in discomfort she vocalizes “uhh, uhh, uhhhh, uhhhh!” Sarah’s support network provides her with a pictorial schedule (photographs) to facilitate predictability and choice making regarding daily activities and social interactions.

During the eighteen month study period, I accompanied Sarah in the community, visited with her and her supports at home, and became increasingly involved in her micro board. Initially, I functioned as an observer at my first few micro board meetings. Increasingly, Al, Karen, Alicia, Nita, Pat (mother), and Sharon (Sarah’s micro board members) included me in their discussions and encouraged my participation. Sharon left Sarah’s micro board in the fall of 1995. In December 1995, I was asked to join Sarah’s micro board, and I accepted and became a full participant in January 1996.
Due to Sarah’s communication difficulties, I was reliant on her family to assist in several areas: (1) Sarah’s personal profile; (2) Sarah’s personal history; (3) the nature and evolution of her support network; and (3) reflections on Sarah’s quality of life. Sarah’s mother, Pat, has been her strongest advocate and support person throughout her life. Pat was the key informant concerning Sarah’s personal history. Al, and Alicia contributed to this segment of the study by confirming and or adding to Pat’s account. Sarah’s apartment is rich in material from her childhood, including photographs from different periods of her life, which were discussed with Sarah, and included in the data base.

Al, Karen, Alicia, and Nita participated in semi-structured interviews throughout the study, adding their perceptions of Sarah’s lifestyle, the evolution of the micro board, their personal values base and world view, and feelings of mutuality in supporting Sarah.

**Personal History**

Sarah has numerous deficit profiles which describe her as severely disabled. Consequently, her family was instructed “to institutionalize her.” Sarah attended segregated schools, and resided in a hospital setting. her personal history reflects past practices in the disability field, and the most restrictive attitudes and practices of the continuum model of supports. Sarah’s personal history was reported by her mother Pat, and her siblings, Al, and Alicia.

**Family Life**

Sarah was born in Lethbridge, Alberta, on June 14, 1970. Sarah’s mother, Pat,

It was a warm June day. I was in trouble two or three days before she was born. Our family doctor was away. I was trusting that things were okay. The doctor returned and did a Cesarean. Brain damage had occurred. No one would say for years what it was. I started asking questions, and she was sent
to X Hospital when she was a couple of months old. She was micro-cephalic. Numerous tests were performed, but they found nothing, the doctors kept telling me “don’t worry everything is okay.”

Shortly after Sarah returned from the hospital her parents separated and Sarah, Pat, Al, and Alicia, moved to Calgary, Alberta, in 1972. At twelve months, Sarah started to talk, could sit up, and was breaking toys. Sarah’s first seizure occurred when she was two and a half years old. Pat explained this time in Sarah’s life.

We had to call an ambulance. We couldn’t get Sarah out of the seizure. She was in the hospital for twelve days. The doctor asked Al (Sarah’s father) and I if he “should do everything for her if something went wrong.” I was totally distraught, I didn’t know what to say. Fortunately Al told him “you should do everything for her, as you would for any other child.” Alicia was twelve at the time and Al (brother) was ten. I stayed with Sarah all the time. I developed a real mistrust of hospitals after that twelve day stretch. I came in one day and Sarah’s face was all puffed up from crying. She had long thick hair at this time, and someone had tied her hair back too tight. Another time she came back from the x-ray room shrieking. I found out later that there was a burn. I felt like I wanted to smash someone. We went home after twelve days, and that experience caused distress.

Sarah’s brother, Al, recalled Sarah’s first seizure. “Alicia heard Sarah. It was major, it happened in the middle of the night. I remember the sound of the ambulance. She went to the hospital. She was just a different person when she got out.”

The Handicapped Continuum of Education

Sarah lived in Calgary for three years and was cared for by Pat, Al, and Alicia. At the age of three, Sarah attended a special school for children with handicaps. According to Pat, “it was a real positive thing for Sarah.” Pat was committed to keeping Sarah at home and
searched for various therapies. She sought volunteers to assist Sarah with physical therapy.

Pat discussed how this event was mutually enriching for both her and Sarah.

We needed volunteers to do patterning with Sarah, so we put an ad on television. Sarah’s name was flashed on the screen during a Calgary Stampeders football game. We got volunteers from all walks of life through that ad. Sarah got to meet a lot of people. People think it is confining having a daughter with disabilities. I used to be studious and introverted.... Life has opened up, she opened doors, Sarah brought interesting people into our lives.

Al discussed Pat’s attitudes towards disability, and how these attitudes influenced his feelings for Sarah.

Mom always said that Sarah brought a lot of people into our lives...She was like a normal little baby, it was such a dramatic thing (seizure), such a huge thing. But also it changed our stereotypical notion of disability, she had an accident or trauma, but she is still a person.

Mom has always been really good at framing things positively around Sarah, and it’s genuine too. She’s quite a special person in terms of her attitude and how she’s reacted towards things, and I’m sure it’s been really difficult but it’s always been like a positive thing and it’s been an inspiration for the rest of us. For myself you know I was never really cold to Sarah but I wasn’t that involved really, Alicia was more involved. But later in life, in my adulthood, Sarah is really important and I’m glad I have the opportunity to be involved. My mom would frame it... you know people with disabilities being secluded...she’s always been a strong advocate against the status quo, and a lot of strong attitudes out there.... To think about it, it’s really been quite amazing.

In October 1974, Sarah, Pat, Alicia, and Al moved to a suburb of Vancouver, British Columbia. Sarah attended school in a treatment centre with other children with severe disabilities.(1975-1977). Pat described that Sarah was deemed to be “too handicapped” to benefit from schooling.

There was a lot happening in my personal life, and it helped to sort things out to leave (Calgary). Sarah went to school at a
treatment centre. She met Anne there (Sarah’s present, communication specialist). She was written up for the funding drive at the centre, but eventually the centre said “she wasn’t making progress, and she was taking up room for someone who could.”

In 1977, Sarah remained at home during the day, and was not provided with any schooling (1977-1978). Sarah’s mother, Pat, was encouraged to institutionalize Sarah. Pat recalled this juncture.

A special needs support person came to the house while I was working. I was getting a lot of pressure to take Sarah to an institution. I had developed a friendship with a social worker. We had a big meeting with all the people in Sarah’s life. I asked, “what can be done to help Sarah and me?” My friend thought she was helping me, she said, “I’ll just take her to an institution, you are ruining the lives of your other children.”

...I did not institutionalize her at this time. The pressures were strong... Sarah has given so much, a lot of joy, I know it sounds awful but I think the way she is has made me a much stronger person.

I asked Al, “Is there any credence to the notion that your life was ruined having a sister with severe disabilities? Al replied, “no, not at all, it’s been like a super positive thing. It just brings the best out in people. Even when I was a self centered rebellious teenager, I never felt that way. I never felt that Sarah was detracting from me, it was always a positive thing.”

Alicia commented,

...I really enjoyed my time with Sarah, you know I had fun with her. I did things to make her laugh and got to know her as a person. I did resent a little bit all the duties I had to do... We did have some help when mom was gone, there were workers there, and there were good things about that. I did get to know a lot of people from Sarah, some were a little weird, but some were great. It definitely added spice to your life... Sometimes it wasn’t that much fun. You always had people in your home, and you had a little less privacy. But for me, I’m a social being,
and I like people, so I enjoyed it. I kind of thrived on it more than maybe other people in the house.

In 1978, Sarah was enrolled in a segregated school comprised of students with severe cognitive and physical disabilities. Sarah was transported to school by a volunteer, as Pat worked as a supervisor of a respite home for handicapped children and battered women. Pat and Sarah received homemaker supports while Pat was at work. Pat noted that Sarah’s siblings provided crucial supports when she was absent, “Alicia and Al were always around to ensure that Sarah was supported when the homemaker left, and I was on my way home from work.”

In 1980, Sarah and her family moved to another suburb in the Lower Mainland of British Columbia. Pat discussed the lack of academic participation at Sarah’s segregated school, and the positive influence of Sarah’s teachers on her non verbal communication.

Nothing much was happening for her academically,... she listened to music... Anne (special education teacher) was there talking to Sarah and she was responding. We had always talked to Sarah, but it was a revelation to me, she(Anne) was getting a real head nod, she (Sarah) was listening and answering back.

**Entering the Continuum of Residential Services**

In 1981 Sarah attended respite care in a hospital setting. Pat described the circumstances leading up to this decision and Sarah’s experiences in an institutional facility.

The only place for respite was a hospital and our family doctor had to give the okay. I wanted to go away for a weekend to Saltspring Island. My doctor thought it was frivolous and didn’t okay it. At the time, I just accepted it. My friends thought I was crazy and told me to get another doctor immediately. Times have changed.

While at respite, Sarah broke a leg and it was two days before someone noticed. It was horrifying, medical staff did not notice. That was the attitude; “she’s spoiled and she just wants attention.” Sarah does not seek attention for nothing.
Sarah returned home with a cast, and Alicia got married. It was hard to move Sarah around, it was a bad house design and we had to carry her up the stairs. It was the second time I felt I was going to die. I had so much pressure, I felt I was suffocating. I started looking into getting Sarah to (a permanent hospital residence). That’s what people said, “don’t wait, get her in now.”

Although Pat resisted the notion of institutionalization for Sarah, intensive, flexible, community based supports were generally not available in British Columbia in the early 1980s. Services were primarily facility based, and persons with severe disabilities were often required to leave their family homes to receive support.

Life in a Hospital

In 1981, Sarah left her family home and resided in a hospital setting on a full time basis (1981-1983). Pat discussed the factors influencing her decision, her relationship with staff at the hospital, and Sarah’s lifestyle quality in an institutional setting.

It was horrible, it was the worst time in our lives...I couldn’t get a break unless you didn’t want to do anything but go to work. I took my life over Sarah’s. I ended up spending a lot of time on the ward anyway.

Sarah fell out of bed, she cut her lip, and one of her ears was torn and bleeding. She also had a bad bruise on her neck. It was a big mystery, no one knew what happened. I found out afterwards that all of the nurses would take lunch together.... We had a big conference... I was beyond anger, I was rational, I had the presence of mind to stay calm and ensure that it didn’t happen again. She could have been killed, she slipped through the bed rail and hung by her ear. The second thing was... the excuse was, her legs were brittle. I told them she never broke her legs the whole time she lived at home. You can’t blame her brittle bones.

Close to where Sarah was staying was a bulletin board. I read that four children had fallen out of bed. Soon after I brought that up, the bulletin board was moved. I would patrol the halls,...doors would be open and cats would be roaming around, all of the nurses would take their breaks together. That
used to get to me. I would ask and ask to get someone to supervise.

They can’t love Sarah like I do, but they can give her better care. The last thing was jungle rot under her arm. They didn’t give her the time. I was seen as such a troublemaker from staff and nurses that they told me to see a psychiatrist. I said, “sure I’ll see a psychiatrist if he would help me not to worry, not to be concerned.” He felt I was pretty normal and he didn’t want to see me anymore...My favorite line from the director was, “Remember, before you start Pat, I have a headache.” Over time Sarah began coming home on weekends, and finally I said, “she is staying home.”

Return Home

In 1983, Sarah and Pat moved to a new, subsidized housing complex in South Vancouver (Sarah’s present home). Pat continued to advocate for community based supports for Sarah. She encountered a resource person from the Ministry of Social Services who was interested in Sarah. Pat stated, “The resource worker was great, Sarah was one of the first to receive home care. Anything I asked for they gave me.” Alicia was married and lived away from home, but was a paid support of Sarah’s in the mid 1980s. Alicia described how this role assisted her to develop a better understanding of Sarah’s needs, and the intensive nature of support required.

.... I worked with her, I guess she was about fourteen fifteen then. And I worked four days a week with her, and it was all checked out everyone knew I was her sister... And I spent a lot of time with Sarah then, getting to know her and taking care of her. And it was heavy duty, I really saw then how much work it was and how it was and it’s hard working for your mother and step dad (laughs). It was interesting. But I did enjoy being with Sarah. I got a lot of peace and fulfillment working with her. But it was a lot of physical work, feeding her, changing her, keeping her clean, just the amount of time it took to feed her. Doing the dishes and the laundry, it entailed looking after her and doing the housework... So that was a good experience for me. I guess my eyes were opened a bit more.
Sarah’s schooling was provided in a hospital setting in Vancouver (1981-1990). Pat described the effects of segregated schooling and busing on Sarah’s skill acquisition and quality of life.

Once again Sarah was considered too handicapped. Her education consisted of putting a doll in her hand, a comb in her hand, that kind of thing, nothing very stimulating. The bus ride was an hour and a half there and an hour and a half back. Sarah was a wreck, she would return home crying, wet, and drooling.

In 1983 Sarah underwent successful hip surgery and in 1985/86 she had surgery on her back to treat scoliosis. A feeding tube was inserted in her stomach. Pat described how the tube compromised Sarah’s quality of life, and how the decision was made to remove the tube.

She had two steel bars put into her back and two steel bars in her hip. Sarah is heavy because she has all this metal in her. In 1986 she also had another severe operation because of her esophagus. I looked into the scope and the esophagus was very irritated. I had to make a quick decision. The doctor convinced me that a tube in the stomach was needed. He patted me on the back and said, “it will be much easier dear (condescending tone).” I said it would be temporary and we would start feeding her again as soon as the esophagus healed. The tube became a crutch for us. The tube kept popping out and we had a public nurse that supported us in the home. She said, “Sarah is too fat, take the tube out, she doesn’t need it.” We took it out and never put it back. The wound healed, and she is fine. She loves chocolate, and she is able to eat it now.

In 1988 Sarah began spending weekends at a group home (respite care) with four other persons with physical disabilities, Sonny, Paul, Craig and Kenny. Pat wanted respite care in a less restrictive setting than a hospital. At first, the respite experience was not good for Sarah. The workers did not treat her well, and thought she was “spoiled.” Over time, Sarah was accepted by the other residents, and began to develop a friendship with Sonny. Pat said, “Her best friends are at that group home now.”
When Sarah was given her second Mul Hallen wheelchair in 1988, Pat noted, “It made a world of difference.” Sarah’s life was stable; she had support in her home, she attended a segregated school during the day, and received respite care in the group home on the weekends. Life had settled for Pat; Al and Alicia had left home, and she shared her comfortable apartment with her partner, Laurie, and Sarah. “Laurie bought Sarah a radio, earphones, and listened to classical music with her. Laurie saw Sarah’s potential.” (MAPS meeting, 1993).

It had taken Pat many years to develop the community-based support structure for Sarah. In 1989, Sarah turned nineteen and responsibility for her care was transferred to adult services. A clear demarcation of supports existed for children and adults with disabilities. Group homes and institutional care were the norm for persons with severe cognitive and physical disabilities. Pat questioned the logic of moving Sarah from her home to the continuum model of supports, and began exploring other support options.

I went to a TASH (Lower Mainland Branch of The Association for Persons with Handicaps) conference about adult supports... There were families, and people there who provided supports (government agents and service providers). It was pretty emotional. People were pretty frustrated with the system. They (some service providers) were talking about beds. One person got up and said “she never wanted to hear that a place to live for her son was called a bed.”

I was so glad I was inspired...I got up and spoke. We had services. I was saying “I don’t hate the social workers, we had services.” But I did say, “Why does Sarah need to leave her home just because she turned nineteen?” I mean Prince Charles lived at home until he was 35.

There were two people at the meeting from Community Services Branch. I discovered [the regional coordinator] through them and Cyndy connected me with Lynn Percy (Victory Housing).
As Pat was exploring residential options for Sarah (1989), Victory Housing and CSB were searching for participants for the micro board pilot project. The regional coordinator of SCL explained this synergy.

I think it was probably Pat who called me, because she was one of those very capable parents that finds her way through systems...And she called and said, “look, here is my situation. Sarah is now an adult, I’m switching services, and I don’t know where I’m going to get my services from. Continuing Care tells me they can’t do this for me, I don’t have a day program, Sarah doesn’t go to school.” It was basically, “help” kind of thing.

... When Sarah came to us she was switching from children’s services to adult services. And there is a quantum leap between those two sets of services in availability and amounts of service. So I started out, literally, trying to figure out how to replace the 50 hours of in home support she was getting. I looked at working with continuing care and ourselves. But then the problem for Pat was ... she trained something like thirty people in one year to support Sarah ... So Sarah’s training issues were massive, and Pat was essentially home bound by it, because these are not skills that Pat could just hand over to these thirty different people that were coming in and out of her life. So these thirty people ended up doing things like cleaning up the house and things like that, and Sarah couldn’t get out and go places unless mum could get out. So, it looked like what Sarah needed and what mum needed was control over their own resources to do their own hiring, and keep good staff. But we didn’t have that mechanism when I first started talking to Pat, so I said, “Pat maybe you want to talk to Lynn Percy.”

The concept of direct funding to families was contrary to traditional support models and traditional role structures. Pat and the regional coordinator of CSB discussed direct funding from familial and bureaucratic perspectives. Pat stated:

The notion of direct funding was a godsend. We could pay people more and charge government less. Sarah would be part of the process. For the first time the family was going to be consulted and respected and trusted. That was a big change, that we could spend the money wisely and not drink it away (laughs).
The regional coordinator of CSB related how the notion of direct funding was being viewed by the traditional disability support structure.

This was like a "no no" (direct funding), anybody I told about this had bells going off all over the place,"...You're supporting and putting in a bunch of money into a family." People were saying, "Well how do you know that Pat's not living off of Sarah's money?"

The administration at CSB realized that fiscal responsibility and close monitoring were essential to promote the micro board concept, and support Sarah in a flexible manner. The regional coordinator explained this process.

Pat used to get irate. In the beginning, we were quite careful, so that the project would withstand scrutiny, and it made her irate that it would have to withstand scrutiny. If I heard once, I heard a hundred times from her: "Why don't you trust parents?" And that's a hard question to answer. I didn't have an answer. All I knew was that I had to protect her, and protect Sarah's situation. So we tried to be very clean and the micro board gave the avenue because essentially an entity called "Sarah Anne Friends Society" is who we paid the money to.

The regional coordinator, and other members of CSB played a key role in the development of Sarah's micro board. Sarah's brother, Al, noted, "Cyndy has been like a huge advocate, even at contract negotiations...She really has been pro making it work, she really walks the walk, she really tries to make things connect for people. She's really been a key person in Sarah's life."

Sarah's micro board ("Sarah Anne Friends Society") was facilitated by Lynn Percy of Victory Housing, and planning began in September 1990. Al, Sarah's brother, described his first impressions of the micro board concept.

I was there when Lynn Percy (Victory Housing) came over the first time. It was just kind of automatic like mum saying, "yeah this lady is coming over to talk to me about micro boards and it sounds really good." I was actually quite skeptical. At that point I really was thinking about Sarah. I was really into Sarah,
and what’s best for her. And when I noticed a certain staff was really inappropriate at one time, I was emphatic, “this staff has got to go.” It was a home care agency providing care, and I basically was saying “this person may be a great person but she shouldn’t be doing this, she was like rough with Sarah.”

And I had to convince mum after a bit, and she was thankful that I gave that input. So I was really inspired. This is my sister who I had fully appreciated up until that point. So I was quite skeptical with Lynn, not because of anything, it just sounded too good to be true. You know like “whoop what is this?” But I was quite involved right away. I really wanted to find out what’s going on. So when Lynn initially talked to mum, I was thinking right away, “this is really cool and this is a huge gift.” And that’s what it’s been, such a great opportunity to do all the things that we wanted to do. But to just clear all of the channels so we could actually do them, and have the authority and resources to do them really effectively. And I was looking for an opportunity to be more involved in Sarah’s life, and there it was, a huge opportunity.

Pat, Al, and Alicia searched for potential board members. Al’s wife, Karen, was well-versed with the continuum model of supports and community inclusion of persons with disabilities. She was a support worker and had worked in various group homes. She explained her philosophical view of disability, her experiences in the disability support field, and her decision to join Sarah’s micro board.

The college program that I attended (Community Support Worker for Persons with Disabilities) was definitely geared to esteeming the people that you’re supporting, but it was definitely still textbook...So I was entering the field more with some preconceived ideas, but also how to break the norms of what has been happening for people. Like, let’s break out, let’s get creative...you know that people with handicaps are people and they need to be valued... In some ways it was almost too idealistic. I think I had to realize that. I went out and starting working with people, and we have to make their life great, and it has to be totally centered around them. And yet I’m in a system of group home settings where your limited. What a frustrating experience (emphatic).
I hit that wall... Even before I went into the program (Community Support Worker), I had a value base that people are people. Who cares what’s going on otherwise. You can’t teach that, you’ve either got it or you don’t. Then I got involved with Sarah and went “wow” what a neat concept. And kind of like me, just diving in with my eyes closed. I had no idea what was involved.

I queried Karen about the development of her values base, and how this influenced her decision to support Sarah as a micro board member. She responded.

I can’t really say it’s how I was raised per-se because my parents hold a lot of prejudices and that kind of stuff. I guess because I was often excluded from things. I was the kid that was picked on. And I guess I could identify with the pain. I don’t know, something innate, something innate telling me that “it doesn’t matter who you are, you’re still a valuable person.”

...And then different experiences...I could identify with being marginalized and how painful that is. So when I started realizing this population of people (people with disabilities) is so marginalized and so stereotyped it’s all surface, you know what does the book look like? Instead of reading the book. And I just hated it, and I thought it’s so ridiculous...Yeah so that wall really hit me and I got disillusioned. And getting involved with Sarah, like I said, I just went “wow, what a neat concept.”

In March 1991, “The Sarah Anne Friends Society” received funding from CSB and was officially recognized as a full functioning micro board. Pat described her feelings when Sarah’s micro board was formed. “There was a big burden lifted off of my shoulders...Now young people who cared about Sarah were in her life. I felt a physical lifting, it wasn’t just me.”

Lynn Percy (Victory Housing) discussed her role in facilitating Sarah’s micro board.

It was clear when I met with Sarah and her family that there were people that really cared for her and loved her. I didn’t have to spend time developing or fostering those relationships. More of my focus was on Pat and recognizing that Pat had been through a lot where she didn’t trust a lot of people, so a lot of my time went into winning Pat’s trust and spending the time
with Pat. You know going over the idea...and trusting me enough to figure out okay we can include this and that (in the micro board proposal). And we proceeded from that point to the pragmatic functions of setting up the board and securing funding.

A summary of the key events in Sarah's life as described by her family is shown.

Summary of Key Events in Sarah's Life

1970

BIRTH
Pat: "I was in trouble 2 or 3 days before Sarah was born
Family doctor was away
C-section performed
I thought something was wrong
Doctors kept saying "don’t worry everything is okay"
Numerous tests performed

1972

PAT AND AL (SARAH’S DAD) SEPARATE. MOVE TO CALGARY
Pat: Sarah could sit up.
She started breaking toys
Said “hi,” and “da”
Family life was in turmoil and we moved to Calgary

1972

SARAH HAS HER FIRST SEIZURE
Pat: “I had to call an ambulance we could not get her out of the seizure
She was in the hospital for 12 days
Doctor asked if “he should do everything with her if something went wrong“
Al (Sarah’s father) told the doctor “to treat her like any other child and do everything”
The seizures were not life threatening but Sarah forgot how to say things, her body went limp, she lost those abilities after the seizure, and they never came back

1973-

SARAH ATTENDS SCHOOL AND HAS HER NAME FLASHED ON TELEVISION DURING A CALGARY STAMPEDERS FOOTBALL GAME
Pat: Sarah went to a special school
She got out with kids with handicaps
It was a real positive thing for her
Sarah’s name was flashed on a screen during a big football game
I was looking for volunteers to do patterning with her
Sarah met a lot of people through that
Summary, Continued:

1974  SARAH, PAT, ALICIA, AND AL MOVE TO THE WEST COAST
Pat: Sarah went to a treatment centre in Surrey
Sarah met Anne (special education teacher) at centre
Sarah was written up for fund drive
centre finally said, “she wasn’t making progress, and she was taking
up a space for someone who could make progress.”

1977  SARAH IS CONFINED TO HER HOME AND NO SCHOOLING IS PROVIDED
Pat: Sarah returned home with no place to go during the day
Special needs support came to the house while I was going to school
I was getting pressured to take Sarah to an institution

1978  SARAH IS ENROLLED IN SEGREGATED SCHOOL
Pat: Sarah was finally enrolled in X school with Rose
and Anne (teachers)
Sarah was picked up by a volunteer twice per week
There was a homemaker while I was working
Alicia and Al were always around to ensure that Sarah was supported
when homemaker left and I was on my way home from work

1980  SARAH AND HER FAMILY MOVE TO PORT COQUITLAM
(NEIGHBOURING COMMUNITY).
Pat: Nothing much was happening academically for Sarah
Anne (special education teacher) was there talking to
Sarah and she was responding
We had always talked to Sarah but it was a revelation to me, she
was getting a real head nod, she was listening and answering back

1981  SARAH BROKE HER LEG ATTENDING RESPITE CARE
(HOSPITAL SETTING)
Sarah went to a hospital for respite care and broke her leg
It was two days before anyone noticed
Sarah returned home with a cast and it was difficult we had to carry
her up and down the stairs
I was getting pressured again to put her in an institution

1981  SARAH MOVES TO A HOSPITAL SETTING
Pat: It was horrible, it was the worst time in our lives
Sarah fell out of bed in the hospital, she cut her lip, one of her ears
was torn and bleeding, and she had a bad bruise on her neck
It was a big mystery, no one knew what happened.
Summary, Continued:

1983

SARAH LEAVES HOSPITAL AND MOVES INTO SUBSIDIZED HOUSING COMPLEX WITH HER MOTHER
Pat: Sarah was one of the first persons to receive home care
Anything I asked for they gave me
The resource worker was great
Sarah was enrolled in day studies at the hospital
Again Sarah was considered too handicapped and nothing very stimulating was happening
Bus ride was 1.5 hours there, 1.5 hours back
Sarah was a wreck, she would return home crying, wet, and drooling

1986-88

SARAH UNDERGOES SURGERY, MEETS NEW FRIENDS AND RECEIVES A NEW WHEELCHAIR
Pat: Sarah had another severe operation, a tube was inserted in her stomach
Sarah's doctor convinced us that a tube in the stomach was needed for feeding
Sarah had respite care at a group home and met Sonny, Paul and the gang
She received a new wheelchair, it made the world of difference
The public health nurse rid Sarah of the tube for feeding
The wound healed and she was able to eat real food.
She loves chocolate

1989-90

PAT ATTENDS A CONFERENCE SPONSORED BY THE BRITISH COLUMBIA CHAPTER OF THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS AND LEARNS ABOUT MICRO BOARDS
Pat: I was inspired by the TASH conference
I began questioning why Sarah had to move out of my home when she turned nineteen
There were two persons from Community Services Branch (CSB) at the conference and they hooked me up with Cyndy Marlin (CSB) and Lynn Percy (Victory Housing)

1991

"SARAH ANNE FRIENDS SOCIETY" (MICROBOARD) RECEIVES FUNDING FROM CSB
Pat: A big burden was lifted off of my shoulders
Now young people who cared about her were in Sarah's life
Al: (Micro board)...was a huge gift
Opportunity to do all of the things we wanted to do
It (micro boards) cleared all of the channels so we could have the authority and resources to do things really effectively
**Sarah’s Present Situation**

Sarah continues to reside in the subsidized housing complex to which she moved to when she was thirteen. Pat left the apartment to Sarah and relocated to a small community in the interior of British Columbia (1994). The complex is comprised of approximately thirty buildings. Each building contains six suites with one two, or three bedrooms. Sarah has a three bedroom apartment that she shares with a roommate. The housing complex is located in the south of Vancouver, a primarily residential district containing subsidized housing, middle income condominiums, and single family dwellings. Several wheelchair accessible parks and marine walkways are within three kilometers of Sarah’s apartment.

The complex is 12 kilometers from downtown Vancouver. Sarah has her own van equipped with a wheelchair lift, and uses it to visit shopping malls, community centres, and restaurants. Her apartment is located on the first floor of the housing complex, and she has her own parking stall in front of the apartment. Since Sarah is unable to operate a power wheelchair, she is reliant on a support person to position her in her chair, and enter and exit her apartment.

Sarah’s apartment is bright and comfortably furnished. There are three bedrooms, a kitchen, a dining area, a living area, and a washroom. Sarah spends most of her time, while at home, in the living room, which has a sliding glass door leading to a small balcony overlooking the Fraser River and the southern slopes of Vancouver. Visitors to Sarah’s apartment comment on “the beautiful view.” Sarah enjoys watching basketball, and other sporting events. Books, a fish tank, plants, family photos, paintings and crafts adorn the walls and shelves in her living area. When Sarah is not seated in her wheelchair, she sits on a couch.
supported by pillows and a wooden foot rest. A palm sized switch (Able Net) is located beside the couch, which can be programmed to operate Sarah's television and radio.

Her small kitchen is equipped with a range of modern appliances. Sarah is unable to participate in meal preparation, and there are no adaptations in the kitchen to enable her to do so. Her large bedroom contains a specialized bed with rails and various support positions. The walls of the bedroom are decorated with sports posters and Christian icons.

The bathroom is small and is not designed for a person in a wheelchair. A specialized lift (a levered sling) is used to maneuver Sarah in and out of the bathtub. The spare bedroom contains a desk and filing cabinets, and is used as an office by her support staff and micro board.

Sarah's Support Network

Sarah's support network consists of both formal and informal supports. Sarah's informal supports include: (1) her micro board (Sarah Anne Friends Society) which is made up of her mother Pat, her sister Alicia, her brother Al, her sister-in-law Karen, and her friends Nita and Sharon (since moved), (2) her neighbor, and (3) Sonny, Paul, and Kenny who reside in a group home which Sarah visits on weekends. Al, Alicia, Nita, and Karen held various jobs in the disability field during their careers, which influenced their ideas of formal and informal support systems within the micro board project.

Nita joined Sarah's micro board in 1993 and had worked with Sarah prior to joining. I interviewed her regarding: (a) her decision to join Sarah's informal support structure; (b) her value base regarding support and persons with disabilities; and (c) the differences inherent in the micro board project and her experiences in the continuum model of supports.
Interviewer: How did you become involved with Sarah and eventually join her micro board?

Nita: I first knew her as a staff person when she was part of the community day program (program operated by non profit agency, spring 1991). I was working with her two days per week. Then the micro board project started up. After the micro board started they asked me if I wanted to run her day supports. I had made a connection with Pat but I wasn’t interested in running a day program.

Interviewer: Did they ask you to join the micro board immediately after it was formed, or did it take awhile?

Nita: Oh Jeez, it was probably a year and a half after I had quit working with her that they asked me to join the micro board (1993). I was still in touch with Sarah and the board.

Interviewer: What made you consider joining the micro board?

Nita: Actually I don’t think I would have joined unless I was asked, no not on my own, it’s not something I would have considered. I wouldn’t have initiated it.

Interviewer: What types of issues were you weighing?

Nita:... It was so close to my personal work and the amount of time that I could give.

Interviewer: Did you feel pressured?

Nita: No I didn’t feel pressured, Al has a very good style he doesn’t pressure.

Interviewer: What were some of the positive aspects that you considered?

Nita: I was into peer interactions, non handicapped friendships, things like that and realizing that friendships and relationships are very important in peoples lives. I was expanding my
notions on support and what traditional day programs could be and the micro board concept fit with my personal philosophy.

The other reason I joined was for my own benefit too, because the micro board had a different organization. I thought I could take on some roles that I didn’t have when I was a front line staff that would expand my own skills.

Racino et al. (1993) discussed the empowering value base of the people who support the person-centered paradigm. I interviewed Nita regarding her personal values.

Well, okay, that’s always hard to say because it changes (values). I guess it was partly helpful working in an institutional setting, at times, especially working at the nursing home was really interesting looking at the rights that the individuals had and didn’t have at the nursing home was fairly atrocious. It was just very obvious and simple that these people didn’t have any rights. I mean they were going to live in this place probably until their death, and they weren’t allowed some obvious and simple pleasures.

And also there was a fair amount of borderline abuse going on, not physical, but verbal abuse going on. So I guess just being put in that situation when you were young and idealistic and realizing that this is wrong. And then at the institution and working in different wards...realizing that each person was unique and had a personality...Just coming out of that and realizing that people with disabilities, they still have worth as a person and they are individuals, and they have a right to a good life.

...And also, I was a bit involved as a social scientist. How to improve their life, and at that time the focus was always on improving them and that was very much on the training and behavior mod focus. And that’s kind of gone down the wayside. It's more with the field realizing that you're not trying to change these people, you’re trying to facilitate their lifestyle, you’re not trying to change them, you’re trying to find their niche in life where they can become comfortable.

The views of the other members of Sarah’s micro board were consistent with Nita’s. Sarah’s micro board is involved in her life, and are encouraging her use of augmentative and alternative communication strategies (head nod “yes, no,” picture communication system).
Her micro board is providing social support, and assisting Sarah with: (a) lifestyle planning (MAPS); (b) hiring, supervising, and supporting staff; (c) monitoring lifestyle quality; (d) negotiating with CSB and preparing budgets; and (e) monitoring health and housing concerns.

Sarah and her micro board held a lifestyle planning session at her home in January 1993, and developed a list of dreams and nightmares which guide Sarah’s formal and informal support structure.

DREAMS for Sarah:

(1) Like Sarah to express what she likes

(2) Have a large circle of friends who truly appreciate her

(3) Van or her own wheels

(4) Her own computer

(5) To enjoy good health for many, many more years

(6) To plan regular activities which will help to build relationships

(7) To have more adventures e.g. travel

(8) Always live with people who love you and care about you

(9) To have a loving relationship with a man, boyfriend

(10) Sarah to learn how to read and write - it would give her lots of pleasure

(11) People around Sarah would get what she was saying, clearly - e.g. if she rebelled, they would know

(12) Sarah would be famous, known for some of her talents

(13) To be happy and content, and have a close intimate relationship with God

(14) To be able to initiate outings with her friends
(15) To have freedom of choice of who she associates with

(16) That she always has a micro board, and that funding is under her control (and boards)

(17) Sarah to have more fun, do things that give her pleasure, more hands on

(18) to finger paint (foot painting)

(19) Hand on hand, hand over hand - eating, self care, cleaning up, folding

(20) Having different tactile experiences

(21) Go to wave pool

(22) Have the opportunity to live on her own or with another person

(23) Comfortable with seating arrangement

NIGHTMARE

(1) Have people in her life that would abuse her!

(2) If she lost direct funding-losing her micro board

(3) Stop listening to Sarah

(4) Sarah is lonely

(5) Sarah is bored

(6) Sarah to become very ill, she would need to be in hospital

(7) To lose all support people, e.g. death or distance

(8) Sarah lives in an environment where she isn’t loved or cared for properly

(9) Sarah doesn’t develop good relationships with staff and friends

(10) To have a bad relationship with a man friend (boyfriend)

(11) That community stops opening up- no opportunity for furthering her education skills

(Excerpted, MAPS session, January 24, 1993)
I attended most of Sarah’s micro board meetings from October 1994, to February 1996. The meetings have both a social and pragmatic function. Pat, Al, and Alicia are informal and emotional. A close family unit, they have been through some difficult times, and this is evident in their interactions. Nita functions as the secretary and treasurer. The meetings take place in Sarah’s living room, and she is often seated on the couch with her micro board in a circle around her. Questions are directed to her. Sarah seemed to enjoy the company and attention she received.

Sarah’s micro board is comprised of a president, vice president, treasurer, and secretary. Initially, I was an observer at board meetings. During the course of the study, my role at board meetings changed from observer to participant (January 1996). I was invited to become a member of the board in December 1995, and in January 1996, I became a full voting member.

Immersion in the micro board process allowed me to experience the range of issues involved in supporting Sarah. Typical agenda items included: (a) Reading of previous minutes, (b) old business and new business arising from minutes, (c) Staff issues (job descriptions, monitoring, quality care) (d) budgeting and financial issues, (e) medical issues, and (f) Sarah’s lifestyle quality.

My fieldnotes from June 2, 1995, describe a typical micro board meeting.

Fieldnotes: Micro board meeting
Place: Sarah’s apartment
Date: June 2, 1995
Time: 6:30 p.m.

Present: Nita (board member), Alicia (board member), Mary (Sarah’s support staff), Karen (board member), Sharon (board member), Ella (support staff), Sarah, and Paul (researcher, and participant observer)

Scene: Sarah’s Living Room
Participants are slowly gathering. Sarah is on the couch with Ella (support person). Ella is feeding Sarah. There is a social “buzz” to the room. Sharon and Karen have their babies with them. Casual conversation, people come in and greet Sarah. Sarah appears to enjoy the excitement and attention. She is smiling and her tongue is curled (signal that she is happy). People are in the kitchen preparing food and drinks. The balcony door is open, exposing an expansive view of South Vancouver and Richmond.

The meeting begins at 7:00. Mary (day support person) begins with a monthly review of Sarah’s lifestyle. Mary added several new community activities to Sarah’s repertoire. Mary and Sarah checked into line dancing at the community centre to see if Sarah would enjoy watching. Mary reported that line dancing occurs on the second floor of the community centre and there is no elevator. Sarah is restricted by this access barrier.

Sarah attended a baseball game at Nat Bailey Stadium. Al asked, “Did she like it?” Mary responded, “yeah, but she fell asleep.” Sarah also attended an evening of music at a local coffee house with Marie (staff person) and Nita (board member). Nita stated that Sarah really enjoys the music and the atmosphere.

Agenda casually drifts to Sarah’s van. Sarah and board members are eating, children are running about playing. Al directs Mary to get Sarah’s van ready for her trip to Grand Forks (three week vacation) at her mother’s place. Several staff will accompany Sarah and her mom. Pat requested help with the driving.

Nita interjects and directs the agenda to Sarah’s health needs. Nita suggests that board members ensure that they check staff log notes to ensure that Sarah’s health care checklist is being followed.

On a more sober note, Al directs the agenda to the financial situation. He stated, “we have made it through the tough times and we are ready to sign a new budget.”

Al discusses the difficulties encountered by having Pat do the books from such a distance. Al has since taken the job over, and will be attempting to negotiate an increased budget to cover higher costs incurred by the micro board and resultant deficit.
Sarah continues eating, and watching the children play. Ella asks, “Sarah are you finished eating?” Sarah nods her head slightly. Ella responds, “Okay Sarah, we are going to go to your room now” (physio and hygiene). Sarah is carried to her room by Mary and Ella (two person lift developed by community based physiotherapist). Ella comments while lifting, “Two small people with big hearts (laughter).”

Discussion moves to buying Sarah a new chair for her living room. Rationale is to purchase a chair with better support than her couch. Alicia comments, (animated tone) “I remember when Sarah was young and I would spin her in the chair. Man I thought she would throw up, but she loved it.”

Nita discusses her concern that certain staff aren’t doing the designated housework.

Al jokes, “I’m scared of x.” Resolution to bring matter up with staff person. Agenda items come to a close and meeting drifts into a social function. Al begins telling stories.

I attended the budget meeting with CSB and took note of the role of CSB.

Place: CSB Office
Activity: Budget meeting
Present: Author, Paul, Cyndy, Karen, Al, Rebecca, and Nita

Chronology/Observations: I met Al and Karen in the parking lot. Rebecca their newborn was with them. I felt somewhat awkward, as I felt I was intruding on sensitive matters. Not so much from Al and Kim’s perspective but from Cyndy and Paul’s. We wait in the open waiting area and Cyndy and Paul greet us. Quickly turns into a family affair. Cajoling, cooing over Rebecca. Very different than some of my experiences with other meetings where it tends to be more formal, and more bureaucratic when dealing with families. Cyndy and Paul disarm and minimize the power imbalance.

Cyndy and Paul direct us to a small meeting room. I briefly describe why I am there and what the study is about. Cyndy makes some jokes and the meeting begins, they do not seem concerned that I am there. The tone is cordial and familial.

Meeting Agenda
(1) Van payment low, need more money: Paul in agreement
(2) Administrative time (Al wants 5 hours of admin time paid out at higher rate to Mary to alleviate stress) Al: “didn’t want to see our involvement as a job. Didn’t want to get burnt out.”

(3) Staff wage is $11.75 per hour. Paul was saying that a 2% increase is really all that he has to play with and that 80% of the 2% should go to boosting wage.

(4) Sarah’s eviction notice: Paul says they will cover Sarah if she needs to move out temporarily while her apartment is repaired.

Analysis/Impressions: The meeting was very different than I had anticipated. It was much more familial than I had expected. Rebecca is brought in to the room. Karen is mostly concerned with the baby, Nita is sitting lotus style in her chair, twisting and singing. Al takes the lead regarding difficult financial situation (books not up to date because Pat in Grand Forks, when books finally prepared they are unable to make payroll).

Cyndy and Paul discuss ways to deal with the financial situation. Clearly Paul and Cyndy are sympathetic to their needs and Cyndy goes as far as suggesting that Sarah’s furnishings are looking a little shabby and refers them to a source for therapeutic furniture.

A great volume of work is performed by Sarah’s micro board, and is characterized by both intensity and humor. There are varying degrees of mutuality in the relationships of its members. Al, Alicia, and Pat found that the micro board enriched their relationship with their sister, and resulted in a deeper understanding of their personal concepts of lifestyle quality and community. Al provided his perspective on the enriching nature of the micro board project.

...(In Sarah’s case) it’s Sarah that’s bringing people to her, and people with the value base and helping that value base to develop. That’s how I see it. Sarah is bringing people together. Our relationships and social life and the quality of our life is enriched by Sarah because of the people that we know on the micro board, like yourself, through other micro boards, through Victory, through the ministry.

You know it’s very enriching, most people don’t have the opportunity to...Sarah’s challenges us to get involved in really thinking about somebody’s life, being involved in their life,
cooperating with other people towards that. I mean that’s a very big opportunity that most people don’t have. And the by-products of that are, you know quality relationships and doing something that is positive that’s good, that’s altruistic, and learning new skills, doing things that you wouldn’t normally be doing, and being involved in something that is just a really good idea.

... It’s cutting edge. It’s not status quo. So in a sense Sarah is at the head of things because Sarah is bringing people towards her. You know we’re doing it because it makes sense and there was a need to do it... We’re just trying to do the best when we’re given these opportunities. We’re not necessarily trying to do what society thinks is normal, or what we think is normal, or else we wouldn’t be doing what we are doing. Because this isn’t normal.

Nita (micro board member) observed that Sarah is more interactive and engaged when Pat (mother) is present at micro board meetings. Due to the distance between Pat’s home and Sarah’s home (700 kilometers), Pat attends approximately three meetings a year, and participates in others by telephone when important issues arise. I had the opportunity to participate in a board meeting with Pat present. My fieldnotes illustrate Pat’s commitment to quality of life issues and the inclusion of Sarah in decision making.

Fieldnotes: Micro board Meeting
Date: Feb.22, 1995
Place: Sarah’s living room
Present: Al, Nita, Karen, Pat, Ella, Sarah, Paul

Scene: Board members gathered around Sarah discussing agenda items ((1) Staff lateness, (2) Financial situation, (3) medical status, and (4) activity patterns and quality of life.

Excerpt: Pat is discussing the mission of the board and the content of the agenda.

Pat is very animated and impassioned. She is visiting Sarah for a week and her presence and energy in Sarah’s home is clearly felt. Pat reviews the agenda and wants to discuss Sarah’s lifestyle and lifestyle quality. She is seated directly across from Sarah and addresses the board, “The board is for Sarah. We
have to keep our focus, ‘How will it change Sarah’s life for the better?’ Everything should involve Sarah directly.’

Sarah is looking around the room smiling, her tongue is curled, and her left leg is kicking slightly (she is happy). Discussion turns to Sarah’s activity patterns, and swimming. Pat recalls her time living with Sarah, and laments the loss of Ruby (pseudonym of previous, preferred staff of Sarah’s). Pat explains that Ruby and Sarah were very close and that Ruby had offered to volunteer to go swimming with Sarah. Pat suggests that the board pursue this. Pat then addresses Sarah directly, “Sarah, do you want Ruby to come back?” Sarah, is looking around the room smiling. Sarah looks directly at her mother and nods her head three times. This is the most definitive “yes” response that I have witnessed. Pat responded, “yes, good, three nods, you can’t get clearer than that.”

Sarah’s Formal Support Network

Sarah’s formal supports include: (1) five support staff whom she hires with the assistance of her micro board, (2) A facilitator from Victory Housing (Lynn Percy), (3) a community based physiotherapist, (4) a community based communication consultant, (5) a literacy tutor, (6) a service coordinator from CSB, and (7) a physician. Sarah’s closest ties are with her direct support staff, on whom she depends for all aspects of her daily living; feeding, dressing, hygiene, physiotherapy, community access, care of her apartment, budgeting, and monitoring her health. Sarah’s home and community support workers are from the Philippines. Pat recruited several direct support staff from traditional support agencies, and several provided care to Sarah prior to the development of the micro board. Alicia and Nita assisted in the hiring, they provided direct care to Sarah in the mid to late 1980s. Criteria for hiring include patience, kindness, respect, inclusive values and community connections. Alicia described her experiences in the hiring process.

We were looking for someone who was loving and patient, and kind. Actually I was involved in hiring someone for the day program so we were looking for someone who had good initiative, a go getter, someone who had access to the
community. We looked at resumes from different offices and asked them questions. I guess that's how we sort of picked, from the interviewing and how people answered the questions. And I guess it was partly just meeting them, feeling, just your first sense sort of how they answer questions and what sort of person they were. It was tough, I mean it was good for me, it was a good perspective because I'd never been involved in trying to hire people. And it was important because I really love my sister, and I really want someone who is a good day program person.

Nita described her perceptions of important hiring criteria.

Well I think the first thing is someone who knows Sarah and someone who has similar values that the board holds...(Those values are) respect for the individual, the right of the individual to have a life in the community, and to have a big presence in the community. Those would be the main criteria...

Most of Sarah’s staff were hired by “word of mouth” and knew one another prior to working together. Sarah’s relationship with her staff is familial. Nita described three aspects of Sarah’s direct support staff which she felt were crucial for success. These are, (a) the stability of staff, (b) the value base and mental attitude of the staff, and (c) the familial nature of Sarah’s staff.

...A lot of the stability has to do with Pat and Al. If Pat thought that the staff was very good and very supportive of Sarah and had a good relationship with Sarah, Pat was very supportive of staff. And the same with Al. Al has such a good rapport with the staff that it makes it comfortable for the staff. It just so happened with our micro board that most of the staff were hired by word of mouth. They were friends who were hired from the social network of the staff who were already there. I think that family thing just evolved too, because all of the staff know each other socially, and that helps with them staying longer...So that helps staff feeling comfortable at their job and they stay longer.

I guess we’ve also been really lucky that the staff are warm and caring people. They may not have come with a lot of skills in their background, but they have a good mental attitude. And that's probably more important when you're looking at getting staff because it's easier to train skills than it is to train a good
attitude. And that’s something that I have learned too, through working with the board, is what’s the most important thing that you’re looking at when you hire staff.

... Another thing that I have learned from being on the board is that the staff are more than staff. I mean the way the staff have on their own included Sarah in their families. I mean she has been included in so many events, christenings and house parties and taking in A’s dance performances. Ohh, it’s amazing (inflection emphasis). And that I think is a real, real, neat thing to have, really neat (slowly articulated and emphatic).

Marie (pseudonym, evening support person) described how she became involved with Sarah, her first impressions, and the inclusion of Sarah in the staff’s social network.

I started working with Sarah in June or July 1994. I knew Ella and Mary as friends (pseudonyms, Sarah’s roommate and day program staff). They told me about the job. I applied and they accept me. I had worked with handicapped people before in Singapore.

... The first night I was not very used to Sarah, I didn’t know what her actions were about, because she cannot talk...After awhile by observing Sarah and then asking the other workers...I know now what she wants and what she needs.

... I ask her first, her opinion, if she wants to. And then she nods and laughs. You cannot really say it is a laugh, her face is something like smiling and her tongue is out with a curl, so it is something like happy...When she is sad, she makes an irritated sound, you can see it in her face. She makes a facial expression.

... When I first met Sarah, I felt pity. She is twenty four and I wondered if she could experience what real happiness is. Now it feels she’s part of my family, and I’m part of her family as well. When I work with Sarah, my affection is getting closer and closer as time goes by...She’s intelligent, even though she cannot talk. She can easily observe people around, through her expression you will know if she is liking it. She’s like us, normal people. Because she can understand, she also has feelings...Only thing is she cannot walk or talk and she needs attention and care.

... Part of our culture is close family ties. If there is a family affair, Sarah is usually invited. Ruby used to work with Sarah,
If Ruby has a party she usually invites Sarah... For Sarah I think she wants her workers to respect her, “respect me, understand me, care for me, and work with me as a family.”

Ella had been Sarah’s live-in roommate and provided various home care duties in exchange for reduced rent and board. Ella commented on her relationship with Sarah.

I started working with Sarah in November 1992. I didn’t have any experience. It was really hard the first three months. It was hard to figure out what Sarah was saying. I can understand Sarah now. When she is happy her face is blooming. Her left foot is kicking, her tongue is out and curled and she makes a happy, higher sound. She likes to sing. Now she is like my sister. We share the apartment together. It is like our home.

Sarah’s autonomy is maintained by her micro board. Sarah’s communication specialist, physiotherapist, and literacy tutor have developed adaptive strategies for Sarah in conjunction with her micro board. The goal of support is to empower Sarah’s direct care staff to carry out lifting, stretching, feeding, and communication goals within the context of her daily schedule. Similarly, Lynn Percy of Victory Housing is available if the board needs support in the areas of budgeting, lifestyle planning, and negotiating with the government.

Sarah’s service coordinator (CSB) is Corey, who visits with Sarah approximately four times per year. I observed Corey’s unobtrusive style in monitoring Sarah’s program. She directed questions to Sarah, and queried Mary about Sarah’s activity patterns, and health status. A formal review takes place at the end of the year, when staff and micro board members are asked to comment on Sarah’s relationships, community involvement, home life, personal communication, and personal care (see Appendix C for example of monitoring reports).

Although the micro board maintains an employer/employee relationship with Sarah’s direct care staff, they have become an “extended family.” This relationship does not apply to
other members of her formal support network (physiotherapy, communication specialists etc.), but there is a partnership regarding the development of adaptive strategies and practices aimed at improving the quality of Sarah’s life.

**Lifestyle**

Sarah typically rises between 7:30 and 8:00 a.m. Ella (roommate) supports Sarah between the hours of 7:30 and 10:30 a.m. Sarah’s morning routine consists of (a) stretching exercises in her bed, (b) lifting and transferring to her couch in the living room, (c) general hygiene, (d) feeding, and (e) dressing. I observed this morning routine and documented the respectful, patient support provided by Ella.

Fieldnotes  
Place: Sarah’s house  
Date: May 14, 1995  
Time: 8:00 a.m.  
Present: Ella, Sarah, Paul,  
Activity: Morning routine

I arrived at Sarah’s at approximately 8:00 a.m. Sarah and Ella were in the bedroom. The radio was playing popular music. The scene was peaceful and relaxed. Ella informed me that she needed to assist Sarah with her hygiene routine and I excused myself and wandered out of sight to give them privacy. The hygiene routine took approximately 15 minutes.

I could hear Ella, “Sarah would you like the red shirt?” Twenty second pause. “Yes, good, it is very pretty.” Sarah is very fond of clothes and Ella patiently waits for Sarah to make her clothing and jewelry choices. Sarah emerged attractively dressed in a floral blouse, matching scarf, and black pants.

Ella’s style with Sarah is relaxed and friendly. Ella is constantly talking to her, “Sarah, Paul is here, we will finish soon and then you can talk etc.” They have a good rapport. After the hygiene and dressing routine Sarah and I sat in the living room while Ella prepared breakfast. Ella stated, “Sarah has a very good appetite, she can finish a whole bowl of porridge.” I asked, “what are Sarah’s favorite breakfast items?” Ella replied, “porridge, cream of wheat, muffins and pancakes.”
As Ella prepared breakfast, I sat beside Sarah and talked to her. I have developed a good rapport and she typically responds to my presence by looking at me, or smiling. I often ask her questions, but do not always get a response. This morning when I asked, “Sarah, would you like to go out for lunch today?” She looked directly into my eyes and nodded her head “yes.” I was moved by this event as this was the deepest connection that we had made.

Ella entered the room and began feeding Sarah (porridge). The conversation was friendly, relaxed, and inclusive. It took approximately one hour to feed Sarah. Ella is very responsive to Sarah’s pace and allows her ample time to enjoy her meal. After breakfast, Ella washed Sarah’s face and helped her brush her teeth. I excused myself once again. The entire morning routine took approximately two hours.

Mary (day support staff) arrives at Sarah’s at 10:30 a.m., and coordinates much of Sarah’s daily schedule. She works with Nita (board member) to develop activity preferences and choices for Sarah. Typically, Sarah has a choice of three or four activities per day. Mary uses photographs to explain activities and then asks, “Sarah do you want to go to x today.”

I observed Sarah in different activities at various times during the course of the study to develop a sense of Sarah’s lifestyle, her level of choice making, and the interaction patterns of her support staff. Although Sarah is not employed, or attending a formal school program, her schedule is varied and reflective of her preferences. There is an effort to include a mix of daily living activities (shopping, going to the hairdresser, banking etc.), and leisure oriented activities in her monthly schedule. My fieldnotes during swimming on May 1, 1995, illustrates the diligent style of Sarah’s support workers.

Fieldnotes
Date: May 1, 1995
Place: Sarah’s house and Kensington swimming pool
Present: Sarah, Mary, Ella, Paul
Time: 11:00
Activity: Swimming
Sarah, Mary, and Ella are in the living room discussing swimming. Mary informs me that Sarah attends swimming every Monday and she has a choice of several pools in her community. Mary offers choices by asking “do you want to go to x.” If Sarah does not respond, or she shakes her head “no,” another choice is offered. Today Sarah was offered three choices and she responded positively to Kensington pool (community swimming pool). Mary used photographs to illustrate Sarah’s afternoon schedule. “Okay Sarah, (points to photographs) we are going swimming at Kensington, then we will go out for lunch, and return home. Okay?” Waits for facial expression or gesture. Sarah looks at Mary. Mary responds, “Yeah, okay, good, let’s go.”

Sarah (in wheelchair) and Mary lead, and Ella and I follow. Sarah’s van is parked directly in front of her apartment. It is an older model, customized Ford (extended roof, wheelchair lift, and locking brackets on the floor). Sarah’s lift is easily operated by one person.

Kensington pool is roughly a ten minute drive from Sarah’s apartment. Mary locates a “Handicapped” parking stall directly in front of the door to the pool. A gentle cut for wheelchairs is adjacent to the parking space. Large automatic doors swing open and Sarah enters the building with ease. Entrance to the facility is very accessible.

Sarah, Mary, and Ella proceed to the change room and I take a seat at the side of the pool. There are approximately ten adults of varying ages in the pool. Large windows surround the pool, exposing well kept gardens in bloom. The setting is serene. It appears that the swim hour is an “adapted” swim class, a low stress therapeutic workout. The pace is very slow, and the participants seem to have difficulty with any type of gross motor activity.

Sarah (in wheelchair), Ella, and Mary emerge after approximately fifteen minutes. Ella and Mary lift Sarah from her wheelchair and seat her at the side of the pool. Access is difficult, as there is no ramp for nonambulatory individuals. I query Ella about this. Ella responds, “it’s not really a problem.”

Sarah wears a lifejacket in the pool and is supported by Ella and Mary. She is gently moved through the water and appears to enjoy the amity and buoyancy. After a half hour, Mary and Ella lift Sarah out of the pool and proceed to the smaller
A whirlpool. Sarah is very calm, relaxed, and appears to be falling asleep.

Sarah stays in the whirlpool for approximately ten minutes and then proceeds to the change room and back to her van. While Mary is making a phone call, Ella asks, “Sarah do you want to eat at x.” Sarah does not respond. Ella then asks, “Sarah, do you want to wait for Mary.” Sarah nods her head slightly. Ella responds, “okay.” Mary approaches the van and Ella informs her that Sarah did not respond to questions about lunch. Mary sits beside Sarah and asks in a calm, soft voice, “do you want to go to Mcdonald’s Sarah?” Sarah responds with a head nod “yes.” Mary and Ella smile at each other and look at me. Mary: “she likes Mcdonald’s

Lunch at a restaurant may take upwards of two hours. Sarah has lunch at a preferred restaurant at least once every month. I accompanied her to a neighborhood restaurant, and observed her interest for visually stimulating environments.

**Fieldnotes**
**Date:** March 10, 1995  
**Time:** 12:00 p.m.  
**Present:** Sarah, Mary, Corey  
**Place:** Local restaurant  
**Activity:** Lunch and informal review meeting with Corey (CSB)

I was late arriving. Sarah and Mary were already seated. The restaurant was crowded, and noisy. Friday lunch crowd. Festive paraphernalia adorned the walls and ceilings. The mean age of the crowd was early thirties. Sarah was in her wheelchair, nattily dressed in pastel colors. She had a full view of the restaurant. I sat down and said “hi.” Sarah was looking around the room, her tongue was curled and she was very animated. Taking in the sights and sounds of the restaurant.

Corey joined us at approximately 12:15 p.m. Casual conversation, Corey directs most of her questions and statements to Sarah. Corey is relaxed and respectful in her interactions. Sarah is excited by the surroundings and Corey acknowledges this and directs her questions to Mary. Corey asks about lifestyle and “how things are going.” Mary comments, “good, it has been good for Sarah, she is healthy and happy.”
Literacy tutoring with Liv (pseudonym) takes place every Tuesday morning. Sarah’s mother has always assumed competence and arranged for a literacy tutor. I had the opportunity to observe a tutoring session and documented (a) Liv’s involvement with Sarah, (b) Pat and Liv’s assumption of competence, and (c) Sarah’s reactions.

Fieldnotes
Activity: Reading with tutor (Liv)
Environment: Kitchen table (Sarah’s house)
Time: 11:00 a.m.
Date: April 25th, 1995
Present: Sarah, Liv, Mary, Ella, Paul

Scene: Busy. Much activity, workers from B.C. Hydro in hallway. Mary is occupied with workers. Sarah is at the table with Liv. Liv is a retired school teacher, in her sixties perhaps. She is taking courses in English as a Second Language (ESL). Liv states “one never stops learning, if I just sit around I will get stale.” She has many materials scattered about. A mix of “beginning reader books,” personalized story books, audio tapes, and articles clipped from the newspaper. Liv, “I like to include some disability articles and good news stories.” Liv is very dynamic. Sunny dress, sunny disposition. She is very open to my presence and welcomes me readily. Sarah is dressed in black pants, nice purple print shirt and a scarf. Sarah appears to be tired, and is not very attentive.

Liv is mostly working on the alphabet. She continues, quite animated and assumes competence even though Sarah is giving limited feedback (looks tired, head is down). Liv looks for a head nod as recognition. Sarah looks at Liv. Liv continues.

Liv became involved via Pat(mother). Pat was a high school teacher. Liv and Pat belonged to the same board of certified teachers, but did not know each other prior to the tutoring contract. Liv has worked with Sarah for 3 years.

Liv: “Pat was a big influence. She had a very strong philosophy. At first I was reading to Sarah as if she were a young child. Pat told me to stop that and treat her as an adult (laughs).” Liv seems to have taken this message to heart. She carries on with Sarah in a respectful manner. Liv, “I miss the time I spent with Pat, but it’s a good thing that Sarah is on her own. She is growing up.”
I question Liv about her relationship with Pat while Sarah has a drink (assisted by Mary). Pat believes that Sarah could benefit from reading. Liv dismayed that Sarah never attended any academic program. Liv discusses Stephen Hawking (physicist, writer, lecturer, also has physical disabilities). Liv feels that people (society) must assume competence when confronted with persons with disabilities. In Sarah’s case, she feels something will register if she provides the input.

Liv discusses how impressed she is with Sarah’s situation. She contrasts Sarah’s situation with institutional care which was the norm for people with disabilities when she was teaching.

Liv: “I look at Sarah and I wonder about all the people in institutional settings laying on their backs all day.”

Sarah finishes drinking and Liv continues reading and engaging Sarah. Sarah vocalizes discontent (low guttural tones). Liv and Mary respond. Liv acknowledges that Sarah is tired and stops working. Mary begins problem solving and checks Sarah’s positioning in her wheelchair. Mary moves Sarah to the patio door to look at the sunny view. Sarah stops guttural tones.

Sarah spends the majority of her time in the community between the hours of 10:00 a.m. and 4 p.m. Ella (Sarah’s roommate) supports her in the home between 4 p.m. and 8 p.m. Sarah relaxes during these hours and Ella prepares her meals and feeds her. Sarah has overnight supports from 7:30 p.m. to 7:30 a.m. Marie (overnight support person) described a typical evening for Sarah.

I usually sit with Sarah on the couch, we watch TV or listen to the radio. Sarah likes to listen to Kenny G (recording artist) or watch basketball games. She likes action...Some times I do hand in hand work. We will make a birthday card together or something...One time we made a gift together and gave it to Sharyn (micro board member) for her shower. And all the micro board said to me “thank you for helping Sarah.” Even such small things, just helping Sarah, it gives me encouragement. We do small things like that and she usually goes to bed around 10:00 p.m. But sometimes if she is very tired she falls asleep at nine and I bring her to bed earlier.

I make sure that her comforter and pillow are in the proper place to make her comfortable so she can have a good sleep. If
she wakes up in the middle of the night upset, I check to see what is wrong, and rub her back. If I can’t figure out what is wrong I just hold her until she stops.

On weekends, Sarah is supported by two persons (Asha and Mirna). Asha works from 8:00 a.m. to 8:00 p.m. on Saturday and Sunday. Mirna provides overnight support and works from 7:30 p.m. to 7:30 a.m. on Saturday and Sunday. Asha has worked with Sarah since the conception of the micro board (1990). According to Asha, “I don’t have difficulty understanding Sarah, I know what she wants.”

Saturday’s are loosely scheduled and Sarah typically stay’s close to home. On May 13, 1995, I visited Sarah. Ella and Asha were watching a basketball game on the television. Asha described a typical Saturday with Sarah.

Usually I wake Sarah up at 8:30 or 8:45. I do her stretching and give her a bed bath. Sarah picks her clothes and we have breakfast around 9:30. She likes to listen to the radio and her favorite station is Q-fm, soft rock. Breakfast is usually finished at around 10:30 and I give her a facial. Then Sarah chooses one of Liv’s tapes (literacy tutor), music, or watching sports on TV. Lunch is usually around one and she picks her dessert and drink. After lunch we might read, go for a walk or hang out. Dinner is at six and I ask her if she wants soup or broccoli or something. Dinner is over around seven and we will watch fashion television, she likes that. Sometimes we watch movies. She likes action movies. Sometimes Sarah gets what we like, but we try different things. If she likes it she is quiet and nodding. Otherwise, she makes unhappy sounds (guttural tones) if she doesn’t like what we’re doing.

On Sunday’s, Sarah attends church and visits her friends, Sonny, Paul, Greg, and Kenny. This is a consistent routine and involves social connections beyond the micro board and staff. Asha stated, “We went to about three different churches, and then we found Burnaby United Church. Sarah likes it because of the crowd and the music. She likes to be
close to the action.” I met Sarah at church on Easter Sunday, April 16, 1995. My fieldnotes describe the atmosphere of the congregation, and Sarah’s reaction to the service.

Context: Easter Sunday. Asha goes with Sarah to church almost every Sunday. Sometimes Sarah goes with her friend Sonny from G House (group home where Sarah occasionally receives respite care). Asha states that Sarah likes the United Church (Burnaby) because of the crowd and the music (likes to be close to the action). Sarah and Asha are restricted in terms of travel because Asha does not have a drivers licence and they are reliant on the Handi-dart. I head to the church and arrive at 10:20 a.m.

Observations: A bright sunny day. Sunday Easter Mass. Middle class suburban neighborhood. Guitars on stage, pastor telling jokes and the parish laughing. No sign of Sarah however. Finally Sarah and Asha arrive. Sarah and Asha wheel right up to the front row. They are in time for Jesus Christ Superstar. Twenty person choir and good organ player. The place is alive and people are smiling and in a good mood. Not the somber affair I remember. Sarah is animated, watching the choir. Her left leg is kicking, signaling that she is happy.

Conclusions: Asha appears to be sincere in knowing what Sarah likes. She stated that it is the music and the feel of the place, as they had tried different churches, and Sarah did not enjoy “quiet” churches.

After church, Asha, Sarah, and I walked up the street to visit Sonny, Paul, Greg, and Kenny at their group home. I documented the interactions of Sarah and her friends, and contrasted life in the group home with Sarah’s lifestyle.

Nice suburban rancher in a middle class neighborhood. Old house torn down and new one built from scratch. Ministry of Health funded the house. Four persons with severe physical needs from X Hospital live in the house. Deluxe furnishings, new computers etc. Despite furnishings, did not have a personal touch, my sense, “it has a slight institutional feel.” Sonny was in his room playing with his computer. Sarah is hanging out in courtyard in social situation with Asha, staff, and Kenny. Sarah is having lunch.

She is happy, enjoying the company and the warm sun. Staff are very friendly, but there is a definite group regiment, lacks
the individualization and "homey" feel of Sarah’s situation.
Staff member asks if "guys want to go for an outing" (drive
around the neighbourhood). Paul and Greg say “yes.”

Quality of Life

Sarah’s lifestyle quality is paramount in the planning and implementation functions of
the micro board. Rigorous efforts are made to include Sarah in all decisions related to her
lifestyle, however, her limited expressive communication necessitates close monitoring and
decision making with the support of her micro board, support staff, and to a lesser degree,
members of Victory Housing, and CSB.

Sarah’s support network do not view Sarah’s lifestyle issues as being substantively
different from their own. Al views intimate relationships as central to his quality of life, and
Sarah’s quality of life.

I think it’s relationships you know. The relationship is really
kind of the key thing in terms of the quality of life. And that’s
what’s different about this model if you will. Even though we
don’t talk about it as if it’s a model (inflection, laughs), it’s our
life, it’s our family and relationships...Which you can’t put in a
box. You can’t put in a formula. And there’s love, there’s
commitment and it’s informal by nature. In a relationship you
can’t put it in a box, it’s an affective thing, you’ve got to
experience it. I think that’s the key thing in terms of quality of
life. Especially for someone with a disability. But it’s true for
anyone...

Pat identified relationships, choice, and respect as important markers of a quality life.

At a personal level quality of life means enjoying and making
new friends. Family is very important and doing the things I
haven’t done for a long time. I mean I used to be a big frog in a
little pond, captain of all of the teams, editor of the paper, won
athletic awards, met interesting people. Presently my life is full
of activity. I am doing the things I want to do. I think these are
all important to Sarah too. Friends and family, being given
choice, love, and respect.”

200
Alicia described intimate relationships, choice, empowerment and community involvement to be paramount to Sarah’s quality of life as well as her own.

Community Presence

Nita is interested in expanding Sarah’s community presence and works closely with staff to ensure that she is involved in all aspects of her daily living. Sarah partially participates in daily living activities such as banking, shopping, purchasing furnishings for her apartment etc. Sarah has her own van and accesses a range of leisure activities including plays at the local college, walks in the park, swimming at various community centres etc. She hires her own supports, and her activity schedule reflects her strengths and preferences.

Respect

Respectful and caring relationships were observed throughout the study. The micro board ensures that Sarah’s supports assume competence. Staff are considerate of Sarah’s need for patience regarding feeding, dressing, bathing, and Sarah is consulted when self care issues arise. Staff are responsive to her non verbal communication, and interact with her as they would with any twenty six year old woman. According to Pat, “I trust her workers. It has just changed her life tremendously. She can take holidays now. It (the micro board and controlling staff hiring) has made things so much easier.”

Marie (support staff) gave her perspective on Sarah’s support needs.

I think what is most important to Sarah is that her workers respect her. I think that’s what she wants, “respect me, understand me, care for me, and work with me as a family”...She needs to have privacy also, and she has privacy, and she can decide for herself now. She has good family relationships. And I know Sarah is being cared (for) and being loved.”
Competence

Sarah’s micro board is directive when training support staff, and enables Sarah to participate in a range of meaningful activities. If documents need to be signed, Sarah signs them with a stamp, or is assisted with direct physical prompts. Many activities involve “hand over hand” support, such as arts and crafts, gift making, and making personalized cards for special occasions.

Community Presence

Sarah’s closest relationships are with her family, her direct support staff, and friends. She has developed a cordial relationship with a neighbor in her housing complex. A circle of support has been created around Sarah, and she is an accepted member in the social circle of her support staff. According to Karen, “she’s been included in their families (support staff), you know and it’s a cultural thing too I think. I mean Sarah is always included in baptisms and christenings and weddings and stuff.” Although a concerted effort is made to involve Sarah in the general community, the community has not embraced Sarah in the way that Sarah’s direct supports have. Al challenged the traditional notions of community inclusion and “normalization.”

... Talking about conforming to society or normalization...I mean it’s a big objective normalization. And there are some good things with that too, especially with that whole idea if you are treating someone different and not giving opportunities for human development...But this objective (emphasizes and mimes as of reading from the scripture), “we have to, we have to be in touch with our community.” You know what happens if you’re community is the Ku Klux Klan? Do you keep trying to penetrate the community (elevates voice in comic tone, laughter)? Do you try to get Sarah out there in a white sheet burning a cross? Is that the only way that her quality of life is going to be improved (voice drops to normal speaking tone)?

I know that is kind of a ridiculous example. But if her community at large, or geographic area is really closed to
someone like Sarah, or she doesn’t get much out of going to her community centre, or the relationships that we really work on with her neighbors, you know at some levels it is very superficial, and there’s not really a value base there, do we really keep pushing that? If let’s say in the Filipino community there is a better quality of life there for Sarah, and it’s receptive, you know sometimes I think we get stuck on this is the right way, and we can bang our head against the wall.

...Even if people read about community integration and read the right articles, if they don’t know a person with a handicap, or if they don’t have a relationship with somebody with a handicap, they don’t get to realize that this is a person... Again it’s where the relationships happen that makes the difference. It’s not just a cognitive thing, that’s part of the problem, that’s where the stereotypes are, but you need to go deeper than purely education.

...So things like a micro board, where people have relationships, it’s an opportunity. Instead of the system ripping people apart, micro boards facilitate the environment for a small community, a small group to support each other. So that in itself, fundamentally, is going in the right way. Because now there are people that have the opportunity to get to know Sarah that wouldn’t otherwise. It’s not just a job. It’s not just the realm of professionals. And the idea that if you have a program and a good mission statement, and you pay people twenty dollars an hour that everything is going to be wonderful. Cause it’s not. That system is very flawed. It doesn’t meet everyone’s needs, and that’s really quite grandiose to think that you pay people and that’s going to meet everyone’s needs. And that their needs are going to just fall into all of that. I mean we all have complex needs.

... Our interest on the board is not that it’s our source of income. It’s not that it’s our prestige as being experts...I mean that’s what I think is so wise about the micro board. The criteria for being a board member is that you have a relationship with the person the board is for. And that’s what’s needed to kind of carry on. That’s what makes the difference, I think.
Choice

Sarah is given the opportunity to make choices in all aspects of her daily living. These include (a) where she lives, (b) with whom she lives, (c) who she hires, (d) what she wears, and (e) where and with whom she spends time with in the community. Karen described the boards role in assisting Sarah with choice making.

I think it is a good idea to try new things. I don’t think it is a fair question to ask Sarah if she would like to do such and such, if she hasn’t experienced it. I’ve always been pushing it on the board and staff, if it’s safe of course, why don’t we go and try this. And if Sarah doesn’t like it we can leave, or if she really likes it, we can do it again. If she just wants to do it once, that’s fine. But not to offer her a choice that she can’t make. We’re so pro on offering choices and all that, and I think that is great, but they have to be fair choices.

In April 1996, Sarah was given the opportunity to move closer to her mother, and experience life in a small town. Sarah’s mother now lives in a small community in southeastern British Columbia, and Sarah has vacationed there. Pat felt that Sarah was very happy during these times and that she may wish to live closer to her mother. The micro board discussed the issue with Sarah and felt that she was receptive to the idea of moving closer to her mother. Pat pursued the idea of Sarah purchasing a condominium across from her house, and she contacted CSB and Victory Housing. Both agencies were supportive of the idea, and agreed that if Sarah finds she is not happy in this small community, she can return to Vancouver.

Conclusions

Sarah’s involvement in the micro board project was initiated by her mother Pat. Throughout Sarah’s life, Pat has challenged traditional support structures, and believed in the principles of person-centered supports. She enlisted the support of Sarah’s siblings and
friends to form a micro board. All members of the board had meaningful relationships with Sarah prior to their roles as micro board members. This relationship allowed the board members to hire staff and develop a life in the community based on Sarah’s strengths, preferences, and needs. Several board members stated, “our strengths are that we have a strong relationship with Sarah, we are her advocates, we share in decision making and we’re not afraid to challenge each other.” Sarah’s home life and specialized care is important to her quality of life. She has a caring, supportive staff that consider her to be part of their “family.” All members of Sarah’s support structure agree that relationships are an important aspect of Sarah’s quality of life.

Sarah’s micro board agreed that Sarah’s quality of life can be further enhanced in a small community where she can be close to Pat. Lynn Percy of Victory Housing described her role in ensuring that Sarah has a strong circle of supports in her new community.

“I had a really good sense when I was there (Pat’s house and community). I thought the potential board members were quite good, and really understood the concept (micro boards)...That is what we do at Victory, we help create circles of support...Sarah can always come back to Vancouver if it doesn’t work out...We have to ensure that we maintain her relationships and contacts in Vancouver while giving her an opportunity to experience a new community and build new relationships.”

Pat summarized her perceptions of Sarah’s life in the micro board project, and her vision for the future.

It (the micro board project) has been great for us. Not every family could do it, but my suggestion is not to be afraid. It’s been wonderful for Sarah. ...(Her present staff) they have included her in their lives, they have been so inclusive...But, Sarah and I have such a wonderful time together, I just think her quality of life can be even better if she could have her own place close to me.
CHAPTER IX
PEOPLE AND ORGANIZATIONS

The study focused attention on the application of support principles represented by the micro board approach, and how this application affected the quality of life of the three participants in this study. The lives of Lisa, Jason, and Sarah changed as a result of the micro board project. The complex interaction of personal/family variables, organizational variables, and person-centered support concepts made a positive contribution to the lifestyles of Lisa, Jason, and Sarah. The study also intended to highlight directions for future research, and contribute knowledge of person-centered supports.

Enabling Organizational Characteristics

Analysis of the data and themes embedded in the multiple case studies revealed five organizational characteristics of Victory Housing and Community Services Branch which contributed to the development of the micro board project, and enabled the achievement of a quality life in the community for the three participants in this study. These organizational characteristics are: (1) willingness to change and examine the efficacy of the organization regarding lifestyle achievements for persons served; (2) development of a strong value base and organizational philosophy with the input of persons with disabilities and their families; (3) small, flexible, and creative support structures based on individual needs; (4) collaborative, non hierarchical planning and implementation strategies; and (5) a holistic view of support and communities grounded in belief in social justice, and equality for all persons.
Willingness to Change

Victory Housing and Community Services Branch worked together and had common aims for funding and monitoring. At similar times in their histories, both organizations examined the efficacy of the continuum model, and determined that this model was not meeting the needs of many persons served. Both organizations realized that the notions of choice, empowerment, and community inclusion were not facilitated by traditional models of support. Had Victory Housing and CSB not sought new ways of delivering support; Lisa, Jason, and Sarah would have remained in the continuum model of support.

Strong Value Base and Philosophy Statement Developed with Persons with Disabilities and their Families

Both Victory Housing and Community Services Branch developed their philosophy statements with the input of persons with disabilities and their families. In the case of the Community Services Branch, the philosophy statement was developed prior to the formulation of the organization. Fundamental principles adopted by CSB include (1) the right to self determination and choice in all aspects of daily living, (2) a focus on quality of life and lifestyle achievements, and (3) a commitment to integrate people with handicaps into the general community.

The philosophy of support at Victory Housing evolved over time and was embodied in the guiding principles and functions of the micro board pilot project. The Victory Housing board of directors is comprised of community members, parents of persons with disabilities, persons with disabilities, and disability advocates. The fundamental tenets of support at Victory Housing are empowerment, community presence, community participation, and autonomy in major and minor life decisions.
As discussed by Racino et al. (1993), a fundamental shift in disability support structures involves the inclusion of persons with disabilities and their families in all aspects of planning and implementation of support. By including persons with disabilities and their families in organizational self evaluation and change, both Victory Housing and Community Services Branch realized what elements of support needed to change. The inclusion of persons with disabilities and their families in decision making requires a fundamental shift in the prevailing organizational structure of the disability field.

**Small, Flexible, and Creative Support Structures based on Personal Need,**

**Rather than Organizational Policy and Procedures:**

Both Victory Housing and CSB recognized that they needed to operationalize their philosophy statements. As Victory articulated their commitment to empowering individuals with disabilities to lead lives of their choosing, and CSB recognized that the continuum model of supports was not meeting the objectives of their philosophy statement, there was a need to identify new, creative ways of supporting individuals. Victory Housing developed a set of guiding principles and functions which represent a shift from the continuum model of supports. These are: (a) the separation of housing and support; (b) home ownership, including tenancy; (c) relationship between individual needs assessment, and individualized funding; (d) flexible and individualized support services; and (e) individual choice or consumer directedness (Racino, 1988).

The values and assumptions inherent in the micro board project are: (a) micro board members must have a relationship with the person for whom the board is established; (b) all people are assumed to be capable of self-determination, which is to be acknowledged and respected; (c) the more complex the individuals’ needs, the more necessary it is to customize
and individualize supports; and (d) all services developed and/or contracted are based on the person’s need, not availability of service (Victory Housing, 1990).

Both organizations believe that supports should be person-centered, and not formula based or prescriptive. The values of empowerment, choice, and control, are central to quality of life, and are central to the design of support structures which need to be highly individualized. The commitment of CSB to the micro board project is evidenced by the fact that they are presently funding and monitoring over thirty micro boards in the Province of British Columbia, which still represent only a small percentage of other funding controlled by CSB.

As noted by Racino et al. 1993, many disability organizations have created philosophy statements which expound the values of inclusion, choice, and empowerment, but they provide support structures which are restrictive and devaluing. An important aspect of the micro board concept and a person centered paradigm of support is the implementation of values in practice. A basic tenet of micro boards and the person-centered paradigm is that separate models and housing structures are not needed for persons with disabilities. All persons need a home, and the general housing market can be modified to meet the needs of persons with disabilities.

During the course of this study, Lisa, Jason, and Sarah were renters in the general housing market, and chose their residences based on personal preferences. Lisa and Sarah are about to buy their own homes, and Jason is pursuing this option. They have autonomy in developing their own budgets for support, and funding flows directly to their micro boards. They are free to hire their own staff, and configure their supports in an individualized manner.
Collaborative, Non Hierarchical Planning and Implementation Strategies

Congruent with a person centered paradigm of support (Racino et al., 1993), CSB and Victory Housing follow non- hierarchical planning and implementation strategies at the organizational level. Both the planning procedures and monitoring functions are consistent with O'Brien's (1987) lifestyle accomplishments. O'Brien identified five lifestyle accomplishments; choice, competence, respect, community participation, and community presence.

Both organizations maintain close ties with persons served, and value and encourage the input of multiple sources, including persons with disabilities and their families. A central theme which emerged regarding CSB and Victory Housing was the importance of ensuring that peoples lives were positively effected by the practices and procedures of both organizations. This is a characteristic of responsive organizations in the person-centered paradigm of support (Racino et al., 1993), and represents a departure from traditional notions of support, which tend to focus on the persons' deficits or disability rather than on personal and social needs.

Social Justice and Equality

Members of CSB and Victory Housing exhibit a holistic view of support extending beyond disability and housing issues. A facilitator from Victory Housing described the pervasive notion of social justice at Victory. “...I guess the majority of people all seem to believe in social justice...It's just amazing how many people believe in social justice and equality at the heart of their being, and many of them try to live it in their work.”

The regional manager of CSB described the organizational goal of CSB.
I think we feel we still have a long way to go before we’d be happy about all of the services we provide... We’re looking for relationships and friendships and meaningful communities that welcome people no matter what their disability, and we’re nowhere near any of that.

The regional coordinator, added.

In the broader scope of service, we’re nowhere near a truly barrier free society, but the micro boards would be among the few situations that we’re pleased with. And I think that is high commendation for what micro boards can offer for people in their living.

...I mean I think the world is richer when we welcome all people. Society is only as strong as it treats its weakest members, and it’s not a very strong society if we don’t have a place for people who need more support than we may need.

The organizational characteristics, assumptions, and procedures of Victory Housing and CSB are reflective of responsive organizations in a person centered paradigm of support, and are illustrated in table 3.

Table 3
Responsive Support Characteristics of Victory Housing and CSB

<table>
<thead>
<tr>
<th>Victory Housing and CSB</th>
<th>Responsive Agencies, Person Centered Paradigm</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Willingness to change</td>
<td>1. Open to change and self evaluation</td>
</tr>
<tr>
<td>2. Philosophy and value base directed to empowerment, and self determination for all persons.</td>
<td>2. Strong philosophy and value base grounded in respect for all people including persons with disabilities</td>
</tr>
<tr>
<td>3. Creative, flexible support structures</td>
<td>3. Decentralized and small. Administrators deeply involved in spirit of organization</td>
</tr>
<tr>
<td>5. Inclusion of persons with disabilities and their families in planning and implementation</td>
<td>5. Decisions not made by remote bureaucracy but by friends and staff who are close to people with disabilities and their families (Adapted from Racino et al. 1990)</td>
</tr>
</tbody>
</table>
Personal Characteristics and Family Support

All three participants reported that their lives had been positively influenced by the assumptions and procedures of the micro board project. The micro board project allowed them to establish new relationships with their family members and express their individuality. Lisa and Jason were receiving services in the continuum model of supports prior to their involvement with the micro board project, and Sarah was about to enter the continuum model of supports prior to her involvement. In each case, there was dissatisfaction with the traditional type of support provided. Lisa approached Cyndy Marlin of CSB regarding her and Jason’s situation, and Sarah’s mother approached Cyndy on behalf of Sarah. Cyndy directed each party to Lynn Percy of Victory Housing, as a creative solution to their support needs. Cyndy Marlin described the common theme regarding their situations.

I wish it all laid in us (service providers) but I’m glad to say it doesn’t. Because Sarah and her family, Lisa and Jason demanded of the service system a different way of doing things. Their lives, their expectations, what they wanted from life, how they wanted their lives... and they said: “We’re not taking what you’re offering us, we want something different.”

There are substantive differences in the personal profiles of Lisa, Jason, and Sarah regarding personal interests and cognitive abilities. However, they share four defining characteristics: (1) they have severe physical disabilities requiring extensive daily supports; (2) they have experienced restrictive aspects of the handicapped continuum and culture; (3) they have a strong will and desire to be active, participating members of their communities; and (4) they have strong ties with family members who care deeply about them, and who are active in their lives.
The degree of their disability did not result in less restrictive placements for Lisa, Jason, and Sarah. The level and type of support varied according to individual need and preference, but choice in residence, nature of support network, and autonomy in daily living matters was evident in each case study.

Central to the lives of Jason, Lisa, and Sarah and the success of their micro boards was the long standing supportive nature of their families and friends. Lisa, Jason, and Sarah were raised in inclusive home environments, and were active participating members in both their family and community life. In varying degrees they each were exposed to the handicapped continuum in education and residential services.

In each case, the effects of life in the handicapped continuum appeared to diminish the ability of Jason, Lisa, and Sarah to assume control of their lives. They rely on their micro boards and formal support networks to assist them in this regard. Each micro board in the study had a stated interest in supporting each individual to assume control of their lives. This is not necessarily the case of all micro boards. Cyndy Marlin of CSB noted that in some instances a person’s autonomy has been diminished because of the close familial contact of the micro board. However, in these instances, CSB as the funding and monitoring agent, is able to reorient family members to the Branch’s guiding principles and notions of support and empowerment.

Lynn Percy of Victory Housing described the importance of relationships and risk taking in developing micro boards.

People keep asking “who are micro boards good for?” And people are looking for a set of circumstances around the person like a type of disability that it’s good for. That’s irrelevant,...this could work for anybody, regardless of where they come from that need some sort of support.
What is critical is someone that’s willing to take some responsibility... To be a serious risk taker... We have set up some very successful micro boards with people who felt they were very isolated and didn’t have close relationships with their families, but we were able to create circles of support and foster those relationships... The key is, if people want to play it safe, then micro boards aren’t the place to do it, as a board member you’re saying “I will be accountable, and I want to make a commitment.” ... With Lisa, Jason, and Sarah it was really clear that there were people who really loved them and that they trusted and they knew they wanted on the board.

Lisa, Jason, Sarah, and their respective micro boards identified that direct funding was axial to their quality of life. Sarah’s mother commented, “direct funding has been a godsend, finally Sarah has young people in her life, who really care for her.”

Jason contrasted the nature of support in the micro board project with his life in a group home, “I can’t believe I used to live there (group homes), I will never go back... I’m the happiest I have ever been... Lynn (Victory Housing) has really helped me... she is my friend... Cyndy and Paul (CSB) they talk the talk, and walk the walk.”

**Freedom to Choose Accommodation and Formal Support Structure**

Jason, Lisa, and Sarah are the central figures in their micro boards. Micro boards are technically non profit societies and are subject to the rules and regulations governing such bodies. Each micro board contracts with Community Services Branch regarding housing needs and support options. Two distinguishing features of the micro board concept are: (1) persons are free to seek accommodation and or home ownership in the general housing market, as opposed to the “handicapped” housing market, where homes are generally owned or operated by service agencies; and (2) persons and their micro boards have sovereignty over the design and make up of their formal, direct care staffing situation. Jason, Lisa, and Sarah
with the support of their micro boards have chosen their own accommodations and direct support cohorts.

Two primary differences between traditional disability based services and the micro board project emerged: (1) in the micro board project, people are free to hire and fire their supports, rather than an agency controlling hiring and firing; and (2) if a problem occurs, a family member or friend on the micro board is empowered to find a solution, rather than an agency manager, or government official. The critical difference is that, in the micro board project, power and authority in hiring and firing rests with the individual and their micro board.

Jason, Lisa, Sarah, and their micro boards have experienced hiring difficulties, which necessitated the “firing” of several individuals. At present, all three participants have relatively stable staffing cohorts. Each person has the opportunity to develop a formal support structure based on his or her personal preferences and needs. Jason chose a loose, informal support structure, and views his support workers as “friends” not “staff.” Jason has become a part of their social circle and vice versa. The relationship is non hierarchical and reciprocal. Racino et al. (1993), and Adler (1993) described a reconfiguration of formal support concepts in the person centered paradigm. In this paradigm, mutuality extends beyond an exchange of services for money; respect and reciprocity are more important.

In Sarah’s case, her direct care staff view themselves as being a part of her family. The relationship is sisterly, and this seems to suit Sarah’s preferences and needs. She is included in the extended “Filipino community” of her support staff, who are similarly included in her own family activities.
Lisa has chosen a more formal structure, which has more clearly defined roles and responsibilities, but the relationship is friendly and respectful. Lisa wanted a formal support structure which combined the elements of a strong work ethic and respect for her station in life. She has achieved this with her present support structure.

Most of the direct support staff in Lisa, Jason, and Sarah’s lives reported that they were attracted to the job because of the non-hierarchical, “real life” nature of the job. Many had worked in traditional support structures and found them restricting for both themselves, and the people they were supporting. It appears that the micro board project facilitates the attraction of support personnel who share its values, and receive personal satisfaction from the mutually beneficial aspects of this relationship.

The formal support structure of Lisa, Jason, and Sarah includes the services of physiotherapists, occupational therapists, physicians, neurologists, wheelchair mechanics, communication consultants, dentists, orthopedic specialists, and literacy tutors. All these services are community based. Jason, Lisa, and Sarah are not required to reside in a hospital setting to receive these services, and they have choice regarding the services they use. This supports the notion that persons with complex physical needs can be supported in the community, and that support is not comprised by a community based model. Racino et al. (1993) noted that informed efforts of formal and informal support systems must focus their planning, implementation, and evaluative procedures on the lives of the people they support. Specifically, support must be examined in terms of increased choice, respect, competence, community presence, and community participation (O’Brien 1987). Otherwise, well intentioned efforts or promising practices may actually encroach on the lives of people receiving support.
Each participant had a particular aspect of O’Brien’s lifestyle accomplishments which was salient to his or her lifestyle and personal profile. According to Jason, “Health and well being, friends, shelter and respect” are important aspects of quality of life.

Respect is most important to me...Here (micro boards) I am respected. I have more say with the government. I don’t think that I got asked in the group home...I’m getting respect in restaurants, at the bar, at the local video place...I’m getting my self respect back...If you don’t respect anyone, then they won’t respect you. I really believe that.

Lisa identified three key areas which are most important to her quality of life, (1) respect, (2) relationships, and (3) an expanding repertoire of activities and life experiences. In discussing her present lifestyle, Lisa signaled “thumbs up,” and stated, “it’s better now, people help me, my supports are good.” In the micro board project, Lisa has experienced different support configurations and has become more directive and assertive in her life. She has identified and hired the types of supports with whom she is most comfortable, she is expanding her relationship circle by reaching out to her birth family, and has a new “boyfriend.” She has chosen a day support agency which provides individualized community based supports, and facilitates Lisa’s preference for an active daily schedule. Eileen, her foster mother, described her sense of Lisa’s lifestyle quality in the micro board project.

...Lisa should have as much peace of mind as possible. We need to continue to encourage her to be an autonomous adult, who can live and love and go on with her life...I find in many ways the micro board can do that for her. I just don’t see her life going wrong in the next little while. Touch wood. I think her life is in a positive path at the moment.
Members of Sarah’s micro board and formal support structure identified relationships, and quality respectful care as markers of her quality of life. Her brother explained the importance of relationships to Sarah, and the mutuality experienced in supporting her.

I think it’s relationships you know. The relationship is really kind of the key thing in terms of quality of life. And that’s what’s different about this model if you will. Even though we don’t talk about it as if it’s a model (inflection laughs) it’s our life, it’s our family relationships…which you can’t put in a box,…and there’s love, there’s commitment and it’s informal by nature, in a relationship you can’t put it in a box, it’s an affective thing, you’ve got to experience it and I think that’s the key in terms of quality of life for Sarah... and it’s true for anyone.

...And it’s Sarah that’s bringing people to her, and people with that value base to develop. That’s how I see it, Sarah is bringing people together, our relationships, and social life and the quality of our life is enriched by Sarah, because of the people we know on the micro board, through other micro boards, through Victory, through the ministry...Sarah challenges us to get involved in really thinking about someone’s life, being involved in their life, cooperating with other people toward that. I mean that is a very big opportunity that most people don’t have.

Cyndy Marlin of CSB attended a monitoring meeting regarding Sarah’s quality of care.

I think you can come so much closer to defining (quality of life) in a situation such as Sarah’s. I am just haunted by that description that one of her staff gave that night (monitoring meeting), about if Sarah is crying, what they do to find out what’s wrong. And she laid out a ten step process, first I check to see if she is uncomfortable and then I check to see if she is hungry, and then I check to see if something is sticking into her, and this litany, it went on, and it ended with, “If I can’t figure it out, all I do is hold her, until she stops.” I mean I just thought to myself, now there is quality of life, here’s a woman who is totally dependent on someone to figure out what is wrong with her, and eventually the woman say’s “if there is nothing wrong I can see from the outside, then I just hold her.” I was really struck by that.
Although Lisa, Jason, Sarah, and their support systems differed in important quality of life criteria, there was a universal commitment to ensure that choice, respect, relationships and empowerment were central to planning and evaluation. Lynn Percy expressed Victory’s commitment to self determination. “Our philosophy statement is what we believe. There truly is a belief that all people should have the opportunity to direct their lives. That’s absolutely fundamental.”

Choice

Lisa, Sarah, and Jason were afforded the same degree of choice in both minor and major life decisions. Choice was offered regarding: (a) where to live and with whom; (b) with whom to spend time with, and hiring of their own staff; (c) which activities to choose and where; (d) what time to get up in the morning; (e) what foods to eat; and (f) choice of furnishings for their apartments etc. These three people shared both the need to be supported, and in some respects “pushed” to exert more choice and control in their lives.

Support persons attributed this to years of living within the continuum model where choice and control were limited. This observation adds impetus to the need to move from the continuum model to a person-centered paradigm. The opportunity to exert more control in their personal lives is not, by itself, sufficiently empowering for Lisa, Jason, and Sarah to achieve full autonomy. They need intentional support from their micro boards and support personnel to learn how to take greater control of their lives. This supports the findings of Kennedy (1993) regarding the residual effects of “learned helplessness” (Seligman, 1975) in institutional care.
Respect

A characteristic shared by Lisa, Jason, and Sarah was the fact that they are respected and valued by their families. This respect is enriched by their micro boards. Jason is now a member of a government steering committee regarding disability issues, and has returned to school to complete his high school diploma.

Through the efforts of Sarah’s support network, she is now able to sign documents, mail letters, and deposit cheques and payroll statements related to the day to day running of her micro board. Deliberate efforts were made to involve Sarah as the key person in the “Sarah Anne Friends Society.”

Lisa has recently chaired a meeting in her housing cooperative and is active in her community on a daily basis, and engages in a range of community activities, such as banking, shopping, attending meetings related to her micro board etc.

Competence

Jason, Lisa, and Sarah have equal opportunity to perform functional and meaningful activities that are personally and socially important to them. All have access to switch technologies supplied and monitored by community based rehabilitation therapists. Jason’s brother, Jim, is exploring adaptive computer technology, Lisa is enrolled in a literacy program at the community college, and Sarah has a literacy tutor once per week. Focused efforts are made at micro board meetings and CSB monitoring meetings to ensure that Jason, Lisa, and Sarah have access to adaptive technologies and individualized support.

Community Presence and Participation

Lisa, Jason, and Sarah have the opportunity to generate activity schedules based on their strengths and preferences. Jason’s desire is to complete his high school degree and

220
possibly pursue a career as a disability consultant, or model. Lisa has expressed a desire to work with children and is in an exploratory career stage. No career plans have been established with Sarah.

Other than the absence of work, their activity patterns more closely resemble those of their nondisabled peers. They are present in their communities tending to daily living needs such as shopping, banking etc. and access a range of recreation leisure activities suited to their personal styles.

**Limitations**

The results of this study must be interpreted cautiously in light of several factors. The most important of these is that the participants in this study were selected because of the positive nature of their support networks and lifestyle. This purposeful sampling was conducted to illuminate the factors contributing to the positive lifestyles of the study's three participants. This selection bias, and the small sample, limit the degree to which the findings can be generalized. The study's findings do not represent all possible micro board situations. The primary support needs of the three participants in this study were physical care and assistance, as they affected choice making and personal autonomy. The three participants had familial support prior to the micro board project.

The study attempted to increase the generalizability of the findings by selecting participants with different degrees of physical disability, and ability to direct their own lives. All three participants experienced restrictive placements in the handicapped continuum prior to the micro board project, which is representative of many persons with severe disabilities living in North America. Persons with behavioral and/or emotional disturbances, and those who are bereft of any social support structures are not represented in this study. In an attempt
to limit researcher bias, and ensure that the outcomes reported in this study reflected the participants' perceptions of lifestyle quality, data were collected from multiple sources (Lisa, Jason, Sarah, micro board members, members of Victory Housing, members of SFCL, friends, and family). In addition, a number of data collection techniques such as videotaping, semi-structured interviews, participant observation, and review of permanent products were used to control experimenter bias. Finally, the length of the study (18 months), and ongoing review of the data by the study's participants minimized the effects of outside influences.

The study identified several strengths and weaknesses of the micro board approach which contributes to the emerging person-centred paradigm of support. Central to the micro board concept is the existence of, or the development of a strong support network, willing to assume the risks and responsibilities of assisting a person with disabilities to manage a small nonprofit agency. When these factors are present, micro boards have the potential to influence positive lifestyle outcomes for persons with disabilities. Conversely, if a person's support needs are high, and family members and friends are nonexistent, or are unwilling to assume risk and responsibility, micro boards are not a viable option.

The three participants in this study have support persons who enable their choice and autonomy. Micro boards do not ensure this outcome. The study reported that in some micro board situations, autonomy can be compromised by the wishes of family members and friends. When this occurs, external monitoring agencies are needed to ensure that the person for whom the micro board is developed is achieving a positive lifestyle in the community, and that their choices are the focus of planning and support.

Over thirty micro boards are operating in British Columbia. The study reported that the principles inherent in the micro board approach are promising regarding improved
lifestyles for persons with disabilities. The strength of the micro board approach lies in the commitment to develop support structures, and funding mechanisms directed to personal choice and autonomy in all aspects of daily living. A present weakness of the approach is the ability of some micro boards to manage the fiscal responsibilities of a small non profit society. Future research is needed to examine micro board situations which were not successful, to further illuminate variables such as disability, relationships, communities, support networks, and fiscal management which enhance or hinder lifestyle quality of the focus person.
CHAPTER X
DISCUSSION

The Disability System and Persons with Severe Disabilities

Research confirms the need to restructure the present disability support system. Despite a pervasive notion that persons with disabilities have the right and ability to lead regular lives in communities of their choosing, the total number of persons with mental retardation living in institutions in the United States is approximately the same today as 50 years ago (Nisbet et al. 1991), and children and adults with various other disabilities continue to be required to attend segregated schools and live in intermediate care facilities and group homes with as many as 8-12 roommates (Meyer, 1993). In British Columbia, four bed group homes are the norm for persons with disabilities.

Investigations of reasons for this segregated, devalued status point to the rehabilitation-deficit framework which girds the continuum model (Taylor 1988; Racino et al., 1993; Meyer, 1991). In this framework, the problem rests with the individual with a disability, and amelioration of deficits is deemed to be necessary before the person can move to a less restrictive lifestyle. Control and power in decision making rests in the hands of professionals, and service and support are delivered in a highly "professionalized," "medicalized" manner (Racino et al. 1993; Mount, 1987). Outcomes in the rehabilitation framework focus on the amelioration of deficits, rather than positive lifestyle outcomes for persons receiving support.

Studies of positive lifestyle outcomes for persons with disabilities indicate that widespread, systems change is necessary. Elements of change include how the problem is...
defined, the locus of the problem, the social roles people play, the solutions to the problem, who controls or holds power, and desired outcomes (Racino et al., 1993). A new support paradigm has emerged, the support/empowerment framework (Racino et al., 1993), which reframes the major theoretical and practical guides in the field of disabilities. The support/empowerment framework reflects an alliance among people with disabilities, professionals, friends, and family and incorporates the following principles and practices: (a) families and persons with disabilities are given greater power; (b) the focus is on the strengths and capacities of the individuals, rather than disability; (c) homes are part of the general housing market; (d) formal and informal support structures are nonhierarchical, flexible, and highly individualized; and (e) desired outcomes are quality lives in the community (Racino et al., 1993).

The Nature of Disability

Recent studies have included the perspectives of persons with disabilities and their families regarding how they perceive disability and relate to the world (Kennedy, 1993; Moore, 1993; Kennedy, 1987). Fundamentally, persons with disabilities and their families are suggesting that the disability field and society in general need to shift their orientation and perception of disability. The disability field typically places emphasis on degree and nature of disability, rather than the personal preferences, strengths, hopes, and dreams of the individual.

Perspectives from persons with disabilities and their families increasingly suggest that persons with disabilities are no different than the nondisabled population concerning a need for a safe personalized home, meaningful work, and supportive relationships (Heumann, 1993; Moore, 1993). This study expands on this reconceptualization of disability. The
participants in this study viewed disability not so much as a personal characteristic, but as a set of attitudinal and opportunity barriers present in the disability system and society in general. Their interests were reflective of the nondisabled culture, and they described their self concept in terms of their strengths, preferences, and abilities. They had dreams of home ownership, working in the general community, and developing intimate relationships. This finding supports the assertion of the support/empowerment framework (Racino et al. 1993) that the locus of the problem must shift from the person with a disability to a much broader and complex interaction involving societal attitudes, building structures, employment opportunities, and housing options.

Participants statements and interactions also suggested that a focus on the person rather than disability created an opportunity for nondisabled support persons to examine their world view, expand their social networks, welcome diversity, and recognize the gifts in people. This finding supports Meyer's (1993) assertion that disability may be viewed as an extension of cultural diversity and that "handicappism, sexism, racism, and ethnocentrism, are reflections of a social structure with unrealistic expectations" (p. 634).

Support Structures

The importance of the combined efforts of formal and informal support systems in assisting persons with severe disabilities to achieve a quality life in the community has been increasingly emphasized in disability research (Malette et al., 1992; Mount, 1987; O'Brien 1987; Vandercook et al., 1989). A shared vision of lives of people with disabilities based on community presence, participation, competence, and choice (O'Brien, 1987) is increasingly sighted as a crucial component of effective formal and informal support structures (Racino et al., 1993).
Participants in this study identified satisfaction with, and the need for an array of supports involving family, friends, and paid personnel. In each case study, both formal and informal supports shared highly congruent value systems, and collaborated to facilitate preferred lifestyles for the studies key participants.

This study supports the assertion of Walker and Racino (1993) that the nature of support roles in the disability system requires a shift from a prescriptive, controlling approach to a flexible, reciprocal approach to empower individuals with disabilities to become equal members of their communities. Each participant in the present study created a highly individualized “weave” of formal and informal supports reflecting their personal preferences. In two situations, paid staff assumed the roles of friend, and attendant. Also, neighbours assumed the role of paid supports as they provided “on call” overnight duties. Participants viewed the flexible, responsive nature of their support structure as a crucial marker of their lifestyle quality.

This study identified that the benefits of this type of flexible relationship accrue to paid staff, as well as the person with a disability. In one staffing cohort a new circle of friends developed from the work relationship, and staff from all three cohorts identified that their job satisfaction was higher in the support/empowerment framework than the continuum model. This was largely attributed to the reciprocal and personalized aspects of support. This finding confirms Adler’s (1993) report that reciprocity, mutuality, and respect are defining characteristics of support relationships in a person centered paradigm extending beyond an exchange of money for services.

This study supports the findings of Paris, DePaepe, and Hayden (1990) that persons with complex medical needs can be served in the community. Participants all required the
services of various health professionals including physiotherapists, occupational therapists, neurologists, general practitioners, orthopedic specialists etc. Prior to the micro board pilot project, each participant was required to reside in continuum based facilities to receive necessary medical and physical supports. Access to, and quality of care was not compromised as a result of “living on their own.”

This finding has implications for several disability and health care support structures. Racino et al. (1993) identified that support structures for persons with head injuries, mental health issues, and aging are closely aligned to the continuum model of support services, i.e., they tend to be facility based and a person must leave their home and family to receive “rehabilitative services.” Support is based on the rehabilitation/deficit perspective. In contrast, formal support agencies in this study (communication specialists, occupational therapists, and physiotherapists) based their service design and support structure on the person-centered paradigm. Individual needs were identified and key support personnel were trained to carry out various therapeutic procedures within the natural rhythm of the day in the person’s own home. Logical extensions of this support model apply to the aging population, and others who need various therapeutic interventions which do not require acute hospital care.

In this study, the role of the specialist changed from facility based expert, to community based consultant. The goal and role of the community consultant was to work with the person with a disability and their support network to assess support needs, and train direct care staff in various procedures. The relationship is reciprocal, and the consultee’s (person with a disability and their support network) are free to seek other services if their needs are not being met.
Gallessich (1985) illustrated that clinical practice in human services has traditionally followed a medical triadic structure where the consultant helps a consultee (a care giver, nurse, etc.) treat a client (an individual for whom the consultee is responsible—a patient, person with a disability etc.). In this medical model, the primary goal is to provide authoritative diagnosis, the consultant’s role is expert, and the relationship with the consultee is hierarchical. Gallesich asserts that traditional clinical practice needs to be examined in light of the changing assumptions and characteristics of support for persons and organizations. The present study suggests that a collaborative, community based model of consultation can meet complex medical needs, and that this type of support has applicability in a number of disability related areas, such as mental health, head injuries, and aging.

Support structures in the disability field have often been dichotomized with professionals holding most of the power in decision making. Persons with disabilities, family members, and community members have typically been excluded from decision making, and have been relegated to the role of recipient of service (Mount, 1987; Racino et al., 1993; Ferguson, Ferguson, & Jones, 1988).

Disability research differs widely in terms of the proper mix of direct professional intervention and naturally occurring support. This study supports Melzer’s (1991) conceptualization of formal support systems. He presents formal support on two axis, one being the extent to which a person is capable of self direction, and the other is complexity of intervention. When self direction is high and service complexity low, he suggests directing support funds to the person allowing them full control of support needs. As self direction diminishes and complexity rises, formal intervention may need to be more directive without being restrictive. Participants in this study differed on self direction and service complexity.
None of the individuals identified that they were fully able, as yet, to self-direct their lives, and all required various formal supports to meet their daily living needs. Participants identified satisfaction with their formal support configurations because they felt they had control of these supports, the support structures reflected their level of need, and they were not restrictive.

**Lifestyle Planning Tools**

Assisting persons with disabilities to plan a quality life in the community is a key objective of a person-centered paradigm of support. Fostering empowerment, and community participation for persons with disabilities are central to this study. The micro board project utilizes various lifestyle planning procedures which are reflective of O'Brien's (1987) lifestyle accomplishments. This study supports Mount's (1987) contention that lifestyle planning tools assist in producing positive changes for people, and that support networks are able to manage change and restructure support concepts based on the directions provided by lifestyle plans.

Organizations and individual participants in this study identified lifestyle planning procedures as an important contributor to lifestyle quality. Lifestyle plans assisted participants during several phases of their lives. First, lifestyle planning tools were used during the development of support structures and individual micro boards. Planning consisted of two phases, building a vision of a quality life in the community, and developing pragmatic plans to identify preferred housing, budget proposals, and support configurations. Second, lifestyle planning procedures were used when major life events or changes were discussed, such as moving to a new community. Individual’s differed in the degree to which they needed guidance in planning their lives, and in each situation the planning procedures did not
encroach on their personal autonomy. Lifestyle planning procedures were viewed as integral at the development stage of individual micro boards.

These findings have implications for numerous support structures. Bolles (1984) developed Life/work planning presently utilized by job hunters and life planners in the nondisabled population. Bolles (1984) describes Life/work planning as a systematic and life long endeavor designed to achieve a balance between learning, working, and playing. Bolles asserts that all members of society, to varying degrees, require a method for achieving positive life outcomes. He further asserts that the obstacles confronted by various disenfranchised groups such as minorities, the poor, the aged, and persons with disabilities do not require entirely separate support systems or planning concepts.

People require different degrees of support in planning their lives, and developing support structures. The nature of support in mental health, geriatrics, and head injury programs are being examined in North America (Racino et al., 1993). As these health care systems attempt to embrace community based services, they confront issues regarding deinstitutionalization and the development of community based support paradigms. Bolles' (1984) assertion that the more disenfranchised a person becomes from the general community, the greater the need for systematic, intentional life/work planning is supported by this study.

The Nature of Organizations in a Person Centered Paradigm

Disability organizations have varying roles in the lives of people with disabilities. Characteristics of responsive organizations, and how they came to be, are emerging research questions in the person-centered paradigm. This study illustrated that direct funding to families and persons with disabilities can create a positive relationship between support
agencies, persons with disabilities, and government funding agents. This study illuminated how two organizations facilitated substantive change in their support practices, and how these changes facilitated quality lives for the three participants in this study.

Previous studies regarding persons with disabilities and their families have reported negative interactions with the professional, formal support structure (Turnbull, 1986; Ferguson, Ferguson, & Jones, 1988). The findings of this study confirm the need to develop new interaction patterns between families, persons with disabilities, and formal support structures. Zagare (1984) placed complex interactions within the framework of game theory, where the ultimate goal is win-win scenarios. Prior to the micro board project, participants in this study characterized many negotiations and interactions with professional support agencies as adversarial, or a “zero sum game” (Zagare, 1984), where one party’s gains are contingent upon another party’s loss.

Central to the success of the micro board project was that both formal support agencies involved developed a clear vision of support including persons directly affected by practice (persons with disabilities, families, advocates, and service providers). Empowerment, choice, control, and community participation were shared values. At the government level, persons in the entire bureaucracy who were involved with the project had knowledge and experience with disability issues.

At the support agency level, members reviewed the organizational philosophy and recognized that existing practice did not facilitate autonomous lives for persons with disabilities. They reviewed promising practices and developed a radically different approach to support, which enabled the studies participants to assume control of their lives, and leave the handicapped continuum of supports.
A win scenario was achieved for each party. The participants in this study were able to assume control of their lives and direct their own funding. The support agency was able to use their expertise and facilitation skills to develop autonomous micro boards. The government funding and monitoring agency was able to (a) pioneer innovative practices, (b) witness, facilitate, and monitor the substantive positive changes in peoples lives, and the actualization of the organizations philosophy statement; and (c) illustrate that the cost of the participants three micro boards were not substantively higher than costs of support in a four bed group home.

The organizational restructuring and support concepts in this study are considered by some in the disability field to be revolutionary and the antithesis of the continuum model. (Racino et al., 1993). Systems level research often classifies disability as an industry, and that necessary changes in support concepts are often secondary to the interests of the industry (Biklen, 1988; Mount, 1987; McKnight). Mount (1987) and McKnight (1977a) suggest that the human service industry depends on the needs and deficiencies of disabled people and that “community systems are weakened as economic incentives strengthen human service systems, and helping professions become increasingly dependent on the deficits and deficiencies of the society for professional and economic growth” (Mount, 1987, p.15).

McKnight (1977b) points to the field of aging to illustrate this point. As the population ages, “oldness” is converted into sets of problems that create jobs, incomes, and professions, and the expansion of the aging industry can damage the caring capacity of families, neighbourhoods, and communities, as more and more older people are taken over by large human service industries.
Within the continuum model, participants were required to leave their homes to receive necessary supports in human service facilities. Once in these facilities, a loss of personal identity, abuse, and learned helplessness (Seligman, 1975) were reported. Similarly, in the present aging system, if a person can no longer support themselves at home, they are often required to leave their family homes and spend their remaining years in extended care facilities. The micro board concept may be one way to assist persons requiring extensive supports to remain in their own homes with a “weave” of formal and informal supports aimed at providing a dignified, quality of life.

This study demonstrated that a collaborative value based support structure can be created within the contemporary socio political context. Thirty five micro boards are now operating in the province of British Columbia.

**People, Relationships, and Community**

Researchers have increasingly suggested the need for qualitative perspectives of persons with disabilities who are well connected members of their communities, and how they came to be. This study examined the lives of three people who have experienced the handicapped continuum of supports, and life in the community. This study supported Kennedy’s (1993) account of life in the handicapped continuum and life on his own. Kennedy described that the differences were immeasurable, and that it took time to trust people in the community, learn to make choices, and exert control in life. Participants in this study were similarly adamant that they will never return to the continuum model, and that they require time and support to adjust to life in the community.

This study illuminates both personal perspectives and a socio-political context which contributes to the emerging person-centered paradigm. Prior to the micro board project, the
three participants began their lives in family homes, attended segregated schools, and lived in institutions and human service facilities.

Goffman (1961) refers to “careers” in his study of life in institutions. Career in this context does not refer to professions, but rather “refers to any social strand of any person’s course through life” (pp. 127). Although Goffman focused primarily on “mental hospitals,” he drew sociological parallels to other institutional settings including “nursing homes, general hospitals, veterans’ homes, jails, geriatrics clinics, homes for the mentally retarded, work farms, orphanages, and old folks’ homes” (p.354). Goffman described the institutional career as occurring in three phases: the period prior to entering the hospital (pre-patient phase); the period in the hospital, (inpatient phase); and the period after discharge from the hospital (ex-patient phase).

The participants in this study experienced similar phases in their lives. Two of the participants experienced what Goffman refers to as “a total institution,... a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life” (p.xiii). All three participants in the present study lived in group homes, which shared some characteristics of the “total institution.”

Goffman described that institutional life often contradicts the explicit organizational purpose of “fixing” the person and preparing them for reorientation to community life. Persons often enter the system against their will, experience abandonment and isolation, a loss of personal identity and autonomy, become acclimatized to institutional life, and experience greater adjustment anxiety upon reentering society. This study supports
Goffman’s findings that the institutional medical model has serious, personal side effects when applied to situations and conditions which are not entirely medical in nature.

The participants in the present study reported that they are “beginning to take more control of their lives” and are developing aspirations and life plans which involve their families, new friends, and previous acquaintances. They continue to require support in these areas. If the disability system embraces a person-centered paradigm of support, it cannot be assumed that opportunity alone to take greater control of one’s life will be sufficiently empowering for individuals who have experienced institutionalized living. Non restrictive, lifestyle support may be necessary.

It is important to note that participants in this study had strong social support from family and friends when their micro boards were formed. Strong relationships are cited as an axial component of micro boards. In other micro boards, responsive social circles have been facilitated and created for individuals who were socially isolated and estranged from family members. This development supports the findings of Mount (1987) and the assertion of McKnight (1991) that community members can provide support once considered the domain of professionals if given the opportunity and facilitation.

Social relations, and social networks have been an important area of study in the disability field (Perske, 1988; Vandercook et al., 1989). All three participants developed meaningful relationships with persons with disabilities, and various staff members while they were in the continuum model, and attending segregated schools. They maintained contacts with some of these persons. The micro board project allowed them to define their social structure, and relationships with nonhandicapped peers were allowed to evolve naturally. This confirms Heumann’s assertion that persons with disabilities “must have the ability and
opportunity to choose from a broad group of people with whom we truly feel most comfortable, which can change over time, the same way that nondisabled people choose their friends” (Heumann 1993, p.246).

Participants reported that the primary barriers to inclusion in the community were access barriers, such as inaccessible buildings, and limited public transport. One participant noted that the societal attitudes in their present community were more open than in the previous community. All participants resided in subsidized or cooperative housing complexes which reflected the cultural diversity of the community. In each setting, the housing community was described as “inclusive,” providing natural opportunities to develop relationships with neighbours, and participate in the running of the housing complex. This finding supports an emerging tenet of the person-centered paradigm; concrete opportunities are provided for groups with diverse perspectives and needs to find common ground to make the changes that are necessary for all people to have decent housing and quality of life (Racino et al., 1993).

**Implications for Future Research**

Although the results offer insights into the organizational characteristics, practices, and support structures inherent in the micro board approach, micro boards are but one option in an array of person centered supports. Future research needs to focus on other direct funding mechanisms which empower individuals to direct their lives, particularly those individuals who have led highly restrictive lifestyles and have little or no connection with family, friends, and the general community.

The person centered paradigm places power and money into the hands of people with disabilities and their families. Presently, in North America, to a large extent, most of the
power and money for housing and disability support rests with disability agencies. Broad-based systems change research is needed to identify how or if these systems intend to support person-centered approaches.

As described by Racino et al. (1993), the continuum model of support is grounded in several diverse fields including mental health, aging, and physical and mental disabilities. Systematic research is needed in each of these areas to develop a broad based paradigm of person centered supports.

**Conclusion**

An examination of the literature in the field of disabilities indicates that there is widespread agreement that deinstitutionalization and the continuum model have not successfully included persons with disabilities in the general community. Small institutional facilities, under the rubric of group home living, share many of the problems and restrictions imposed by larger institutions. Presently, the disability field is exploring new paradigms of support which hold a vision of an inclusive society for all citizens.

This study attempted to address these issues through investigation of micro boards. Two organizations and three micro boards were the focus of study. The findings of this study indicated that the micro board concept did assist persons to experience autonomous lives, and facilitated participation in the community. The micro board concept emphasises the importance of direct funding mechanisms, separating housing from support, and the creation of flexible, individualized support structures. The non-prescriptive nature of support structures is central to the micro board concept, and the lifestyle quality of the three participants. Support was provided only where needed, and as directed by persons with disabilities and their micro boards.
Formal support organizations involved in the micro board project demonstrated the importance of a clear vision of support based on empowerment, choice, and community participation. Involving persons with disabilities and their families in decisions affecting their lives appears to be central to the creation of responsive organizational practices. This study illustrated that a focus on homes, individual need, and creative support structures rather than segregated facilities, services, and habilitation goals has the potential to ameliorate attitudinal, access, and opportunity barriers too often experienced by persons with disabilities.
REFERENCES


Baltimore: University Park Press.


249


APPENDICES
APPENDIX A
SAMPLE LETTER

DESCRIPTON OF STUDY

Dear Potential Participant,

My name is Paul Malette and I am currently a doctoral student in the Department of Educational Psychology and Special Education at the University of British Columbia. I have been working with persons with disabilities for approximately ten years. During this time I have attempted to research and practice ways and means of improving the quality of life of persons with disabilities. I am asking for your permission to participate in a study that examines what types of supports and activities are important to your quality of life.

You are presently involved with an innovative project through Community Housing that helped you to develop a home and lifestyle of your choosing. Through this research I hope to identify from your perspective what types of supports have been most helpful in allowing you to make friends in your community, to schedule and choose your daily activities, and to take control of your lifestyle. I anticipate that this information will help government agencies and other persons with disabilities to develop innovative housing options that support the dignity and choice of the individual. I will be working on this project under the supervision of Dr. Sally Rogow, Professor in the Department of Educational Psychology at the University of British Columbia.

I have attached a separate sheet which describes exactly what participation in this study will entail. Please be assured that any and all information gathered in this research will be strictly confidential. Your name will not appear on any written interviews, tapes or forms. If you choose to participate your letter of consent will be sent directly to me in the enclosed envelope. the findings of the study will be submitted as a research project to the University of British Columbia as part of my doctoral program requirements and may be submitted at a later date to professional journals. However, neither the report or any professional articles will contain information which specifically identifies any person or their support network.

If you choose to participate in this study you may withdraw at any time and this withdrawal will in no way effect your housing situation. If you wish to participate in this study please sign the enclosed permission letter and send it to me in the enclosed envelope. I have forwarded a separate copy of the study description and consent form for your personal records.

If you have any questions about the study please feel free to contact Paul Malette or Dr. Sally Rogow We look forward to hearing from you soon.
Participation in this study will involve the following components:

1. **Interviews with participants and their support network.** These interviews will take place during a period of four to six months. The interviews will be conducted with the focus person and the key people in their lives. The questions will involve issues such the development of friendships, who helped the focus person become connected in the community and what factors the focus person feels are most important to their quality of life. Interviews will be on going during the research project.

2. **Participation with Paul Malette in home based and community activities.** Paul Malette will spend scheduled time with each focus person to understand quality of life issues from their perspective. This will involve meeting the focus persons friends, going out in the community together and spending time in the focus persons home. Participation is completely negotiable and Paul Malette will be sensitive to and respectful of each participants privacy and personal space.

3. **Videotaped recordings of mutually agreed upon events.** As this study is designed to show the positive connections in the focus persons life it is important to capture key social events on film. The purpose of this exercise is to have the focus person identify events, interactions, and people who were most meaningful to them. Please be assured that all information gathered in this study will be strictly confidential.
LETTER OF INFORMED CONSENT

I have read the description of the research study being conducted by Paul Malette under the supervision of Dr. Sally Rogow, Professor in the Department of Educational Psychology and Special Education at the University of British Columbia.

I understand that if I agree to participate in the study I will be interviewed by Paul Malette. These interviews will be ongoing throughout the study. The types of questions that I will be asked relate to my quality of life. Specifically, I will be asked questions about my social network, how I became connected in my community, what my favoured activities are in the community, how I make choices and control my daily schedule, and how I deal with barriers to participation in the community. In addition I understand that this is an in depth study and Mr. Malette will be spending time participating with me in community and home based activities to better understand my perspective on dignity, choice and control as it relates to my daily life. I understand that this study may take up to six months and may involve up to 100 hours of my time.

I will receive a summary report at the end of the study and will have the opportunity to discuss any information pertinent to me with the researcher. I understand that I have the right to withdraw from this study at any time and this withdrawal will in no way jeopardize my housing situation.

I understand that my identity and the identity of my support network will be confidential. My name or any one connected with me will not be used in any written or oral reports. The information gathered during this study will not be shared in any manner which will make my identification or the identification of my support network possible.

I have read the above four paragraphs and agree to participate in the study.

Signature_____________________

Date_____________________

Name_____________________

Address_____________________

Phone_____________________

259
SAMPLE INTERVIEW BLOCKS

Sarah, Lisa, Jason

Block 1: Personal History
Block 2: Perception of Disability
Block 3: Life in group homes
Block 4: History of the micro board
Block 5: A day in the life
Block 6: Formal and informal support configuration
Block 7: Perception of formal and informal support configuration
Block 8: Friends and family
Block 9: Personal perceptions of lifestyle quality and the micro board project
SAMPLE INTERVIEW BLOCKS
CSB AND VICTORY HOUSING

Block 1: History of the organization
Block 2: People in the organization
Block 3: Philosophy of the organization
Block 4: Mission of the organization
Block 5: Personal values of individual members
Block 6: Role of individual members
Block 7: Organizational view of support
Block 8: History and evolution of the micro board project
Block 9: Personal perspectives on the micro board project
Block 10: How does the organization view quality of life
Block 11: Personal views of quality of life
SAMPLE INTERVIEW BLOCKS
MICRO BOARD MEMBERS

Block 1: Relationship with micro board focus person
Block 2: History of the micro board
Block 3: Perceived personal role in the micro board
Block 4: Perceived role of the micro board in the life of the focus person
Block 5: Perceived role of CSB and Victory Housing
Block 6: Personal perceptions of lifestyle quality
Block 7: Perceptions of micro board in terms of enhancing, inhibiting quality of life for the focus person
Block 8: Perception of disability
Block 9: Value base regarding persons with disabilities
Block 10: Origin of value base
APPENDIX C
INSTRUCTIONS

BEFORE CONDUCTING REVIEW, PLEASE DO THE FOLLOWING:

1) Familiarize yourself with other material contained in the Branch’s Guidelines For Personal Planning, Monitoring and The Provision of Supports, which include (Monitoring Overview, Philosophy Statement, Definitions of Quality Service Delivery, Example Schedules “A1 and A2” of the Contract, etc.) as well as the person’s Planning documents and other important documentation.

2) For each of the following Personal Support and Service Delivery components, consider/utilize these points in your analysis:
   
   a) level of service provider’s awareness of the importance of each specific component for the individual being served. This “importance” must be determined in consensus with the person, members of their network, care providers, and a representative of the SFCL Branch;
   
   b) commitment and practice on the part of service providers to generate “self determination” and input by the person;
   
   c) variety of strategies attempted;
   
   d) measure of performance and outcomes.

3) Keep in mind, it is important to try to focus on the dynamic gifts, capacities and potential of each person and how the provision of various supports and services impacts upon his/her life, be they positive or negative.
THE REVISED GUIDELINES FOR MONITORING (1994) WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>1. PERSONAL SUPPORT NETWORK/RELATIONSHIPS</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td>. family involvement</td>
</tr>
<tr>
<td></td>
<td>. significant relationships</td>
</tr>
<tr>
<td></td>
<td>a) maintaining past relationships</td>
</tr>
<tr>
<td></td>
<td>b) strategies for the expansion of network</td>
</tr>
</tbody>
</table>

WHAT DO WE UNDERSTAND THIS PERSON'S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING:

Services for Community Living Branch
Ministry of Health
THE REVISED GUIDELINES FOR MONITORING (1994) WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>2. COMMUNITY INVOLVEMENT AND VALUED SOCIAL PARTICIPATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
</tr>
<tr>
<td>------</td>
</tr>
<tr>
<td>MON</td>
</tr>
<tr>
<td>TUES</td>
</tr>
<tr>
<td>WED</td>
</tr>
<tr>
<td>THURS</td>
</tr>
<tr>
<td>FRI</td>
</tr>
<tr>
<td>SAT</td>
</tr>
<tr>
<td>SUN</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

WHAT DO WE UNDERSTAND THIS PERSON'S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING
THE REVISED GUIDELINES FOR MONITORING (1994) WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>3. PERSONAL PLANS AND DOCUMENTATION</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td>. degree of input by the person and network members</td>
</tr>
<tr>
<td></td>
<td>. effort committed to support the person to develop a sense of possibilities</td>
</tr>
<tr>
<td></td>
<td>. relevant to person</td>
</tr>
<tr>
<td></td>
<td>. documented</td>
</tr>
<tr>
<td></td>
<td>. workable/manageable format</td>
</tr>
<tr>
<td></td>
<td>. creativity of personal strategies</td>
</tr>
<tr>
<td></td>
<td>. feasible</td>
</tr>
<tr>
<td></td>
<td>. time frames</td>
</tr>
<tr>
<td></td>
<td>. regularly reviewed/updated?</td>
</tr>
<tr>
<td></td>
<td>. personal financial planning and management</td>
</tr>
<tr>
<td></td>
<td>. consistent with or satisfies SFCL Branch expectations for planning. See: Revised Guidelines for Planning (1994)</td>
</tr>
</tbody>
</table>

WHAT DO WE UNDERSTAND THIS PERSON'S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING:
THE REVISED GUIDELINES FOR MONITORING (1994) WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>4. PERSONAL CARE, HEALTH RELATED SUPPORTS AND PROTOCOLS</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
</table>
| Given the importance of these considerations for all people and the possibility of needing professional expertise in the analysis of this component, this is an area where the reviewer may want to involve the individual's personal physician and/or other appropriate professionals. And, if this person has a formal Health Care Plan, it will not be necessary to repeat the same issues. | . current physical health  
. awareness and consideration of past medical history and vulnerabilities  
. support to ensure optimal health in all areas (see appendix page 4a)  
. process for identifying, reviewing, clarifying, updating, documenting, communicating and monitoring health care concerns  
. attention to orientation and training of all support staff  
. awareness of personal indicators of poor or failing health  
. support for personal self-care  
. support for personal competency and adaptations to enable increased independence  
. opportunities for healthy lifestyle, exercise and therapeutic intervention  
. support for decision-making re: health  
. availability of advocacy supports and/or safeguards in the event of serious health crisis  
. consistent with or satisfies SFCL Branch expectations for planning. See: Revised Guidelines for Planning (1994) |

WHAT DO WE UNDERSTAND THIS PERSON’S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING:
## SECTION I

<table>
<thead>
<tr>
<th>DATE</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- current physical health</td>
</tr>
<tr>
<td></td>
<td>- increased independence</td>
</tr>
<tr>
<td></td>
<td>- diet/nutrition</td>
</tr>
<tr>
<td></td>
<td>- lifting/transferring</td>
</tr>
<tr>
<td></td>
<td>- positioning</td>
</tr>
<tr>
<td></td>
<td>- skin integrity</td>
</tr>
<tr>
<td></td>
<td>- appearance</td>
</tr>
<tr>
<td></td>
<td>- exercise/outdoor activity</td>
</tr>
<tr>
<td></td>
<td>- therapies</td>
</tr>
<tr>
<td></td>
<td>- doctors/dentists</td>
</tr>
<tr>
<td></td>
<td>- meal times/nutrition</td>
</tr>
<tr>
<td></td>
<td>- bathing</td>
</tr>
<tr>
<td></td>
<td>- mouth and health hygiene</td>
</tr>
<tr>
<td></td>
<td>- skin care</td>
</tr>
<tr>
<td></td>
<td>- dressing</td>
</tr>
<tr>
<td></td>
<td>- medications/P.R.N.</td>
</tr>
<tr>
<td></td>
<td>- physiotherapy</td>
</tr>
<tr>
<td></td>
<td>- therapeutic equipment</td>
</tr>
<tr>
<td></td>
<td>- sleeping patterns</td>
</tr>
<tr>
<td></td>
<td>- chronic health concerns</td>
</tr>
<tr>
<td></td>
<td>- seizures</td>
</tr>
<tr>
<td></td>
<td>- critical/acute health concerns</td>
</tr>
<tr>
<td></td>
<td>- current medical/personal statistics</td>
</tr>
<tr>
<td></td>
<td>- bowel/bladder regime</td>
</tr>
<tr>
<td></td>
<td>- therapeutic interventions</td>
</tr>
<tr>
<td></td>
<td>- important personal information,</td>
</tr>
<tr>
<td></td>
<td>(e.g. family contact)</td>
</tr>
</tbody>
</table>

Services for Community Living Branch
Ministry of Health
THE REVISED GUIDELINES FOR MONITORING (1994) WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>5. PERSONAL RECORDING PROCEDURES</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td>. strategy for appropriate record keeping and documentation in place</td>
</tr>
<tr>
<td></td>
<td>. is the strategy appropriate and relevant for this person, currently</td>
</tr>
<tr>
<td></td>
<td>. does the person and/or their family understand it</td>
</tr>
<tr>
<td></td>
<td>. is the process adequate and accurate</td>
</tr>
<tr>
<td></td>
<td>. is it working</td>
</tr>
<tr>
<td></td>
<td>. is the service provider monitoring</td>
</tr>
</tbody>
</table>

WHAT DO WE UNDERSTAND THIS PERSON'S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING:
## APPENDIX TO SECTION I (5.)

### 5. PERSONAL RECORDING PROCEDURES

<table>
<thead>
<tr>
<th>DATE</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>If appropriate:</td>
</tr>
<tr>
<td></td>
<td>- skill development</td>
</tr>
<tr>
<td></td>
<td>- nutritional requirements</td>
</tr>
<tr>
<td></td>
<td>- menu plan</td>
</tr>
<tr>
<td></td>
<td>- medication</td>
</tr>
<tr>
<td></td>
<td>- support in personal hygiene</td>
</tr>
<tr>
<td></td>
<td>- daily journals</td>
</tr>
<tr>
<td></td>
<td>- therapeutic interventions</td>
</tr>
<tr>
<td></td>
<td>- medical appointments</td>
</tr>
<tr>
<td></td>
<td>- incident reports</td>
</tr>
<tr>
<td></td>
<td>- sleep patterns</td>
</tr>
<tr>
<td></td>
<td>- financial</td>
</tr>
<tr>
<td></td>
<td>- bowel/bladder issues or concerns</td>
</tr>
<tr>
<td></td>
<td>- menstruation</td>
</tr>
</tbody>
</table>

Services for Community Living Branch
Ministry of Health
THE REVISED GUIDELINES FOR MONITORING (1994)
WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>6. COMMUNICATION</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td>. current ways of expressing him/herself and their effectiveness . level of effort committed to ensuring the person receives and understands information and ideas . current and future (planned) strategies to support/maximize communication skills . level of effort committed to interpreting personal ways of communicating (eg. does the person have a way to protest/say &quot;No&quot;) . how is the person supported to communicate in an emergency . how is the person supported to make well-informed decisions . what kinds of choices are available to the person in their day-to-day life . if the person is unable at any time to communicate their preferences regarding an important decision, who is available to act on their behalf</td>
</tr>
</tbody>
</table>

WHAT DO WE UNDERSTAND THIS PERSON'S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING:
THE REVISED GUIDELINES FOR MONITORING (1994) WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

7. PERSONS PROVIDING CARE AND SUPPORT/STAFF

<table>
<thead>
<tr>
<th>DATE</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>FOR ALL THE FOLLOWING PEOPLE:</td>
</tr>
<tr>
<td></td>
<td>- supervisors/P.I.C.</td>
</tr>
<tr>
<td></td>
<td>- staff/support staff</td>
</tr>
<tr>
<td></td>
<td>- volunteers</td>
</tr>
<tr>
<td></td>
<td>- professionals/therapists</td>
</tr>
<tr>
<td></td>
<td>- organizational leaders</td>
</tr>
<tr>
<td></td>
<td>- consultants</td>
</tr>
<tr>
<td></td>
<td>CONSIDER THEIR:</td>
</tr>
<tr>
<td></td>
<td>- &quot;qualifications&quot;</td>
</tr>
<tr>
<td></td>
<td>- familiarity with person</td>
</tr>
<tr>
<td></td>
<td>- specific expertise</td>
</tr>
<tr>
<td></td>
<td>- orientation to rights of individual</td>
</tr>
<tr>
<td></td>
<td>- communication skills and approaches</td>
</tr>
<tr>
<td></td>
<td>- role modelling attributes</td>
</tr>
<tr>
<td></td>
<td>- overall effectiveness</td>
</tr>
<tr>
<td></td>
<td>- quality of interactions</td>
</tr>
<tr>
<td></td>
<td>- continuity vs turnover</td>
</tr>
<tr>
<td></td>
<td>and in particular...</td>
</tr>
<tr>
<td></td>
<td>- support to facilitate choice of</td>
</tr>
<tr>
<td></td>
<td>- or preference of support staff</td>
</tr>
<tr>
<td></td>
<td>- individual's response to caregivers</td>
</tr>
</tbody>
</table>

WHAT DO WE UNDERSTAND THIS PERSON'S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING:

Services for Community Living Branch
Ministry of Health
THE REVISED GUIDELINES FOR MONITORING (1994)
WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in
the community. Please use the spaces provided to keep record of important information and ideas that
pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of
ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>8. THE HOME/RESIDENCE/PERSONAL EQUIPMENT</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td></td>
</tr>
<tr>
<td></td>
<td>evidence of investment by this person/family/</td>
</tr>
<tr>
<td></td>
<td>friends</td>
</tr>
<tr>
<td></td>
<td>degree of reflection of this person's tastes in</td>
</tr>
<tr>
<td></td>
<td>decor, etc.</td>
</tr>
<tr>
<td></td>
<td>location</td>
</tr>
<tr>
<td></td>
<td>proximity to social opportunities</td>
</tr>
<tr>
<td></td>
<td>external accessibility</td>
</tr>
<tr>
<td></td>
<td>internal and external</td>
</tr>
<tr>
<td></td>
<td>appropriateness/ attractiveness</td>
</tr>
<tr>
<td></td>
<td>internal adaptations and</td>
</tr>
<tr>
<td></td>
<td>accessibility to support</td>
</tr>
<tr>
<td></td>
<td>independence</td>
</tr>
<tr>
<td></td>
<td>private/personal space</td>
</tr>
<tr>
<td></td>
<td>roommate(s) and their impact</td>
</tr>
<tr>
<td></td>
<td>status of personal equipment</td>
</tr>
<tr>
<td></td>
<td>(e.g. wheelchairs, communication equipment,</td>
</tr>
<tr>
<td></td>
<td>adaptive technology for independence)</td>
</tr>
<tr>
<td></td>
<td>licensing requirements (where applicable)</td>
</tr>
<tr>
<td></td>
<td>support for home-based leisure interests,</td>
</tr>
<tr>
<td></td>
<td>hobbies, etc.</td>
</tr>
<tr>
<td></td>
<td>&quot;does it feel like home&quot;</td>
</tr>
<tr>
<td></td>
<td>awareness of and commitment to lifestyle</td>
</tr>
<tr>
<td></td>
<td>preferences and personal routines</td>
</tr>
</tbody>
</table>

WHAT DO WE UNDERSTAND THIS PERSON'S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING:
THE REVISED GUIDELINES FOR MONITORING (1994) WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>9. SAFETY AND SECURITY</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
</table>
| This module may best be considered by cross-referencing to a number of other modules in these Guidelines. Primarily consider module #3. Personal Plans and Documentation; #4. Personal Care, Health Related Supports and Protocols; #5. Personal Recording Procedures; and, #7. Persons providing Care and Support/Staff. | policy and procedures
| | . practices with the agency or home; eg communication strategies, coordination
| | . staff training
| | . emergency plans
| | . review/practice/updates
| | . medications: administration and errors
| | . seizure management
| | . household poisons
| | . environmental hazards
| | . safety precautions
| | . attention to the development of safeguards during change or transition

WHAT DO WE UNDERSTAND THIS PERSON’S EXPECTATIONS TO BE

POSSIBLE IMPLICATIONS FOR STAFF TRAINING:
THE REVISED GUIDELINES FOR MONITORING (1994) WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

**SECTION I**

<table>
<thead>
<tr>
<th>10. EMERGENCY PROCEDURES</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td>. medication error</td>
</tr>
<tr>
<td></td>
<td>. fire safety</td>
</tr>
<tr>
<td></td>
<td>. emergency evacuation</td>
</tr>
<tr>
<td></td>
<td>. critical illness</td>
</tr>
<tr>
<td></td>
<td>. staff accident</td>
</tr>
<tr>
<td></td>
<td>. vehicle accident</td>
</tr>
<tr>
<td></td>
<td>. power outage</td>
</tr>
<tr>
<td></td>
<td>. criminal</td>
</tr>
<tr>
<td></td>
<td>. family emergency</td>
</tr>
<tr>
<td></td>
<td>. neighbourhood emergency</td>
</tr>
<tr>
<td></td>
<td>. personal emergency, potential situations specific to an individual (e.g. seizures, person missing, etc.)</td>
</tr>
<tr>
<td></td>
<td>. protocol in situations of suspected or alleged abuse</td>
</tr>
</tbody>
</table>

**EMERGENCY FOLLOW-UP**

| DATE | . notification of family, friends |
|      | . additional support requirements  |
|      | . additional equl. requirements    |
|      | . communication of pertinent information |
|      | . analysis of incident reports    |

**POSSIBLE IMPLICATIONS FOR STAFF TRAINING**

Services for Community Living Branch
Ministry of Health
THE REVISED GUIDELINES FOR MONITORING (1994)
WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

11. ORGANIZATION STRUCTURE/EFFECTIVENESS

INTRODUCTION

This last service delivery component will be of particular interest at certain crucial times before and during an organization’s or agency’s contracted involvement with the Services for Community Living Branch. This list of service delivery considerations make up a skeletal overview of what would constitute an organizational analysis when:

i) the SFCL Branch is considering the organization as a future contractor;
ii) preparing for an annual review for the purpose of considering re-contracting; and,
iii) at times during the contract year when any of these issues might be directly negatively impacting the lives of the people being served.

(It should be noted that this overview is by no means a complete list of all the organizational components the Services for Community Living Branch will consider.)

<table>
<thead>
<tr>
<th>11. ORGANIZATION STRUCTURE/EFFECTIVENESS</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Although included in the format of each person’s ongoing monitoring review this component is used at the discretion of the Service Co-ordinator, Regional Coordinator and Regional Manager. This information has proven to be most helpful when several people receiving support from the same organization have their services monitored and key themes emerge)</td>
<td>Board of Directors/Proprietors (leaders)</td>
</tr>
<tr>
<td></td>
<td>consumer involvement</td>
</tr>
<tr>
<td></td>
<td>philosophy,mission + mandate</td>
</tr>
<tr>
<td></td>
<td>commitment to personal consumer rights and self-determination</td>
</tr>
<tr>
<td></td>
<td>clarity of purpose/direction</td>
</tr>
<tr>
<td></td>
<td>policies/statements of guidance</td>
</tr>
<tr>
<td></td>
<td>recruitment/selection strategies for Board members</td>
</tr>
<tr>
<td></td>
<td>training for Board members</td>
</tr>
<tr>
<td></td>
<td>organization chart/hierarchy</td>
</tr>
<tr>
<td></td>
<td>delineation of responsibility and clarity of roles</td>
</tr>
<tr>
<td></td>
<td>liaison and support to services</td>
</tr>
<tr>
<td></td>
<td>job descriptions</td>
</tr>
<tr>
<td></td>
<td>regular meetings/reporting</td>
</tr>
<tr>
<td></td>
<td>self review/evaluation</td>
</tr>
</tbody>
</table>

For:
Date
Reviewer:

DATE
<table>
<thead>
<tr>
<th>DATE</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>. home or service specific policies and procedures</td>
</tr>
<tr>
<td></td>
<td>. staff orientation</td>
</tr>
<tr>
<td></td>
<td>. ongoing staff training</td>
</tr>
<tr>
<td></td>
<td>. staff communications</td>
</tr>
<tr>
<td></td>
<td>. decision making protocol</td>
</tr>
<tr>
<td></td>
<td>. shift/job descriptions</td>
</tr>
<tr>
<td></td>
<td>. staff schedule</td>
</tr>
<tr>
<td></td>
<td>. staff evaluation procedure</td>
</tr>
<tr>
<td></td>
<td>. staff conflict resolution process</td>
</tr>
<tr>
<td></td>
<td>. family involvement</td>
</tr>
<tr>
<td></td>
<td>. advocacy/friend involvement</td>
</tr>
</tbody>
</table>
THE REVISED GUIDELINES FOR MONITORING (1994)
WORKSHEETS

The following personal support and service delivery component(s) is/are crucial to a safe and valued life in the community. Please use the spaces provided to keep record of important information and ideas that pertain to this person. The items listed in the right-hand column are a non-exhaustive list of examples of ideas for you to choose from or add to, in order to help facilitate your assessments, as required.

SECTION I

<table>
<thead>
<tr>
<th>12. NOTABLE SIGNIFICANT/INNOVATIVE PERFORMANCE</th>
<th>ITEMS FOR THE SERVICE COORDINATOR TO CONSIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td>evidence of any exemplary/unique/creative performance on part of service provider and/or caregivers, (e.g. high degree/level of sensitivity, individualization, responsiveness, flexibility, etc.)</td>
</tr>
</tbody>
</table>

| 13. URGENT CRITICAL ISSUES | ITEMS: Identification of any ISSUES which require immediate or urgent action or rectification. |
| DATE                        |                                             |

Services for Community Living Branch
Ministry of Health Page 12
THE REVISED GUIDELINES FOR MONITORING (1994)
MONITORING SUMMARIES

For:
Date:

SECTION II

A. PERSONAL MONITORING SUMMARY

The following narrative provides an overview of the most important issues (positive or negative) that pertain to this person and the supports and services they are receiving at this time. Use additional paper as required.
THE REVISED GUIDELINES FOR MONITORING (1994)
MONITORING SUMMARIES

SECTION II

<table>
<thead>
<tr>
<th>For:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
</tr>
</tbody>
</table>

B. SUMMARY OF REQUIREMENTS FOR STAFF SUPPORT AND TRAINING

The following narrative provides an overview of the most important issues (positive or negative) that pertain to staff training and development as they relate to serving and supporting this person. Use additional paper as required.