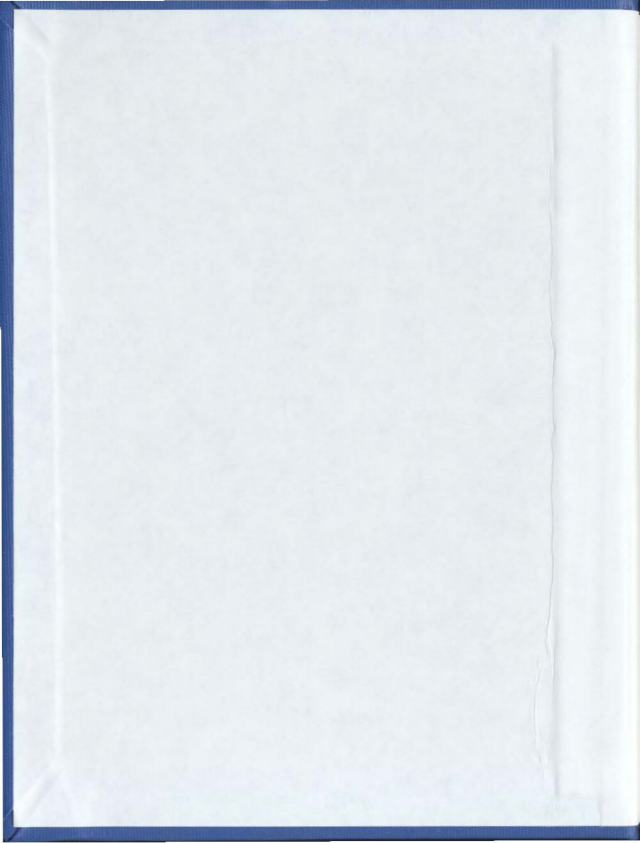NOT SO GOOD, NOT SO BAD
AN ETHNOGRAPHIC STUDY OF THE LIVES OF FORMER
RESIDENTS OF EXON HOUSE FOLLOWING
DEINSTITUTIONALIZATION

ALLAN FRANCIS CORBETT

NOT SO GOOD, NOT SO BAD

An Ethnographic Study Of the Lives of Former
Residents of Exon House following
Deinstitutionalization

by
Allan Francis Corbett

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Department of Sociology Faculty of Arts
Memorial University of Newfoundland

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ABSTRACT

Deinstitutionalization has been a policy of governments throughout North America for many years. The policies were supported by advocacy groups and by persons who lived in the institutions. The government of Newfoundland closed two institutions, Children's Home in 1983 and Exon House in 1988. The research in this thesis was conducted in an ethnographic model using semi-structured interviews with thirteen former Exon House residents. An important aspect of this research was to allow the voices of the former residents to tell the stories of their lives following deinstitutionalization in Newfoundland. Because normal- ization was an important driving principle behind deinsti- tutionalization, it was utilized to aid in the analysis of the data collected. Four major areas were explored, social linkages, personal autonomy, personal satisfaction and self- concept. The findings from the research indicate that the former residents had few friends that were not in paid relationships, they were not satisfied with family rela- tions, there were limited efforts to teach activities that would enhance autonomy, few worked and many had a strong sense of who they were. The analysis of the data strongly suggests a re-focusing of efforts toward the goals of normalization.

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Introduction

On August 9, 1982 the Honourable Mr. T. V. Hickey
announced that "Institutions have no place in the lives of
mentally retarded people in Newfoundland and Labrador"
(Hickey, 1982, p. 2). This statement marked the official
adoption of a policy of deinstitutionalization for persons
with intellectual disability[1]. For the custodial care of
such persons Newfoundland had two facilities: Exon House
and the Children's Home. Deinstitutionalization in
Newfoundland meant a move of all children currently in
institutions to less restrictive, more developmental living
environments in the community (Hickey, 1982). The study
described in this thesis is designed to explore the impact
of deinstitutionalization on persons with intellectual
disability by examining the life experiences of former
residents of Exon House.

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[1] The term intellectual disability will be used throughout
this text to replace the terms: mental retardation, developmental
disability, developmentally disabled, developmental delay, and
any other similar terms. Such terms will only be used in direct
quotations or to indicate historical context.

Statement of Problem

As a result of deinstitutionalization, persons who lived at Exon House were moved to a variety of other residential alternatives. This thesis explores the impact of that experience on persons with intellectual disability. Residential alternatives were a combination of new options developed by government staff in conjunction with the Canadian Association for Mental Retardation (now the Canadian Association for Community Living) and other residential systems in operation throughout North America. One additional unique aspect of the plan was that it was designed to serve not only the group targeted for deinstitutionalization but also the entire community of persons with intellectual disability. Specialized services were created both in the residential domain and in other direct intervention areas. Available services were enhanced along with the creation of new services to further reduce the demand/necessity for institutionalization.

This research was designed to explore the impact of deinstitutionalization on persons who formerly lived at Exon House. The impact of deinstitutionalization on persons with intellectual disability has been extensively discussed in the literature. Much of the recent work in this area has

been through Quality of Life research and has been conducted through questionnaires and surveys (Schalock, 1990). In pursuing the research for this project, gaps were found in the completeness of data which was collected from particular instruments (eg. QUOLIS, Life Satisfaction Survey). It was not until reviewing the work of Robert Edgerton that the reasons for this gap became evident. Edgerton (1990) asserted that discussions of quality of life for persons living with intellectual disability must include the voices of persons living with those challenges. It is Edgerton's work which helped set my goal that the research project must capture the voices of persons with intellectual disability.

Larson and Lakin (1989) in a review of eleven years of Psychological Abstracts and the ERIC database, as well as eight years of selected journals, Dissertation Abstracts and other sources, analyzed fifty studies which suggested that in terms of the adaptive behaviour of individuals with intellectual disability, institutions appeared to be consistently less effective than community-based settings. Larson and Lakin's research supports the majority consensus in the field that deinstitutionalization has generally provided positive benefits to those affected. Problems with deinstitutionalization can be found but these are generally a result of delivery issues in the community-based services

which have developed to support persons after they have been moved out of institutions. In a research review, Emerson (1985) identified some outcomes which did not benefit persons who had left institutions: they may experience loneliness as a considerable problem; they may interact mainly with other disabled persons and paid staff; they experience little autonomy; they may be excluded from the workforce; and they may not have the typical life experiences of the wider society. While Emerson's research was done in 1985, it still suggests some grave outcomes of deinstitutionalization. My research has been developed to examine if such negative or more positive outcomes are the present experience for former Exon House residents.

Development of custodial institutions for persons with intellectual disability

In 1848 Samuel Gridley Howe opened the first institution for persons with mental retardation in the United States (President's Committee on Mental Retardation [PCMR], 1977). This was the first of many training schools which appear to have been modelled after Jean Itard's work with Victor, the Wild Boy of Aveyron. Edward Sequin, after having studied with Itard, emigrated to the United States. Reports at the time indicated Itard and Sequin were able to

solve the problem of "idiot children" (National Institute on
Mental Retardation [NIMR], 1981). Howe and Sequin worked
together to insist that: training schools be organized on
the plan of a family; education be focused in the early
years; and children with intellectual disability would be
returned to their families (PCMR, 1977). The early devel-
opment of institutions for children with intellectual
disability appears to have stemmed out of a concern for
their education, treatment and training so that they could
return to the mainstream of society (NIMR, 1981). In later
years, Howe became concerned about misdirection of the
training schools. In his final report to the Trustees of
the Massachusetts School for Idiotic Children, in 1874, he
warned that the close congregation of large numbers of
persons with intellectual disability for long periods of
time would tend to make the schools "asylums for life"
(PCMR, 1977). In the years which followed, institutions did
not heed Howe's warning and training schools generally
became custodial institutions.

In Canada, the first institutions housing persons with
developmental challenges were asylums for the insane. After
1860 in Upper Canada persons with intellectual disability
were increasingly diverted to the Orillia Branch Lunatic
Asylum (Simmonds, 1982). By 1870 the building was deemed to

be unsuitable; in 1872 the Asylum for Adult Idiots was opened in London, Ontario (Simmonds,1982). After extensive renovations in 1876, the Orillia facility re-opened as the Asylum for Idiots, and was designed to hold about 155 persons (Simmonds, 1982). One year later it was full and a new building was built to hold 550 persons. At the turn of the century the population at the new Orillia facility was 654 persons (Simmonds, 1982). The speed at which Orillia filled to over-capacity reflected the situation across North America. Simmonds (1982) reviewed contemporary statutes and found the term "lunatic" often subsumed the term "idiot"; thus it was likely that similar treatment was offered to both groups - an asylum.

Institutions in Newfoundland

In Newfoundland the first facility to house persons with intellectual disability was the civilian hospital in St. John's (O'Brien, 1989). O'Brien (1989) tracked references to "idiots" and "defectives" at the health facilities in _Out of Mind, Out of Sight,_ from the first civilian hospital (circa 1813) to the Waterford Hospital, 1972. O'Brien (1989) and Simmonds (1982) indicate a similar process of institutionalization for persons with intel-lectual disability in Newfoundland as in Ontario.

Newfoundland and Labrador opened it's first facility for children with developmental disabilities in 1963. Prior to 1963 there was a facility, Waterford Hall, which held and cared for children awaiting adoption (Annual Report of the Department of Public Welfare, 1963). It appears a number of children with intellectual and physical disabilities also lived there. Exactly how children with disabilities came to live at the infant's home is not entirely clear but one might speculate that some children intended for adoption had handicapping conditions which were only discovered after placement at the infant's home at Waterford Hall. The children with handicapping conditions were likely considered unadoptable and were cared for by the state.

A foster home program established in the 1960's replaced the Waterford Hall infant's home because pre-adoptive babies were placed either in foster homes or receiving homes directly from the maternity hospitals. The action of the Department of Public Welfare to initiate a foster home program to reduce the number of adoptive children in Waterford Hall did not include children with disabilities. In 1963 children with disabilities were moved to Building 1054 at Fort Pepperrell and the facility's name was changed to Children's Home (Annual Report of the Department of Public Welfare, 1963). In August 1964 the

children at the Fort Pepperrell location were moved to the
new Children's Home on Water Street (Annual Report of the
Department of Public Welfare, 1965).

The demand for placements at the Children's Home for
children with handicapping conditions rose quickly. In
March 31,1967 there were 74 children in residence with 90
children waiting for placement (Study of Physically and
Mentally Handicapped Children in Newfoundland and Labrador,
[Study], 1970). In 1967 a special foster home, the Hart
Home, was opened just outside St. John's to accommodate 10
children under three years of age (Study, 1970). The Hart
Home may have been an effort to provide a home-like
residential placement for some infants with disabilities.
Also, the Hart Home would have provided relief to some of
the families with children waiting for placement. The Study
of Physically and Mentally Handicapped Children in
Newfoundland and Labrador (1970) concluded that there was a
need for two residential facilities for children with mental
and physical handicaps. The report also recommended that a
Children's Home be established in a more suitable building
as soon as possible (Study, 1970). Exon House opened in
1969 as a training home for children with intellectual
disability. Children's Home closed on June 30, 1983 with

many of the residents moving into Exon House (Annual Report Department of Social Services, 1984).

Exon House

Exon House was located in a building that had been an Anglican Church orphanage. But orphanages had been gradually phased out by the Department of Public Welfare in favour of foster homes. As an orphanage, the building held: single and double bedrooms, studies complete with fireplaces, and a stage. The orphanage was initially leased and subsequently purchased by government in 1971 to become the new training home for persons with intellectual disability (Annual Report Department of Social Services and Rehabilitation, 1972). Children were placed in Exon House beginning in 1969 after the building was extensively renovated. Fireplaces were covered over, bathing/changing facilities constructed, and 10-12 person dormitories built. The building was officially opened as a training home in August 1971 by then Premier Mr. J. R. Smallwood (Annual Report of the Department of Social Services and Rehabilitation, 1972).

In Exon House's initial years of operation there were several public outcries centering on alleged abuse (Canadian Association for the Mentally Retarded [CAMR], 1977). Seven

employees were dismissed based on allegations of ill-treatment (Doyle, 1973). The Association of Registered Nurses of Newfoundland complained about the way children were handled and expressed concerns over the use of behaviour modification ("Ready for Tom," 1977). Allegations by staff of abuse (CAMR, 1977), a Magisterial Inquiry surrounding a resident's death ("Report on death," 1977), and the charge of rape of a resident by an administrator ("Pleads not guilty," 1977), compelled government to seek expert opinion regarding the facility.

In 1977 the Canadian Association For the Mentally Retarded was invited by the Premier, Mr. Frank Moores, "To undertake an assessment for the purpose of coming to grips with the problems" (CAMR, 1977, p. 1) arising from Exon House. The report, A Report of An Assessment of Exon House and Related Programs (CAMR, 1977), contained many descriptions of life inside Exon House. It also included recommendations to make the facility a better place for the children living there and to develop intervention programs outside the institution. In 1981 a follow-up report was commissioned by the Government of Newfoundland; the Canadian Association for the Mentally Retarded agreed to provide the follow-up study. The authors of the follow-up report,

People and Communities (1981), described the environment at
Exon House as follows:

> The building is a large, three-floor structure that
> resembles a school, not a home, on the outside. On the
> inside, the environment is characterized by heavy gauge
> wire mesh on the windows; locked doors; doors with
> knobs that are over five feet off the floor;
> indestructible plastic furniture; bare and bleak
> floors; chipped and damaged walls; impersonal, cold
> bedrooms with inadequate coverings; a total lack of
> privacy in bath and toilet areas. (Vol. II, p. I-4)

The 1977 Report team summarized its early observations
of Exon House and Children's Home to be "Of a sad and
discouraging situation" (CAMR, 1977, p. 7). Early
observations by the team described sixteen feet square
playrooms without furniture. Each room was supervised by a
staff person sitting with a leg propped across the door so
that no-one would run out and get lost. They described the
playrooms as decorated in a cheerless manner: without
murals or pictures on the walls; windows in a poor state of
repair; and dirty walls and floors (CAMR, 1977). The team
observed that "Up to 20 children at a time might be found in
one of the playrooms" and "That a substantial number of toys
are kept in various cupboards but these were hardly ever

used" (CAMR, 1977, p. 59). These early observations led to
a statement of the team's first impression, as a "General
atmosphere approaching decrepitude" (CAMR, 1977, p. 8). The
report continued to elaborate upon this, observing that
children usually indulged in unstructured and solitary
behaviour which would range from sitting mute, leaning
against the walls, to self-stimulating behaviour such as
banging their head or spinning around endlessly in one spot.
The second major impression of Exon House reported by the
team was the smell. The odour is "Unmistakable to those who
have known it, composed of recent and stale urine, feces,
food residue, and disinfectant" (CAMR, 1977, p. 8).

"During our visit there was a clear lack of training
and direction in each of the components of individual
program planning" (CAMR, 1981, v. 2, p. I-8). The lack of
adequate staff training contributed to the poor care and
developmental atmosphere of the place, "It is small wonder
that the ... assigned program staff developed a disinterest
in disciplining those who persistently crawled up on the
window sill to gaze through the window at the world beyond"
(CAMR, 1977, p. 105). The routines within the building were
characterized by public bathing and toileting; portioning
out meals from trolleys delivered to the four units (wards)
in which the residents lived; use of personal hygiene items

(toothbrushes, deodorant, etc.) by groups of residents; and the mass movement of people from place to place (CAMR, 1981). The movements of the residents were all restricted to the same degree because all of the units were locked. The opportunities to explore the community were restricted since all of the outings were done in groups (CAMR, 1977). "There was inadequate orientation and training and confusion regarding roles and responsibilities" (CAMR, 1981, p. 66).

The report goes on to describe that "Residents are awakened so that morning baths can be done as early as 5:00 AM in order to get through the number of people" (CAMR, 1977, p. 59). Staff were assigned lunch and dinner breaks at the same time as meals for residents, which led to "Rushed and hectic meals for the residents as well as the staff" (CAMR, 1977, p. 59). It was also reported that "There was an inadequate supply of juice and snacks provided on each of the units" (CAMR, 1977, p. 59). The report team summarized the activity patterns, "The routine at Exon House is that of a *hospital model* [italics added]. Even though there have been attempts to move away from that model, they have managed to retain some of the most undesirable features of the hospital-based routine" (CAMR, 1977, p. 65).

Some of the observations of the review team concerned the management of clothing. There were no private clothing lockers. Consequently, the residents did not have clothing that was their own, nor did they participate in the purchase of clothing (CAMR, 1977). It was reported that there was a lack of variety of clothing, lack of appropriate sizes, and an apparent high loss rate for clothing. Clothing was repaired so often as to be undesirable, and there existed a preferential policy of issuing newer clothes to children who were to be visiting outside Exon House (CAMR, 1977). The shortage of diapers was chronic as was the lack of systematic toilet training programs. Staff reported having to tear up good pillow cases and sheets to use as makeshift diapers (CAMR, 1977).

The 1977 report team observed "From the outside Exon House is an acceptable looking building, much of the interior and grounds require attention urgently" (CAMR, 1977, p. 77). The areas observable by the general public as they passed by the building were noted:

> Windows and window frames needed to be repaired, the
> interior of the playrooms and corridors seem to be
> overdue for redecoration. The continuing problem with
> the fence in the yard, where guards have to be placed
> to prevent children from running away, is a minor

disgrace to the Public Service of Newfoundland. So is the fact that the gate to the yard has to be secured by a series of bandages (diapers)! (CAMR, 1977, p. 77)

The team found, "A wall located on a lower living unit had been in a state of partial destruction for six to eight months with no end in sight" (CAMR, 1977, p. 106). They also observed, "Unrepaired windows with broken, jagged glass in them even though at the same time children were using the room" (CAMR, 1977, p. 107). The report team discovered that an emergency telephone number for repairs to plumbing or electrical malfunctions was no longer available necessitating a longer formal request route (CAMR, 1977). Staff expressed profound frustration with these and other problems. After close examination, the review team suggested that, "Carpets on the floor and pictures or murals on the walls, and toys scattered about would lead to an atmosphere in which the comfort and stimulation of children had higher priority" (CAMR, 1977, p. 78).

The 1977 study A Report of An Assessment of Exon House and Related Programs made 50 recommendations mostly related to functions regarding care of the children; one very important recommendation suggested a follow-up report. The review team which conducted the follow-up report in 1981 did not report detailed descriptions of the living environment

at Exon House but focused upon descriptions of the changes that had occurred within the three years since the last report and upon immediate and long-term recommendations. One of the observations made was, "The residents are severely disturbed, the staff are untrained, the physical environment is poor, the management style is unmotivating, and the proper assessments and program systems are lacking" (CAMR, 1981, Vol. 2, p. IV-30).

The recommendations of the 1981 report confirmed the situation found in the 1977 report. There was limited privacy in bathing and toileting activities. Housecoats were not used when residents moved from bathing areas to dressing areas. A staff person reported to the review team that one toothbrush was all that was available for more than 12 residents. Residents were often taken on rides around town in Exon House vans rather than purposeful outings to parks or other places. Many recommendations of the 1977 report had not been implemented. For example, accessible clothing racks for residents or areas accessible to residents for personal possessions were not present. The review team also commented on toilet training procedures that involved using locked bathrooms, bathing in very public places, and joint birthday parties (CAMR, 1981). The team

found considerably more plans on paper than in 1977 but essentially the situation had not changed.

The philosophy or goal of Exon House, likely written after the 1977 study, stated that "It is our responsibility as an educational/developmental centre to provide an environment wide and enriching enough to allow each individual to attain his/her full potential" (CAMR, 1981, Vol. 2, p. I-4). The review team reported that they could find no evidence to believe the philosophy was in practice (CAMR, 1981).

The follow-up study team who wrote People and Communities (1981) found that "Despite the energy and dedication devoted to making changes in Exon House and Children's Home, the situation for those living in them was essentially the same in 1981 as it was in 1977 - desperate" (Kappel and Cawthorpe, 1982). Thus, amid political pressure and public reports, the only alternative remaining was closure. Politically this was an acceptable alternative as it suggested a better quality of care for the residents and ensured the elimination of a major problem for the government. There was the suggestion that after closure services could be maintained at a lesser cost than that of the institution (CAMR, 1981). Thus government had at least

three substantial reasons to support closure: halting the
public outcry; diminishing the responsibility of the
politicians; and increasing the quality of care which the
government likely could do and at a lesser cost.

In 1891 Howe had warned that the congregation of large
numbers of persons might lead training homes to become
asylums for life for persons with intellectual disability.
The author of the 1981 report asserted that " The problems
stem from the very nature of institutions, the congregation
of large numbers of people in a segregated setting (CAMR,
1981, v. 2, p. I-4).

Deinstitutionalization

On August 9, 1982 the government's plan for the
deinstitutionalization of Exon House was released. <u>A Plan
For the Development of Community Living Arrangements and
Related Support Services for Developmentally Delayed Persons
In Newfoundland And Labrador as a Practical Alternative to
Institutionalization</u> (A Plan, 1982) was dated January 1982.
This indicated the process of deinstitutionalization had
been adopted before the release of the plan. The plan laid
out a detailed description of the moral and legal ration-
ales, financial implications, and the necessary continuum of

support services which was to affect dramatically the lives of the people living at Exon House.

The deinstitutionalization of persons with intellectual disability likely benefited from earlier deinstitution- alization efforts for persons with mental illness. Deinsti- tutionalization for persons with mental illness has been defined as a three part process including: depopulation, diversion, and decentralization. Depopulation is the shrinking of residential facilities' rosters; diversion, the deflection of residential admissions to community-based services; and decentralization, the transfer of patient care from single service facilities to multiple service agencies (Bachrach, 1989). The closure of Exon House and Children's Home closely followed this process. As the facilities' management considered closure, admission applications were frozen and alternate supportive services were developed to divert referrals. In addition, many services were removed from the direct control of the Department of Social Services and placed in the hands of community members (such as boards of directors or private agencies).

There was limited opposition to deinstitutionalization in Newfoundland and Labrador. The Newfoundland and Labrador Branch of the Canadian Association for the Mentally Retarded

(and local chapters) advocated normalization principles and supported the policy of deinstitutionalization. Parents may have found it difficult to find support for their concerns from this advocacy association. Family members were subjected to a great deal of anxiety and stress over moving persons from large institutions to smaller facilities. Stress like this peaks at the time of placement and tends to lower after transfer. Heller, Bond and Braddock (1988) speculated that this stress arises from re-living the time of the institutionalization of the family member charged with intellectual disability. This type of conflict has parallels with a problem experienced with some self-help groups which also provide services to constituent members. The organization might be coopted by the established system thereby compromising some of their goals (Aviram, 1990). If this type of stress occurred within the system, then the formal support systems could do little to assist parents who were opposed to deinstitutionalization. Some parents felt compelled to take their concerns and objections directly to newspapers (Callanan, 1986) suggesting that even with the closure of Exon House all was not well.

People were moved into Exon House because it was thought to be beneficial for them. People were later moved out of Exon House based on a policy of deinstitutional-

ization. Moving persons out of the institution and into the
community was believed to be beneficial. The impact of
deinstitutionalization on persons who were moved from Exon
House will be explored in this research project. Having
described the institutional setting and the reasons for
deinstitutionalization in this chapter, Chapter 2 will
include a discussion of literature related to deinstitution-
alization and the life experiences of persons with intellec-
tual disability. Chapter 3 will outline the methodological
approach taken to collect data from the former residents of
Exon House. Chapters 4 and 5 report the data collected from
the study group, as much as possible using the words of the
former residents. The final chapter presents conclusions
from the data.

Chapter 2

Literature Review

Introduction

Dugdale's (1877) <u>The Jukes</u> and Goddard's (1912) <u>The
Kallikak Family</u> (both cited in Scheerenberger, 1983) were
two of the first sociological studies on the subject of
mental retardation. Dugdale's and Goddard's work
strengthened the popular belief in genetic inheritance and
encouraged the view that mental retardation was to be feared
and hidden. The development of psychometrics (the psycho-
logical theory of mental measurement, Websters, 1990) pro-
vided a scientific, numerically based, identification system
for those persons who were intellectually disabled. The
belief in genetic inheritance and the scientific measurement
of the mind allowed professionals and the general public to
accept the condition of mental retardation as scientifically
determined, unchangeable, to be feared, and hidden. The
determination that mental retardation was unchangeable led
to the focus on removing certain citizens from their com-
munities and requiring them to take up residence in
custodial institutions.

There has not been much sociological research on the
lives of people with intellectual disability. Close review

of the literature demonstrates that several sociologists
considered the limits that the label of mental retardation
placed upon such people (Blatt, 1961, 1977; Dexter, 1960;
Mercer, 1973). These authors and others (Bogdan and Taylor,
1987; Ferguson, 1987) argued that mental retardation should
be seen as a social construct rather than a psychometrically
defined condition. Recently, the American Association on
Mental Retardation (AAMR) issued a new definition of mental
retardation which indicated a paradigm shift within the
field. The former definition of the AAMR, developed in
1983, was as follows: "Mental retardation refers to
significantly subaverage general intellectual functioning
resulting in or associated with concurrent impairments in
adaptive behavior and manifested during the developmental
period" (cited in Kidd, 1983 pp. 243-244). The 1983
definition focused upon the individual and the IQ score.
The new definition is:

> Mental retardation refers to substantial limitations in
> present functioning. It is characterized by signif-
> icantly subaverage intellectual functioning, existing
> concurrently with related limitations in two or more of
> the following applicable adaptive skill areas: com-
> munication, self-care, home living, social skills, com-
> munity use, self-direction, health and safety, func-

tional academics, leisure, and work. Mental retard-
ation manifests before age 18. (AAMR, 1992, p. 1)
The new definition broadens the criterion from an emphasis
on a numerically based system of intelligence scores in
favor of understanding the adaptive skills of the person.
The new paradigm assumes as an essential element that mental
retardation is an expression of the functional impact of the
interaction between the person and his environment
(Luckasson and Spitalnik, 1994; Schalock, Stark, Snell,
Coulter, Polloway, Luckasson, Reiss and Spitalnik, 1994).
The 1992 definition will be used through-out this thesis.

Bersani (1996) has identified three shifts of
leadership in the area of intellectual disability. The
first wave, professionalism, occurred when professionals
defined the issues, formulated the solutions and made the
decisions. The second wave, parents as partners, occurred
with the development of the consumer movement and was
supported by the writings of people like Wolfensberger. The
second wave was "Responsible for the proliferation of
services" (Bersani, 1996, p. 261). The third wave, self-
advocacy, has involved persons with intellectual disability
forming local and national organizations as they speak out
on important issues. This self-advocacy model suggests that
the paternalistic role of professionals and service

providers will come under increased pressures as rights to full and equal citizenship are claimed by consumers (Stainton, 1994).

Deinstitutionalization

There are four major paradigms for studying the impact of deinstitutionalization: evaluation study; adjustment of persons; quality of life; and the qualitative method. Evaluation studies examine the consequence of efforts to intervene in ongoing social processes (Deutscher, 1979). Adjustment studies examine the skills necessary for the individual to adjust to the environment. Quality of life research, the newest direction of research in the area of disabilities, tends to examine the fit between the individual and the environment (Schalock, Kieth, Hoffman and Karan, 1989). Qualitative research includes participant observation, in-depth interviewing, and life history methods which examine descriptions of people's lives and the meaning people make out of them (Bilken and Moseley, 1988). The research conducted and described in this thesis has followed a qualitative approach in order to allow, as much as possible, the voices of the former residents of Exon House to be heard.

The movement of persons with mental retardation from large custodial or training facilities to community-based residences has been called deinstitutionalization. In 1974 the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded defined deinstitutionalization as three inter-related processes: first, the prevention of admission to custodial institutions and the development of alternative community care and training; second, the return to the community of those residents who have been prepared to function adequately in local settings; and third the establishment and maintenance of a responsive residential environment which protects civil and human rights (cited in Scheerenberger, 1976). Another definition from an influential source was John F. Kennedy's President's Committee on Mental Retardation (1977) which suggested "It means avoiding the institutional route by early care and treatment, providing alternate living arrangements, or changing the lifestyle and environment of an institutionally molded patient" (p. 202). These and other definitions have fostered a semantic debate often exercised in the media which has frequently reported deinstitutionalization as passing off responsibility, dumping, cutting budgets and gross dereliction of duty (Bachrach, 1989). The definitions cited above suggest there may be a difference of opinion within the mental retardation

field; that deinstitutionalization does not have to mean
closure of institutions. The cited definitions suggest
population reduction in the institutions for those who are
ready through the avoidance or prevention of admission and
the development of alternatives along with movement out of
the institution. In the former definition, by Kennedy's
Committee on Mental Retardation, deinstitutionalization
appears to be only for those who have been made ready to
leave the institution. It would appear that deinstitution-
alization as a process may not have been intended for all
inmates with intellectual disability.

An alternative definition of deinstitutionalization is
prescribed by Bachrach as follows: "The shunning or
avoidance of traditional institutional settings particularly
state mental hospitals, for chronic mentally ill individ-
uals, and the concurrent development of community based
alternatives for the care of this population" (Bachrach,
1989, p. 165). This definition also suggests the distinct
processes of diversion, depopulation and decentralization by
avoiding institutional placements and developing alterna-
tives to institutions. While Bachrach's definition focuses
upon persons with mental illness, it also captures the
themes expressed in other definitions of deinstitutional-
ization for persons with developmental challenges.

The definitions of deinstitutionalization given in this chapter demonstrate a significant difference in the conceptualization of deinstitutionalization as it applied to Newfoundland. The process in Newfoundland began with an attempt to avoid institutional placements, develop community based alternatives, and improve existing institutions. The conclusion was a plan stating that, "Institutions have no place in the lives of mentally retarded people in Newfoundland and Labrador" (Hickey, 1982, p. 2).

In 1988 the Provincial Government of Newfoundland closed the second of its two residential facilities for persons with intellectual disability. The policy of deinstitutionalization was driven in part by an understanding that life would be better for persons living in the community and that there would be fiscal savings in the longer term (CAMR, 1981). The Government of Newfoundland supported deinstitutionalization as the diversion of referrals for placement, the development of alternative residential services, and the closure of the facility (Efford, 1990).

Underlying pressures toward deinstitutionalization

The welfare state has made the well-being of its citizens a matter of public policy. Therborn (1984) suggests that the forms and principles of public social commitments are controversial and that there are opposing views of administrative control for social security schemes. The basic issue is whether control should be exercised by employers or insurance companies as opposed to unions or the state. These opposing views have become more pronounced since the 1970's with the "Renaissance of conservative theories of crisis" (Offe, 1984, p. 65). Offe (1984) also suggested that privatization was but one strategy in the conservative effort to regain control of the welfare state. Another strategy involves agents of social control promoting values of self-restraint and community spirit (Offe, 1984; Vettenranta, 1986). Residential facilities for persons with mental illness and intellectual disability grew rapidly in the post World War II period as the welfare state developed. Since that time neo-conservative values have had great influence upon services.

Newfoundland has not been isolated from the influence of privatization in health care and social services. Privatization has had an influence on deinstitutionalization

in Newfoundland. Community-based residential services are
not operated by government. Community boards of directors
operate group homes and co-operative apartments. Foster
homes, alternate family arrangements, and board and lodging
situations are operated by families or individuals. It is
also important to note that both the federal and provincial
governments have provided funding to advocacy and service
organizations in an effort to ensure and develop the support
of the community.

Emerson (1985) reports research which suggests there
are three major factors which spawned the deinstitution-
alization movement: a growing consumer movement, growing
public awareness of the negative aspects of institutional
care, and alarm at escalating costs of institutional
services. The rise of libertarian values has supported
deinstitutionalization. This is most pronounced in the
United States where litigation has forced the closure of
many facilities on the basis of human rights. In Canada,
the libertarian view is equally as prominent but manifests
itself in different ways. Community organizations have led
the way as advocates for deinstitutionalization by raising
issues of inadequate treatment.

Deinstitutionalization has been pursued by policy makers, administrators, litigators, and others concerned with mental illness and mental retardation for nearly 30 years (Dear and Wolch, 1987). For many persons with mental illness, deinstitutionalization involved their discharge from large mental hospitals to small scale community-based facilities (Dear and Wolch, 1987). The evolving welfare state and the development of psychotropic drugs combined to provide the catalyst for the movement of persons from residential facilities to social assistance support as disabled persons (Lerman, 1982).

Some writers in the mental health field have questioned the effectiveness of deinstitutionalization and raised issues of ghettoization and homelessness as outcomes of the movement (Aviram, 1990; Dear and Wolch, 1987; French, 1987; Mechanic and Rochefort, 1990). It has been suggested that as many as 25% of homeless persons in larger cities are mentally ill or alcoholics (Dear and Wolch, 1987). The impact of deinstitutionalization on persons who are consumers of mental health services has been significant. Some have experienced the worst consequences of deinstitutionalization: homelessness, recurrent illness, lack of treatment and abuse (French, 1987). The neo-conservative view of the state may well be more concerned with easing

fiscal strains than with the well-being of citizens who have difficulty speaking for themselves.

It was likely that Erving Goffman's essays in <u>Asylums</u> contributed to deinstitutionalization policies. Goffman's (1961) description of total institutions, which was contrary to popular beliefs, gave rise to an understanding that life in mental health facilities was not therapeutically oriented. As community groups rose up to contest the situation for persons with mental illness, they also became aware of the less than therapeutic orientation of these facilities. As community awareness developed for persons with mental illness, similar groups developed on behalf of the persons with intellectual disability who had been placed in mental health facilities. One of the problems such groups faced was that many professionals and others thought that institutions for the mentally ill were a reasonable placement for persons with intellectual disability, particularly because no other option existed for their removal from the community.

The development of psychotropic medicines was a major contributing factor to deinstitutionalization for persons with mental illness. The claim to cure persons of their illnesses permitted transfer out of the facilities (French,

1987; Mechanic and Rochefort, 1990; Starr, 1982; Warner,
1989). Andrew Scull (1984) considered this issue and
reported the situation to be overstated. Scull convincingly
argued that a primary condition for deinstitutionalization
was the provision of financial support through public
assistance programs (Scull, 1984). The combination of a
well-developed social welfare system and the intensifying
fiscal crisis of the state also created structural pressures
to adopt a policy of deinsititutionalization (Scull, 1977).
While Scull's explanation of decarceration is based on
research of penal institutions and institutions for persons
with mental illness, I believe it parallels the process that
developed for persons with intellectual disability.
Bacharach (1985), Scull (1977, 1981, 1984) and Felton and
Shinn (1981) have argued that aspects of deinstitution-
alization are similar for criminals, persons with mental
illness, and the elderly. There are many parallels to
persons living with intellectual disability and a similar
discussion of state influences. Thus I would suggest that
persons with developmental challenges have undergone a
similar process and have had similar experiences.

The developing consumers' movement and the growing
awareness of the negative effects of institutional life
raised public concerns. Institutions were sensationalized by

the press. Professionals in the field wrote of horrors they
observed and news reporters interviewed, filmed, and exposed
the quality of care in institutions across North America
(Blatt and Kaplan, 1974; Edgerton, 1967; Radford and Tipper,
1988; Rivera, 1973). Normalization provided a response to
the questions of service providers as advocacy increased.
Associations of advocates comprised two main groups.
Parents joined organizations such as the Canadian
Association for the Mentally Retarded and the Association
for Retarded Children in the United States. In addition,
professionals joined organizations such as the National
Institute on Mental Retardation (now the Roeher Institute)
and the American Association for Mental Retardation. All
the advocacy organizations which adhered to the normal-
ization principle had a guiding ideology to assist in
improving institutions; to move persons to community-based
residential services; and, finally, to promote the closure
of institutions. Coincidently, the community advocacy
organizations and governments had some common goals. First,
to control the fiscal crisis caused by rising institutional
costs through deinstitutionalization and secondly, to bring
an end to the mistreatment of the intellectually disabled
who were in institutions. An announcement by a Minister of
the Government of Newfoundland indicated that there would be

a projected savings of $10M by 1992 as a result of deinsti-
tutionalization (Efford, 1990).

The National Institute on Mental Retardation (1981)
suggested that the revival of optimism for persons with
developmental challenges, the development of community
services, research, and the impact of new ideologies of
human services, all supported a new way of providing
services for persons with intellectual disability. The new
ideology of normalization and recognition of human rights
for all persons fit in well with a renewed optimism about
teaching life skills that a person with developmental
challenges could use to function independently in the
community (Willer and Intagliata, 1984). The research which
indicated persons with mental retardation improved after
moving out of large residential facilities also supported
deinstitutionalization (Edgerton, 1967; Larson and Lakin,
1989; Mallory and Herrich, 1987; Nesbit, Clarke and Covert,
1991).

In summary, the major factors driving deinstitution-
alization developed from several perspectives. Advocacy
organizations, social policy analysts and critical criminol-
ogists each contributed to an understanding of the driving
forces of deinstitutionalization which are as follows:

- new ideology of normalization,
- a revival of the developmental model,
- development of social welfare policy,
- the neo-conservative response to the high cost of institutions,
- growing awareness of quality of care in institutions for marginalized persons,
- developing parent, advocacy, and consumer movements.

Normalization was a principle that strongly supported the deinstitutionalization of persons with intellectual disability. The principle provided a basis for proponents of deinstitutionalization because it offered processes that matched the goals of the state - to move people from institutions.

Normalization

Normalization provided many advocates, parents, community organizations and service providers with an ideology which would powerfully influence deinstitution-alization and the development of community based services. The first reference to normalization was by Maria Montessori in 1950; the reference was about enabling mentally retarded children to pass school examinations (Wolfensberger, 1980,

p. 73). The principle of normalization was developed by Neils E. Bank-Mikkelsen but the first systematic statement was by Bengt Nirje (Flynn and Nitsch, 1980). Nirje asserted that the application of the normalization principle would not "Make retarded people normal, but it will make their life conditions as normal as possible, respecting the degrees and complications of the handicap, the training received and needed, and the social competence and maturity acquired and attainable." (Nirje, 1980, pp. 33-34). In its North American version, normalization was defined initially as the "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal characteristics which are as culturally normative as possible" (Wolfensberger, Nirje, Olshansky, Perske, and Roos, 1972, p. 28).

Wolfensberger's normalization principle is promoted as one of the very few overarching theories or guiding conceptualizations that may be used to govern the design and conduct of virtually any human service (Wolfensberger and Thomas, 1983). Its single major goal is to create or support socially valued roles for people in their society.

All other elements and objectives tend to be subservient to this end, because if a person's social role were a societally valued one, then other desirable

things would be accorded to that person almost automat-
ically, at least within the resources and norms of
his/her society. (Wolfensberger and Thomas, 1983, p.
23)

A second statement contributes to understanding the major
points of normalization, "Maximal feasible integration of
deviant persons into the cultural mainstream has been
defined as a major corollary of the principle of normal-
ization" (Wolfensberger et al., 1972, p. 209). The
normalization principle is proposed as a two-pronged
strategy to attain valued social roles for devalued persons.
The first strategy is to reduce the stigma associated with
the person and the second is to change societal perceptions
and values in regard to a devalued person or group so that a
given characteristic is no longer seen as devalued
(Wolfensberger and Thomas, 1983).

Butler and Bjaanes (1978) found that to provide a
normalizing environment, a residential facility must be
"activity-enriched" with both internal programs and external
contact and exchange. Life in an institution has all phases
of a day's activities tightly scheduled and imposed from
above (Goffman, 1961). Deinstitutionalization should allow
influences of the community to affect peoples' lives
throughout the day, week and year. Bercovici (1981) found

that individuals who were placed in the community were not
provided with natural opportunities to learn and practice
many daily living skills. Moreover, Emerson (1985)
suggested that researchers must go beyond the study of
adaptive behavior and the evaluation of activity patterns to
provide a comprehensive framework that evaluates the
opportunity framework which shapes values and behavior.

Few activities in our culture are as normative as work
(Wolfensberger et al., 1972). Without work a person is left
with few options for income and frequently unemployed people
look to financial support from the state. Wolfensberger et
al. (1972) suggested that it is paradoxical that society
condemns dependency and public welfare as an alternative to
work, yet it offers only limited opportunities to work
especially for persons with disabilities.

There is a competing opinion to Wolfensberger and
Thomas' (1983) strategy to change societal perceptions and
values in regard to devalued persons. Gottlieb (1975, 1981)
and Williams (1986) have suggested that increased contact
between intellectually disabled and non-retarded persons
does not necessarily result in more positive perceptions of
intellectually disabled persons. Gottlieb later suggested
that unless the behaviour of retarded children is normal-

ized, the level of acceptance of others toward them will
remain low (cited in Seltzer, 1985). My personal observa-
tions of persons with intellectual disability going about
the community indicate a general acceptance as they partici-
pate in community activities in Newfoundland.

Jean Vanier (1995) writes that there "Is something very
beautiful in the theory of normalization: people with
mental handicaps are complete human beings ... they should
be welcomed into society on an equal basis" (p. 59). The
questions that rose for Vanier as he became more aware of
normalization seemed to support the reformulation of the
normalization concept to one of social role valorization.
Vanier goes on to say that persons with intellectual
disability need above all a whole network of friendships and
sense of belonging to a community.

Wolfensberger renamed normalization as social role
valorization in 1983 in an attempt to change people's focus
away from any preconceived negative associations toward "The
most explicit and highest goal of normalization... the
creation, support, and defense of valued social roles for
people who are at risk of social devaluation"
(Wolfensberger, 1983 p. 234). There has been an interesting
debate in the academic literature regarding the research

base to support the ideology of normalization (Emerson, 1992; Zigler, Hadapp and Edison, 1990). Wolfensberger's comment on the debate was that the service patterns of segregation, institutionalization, school exclusion, etc. were shaped by Social Darwinism and eugenics which themselves are now considered to be based on faulty research and racist ideology (Wolfensberger, 1995a). Interpretations and explanations of normalization and social role valorization by Dr. Wolfensberger continue to be published in academic journals (Wolfensberger, 1995b).

In a review of the various definitions of normalization, Emerson (1992) has concluded that neither Bank-Mikkelsen, Nirje, nor Wolfensberger have confronted directly the issue of segregation in service design. Wolfensberger strongly contests this point (Wolfensberger, 1995). Emerson (1992) has suggested that the transformation of normalization into social role valorization was based upon societal reaction to theories of deviance which have largely been abandoned. Emerson (1992) also suggests that the absence of empirical research and a coherent historical analysis of change in societal reactions to deviance challenge the principle. It has been suggested that normalization inadvertently portrays people as victims and that there will always be devalued victims particularly if the underpinnings

of normalization is deviance theory (Whitehead, 1992).
Normalization may also be viewed as a process designed to
reduce the deviant image of persons. However, a full dis-
cussion and analysis of normalization must be reserved for
other researchers.

In 1983 Wolfensberger re-named normalization as social
role valorization (Wolfensberger, 1983). The use of the
term social role valorization has not gained a place in the
academic literature. The current literature describing or
discussing the principle, including the writings of Dr.
Wolfensberger, utilize the single term, normalization. In
this thesis I will follow this practice and utilize the
term, normalization.

Recently a new conceptual framework termed "social
well-being" has emerged in Canada. To achieve social well-
being "Institutional arrangements in Canadian society
[should] contribute to, rather than diminish, well-being
(Roeher Institute, 1993, p.2). The contribution is to be
advanced through self-determination, democratization, and
equality. Within the social well-being framework "Self-
determination means that choices are made autonomously and
free of coercion and that people consent in an informed way
to their rule by others or by government" (Roeher Institute,

1993, p. 30). Democratization is "The process of enabling the democratic participation of individuals and diverse groups in a wide scope of decision-making processes that directly affect their lives and their well-being" (Roeher Institute, 1993, p. 34). Equality is "The absence of barriers to mutual respect and recognition between people who are equally free from political control, social pressure and economic deprivation and insecurity to engage in valued pursuits, and who have equal access to means of self-development" (Roeher Institute, 1993, p. 37).

This new ideological framework of social well-being has yet to reach many professionals. However, it has been accepted by groups representing people with disabilities as evidenced by the number of coalitions which have been struck to combat government restraint policies. Future research will assist in understanding the value of this new conceptual framework designed to support an egalitarian Canadian society.

Framing the present study

A wide range of literature was reviewed to provide the context for the development and design of the research reported in this thesis. A review of literature on

deinstitutionalization conducted by the Roeher Institute (1995) revealed the focus was on broader process and systems developments in the area. In addition to other research cited later in this section "quality of life" research was reviewed. Quality of life research began in the 1930's with President Hoover's Committee on Social Trends (cited in Wish, 1986). It is only since the late 1980's that quality of life researchers directed attention to the area of intellectual disability. Quality of life research has become a dominant theme in the planning and evaluation of services for persons living with intellectual disability (Dennis, Williams, Giangregco, and Cloninger, 1993). A recognition within quality of life research that subjective and objective indicators should be combined (Felce and Perry, 1995) in research instruments was valuable to the development of this thesis. Researchers in the quality of life field tend to prefer survey instruments as the data collection mechanism (Schalock, 1990). In a study conducted by Gilner and Sample (1996) the survey questionnaire failed to show statistically significant improvement in quality of life following intervention, although subjective assessments and case study methods revealed change in some participants. Quality of life research appears to arise from issues such as normalization, human rights, due process, etc. for the thrust in the area appears to examine issues which directly

affect the lives of persons with intellectual disability.
Thus for several reasons the quality of life model would
contribute to the design of this research.

Nesbit et al., (1991) in a review of research on
community living reported that ethnographic methods which
attempt to capture community, lifestyles, and interactions
appear appropriate for use with persons who have intel-
lectual disability. A recently reported study utilized par-
ticipant observation, in-depth interviews and document
analysis to study a person-centered planning approach in
Massachusetts (Hagner, Helm, and Butterworth, 1996). Some
of the early researchers in the area, Bogdan and Taylor
(1982), Edgerton (1967, 1993), Edgerton and Bercovici
(1976), Edgerton and Langness (1978), continue to be cited
in literature about persons with intellectual disability.
Ethnographic research has not been prolific on persons who
have intellectual disability. It has been said that
Edgerton's studies stand alone as prominent sociological
work in the area (Simpson, 1996).

Emerson (1985) suggested that, "All too often community
services conspire to re-enact the very same institutional
process of ensuring the physical and social isolation and
stigmatization of handicapped persons, maintaining the

degrading asymmetrical power relationships between residents and staff and encouraging dependency and regimentation" (p. 282). Lakin, Bruininks and Sigford (1981) found that the social status and personal power of persons with intellectual disability remained unchanged following the widespread adoption of the normalization principle. Further, Edgerton (1975) suggested that persons with developmental disabilities seemed to be caught in "Elaborate and tenacious dependency relationships" (p. 132). Edgerton (1975), Lakin, Bruininks and Sigford (1981), and Emerson (1985) found dependency relationships were maintained as opposed to skill development in issues of personal autonomy. The power relations between caregivers, government, and community boards will be an important area of inquiry for this thesis. The affect of paternalism would be to limit autonomy (Stainton, 1994); the implications for the former residents of Exon House would be important to uncover and would likely affect policy and practices in the field.

It has also been reported by other researchers that persons with intellectual disability living in the community interact mainly with other intellectually disabled people or paid staff, and experience loneliness as a considerable problem (Bercovici, 1981, 1983; Gollay, Freedman, Wyngaarden and Kurtz, 1978; Hayden, Lakin, Hill, Bruininks and Copher,

1992; Rosen and Burchard, 1990). Henry, Keys, Balcazar and Jopp (1996) found that differences in staff attitudes existed only in higher job levels when compared to the general population and that on at least one sub-scale, community support staff had less positive attitudes than a comparison group from the general population. Two studies have found that workers with intellectual disability employed in integrated work settings have little interaction with co-workers during breaks, lunches and after hours (Parent, Kregel, Metzler and Twardzik (1992), and Chadsey-Rusch, DeStafano, O'Rielly, Gonzales and Collet-Klingenberg (1992). The participation of persons with intellectual disability in non-disabled groups was a major goal of the deinstitutionalization process. This thesis will explore and report on the social linkages of the former residents of Exon House.

Social linkages of the former residents of institutions has been an area of study by other researchers. Bercovici (1981) found that former residents of institutions were prohibited, discouraged or not shown how to go out into the community and/or establish relationships with persons other than those from the facility, sheltered work centre, or activity program (essentially staff or other persons with delayed development). Bercovici (1981) suggested further

that the preponderance of interaction with normal others was with the facility staff. Rosen and Burchard (1990) found that over half of their study group named a staff person as being their most frequent source of companionship and support. Bercovici (1981) suggested that for persons with intellectual disability living in the community the fact of separation, segregation and isolation from the larger community was conducive to the development of a sub-culture. Cahill and Eggleston (1995) reported that companions of wheelchair users (persons with physical disabilities) may draw attention from or draw too much attention to the wheel chair users. Attention drawn to persons with intellectual disability because of staff who might accompany them conflicts with the application of normalization. A study of the social contacts of the former residents of Exon House will be contrasted with other research in the area and the emergence of a sub-culture shall be considered.

Other authors have reported that family visiting patterns had not changed significantly in the move from institution to community (Conroy and Bradley, 1985). However, research by Lord and Hearn (1987) following the closure of Tranquille in British Columbia reported that visiting by family members had increased for approximately 80% of the persons who were moved to the community. The

planning process described by Hagner et al. (1996) seems to
have some common elements with the degree of consumer
involvement at Tranquille; additional research in this area
may lead to greater knowledge of life enhancement planning
processes.

A significant portion of the research reviewed in
preparation for this thesis considered satisfaction in
relation to residential placement. Burchard, Pine and
Gordon, 1990; Halpern, Close and Nelson, 1986; and Burchard,
Hasazi, Gordon and Yoe, 1991; have all associated personal
or lifestyle satisfaction with community adjustment. Much
of the research reviewed was premised on the belief that a
person has adapted or adjusted to the extent that there have
been improvements in performance, fewer problem behaviors,
and increased satisfaction compared to institutional living.
The research reviewed did not utilize the voices of the
subjects in an ethnographic research model, however the
issues will be considered in the design of questions for
interviews.

Burchard et al. (1991) found that persons living in
foster homes had similar levels of personal satisfaction as
those persons living in unsupervised apartments. They did
find a number of significant differences across residential

types when considering lifestyle normalization, social
integration, personal satisfaction and well-being. The data
of a study conducted by Seltzer (1981) suggest that when
residential environments are more normalized in training
opportunities, increased opportunity for responsibility in
home related tasks, more autonomy and increased access to
resources, people are more likely to be satisfied with the
residence. Seltzer's (1981) findings seem to be in
agreement with the work of Bercovici (1981), Butler and
Bjaanes (1978), and Emerson (1985) in that opportunities
must be provided for particular activities in order to
participate in community living. Emerson and Hatton (1994)
cited in Hatton, Emerson, Robertson and Cooper (1995)
reported that residents in a variety of residential
situations received staff support and were engaged in
constructive activity at levels observed in institutions.
Research by Lancioni, O'Reilly and Emerson (1996) concluded
that people with severe or profound developmental disabil-
ities seem to have the capability to make choices and
indicate preferences and that choice opportunities remain a
limited experience. "Attempts to enhance the quality of
life for persons with disabilities should include increased
opportunities to express preferences and to make decisions
based on those preferences" (Faw, Davis, and Peck, 1996, p.
174). Opportunity to experience and participate in typical

life experiences within the community have been noted by
Emerson (1985) and Wolfensberger et al. (1972), the former
residents of Exon House left the facility under the
direction of the goal of normalization and its corollary.
These will be important issues to explore through the
interviews with the study group.

Edgarton (1990) observed that "Internal dispositions
... are better predictors of people's satisfaction with the
quality of their lives than our environmental objectives"
(p. 157). The attitudes of staff (Emerson and Hatton,
1994), the choices offered to persons (Faw et al., 1996) and
the intersection with their persona (Edgarton, 1990) would
appear to be areas for researchers on which to focus future
endeavors.

Edgerton (1967) reported the adaptive strategies of
denial and passing as activities to invoke non-retarded
personal identities. In Edgarton's 1967 study it was
suggested that a significant goal of the former residents of
the institution was to "pass" into the community. Edgerton
and Bercovici (1976) found that after 12 years of living in
the community, former residents' concerns with concealing
their deviant image seemed to have faded. In the follow-up
study of 1976 few of the former residents were concerned

about others finding out about their former institutional lives. It appeared that as time passed self-perception of the stigma of a handicapped identity dissipated (Lakin et al., 1981, p. 396). Self-advocacy recently has received much attention in the literature and may be strongly related to notions of stigma. Self-advocates are calling for greater involvement in policy development, professional organizations, research, and information sharing on rights (Bersani, 1996; Castles, 1996; Goode, 1996; Kappel, 1996; Monroe, 1996; Ward, 1996). Self-advocates have formed a number of groups, in Canada they are called People First. People First advocate at provincial and national levels. The effects of stigma for participants in People First groups will provide rich opportunities for researchers.

For the present study, framed within a qualitative model, many aspects of the lives of the former residents of Exon House were considered. A number of reviews, studies, and quality of life instruments were reviewed in preparation for developing a framework for the in-depth interviews reported in this thesis. Some of the subjective conceptual areas summarized from the review were: social contacts, satisfaction, self-determination, recreation, employment, environmental comfort, psychological well-being, health, integration, personal competence, normalization, support

services, independence/interdependence, productivity and
civic responsibility (Brown and Bayer, 1992; Evans, Burnes,
Robinson, and Garrett, 1985; Harner and Heal, 1993; Hayden
et al., 1985; Hughes, Hwang, Kim, Eisenman and Killian
(1995); Lord and Pedlar, 1991; Ouillette-Kuntz, 1990; Rosen,
Simon and McKinsey, 1995; Sands and Kozleski, 1994; Sands,
Kozleski and Goodwin, 1991; Schalock, 1994; Stones and
Kozma, 1989; Wolfensberger and Glenn, 1975). The research
review shaped the focus for research in this thesis. From
the concerns identified by Emerson (1985) and others, and
the literature review undertaken for this thesis three major
areas for inquiry were identified: social linkages,
personal autonomy and personal satisfaction. The questions
asked of the former residents of Exon House were framed by
the above cited research. The study will report on the life
experiences of the former residents of Exon House and
consider the impact of normalization on their lives.
Several tools have been designed to evaluate the effects or
adherence to normalization (Flynn and Heal, 1981;
Wolfensburger and Glenn, 1975; Wolfensberger and Thomas,
1983). However, they do not encompass the ethnographic
model. Normalization principles will be utilized as a
backdrop to guide the discussions of the experiences of the
former residents. Normalization principles as one of the

major driving forces of deinstitutionalization may explain some of the impact of the deinstitutionalization process.

One additional concept for inquiry in this study was self-concept. Durkheim (cited in Rosenberg, 1989) suggested that sociologists should focus upon social facts as phenomena that exist outside individual consciousness. Rosenberg (1989) suggested that it is less the formal methodological approaches that separate the social from the physical sciences than the question of subjective meaning. He further asserted that self-concept was a product of social interactions and suggested it was in the domain of sociology (Rosenberg, 1989).

Some of the research on self-concept reviewed was related to how persons with intellectual disability viewed themselves in relation to the general population. Lawrence and Winschel (1973) suggested that "Segregated placement patterns are not ordinarily conducive to overall positive concepts of self and cannot be justified on that basis" (p. 316). Jahoda, Markov and Catternole (1988) reported that 75% of subjects saw themselves the same as the general population. Turner (1983) found that half the study group were highly sensitive to their mentally retarded status. Turner and Gallimore's study in 1979 (cited in Zetlin and

Turner, 1984) found there were four distinct groupings of
persons with mental retardation by their strategies of
coping with a handicap. Further, in the 1979 research by
Turner and Gallimore (cited in Zetlin and Turner, 1984) they
found that 50% of their subjects had continuing concern for
their image and utilized some form of self-presentation in
order to diminish the deviant image. Following the review
of these and other studies it was felt that self-concept
should be integrated into this thesis.

Reiter and Bendov (1996) suggested that persons with
intellectual disability may have insight into their
difficulties and can distinguish between the areas in which
they have difficulty and those they do not. Moreover,
Zetlin and Turner (1988) reported that adults with mild
disabilities were able to provide a well balanced picture of
their strengths and weaknesses. Castles (1979) found that
persons with intellectual disability frequently reported
their abilities as "Concrete, specific, and limited,...
while they tend to view their deficiencies in more global
terms" (cited in Castles, 1996). Zetlin and Turner (1988)
noted the abandonment of standardized measures of self-
esteem in favor of self-descriptive, open-ended narratives.
The research on self-concept was not without cautionary
statements. Zetlin, Heriot and Turner (1985) found that in

a study of self-concept of persons with developmental
challenges the responses were problematic because of
acquiesence, social desirability, personal agendas, and item
comprehension. These issues will have to be considered as
questions are developed for use in interviews. Discussions
of self with the former residents of Exon House will help
reveal how they take meaning from membership in the com-
munity in which they live.

Summary

The research in the area of intellectual disability
tends to suggest that deinstitutionalization is beneficial.
Some cautions have been recorded by Emerson (1985) and
others. This research explores the lives of persons who
were moved from an institution to the community under a more
unique experience of deinstitutionalization. Deinstitution-
alization in Newfoundland meant the closure of the facility.
The development of supportive services was guided by normal-
ization principles and thus some of the impact of deinstitu-
tionalization would be created by the community based
services. The life experiences of the former Exon House
residents will be contrasted to the goal of normalization.
The contrast to normalization will reveal the effects of the

influence of a major driving force on deinstitutionaliz-
ation:

The following chapter will discuss the identification
and selection of the study group and the preparation of the
interview schedule. Several interesting and challenging
experiences occurred as persons were contacted for
participation in the study. These experiences are also
discussed in the chapter on methodology.

CHAPTER 3

Research Methods

Introduction

This chapter will outline the methodological approach taken to conduct this project. Also, it will discuss the process of determining which former residents of Exon House would be invited to participate in the study. There will be a description of the approach to data collection including the interview process. In addition, I will include a description of some of the challenging experiences associated with data collection for this project.

Research problem

Persons who lived at Exon House were moved to a variety of residential alternatives as a result of deinstitution-alization. The research undertaken in this project was designed to understand the impact of deinstitutionalization upon the experiences of the former residents. Edgerton (1990) asserted that discussions about life's quality for persons with intellectual disability must include their voices. It was Edgerton's work which helped set my goal that the research for this thesis would capture the voices of persons who lived at Exon House. Deinstitutionalization was driven, in part, by the normalization principle, the

research presented will contrast the community experiences of the former residents with the principle of normalization.

Research design

The initial goal of this research was to interview the entire former resident population. Action was taken to find lists to determine the population. The Department of Social Services was contacted in order to describe fully the scope of the proposed study and to seek its support to pursue this work. Consideration was also given to identify research instruments which could be useful in gathering data on issues related to this research on persons living with developmental disabilities. Knowledge of the population indicated that there were persons with a wide range of developmental skills who had resided at Exon House. Some of the former residents would not be able to answer questions requiring verbal responses. In a situation such as this it would be necessary to have someone else answer questions on behalf of the former resident of Exon House. There appeared to be only two groups who could act as respondents in these situations, family members and paid staff persons who would be living with the individual. Since many family members seemed to have only very limited contact with the inform-ants, questions would most likely be deferred to staff.

This led to an important consideration. The data set could contain both information from staff on those former residents of Exon House who were not capable of verbal responses and information collected directly from former residents who could speak for themselves. It was important to understand if this kind of data would be representative of the entire population.

The initial idea that the total population of former Exon House residents would constitute the sample was found to require enormous resources. It would require the following data collection processes:

- interviewing several persons (family and paid staff) if an individual could not speak for themself,
- interviews with former residents who could speak for themselves and
- observations of the day to day experiences of the individual.

This process would require a great deal of time and co-ordination of effort as well as financial resources to support travel and accommodation costs. It quickly became apparent that to cover the entire population was unfeasible.

Probability sampling was considered as a methodological approach to reduce both the sample size and to ensure a representative group. It was also recognized that at least two additional important factors must be considered in choosing a representative sample. The first was geographic distribution, the second was possible sources of bias. The geographic dispersal of the residential settings of former residents of Exon House was described by an official of the Department of Social Services to be all parts of the province of Newfoundland including Labrador. Financial resources were insufficient to reach all areas and interview all former residents. Another factor for consideration was that most of the research on this topic has been conducted in larger metropolitan areas. This necessitated a decision regarding the catchment area for the research. It was decided that the study would be focused upon former residents of Exon House who lived in the north-east Avalon peninsula of the Province of Newfoundland (St. John's metropolitan area). The north-east Avalon metropolitan area would facilitate comparative analysis with other similar areas of research.

The second complex issue of bias was related to collecting data from persons who had intellectual disability to degrees which interfered with verbal communications.

This issue raised several questions which needed to be addressed in the project's design. Who would speak for this group and what type of bias might be reflected? Important issues of respondent bias (by family or paid staff) had to be considered if the person with disability could not answer the questions for himself/herself and in order for this project to be relevant to sociology and useful in the study of intellectual disability.

Bias will always be a relevant part of discussion even when the voice of the group being studied is heard. Bias of the recorder may also be a factor. A researcher must recognize this issue and take care to identify any effects on the data or the analysis. In this work, the use of family and/or paid staff as informants would have introduced a major source of bias. Families often struggle with decisions regarding intellectually disabled family members and look to professionals for recommendations. Power relations necessarily become part of the discussion when a client relationship is claimed. Professionals may make recommendations which are thought to be in the best interest of the client but these may in fact be representing the interests of the institutional or social services system rather than those of the client. The professional-client relationship may not permit persons with intellectual

disability to speak for themselves. Thus a system which prescribes for people rather than participates with people may be maintained.

These considerations of bias led me to decide that, in order to reduce bias, interviews be conducted directly with people who lived at Exon House. This would also ensure that the research might benefit directly those who experience daily intellectual disability. This led to the decision that for this study only persons who could speak for themselves, who had lived at Exon House, and who resided in the north-east Avalon of the Province of Newfoundland would be invited to participate.

The sample was being shaped by issues other than statistical representativeness. Having recognized this throughout, I had to consider one more factor in order to fully define the population. If only persons who could speak for themselves were to be invited to participate, this criterion would have to be defined. The final criterion for a request to participate in the study was necessary to ensure a person could fully participate in the discussions and not require any other person to respond on his/her behalf. The criterion was defined as a person who could speak for himself/herself in issues of daily living and

could typically make his/her daily needs known through verbal communication.

Before contacting prospective participants in the research, an application was made to the Memorial University of Newfoundland Arts Research Committee who adjudicate the ethical acceptability of research projects involving human subjects. In the application the research project was described in detail including the procedures used to obtain consent from the participants. Appendix 2 contains the Certification of Ethical Acceptability For Research Involving Human Subjects. It should be noted that the title of the research project was changed when the thesis was written up.

It was determined from informants that there were twenty-three persons in the north-east Avalon metropolitan area who met all the criteria. Professional persons who knew these potential study participants were approached and advised of the research. Sample questions were used as a basis for confirming verbal skills for participation in the research. The interviewer also met many of the prospective interviewees. Through this process five persons were judged to possess insufficient verbal communicative competence to

respond to questions. This left a population of 18 persons, who filled all the criteria for inclusion in the study.

Interview schedule

The collection of data through an interview process necessitated developing a sufficiently structured question- naire that would ensure consistent exploration and discus- sion of specific questions but not limit the issues which might arise during the interviews. Four conceptual areas were selected to be explored in the study. Questions were organized by conceptual group. However, some questions were relevant to more than one conceptual area. The concepts to be studied and measured in this research were: social linkage, personal autonomy, personal satisfaction and self- concept. These concepts were determined from the literature review to be the most important ones in developing an understanding of the impact of deinstitutionalization on the lives of the study group.

Questions regarding the social connections of the intellectually disabled study group provide data with which to analyze the degree of integration of these individuals into the community at large. To some extent such data will permit generalizations regarding the acceptance by the

general community of persons with intellectual disability.
Understanding social linkages will reveal the study group's
social world and permit an analysis related to one of the
basic tenants of deinstitutionalization - integration into
the community. The personal autonomy concept was also
explored in order to understand if there has been a shift to
client-centred decision making and whether or not the former
residents make real and important decisions in their own
lives.

The third concept to be studied was personal satis-
faction. This concept is important for if deinstitution-
alization was undertaken because it was thought to be
beneficial for people who lived in institutions, then the
question arises are these people happy or satisfied with
their changed lives. Personal satisfaction is linked to the
fourth important topic that of self-concept or sense of
self. What the subject thinks of himself/herself as a
person or member of a group will reveal some of the more
personal impacts of deinstitutionalization. It may also
reveal something about the barriers to participation in
community life (real or otherwise) experienced by the former
residents of Exon House.

Social linkage is the first concept to be measured in this study. For the purpose of the study, social connections are defined as the typical interactions with other persons in the course of living one's life. These connections will reveal a great deal of information regarding the life experiences of the people with developmental challenges in this study. The types of connections to be measured are:

- staff linkages,
- family linkages,
- friend linkages,
- neighbour linkages,
- advocate linkages,
- professional linkages,
- opportunity to access the community and the types of places and events which are offered and
- the community activities and events experienced.

Personal autonomy is the second concept and this is closely related to participation in decision-making. This concept is also related to one's ability to control aspects of the environment in which one lives. This concept will be

measured by exploring the degree of participation in
decision-making relating to such things as:

- home location;
- clothing purchases;
- house decorations and furnishings;
- grocery shopping and meal preparation;
- work options;
- supportive services;
- staff selection, staff schedules;
- outings, activities and events;
- bill payments and financial planning;
- leisure/recreation activities; and
- decision-making while in community settings.

The third concept to be explored in this study is that
of personal satisfaction. This concept indicates one's
level of contentment with present life experiences. This
concept will be measured by exploring such things as:

- satisfaction with living arrangements,
- feelings of fear and loneliness,
- feelings of happiness,
- satisfaction with work/day programs,
- satisfaction with friends/family and
- satisfaction with services.

The final concept to be measured is the individual's sense of self. A person who lived at Exon House most likely experienced being labelled as having deviant characteristics including mental retardation. Persons with mental retardation have some sense of who they are and this has received some attention by researchers including Edgerton (1967), Bogdan & Taylor (1982) and Goffman (1963). I believe it is important to place perceptions in context against a backdrop of de-labelling principles such as normalization. Further, because of the descriptions of conditions at Exon House as reported by two study teams (CAMR, 1977; CAMR, 1981) it is only reasonable to hypothesize that persons in Newfoundland experience a more positive self-concept as a result of deinstitutionalization.

Self-concept will be measured by exploring such things as:

- the acceptance of diagnosis (label),
- strategies of "passing",
- perceptions of others with intellectual disability,
- impact of their intellectual disability and
- perceptions of society of persons with intellectual disability.

For a complete set of interview questions see Appendix A.

Data collection

The concepts to be studied in this project were measured through field observations and interviews. For the interviews a list of questions was developed to glean data in each of the areas under study. The questions were designed to encourage discussion within the conceptual area.

Retrospective questions were kept to a minimum in the interview schedule. The former residents of Exon House had left the facility many years before the interviews. Several factors might impact the accuracy of responses to retrospective questions. Memory can be affected by time and can be affected by the age of the person when they left the facility. There may also be influences on the ability to recall thoughts and incidences because of "the times" of deinstitutionalization. At the time of the former residents leaving the institution and through later times their recollections may have been influenced by other persons rationale for deinstitutionalization. The idea that it was fashionable to condemn institutions could play a part in the accuracy of the responses to questions. It was further considered that if participants might have harboured ill feelings about having lived there that retrospective

questioning might raise challenging thoughts and feelings. For these reasons a style of questioning focused toward present times was favoured.

Questions were always short and were used to encourage discussion. Tape recording was utilized with the permission of the interviewee. Field observations were done in the home of the participant and observation notes were recorded as soon as possible after the interview visit. The interviews were informal, utilized a set of semi-structured questions, and began after a warm-up period of up to one hour. Written notes were taken during the interview as each issue was explored. At the end of the interview there was a review of the responses to ensure accuracy of written notes.

All persons who participated in the interviews were given a complete description of the project including reference to approval by a university ethics committee. The researcher's commitment to confidentiality and autonomy was explained to each of the respondents. Each individual was invited to sign a consent form to indicate his/her willingness to participate. See Appendix 3 for a sample of the form participants were invited to sign. The form outlined the purpose of the study, acknowledged confidentiality of

data, and assured the researcher's commitment to individual anonymity.

In the data collection process there had to be some acknowledgement that many of the persons, who were former residents of Exon House, now lived in the homes of other persons or in board operated Co-operative Apartments. As a result of this, the "caregiver" was approached and advised that a research project was being conducted with former residents of Exon House and that the person living with them would be contacted. When the caregiver was contacted to discuss the individual's participation in the research a description of the project was offered. A letter of intro-duction from the Department of Social Services was also included.

In two instances the caregiver became very challenging when informed of the purposes of the study. In one situation the caregiver was very resistant to allowing me to speak to the potential informant and refused participation indicating she had to live with the person afterwards. I again described the project and strongly indicated that I did not believe any of the questions and subsequent discussions would cause a problem for any individual participating in the study. I further advised this

caregiver that it would be acceptable for the respondent to refuse to discuss any particular question or issue. There appeared to be no way to allay this caregiver's fear of the outcome of the interview. It was difficult to determine if the requirement of several hours of my presence in the home played any role in the refusal. As a final option, I asked to speak to the former resident in person to ask if he would participate and the caregiver refused to grant access to the potential participant. It was obvious that the rights of the individual to determine participation in the study were constrained. I did not pursue the matter further for concern of the impact on the individual.

There was another situation which arose during the collection of data, this case was similar to the previous one. At this home I had telephoned and spoken directly to the former resident of Exon House. He was hesitant but agreed to a meeting. Upon arrival at the home the caregiver was not interested in allowing me into the home. Through persistence and the letter of introduction from the Department of Social Services, I was permitted into the porch with an agreement to 'see how it would go'. About an hour into the initial interview, tea and biscuits were offered. Because of the breadth of the material covered in the interviews several evenings were required to complete

the data collection. After the third evening of inter-
viewing in this home, I was invited into discussion with the
family about hunting, fishing, going in the country and the
family picture album was offered for viewing. This family
became very interested in the findings of the research. I
advised I would return when the project was completed to
report on the findings.

There was one other situation which is worthy of note
in the discussion of challenges to the data collection.
With each person interviewed I would ensure my telephone
number was available in case of a need to re-schedule
interviews. One person, between interview sessions, began
calling my home while I was out. The person would call and
speak to one of my children. The conversations were
frightening as the person stated they could see my child
going in the house and claimed to have seen her getting on
the school bus. I spoke to the interviewee involved, stated
he should call in the evenings if it was necessary to re-
schedule our meeting time. Calls persisted, I again spoke
to him about my concerns and installed an unlisted second
line for the children. The individual was contacted and
advised that it was not necessary to have any contact.

In attempting to complete an interview with another person I had to visit many times. For that interview there were nine sessions scheduled with five having to be rescheduled. There were an additional six telephone contacts made to schedule times which were turned away by excuses such as call back tomorrow.

Another individual who was invited to participate did not answer correspondence. This person was known to live in the metropolitan area but could not be located in the phone book. A city directory was utilized in an attempt to find the address and phone number, however the phone number was unlisted. Two letters were sent requesting a return telephone call to discuss participation but no response was received. One individual was not contacted as there was reported to be a family crisis during the period of data collection.

As a result, the total number of interviews conducted was thirteen out of the total population of eighteen. Each interview consisted of a preliminary contact to determine their willingness to participate. If initial willingness was expressed, a time was established to visit the home. Each series of interviews lasted between six and ten hours. Data were collected in note form by the researcher and eight

of thirteen (61.5%) of the individuals interviewed permitted tape recorded sessions. Tapes were reviewed as soon as possible to add to the hand recorded data. For those interviews without a tape recording, the written records were reviewed as soon as possible after the sessions to ensure the data collected during the session was accurate and as complete as possible. In addition "stream of consciousness" notes were written as soon as possible after each session to record impressions and the events of the session. Interviews were most often held in kitchens; a bedroom was used once, a dining room was used once, and a living room twice.

Summary

To represent the voices of persons living with intellectual disability, I felt that the only methodological approach which could accomplish this was an ethnographic approach. Conceptual areas for inquiry were selected after a review of the literature and questionnaires from quality of life research and research in the area of intellectual disability. The many conceptual areas found were analyzed and collapsed into three areas; social connections, personal autonomy and personal satisfaction. Additional review of the sociological literature revealed that a fourth area,

self-concept, would likely contribute to the research being
undertaken for this thesis.

The data collected in interviews with former residents
of Exon House are reported in the following two chapters.
The chapters each discuss two conceptual areas and discuss
in detail the experiences of representative members of the
study group.

Chapter 4

The Social World and Autonomy of Former Exon House Residents

Introduction

The data reported in Chapters four and five of this thesis provide descriptions of the life experiences of former residents of Exon House. The data describe the impact of deinstitutionalization on family relations, decision-making, and self-concept and it also alludes to other experiences. This chapter examines social relations and the degree of autonomy of former residents.

Selected sample characteristics

The data reported in this chapter and the next were collected from interviews with 13 former residents of Exon House. They lived in a variety of living situations: some worked, attended educational or training programs, and they had different income sources. In order to report the data in a meaningful manner a useful strategy was to develop a typology from which members of the study group could be selected to represent each category. A number of variables were considered in order to create the typology. For the purpose of creating representative groupings of the former residents of Exon House, and to provide comprehensive

reporting of the data, six variables were chosen: age,
gender, participation in an educational or training program,
labor force participation, residential type and income
source. Table 1 outlines the selected characteristics.

Table 1

Sample Characteristics of Former Exon House Residents

Name	Age	Gender	E/T pgm	Work	Res Type	Income
Bill[i]	35	M	no	no	b	allow
Christine	33	F	no	no	b	allow
Dennis	29	M	no	no	c	SA
Doug	31	M	yes	yes	c	W & SA
Frank	33	M	yes	no	c	SA
Joan	33	F	yes	no	a	SA
Marvin	31	M	no	no	a	SA
Midge	25	F	no	no	b	allow
Nick	33	M	no	yes	c	W & SA
Rob	28	M	no	no	a	SA
Sarah	35	F	yes	no	a	SA
Tom	30	M	no	yes	c	W
Walter	34	M	no	yes	b	W & allow

Within the variable residential type, three categories
were used; Residential Type a indicates persons who lived on
their own or with companions; Residential Type b indicates
community board residences; and Residential Type c indicates

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[i]Names and other identifying factors have been changed
through-out this thesis to protect the anonymity of the former
residents of Exon House.

either alternate family care or board and lodging arrangements. In the income variable, three categories — allowance (allow), social assistance (SA), or wages (W) were utilized. Variables such as communication skills, level of personal support, degree of community participation, and time since labor force participation were considered as additional factors that could be used to select a representative from each group.

The former Exon House residents who participated in the study showed little difference in age which ranged from 25-35. There were four females and nine males who commenced the study, one male dropped out part way through the interviews. Nine participants were not in educational or training programs, two were female. There were five participants in residential type a, two were female and all received social assistance. Four participants were in residential type b, two were female and all received an allowance. Four participants were in residential type c, all were male and the group had a mixture of incomes. One person worked from each of residential type a and residential type b; two persons worked from residential type c. The selected characteristics formed the basis for the development of the typology.

Residential Typology

Residential type was the category selected from Table 1 to aid in the representation of the population. Deinstitutionalization was a process that moved persons from the institution to the community. The movement of the former Exon House residents into community based residential options was the heart of the process. Other consequences of deinstitutionalization were secondary to residential move. A list of community residential options, including apartment living, was described in government's plan of alternatives to institutionalization (A Plan, 1982). The Alternate Family Care program for adults with intellectual disability was patterned on the Foster Home Program for children and replaced Special Foster Homes. Living alone or with a companion was a residential option that was developed later. It was patterned from the idea that certain persons with intellectual disability could live in their own home as long as supports were provided.

Tables 2, 3 and 4 indicate the residential groupings; Residential Type A: Living Alone or with companions; Residential Type B: Community Board Residences; and Residential Type C: Alternate Family Care or Board and Lodging.

Table 2

Residential Type A: Living Alone or with Companions

Name	Age	Gender	E/T pgm	Work	Income
Joan	33	F	Yes	no	SA
Marvin	31	M	no	no	SA
Rob	28	M	no	no	SA
Sarah	35	F	yes	no	SA

Residential Type A includes persons living alone or
with companions. There were two males and two females in
this category. Joan and Marvin lived with companions and
Rob and Sarah lived alone. Joan lived in an apartment
building with a companion who provided support with personal
care, cooking and cleaning. Marvin and a female companion
lived in an apartment in a residential neighbourhood. Rob
and Sarah each lived alone in rented houses. Two persons,
Joan and Sarah, were in educational programs but no-one was
employed; all were on social assistance.

Two representatives from this group were selected for
the data report. Rob and Sarah were selected. Rob was
selected, as was Sarah, in order to represent the
experiences of persons living in the least restrictive
residential grouping. The principle of normalization

suggests the least restrictive residential placement.
Therefore this group receives more detailed examination.
This group also received a lower level of service and
support than the other groups. The selection of Sarah also
ensured gender balance in the data report. The addition of
a fourth representative allows for a more comprehensive
discussion of data which describes their life situations
following the movement from institution to community living.

Table 3

Residential Type B: Community Board Residences

Name	Age	Gender	E/T pgm	Work	Income
Bill	35	M	no	no	allow
Christine	33	F	no	no	allow
Midge	25	F	no	no	allow
Walter	34	M	no	yes	W & allow

Residential Type B was Community Board Residences.
Community boards of directors operated Group Homes and Co-
operative Apartments with professional support and funding
grants provided by the Department of Social Services. The
boards of directors were incorporated entities elected by
the community. The Cooperative Apartments were rented
houses where live-in staff and usually two persons with
intellectual disability lived, additional staff came by day.

Midge was selected to represent Residential Type B: Community Board Residences. Midge's characteristics on five variables was similar to half or more of the other persons who lived in this residential group. Both Bill and Christine experienced greater communication challenges than Midge, indicating that Midge could best represent the group.

Table 4

Residential Type C: Alternate Family Care or Board and Lodging

Name	Age	Gender	E/T pgm	Work	Income
Dennis	29	M	no	no	SA
Doug	31	M	yes	yes	W & SA
Frank	33	M	yes	no	SA
Nick	33	M	no	yes	W & SA
Tom	30	M	no	yes	W

Residential Type C was Alternate Family Care or Board and Lodging arrangements. Alternate Family Care was a program patterned after the Foster Care Program for children. Families apply for approval as an Alternate Family Care home. Following approval, the family may be introduced to a person with intellectual disability and a decision made regarding placement in the home. Board and Lodging arrangements also require approval but the approval requirements are less stringent.

From Residential Type C, Tom was selected to represent the group. Tom's position was similar to more than half of the persons who lived in this residential group. Tom did not experience communication challenges, once lived on his own, participated in the community at about the same rate as others, and worked full time. Based on these factors it was felt that he would best represent the group. Rob's, Midge's, Tom's and Sarah's stories will be reported in detail within each conceptual area. The life histories of other participants will be utilized to enrich the data and identify complementary or contrasting issues.

Social linkages

Normalization principles, one of the driving forces of deinstitutionalization, were a major influence in the planning of the service system designed to support people moving from the institution to the community. Therefore, it could be expected that the lives of the former residents of Exon House were affected by the process of normalization. An examination of their social linkages following a period of living in the community would reveal information about the study group's social integration into the community.

Through the course of the interviews with the former residents of Exon House a great deal of information was gathered about their social linkages. This data revealed much about the life experiences and the impact of normalization principles on the persons who were taken from Exon House and brought to live in the community.

Who was Rob?

Rob was selected as representative of the group of former residents who lived on their own or lived with roommates. A review of the typology revealed that Rob's experiences would be representative of the group identified in Residential Type A. Rob, 28 years old at the time of the interviews, lived on his own in a rented house and had been there for a few months prior to the interviews. When I met Rob at his place for our first interview I found him to be polite and articulate. Like his home he was clean and tidy. The home was a small unattached dwelling in the centre of the city. The living area was well lit, spartan, and separated from a small cooking area by a counter. We sat at a cozy kitchen style table immediately outside the cooking area for all of our discussions. Interspersed throughout our conversations were discussions about Bouchard's amputation, the O. J. Simpson trial, Buddy Holly's airplane

crash, the Nancy Kerrigan incident and several other topics of general interest. Rob indicated that he did not work and received social assistance (welfare) as his only income. Since leaving Exon House 14 years before, Rob had lived in 10 different places. All the places, except one, were found by people acting on his behalf.

Rob moved freely about the community and until recently had a number of people working on his behalf to provide him with support, guidance, and companionship (in a paid relationship - 24 hours a day). The Department of Social Services provided funds to hire staff through a Home Support Program. The Home Support Program provides funds, following application and approval, to an individual (or person acting on behalf of the individual in need of the supports) to assist people with disabilities and demonstrated needs to live in the community. The staff/personnel were hired by or on behalf of the person with a disability. The qualifications included high school graduation and some experience with persons who had a disability. The pay would be usually $5.41 per hour.

At the time of the interviews the staff provided support at Rob's place throughout most of the day and over night up to 16 hours a day. Rob said, "I always had staff

even when I moved in here except for now only except for a
couple of hours." Rob stated he was trying to become more
independent, and that they (staff, professionals, and
friends) "Said that's good for me". He indicated that he
was cooking some meals: "I cooks my breakfast and supper ...
I can cook bologna, eggs, and sausages". He was conscious
of his financial situation and with the help of a staff
person was learning about "Specials", "Bargains" and "Good
deals" at the supermarket and in other stores. Rob thought
that eventually he would live without daily staff direction
and be on his own.

Rob and involvement with his family

An institution, following Goffman's description,
regulates the life experiences of the inmates. Research has
shown that following release from an institution family
involvement may increase (Lord and Hearn, 1987) or show no
change (Conroy and Bradley, 1985). The experiences of the
former residents of Exon House with the involvement of their
families may address an important outcome of deinstitution-
alization.

Rob reported that he had some contact with his
biological family. He had recently found out for certain

that he had significantly fewer siblings than he previously understood to be in the family. Rob reported that he always thought there were fourteen in the family, but recently found out from Social Services records that it was eight. Rob enjoyed contact with one of his brothers: "Lots, one, two, three times a month or something". They exchanged letters and Rob called him on the phone. In addition, Rob reported that he wrote and also talked to his father "Couple of times a year, might call Christmas Day". When asked if any family called or visited, Rob indicated that there had been no visits and that he always called them, "I calls them and pays for it on my own. I got a budget." Rob's mother did not live with his father. Rob reported that he had given permission to a person in a paid relationship to initiate a search for identifying information on Rob's mother from the Department of Social Services records. He appeared very interested in obtaining information so he could contact her. Rob was aware of her christian and maiden names but thus far had been unable to secure enough information to establish contact. Rob felt strongly that "Everyone deserves to look for their parents" and that finding his mother could, "Help change my life".

Often the most important social linkages for an individual are with family. Family contacts were discussed

with the other former residents of Exon House. All, except
one, had had some type of contact with their families since
leaving Exon House. As in Rob's situation, most study group
members reported that they were not satisfied with the
frequency or quality of their family contacts. For seven of
the former residents the contacts were monthly or fewer.
The most frequent type of contact was by phone and more of
the contacts were initiated by the former residents than by
their families.

Rob had not had face-to-face contact with his father or
siblings. He hoped that, "When I gets in contact with my
mother she'll visit me." Participants in the study reported
they had visited family members more than family members
visited them. Eight participants reported that family
members had visited but don't any more and in fact one
participant was no longer permitted to visit the family
home. This data stands in contrast to that reported by Lord
and Hearn (1987). Family issues generally were a troubling
topic for the former residents of Exon House. The most
troubling aspect appeared to focus on contact with parents.
Relationships with siblings were generally perceived as not
so troubling.

During the interviews I discovered that in the past two years five members of the study group had received their first ever contacts from family members since leaving Exon House. Members of the study group reported that the reaction of their siblings seemed to be joy in finding family members. However, it was not the same joyful experience for many of the former residents of Exon House. Several of the persons interviewed were having difficulty coping with the experience of re-acquainting themselves with family members after so many years apart. Several of the persons interviewed grappled with questions such as, "My sisters talk to me" but "Mom won't talk to me", or "I suppose she (mother) don't want to talk to me", or "It's difficult to have emotion with parent. I wrote them a couple of times, they didn't respond", and "Me and my sister are best friends now". Except for the last quote no other participant indicated satisfaction with family contacts.

Each individual's understanding of the reasons for deinstitutionalization and their personal experiences of living in the institution likely contributed to the struggle to understand the actions of the individual's family. This was possibly because meeting family members necessitated having to confront a complex set of reasons why they had been made to leave their family and had been forced to live

at Exon House in the first place. Confronting such issues could be emotionally difficult for many members of the study group for there was an expectation that meeting family and renewing relationships would solve life's problems not create new ones. Most participants reported that contacts with their families had fallen from a high frequency immediately after initial contact to no more than monthly contacts at the time of this research. When the study group members were asked how they felt about contact with family and if they would like it to be different, only two stated that they thought the contact was "Alright" or "It's good". All others wished the contact with family to be different in some way. The former residents of Exon House felt the contact could be more frequent, amiable and open.

Who was important to Rob?

In addition to family, close personal contacts are found with friends. To further explore the extent of social linkages, Rob was asked about his friends. He stated he had lots of friends. However, except for one name, all the persons reported as friends were in some sort of paid relationship to Rob. The exception was a friend and confidant for more than five years. This is not to say that persons in paid relationships could not be friends but that

they were in close social contact likely because of a wage
relationship. Rob's situation with friends was not unlike
the other persons who participated in the interviews. The
data collected from the interviews with the other former
residents of Exon House indicated that there were few friend
relationships which were not derived from paid contacts.

Rob was asked about his travels in the community with
friends. He reported that he only went to the store or the
mall, he added that he was allowed to go but had to leave a
note for staff. Rob was asked if he participated in any
recreational activities or what he did for fun with his
friends. He responded that he usually went by himself to
the mall, "That's my spot", or to Tim Horton's. Rob also
stated that he went to meetings, the bank, shopping, and the
like with a particular staff person. Rob went out more
frequently than most study participants who went out "Not so
often" or about once a week. Only five reported they went
out at least three times a week.

In addition to friends, it was important to understand
about the confidants of the former residents of Exon House.
The other people who were important to Rob might reveal the
source of influences on his life experiences. One area of
inquiry was the frequency of visits to helping professionals

such as social workers, physicians (general practitioners), health specialists, etc. Rob indicated that there were helping professionals that he visited on a regular basis. As mentioned earlier, Rob visited the Department of Social Services staff for meetings three or four times a month. Rob also said that he visited a mental health professional on a monthly basis. In addition, he had recently become involved with an agency that might assist with finding and coordinating educational services. He reported having several visits there and would be continuing to go for a period of time.

The final questions about confidants were about in whom the former residents of Exon House could confide. Rob reported that there were four people that he would talk to if he worried about something. Rob said "I usually talks to someone I trusts [sic]", indicating that the names given were held in such regard. Three of those he named were in paid relationships and the other was his friend of many years. Rob gave the name of a person in a paid relationship as the first name in the response.

The other members of the study group were also asked the same question. For the total group, responses were collapsed into four categories comprising family, friend

(un-paid relationship), staff (paid relationship), or talk to no-one. All the responses of participants were included because many reported they would speak to more than one person. The responses indicated that significantly more people in paid relationships were named than friends or family. These findings are similar to those of Bercovici, 1981, 1983; Emerson, 1985; Gollay et al., 1978; Hayden et al., 1992; and Rosen and Burchard, 1990. The responses to this question suggest whom the former residents of Exon House consider to be the most supportive in their lives. Their support networks were composed almost entirely of persons in paid relationships.

To further acquire information about valued relationships, I asked Rob who were the most important people in his life. Rob indicated, "Everyone that work [sic] with me". He then stated eight names all of which were persons in paid relationships apart from his one friend of many years. The first name given was a person who was in a paid relationship. In response to the same question, most study group participants gave more than one name. Again, there were significantly higher numbers of persons in paid relationships reported than those of family or friends.

Examining the first name reported by the former residents of Exon House to the question, "Who are the most important people in your life?", the responses for nine of thirteen participants were persons in paid relationship. Three of the thirteen participants gave a family member's name as the first name offered and one participant gave a friend's name first. When residential groups were compared Residential Group B reported no friends' names, and Group C reported no family members' names. Examining the total number of names reported, 26 of 43 names given were people in paid relationships.

To the question, "Who would you speak to if you were worried?", 19 of 28 names given were persons in paid relations. The high proportion of the number of paid staff as responses to both questions suggested that members of the study group strongly valued these relationships and that the staff held powerful positions in the relationship with an intellectually disabled person.

Examination of the responses to these two questions revealed something about the relationships with family. In the responses to the question, "Who would you speak to when worried?", only 6.25% of the total responses were of family members, and those responses were from Residential Group A.

To the question, "Who are the most important people in your life?", responses indicating family members were slightly higher at 15.7%. Analysis of the responses to these two questions suggested that the family roles of the former residents of Exon House had been greatly affected. Data reported in the 1977 report on Exon House indicated that parents who were contacted by the report team indicated their interest in having their children closer to home, particularly for those families who lived beyond the Avalon Peninsula. The authors of the report also reviewed records about the home situation at the time of admission and found,

> in 77 instances parents were finding it difficult to
> cope with their child, and in 62 cases parents felt
> impelled [sic] to give up their child because they
> wished to devote more energy to other children in their
> families. Factors such as financial insecurity, parent
> irresponsibility, and others were also in evidence but
> tended to be fairly infrequent (CAMR, 1977, p. 51).

This data from the 1977 report and the responses to the previous two questions strongly suggest that family relationships were affected by the experiences of the former residents in living at Exon House.

Rob and work

In the world of work many friendships can be established. Also, work provides income which may provide an opportunity for more independent decision making. Work can also provide stimulating activity and help to give meaning to life. These issues were explored with members of the study. Issues associated with work will be briefly analyzed here for their relevance to social linkages. A more detailed analysis of work, wages, income and spending power will be provided in Chapter 5.

It appears that work opportunities were absent for many of the former residents of Exon House. Only 4 of the 13 study participants had been employed at the time of the interviews, although six had been employed at some time during the past year. Rob had not worked for about five years and indicated there were no prospects in sight. His last job was in light construction and it lasted for about three months. Rob talked about his plans to get work. He stated that he had told the counsellor, "I wanted upgrading to get a job. I want to do a trade". Rob went on to describe in some detail several trades he had been considering.

Four members of the study group were employed; of these two reported going out places with co-workers after hours. In addition, three who worked went to dances or other events organized by volunteers specifically for persons with developmental challenges. The research undertaken by Parent et al. (1992) and Chadsey-Rusch et al. (1992) found similar low rates of interaction with non-disabled co-workers.

Rob's neighbourhood and community

Neighbourhoods present rich opportunities for social linkages. Volunteer activities tend to strongly connect people to communities. The interaction of the former residents of Exon House in their neighbourhoods and communities will help us to understand their connections to the "normal" world. Rob indicated that he did some volunteer work about ten years ago "At the [service agency] at janitor work", but had not done any since then. Rob did indicate that he liked to help people and spoke of an incident that occurred at a service agency where he cleaned up a spill. Volunteer activities were not common-place among the former residents of Exon House. Only two persons reported they had done any volunteer work in the past and they were not doing any at the time of the interviews.

Participants reported that in their neighbourhoods they knew most of the people who lived near. They reported speaking to neighbours when they saw them. Most members of the study group, with two or three exceptions, had not visited neighbours' homes nor had neighbours visited their homes. Rob's experience was not different from the other study participants. He indicated he knew only one neighbour and that they sometimes met on the street or at the neighbourhood convenience store. If at the store, Rob indicated he would say hello if the neighbour spoke but "I wouldn't recognize him unless he said hello first, probably". Neighbourhoods were not always safe places. One study participant reported that young people from the neighbourhood sometimes threw rocks and chased him.

Rob discussed the activities that he attended. At the time of the interviews he attended one regular structured activity. The staff from the Department of Social Services held regular meetings with Rob. He said that he'd like to be going to floor hockey and bingo but "money was short". We discussed the NHL strike and the price of AHL tickets. Rob listened to many evening and late night radio programs and also indicated that he used to go to church and liked it, but offered no reason why he did not currently attend. Four participants reported they attended church regularly

but none were involved as members of a service organization, group or club that held regular meetings. Like Rob, the former residents of Exon House reported they did not belong to groups such as dart leagues, church choirs, church groups (Anglican Church Women, Star of the Sea, etc.), or service clubs (Kinsmen/Kinnettes, Lions/Lionesses, etc.). Bercovici's (1981) findings appear to hold true for the former residents of Exon House. They neither were encouraged nor shown how to go out and establish relationships in the community.

Community groups can be a very functional means to connect with other people in a community. These measures of connection to neighbourhood and community offer some insight into an understanding of integration and inclusion experienced by the former residents of Exon House. The former residents of Exon House were living in the neigh- bourhoods and community but were neither involved nor included in community activities. Members of society tend to participate in the place where we live and with groups when there are other common interests. Consider, for example, an academic community, a sports community, a religious community, or a professional community. Wolfensberger et al. (1972) indicated that participation in the community was a major tenant of normalization. The data

collected from the study group suggest minimal community participation. The former residents of Exon House indicated they did not participate in community groups. On the whole, members of the study group were not well connected to the activities of their neighbourhoods or community.

Personal Autonomy

The second conceptual area explored in the interviews conducted with former residents of Exon House was personal autonomy. This area of inquiry focused upon decision making, choice and personal freedom. If community partici- pation was defined as a preferred outcome of deinstitution- alization for the former residents of Exon House, another goal was an increase in the extent to which individuals with developmental disability could exert influence over their own lives.

Midge's story

Using the typology presented earlier in this chapter, Midge was selected from Residential Type B: Community Board Residences. She was selected as representative of factors common to the group. She did not participate in a struc- tured educational or training program; she did not work; and

she received income of the same type as other members of the group. She lived in a Community Board Residence with another person who had intellectual disability. There was a staff person who lived in the home but this individual had a permanent residence elsewhere. There was also staff supervision at the home 24 hours a day. These factors were typical of other homes of this type. Midge was polite and well groomed at our first meeting and seemed to wait for the staffer's instruction as to how to proceed following our introduction and greeting.

When I was greeted for our first interview, the staff person introduced me to Midge and we went to the kitchen to sit and chat. Within a few minutes Midge asked if I would like to see the house and took me on a tour. At this point, the staff person joined us for the tour and returned with us to the kitchen and stayed for the initial part of the interview. During this time, the staff person frequently added to Midge's responses. After about fifteen minutes or so the staff person left the room but stayed within earshot and continued to add to Midge's responses to several additional questions. The early part of the interview was intended to gather some basic information and also attempted to set the interviewee at ease. It was difficult to determine whether or not intrusions by the staff person

detracted from the validity of the data collected. Edgerton (1975), Emerson (1985) and Lakin, Bruininks and Sigford (1981) have discussed the power relations between staff and persons with intellectual disability following deinstitutionalization. What was experienced by Midge at the outset of the interview may have been part of a subtle exercise of power relations or a paternalistic view of how to address the interview situation. After I asked Midge to sign a consent form to participate in the study, the staff person ceased intrusions into the interview.

One aspect of personal autonomy has to do with the residences of participants. Many decisions are made about a place of residence. The people who participated in this study were supposed to be treated just like their neighbours and to have an opportunity to make decisions about their homes. Midge moved homes during the few weeks of the interviews process. The home that her roommate and she moved from had been their residence for over three years. The home was rented by a community based residential board and this board made the decision to move her to a more suitable home which was six or seven kilometres from her former residence. Both of the residents and staff personnel viewed the new location before the move. Midge stated that

she had been in five different homes in the approximately fifteen years since leaving Exon House.

Midge was asked about how the new home was selected. Her response indicated that the board and staff selected the house before Midge and her roommate saw it. She said, "They try to surprise us". Midge very proudly described the new house, the bathrooms, sleeping arrangements and furniture. The new residence was a sharp contrast to the descriptions of Exon House from the 1981 report <u>People and Communities</u>.

Midge had been working for several weeks up to the time of our interviews, but following our first interview she was asked to leave her employment. Apparently, difficulties arose at work and the personnel who had supported that work placement felt that the best alternative was to look for another. Midge felt very upset and confused about losing her job and did not wish to speak about it. She received the support of an employment-support agency through an employment counsellor and a co-worker. The co-worker's role was to assist and support Midge at the job site in order to ensure that the assigned work was completed. The employment coordinator's role was to seek work opportunities, arrange support and training with the employer, prepare an individual for employment, and work in conjunction with the co-

worker to remedy difficulties that might arise at the jobsite. Midge did not report if there were any plans to work elsewhere subsequent to the termination of her job. Midge stated that she loved her work and felt that the most important aspect of her job was the friendships she made.

Household activities

Some of the areas discussed with Midge were house cleaning, grocery purchasing and meal preparation. These areas revealed a great deal about the level of autonomy related to some of the major activities in her home. The first information that was gathered related to the cleaning and decorating of the home. Midge reported that, "All of us" in the house shared with the cleaning. There was a schedule for things like scrubbing the floors: "Once a week I do the floors, [staff] will mop it sometimes. [Staff] will do the bathroom if I don't have time". What was not clear was how the tasks were chosen or assigned. Midge did make it clear that if she was short of time the staff would do the cleaning task. When Midge was asked how most decisions were made in their house, she replied that, "Everyone is pretty easy to get along with". In respect to decorating their house, Midge replied, "We all share about

that. I can decorate it (her room) sometimes". Midge's
report that everyone at the home was easy to get along with
may have been a recognition of the hierarchical power
structure in the home, which may be evidenced by the home
finding, decorating, cooking, meal planning and grocery
purchase.

Midge reported sometimes participating in grocery
shopping. According to Midge, when the staff members of the
house went grocery shopping, they alternated each week
between the two residents of the home. Midge reported that
the staff were teaching her about price checking, "Yes I be
with them. They take me with them. I check on the price,
[staff] teach me. [Co-resident] has turns each week. [She]
went last week, I go this week". The purchasing of the
groceries remained the responsibility of the staff and Midge
reported that she had no role in handling money. Further,
Midge did not indicate any role in assisting with decisions
regarding the grocery list.

Meal preparation arises from grocery planning and
purchase. Midge said "Sometimes yes, sometimes no" when
asked about the meals. She did report that sometimes if she
didn't like or want what was cooked then she could cook

something for herself. However, when asked what she might cook, Midge stated that she didn't prepare food:

> Sometimes I don't like certain things, if [staff] cook and I don't want it I cook something for myself. Sometimes I cook on my own, sometimes I cook - heat up food, leftovers. Don't make food only leftovers until [staff] teach me the right way.

Midge was also asked about breakfast because sometimes she rose very early. She said that breakfast was ready when she got to the table. The role staff played regarding meal preparation may be an act of kindness or support but it may also limit opportunities of decision making, independence and skill development for Midge and her roommate.

The other members of the study group were also asked how decisions were made in their homes. Responses were split among others deciding, participant deciding and a compromise between the two. The degree of influence by others on the decisions of the former residents of Exon House has significant impact on their personal autonomy. Participants were asked if others influenced their decisions. Ten participants reported that they decided about things on their own and three indicated some influence by others. Midge indicated that others had influence on her decisions mainly because she asked for help when making

decisions. Influence on decisions can be exercised in subtle ways and may occur without direct intention, persons working with people who have disabilities must be skilful in ways of accommodating for issues of dependency. I don't know if Midge would understand paternalism but an outside observer could reasonably conclude that paternalism likely has an effect in such a fashion, stemming from a hierar- chical power relationship.

Meals, food purchase and preparation, cleaning and home decoration require many decisions and a high level of cooperation among persons living (and working) in a home. When other former residents of Exon House were asked if they purchased groceries, four indicated yes. All the affirmative responses were from persons who lived on their own. In addition to Midge, two indicated they took turns or sometimes went for groceries with staff. In fact, one person reported not ever having been in a grocery store. Only one person, other than those who lived alone, indicated making a contribution to a grocery list.

The study group was asked about decisions on meals. Eight indicated they did not generally decide on meals. Only one person reported having had any significant contribution to meal planning, and participated in making a

grocery list. However, that person did not regularly
participate in grocery shopping. Comparison by typology
groups indicated that decisions about meals were skewed
toward persons in paid relationships in Groups B and C.
This would be accounted for by the high number of persons in
paid relationships at these residential settings. Prepara-
tion of meals, grocery shopping, decorating the home, and
cleaning are areas where skill development could be encour-
aged. Developmental or learning opportunities could arise
on a regular and frequent basis in the area of grocery
shopping and meal selection and preparation.

Only five members of the study group reported that they
had prepared a complete meal. It should be emphasised that
four persons lived on their own and only one of them had any
difficulty cooking. Eleven indicated they at least made
simple meals such as toast for breakfast or hot dogs for
lunch. The data about meal preparation suggests that some
teaching and practice had occurred to enable the reported
level of skill. Responses also indicated that there was
very little of such developmental work occurring during the
time of the interviews.

These data from questions about household activities
suggest that only a limited effort had been undertaken to

enhance the life skills of the persons who once lived at Exon House. The relationship between grocery selection and meal preparation is important in the above discussion for if there were more involvement in grocery selection and purchase it could have led to greater involvement in meal preparation. Further, the skill level within the study group for meal preparation would possibly improve and may have a positive affect on autonomy and self-esteem. In contrast, low skill and the absence of efforts to enhance skill may serve to maintain the inequitable power relationships between staff and respondents and limit the autonomy of persons with intellectual disability.

Other influences on autonomy

In this section other factors which could affect the level of autonomy experienced by Midge were explored. There were several: with whom she lived; could she move; how did she get placed with the residential board?; restrictions on movement; and any other restrictions or rules. Decisions about with whom the former residents of Exon House lived were part of the subject of this thesis. Midge indicated that she had invited her roommate to live with her at the community board residence. Midge was asked, "Could you move if you wanted to?"; she replied, "Yes, moving later this

week". I was not sure of Midge's understanding of the
question for her response seemed to be in relation to the
present situation of moving to a new house. However, it
appears incongruent with choice giving and normalization
that Midge would not have input into the decision about the
selection of their new home. The subtlety of the power
relations between the board and the residents of the home
appeared to be concealed from Midge. While boards of
directors are responsible to provide the living arrangements
for some of the former residents of Exon House they must be
diligent in advancing the skills and independence of the
individuals in their charge.

When the other participants were asked could they move
if they wanted to, all persons indicated yes. The responses
to the question about moving from the place where they lived
were compared to responses of a previous question: "How did
you come to live in this place?". The responses indicated
that most participants were placed in their living arrange-
ments by others. The issue which was the focus of this
inquiry was the choices of the former residents of Exon
House. It would appear that choice was limited,
particularly as evidenced by Sarah. Sarah spoke about the
choice given while living at Exon House when a foster home

became available: "There was an option to refuse to go but this was the only choice - who would take someone my age".

Christine reported about moving to a co-operative apartment, "No, that was understood when we moved there, we didn't know who we were going to see". When asked did you choose the people you lived with Walter reported "Not really, not me, no". Further, when Marvin was asked to describe the present living arrangement, he stated "I belong to [a community-based residential board]", suggesting strong influence of the board on the individual. Christine, Walter and Marvin were from Residential Type B: Community Board Residences.

A comparison of the responses to both questions about residential choice leads one to the conclusion that little if any decision making was granted to the study group about their living arrangements. Given that most participants were placed by professionals into the care of people in paid relationships, systemic support for moving outside the residential program might be questionable. Participants believed they could leave their current residence. However, if any of the participants attempted to exercise their freedom to choose their residential situations one would

have to wonder about the system-wide support for such a decision.

Another indicator of personal autonomy was explored by asking study participants if they could come and go as they wished. Midge initially indicated that she could go out by herself. Further discussion indicated that there were restrictions placed upon this 27 year old woman. Midge didn't have to be accompanied when she went out but it did not appear that she went very many places on her own. Midge reported that she could go on her own in the daytime but "Not after dark". In respect of freedom of movement, only four persons indicated they did not go out unaccompanied or had certain restrictions of movement placed upon them such as the time of approaching darkness. However, subtle restrictions could not easily be measured but it did appear that in addition to Midge, several other persons had restrictions in the area of personal movement. Some examples were: having to rely on rides to and from places; having to report the destination when going out; not having employment; or not being in a training program. The two latter restrictions are subtle for if a person worked or was involved in a training program there would likely be expectations to participate in activities evolving from the social structures with that organization. For example, co-

workers could go out for a meal or attendants of the training program might volunteer at a community function - to limit participation in work or training programs would limit·choices and decisions about social activities and participation in the community.

To inquire about other forms of restrictions the study participants were asked if there were rules in the house that they did not like. Midge reported that she did not like "To have to call home, to have to be in at a certain time, dishes, chores, to tell where I'm going". And she added people nagged at her. Seven other members of the study group reported that there were rules in their houses that they did not like. Some included not touching other people's belongings, overnight guests of the opposite gender having to sleep on the couch, and being told what to do.

Midge was asked, "Are you able to have friends over to visit at any time?" This question was also used to ascertain the level of the decision making granted the former residents of Exon House in the places they now lived. All participants answered yes to this question. However, as reported earlier in the chapter, most friends of the study group had staff responsibilities or were in a paid relation- ship. Thus the notion of friends coming over at anytime had

less significance in that few of the former residents of
Exon House had non-paid friends. Several participants in
the study qualified their response and reported that they
could have people over if it were not too late, or if
someone in a staff or paid relationship was also home.
Again there remains some question about the measure of
control that existed when it might be determined that the
former Exon House residents had few friends and limited
family relationships.

Summary: Social linkages and personal autonomy

Family involvement was found to be a less than
satisfying situation for the former residents of Exon House.
Lord and Hearn (1987) reported on a family support strategy
which focused on individualized services and meaningful
parent involvement in planning for the family member. This
strategy may have contributed to the differences found
between the findings of this thesis and the situation in
British Columbia. The findings of this thesis suggest that
little meaningful effort had been made to work with the
former residents of Exon House and their family members in
re-acquaintance processes. The study findings reported by
Conroy and Bradley (1985) that visiting patterns had not
changed following movement from the institution may have

been replicated in the situation of the former residents of Exon House had it not been for the current trend of researching family tree and finding family members.

The data reported in this thesis indicate that the former residents of Exon House had few friends and that most of the people they called friends were persons in paid relationships. When asked to whom would you speak if you were worried about something, well over half (65.6%) of the names given were persons in paid relationships and only persons in Residential Group A reported they would speak to family. The situation regarding the social linkages of the former residents of Exon House appears to confirm the report of companionship found in the research of Bercovici (1981). Rosen and Burchard (1990) reported similar findings regarding the role of staff in companionship and support roles.

Many opportunities for social linkages were absent because so many of the former residents of Exon House did not work. The issues related to work are more fully discussed in Chapter 5.

Volunteering is one of the easiest ways to become involved in neighbourhoods and communities. Not one of the

study participants were volunteers during the time of the
interviews, and participation with neighbours was limited.
The goal of normalization states that maximum community
participation should be sought for persons with intellectual
disability. This has not been found to be the case for the
former residents of Exon House.

The personal autonomy of the former residents of Exon
House has been influenced by their experiences outside the
institution. The research of Butler and Bjaanes (1978) and
Bercovici (1981) strongly suggested that teaching opportu-
nities must be provided to enhance skills needed for com-
munity participation. Many of the former residents of Exon
House reported that they were not involved in training
programs that could positively affect autonomy eg., making a
grocery list, paying for groceries, cooking, etc. No-one
from Residential Type c attended any formal educational or
training program. Two individuals from each of Residential
Types a and b attended formal educational or training
programs. A comparison of the Residential Types indicates
that for all groups participation in such programs was low
or non-existent. No participation by members of Residential
Type c suggests that less emphasis was placed on partici-
pation in formal skills training programs for persons living

in Alternate Family Care or Board and Lodging arrangements than the persons in other Residential Types.

There were a number of examples that seem to substantiate an assertion that there was limited activity focused on personal autonomy. Midge periodically accompanied the staff to purchase groceries while retaining a minor role in this activity. She reported a lack of participation in making a grocery list. She neither handled money nor participated in the purchase of the groceries. Furthermore, she did not attend every grocery shopping event. While Midge did report that she checked the prices, she did not have any significant responsibility for the activity. In addition, meal preparation activities (cooking) reported by Midge indicated that there was also a lack of instruction provided in this skill area. The situation was similar for other members of the study group except for those who lived on their own. It appeared that where staff lived with the members of the study group there was less instruction in the activities that could increase autonomy. Emerson and Hatton (1994) reported that in some residential settings, activity levels observed were at the same level observed in institutions. The data collected in this thesis and the work of Henry et al. (1996), Bercovici (1981), and others suggest that much work remains to ensure

that the goals of deinstitutionalization are accomplished
for the former residents of Exon House. An example would be
the case where I was not even permitted to ask a former Exon
House resident to participate in the research. That former
resident was restricted in making a decision about
participation in this research.

Absence of skill development in the home, not having
friends over and the subtle restrictions on movement
strongly suggest structures of dependency. Few of the homes
in which the former Exon House residents lived seemed to
provide enriched activities in either internal programs or
external contacts. In fact, there seemed to be little
encouragement for external contacts as might be found in
jobs, educational programs, volunteer activity or
club/service group activities. It may be that few external
activities are provided because few preparatory skills have
been taught. These themes arising from a discussion of
autonomy may stem from a paternalistic attitude of persons
in close contact with the former residents of Exon House.
Henry et al. (1996) reported differences in attitudes
between higher level staff and support staff. This may help
to explain how normalization goals may be a focus for
community boards, government organizations, etc. but these
groups must ensure the guiding orientation is brought to all

staff involved in the delivery of service to persons with intellectual disability.

This chapter contained data and discussion of social linkages and personal autonomy. Chapter 5 will contain data on personal satisfaction and self-concept along with a discussion of the data in relation to a major driving force of deinstitutionalization - normalization.

Introduction

Chapter 5 explores the issues of personal satisfaction and self-concept of former Exon House residents. This chapter, like chapter 4, contains data from semi-structured interviews conducted in their homes. In particular it examines how work, wages, income and other related areas might contribute to personal satisfaction. Additionally, the chapter explores the respondents' self-concept. Finally, in order to examine the influence of one of the major driving forces of deinstitutionalization, the reports of the study group have been contrasted with the principle and practices of normalization.

Personal Satisfaction

The concept of personal satisfaction is important to an understanding of the effects of deinstitutionalization on the former residents of Exon House. Deinstitutionalization was undertaken because it was thought to be beneficial for residents. An important indicator of being beneficial is the satisfaction of the interviewees with the experiences at their new residences, and in the community. Personal

satisfaction is linked closely to the second concept discussed in this chapter, self-concept.

Personal satisfaction is thought to indicate one's level of contentment with current life experiences. It is presumed to have several dimensions: living arrangements, income, employment, recreational activity, etc. These dimensions will be discussed in this chapter.

Tom's story

The typology, described in Chapter 4, was developed to assist in illustratively summarizing the data collected from the former residents of Exon House. Tom was chosen from the group in Residential Type C, because his position was similar on most variables to other members of the group. He worked, had wages as income but did not attend an educational program. He had been reunited with some of his family members 6-8 months before the interviews for this thesis, he received phone calls from one sibling "Scattered time" after the initial contacts. Tom was tall, tidy in appearance and cleanly dressed in comfortable clothes for the interview sessions. As I was welcomed into the house for our first interview session, Tom appeared polite, articulate, and confident.

At the time of the interviews Tom, a 30 year old
bachelor, lived with a family as part of a program called
Alternate Family Care. He considered the people with whom
he lived to be like "family". In the home, Tom had his own
small room and access to the common areas of the house. He
had a stereo in his room but no TV or other items of large
financial value. The family prepared the evening meal while
he was responsible for his breakfast and a bag lunch to take
to work. Tom did not assist with groceries, cleaning or
laundry. He reported that he could use the telephone when
he wished and have friends over to visit. Tom went out
alone and reported that he often went to a local mall. He
did not go out often because of a traumatic experience -
some youths harassed and chased him. Tom felt his health
was all right, and reported that he ate well but felt he
might like to eat different sorts of foods. He did not
smoke or drink alcoholic beverages and the only drugs used
were by prescription.

Tom's income and living arrangement

For many people income and living arrangements are
inextricably linked; for the former residents of Exon House
this also appeared to be the case. The data reported in
this section include information about wages, other forms of

income, and the cost of living for the informants. In
addition, there will be some data on the ability of income
to meet the needs of the former residents of Exon House.

Money appeared to be a sore point for Tom, although he
earned an average wage (above average relative to the study
group) and he felt that the wages he received were enough
for the work performed. However, he did indicate it cost
him a great deal to live. Because he was working, Tom was
required to contribute to his cost of living. Based on
Department of Social Services regulations for persons with
disabilities, earnings from wages had to be applied to
support costs with the remainder retained by the individual.
Because Tom worked, the formula used by the Department of
Social Services was that he could keep the first $95 of his
monthly wages and the remaining wages would be applied
against his support costs. Tom could keep any additional
wages remaining after his support costs were paid. The
Department of Social Services would pay any difference if
wages were insufficient to cover the support costs. Support
costs include: board and lodgings; respite; weekend
respite; vacation respite; home support worker wages; etc.
Tom's support services costs were probably quite low;
therefore, he might be retaining slightly more than the $95
allowable earnings per month. The wages retained by Tom

would have to cover recreational and clothing costs as well
as pocket money for the month.

When Tom was asked if he had enough money to purchase
the things he needed, he replied: "Not so often". Tom said
he had enough money left over for clothes, bowling, tapes
and CD's. However, in responses to other questions a
contradiction was noted, it appeared that Tom did not
regularly go bowling nor did he own any CD's. Tom's
responses in this area suggest that after paying support
costs, clothing expenses and other basic expenses there was
little money available for recreational or social activity.
Tom was regularly exercising choices regarding money but the
choices were likely severely limited by available funds.

When the other participants were asked if they received
enough money to purchase needed items, all of the former
residents except three responded in the affirmative. Sarah
and Rob (two people who did not work) in addition to Tom
felt they did not have enough money to provide the things
they needed. No-one from Residential Type B reported they
did not have enough money to purchase the things they
needed.

Wages and income when considered with some of the costs of living revealed that many members of the study group lived in poverty. Tom was the only member of the study group who worked full-time and directly contributed to his cost of living from wages. Members of the study group who lived in Residential Type B: Community Board Residences, did not contribute to their support and living costs. They did not receive social assistance. Funding for their care was provided directly to the board from the Department of Social Services and an allowance was provided for discretionary spending. Persons, who lived in Residential Type C: Alternate Family Care or Board and Lodging arrangements and were not employed, received social assistance and support services paid by the Department of Social Services.

For the people in Residential Type A: Living alone or with companions, the situation was similar. If not employed, they also received social assistance and their support costs were paid. Both Sarah and Rob reported they did not receive enough money to buy the things they needed. Sarah had recently closed a claim with the Unemployment Insurance Commission after 13 years of work and had to apply for social assistance. She would receive substantially less income than enjoyed in previous years.

Satisfaction with income likely was related to the Residential type. Only three respondents from Residential Types A and C indicated any dissatisfaction with income. The ability to be self-sufficient is directly related to income and an individual's ability to manage financial resources. For persons living in Residential Type A: Living alone or with companions and in Residential Type C: Alternate Family Care or Board and Lodging arrangements, income was very important because they had to pay their own way. For persons who lived in Residential Type B: Community Board Residences income was only important as pocket money because it appeared they did not contribute financially to their living situation.

Several members of the study group managed money with the assistance of paid staff. While the level of responsibility granted to members of the study group who managed their own money may have been high, the responsibility of the staff to provide guidance in money management was also probably high. The data indicated that generally speaking most persons reported that they had sufficient money to manage their needs. However, this statement must not go without qualification; wages were low; persons in paid positions helped to manage income; and for some no wages went towards living costs. There were likely

disincentives to work, for example, if more members of the
study group worked and earned wages they would also have to
contribute to their cost of living as did Tom.

Tom's work and recreational activities

An individual's feelings of satisfaction may be linked
to the activities and experiences which fill up their
available time. Tom's experiences and activities may reveal
how opportunity, as discussed by Emerson (1985), can have an
impact on the lives of persons moved from institutions to
life in the community. The dependency relationships between
care providers and persons with intellectual disability is
also important in the discussion of personal satisfaction.

Tom, employed full time in an office setting comprising
about 15 people, liked his supervisor because he had done
several favours for Tom and appeared to look out for him at
the office. Tom reported that he enjoyed his work and had
no wish to perform any other kind of work. When asked what
was the most important part of his work, he replied, "All of
it". The people at work treated him, "Alright", and if Tom
were ill, "Sometimes someone else would take my work". Tom
was quick to point out that he wasn't sick very often. From
the discussions with Tom it certainly appeared that he liked

his work and that his work attitude was likely the sort an employer might value.

When asked what was the most important part of work the responses included: "Balance the cash", "All of it", "Get it finished", "Customer satisfaction" and two respondents stated "Be on time". Members of the study group reported they enjoyed their jobs when they could get employment and seemed to understand the important aspects of their jobs.

One participant, Dennis, captured a sense of futility about finding employment, likely held by many people, he said, "I know there's not much work around, so why bother". Employment support programs for persons with intellectual disability were available to the former residents of Exon House. However, this does not appear to have had any significant effect. There is a phenomenon called "creaming" in which the most able members of a group or those most likely to succeed are taken into a program. If the creaming effect occurred in employment programs one would find that only the least intellectually disabled persons would be involved in a support program, and conversely persons who were significantly more challenged would not be involved in the program. For employment programs it is difficult to tell if the creaming phenomenon is in effect because I have

very limited information about anyone other than the former
Exon House residents who participated in the programs.

Tom's recreational activities included bowling
organized once a week by volunteers for persons with
intellectual disability, visits to the mall, and sometimes
attendance at church. In the summertime Tom went on long
day trips to places such as the waterfront or the airport.
He was not involved in any volunteer work but did state that
he helped people by shovelling driveways, carrying in
groceries, and helping with the dishes. The other study
group members reported that they participated in a wide
range of recreational activities. They reported; bowling,
going to the mall, listening to music, darts, softball,
floor hockey, tennis, and play electronic games.

Tom's health, hunger and thirst

In the area of personal satisfaction issues of personal
comfort are important. They include health, food prep-
aration, food consumption, alcohol use and drug use.
Examination of these and other areas provides an indication
of the level of comfort experienced in the lives of the
former residents of Exon House.

Tom, like other members of the group, was asked about his health and if he were on any medication or receiving treatment for any illness or condition. To the first question, Tom and most other participants reported their health was fine. The only exception was Joan who reported a problem. She reported "I have a problem but the doctors can't find out what it is". The responses to the question on the use of medication or treatments added information to the self-reported descriptions of health matters. Seven participants reported some use of medications and treatments for illnesses or conditions. Tom and four others admitted taking medication for seizures. The medical conditions that the other study group members reported appeared to be well managed, and no-one, other than Joan, provided reports of any unresolved health issue.

The former residents of Exon House were asked about their diet. They suggested they were satisfied with the foods eaten. Persons who lived on their own reported eating a wide variety of foods. Only those who lived in community-based board residences, described consuming junk food. Likely, several factors were involved; some maybe could not afford to purchase junk food because of low income, the influence of persons in paid relationships, or choice. The former residents of Exon House who lived with others

reported generally having their meals prepared for them. The responses to the questions about food consumption suggest that the former residents of Exon House ate reasonably well and had ample food available to them.

The study group members were asked about tobacco, alcohol, and drug use; the frequency of use, effect on health, and financial cost. Only Bill and Rob reported that they smoked cigarettes at the time of the interviews. Bill, who lived in a community board residence, said he spent $6 a week and Rob, $18.

When participants were asked whether they used drugs or alcohol, no one reported using drugs. Seven of the participants reported the use of alcohol (beer, spirits, or wine); four, using alcohol when it was offered every couple of months or on special occasions. Midge was asked if she and her roommate could consume alcoholic beverages (beer, liquor or wine). Her response was, "Yes, beer, rum, wine coolers, and vodka. Don't drink very much, once in a blue moon." She did indicate that, "At a friend's house I chipped in on a case of beer." Four reported that they did not drink, and two participants stated they were not permitted to drink when they wished. Tom said he did not consume alcohol. Bill reported consuming two beers about

every two weeks when out at a bar; and Rob, consuming a six-pack of beer each week. There did not appear to be widespread use of alcohol. This might have been mitigated by a number of factors including subtle controls imposed by those in charge, lack of discretionary income, influence of staff, and personal choice.

The final question asked in this grouping of questions was: "Are you satisfied with your life?". All members of the study group responded yes. Only three members of the study group provided more than a simple affirmative response. Midge reported, "I'm trying to change my life, ... I'm trying to be a better person". Rob responded, "Satisfied with everything that's going well for me". Sarah also stated yes to being satisfied but added, "Sometimes it's lonely, the majority of places I go, I go alone; it would be nice to have someone to do things with". Tom replied, "Oh yea".

Self-concept

The final conceptual area explored in the interviews with former residents of Exon House was self-concept. Wolfensberger et al. (1972) and Wolfensberger and Thomas (1983) suggested that there was circularity between

expectations and role; the way others react to a person with a label and the way a person with a label responds. These suggestions confirm the notion that self-concept changes based on interaction with the social environment. The research undertaken for this thesis examines self-concept from a "moment in time" perspective. This involves the following issues: differentness; thoughts and aspirations; and why they had to live at Exon House.

Who was Sarah?

Sarah was selected from the typology because she represented the experiences of the persons living in the least restrictive residential grouping. She had been moved from Exon House to a foster home where she stayed for about 10 years. After leaving the foster home she had lived in her own place for nearly 7 years. Sarah had not frequently moved residence as had been the situation of other members of the study group. Sarah's home was neatly kept, with personal mementos and pictures around the home. A little over a year ago Sarah had chosen to leave work and subsequently elected to attend school for upgrading. She had been living on social assistance since unemployment insurance benefits expired. This resulted in a substantial drop in income in the past year. Sarah reported she had

been able to manage her own financial affairs over the years for she had purchased and paid for several major appliances and furniture.

Sarah became re-acquainted with some of her family and maintained contact with several sisters. Sarah said she did not understand why her parents never contacted her over the years. The relationship with her mother was seriously affected by Sarah's institutionalization. Sarah reported that the contact with her mother felt odd and Valentine's cards were too mushy to send. Sarah stated: "I don't know her, she wasn't there when I was growing up". Sarah also reported that her foster mother was one of the most important people in her life, and that Sarah called her every day. The foster mother didn't phone Sarah. She wished, "I'd like her to call me sometimes, I send her cards". She considered her foster family to be her "real family".

Sarah enjoyed an amiable relationship with the neighbours. They fed her cats when she was away and they came over to borrow items. Sarah said she would drop in to her neighbours' homes but not so much in the winter because it was difficult. She indicated that she enjoyed dancing and swimming but did not do a whole lot of those types of

activities any longer. Sarah reported that she did not go out often "I figure most other people are busy, my time might not be their time."

Sarah and some thoughts on differentness

Sarah was asked: "If people ask is there something different about you, what would you say?" Sarah indicated that sometimes people have said to her that "You look happy today" or "You get around well". She said: "I'm used to that"; most frequently her reaction was to "Pass them off". Sarah reported "It's the least of my worries what someone thinks about me because of my disability." Other members of the study group offered responses that suggested they did not think of themselves as very different from the general public. Some of the other responses were, "I'd say something like, 'I'm the same as you'"; "Nothing different about me, they think I'm different"; and "I'm not handicapped, ... probably I was then, but not now".

The responses of the study group were defined by two categories, those who seemed to recognize differences between themselves and others and those who saw no difference. Of the respondents in Residential Type A: Living alone or with companions, no-one reported that they

were different from the general population. The reports of
the study group indicated that eight of twelve respondents
(or 67%) reported that they thought of themselves as the
same as the general population and only four (33%) thought
of themselves as different from the general population.
Jahoda et al. (1988) observed that 75% of their subjects saw
themselves as the same as the general population. There was
sensitivity to the disability status but it did not appear
as high as the 50% rate found by Turner (1983).

The second question was, "Do people treat you
differently from the way that everyone else is treated, and
if so, why do you think that happens?". Seven persons felt
they were treated differently than everyone else and
provided some indication of the context in which it had
occurred. Sarah offered a reason why persons might be
treated differently. Her speculation was that "Some see the
disability first, it comes down to attitude, it's what
people think. No-one got control over that, other than that
person". Joan reported that people tended to treat her as
if she were a little girl. Other responses were: "People
try to make me happy"; "When I go to a store people will
help now"; "Nasty sometimes"; and "People won't leave me
alone". For the remaining members of the study group who
believed they were not treated differently, the data

indicated they felt accepted by the community as they went about their daily activities. It may have been that any different treatment was affected by companions because many of the study group were accompanied when they were out and about the community. Three of the persons who reported differences in the responses from the community lived with mobility challenges. The findings of Cahill and Eggleston (1995) suggested that companions of wheelchair users may affect the attention drawn to or away from the person with a disability. The data from the former residents suggest that similar effects may exist for the former residents of Exon House.

How the public treated the former residents of Exon House could not have been as a result of living at Exon House because most of the public would not know who had resided there. Differential treatment would be more likely because of readily identifiable aspects of the disability. Most of the former residents of Exon House had experienced being treated differently. The former residents of Exon House who received differential treatment from community members would have a self-concept shaped by this experience. The data reported in this section suggest that many of the study group have been treated differentially and that their self-concept was likely affected by those interactions.

Sarah was asked,"If you could change anything about yourself, what would you change?". Sarah was one of three who answered they would change nothing. Sarah stated, "I'm contented with who I am that's what it all boils down to in the end" and Tom said, "I'd be the same". In the study group nine of twelve respondents offered things they would change about themselves and almost half of the changes identified were about behavior. The data may be significant in that they may mirror the general public's attitudes. Many people would like to change things about themselves.

Sarah and the others were also asked, "Do you sometimes help other people, what are some of the things you do to help others, and how does helping others make you feel?". Sarah indicated, "I help people sometimes and don't even realize it. Being able to sit and listen to someone is very helpful. I'm a good listener." Sarah told about offering to volunteer; "I knew they needed volunteers, I offered but they didn't reply". Participants reported helping others by, "Talking and support"; "Shovel driveway [and] help with dishes"; "Being nice to others"; "Hold the door"; and "Clean-up". One participant reported frequently offering help but that people always said no to the offer. The absence of volunteer activities appears to be inconsistent

with the aspirations of the group. It may be that organizations that use volunteers believe that persons with disabilities are not able to contribute in any meaningful way. People in support roles to former residents of Exon House may also believe such an idea. The combined result would be limited opportunities for the former residents of Exon House to engage in volunteer work.

The data reported in questions related to differentness suggest that 8 of 12 respondents did not think of themselves as different from other community members. The study group knew of areas in their personal development that they might like to change and some physical attributes they wished they could change; not unlike the general population. In addition, the data strongly indicated that many of the participants in the study were proud that people they knew spoke positively about them, and that they liked to help others.

Some of Sarah's thoughts and aspirations

Sarah and the study group were asked several questions about their lives. In response to the question, "What do you think about your life?", Sarah responded

No complaints about my life, my life is good. I think
sometimes I'm lucky. I got a half-decent place. I
have the Lord in my life, that's the most important.
I'm happy most of the time, you have your down days and
your up days.

Several persons had negative opinions of their lives: "It's
not a good life"; "Good life sometimes and sometimes a bad
life"; and "Not the same this past two years". All other
responses were positive.

Participants were asked did they think their lives were
better now than last year and did they think their lives
would be different in the future (or next year)?" All the
respondents indicated "Yes" their lives were either better
or the same as those of last year. Five respondents did not
answer the questions. Sarah had clear ideas of what the
future would hold for her.

I just can't see myself inside these four walls until
I'm 65. I have to keep on going at what I'm doing. I
always know where I'm going and that sometimes scares
people off. I'd sooner be alone than be married and
unhappy. I'd like it to be different (in the future),
get my grade 12 and my computer course, serve (the
church), and get married.

Some of the other responses regarding the future were:
"Schooling ... and a job", "An apartment", "A close personal
relationship" and "Not too much different".

The thoughts of the study group on their aspirations
for the future suggested they had long term plans about
residence, employment and relationships. Most participants
spoke positively about their lives but there were several
who indicated that their lives were less than positive. The
majority of the study group indicated they expected life to
be different; and they seemed to have formed some goals in
this regard. The data strongly indicated that participants
felt that their lives were either the same or better than
previous times.

Why they lived at Exon House

Members of the study group were asked why they thought
they were sent to live at Exon House. Sarah reported that
as far as she knew she was told that "They felt they were
doing better by me to put me elsewhere". Joan suggested
that the family's decision must have been difficult; "I
think my father did not want me there, mother could not
handle" the challenges of raising a child with a disability.
The responses indicated that nine former residents believed

that their families were unable to look after them or that it was the best thing. Three former residents reported they did not know why they went to live at Exon House.

The reasons that members of the study group went to live at Exon House were related to the issues of their care. Few community-based supports were available and likely the consensus of opinion was that children with disabilities needed special care. Families probably believed they could not provide the necessary care for their child. The new residential institution provided an additional challenge to families because "professional" services were available at the institution. These events placed families in a dilemma - send a child away or keep them at home (and provide less than the best opportunity).

Summary: Personal satisfaction and self-concept

The data strongly suggested that the health of the former residents of Exon House was satisfactory, and health issues appeared to be well managed or had received investigation. Support staff or persons in paid relationships and helping professionals would likely ensure that health issues, as well as money management and alcohol use, were attended to and well managed.

The incidence of low wages, having to ask for money (allowance), few friends, and the influences of persons in paid relationships could be expected to have a limiting effect on many aspects of life. It is likely that if persons lived in the homes of others, Residential Type C: Alternate Family Care or Board and Lodging, or in Residential Type B: Community Board Residences there would be heightened awareness regarding health issues, money management and the use of alcohol or drugs. Because helping professionals, family and friends have an interest in the well-being of the former residents of Exon House and interact with caregivers, residential board staff and other persons in paid relationships - their influence would have significant impact. Further, when social workers paid out funds on behalf of the provincial government there would be some responsibility to ensure that adequate care and support were provided. It was likely that if alcohol use was anything more than minimal, health was poor or finances were not well managed, concerns would rise. The situations might be heightened in Residential Type B: Community Board Residences where there was further monitoring by boards of directors. Even in situations like Residential Type A: Living alone or with companions, people in support positions would be concerned about alcohol use, poor health or poor money management especially in situations where paid support

staff were involved. If such behaviour occurred there would
likely be negative effects for these staff. Negative
effects on staff would suggest that for the former residents
of Exon House there were also strong but subtle controls.

Responses to questions about employment indicated that
approximately 70% of the former residents of Exon House were
unemployed. The data from the interviews indicated that 54%
of the former residents of Exon House had not been employed
for one year or more. The time spent unemployed was
significant because it meant that they would not be eligible
for federal government employment benefits and employment
training programs. They would have been eligible for at
least one program from the federal array of programs - the
self-employment program for persons with disabilities. The
study group members were also eligible for programs
available through the provincial government. There were
employment and training programs designed to increase the
employment of welfare recipients. In addition, there were
services at the provincial level designed to assist persons
with intellectual disability to secure and maintain
employment. From the data revealed in the study, programs
focused directly on persons with disabilities appear to have
been only marginally successful at finding or maintaining
employment for the former residents of Exon House.

Wolfensberger et al. (1972) commented on a paradox of
society; public welfare and dependency are condemned but
there is limited opportunity for persons with intellectual
disability to work even with available structured programs
to remedy the situation of unemployment.

The valued social role associated with employment has
not been extended to most former residents of Exon House.
It could be argued that the significantly high number of the
study group who were unemployed might be the result of the
high unemployment rate in Newfoundland and particularly
because the participants were from a marginalized group.
However, the array of federal and provincial programs
focused on employment for people with disabilities indicates
that policies have been developed to affect the situation.
Members of the study group want to work; yet only a very
small proportion of the group are employed. For those that
are not employed deinstitutionalization may result in
poverty. The situation for the former residents of Exon
House requires the development of a renewal strategy,
including evaluation processes, to secure and maintain
employment for persons with intellectual disability.

The issues which arose in the area of personal
satisfaction are strongly linked to the opportunity

framework discussed by Emerson (1985) and may have strong affects on self-concept. Employment income would provide increased opportunity for choices related to: spending, accommodations, social activities, recreation activities, etc. Such opportunities should be pursued.

The process of deinstitutionalization likely enhances the self-concept of the person leaving the institution because it could be regarded as confirming confidence in the individual. It is known that institutions, as described by Goffman (1961), provide a barrier to social intercourse with the outside community. Persons who might be perceived to be incapable of looking after themselves but who left the institution have increased opportunities for social interaction. Increased social interaction permits former inmates to believe that they had not needed to be so confined and consider as a reason for their release that they can look after themselves. This process would likely have a positive influence upon self-concept. The implications for self-concept of release into the community appeared to have allowed many of the former residents to reflect upon their skills and abilities. Further, they knew why they had been sent to the institution and the data revealed some of the effects on the relationships with their families.

Edgerton reported the adaptive strategies of denial as an activity designed to invoke non-retarded personal identities. Edgerton and Bercovici (1976) found that former residents, after living twelve years in the community, were not concerned with concealing their deviant image. As Turner (1983) found for a similar population, a number of the former residents of Exon House appeared to be very concerned with their status. Rob provides the strongest example in that he implied having mental retardation as a child but denied it as an adult; also he would not tell anyone that he lived at Exon House. It was not determined if there were any positive aspects to stigma (Herman and Miall, 1990) for the former residents of Exon House beyond the eligibility for support services and the availability of special residential services available to all persons with intellectual disability.

The notion of self-concept of persons with intellectual disability is entwined with the concept of stigma. While they remain separate concepts, it would appear that stigma could have significant impact upon the self concept of the former residents of Exon House. There was no direct comparative data for the group of former residents of Exon House. However, it is likely that they had high self-perception of stigma. This assertion is reasonably made

from the descriptions and reports of their life experiences in the institution. The self descriptions indicated that 8 of 12 (or 75%) of the former residents of Exon House, and all of Residential Type A: Living alone or with companions, did not find themselves to be different. The data were found to be similar to Lakin et al. (1981) and Edgerton and Bercovici (1976) that self-perception of stigma had dissipated since deinstitutionalization.

Chapter 6

Conclusions

Introduction

This chapter summarizes and discusses the implications
of the findings reported in the two preceding chapters and
describes some suggestions for practices in the field and
future research.

Summary of findings from the data

The major objective of this research has been to
examine the effects of deinstitutionalization on former Exon
House residents. The problem focused on in this thesis was,
what has been the impact of deinstitutionalization on their
lives so many years after the institution's closure? It was
critical to utilize the normalization principle as a back-
drop to this analysis for this idea helped guide the
development of support strategies and services. Deinstitu-
tionalization was the process that brought former residents
of Exon House into the community. Their lives were dramat-
ically affected. A description of the conditions at Exon
House supports deinstitutionalization.

Social linkages, personal autonomy, personal satis-
faction, and self-concept were the major conceptual areas of

inquiry for this thesis. The voices of the former residents were recorded wherever possible in the data so that they could be clearly heard as they described their experiences. The reports of the former residents indicated several major issues within each area of inquiry. The findings which emerged from discussions of social linkages were:

- the high number of persons in paid relationships may have impeded the development of friends,
- contacts with family were severely affected by institutionalization and
- the low community involvement found may be a result of the attitudes of persons in paid relationships and of the general public.

The findings which emerged from the discussions of personal autonomy were:

- the low skill level of the former Exon House residents impeded participation in typical community activities,
- competencies must be developed to support choice development and decision making and
- the persistence of low skill levels supports dependency relationships with persons in paid relationships.

From the area of personal satisfaction several findings emerged:

- there was unequal treatment of the former Exon House residents with regard to income and residential type,

- efforts to secure employment for the former Exon House residents have not been successful,

- there appeared to be few options and limited encouragement for the former Exon House residents to pursue educational or training programs and

- there appeared to be factors which contribute to inequitable power relations that may diminish choices and decision making activities.

Self-concept discussions revealed that the members of the study group held a strong sense of who they were and that 8 of 12 participants did not think of themselves as being different from the general public. Because the concept of self is an interactive process the examination of data was limited by the methodology of this research. The self-concept of the former Exon House residents was examined through self reports to questions in the interviews. Self-concept was also linked to notions of normalization for if positive social roles (eg. work) were offered to the former Exon House residents then there could likely be positive feedback from persons they interacted with. Further,

participation in opportunities that would positively affect the valued social role of individuals could have had a positive effect on the value the former residents of Exon House placed on themselves.

In the discussions with the former residents of Exon House it became apparent that there was a strong sense of sheltering from the challenges and opportunities of the world: few persons worked; few attended educational programs; all had their living arrangements planned and organized by persons in a paid relationship; and most lived on meagre amounts of money. These factors combined to foster dependency and hierarchal relationships. The former residents of Exon House have not attained valued social roles and maximum community participation.

Community participation

Community participation was measured by volunteer activity, work, reports of going out, church attendance, and several other factors. No former Exon House resident who participated in the study was engaged in volunteer work. Only thirty percent of the study participants were employed, few reported going out more than once a week, and only one

person attended church regularly. These factors indicate
that participation in the community was very limited.

Volunteer activity can develop from a number of
sources. It can be pursued by an individual or an agent
could broker volunteer work. Generally, it might be thought
that there is an abundance of organizations seeking
volunteers. Therefore, it would seem that there would be
ample opportunity to access volunteer work. There may be
several factors which could interfere with volunteer work
for the former residents of Exon House. They are: attitude
of the organization; attitude of persons in support rela-
tionships to persons with intellectual disability; interests
of persons with intellectual disability; and the skills of
persons with intellectual disability. Normalization
suggests that competency and attitudes can be changed,
further that interests can be fostered and developed.

Church attendance, and going out into the community may
be affected by many of the same factors. Because of notions
deeply imbedded in religious experiences, churches would
likely accept the participation of persons with intellectual
disability. Further, church attendance could lead to
opportunities that would foster participation in church-
based volunteer activities. Both church attendance and

volunteer activity require interest by both individuals with
intellectual disability and people in support roles.
Interest by a person with intellectual disability and the
persons in support roles may need to be developed within the
hierarchy and philosophy of services. John McKnight (1989)
has written about the regeneration of community and the
participation of persons with intellectual disability; he
believes that communities can be strengthened by involving
persons with intellectual disability. This discussion is
relevant to changing the situation for the former Exon House
residents.

Work is an activity that received substantial exam-
ination both in the interviews and the analysis of the
experiences of the former residents of Exon House. Employ-
ment is an activity that is sought after by the vast
majority of society. Yet only 30% of the study group were
employed. North American society often develops impressions
about others based upon their work and friendships. If a
person does not work and has very limited friendships then
their value to society may be considered suspect by some
members of society.

There was a number of programs designed to find and
maintain employment for persons with intellectual disa-

bility; yet few of the former residents of Exon House
worked. The persons selected for participation in the
interviews for this thesis were those most able to speak for
themselves and who experienced the least level of impair-
ment. The study group's skill level and employment
experiences suggest that outcomes related to employment for
all persons with intellectual disability must be very low.
In the area of work and employment, for the former residents
of Exon House, adherence to the principle of normalization
was marginal.

Persons in professional relationships and persons in
paid relationships have powerful influences upon the lives
of the former Exon House residents. There appeared to be
limited application of the normalization principle within
support systems for the former Exon House residents who
needed encouragement and support to facilitate participation
and inclusion into neighbourhoods and communities. Efforts
toward the inclusion of the former Exon House residents into
the community did not appear to be strongly pursued by those
in paid relationships, friends, advocates, or families of
the former residents of Exon House. Henry et al. (1996)
reported that staff at different levels in organizations had
different ideas about normalization. The data suggest that
finding is relevant, for the goals of normalization may not

be integrated into the activities of the staff and persons
in support roles to persons with intellectual disability.

Family and friends

Contact with family and friends was a major focus in
the interviews with the former Exon House residents. The
investigation with the study group members revealed that
they were not satisfied with the amount or quality of the
contact with their families. The frequency of contacts with
family members had fallen off for those who had recently
become re-acquainted with their families and most family
contacts were by telephone as opposed to face-to-face.
While geographic location could be a factor in face-to-face
contacts, the low frequency of home visits suggested
strained family relationships. This assertion was supported
by other data, for example, responses to the question about
who is important to you and who would you talk to if you are
worried. The role of persons in paid relationships appeared
to have replaced the typical role of the family for the
former residents of Exon House. The connection with family
had been supplanted by institutionalization. It would
appear that one of the most devastating effects of institu-
tionalization was the absence of family relationships and
that processes of deinstitutionalization had not signif-

icantly or positively affected those relationships. Efforts
should be directed to strengthen family relationships
through family and personal counselling.

The former residents of Exon House report that they
have friends but most of these friends, in fact, were in
paid relationships. It is likely that if there were more
friends in the current ratio of friends to persons in paid
relationships then community participation and inclusion
could be strengthened. Efforts should be directed at
strategies which would develop friendships and advocates
from the community.

The principle of normalization suggests that people
with intellectual disability will be perceived as valued in
society when they have valued social roles. This implies
that when people with intellectual disability have friends
who are valued there is a likelihood that they will develop
more positive reputations in the community (Wolfensberger
and Thomas, 1983). Similarly, when members of the general
public observe people with intellectual disability partici-
pating in the community with persons who have valued social
roles the public perception may become more positive. And
it is likely that when people with an intellectual disa-
bility have friends who participate in the community they

will have greater access to experiences which otherwise would not be available. With friends and neighbours there is a possibility of living an active, more typical life as members of a community (Strully and Strully, 1993). Research conducted in 1990 by Amado, Conklin and Wells (cited in Lutfiyya, 1993) reported that client staff friendships may be rare. Lord and Pedlar (1991) reported similar findings regarding client and staff friendships. There may be concerns by persons in paid relationships that more involvement in the community with friends and family could threaten the hierarchical relationships that have developed.

Policy recommendations

The analysis of the data has led to some understanding of the exercise of power and authority and the impact on decision making for the former residents of Exon House. Residential environments and support services appear to be organized around a strongly hierarchal power relationship skewed away from control by the person with intellectual disability. Several direct and indirect examples were discussed in the data chapters. Through the data analysis in the personal autonomy area it was found that members of the study group required new skills and opportunities to

further engage in community activities. The competencies
required would likely be taught as a result of efforts
provided by persons in paid relationships as directed and
facilitated by community boards, service organizations and
government employees. Also, the data analysis revealed that
efforts directed at competencies would not only enhance the
autonomy of the study group, they would likely have a
positive impact on their self-concept. These skill
enhancement projects would require sincere and skilful
application of teaching strategies (regularly reviewed and
evaluated) guided by the goals of normalization. Further,
based on assertions made in Chapters four and five, all
services providers, agencies, etc. should review and
evaluate goals for the former residents of Exon House
juxtaposed with the goals of normalization.

In addition to skill enhancement in the above areas
there should be a review and evaluation of the more subtle
and strongly influential power relationships that existed.
These influential relationships may, in part, be structured
because persons with intellectual disability live in poverty
and many had their financial resources managed by others.
Some of the study group who worked were left with very
little money after paying for room and board. Further, it
is possible that many did not work because of systemic

disincentives. The factors contributing to disincentives to labour force participation were:

- the system of allowable income (as discussed in Tom's experience),
- wages must pay for disability related support services,
- the reduction of need for residential support staff during working hours,
- the provision of transportation to and from work and
- the cost of provision for supports (if necessary) to the employer and work place.

The benefits of work are well known, work can create opportunities that otherwise might never have existed and thus it is critically important to create incentives and opportunities for people to work. The area of employment for persons with intellectual disability is an area that warrants further research.

The findings of this study suggest that the Department of Human Resources and Employment, which is responsible for residential programs, should utilize measurement tools and processes that will capture both subjective and objective data to evaluate the experiences of persons in residential programs. The measures should include, at least, social

linkages, autonomy and satisfaction self-reports from persons with intellectual disability. Further, data collection should be frequent and cumulative, collected from significant contacts or interviews with the individual with a disability. Data from significant others should also be included in the reports. Through such activity the efforts of service providers can be regularly evaluated and enhanced.

Improvement processes must be encouraged and even mandated with service providers and agencies. The values and principles which guide the agency must be clearly stated, in common language, and agreed upon by the funding entity. Evaluation processes (eg., cost benefit analysis) should be incorporated into funding agreements. This policy implication will have wide reaching value for individuals with intellectual disability who receive services (employment, residential, etc.) funded by government departments. There will also be wide reaching implications for those people and agencies which provide services funded by government departments.

Opportunity framework

A major finding of the analysis of the data was the limited opportunities available to the former residents of Exon House. The data revealed that their needs relating to shelter, food, and health were well provided for. Yet opportunities for community participation, and the attainment of valued social roles appeared to be few. Combined with increased opportunities there should be options, preferences and decision making. A framework that would develop opportunities should accept the choices and decisions of persons with intellectual disability, unencumbered by paternalistic notions. Planning for and with persons with intellectual disability should include opportunity for their meaningful participation.

The data also suggested that there must be a focus on the opportunity framework that can shape the values and behaviour of administrators who move persons from institutions and provide services in the community and the persons whose lives have been affected by the change in residence. The opportunity for social contacts and training to participate in the community must be re-emphasised for the former Exon House residents.

Intellectual disability: Fruitful areas for research

The research conducted for this thesis was exploratory
and revealed a wide array of future research options.
Several areas for research that would be specifically
relevant to the former Exon House residents, persons with
intellectual disability in general and the field of
sociology have been identified in the preceding chapters.

Edgerton's (1990) suggestion of "internal disposition"
may be an area for further research. The idea that person-
ality type influences deinstitutionalization outcomes has
yet to be examined by researchers. Different people may
have different satisfaction levels with the same item and
this warrants examination regarding persons with intel-
lectual disability. Edgerton's concept of internal
disposition may encourage researchers to examine more
closely the factors that differentiate people with
intellectual disability from the general public.

The area of employment for persons with intellectual
disability was outlined in Chapter five as an area that
would benefit from critical review. Issues such as
"creaming" and cost benefit analysis may be important to
understanding the low employment rate for the former

residents of Exon House. The goal of self-employment for persons with intellectual disability is an area that also warrants examination. With regard to self-employment an important issue is business failure. Are "safety net" services available eg. training programs, employment insurance benefits, for dealing with businesses becoming economically unsustainable.

Research efforts should also be focused on how acceptance of persons with intellectual disability is accomplished, for example, in the work place, at educational programs and at places of worship. The research reported in this thesis has shown that there can be many factors which limit participation in the community. Research efforts must be focused on models and practices that successfully gain community participation and valued social roles for persons with intellectual disability.

The lack of full integration into society and the extent to which the former residents socialize amongst themselves raises the possibility of an intellectual disability sub-culture arising. They often lived together and when they went out into the community they went to places and events in groups. The data also suggested that the former Exon House residents were lonely. If a sub-

culture were to form there may be some relief to the experience of loneliness. However, the existence of a sub-culture would conflict with the goal of normalization. A sub-culture may result from service providers and agencies wishing to bring persons with disabilities together. If such a process had occurred it would appear to have mirrored the reasons for institutionalization. Issues relating to sub-culture merit more than the limited speculations offered in this thesis. They require specific study by other researchers.

The idea that persons with intellectual disability are more readily accepted by society and that there is a tendency for some to not see themselves as different from the general population challenges the use of notions of stigma. Research focused on stigma and acceptance would provide valuable insights into self-concept and societal perception of persons with intellectual disability.

Finally, research must be focused on the development and evaluation of planning processes that enhance the life experiences of persons with intellectual disability. Planning processes that are holistic and include evaluation measures are important to support the members of society that can not fully represent themselves.

Final comments

The former residents of Exon House were moved for many
reasons from an institution to the community. Their lives
since that move have been explored. In so far as possible,
the experiences of deinstitutionalization has been recorded
in the words of the interviewees themselves. From the
analysis of the data findings recommendations were form-
ulated that should guide individuals, organizations, and
government in efforts to enhance the lives of persons with
intellectual disability who live in the community.

It is imperative to change the practices that affect
the lives of the former Exon House residents. They have few
friends, family contact is less than satisfying, they go out
into the community without meaningful involvement and many
live in poverty. With all this impacting their lives the
majority of them do not see themselves as different from the
general public. This represents a substantial accom-
plishment. The thesis strongly suggests a number of areas
where successful integration can be enhanced if areas of
current policy are carefully and reflectively reconsidered.

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Appendix 1

Interview Questions

SOCIAL LINKAGES

How long have you lived here?
Where did you live before this place?
Have you had many homes?

Who do you live with?
Did you choose the people you live with?
If living on own-- How long have you lived on your own?
Would you wish to live on your own\with others?

Do you have contact with your family?
How often?
Do they call you ?
Do you call them?
Do you visit them?
Do they visit you?
How do you feel about this contact - would you like it to be
different? In what way?
Do you think of anyone else to be "family"?
Do others think of you as family?
How do they show that?

Do you know your neighbors?
Do you speak with them -
Do you go to their homes?
Do they come to your home?
Do you go for walks with them?
Do you speak to them if you meet them in a store?

Who are the friends you have?
Where do you usually see them?
Where do you go with them?
Do you visit their home or do they visit your home?
How often do you go out with your friends?

Who else do you speak with?
What is your relationship to them?

Do you go out of the house often?
Are you accompanied? by whom?

Do you decide your recreational activities and the time,
amount of money, getting to & from, and whom would accompany
you (if necessary).
Where do you generally go for fun?

Do you work?
Do you go to a day program?

How do you get there?
Do you bring a lunch?
Who do you eat your lunch with?
Can you go out during your lunchtimes?
If you wanted could you?

Do you think of the people you work with as your friends?
Do you go places with them after work, in the nightime, or on weekends?
How often?

Do you participate in volunteer activities? Where?
How did you get involved in it?

Do you participate in any group activities such as Clubs, Church, or any other group meetings?

What do you do for fun?
With whom? Are they friends or staff?

Do you use the telephone to talk to people?
Who do you usually call?

Do you visit professional persons on a regular basis?
psychologist, Social worker, physician, psychiatrist etc.
For what purpose?
Do you receive the services you feel you need from these persons or agencies?
Do professional persons affect on your life in other ways such as advocates, supportive, volunteers,etc.

If you were really worried about something who would you talk to?

Who are the most inportant people in your life?

PERSONAL AUTONOMY

Do you think of the place you live to be your home?

How did you come to live here?

Could you move if you wanted?

Do you have a key to this house?

Can you use the telephone anytime you wish?

Do you have your own room? Whom do you share with? Do you like sharing?

Do you decorate your house/apartment? If you don't who does? Do you like the way your house is decorated?

Do you decide on meals? Who cooks? Do you sometimes cook?

Do you purchase groceries? Are you accompanied and do you decide what to purchase and then pay for the goods?

Do you do the cleaning? How much? What parts are you responsible for? How often do you do the cleaning?

Are you able to have friends over to visit at any time?

Can you go out alone?

Do you decide on the time you go to bed? ... get up out of bed?

Do you go to the church of your choice\of your religion?

Personal belongings: Do you purchase your own clothes? Personal articles? Is it done for you or do you go along?

What sort of things do other people do for you?
Who are the people who help you outside the home?
In what ways do they help?

What influence do others have on your decisions about different things? for example: furnishings / groceries / bills / outings?

Do you get to spend money the way you want?
Do you have enough money to get the things you need?

If you had more money what are the things you would like to buy with it?

Are there rules in your house that you do not like? What are they?

How do you make decisions in your house (if more than 1 person lives there)?

Can you come home any time you want?

Can you have a beer or drink anytime you want?

Do you sometimes ask for help to make decisions? If yes, what types of decisions and whom do you ask?

Do you have privacy in your life? What do you call privacy?

PERSONAL SATISFACTION

What kind of work do you perform?
Do you enjoy your work?
Would you like to do another kind of work?
What sorts of activities are involved in your work?
What is the most important part of your work?
What would happen at work if you were ill and could not go to
work?
Can others do your work?
How do people at your work treat you?
Do you think your wages are enough for the work you perform?

Do you get enough money to purchase the things you need?
Does your money last you for each pay period - if welfare,
does it last you from month to month?

How is your health?
Are you on medication or recieving treatment for an illness or
condition?

Do you eat well?
What sorts of things do you eat?
Would you like to eat different things?

Do you use alcohol or other drugs?
How often?
How much money do you spend on these activities?
How much do you consume in one day/week?
Where do you do these things?

Do you smoke? How much?
How much money do you spend on cicarettes each week?

Do you have friends?
Do your friends make you happy?
Do you sometimes help other people?
How does that make you feel?

Do you enjoy your recreational activities?
What are some of the things you do for relaxation?

What do you think about your life?
Do you think your life will be different in the future\next
year?
In what ways might your life be different next year?
Do you think your life is better than last year?
In what ways is your life different than last year?
Are you satisfied with your life?

SELF-CONCEPT

If people ask is there something (special) different about you what would you say?

If you could be different (change yourself) what things would you change about yourself?

Have you done things you are proud of? Things other people are proud of?

What do you like best/least about yourself?

What are some of the things people you know say about you?

Do you get along with other people?

Are you a friendly person?
        happy
        honest
        likable
        good
        lazy
        co-operative
        polite
        clean
        helpful

What are some of the reasons you do/do not live by yourself?

What are some of the reasons you do/do not go out by yourself?

What are some of the reasons you work/do not work?

What are the things about your life that cause you the most difficulty? ... the least difficulty?

Do you need help sometimes? What do you need help with?
What are some of the things you would like to do but cannot?

People lived at Exon House for many reasons, you lived there for part of your life, what was the reason you came to live there?

The reason you came to live at Exon House was_____.
What do you think it means to other people - staff, friends, family, others?

Some people act differently towards people who are different.
Does that affect the things you can do?

Do people treat you differently than everyone else? Why do
you think that happens?

Has your life been affected by the way people have treated
you?
Are people affected by their interactions with you? How have
you affected other people?

Please tell me how you describe yourself?

Appendix 2

Certification of Ethical Acceptability for Research Involving
Human Subjects

CERTIFICATION OF ETHICAL ACCEPTABILITY
FOR RESEARCH INVOLVING HUMAN SUBJECTS

Date: August 20, 1993

Name of applicant: Allan Corbett

Department: Sociology

Agency: Internal

Title of project: After the Institution

We the undersigned members of the Memorial University of Newfoundland Arts Research Committee, having examined the application for a grant to support the above-named project, consider the experimental procedures, as outlined by the applicant, to be acceptable on ethical grounds for research involving human subjects.

MEMBERSHIP OF THE REVIEW COMMITTEE

NAME	DEPARTMENT	POSITION	SIGNATURE
J. Hare	French and Spanish	Assoc. Professor	
M. Joyal	Classics	Asst. Professor	
P. Narváez (Chair)	Folklore	Assoc. Professor	
U. Sampath)Chair 1993β94	German	Assoc.Prof.	

HEAD OF DEPARTMENT   DEAN OF FACULTY   DIRECTOR, OFFICE OF
                                                    RESEARCH for President

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Appendix 3

Sample Consent Form

I give consent to Allan Corbett to gather information by
interview with me and by observer participation. I understand
the information is to be used in the research project _Life After
the Institution_. I understand that as much as possible
identifying information will not be used in the report. I also
understand that all information collected will be held in the
strictest confidence.

_____

Respondent