TINY SPECKS IN MICROSCOPES:
THE IMPACT OF HUMAN SERVICE WORKERS ON THE LIVES OF PARENTS WITH INTELLECTUAL DISABILITIES

by

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Abstract

This exploratory study used grounded theory methodology to examine the interactions between human service workers and parents with intellectual disabilities. Seven in-depth interviews were conducted with 3 parents. These parents were all receiving voluntary, formal support services. The findings of this study indicated that parents recognized that they needed voluntary, formal support services to manage some aspects of their lives. Other findings indicated, however, that support was not always viewed as being beneficial. Human service workers were often perceived as social control officers. A number of mechanisms such as coercion and blaming were used to maintain social control. The social control parents experienced led them to feel a sense of hopelessness about their situations which resulted in parents inventing new ways to adjust or adapt to their situations.
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Chapter 1

Introduction

This thesis will explore the impact of human service workers on the lives of parents with intellectual disabilities. To fully appreciate how human service workers impact the lives of parents with mental disabilities it is necessary to develop an understanding of the wider society and how it has influenced and continues to influence our values, attitudes, and practices towards people with intellectual disabilities. To achieve this objective, a step back in time is warranted as remnants of our not too distant past are reflected in our current practices.

This chapter will first discuss the changes in western societies from the preindustrial era to industrialization. This discussion will specifically deal with changes as they relate to people with disabilities. This chapter will then describe Social Darwinism and Eugenic theories because they were instrumental in influencing social policy concerning people with mental handicaps during the nineteenth and twentieth century. It will also briefly summarize a study conducted in the early 1900s by the American psychologist Henry Goddard. The reasons for citing this particular study are twofold: first, the study provides an excellent illustration of society’s fears and attitudes toward individuals with disabilities during that period; and secondly, it was considered famous in its time. This fame served to reinforce, and perhaps escalate, North Americans’ fears toward people with intellectual disabilities. In addition, a brief history will be provided regarding the sterilization of people with mental handicaps including some of the events
leading to the enactment of sexual sterilization legislation in British Columbia in 1933. Following this discussion, some of the factors contributing to the public’s change in attitudes and practices toward people with intellectual disabilities will be outlined. Finally, the purpose for this research will be discussed.

The Preindustrial Era to Industrialization

Western societies in the preindustrial era were structured in such a way that they did not prohibit most people with mild or moderate mental handicaps from participating in the agricultural, home-based work that needed to be done (Abbott & Sapsford, 1988). The way in which work was organized, however, changed dramatically during the industrial revolution and had negative implications for people with disabilities. For instance, people were hired to work in factories in urban centers. This type of work required ‘disciplined individuals’ (Abbott & Sapsford, 1988) and certain skills such as the ability to follow directions and meet production deadlines. Those individuals who were unable or unwilling to meet the demands of this changing work environment were excluded from participating in the work force (Oliver, 1990). Furthermore, individuals who did not conform to this new society, for whatever reasons, were seen as a social problem.

Abbott & Sapsford (1988) note that it was during the move from a rural, agricultural based economy to industrial capitalism when people with mental handicaps were defined “as a distinct and serious ‘problem class’” (p.14). They also note that the way in which the mentally handicapped were perceived and
treated during that period and into the twentieth century can be attributed to the development of two theories. These theories are Social Darwinism and Eugenics.

**Social Darwinism**

Social Darwinism was developed by the philosopher Herbert Spencer in the late nineteenth century (Abercrombie, Hill, & Turner, 1988). Spencer’s Social Darwinism was drawn from Darwin’s Theory of Evolution (Chase, 1977) and it operated from two central premises.

(1) There are underlying, and largely irresistible, forces acting in societies which are like the natural forces which operate in animal and plant communities. One can therefore formulate social laws similar to natural ones.

(2) These social forces are of such a kind as to produce evolutionary progress through the natural conflicts between social groups. The best adapted and most successful social groups survive these conflicts, raising the evolutionary level of society generally (‘the survival of the fittest’). (Abercrombie et al., 1988, p. 225).

In summary, Spencer’s theory suggested that the weaker members of society would be weeded out through natural forces and over time the human race would become more superior.

According to Abbott & Sapsford (1988) it was Spencer’s ideas that were at the forefront of the Eugenics Movement. And it seems from Abbott & Sapsford’s account of these events that it was the combination of the two forces, Social Darwinism and Eugenics, which shaped the larger society’s attitudes toward people with intellectual disabilities. They add that Eugenics had a profound affect on the development of social policy concerning people with mental handicaps at the turn of the twentieth century.
Eugenics: Improving the Human Species

Eugenics was developed in England in 1883 by Francis Galton (Abercrombie et al., 1988; Kevles, 1985). Galton’s theory was that the human race could be improved by implementing measures to increase the number of offspring of the ‘fittest’ members of society while reducing or eliminating altogether the number of offspring of the ‘unfit’ (Kevles, 1985; Chase, 1977). His ideas were based on the premise that all human traits, including such things as intelligence, musical ability, poverty, prostitution, criminality and alcoholism were inherited (Kevles, 1985). His ideas had profound implications for the treatment of those labeled by society as ‘feeble-minded’.

The Eugenicists in the early 1900s targeted the feeble-minded as a threat to society (Abbott & Sapsford, 1988; Scheerenberger, 1983; Chase, 1977). They were blamed for many of the social problems during that period which included poverty, criminality, prostitution, and venereal disease (McLaren, 1990; Institute of Law Research & Reform: Alberta, 1988). Eugenicists were concerned that the feeble-minded could be mistaken for ‘normal’ thereby transmitting their undesirable traits to their offspring which would eventually lead to the degeneration of the human race (Goddard, 1973).

The types of social policies arising from these ideas at that time were segregation and sterilization. One highly regarded study conducted in the early 1900s by Goddard (1912) demonstrated how “bad” traits and “good” traits were passed on from generation to generation. This work escalated public fears toward
the feeble-minded and likely instilled a sense of urgency to deal with the problem. The following section summarizes this study.

A Summary of Henry Goddard’s 1912 Study called “The Kallikak Family”

Henry Goddard, the American Psychologist and Eugenicist conducted a study on Deborah Kallikak and her ancestors (Goddard, 1973). Deborah, the subject of the study, was a twenty-two year old woman who resided at The Training School for Backward and Feeble-minded Children in Vineland, New Jersey. Goddard and his assistants traced Deborah’s ancestry back six generations and found that Deborah had a great-great grandfather named Martin Kallikak. They also found that another Martin Kallikak existed who was a generation older than Deborah’s great-great grandfather. This older Kallikak is referred to in the study as Martin Kallikak Senior. As Goddard and his research assistants examined Martin Kallikak Senior’s life more closely they pieced together information indicating that Martin Kallikak Senior, when he was just a young man, met a feeble-minded woman in a bar and they had a feeble-minded son out of wedlock. That son was named Martin Kallikak Junior; Deborah’s great - great grandfather.

It was determined by Goddard (1973) and his assistants that Martin Kallikak Senior later ‘smartened up’ and married a ‘decent’ woman from a decent family. The two sides of the family, the Martin Kallikak Junior “bad” side and the Martin Kallikak Senior “good” side, were compared and the following conclusions were reached.
Goddard found that from Martin Kallikak Junior’s bad side of the family there were four hundred and eighty descendants. Apparently, one hundred and forty-three of them were found to be feeble-minded while forty-six were reportedly normal. Goddard does not appear to comment on the status of the remaining two hundred and ninety-one descendants. He does note, however, that of the total number of descendants, it was determined that thirty-six were “illegitimate,” thirty were “sexually immoral,” twenty-four were “alcoholics,” three were “epileptics,” three were criminals, eighty-two “died in infancy” and “eight kept houses of ill fame” (Goddard, 1973, pp. 17-19).

Goddard also found that from Martin Kallikak Senior’s good side of the family there were four hundred and ninety-six descendants. All of these descendants were reportedly “normal,” although a few were described as alcoholic and one was referred to as “sexually loose.” The descendants from this good side of the family reportedly all did well for themselves, holding such esteemed positions as educators, judges and lawyers (Goddard, 1973, pp. 29-30).

Goddard (1973) makes the following observations about the research findings in the chapter of the study titled “What Is To Be Done?”.

No one interested in the progress of civilization can contemplate the facts presented in the previous chapters without having the question arise, Why isn’t something done about this? It will be more to the point if we put the question, Why do we not do something about it? We are thus face to face with the problem in a practical way and we ask ourselves the next question, What can we do? For the low-grade idiot, the loathsome unfortunate that may be seen in our institutions, some have proposed the lethal chamber. But humanity is steadily tending away from the possibility of that method, and there is no probability that it will ever be practiced.

But in view of such conditions as are shown in the defective side of the Kallikak family, we begin to realize that the idiot is not our greatest problem.
He is indeed loathsome; he is somewhat difficult to take care of; nevertheless, he lives his life and is done. He does not continue the race with a line of children like himself. Because of his very low-grade condition, he never becomes a parent.

It is the moron [or feeble-minded] type that makes for us our great problem. And we face the question, “What is to be done with them - with such people as make up a large proportion of the bad side of the Kallikak family?” we realize that we have a huge problem. (Goddard, 1973, pp. 101-102).

As illustrated by this quote, this study reinforced and scientifically substantiated, that bad traits were passed on from one generation to the next and that the feeble-minded were a group of people to be feared.

Despite later criticisms of Goddard’s study and Eugenics theories in general, this information instilled fears in the public toward the feeble-minded. Such fears led to the implementation of sterilization legislation in the United States and Canada in the 1900s. Thirty states in America enacted such legislation (Chase, 1977) as well as two provinces in Canada; British Columbia and Alberta (McLaren, 1990).

The Enactment of Sterilization Legislation in British Columbia

McLaren (1990) in his book titled Our Own Master Race: Eugenics in Canada, 1885-1945 outlines in the chapter “Creating a Haven for Human Thoroughbreds” (pp. 89-106), some of the events leading to the implementation of the “Sexual Sterilization Act” in British Columbia. A few of these events will be summarized because they shed light on the debates that took place in the early 1900s around this issue.
McLaren (1990) writes that a "Royal Commission on Mental Hygiene" was established to look into the state of Mental Retardation in British Columbia in 1925. There were three reasons for the establishment of the Commission. First, there were concerns that mental disorders had significantly increased in British Columbia. Second, it was generally believed that British Columbia was attracting "foreign misfits." Third, there were concerns regarding British Columbia’s ability to continue to foot the bill for segregation.

In addition to determining whether the number of people afflicted with mental disorders had increased; and whether foreigners with mental disorders were in fact choosing to live in British Columbia, the Commission had the important tasks of investigating how to prevent mental disorders and how to provide better care to the feeble-minded. Sterilization was one of the suggestions provided to the Commission for preventing mental disorders.

McLaren (1990) outlines three central arguments presented to the Commission in support of sterilization as a preventative measure. These arguments are based on economic, hereditary and moral factors. The first argument raised was how much it was costing British Columbia to keep people in institutions. Sterilization was presented as a cost cutting measure. Surgical intervention would prohibit reproduction of the feeble-minded thereby reducing institutional costs by safely allowing some "inmates" to be released into the community.
The fear of undesirable traits being passed on from one generation to another, as well as the belief that the feeble-minded were more fertile than the 'average' citizen formed the basis of the second argument. Sterilization, it seemed, offered one way of ridding society of 'defective' individuals who would likely produce children with the same undesirable traits. Some argued that not all feeble-minded individuals would produce defective offspring. They were reminded, however, that feeble-minded parents would be unable to properly care for their children and should not be permitted to have them.

The final argument supporting sterilization legislation was based on moral convictions. Some viewed sterilization as a justified form of punishment whereas others equated implementation of the policy with freedom. For example, institutionalized individuals agreeing to the surgical intervention could leave asylums and get married without posing a threat to the health and well-being of the greater society.

Based on all the information gathered by the Commission, a decision was made in the Royal Commission's 1927 report to support the sterilization of institutionalized people who would be eligible for release into the community (McLaren, 1990). One of the reasons that the report's recommendations were not implemented until 1933 was the need to ensure that the majority of British Colombians would support the proposed sterilization policy. Apparently the Vancouver Sun played a role in disseminating information to the public concerning the benefits of sterilization. McLaren (1990) states that the Vancouver
Sun ran a number of articles written by Emily Murphy, a supporter of sterilization, who assisted Alberta in its sterilization campaign. The Sun also supported United States Supreme Court Justice Holmes's decision in the case of Buck vs. Bell.

Carrie Buck was an eighteen year old woman who lived in an institution for Epileptics and the Feeble-minded in the state of Virginia (Chase, 1977). She had an illegitimate child while in the institution and, it seems, this is the reason why she was selected as a candidate for sterilization under the newly instituted Virginian compulsory sterilization law. Under the newly formed law, the superintendent of an institution had the power to ask a Eugenics Board for the permission to sterilize "inmates" (Reilly, 1991).

The Superintendent of Carrie Buck's institution petitioned the Eugenics Board for permission to sterilize Carrie. This was based on the grounds that she might bear more children like herself (Reilly, 1991). A young lawyer who had been appointed Carrie's guardian, however, appealed the Board's decision and took the case all the way to the Supreme Court (Reilly, 1991). In 1927 the final decision concerning Carrie's fate was made by Supreme Court Justice Oliver Wendall Holmes. In his judgment he wrote:

It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. (Reilly, 1991, p. 87).
This judgment further reinforced the justification for sterilization legislation and inspired other states to introduce such measures (Reilly, 1991). The *Vancouver Sun*'s editorialist supported the idea and suggested that Canada should follow the United State's lead (McLaren, 1990). Although there was some opposition to the bill, particularly by Catholics, "An Act Respecting Sexual Sterilization" was proclaimed in British Columbia on April 7, 1933 (McLaren, 1990; Sexual Sterilization Act, 1933).

The Act allowed the Superintendent of a public hospital for the insane to decide whether an "inmate" of that institution should be referred to the Board of Eugenics (Sexual Sterilization Act, 1933). Referrals to the Board were based on whether the Superintendent felt an inmate, once discharged from the institution, would likely have children with mental deficiencies (Sexual Sterilization Act, 1933). Upon receiving such a referral from the Superintendent, it was the Board's job to examine the inmate in order to assess whether he or she "would be likely to produce children who by reason of inheritance would have the tendency to serious mental disease or mental deficiencies." (Sexual Sterilization Act, 1933, p. 200). If the Board determined that there was a risk that an inmate would produce deficient offspring, sterilization was recommended.

Unlike compulsory sterilization laws introduced in the United States, before such an operation could be performed in British Columbia, the inmate was required to provide written consent. If it was determined that an inmate was incapable of authorizing consent, it was the Board of Eugenics' responsibility to
obtain written consent from a spouse, parent, guardian or the Provincial Secretary (Sexual Sterilization Act, 1933). The operation could not be performed without the required consent (Sexual Sterilization Act, 1933).

The sexual Sterilization Act remained on British Columbia’s statutes for 40 years. It was repealed in 1973. The Minister of Health Services in British Columbia at that time introduced Bill No. 45, “Sexual Sterilization Act Repeal Act”, in the Legislative Assembly on March 29, 1973. Discussion around the repeal of the Act commenced on April 5, 1973. At that time the Minister of Health Services stated:

In the past 10 years, there have been very, very, few calls for the use of the eugenics committee that was set up. We find it quite archaic to provide for sexual sterilization of people who are in mental institutions.

Not only that, Mr. Speaker, it provided for sterilization of people who were in boys’ industrial schools, girls’ industrial schools and that type of situation. The people in our health department and the people in the professions feel that it was most archaic (British Columbia Legislative Assembly Debates, 1973, p. 2298).

Following this discussion, A decision was made in the Legislative Assembly to pass Bill No. 45 on April 13, 1973 (British Columbia Legislative Debates, 1973). The Sexual Sterilization Act remained in force in British Columbia for most of the twentieth century, even though society was beginning to question Eugenics theories as early as 1940.

**Changing Attitudes Toward People with Intellectual Disabilities**

For the most part societal attitudes toward people with disabilities began to change around the Second World War when the effects of Nazism came to light
(Abbott & Sapsford, 1988; McLaren, 1990). After the public learned that sterilization of people with disabilities led to their eventual extermination in Germany, professionals began to dissociate themselves from eugenic policies (McLaren, 1990). In addition, there was considerable opposition to sterilization from Catholics and 48% of Canadian citizens were Catholic (McLaren, 1990).

Also in the early post-war period, knowledge about genetics was becoming more sophisticated. Scientists began to question the validity of eugenics (McLaren, 1990). The middle class placed less blame on individuals for social problems and there was some recognition that people require assistance to survive in an unpredictable, industrialized market economy (McLaren, 1990).

It was not until the 1970s, however, that a major shift in Canada occurred toward providing care to people with disabilities. Lord and Hearn (1987) in their study of deinstitutionalization identified five social trends prevalent in the 1970s and 1980s that precipitated the closure of institutions for people with intellectual disabilities in Canada (pp. 3-4).

The first social trend identified is the human rights movement. They point out that the Canadian Charter of Rights and Freedoms was proclaimed in 1982 which led to increased public awareness concerning discrimination towards people with disabilities.

Secondly, during the early 1970s scholars began to publish on the effect of institutional living. This body of knowledge was used by advocates to promote community living. Thirdly, those in the position to create change were becoming
more knowledgeable about the process of deinstitutionalization and about serving people with disabilities in their own communities. Fourthly, economics was a concern. Due to the high costs involved in operating institutions, it was generally believed that services to people with disabilities could be provided more cheaply in the community.

Finally, the principle of normalization was increasingly popular in designing services for people with disabilities in North America (Dalley, 1992; Lord & Hearn, 1982). The principle of normalization first originated in Denmark in the 1950s (Dalley, 1992). Its primary objective was to ensure that people with disabilities enjoyed the same rights and opportunities as nondisabled citizens (Dalley, 1992). This definition was apparently later expanded upon by Wolf Wolfensburger in the United States in the 1970s (Dalley, 1992). According to Dalley (1992) at that time “Wolfensberger defined normalization as the ‘utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behavior and characteristics which are as culturally normative as possible’” (p. 101). Dalley comments on this definition stating that “it implies an acceptance of the status quo (which is governed by the dominant ideology) and a conservative unwillingness to challenge existing norms” (p. 103).

Although there has been considerable debate around the North American definition of normalization in that it maintains the status quo, fulfills the interests of the dominant society at the expense of the individual, and stresses conformity
rather than individual differences (Dalley, 1992), it was nevertheless, instrumental in changing society’s attitudes concerning how care is provided to people with intellectual disabilities.

People are no longer segregated from the larger society by the ominous walls of the institution because of eugenic fears. They are living and working in the community as well as marrying and becoming parents. The question that now arises is whether these parents can adequately care for their children (Booth & Booth, 1994a).

Espe-Sherwindt & Crable (1993) state that there is “no direct correlation between a higher IQ and ‘better’ parenting” (p. 157). They note, however, that there are seven factors which may be valuable in identifying those parents with intellectual disabilities who will perhaps have a greater likelihood of being successful. These include having an IQ of over 50, having a spouse, raising fewer children, having an adequate income, having a support network, and being willing to accept the support that is offered. It is important to note that support may be provided through both formal and informal networks.

In fact whether parents receive adequate support seems to be an important factor in determining whether their children are apprehended. Booth & Booth (1994a) state, “that families whose children were removed permanently typically had only limited support, lost their support at a crucial time, or were viewed as incompetent by key figures within their support system” (p. 30). Because adequate support and the willingness to accept support have been identified as
important factors in keeping parents with intellectual disabilities and their children together, it is necessary to determine how service affects these parents' lives.

**Purpose of the Research**

This study will focus on the impact of formal support systems as they play a significant role in assisting parents with intellectual disabilities. For example, Espe-Sherwindt & Crable (1993) observe "that many parents with mental retardation continue to find themselves controlled by the expectations and guidelines of the multiple agencies involved with them and their young children" (p. 60).

The purpose of this research, then, is to explore how human service workers impact the lives of parents with intellectual disabilities. Are they perceived by these parents to be a help or a hindrance?

To answer the research question, parents with intellectual disabilities who receive services from the Ministry of Social Services, Services to People with Mental Handicaps (now known as the Ministry for Children and Families) will be interviewed.

Additional terms used in the study that require clarification are human service workers and the word "impact". Human service workers are defined as social workers, homemakers, life skill workers, family support workers, daycare workers and physicians. These professionals and paraprofessionals are included under the human service worker definition because these are the people participants
mentioned during the interviews. The word “impact” will be defined by such concepts as intrusiveness, control, and power. Grounded theory methodology will also be used because a qualitative research approach is recommended when one wishes to gain a deeper understanding of “complex social interactions” (Wells, 1995, p. 34).


Chapter 2

Methodology

This study uses grounded theory methodology to examine the basic social process underlying the interactions that occur between human service workers and parents with intellectual disabilities. Glaser and Strauss developed this qualitative research approach in 1967 (Simms, 1980) because “they believed that adequate theory could emerge only from intensive involvement with the phenomenon under study” (Wells, 1995, p. 34). This kind of intensive involvement is achieved by various data collection methods used in qualitative research. Some of these methods include in-depth interviewing, observation, the use of books, videos, government documents or any other medium that may be useful in making sense of the research question (Wilson, 1985).

Grounded theory methodology was selected for this research for four reasons. First, the rich data that can be collected using this approach will be helpful in identifying “structural conditions”, “consequences” and “processes” that are imperative for understanding “complex social interactions” (Wells, 1995, p.34) such as the interactions that occur between human service workers and parents with intellectual disabilities. Second, this approach is recommended for use in areas of study where there is little research. Third, it provides opportunity for the voices of participants to be heard through the use of in-depth interviews. Booth and Booth (1994a) note that research to date on parents with intellectual
disabilities “fails to convey any impression of the parents as people or of the lives
that they lead” (p. 31). And fourth, this methodology, unlike other qualitative
research methodologies, emphasizes theory development (Corbin & Strauss,
1990). Therefore, it both describes and provides an adequate explanation of the
phenomenon under study (Corbin & Strauss, 1990).

Because theory is being developed, this approach involves the researcher’s
interpretation of the data. A tentative analytic framework is developed by the
researcher in the early stages of data collection and further verified in the field as
the theory emerges (Glaser & Strauss, 1970). This process is complete when no
more new information is obtained from the field and “when the researcher is
convinced that his [or her] analytic framework forms a systematic substantive
theory, that is a reasonably accurate statement of the matters studied.” (Glaser &

Method

Procedure

Identifying and Selecting Participants

A letter was sent to the local Ministry of Social Services (MSS), Services
to People with Mental Handicaps, now called the Ministry for Families and
Children, to request permission to carry out this study. Once granted, the District
Supervisor of the local MSS office was approached for the purpose of identifying possible participants. Fourteen prospective parents were identified. Of these fourteen parents six were chosen as possible participants for the study. These parents were selected because the researcher carrying out the study had no previous contact with them. (Prior to and during part of this study the researcher worked in the office as a social worker.) Due to the limited number of possible participants, parents could not be chosen according to the variability of characteristics which is recommended in the grounded theory approach.

**Initial Telephone Contact**

The Ministry of Social Services Clerk, who signed a form to keep participants’ names confidential, contacted prospective parents to determine whether they would be interested in being involved in this project. If participants expressed an interest, the clerk asked them if they would be willing to accept a phone call from the researcher to arrange a meeting for further information about the project.

**Second Telephone Contact**

Once prospective participants agreed, they were contacted with a telephone call to their homes within the first week of the initial contact. This telephone call consisted of mentioning the phone call they had received from the clerk, providing them with information about the researcher, as well as providing a brief description of the research project. Prospective participants were then
asked if they would be willing to meet to further discuss the research project. If parents were willing to meet, an appointment was scheduled at their convenience.

**First Meeting**

During the first meeting the project was discussed in detail so that participants would have the required information needed to make an informed decision about participating. Participants’ questions were answered and it was stressed that the project was voluntary. Participants were provided with the name of a contact person at The University of Northern British Columbia should they have any concerns about the research project. They were also asked to sign a consent form that gave permission to tape the interviews and use the taped information for the project. Together participants and the interviewer developed code names to protect their identities. During this meeting participants were also introduced to the tape recorder enabling them to feel more comfortable with it prior to the first interview. A future interview date was scheduled at the participant’s convenience.

**Preparation for Interviews**

Lindsay’s (1996) audio tape guidelines were used to ensure the taping of all the interviews went smoothly. Prior to the scheduled interview dates, tape recorder equipment was tested to ensure it would operate. A durable tape recorder was used with a pop-up microphone to ensure taped interviews would be as clear as possible. In addition, two sets of batteries were charged so a backup was
always available if needed and an extra standard size cassette was always carried to the interview site.

**Data Collection Method**

**In-Depth Interviews: Number of Participants Interviewed**

In-depth interviews were carried out with three parents (i.e., one mother and two fathers). Of the six parents originally approached to participate in the research project, three parents later declined. After the first meeting, one parent decided that there would be too much risk involved in participating in such a study. For example, it is important to mention that it may have been too risky for some parents to agree to participate in the project because the researcher worked in the same office from where the participants were selected. Participants were required to trust that the researcher would not divulge confidential information to her co-workers. In retrospect, it would have helped to reduce participants' anxiety if the researcher had chosen an office where she did not work. The other two parents who expressed an interest in participating in the study were unable to make the first meeting. They were contacted again and a second meeting was scheduled which they were also unable to attend. A message was left on their answering machine asking them to contact the researcher about rescheduling the meeting if they were still interested in hearing more about the project. It was later learned that these parents were right in the midst of dealing with some difficult
family circumstances which would have made it hard for them to participate in the project.

Interviews

A total of seven interviews were conducted over a three month period. Parents were interviewed in their homes. The first parent was interviewed twice, the second parent was interviewed three times and the third parent was interviewed twice. Each interview, on average, was about one hour. Initially, a semi-structured interview guide was used. After the first interview, however, the interviewer realized the guide was an unhelpful tool for encouraging parents to provide a full account of their experiences. It was also discovered that an unstructured interview would give the interviewer the flexibility to ask questions important for identifying a wide range of events relevant to the topic under study. Furthermore, it became apparent that it is important to adapt the interview to respect the individuality of the interviewees.

Structure of Interviews

Each interview began with an informal visit and snack. It was also confirmed that it was still a good time for the interview to take place. In some cases it was not convenient for parents, so another time was scheduled. Participants were reminded that the tape could be turned off if they preferred not to have a segment recorded. Equipment was tested to ensure it would operate
smoothly. Participants were thanked for the interview. Usually a visit would take place after interviews.

**Taping**

Once interviews were completed, duplicate tapes were made for back-up purposes. All the tapes were labeled with participants' identity codes and the date of the interview. Each participant was also assigned a specific color. Colored dots were then used to mark the participants' tapes for easy identification. The dots were also used to mark the sides of the tapes that had already been used. This was done to guard against taping over already recorded information.

**Transcriptions**

Interviews were transcribed immediately as the data obtained from each interview influenced the direction of future interviews. Lindsay's (1996) "transcription conventions" were used to capture the emotional content of the interviews. For example, as illustrated in Figure 1, higher font sizes were used to indicate an increase in voice volume, while lower font sizes indicated low voice volume. Other transcription conventions were used to indicate pauses, accelerated speech and speech rates.
**Figure 1.** Transcription Conventions from a Sample of the Transcripts.

<table>
<thead>
<tr>
<th>Transcript</th>
<th>Symbols</th>
<th>Explanations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mhm. Can you tell me a little bit about.. um.. (smack lips) about that last.. um comment that you made. That s.h.e.'s <em>in your life too much</em>? Can you tell me what that's like?</td>
<td>about.. um.. s.h.e.'s <em>in your life too much</em></td>
<td>longer than normal pause between words.</td>
</tr>
<tr>
<td><em>(Big Sigh)</em> Well (sigh) any l.i.t.t.l.e... thing we so she has to know about it. A. For an example.. If.. we.. run out of food.. for, for our little one she has to make a huge statement about it. Like, don't ever let it happen again.</td>
<td><em>(Big Sigh)</em> Well (sigh) don't ever let it happen again.</td>
<td>higher font size indicates higher volume, lower font size indicates lower volume.</td>
</tr>
<tr>
<td>The only supervision I’ve ever had was.. my family = But I’ve never had people looking at us like.. we’re.. tiny specks in magnifying = glasses or in.. a.. in microscopes.</td>
<td>my family = But</td>
<td>change in font type indicates speaker is using someone else’s words.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>time between words is either shorter or longer than normal.</td>
</tr>
</tbody>
</table>

It is important to note that at the time of the interviews it was not always possible to detect the emotional content of the interview due to the emphasis that was placed on understanding the content. The transcription conventions were ideal for back tracking later to gain insightful information. For instance, the transcription conventions were helpful for detecting emotions such as anger which was often indicated by higher voice volume. In subsequent interviews the area of
the transcript where such emotion was detected could be further explored which led to more detailed discussions about a particular incident.

**Data Analysis**

The transcribed interviews were coded and analyzed as soon as possible after each interview. In grounded theory it is important for analysis to begin early on in the interview process as the analysis dictates what information is sought in future interviews.

Once the interviews were transcribed, each comment made by the interviewer and interviewees was coded using a method from *Experience Research Social Change: Methods from the Margins* (Kirby & McKenna, 1989). For example, comment number one by the interviewer in the first interview was coded H1JH1 and comment number one by the interviewee in the first interview was coded H1JR1. H1 refers to the first interview in the interviewee’s home. The letters JH and JR are the interviewers and interviewee’s initials and the number 1 refers to the first comment made by both the interviewer and interviewee. These codes, shown in Figure 2, were used to protect participants’ identities and they also proved helpful later for tracking the interview data.
Figure 2. Sample of Coding and Transcript.

<table>
<thead>
<tr>
<th>Coding</th>
<th>Transcript</th>
</tr>
</thead>
<tbody>
<tr>
<td>H1JR4</td>
<td>Well.. It was basically.. um the Ministry.. who.. a, was saying either do this or we = can’t help you, you know. So, a, the first.. social worker I had was Stephanie Winters (not the social workers real name) and.. she was there when I needed her and.. she decided just to quit because she didn’t have much time for her, or her boyfriend. So.. she just quit and now.. another social worker come, came in.. and it’s like.. She, I think she is in our life too much.</td>
</tr>
<tr>
<td>H1JH5</td>
<td>Mhm. Can you tell me a little bit about.. um.. (smack lips) about that last.. um comment that you made. That s.h.e.’s in your life too much? Can you tell me what that’s like?</td>
</tr>
<tr>
<td>H1JR5</td>
<td>(Big Sigh) Well (sigh) any l.i.t.t.l.e.. thing we so she has to know about it. A. For an example.. If.. we.. run out of food.. for, for our little one she has to make a huge statement about it. Like, don’t ever let it happen again. A, she threatened us a few times to take him away. Um.. I’ve just. Bluntly, I think she is in our life too much. And I’d prefer just.. for her to back completely away from us. Um, I’m going to request another worker. I’m going to talk to her supervisor and I’m going to tell him I’d like to have another worker because I think she’s in our life too much.</td>
</tr>
<tr>
<td>H1JH6</td>
<td>Mhm. Okay. And had you had workers before coming to Prince George at all or was this the first, um, time that you’ve had them?</td>
</tr>
<tr>
<td>H1JR6</td>
<td>I’ve.. The only supervision I’ve ever had was.. my family = But I’ve never had people looking at us like.. we’re.. tiny specks in magnifying = glasses or in.. a.. in microscopes. They look at us like sh, okay .. that bug needs help you know . We’re looked on all the time. We can’t make any moves. I feel like we have to get permission even to go outside.</td>
</tr>
</tbody>
</table>

After the transcripts had been coded, they were entered into the “Nud•ist” computer program which is used for analyzing qualitative data. “Nud•ist” was used to mark and track incidents in the transcripts relevant to shedding light on the research question. Once incidents were identified the program provided a means for attaching conceptual labels to these incidents which could then be
tracked throughout all the transcripts. This allowed each piece of data to be
compared for similarities and differences. Similar concepts that continued to
appear in the transcripts were grouped together to form categories and
subcategories. As shown in Figures 3 and 4, these categories were then defined
using concepts that had been previously identified.

**Figure 3. Subcategories and Definitions.**

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coercive Intervention</td>
<td>making and/or carrying out threats for the purpose of controlling client’s behaviors that are judged by human service workers to be negative.</td>
</tr>
<tr>
<td>Control</td>
<td>Power of directing means of regulating (Dic. of Sociology, p. 183). Also evidenced by: clients are given no choice; human service workers need to know everything; human service workers telling people what to do or what is needed; human service workers making the decisions; client’s feelings that they are being looked over all the time. This includes such things as checking, correcting and having to ask for permission.</td>
</tr>
<tr>
<td>Power</td>
<td>Exercised over other individuals There are differences of interest Power is negative involving restrictions and deprivations for those subjected to domination (Dictionary of Sociology)</td>
</tr>
<tr>
<td>Victims Blaming Themselves</td>
<td>Turning inwards i.e., not trying hard enough Includes judgments as a means of keeping people in their place Assigning fault and/or responsibility to oneself</td>
</tr>
<tr>
<td>Blaming the Victim</td>
<td>Assign fault or responsibility to (Webster Dictionary) Includes a judgment from the outside/others May include others asking for explanations such as where, why and how.</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>Referring to their disability as to why they need assistance.</td>
</tr>
<tr>
<td>Powerlessness</td>
<td>Inability to change situation/hopelessness</td>
</tr>
<tr>
<td>Adjustment</td>
<td>Things done, adjustments made to make the best of the situation.</td>
</tr>
<tr>
<td>Practical Assistance</td>
<td>Help with day to day affairs.</td>
</tr>
<tr>
<td>Companionship</td>
<td>Company/having someone to hang out with. Fun stuff.</td>
</tr>
<tr>
<td>Hearing Through the Grapevines</td>
<td>Process of keeping watch over other parents with intellectual disabilities to determine if their children have been apprehended.</td>
</tr>
</tbody>
</table>
**Figure 4. Categories and Definitions.**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognize need for support</td>
<td>Stating need service due to disability.</td>
</tr>
<tr>
<td>Maintaining Social Control</td>
<td>Strategies that maintain social control. Social control as defined as Fook’s definition (1993).</td>
</tr>
<tr>
<td>Adapting Parents’: Survival Tactics</td>
<td>Things done, adjustments made to make the best of the situation. People comply even though they may not like it.</td>
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</tbody>
</table>

Nud•ist was then used to create a tree to show the links or relationships between concepts, subcategories and categories. These relationships were continually tested against the interview data. Once these relationships began to become evident, the computer program “Word” was used to make two figures. The first figure was made to show the linkages between the actual words of the interviewees or the raw data and the subcategories. The second figure showed the linkages between the raw data that had been previously coded, the subcategories and the categories. These figures, illustrated in Figure 5, were useful for developing a framework to explain how human service workers impact parents with intellectual disabilities because it provided a method for working within the entire framework. In addition, the figures were used as visual tools in order to obtain an overall sense of the participants’ situations.
Figure 5. Linkages between the Raw Data, Subcategories and Categories.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Codes</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain</td>
<td>Coercive Intervention</td>
<td>H1JR3</td>
<td>Uh.. When I first came to Prince George. I... got into the AIMHL program and... AIMHL was supported by... the Ministry of Social Services. And that's how I became between em. It was like two walls. And, I really. To them I really had no choice. They were saying either you get help or you're out on the street with no food or money.</td>
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<tr>
<td>Social Control</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>H1JR4</td>
<td>Well... It was basically... um the Ministry... who... was saying either do this or we can't help you, you know. So, a, the first... social worker I had was Stephanie Winters (not the social workers real name) and... she was there when I needed her and... she decided just to quit because she didn't have much time for her, or her boyfriend. So, she just quit and now... another social worker came in... and it's like... She, I think she is in our life too much.</td>
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<tr>
<td></td>
<td></td>
<td>H1JR5</td>
<td>(Big Sigh) Well (sigh) any little... thing we so she has to know about it. A. For an example... If... we... run out of food... for, for our little one she has to make a huge statement about it. Like, don't ever let it happen again. A, she threatened us a few times to take him away. Um... I've just. Bluntly, I think she is in our life too much. And I'd prefer just... for her to back completely away from us. Um, I'm going to request another social worker. I'm going to talk to her supervisor and I'm going to tell him I'd like to have another worker because I think she's in our life too much.</td>
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<td></td>
<td>H1JR10</td>
<td>Well, it's like... somebody holding a gun to my head and say you either do this or we'll kill you you know. And it's like being robbed. Either give me all your money or I'll put a bullet in your head... It's like the Ministry is doing that. Either have all these workers or you lose everything. It's like um... being, being really rich you know. Either do this or you'll be cut off you know.</td>
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<td></td>
<td></td>
<td>H1JR11</td>
<td>T.h.e., the actual service of them and life skills and the health nurse. Either... have all these people come over... or (gah) you lose, you lose the baby because... you won't know what to feed him or...</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>H1JR5</td>
<td>Well (sigh) any little... thing we so she has to know about it. A. For an example... If... we... run out of food... for, for our little one she has to make a huge statement about it. Like, don't ever let it happen again. A, she threatened us a few times to take him away. Um... I've just. Bluntly, I think she is in our life too much. And I'd prefer just... for her to back completely away from us. Um, I'm going to request another worker. I'm going to talk to her supervisor and I'm going to tell him I'd like to have another worker because I think she's in our life too much.</td>
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<td></td>
<td>H1JR15</td>
<td>Well... It doesn't seem too bad now. Um... Now it's hard for me to make friends... because I almost made a friend there and... the guy left and started... and, he was, he's working now. So I, I almost made a friend there. But, a, it's hard for me to make friends. It's like... the Ministry if saying to me hey, no friends. You're with us... that's our restriction. And, it's like we're behind bars and we hafta... do whatever they say.</td>
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<td></td>
<td></td>
<td>H1JR52</td>
<td>Um, well, it depends what they schedule me for, like, for... a budgeting and grocery shopping or um (smack lips). If I'm moving we look for a, a apartment or um... or if I have an appointment with somebody else and they can take me there.</td>
</tr>
</tbody>
</table>
Chapter 3

Findings

As indicated in Figure 6, some interesting categories and subcategories emerged from the information provided by the participants in this study. A summary of these categories provides some insight into the interactions that occur between human service workers and parents with intellectual disabilities.

Figure 6. Theoretical Framework

- **Recognize Need for Support**
  - Intellectual Disability
  - Practical Assistance
  - Companionship

- **Maintaining Social Control**
  - Hearing through the Grapevines
  - Coercive Interventions
  - Power and Control
  - Blame the Victim
  - Victims Blaming Themselves
  - Powerlessness

- **Adapting: Parents’ Survival Tactics**
  - Adjustment

1 Italics indicates categories.
2 Small font indicates subcategories.
Recognize Need for Support

The parents in this study all indicated in one way or another that they required support from human service workers. For instance, Jesse\(^3\) explains:

*I need a lot of help financially wise... because I'm slow.*

And George states:

*I'm pretty slow at it... I get some confused and lost.*

Ginger adds:

*I couldn't figure out anything and I was about 28 going on 29.*

Parents seemed to value the practical support they received from human service workers, although it was clear that they would have preferred to be the ones to choose or judge when this support was needed.

...*[T]he first social worker I had was Stephanie Winters and she was there when I needed her.* ...*[A]nother social worker came in and it's like... I think she's in our life too much.*

*If I need help, they'll be there... Last week I didn't have a car... My bumper was smashed into and [all] I did was call Josephine and... I just told her my car is broken could you pick up John and she did. So it works out good that way if you need help.*

In addition to the practical support provided by human service workers, these parents saw service providers as fulfilling the role of a companion or friend.

\(^3\) All the names used in the findings are pseudonyms.
Sometimes I have other things on my mind than life skills coming in all the time, but I enjoy their company... Josephine is outgoing and Irene is pretty outgoing. They are pretty good people to hang out with.

Having company seemed to be one of the positive spin-offs of receiving support from human service workers as well as alleviating worry. George states:

Everything is clean when I get home... Relaxing more. I don’t have to worry about doing any work.

Jesse comments on how he felt when the life skills worker used her credit card to assist him with purchasing a money order.

... I didn’t have to worry about [getting change] because the person had their gold card with them.

In these examples the support parents received was welcomed. However, in other instances the assistance parents received from human service workers was clearly unhelpful and although parents recognized they needed support in some areas, it was sometimes viewed as an intrusion:

Sometimes it’s like an invasion. Get out! Get out!

Or, in it’s most extreme form, it was viewed as a gamble with high stakes at risk.

Either have all these people come over or you lose... the baby because you won’t know what to feed him...

In this example Jesse feels that if he doesn’t do what he is told he will lose his son. Another parent comments:
"At times I want to take her [out of the daycare], but I leave her in because it's the best of her... I want her to be more better in school than I have been."

This mother is thinking about taking her daughter out of daycare because the daycare staff are telling other service providers that she is not feeding her daughter a proper diet. She decides on her own, however, that it is in her daughter’s best interest to stay in daycare.

As illustrated in these excerpts, parents recognized that they required some support, but being the recipients of service was at times risky and overwhelming. Once in the service system these parents quickly discovered that services were not always delivered according to their terms (or without some consequences). In fact the parents interviewed for this study reported experiencing more grief because of their involvement with human service workers. What seems to stand out for these parents is the control that is exercised over them by the people that are supposed to be providing services to assist them.

Social Control

It appears that what is reflected in these parents’ experiences is the social control function that is consciously or unconsciously embedded in helping relationships. “The process of social control refers to the way in which society ensures that its members behave in socially approved and accepted ways. If these norms are contravened there are sanctions which apply.” (Fook, 1993: 60).

Human service workers, and particularly those that work in child welfare, are
often referred to as agents of social control. They are given the job of ensuring
members of society behave in a socially acceptable manner.

As illustrated in the following examples, the parents in this study experienced
this kind of control in every aspect of their lives. Social control presents itself in
its extreme form in this example.

Well [the social worker] is ready to take [our son] anytime. If we step out of
line or something she is ready to take him. I mean she has the authority to do
that, but she has threatened us with that. If that happens again, I'm taking him
away. I'm reporting you.

The social worker communicates her disapproval of this parent’s behavior by
making it understood that the behavior which is perceived to be unacceptable had
better not occur again or drastic consequences will follow. The message is clear.
Behave accordingly or be reported to Child Protection. Parenting, however, is not
the only area where this control is exercised. Jesse comments on how his finances
have changed since the birth of his son.

Well, the worker claimed that Jasmine (the baby’s mother) was spending [her
cheque] on her own, for herself which was not true. She was buying the baby
accessories, diapers, food, whatever he needed. And I was really disappointed
with her because she didn’t believe that. She thought Jasmine was spending it
for herself so she fixed it so we’d have one voucher and one cheque while the
rest of the people out there get four or five hundred dollar cheques and they
can do whatever they want with.
Jesse was also concerned with the control that was being exercised around childcare for his son.

...that was another problem... we’d have to look for baby-sitting. We’d have to make it a goal. Well, I didn’t feel right because I didn’t think that should be a goal. I think that should be up to us show we want... We should pick our own baby-sitters. But apparently [they] want us to make sure the baby-sitter has first aid, knows what they’re doing, has kids of their own... Know what kind of formula the baby takes.

Ginger describes her experience of being told to move because their home is too cold.

I have to move because of Betty (her daughter). It’s too cold in the winter time for her and she’d get sick and I have to have a warmer place... so then she isn’t having a runny [nose] and cold-cold hands.

Ginger also talks about a complaint from daycare staff concerning her daughter’s diet.

I didn’t know which person or daycare, [but] Betty doesn’t have the right amount of fruit and that.

She later states that she heard this piece of information from her life skills worker.

I heard it from Sarah. I’d rather have it through the person that says it.

Ginger also spoke about an incident when one human service worker would come to her home even though she had canceled the appointment.
*She'd come on days when I have told her not to come and she's there...*

*Sometimes if my company is here, sometimes I don't even tell [them] that I'm not around. I will be with [my company] and they have to track me. Well, Brenda used to track me down.*

These examples indicate the degree of control, or lack of control, parents experienced in many facets of their lives ranging from their finances to the use of their spare time. Ginger sums up her feelings with a general comment about how people with disabilities are treated.

*...[S]ome people with disabilities they end up having their children taken away. And with me, I'm having problems with Betty. They seem to just pick on certain people all the time and I think it's not right.*

Ginger is questioning whether she and other parents with disabilities are treated fairly. She is aware of the risk of losing Betty if there are problems. This awareness seems to stem from the constant reminders she receives from human service workers and from what she hears “through the grapevine.” Because of these reminders, she knows she has to adjust her behavior to meet the larger society’s expectations or she may lose what she loves the most...Betty.

**Maintaining Social Control**

**Hearing through the Grapevines**

Hearing through the grapevine appears to be one way that social control is maintained.
It's like poor Helen - She had her little girl taken away and she can only see it maybe ... only a couple of hours a week ... And then another person, she's not really a friend either, but through the grapevines I heard she ended up having her little girl taken away too.

Ginger seems to keep abreast of what happens to other parents with disabilities. This is yet another reminder for her of what could happen if societal expectations around parenting are not met. Ginger states:

*S sometimes it's like I'm lucky that I have Betty around even though she had so many problems at the beginning.*

In the back of Ginger’s mind she realizes that there is a risk that she could lose Betty too. Not only does she hear what has happened to other families, but she has also been warned that Betty could be taken away.

Hearing through the grapevines was not the only way social control was maintained. It became evident from parent’s experiences that various strategies were used by human service workers to maintain social control. These strategies involved the use of coercion, power, control and blame.

**Coercive Interventions**

In many instances parents were informed that they would lose something important to them if they did not follow through with human service workers recommendations. They were coerced or forced into accepting service or changing some aspect of their behavior.
Last year Betty was very, very tiny. She still is, but they were going to take - someone was going to call up some kind of thing so then Betty would be taken away and life skills and family support jumped right in which was good... I had to get warmer clothes for Betty and start thinking much more ahead than I was.

In this example, support was enlisted to ensure that Ginger was dressing Betty in warmer clothing. Ginger felt she had to demonstrate that she could think ahead and dress Betty properly or else she would lose Betty to the authorities. Jesse relays a similar experience.

... [A]ny little thing we do she has to know about it... For an example, if we run out of food for our little one she has to make a huge statement about it like, “Don’t ever let it happen again!” She threatened us a few times to take him away.

In this example Jesse feels that he must not only resolve the identified problem but he also has to ensure that it never happens again or Bill could be apprehended. Jesse later provides the following comment about his relationship with the agency that coordinates his service.

Either have all these workers or you lose everything. It’s like being... really rich you know. Either do this or you’ll be cut off.

Jesse feels he has to conduct himself accordingly in order for the family to remain together. He must accept all the help that is offered and he must correct any
problems that have been identified. He uses the word “pressured” to describe how his service has changed since the birth of the baby.

...[w]e’re actually being more pressured.

This feeling of pressure seems to stem from being threatened and controlled. Parents frequently reported that they were given no choice or say in important life matters.

Power and Control

Power and control were used, for example, to ensure that parenting courses were attended, money was spent appropriately, children were well clothed and fed and medical concerns were addressed.

Jesse felt he didn’t have a say in whether to participate in a parenting course or not.

...[b]efore I knew it, I was in this program. I didn’t have a chance to say, “well, can we think about this”... Before we knew it, we were in there... I didn’t have a chance to sit down and go, “hm, I’d like to really look at this place and take a tour. They didn’t give me a proper tour at all. Just bang - you’re in it whether you like it or not.

He also felt he didn’t have a say in how his money was distributed.

... for some reason we kept running out of stuff like baby formula and so it was turned around that we got a hundred and twenty-five dollar voucher and a fifty dollar cheque.
Ginger expressed these feelings about Betty’s clothing.

... and I have to double layer Betty’s clothes in the winter too and I only put two layers on Betty which is good so then I have no problems with them on my back now.

When parents talked about their experiences with human service workers they often reported feeling watched and checked upon.

The doctors were checking up on me almost every week or every month. Sarah had to come in for six months and its like, “No way - I don’t want nobody to come in. I can do this on my own. Sarah would come around eight o’clock in the morning [everyday of the week except Saturday and Sunday] and stayed until eight-thirty and just watched me with Betty.

George says,

They’d see if Donna’s okay. Check her out and see if she’s okay.

Jesse expressed how it feels to be controlled with this powerful statement.

The only supervision I’ve ever had was my family. But I’ve never had people looking at us like we’re tiny specks in magnifying glasses or in... microscopes. They look at us like, oh... that bug needs help you know. We’re looked on all the time. We can’t make any moves. I feel we have to get permission even to go outside.

Being observed like “tiny specks in microscopes” was not without purpose. Jesse states:
They're always on us about something... [t]he social worker we have now her mind is all baby. If something happens to our little boy we pay the penalty. We pay the price. We pay for his damage.

It is evident from Jesse's comment that he feels he never gets a break. He knows that if he doesn't tow the line, he will "pay the price."

If we step out of line or something [the social worker] is ready to take [our son].

It appears that when events in these parents' lives took a downward turn, they got the blame.

Blame the Victim

The blaming the victim strategy whether engaged in consciously or unconsciously, puts the responsibility for change solely on the individual rather than on society as a whole. Blaming the victim maintains social control as well as the status quo. It is the victim who is at fault and must adjust his or her behavior to meet middle class standards. Unemployment, low income, substandard living conditions, limited access to resources and discrimination are not factored into the overall equation.

Jesse describes how he was blamed when he went to his social worker for help.

Before we moved I didn't have very many patience when our little boy started crying and... he didn't want to be fed or changed or played with... I got very
frustrated and I hit him and... that shouldn’t have happened, but I went to my social worker and she was proud that I did that - that I went to her, but she questioned me and said “why did I do that? What possessed me to do that?”

Ginger also talks about how she has been judged for the wrong reasons.

... I am always trying to do what’s best for Betty and sometimes people are judging you for the wrong reason... And it’s like, “lay off. I don’t want you in my life.”

As can be seen from this example, human service workers, at times, created difficulties for parents which resulted in negative spin-offs i.e., parents not wanting service providers in their lives. Ginger adds how being blamed has affected her.

I ended up crying for the first little while then I started talking to my... Mom. My mom just sort of said, “humph.” She shrugged her shoulders and... she just started not screaming but telling me that I have to... be better... make everything work out right.

Blaming the victim leads to parents blaming themselves.

Victims Blaming Themselves

The external blame parents experienced was internalized. Ginger talked about how she felt when she received a complaint from human service workers.

It made me feel like I’m not a good mother and... I am trying... I am no good and worthless... that’s it... It can be fixed up - I just have to work at it.
Ginger blames herself. She sees herself as "no good" and "worthless." She feels she needs to try harder to be a 'good mother.'

Jesse talks about the importance of having a job and his own money so that he can buy what he wants for his son and partner. He describes what he feels he needs to do to succeed at work.

*All I'd have to be is motivated and know what I'm doing and how hard I'm suppose to work and not dawdling.*

The parents interviewed for this study blamed themselves; they felt they needed to work harder to become good parents or to succeed at work even though they were faced with such obstacles as low income, substandard living conditions, discrimination and limited education.

In addition to these obstacles, parents' behavior was continually monitored to ensure it met 'acceptable' standards. If it was decided that the 'standard' was not being met, such tactics as coercion, control and power were used. This led to parents feeling hopeless and powerless to change their situation.

**Powerlessness**

Powerlessness was demonstrated by parents' apparent apathy and passivity concerning their lives. In the following example Jesse talks about how he keeps quiet if he disagrees with what service providers are proposing.

... *I don't say, "look... it's our baby"... because I don't want to start a big, a big argument over it... I don't say anything because it would start a big fight.*
Ginger provides an example of what happens if she is not home in time for her homemaker’s appointment.

I’ve left my cleaning lady... without remembering to come home and she gets mad at me. She just says “Ginger... you have to be here or else the Ministry won’t pay for cleaning up, helping you clean up...” So it’s like, I’m here.

She also talks about how she comes to accept certain services even though she feels she does not need them.

They would always put words in my mouth and say you need it. And it’s like, I don’t need it.

These examples seem to illustrate that there were times when parents did not see eye to eye with human service workers, but they went along with the service plan anyway. In these instances, they felt they had no choice or were afraid of what might happen if they refused.

Parents also seemed to feel that no matter how hard they tried to be ‘better’ parents, they were in a hopeless situation. Jesse explains:

Well... I think our social worker is ready for us to do something really bad, like beat Bill up or something.

Ginger also states:

If Betty has a black eye they’d probably think I punched her or something. They would not think of a chair being in the way.

Both Jesse and Ginger felt human service workers would not give them the benefit of the doubt should something happen to Bill or Betty.
It seems that the parents interviewed for this study were in a no-win situation. They had limited options and choices over what services they wanted and they had the perception that human service workers were waiting in the wings for them to make a mistake. To make matters more complicated, they were unsure about whether human service workers would believe them should something happen to their children. Considering all of these factors, parents had no choice but to adjust or adapt to their situation.

**Adapting: Parents’ Survival Tactics**

Parents had to find some way of dealing with a seemingly hopeless situation. Some of the ways they dealt with the demands of human service workers ranged from altering the events in their day to ignoring events that they felt they were powerless to influence or change.

For instance, Jesse talks about how he adjusts his schedule to accommodate human service workers.

... *I know this person’s coming I can’t go anywhere. I have to wait for em... but, I can do other things. I can watch a movie or clean house or something until they come... We have to set [aside] whatever project we’re working on and we have to deal with that person and then that person leaves we can go back to whatever we’re doing.*

Ginger handles the demands of human service workers in a different manner.
Sometimes if my company is here sometimes I don’t even tell that I’m not around. I will be with [my company] and they have to track me.

In this example, Ginger decides to do what she wants anyway and waits for the consequence of being tracked down. It seems she decides to take the risk because the consequences are not too severe.

One parent also reported using his or her disability to buy some freedom.

*If I say I forgot [the appointment], they believe me.*

**Summary**

These findings seem to suggest that parents recognized that they required some formal support to manage their daily affairs. The support parents seemed to welcome consisted of such things as practical support in crisis situations, support aimed at alleviating worry, and the experience of companionship that ensued from the helping relationship. At times, however, the support reflected a social control function which parents found unhelpful.

Social Control appeared to be maintained through various mechanisms leading parents to experience a sense of powerlessness over their situations. Some control seemed to be regained, however, through the use of certain survival tactics.
Chapter 4

Under the Microscope

To gain a deeper understanding of what is reflected in the findings of this study, it is necessary to consult some of the work that has been done in the field of child welfare, radical social work and disabilities. These particular resources have been selected because they analyze problems from a structuralist viewpoint. They also demonstrate how problems tend to be viewed by helpers as being caused by individual inadequacies rather than how our society is constructed.

This chapter will attempt to use the literature to show how elements of the larger society are reproduced in human service work. Hopefully, this approach will help to shed some light on why parents with intellectual disabilities reported many negative experiences in their dealings with human service workers.

One of the reasons why the parents interviewed for this study may have reported these negative experiences in their interactions with human service workers is because there is no clear definition on the meaning of adequate parenting. For example, Espe-Sherwindt and Crable (1993) state that “perhaps the greatest difficulty facing parents with mental retardation is that society has not come to a consensus on what is meant by adequate parenting” (p. 158). They add that this lack of consensus poses additional problems for people with intellectual disabilities because there is a risk that they will be judged according to a variety
of standards depending on the different professionals they are involved with at any given time. What is particularly disconcerting about this is that the criteria that parents seem to be evaluated against reflect what the larger society views as ‘good parenting.’ More specifically, parents are judged on their ability to parent according to middle-class standards. For instance, Armitage (1993) states, “the concept of ‘neglect’ is used to indicate child care that does not accord with middle-class standards” (p. 39).

Swift (1995), who does research in the area of child neglect, shows that child welfare workers’ assessments of parents can be influenced by the larger society. Furthermore, she points out that this is often done unknowingly because child welfare workers, like all human service workers, are part and parcel of the society in which they live. To further illustrate her point, Swift makes some interesting observations about parenting discourse and how it can affect the way in which parenting is evaluated. One of the examples she uses to form her argument involves the critical analysis of parenting magazines. Swift observes that the advice given in parenting magazines is geared mainly toward the stereotypical family comprised of mom, dad and the two children. The magazines, she notes, also often make assumptions that mom is trying to juggle both career and homemaking responsibilities. She states that the advertisements in these magazines depict mothers as primarily “white, young, well cared for, alert, attentive, attractive woman” (p. 106). She then suggests that it is against these kinds of standards that parents are evaluated. Her research provides examples of
notes written in child welfare files about mothers whose personal appearances and character traits are described as diametrically different to the women portrayed in these magazines. For example, “mom has dirty blonde hair and protruding teeth. She is tense, weepy, possibly having a low IQ” (p.108).

In this example, the mother’s physical appearance as well as her presumed low intellectual functioning are tied to her ability or inability to parent. According to Swift (1995) this is not a new phenomenon as this kind of discrimination frequently appeared in child welfare file recordings in the 1930s when concerns about the feeble-minded had escalated.

What is apparent from these examples is how decisions can be made and justified about a person’s ability to parent based on ‘how they look,’ ‘how smart they appear’, or how ‘emotionally together’ they seem. What is problematic about this is that these arbitrary standards are based on what the larger society defines as the requisites or even the prerequisites for ‘good parenting’. In fact, Hayman (1990) argues that “class and cultural biases” are exacerbated when parents appear to be mentally handicapped because their behaviors tend to be compared to the “norm” (p. 1228). He suggests that cases where parents with mental handicaps have had their children apprehended soon after birth reflect this bias. These children, he argues, have been removed on the belief that they are mentally incapable of parenting. They have not been given the chance to show whether they can or cannot parent. In addition to needing the prerequisite of intelligence to parent, it appears that parents must be able to prove that they can fulfill certain
parenting obligations. For instance, Hayman points out that there are several areas upon which parents seem to be evaluated. These areas include, meeting the child’s physical and emotional needs, ensuring the child is intellectually stimulated, and preserving the child’s “health and safety.” As Callahan (1993) explains, “parents, usually mothers, are judged largely on the visible aspects of their work, the children’s health, clothing, behavior, etc” (p. 80).

These “visible” standards require money and resources to uphold. Perhaps this is why Armitage (1993) defines neglect as “child care that does not accord with middle-class standards” (p. 39). It is primarily the poor and other minority groups that are accused of neglect (Swift, 1995). Furthermore, if one of these parenting standards is identified as not meeting societal expectations this justifies a visit from child welfare authorities (Swift, 1995). Once child welfare is involved parents are subjected “to ongoing scrutiny and criticism” while the children remain in the home (Swift, 1995, p. 123). In addition, the human service workers enlisted to assist these parents play a dual role (Swift, 1995). They are both helpers as well as “scrutineers” to use Swift’s word. Therefore, helpers not only assist parents to change the undesirable behaviors that have been targeted, but they also supervise and monitor parents’ progress, reporting any further parenting deficiencies to the authorities (Swift, 1995). Swift adds that this is often how child welfare workers justify keeping children in questionable circumstances.

From the perspective of the parents with mild intellectual disabilities that were interviewed for this study, this type of surveillance occurred even before they
failed to meet one of these parenting obligations. The parents who were all receiving voluntary support services noted that after children came on to the scene the number of voluntary services they were getting increased whether they needed them or not. Their lives became chaotic. They were invaded, supervised, watched and checked up on. In short, they lived life under the microscope as illustrated by this parent’s comment: “The only supervision I’ve ever had was my family, but I’ve never had people looking at us like we’re tiny specks in magnifying glasses or microscopes. They look at us like, ‘Oh, okay, that bug needs help’.” This is yet another example of how “class and cultural biases” (Hayman, 1990) are compounded when mental handicap is added to the parenting equation. The parents in this study, because of their intellectual disabilities, were over serviced to the extent that their lives were not their own anymore. They were judged according to how they spent their money, how much food they had in the refrigerator, who baby-sat for them, how their children were dressed and whether they were feeding their children a ‘proper’ diet. Booth and Booth (1994b) noted similar examples in their book Parenting Under Pressure: Mothers and Fathers with Learning Difficulties. One parent that they interviewed, who was receiving statutory services, saw human service workers as a source of interference as illustrated by the following comment: “I just want them to leave me alone, let me get on with my life. I don’t want anybody telling us what to do” (p.57).

Galper (1975) observes that this type of behavioral control seems to go hand in hand with receiving social services. He states:
In all programs, a variety of notions about the ways in which people are expected to behave are structured into the rules and regulations. It is very difficult to think of any social service which is available to people simply as a consequence of their human existence. (p.52).

He adds that welfare regulations have been used to alter clients' behavior and keep it in line with conservative values. In addition he notes that all aspects of people's lives seem to be regulated including their sexual conduct, work ethic and household budgeting. Galper's observations resemble what parents experienced in this study. As noted earlier, parents were told what parenting classes to attend, what qualities their baby-sitter should have, what type of home was suitable and how to spend their money. As noted above, one parent reported the following:

We used to get a hundred and twenty-five dollar baby cheque. It was only for Bill, for our little boy. Well the worker claimed that Jasmine was spending it on her own, for herself which was not true. She was buying the baby accessories, diapers, food, whatever he needed. And I was really disappointed with her because she didn't believe that. She thought that Jasmine was spending it for herself, so she fixed it so we'd have one voucher and one cheque while the rest of the people out there get four or five hundred dollar cheques and they can do whatever they want with.

This example illustrates how this parent's behavior was altered to meet societal expectations. He was given a food voucher to ensure that part of his welfare cheque would be spent on food. It is important to note that all the examples cited by the parents in this study, where behavioral or social control was exercised, involved the "visible" (Callahan, 1993) work of parenting.

In fact Hayman (1990) observes that love is considered to be unimportant in the overall parenting equation.

Love is not insignificant; it is, as many children know, not that easy to come by. When the courts insist that "love" is not enough, they speak in the voice of
reason. But that voice may not know love; it may reduce love to sentimental visions. (Hayman, 1990, p. 1263).

This apparent over emphasis on the part of human service workers and other decision makers regarding the "visible aspects" (Callahan, 1993) of parenting while minimizing other factors such as love and socio-economic circumstances is reflected in a study by Walton-Allen and Feldman (1991). They asked twenty-two mothers with mental handicaps about their service needs. The mothers' answers were then compared to their social service workers' answers who were also asked to identify what services they felt these mothers needed. The areas of investigation included child care and domestic responsibilities as well as psychological skills. Under the category of child care was "child safety, hygiene, development, discipline, stimulation [and] medical emergencies" (p. 141). Domestic responsibilities included "budgeting, food preparation, cleaning, shopping [and] nutrition" (p. 141). Psychological skills involved "vocational, assertiveness, personal relationships, access to community resources, communication, leisure [and] friendships" (p. 141). The study concluded that social service providers felt mothers with mental handicaps needed more services than they were getting while the mothers felt they were being over serviced in the area of child care skills. In addition, this study found that workers believed that mothers with intellectual disabilities were rating their child care abilities too high. These findings are similar to what the parents in this study said about their own situations. For instance, they reported that after their children were born the
voluntary services they received increased. In some cases they were provided with services they felt they did not need, but were told that they needed. These services were provided to ensure parents were attending to their children’s health, diet and clothing requirements.

Walton-Allen and Feldman’s (1991) research as well as this research seems to reinforce that the “visible aspects” (Callahan, 1993) of parenting are given the priority by social service personnel working with parents with intellectual disabilities. Socio-economic factors, it seems, are not considered to be part of the parenting equation. For instance, it is difficult for parents with low income and limited access to resources to be able to meet what the larger society expects in terms of parenting. Therefore, it appears that some parents are further victimized when the solution becomes to watch their every move to ensure that they are fulfilling their parenting obligations. Also, it seems when the “visible” work of parenting becomes the focus for change it is easy to blame individuals for not satisfactorily following through with the work. The individual, not society becomes the target for change. (Fook, 1993).

This “blame the victim” (Ryan, 1971) philosophy or “deficiency perspective” (Booth & Booth, 1994b) attributes people’s problems to their own limitations and incompetence (p. 81). The parents in this study expressed time and time again that they were blamed for their parenting difficulties. One parent stated that she was trying her best to be a good parent, but was continually blamed for the wrong reasons. One example she provided was that she had received a complaint about
her daughter's lunches from the daycare staff. The staff at her daughter’s daycare felt the lunches were not nutritious because a fruit was not included. This was upsetting to this parent, first, because the daycare did not communicate their concern to her directly and; second, because she did not get an opportunity to explain that her daughter could not digest fruits due to health reasons. Booth and Booth (1994b) also reported in their study that some parents with intellectual disabilities felt they were continually criticized, and were fearful that their children would be apprehended if they did not meet certain parenting standards set by the authorities. A relative of one of the parents in Booth and Booth’s study commented: “Sometimes they say to her, ‘Your baby’s not clean enough. If you don’t clean him up, we’ll have to take him off you’” (p.57).

Mullaly (1993) observes that social problems viewed in terms of individual weaknesses and deficits result in interventions that are controlling and coercive. He adds, “because the nature of human beings is viewed as contentious, competitive and self-absorbed, then social work must use coercive measures to make sure people look after themselves” (p. 59). Interestingly all the parents in this study reported experiencing coercive interventions. The most extreme form used was the threat of involving the child protection authorities if identified problems were not resolved.

Mullaly (1993) notes that this method of defining and intervening in social problems stems from the “order perspective” which “dominates North American social thought” (p.134). He states that order theory maintains that all people in
society agree with the values and the rules that govern society. He adds that this shared agreement about how society should operate dictates what behaviors are acceptable and unacceptable. For example, he says that if people do not conduct themselves in a manner that is expected of them, then assumptions are made indicating that something went awry with their socialization and rehabilitation is warranted. He then notes:

If society's official agents such as teachers, social workers or police fail to correct or control the malfunctioning or out-of-step person, then she or he may have to be removed from society and the individual's behavior neutralized by institutionalization. This removes a threat to social stability and also serves as an example to other would-be non-conformists and deviants. (Mullaly, 1993, p. 135).

Order theory reflects the parents' experiences in this study. First, parents are expected to adhere to certain parenting standards which seems to include a certain level of intelligence. Second, when the parenting standards are perceived to be inadequate, social services are provided to correct the identified problems. Over time, if the problems are not remedied threats are given and sometimes carried out. Other parents in similar situations then hear about these threats and the negative outcomes that can result which further reinforces the importance of complying with human service worker requests. For example, as noted in chapter three, one parent in this study spoke at length about how she kept track of which parents in the intellectually disabled community had their children apprehended. She referred to this process as "hearing through the grapevines." This process in
itself reinforced for her that her child could be taken away too if she failed to follow through with human service workers' recommendations.

Furthermore, this mother expressed feeling a sense of powerlessness or hopelessness about her situation. She felt compelled to go along with service recommendations even though she did not agree with some of the suggestions because she was afraid of what might happen if she refused. She was also afraid that she might be blamed for events that were out of her control. These feelings of powerlessness led parents to develop unique strategies to deal with the demands of human service workers. It is interesting to note that Mullaly (1993) explains the behavior of people who are poor in terms of the strategies that they must develop to deal with poverty. For instance, he states that “the cycle of poverty theory” attributes such traits as apathy and dependency among the poor to a dysfunctional socialization process. He then adds that “no thought is given to the possibility that many of these so-called traits of poor people are actually adaptations and adjustments on the part of the poor to cope with poverty rather than actual causes of poverty” (p. 137). In other words, he is suggesting that poor people have developed strategies to deal with being poor. They are not poor because they are apathetic or dependent.

This idea can also be applied to the parents in this study. It seems reasonable to suggest that these parents developed the strategies of ignoring unreasonable human service worker requests, and using their disabilities to buy some personal space as a means to cope with human service worker demands. The concern that
arises due to the adoption of these strategies or survival tactics by parents with intellectual disabilities is that, they may not receive the support that both they and their children may need. In fact, it has been reported that some parents have had such negative experiences with service agencies that they avoided them, thereby “cutting themselves off from potential sources of support or help in crises” (Booth & Booth 1994a, p. 31). Perhaps this can also be one way of looking at Verna Vaudreuil’s situation in the widely publicized child abuse case in British Columbia, involving five year old Matthew Vaudreuil which resulted in the Gove Inquiry (Gove, 1995).

In the Gove Report an incident was cited which indicated that Verna’s support was reduced because she was overwhelmed by all of the assistance. In addition, two incidents were cited where social workers’ denied Verna’s request for Matthew to be taken into care on a temporary basis because they felt she was using the Ministry services to shirk her parenting responsibilities. There were also examples noted where services were terminated because she was not cooperating. These incidents provide an example of how social service agencies sometimes regulate clients’ behavior to ensure it meets society’s expectations. In fact, it appears, that there is a general understanding that institutions will provide this function. Furthermore, it seems apparent from these examples and this study that parents may not seek the help they may need because of such negative experiences with human service workers.
Espe-Sherwindt and Crable (1993) note that “the attitudes of professionals may be the key piece of the puzzle of success for parents with mental retardation” (p. 171). Because the attitudes of human service workers are important to the success of parents with intellectual disabilities, an understanding of the larger society and how it shapes our attitudes, values and practices including the way in which we define, construct and resolve problems is needed. Without this awareness, human service workers may continue to unknowingly reproduce the inequalities that exist in society by unknowingly engaging in unhelpful interventions.
Chapter 5

Conclusions

Overall, four main findings emerged from this exploratory study. First, the parents with intellectual disabilities in this study all recognized that they required some sort of formal support due to the nature of their disability. The sources of support they considered to be most valuable included such things as practical assistance in crisis situations, practical help to manage such day to day activities as finances and shopping, and practical support to alleviate worry. Interestingly, one positive spin-off identified to receiving formal support services was the company or companionship ensuing from the helping interaction.

The second major finding indicates that formal support was not always delivered according to parents' wishes, particularly after children came on to the scene. In fact, human service workers were more likely to be viewed as social control officers. Parents reported feeling watched, checked up on, invaded, supervised and told what to do. The areas of their lives reportedly affected included everything from the use of their spare time to child care responsibilities. Galper's (1975) work seems to support these conclusions. Although he does not use the term social control, he suggests that behavioral control often goes along with receiving social services. He states that all aspects of people's lives often become regulated once they are in the welfare system including their sexual conduct, work ethic and how they budget their money. Booth and Booth (1994b)
who interviewed parents with intellectual disabilities, all of whom were receiving statutory services, also found that parents recognized a need for support, but frequently complained about how this support was delivered. One parent that they interviewed saw the services that they were getting as a source of interference. Unlike the participants in Booth and Booth’s study, however, the parents interviewed for this study received only voluntary services and yet they experienced a tremendous amount of interference and social control. One parent equated receiving voluntary formal support services with living life under a microscope.

Thirdly, it became apparent from parents’ experiences, that social control was maintained through various mechanisms. These involved hearing through the grapevine, coercion, power and control, blaming the victim and the victims blaming themselves.

Hearing through the grapevine refers to the process of keeping watch on whose children in the intellectually disabled community have been apprehended by the authorities. Hearing how other parents with intellectual disabilities had lost their children seemed to reinforce, for these parents, how it could also happen to them if their parenting skills were perceived to be inadequate. This experience of hearing through the grapevine resembles the way in which Mullaly (1993) describes how people’s behavior is regulated according to order theory. The difference in order theory, however, is that people’s behavior is kept in line by the possible threat of incarceration if societal expectations are not met. In this study,
parents' made an effort to comply with human service requests because of the possible threat that their children could be taken away if their parenting skills were judged to be inadequate. They tried their best to be 'good parents' because they saw what happened to those parents who did not meet the prescribed parenting standard.

Coercion was used as another method to ensure parents met their parenting obligations. These kinds of interventions involved the direct use of threats. The most extreme form of coercion identified was workers threatening to report parents to the authorities if parenting was inadequate or if the negative behaviors targeted for change were not up to standard. The behaviors that were targeted for change by human service workers, in this study, included such things as how parents' spent their money, how they dressed and disciplined their children and whether they fed their children a 'proper' diet. Callahan's work (1993) supports these findings. She explains that it is primarily the "visible aspects" of parenting (which is what the parents' examples in this study illustrate) that are often judged as inadequate. Swift (1995) also agrees that parents are judged on their ability to fulfill certain parenting tasks which include the more observable parenting functions described above. Swift notes that if these tasks are not carried out, this often results in a visit from child welfare workers. It is interesting to note that the parents interviewed for this study indicated that they had received threats that their children would be removed if they did not fulfill one or more of their parenting obligations. Coercion was also applied to ensure, for instance, that
parents showed up for appointments. The threat in these cases became the loss of service.

Another strategy employed as a social control mechanism was power and control. It was used to ensure parents complied with workers' expectations. Parents described how they had little choice or say in matters regarding what services to access. They complied with workers' requests because they were afraid of what might happen if they refused.

Blaming the victim and victims blaming themselves were other ways in which social control was maintained. Parents in this study cited many examples where they felt that they had been blamed for the wrong reasons. Booth and Booth (1994b) noted similar findings in their study. They found that some parents with intellectual disabilities were criticized by the people that were supposed to be assisting them. They also found that some parents were fearful that their children might be apprehended. It is interesting to note that the parents in this study, who were all receiving voluntary services, and the parents in Booth's and Booth's study, who were all receiving some type of compulsory service, cited similar examples. It seems the parents in this study may have had similar experiences to the parents in Booth's and Booth's study because they, in fact, experienced their voluntary services as involuntary.

The blame the victim strategy described above led to parents blaming themselves. Parents seemed to internalize this external blame which resulted in them placing the blame for their difficulties on themselves. They felt that if they
tried harder they might succeed at being ‘good parents’. On the other hand, they also seemed to feel a sense of hopelessness about their situations because they felt they might be blamed for parenting difficulties that were out of their control. They also expressed a sense of powerlessness or hopelessness about their situations because they felt they had to accept all the formal support offered. If they refused support they were fearful that they could lose their children to the authorities.

This leads to the fourth interesting finding. Parents seemed to invent ways to deal with a seemingly hopeless situation because they felt they had little control over the services they received. They kept quiet, silently ignoring unreasonable demands, they altered the events in their day to accommodate human service workers, they used their disability as an excuse to forget appointments to obtain some personal freedom, or they did what they wanted anyway providing that the consequences were not too severe.

The adoption of such strategies to deal with the demands of human service workers raises the issue of whether parents will receive the support they may require to meet both their needs as well as their children’s needs. There is a risk that some parents may find the service system so demanding that they develop ways to avoid it in order to cope. As noted earlier, some parents have had such negative experiences with service agencies that they avoided them thereby “cutting themselves off from potential sources of support or help in crisis” (Booth & Booth, 1994a, p. 31). And because it has been reported that support is an important factor in keeping parents with intellectual disabilities and their families
together (Booth & Booth, 1994a; Espe-Sherwindt & Crable, 1993), it is important to hear from parents about their experiences concerning the support they are receiving. In addition, it is important to ensure that parents feel comfortable with the support they are getting so that they may access it when they choose.

**Limitations of the Study**

These findings must be interpreted in light of the following considerations. First, three parents were interviewed for this study. They all came from the same geographical area and their services were coordinated through the same office. In addition, because there was such a small number of parents to select for participation in this study, and because some parents declined to be interviewed, the interviewees were not chosen based on varying characteristics which is recommended when using the grounded theory methodology. For example, all of the parents participating in this study had one child under five years of age. They could all read and, at the time of the study, they all had partners. The parents' ages, however, ranged from the late twenties to the early forties. Ideally, with the grounded theory approach it would have been better to also select participants with more than one child. Furthermore, participants selected from different geographical locations and Ministry offices could have been interviewed as well as single parents and so forth. Therefore, these findings are limited to those parents with intellectual disabilities receiving service through the same office and displaying similar characteristics to the parents interviewed for the study.
A second factor for consideration is that no formal documentation was obtained regarding participants' IQs and adaptive functioning. Therefore, it is possible that the parents interviewed for this study had IQs ranging from borderline to mildly mentally handicapped. Consent was obtained to review files to collect this information, but a decision was made not to consult the files based on one participant's concern about trust and privacy issues.

A third factor that needs to be addressed is the use of in-depth interviewing as a data collection method. This method of data collection has rarely been used with people having intellectual disabilities. Booth and Booth (1994b) suggest that perhaps one of the reasons for this is that researchers assume "that the subjects in this kind of study should be fairly articulate, able to verbalize and have a story to tell" (p. 23).

Researchers using in-depth interviews as a means of data collection with participants that have intellectual disabilities seem to agree, however, that open-ended questions can be used successfully with participants who have moderate to mild mental handicaps, providing that the questions are simply phrased (Flynn, 1986, p. 371).

Booth and Booth (1994b) conducted in-depth interviews to learn about parents with intellectual disabilities child rearing and parenthood experiences and they report that participants often answered questions with a word, a phrase or a sentence. They further state, however, that this did not pose a problem in terms of participants telling about their experiences. Of the three participants interviewed
for this study, one respondent answered questions with a word or short sentence while the other two expressed themselves quite fluidly.

Suggestions for Future Research

It is evident that there needs to be more opportunities for parents with intellectual disabilities to evaluate the services they are receiving. They also need to be given the chance to provide input into what services they would find the most beneficial and how they would like those services to be delivered. In addition, it also seems apparent from the findings of this study and Swift's (1995) research that more work is needed in the area of societal influences on human service work practice.

One piece of research that could be done to address some of the above issues would involve educating human service workers concerning the larger society and how it influences human service practice with parents with intellectual disabilities. This education could lead to human service workers becoming more critical of their practice and the interventions they engage in. It could also change the nature of their interventions with parents which could have the effect of altering parents’ perceptions of workers. This research could be done in the form of a comparative study. For example, parents could be asked to talk about their experiences with human service workers both before and after the human service worker education and then parents’ responses could be analyzed for differences.

Furthermore, it would be interesting to apply the theoretical framework that was developed from the parents’ responses in this study to child abuse cases.
involving parents with intellectual disabilities. For example, one recent child
abuse case that was widely publicized in British Columbia that could be examined
is Verna Vaudreuil's (Gove, 1995). This research could possibly lead to a deeper
understanding of the factors that contributed to Matthew Vaudreuil’s death.
Verna’s story might also help to shed light on some of the societal problems that
contributed to her tragic situation. Booth and Booth (1994b) agree that hearing the
stories or experiences of parents “reveal[s] how their lives are shaped by the wider
society and throw[s] light on the network of social relations to which they belong”
(p.24). More of these stories need to be told. This is one way that we will begin to
understand the impact that human service workers have on the lives of parents
with intellectual disabilities.
References


