YOUNGER ADULTS WITH SEVERE PHYSICAL DISABILITIES IN THE CAPITAL REGION

Dr. Gloria M. Gutman, Keith G. Anderson
and Judith B. Killam

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THE GERONTOLOGY RESEARCH CENTRE
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ACKNOWLEDGMENTS

The research team gratefully acknowledges the many people who assisted with this project. These include: Susan Frizzell who served as liaison with the Continuing Care staff; Faith Magwood from Gorge Road Hospital and David Hook from the Vancouver Island Housing Association for the Physically Disabled who assisted with identification and recruitment of participants for the interviews and focus groups; and Susan Nickum and staff at Queen Alexandra Centre for Children's Health who completed LTC-1 forms for the 10 adolescents whose profile was the subject of the sub-study.

We wish to thank the excellent team of SFU Gerontology Research Centre interviewers Monica Bischof, Maureen Maclachlin, and Diane Sawicki; GRC Information Officer Arlene Higgs who assembled the extensive material that formed the basis of the literature review; and GRC Data Analyst, Doug Talling who processed the information from the LTC-1 forms and interviews. As well, thanks go to Carole Quick, Secretary, Pacific Health Care Society for typing the interview schedule and selected other materials.

Especially, we wish to thank the 50 clients and the 24 family members who so generously contributed their experiences and opinions in the interviews and focus groups. We trust that we have done justice to these individuals in our description of findings and recommendations to the CRD.

Gloria Gutman
Keith Anderson
Judith Killam

April, 1995

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1.0 INTRODUCTION

1.1. BACKGROUND AND OVERVIEW OF THE PROJECT

In Spring, 1994 the Gerontology Research Centre at Simon Fraser University was commissioned to undertake a project that would provide the Health Planning Division of the Capital Regional District of British Columbia (CRD) with information that would facilitate strategic planning for younger adults with severe physical disabilities.

The specific goals of the project were to:

1) define the pertinent characteristics of persons aged 19-55 with severe physical disabilities living in the CRD, including: their socio-demographic characteristics (age and gender distribution, education, marital status, housing and living arrangement, sources of income); health and functional status (diagnosis, level of performance of Activities of Daily Living and Instrumental Activities of Daily Living); and available social supports.

2) ascertain consumer preferences (clients and their families) as to the type and location of housing and support services they require.

3) critically review existing health and social service programs in the CRD and province, and policies targeted to/encompassing younger adults with severe physical disabilities, with respect to their ability to respond to the identified consumer preferences.

4) recommend the type and level of resources required to meet consumer preferences.

To fulfill the commission, the following activities were undertaken:

Phase 1. Literature Review

An extensive electronic literature search and review was conducted. Unpublished material obtained from the Ministry of Health and other contacts was also reviewed (see Gutman,1995).

Phase 2. Profile of Continuing Care Clients

Assuming that most younger adults with severe physical disabilities living in the CRD were known to the Continuing Care Division of the Ministry of Health, a client profile was constructed using information from 153 clients' LTC-1 forms, the Division's standard assessment form (see Chapter 2 of this report for findings).

Additionally in this phase of the project, a comprehensive inventory was to have been compiled of existing facilities, in-home services and resources available to younger adults with severe physical disabilities living in the CRD. This was not done since the information was found to already be available (see Appendix 1 for relevant listings from a directory compiled by CRD Health).

Phase 3: Client Interviews

Personal interviews were conducted with a sample of 50 younger adults with severe physical disabilities: 21 living in facilities, 7 living in group homes, and 22 living in the community in conventional housing (see chapter 3).

Phase 4: Family Focus Groups

Three focus groups were conducted with relatives of younger adults with severe physical disabilities. Group 1 represented individuals living in institutions, Group 2 represented persons who could not speak for themselves due to cognitive or communication impairments. Group 3 were families of individuals living in the community. The majority in Groups 1 and 3 were relatives of persons interviewed in Phase 3(see Chapter 4).

Phase 5: Sub-study of Queen Alexandra Residents

To facilitate planning for persons who, in future, would be part of the CRD's population of younger adults with severe physical disabilities, a profile was constructed of 10 of the eldest residents of Queen Alexandra Centre for Children's Health. The profile was based on information from LTC-1 forms specially completed for the study (see Appendix 2).

1.2. SCOPE AND LIMITATIONS OF THE PROJECT

The recommendations contained in this report for more appropriately meeting the needs of clients and assisting them to remain in the least restrictive environment are based on the literature review, the Continuing Care client profile, the client interviews and the family focus groups. As well, they reflect a review of current resources, policies and programs, examination of available population projections, and discussion with personnel in various divisions of the Ministry of Health.

While there are many questions around costs and benefits that need to be explored, it was beyond the scope and time frame of this project to undertake these in any detail.

2.0 THE LTC-1 STUDY

This chapter describes the characteristics of 153 younger physically disabled adults who were enrolled in the Continuing Care Program in the CRD in June, 1994. Data derive from the LTC-1 Form, the Program's standard client assessment form. Copies were received by the study team, with identifying information removed, in response to a request for forms for all clients in the CRD aged 19 to 55 with severe physical disabilities. The definition of "severe physical disabilities" was left to the Continuing Care Program staff to decide.

153 in a total population of 324,586 (BC STATS, 1994) yields a rate of 47 per 100,000. This rate is mid-way between the 40 per 100,000 reported by Harrison (1986) and the rates of 57.4 and 59 per 100,000 reported respectively, by Curry, Barton & Dansie (1987) and by Castree and Barnes (1993) in studies conducted in the U.K. While persons with some of the diseases represented in this client group (e.g. muscular dystrophy) are living longer than ever before, the profile of the group as a whole does not suggest a dramatic increase in numbers. Using population projections for the CRD shown in Appendix 6 and a rate as high as 59 per 100,000 yeilds only 209 by the year 2001 and 263 by the year 2021. As indicated in the sections that follow, although small in numbers, this group does, however, have significant service needs.

2.1. LEVEL OF CARE OF LTC CLIENTS

An earlier literature review (Gutman, 1989) and interview study of younger severely disabled adults in B.C. (Gutman & Killam, 1989) had indicated that among those who were residents of extended care facilities, there was an approximately equal sex distribution, most tended to be middle-aged at time of admission and the single most common diagnosis was multiple sclerosis followed by "other neuromuscular disorder".

Table 2.1 shows the level of care of the Continuing Care clients included in the present study. Consistent with the criterion of "severe physical disability" most (77.6%) were at the Extended Care Level.

TABLE 2.1: LEVEL OF CARE OF LTC CLIENTS (N=152)*

	n	%
Personal Care	6	3.9
Intermediate I	4	2.6
Intermediate II	5	3.3
Intermediate III	19	12.5
Extended Care	118	77.6

* as at most recent LTC assessment or review

2.2. LIVING ARRANGEMENT, GENDER, AGE AND MARITAL STATUS

Table 2.2 shows that approximately two-thirds (67.8%) of the clients were living in the community, either independently (24.2%) or with a caregiver (43.6%); 4.0% were living in group or associate family homes and 28.2% in a care facility. Their gender and age distribution was, however, very similar to that identified previously for facility residents only.

As can be seen, approximately equal proportions were male (50.3%) and female (49.7%). Just over 10% (11.3%) were aged 19-29, 50% were aged 30-44 and 38.7% were aged 45-59. The average age of the clients was 41.5 years (s.d.=9.3 years).

TABLE 2.2: SOCIO-DEMOGRAPHIC CHARACTERISTICS OF LTC CLIENTS

	n	%
Living Arrangement (n=149)**		
Own home independently	36	24.2
Own home with caregiver	65	43.6
Group Home/Assoc.Family Home	6	4.0
Facility	42	28.2
Gender (n=153)		
Male	77	50.3
Female	76	49.7
Current Age (n=150)*		
19-24	8	5.3
25-29	9	6.0
30-34	22	14.7
35-39	25	16.7
40-44	28	18.7
45-49	25	16.7
50-54	25	16.7
55-59	8	5.3
Mean age (in years)	41.5	
s.d.	9.3	
Range	19-57	
Marital Status (n=147)**		
Single	73	49.7
Married	44	29.9
Common law	2	1.4
Divorced/Separated	26	17.7
Widowed	2	1.4

* as at June 1, 1994
** as at most recent LTC assessment or review

The Continuing Care clients were also similar to residential clients described in the literature (e.g. Currey, Barton & Dansie, 1987) in showing a relatively high proportion who were or had been married. Approximately one-third (29.9%) were married, 1.2% were living common law, 17.7% were separated or divorced, and 1.4% were widowed. The remainder, just under half (47.7%) had never been married. These data, as with other information that will be presented in this report, underscore the diversity of the younger adult with severe physical disability population. The importance of considering this diversity in planning services is a recurrent theme throughout the literature (c.f.Curry, Barton and Dansie, 1987; Gloag, 1985a&b; McQuaig & Frank, 1991).

2.3. PRIMARY DIAGNOSES OF LTC CLIENTS

Table 2.3 shows the primary diagnoses of the LTC clients. The single most common diagnosis was multiple sclerosis (27 of 131 LTC clients for whom a diagnosis was available on the lTC-1 form). There were an additional four with amyotrophic lateral sclerosis, three with Parkinson's disease, and one each with Duchenne muscular dystrophy, Freidrich's ataxia, Werdnig-Hoffman muscular dystrophy, Huntington's chorea, cerebellar atrophy, and syringomyelia, making **"degenerative neurological disorder"** the most common diagnostic category (30.5%).

Head injury was the second most common diagnostic category (15.3%). Third was **spinal injury** (13%), this latter category including 15 quadriplegics and 2 paraplegics. The fourth most prevalent condition was **cerebral palsy** (12.2%). Together these four diagnostic groupings accounted for 71.0% of the Continuing Care clients.

TABLE 2.3: PRIMARY DIAGNOSES OF LTC CLIENTS (N=131)

	n	%
Degenerative neurological	40	30.5
Head injury	20	15.3
Spinal injury	17	13.0
Cerebral palsy	16	12.2
Cancer & HIV/AIDS	10	7.6
CVA (stroke)	9	6.9
Arthritis & joint disease	6	4.6
Metabolic conditions	3	2.3
Epilepsy	2	1.5
Gardner's syndrome	1	0.8
Multiple disabilities	7	5.3

2.4. MEDICATION USAGE

The number of prescription and non-prescription medications used ranged from 0-14 (mean = 3.81, s.d.=2.89). Only nine clients (7.0%) were reported to use no medication.

Table 2.4 shows that the medications most commonly used were: tranquillizers or hypnotics (used by 39.5% of clients), analgesics (used by 32.6%), laxatives (used by 30.2%) and vitamins and minerals, anti-convulsants and muscle relaxants (each used by 20-29%).

TABLE 2.4:TYPES OF MEDICATION USED BY LTC CLIENTS

	n	%
No medications	9	7.0
Tranquillizers/hypnotics	51	39.5
Analgesics	42	32.6
Laxatives	39	30.2
Vitamins/minerals	32	24.8
Anti-convulsants	26	20.2
Muscle relaxants	24	18.6
G.I. agents	22	17.1
Antidepressants	19	14.7
Anti-biotics/anti-infectives	18	14.0
Skin preparations	13	10.1
Anti-inflamatory agents	13	10.1
Steroids	11	8.5
Anti-parkinsonism agents	9	7.0
Bladder anti-cholinergic	8	6.2
Anti-hypertensives	6	4.7
Cardiac therapy	6	4.7
Diabetic agents	5	3.9
Anti-histamines	4	3.1
Anti-asthmatics	4	3.1
Anti-emetics	4	3.1
Oral contraceptives	2	1.6
Thyroid therapy	1	0.8
Eye treatments	1	0.8

Note: Percentages represent proportion of clients using a particular type of medication. Columns cannot be summed as up to six medication groups were recorded for each person. Regardless of the number of medications used, a category was recorded only once per client.

2.5. TREATMENTS

Half (50.5%) of the LTC clients receive some form of regular treatment. Table 2.5 shows that the most common treatments were concerned with elimination of urine and feces (e.g. enema/bowel routine; catheter care; condom drainage; bladder irrigation). In this population rehabilitation therapy was minimal. Only 2.3% receive Occupational Therapy, 4.7% receive Speech Therapy and 15.5% receive Physiotherapy.

TABLE 2.5:TREATMENTS ADMINISTERED TO LTC CLIENTS (N=129)

	n	%
No treatment	64	49.6
Enema/bowel routine	25	19.4
Catheter care	20	15.5
Physiotherapy/exercise	18	14.0
Condom drainage	12	9.3
Speech therapy	6	4.7
Occupational therapy	3	2.3
Bladder irrigation	2	1.6
Tube feeding	2	1.6
Gastric pump	1	0.8
Surgical dressings	1	0.8
Pressure sores	1	0.8
Oxygen therapy	1	0.8
Other	20	15.5

Note: Columns cannot be summed as some clients receive more than one treatment

2.6. MENTAL HEALTH

Since 1990, mental health has been reflected on the LTC-1 form via a set of 10 measures. The measures and their response categories are shown in Table 2.6.[1] They indicate that most of the time the vast majority of clients are:

- cooperative (95.1%)
- adequately or well groomed (85.7%)
- behave normally (84.3%)
- show appropriate affect (80.0%)
- have normal thought content (82.9%)
- have normal perceptions (97.5%).

Fewer, but still a majority, have no cognition impairment (75.0%), are self-directing (60.0%), show at least adequate judgment (77.8%) and have good insight (56.1%).

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[1] There was a large amount of missing data for these measures (n's ranged from 72 to 85 from a sample of 153). Some of the attrition derives from use of pre-1990 forms which do not contain all of the categories included on the present form.

TABLE 2.6:MENTAL HEALTH OF LTC CLIENTS

Attitude (n=82)	n	%
Cooperative	68	82.9
Occasionally demanding and/or resistive or hostile	10	12.2
Freq. suspicious or demanding & hostile	2	4.4
Indifferent	2	2.4
Appearance (n=84)		
Well groomed	38	45.2
Adequate	34	40.5
Dishevelled	4	4.8
Ill, not dressed	8	9.5
Self-direction (n=85)		
Independent	51	60.0
Needs motivation	7	8.2
Needs direction	12	14.1
Dependent	15	17.6
Behaviours (n=83)		
Normal	65	78.3
Occasionally physically aggressive and/or restless or sexually inappropriate	6	7.3
Frequently aggressive and/or restless	6	7.3
Withdrawn	2	2.4
Self-destructive	1	1.2
Other	3	3.7
Affect (n=85)		
Appropriate	60	70.6
Occasionally anxious and/or labile, inappropriate, blunted, depressed, angry	8	9.4
Frequently anxious and/or labile, inappropriate,blunted,depressed,angry	17	20.0
Thought content (n=82)		
Normal	67	81.7
Normal but repetitive	1	1.2
Obsessions and/or persecutory delusions	3	3.7
Preoccupation	1	1.2
Not able to assess	9	11.0
Other	1	1.2
Perceptions (n=79)		
Normal	77	97.5
Other	2	2.5

Cognition (n=72)		
Normal	54	75.0
Mild impairment	8	11.1
Moderate impairment	6	8.3
Severe impairment	4	5.6
Insight (n=82)		
Good	46	56.1
Partial	27	32.9
None	9	11.0
Judgment (n=81)		
Good	43	53.1
Adequate	20	24.7
Poor	18	22.2

2.7. COMMUNICATION ABILITIES

Table 2.7 shows that the vast majority of the LTC clients have adequate vision for personal safety (93.6%), unimpaired hearing (91.4%) and can understand normal speech (83.2%). However, almost one-third (30.7%) have a significant communication problem.

Among the 35 clients with significant speech impairment, three were reported to use a "Bliss" or alphabet board with moderate to good success and one to use a computer with voice output. One uses sign language and five others can make at least some of their needs known by speech, body language and/or facial expression. No information was provided on the mode of communication or the communication effectiveness of the remaining clients.

TABLE 2.7:COMMUNICATION ABILITIES OF LTC CLIENTS

Vision (n=110)	**n**	**%**
Unimpaired	47	42.7
Adequate for safety	56	50.9
Distinguishes only light or dark	3	2.7
Blind, safe in familiar locale	1	0.9
Blind, requires assistance	3	2.7
Hearing (n=116)		
Unimpaired	106	91.4
Mild impairment	5	4.3
Moderate impairment, adequate for safety	2	1.7
Impaired, inadequate for safety	2	1.7
Totally deaf	1	0.9
Speech (n=114)		
Unimpaired	79	69.3
Simple phrases, intelligible only	10	8.8
Simple phrases, partially intelligible only	1	0.9
Isolated words intelligible only	12	10.5
No understandable speech	12	10.5
Understanding (n=113)		
Unimpaired	94	83.2
Understands simple phrases	8	7.1
Understands key words only	2	1.8
Understanding unknown	6	5.3
Not responsive	3	2.7

2.8. LEVEL OF PERFORMANCE OF ACTIVITIES OF DAILY LIVING

Table 2.8 shows the LTC clients' level of performance of activities of daily living(ADLs). As can be seen, a high degree of assistance is required by most. In total, 18.1% are completely dependent for all movement. Including these individuals, approximately three-quarters (70.7%) require continued assistance with bathing; half require significant or continuous assistance with ambulation (50.0%) and with transfer (52.6%) and half must be dressed (51.7%); more than one-third (39.1%) require total assistance for grooming. While only a small proportion are shown to be incontinent, approximately one-quarter require a bowel routine and/or regular catheterization or monitoring of drainage equipment.

TABLE 2.8:LEVEL OF PERFORMANCE OF ACTIVITIES OF DAILY LIVING OF LTC CLIENTS

	n	%
Dependent for all movement (n=116)	21	18.1
Ambulation (n=88)		
Independent - normal environment	15	17.0
Independent - specific environment	17	19.3
Requires supervision	4	4.5
Requires minor assistance	8	9.1
Requires sig./continued assistance	44	50.0
Transfer to/from bed, chair & toilet (n=117)		
Independent	30	25.6
Requires supervision	3	2.6
Requires intermittent assistance	13	11.1
Requires continued assistance	71	60.7
Bathing (n=116)		
Independent	13	11.2
Independent with aids	7	6.0
Requires minor assistance/supervision	14	12.1
Requires continued assistance	82	70.7
Dressing (n=118)		
Independent	25	21.2
Requires supervision	1	0.8
Requires periodic or partial help	31	26.3
Must be dressed	61	51.7
Grooming/hygiene (n=115)		
Independent	29	25.2
Requires reminder/direction	4	3.5
Requires some assistance	37	32.2
Requires total assistance	45	39.1
Eating (n=116)		
Independent	45	38.8
Independent with aids	27	23.3
Requires intermittent help	27	23.3
Must be fed	17	14.7
Bladder Control (n=129)		
Totally continent	56	43.4
Routine toileting or reminder	15	11.6
Incontinent - identifiable reason	3	2.3
Incontinent <1 per day	2	1.6
Incontinent >1 per day	19	14.7
Indwelling catheter	19	14.7
Regular catheterization	4	3.1

Condom drainage	9	7.0
Urostomy	2	1.6
Bowel Control (n=124)		
Totally continent	59	47.6
Routine toileting	21	16.9
Incontinent - identifiable reason	5	4.0
Incontinent <1 per day	4	3.2
Incontinent >1 per day	7	5.6
Bowel routine	27	21.8
Ileostomy	1	0.8

2.9. SUMMARY

This chapter has presented detailed information on the socio-demographic, clinical and functional characteristics of 153 younger severely physically disabled adults who are Continuing Care clients in the CRD. While there is considerable information in the literature concerning the biomedical and clinical manifestations of the various medical conditions represented among the Continuing Care clients (e.g. multiple sclerosis, cerebral palsy), there are very few population studies describing this client group as whole.

The data show a client group that is composed of equal proportions of males and females, a majority of whom are middle aged. Four diagnostic groupings describe 71.0% of the Continuing Care clients: degenerative neurological disease, head injury, spinal injury and cerebral palsy. The data on medications and treatments suggest that most are medically stable and that some have no medical problems. Gloag (1985b) and McQuaig and Frank (1991) note that the latter typically are persons with spinal injury or cerebral palsy. Consistent with their classification as mainly at the Extended Care level, the data on functional status indicate, however, that this group requires substantial assistance in order to perform activities of daily living. For example, approximately three-quarters require significant assistance with bathing, 53% with transfer, 50% with ambulation and 52% must be dressed.

Proportions are similar to those reported in the only prevalence studies located to date that report ADL data for younger adults with severe physical disabilities (Castree & Barnes, 1993; Currey, Barton & Dansie, 1987; Miller & Gwynne, 1972).

3.0 THE CLIENT INTERVIEWS

This chapter presents findings from interviews conducted with 50 younger adults with severe physical disabilities. Of these:

- 21 were living in an institutional setting (18 at Gorge Road Hospital; 3 at Nigel House)
- 7 were living in group homes (4 at Anscomb House; 2 in group homes managed by the Vancouver Island Housing Association for the Physically Disabled and 1 from another group home)
- 22 were living in conventional housing in the community.

3.1 RESERARCH METHOD

3.1.1. PARTICIPANT RECRUITMENT

FACILITY SAMPLE

At the time the study was conducted, there were 48 residents of Gorge Road Hospital who met the age and disability criteria for inclusion in the study (i.e. age 19-55; severe physical disability). The hospital staff identified 28 who, in their opinion, were able to comprehend/communicate sufficiently well to complete valid interviews. Of these, two refused to be interviewed and eight were judged by the study interviewer to be unable to be interviewed. Full interviews were conducted with the remaining 18. The Vancouver Island Housing Association for the Physically Disabled identified the three residents from Nigel House who were interviewed.[1]

Group Home Sample

Four of the group home sample were recruited by Anscomb House staff, two by The Vancouver Island Housing Association for the Physically Disabled and one was a recently discharged patient suggested by the Gorge Road Hospital staff.

Community Sample

This group included one swing-bed client suggested by the Gorge Road Hospital staff and 21 individuals recruited from among Continuing Care clients whose LTC-1 forms had been analyzed in Phase II. The procedure used in recruiting them was as follows:

The LTC numbers of 32 individuals, chosen so as to reflect the Continuing Care clients' age, sex and diagnostic profile, were sent to CRD Health with a request for names and addresses so that they could be invited to take part in the interview portion of the study. The 29 persons for whom addresses were received (3 LTC numbers were duplicates) were sent an invitation to

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[1] See Appendices 2 and 3 for a description of the facilities and group homes in which interviewed respondents were living.

participate signed by the Project Coordinator. This was accompanied by a letter from the Regional Medical Health Officer verifying the credentials of the study team and a copy of the SFU Ethics Review Committee Certificate (see Appendix 4 for copies). Telephone calls followed 3-5 days later to confirm the invitation recipient's willingness to participate in the study and to arrange a time for the interview. (The Social Work Department at the Gorge Road Hospital was sent similar letters to distribute to potential study participants living there).

When telephoned, two persons declined to participate and three were eliminated due to cognitive or communication impairments. Five letters were returned unopened. Two additional names were drawn from the Continuing Care client list to yield the planned 21 participants.

3.1.2. LOCATION AND DURATION OF INTERVIEWS

All but three of the interviews took place in the respondent's place of residence. They ranged from 45 minutes to two hours in duration. The Project Coordinator conducted 12 of the 50 interviews. The remainder were conducted by three research assistants trained by her.

3.1.3. CONTENT OF THE INTERVIEW SCHEDULE

Prior to beginning the interviews, respondents read/were read an Information Statement outlining the purpose of the study, the approximate duration of the interview, the topics that would be covered, and their right to confidentiality, to refuse to answer questions and to terminate the interview at any time. Where feasible written and otherwise verbal consent was obtained. (See Appendix 4 for copies of the Information Statement, which was left with the respondent, the consent form and the interview schedule.)

The interview was divided into five main parts:

Part I: Socio-demographic characteristics

- respondent's household composition/living arrangement, marital status, number and age of children, highest level of educational achievement and whether they did any paid or voluntary work or attended school/college.

Part II: Satisfaction with housing and care

- how long respondent had lived in their current residence, who decided that they would live there, why that site had been chosen, what they liked most and least about their current residence, what could be done to make it better, whether they had any plans to move and if so, when, why and where. Respondents were also asked about the amount and type of help they received and needed and about their satisfaction with the physical design of their accommodation, the degree of privacy and private space they had and with the social atmosphere.

Part III: Service utilization and satisfaction

- use and satisfaction with services offering transportation, recreation, home support, housing, equipment loan, Meals-on-Wheels, education, advocacy, counselling, information/public education, associations for specific conditions, vocational services, barriers to service utilization and unmet needs.

Part IV: Equipment

- equipment respondent had now and what they would like to acquire.

Part V: Control and decision making

- degree of input into decisions concerning entertainment, activities, meals, attendants, physical space, breakfast and bed-time; rating of health and social services responsiveness; any complaints made to these services and their outcome.

Additionally, respondents were asked two questions assessing their morale and three enquiring about possible future use of the space to be vacated in the Rehabilitation Unit at Gorge Road Hospital. If sections of the LTC-1 form concerned with ADLs and self care were incomplete or, the form was dated earlier than 1993, these were completed prior to terminating the interview.

3.2. CHARACTERISTICS OF INTERVIEW RESPONDENTS

3.2.1. SOCIO-DEMOGRAPHIC CHARACTERISTICS

A) Age, Gender, and Education[2]

Table 3.1 shows that males were disproportionately represented among those interviewed. Approximately two-thirds of the respondents (68%) were male compared with 50.3% in the LTC sample. Twenty percent were between the ages of 18-29, 38% were aged 30-44 and 42% were aged 45-54. Their mean age was 37.9 (s.d.=9.9) compared with a mean age of 41.5 years in the LTC sample.

Reflecting the heterogeneity of the population of younger adults with severe physical disabilities that is stressed in the literature (cf. Gloag, 1985b), a fairly wide range of educational

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[2] Unless otherwise noted, tables in this chapter present data for all 50 respondents

achievement was represented (from 4% with no high school to 20% with one or more university degrees).

B) Marital Status and Number of Children

The marital status distribution was very similar to that of the LTC sample. As shown in Table 3.1, 24% of the respondents were currently married, 2% were living common law, 14% were separated or divorced, 2% were widowed and 58% had never married.

Fifteen respondents (30%) were parents, 12 of children under age 19 (the youngest was 19 months). Family size ranged from one to four children (four respondents had only one child, five had two children, five had three children, and one had four children).

C) Housing and Living Arrangements

A variety of housing and living arrangements were represented: 12% of respondents lived alone, 22% lived with a spouse, parent(s) or other family member(s), 6% lived with a paid caregiver, 4% had a swing-bed arrangement with Gorge Road Hospital, 14% were group home residents, and 42% lived in institutional settings. In order to ensure that their views would be sufficiently represented, there was deliberate over-sampling of residents of group homes (14% compared with 3.4% in the LTC sample) and institutions (42% compared with 26.2% of the LTC clients).

D) Work Status

Seven respondents (14%) engaged in some paid work (range: 3 hours per week to full-time). Three worked in sheltered workshops, two provided research/public education regarding persons with disabilities, one was a teacher and one was an administrative assistant.

Sixteen (32%) do volunteer work. There was a considerable range in the time commitment and level of service provided, particularly by community-based respondents. For example, one had recently completed two years service as the Chairperson of a high school Parents' Advisory Council, another was a student representative on a faculty committee at a local university, three were members of executive or advisory boards and six worked occasionally for an organization providing service to people with disabilities. Other activities included work with church and theatre groups and counselling. Facility-based respondents gave out snacks, patrolled grounds, helped with brochures, and were members of the Residents' Council.

TABLE 3.1

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF INTERVIEWED CLIENTS (N=50)

	n	%
Gender		
Males	34	68
Females	16	32
Age		
18-24	6	12
25-29	4	8
30-34	8	16
35-39	11	22
40-44	5	10
45-49	9	18
50-54	7	14
Mean age (in years)	37.9	
s.d.	9.9	
Range	18-54	
Education		
No high school	2	4
Some high school	20	40
High school graduation	10	20
Some college/university	8	16
University graduation	6	12
Post grad. diploma/degree	4	8
Marital status		
Never married	29	58
Married	12	24
Common-Law	1	1
Divorced/separated	7	14
Widowed	1	2
Housing and Living Arrangement		
Alone in community	6	12
With live-in caregiver	3	6
With spouse/family	11	22
Swing-bed (comm.-GRH)	2	4
Group home	7	14
Institution	21	42

E) School Attendance

Eight respondents (16%) were currently attending school or taking college or university courses. One, living in the community, was a full time graduate student. Three, living in facilities, were taking university or college courses. Two living in group homes attended high school, one attended university and one was taking correspondence courses.

3.2.2. LEVEL OF CARE

Table 3.2 shows respondents' level of care by type of residence. The distribution is highly similar to the Continuing Care clients in showing approximately three-quarters (76%) classified at the Extended Care level. Of the remainder, 6% were at the Intermediate I level, 4% at Intermediate II, 6% at Intermediate III; 8% had not yet been classified/admitted to the Continuing Care Program.

TABLE 3.2

LEVEL OF CARE OF INTERVIEWED CLIENTS

	Facility	**Group Home**	**Community**	**Total**
	(n=21)	**(n=7)**	**(n=20)**	**(n=50)**
Personal Care	0	0	0	0
Intermediate I	0	1	2	3
Intermediate II	0	1	1	2
IntermediateIII	1	0	2	3
Extended Care	20	1	17	38
Not in LTC Program*	0	4	0	4

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* These clients were drawn from the Queen Alexandra sub-study. They are transitional between the child and adult health networks and have not yet been assessed and assigned a Long Term Care Program number and level.

3.2.3. PRIMARY DIAGNOSES

A slightly higher proportion of interview respondents than in the Continuing Care sample suffered from **degenerative neurological conditions** (38% vs. 30.5%). These included eight persons with multiple sclerosis, four with muscular dystrophy, two with amyotrophic lateral sclerosis, two with Friedrich's ataxia and one each with muscular spinal atrophy, cerebellar atrophy and Parkinson's disease. The next most common diagnostic groups were **cerebral palsy** (18%), **spinal injury** (18%) and **head injury** (16%).[3]

Of the eight with head injuries, three had additional significant physical impairments - one each with hemiplegia, paraplegia and spastic quadriplegia. In total, there were 14 individuals in the sample who were effectively quadriplegic, eight due to spinal injury and six in whom spastic quadriplegia was secondary to head injury or disease (eg. cerebral palsy, multiple sclerosis).

TABLE 3.3

PRIMARY DIAGNOSES OF INTERVIEWED CLIENTS (N=50)

	n	%
Degenerative neurological disease	19	38
Spinal injury	9	18
Cerebral palsy	9	18
Head injury	8	16
Arthritis	1	2
CVA (stroke)	1	2
Epilepsy	1	2
Hydrocephalus/spastic quadriplegia	1	2
Multiple disabilities	1	2

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[3] Sweeney, Sadovnick and Brandejs (1986) estimate the prevalence of multiple sclerosis in B.C. at 93.3 per 100,000. Rates are higher for females (126.4) than males (59.8). See Appendix 2 for information on prevalence and sex distribution of mulscular dystrophy and related disorders.

3.2.4. FUNCTIONAL STATUS

A. Level of performance of activities of daily living

Eighty percent of the respondents can move about independently with a wheelchair. However, as shown in Table 3.4 these individuals require a considerable amount of assistance with activities of daily living. For example, mirroring the Continuing Care sample, 70% need continued assistance with bathing and 66% with transfer, 54% must be dressed, 34% require total assistance for grooming and approximately 25% require a bowel routine and/or regular catheterization or monitoring of drainage equipment.

TABLE 3.4

LEVEL OF PERFORMANCE OF ACTIVITIES OF DAILY LIVING (N=50)

	n	%
Completely dependent for all movement	14	28
Mobility aids used (n=49)*		
Cane	2	4
Walker	3	6
Wheelchair	45	92
Other	2	4
Ambulation		
Independent - normal environments	1	2
Independent - specific environment	4	8
Independent in wheelchair	40	80
Assistance in wheelchair	5	10
Transfer		
Independent	12	24
Requires supervision	1	2
Requires minor assistance	4	8
Requires sig./continued assistance	33	66
Bathing		
Independent	8	16
Independent with aids	3	6
Requires minor assistance/supervision	4	8
Requires continued assistance	35	70

Dressing		
Independent	13	26
Requires supervision	1	2
Requires periodic or partial help	9	18
Must be dressed	27	54
Grooming/hygiene		
Independent	11	22
Requires reminder/direction	2	4
Requires some assistance	19	38
Requires total assistance	17	34
Resists	1	2
Eating		
Independent	19	38
Independent with aids	13	26
Requires intermittent help	8	16
Must be fed	8	16
Resists	2	4
Bladder Control		
Totally continent	25	50
Routine toileting or reminder	12	24
Incontinent - <1 per day	1	2
Incontinent - >1 per day	2	4
Regular catheterization /Condom drainage	10	20
Bowel Control		
Totally continent	26	52
Routine toileting	11	22
Incontinent <1 per day	2	2
Bowel routine	11	22

* Column cannot be summed as multiple responses were allowed

B) Self-care abilities (IADLS)

"Self-care abilities", often called "Instrumental Activities of Daily Living" (IADLS), are shown in Table 3.5. Examination of these data indicate that for all except travel, from 25% to 50% of the respondents lack the capacity to undertake the activity.

TABLE 3.5

SELF CARE ABILITIES (IADLS)

	n	%
Food Preparation (n=47)		
Independent	3	6
Adequate if ingredients supplied	4	8
Can make/buy meals but diet inadequate	1	2
Physically or mentally unable	21	45
No opportunity or does not participate by choice	18	38
Housekeeping (n=47)		
Independent w/help for heavy tasks	1	2
Can perform light tasks adequately	4	8
Performs light tasks inadequately	3	6
Needs regular help and supervision	8	17
Physically or mentally unable	17	36
No opportunity or does not participate by choice	14	30
Shopping(n=46)		
Independent	8	17
Independent only for small items	9	20
Must be accompanied	9	20
Physically or mentally unable	10	22
No opportunity or does not participate by choice	10	22
Travelling (n=47)		
Independent	14	30
No public transport, uses private vehicle or taxi	9	19
Can travel only if accompanied	16	34
Physically or mentally unable	3	6
Requires ambulance	2	4
Uses HandyDART	3	6
Telephone (n=47)		
Independent	28	60
Dials well known numbers	3	6
Answers telephone only	3	6
Physically or mentally unable	12	26
No opportunity or does not use phone	1	2
Medications and Treatments (n=46)		
Completely responsible for self	10	22
Requires reminder or assistance	13	28
Responsible if meds prepared in advance	8	17
Physically or mentally unable	13	28
Staff responsible	2	4

3.3. SATISFACTION WITH HOUSING AND CARE

3.3.1. DURATION OF RESIDENCE IN CURRENT ACCOMMODATION

Following the initial questions designed to ascertain respondents' socio-demographic characteristics, the interviewer introduced the first set of questions concerned with substantive issues. These dealt with satisfaction with housing and care. To provide a context for interpreting their response, respondents living in group homes and institutional settings were first asked how long they had lived in their current accommodation.

As shown in Table 3.6, among residents of institutions responses ranged from less than one year to more than 25 years. Residency of under five years was clearly the norm among the group home residents, only one of whom (14%) had lived in his/her current accommodation for 5 or more years.

TABLE 3.6

DURATION OF RESIDENCE IN CURRENT ACCOMMODATION (Facility and Group Home residents only)

	Facility		Group Home	
	n	%	n	%
<1	2	11	2	29
1-4	8	42	4	57
5-9	5	26	1	14
10-14	1	5		
15-19	1	5		
20-24	1	5		
25-29	1	5		

3.3.2. CHOICE OF CURRENT ACCOMMODATION

When asked "Who made the decision that you would come here to live?" three of the seven living in group homes (42.9%) reported having made the decision alone, two (28.6%) said it had been made jointly with their family and two (28.6%) said jointly with professionals. Among those in facilities, proportionately fewer (28.6%) reported having made the decision alone; 42.9% said jointly with their family and 14.3% said jointly with professionals. The remaining 14.3% attributed the decision solely to their parents.

When asked the reason(s) for choosing their current residence, group home residents (see Table 3.7) most frequently mentioned the range of programs and services offered and their desire to be with other young people. The institutional sample most frequently mentioned the range of programs and services offered and that their residence was close to family. The community sample most frequently said that their current home was accessible, "roomy" and had a reasonable cost.

TABLE 3.7

REASONS FOR CHOOSING CURRENT RESIDENCE*

	Facility (n=21)	Group Home (n=7)	Community (n=22)
Close to family	9	0	3
Accessible	0	1	12
Range of programs & services	9	2	0
No other place to go	3	0	2
Roomy, good size	0	0	4
Close to services	1	1	1
Familiar neighbourhood	1	0	1
To be w/other young adults	2	2	0
Close to public transport	1	1	1
Always lived here	0	0	2
Reasonable cost	0	0	4
Feel safe here	1	0	1
Layout	0	0	1
Family atmosphere	0	1	0
To live with family	0	0	1
Increase independence	1	1	0

* Columns cannot be summed as more than one reason was permitted.

3.3.3. BEST AND LEAST LIKED FEATURES OF CURRENT RESIDENCE

Response to the question "What do you like best about your current residence?" tended to parallel respondents' reasons for choosing it. For example, the most frequent themes among the community sample revolved around the affordable nature of their current residence, its relatively spacious size, its accessibility and its favourable location with respect to transportation, facilities and services.

The most common complaints were the mirror image of the above - i.e., that it was poorly designed, not accessible, poorly located, and had halls and bathrooms that were too small.

When asked what could be done to make their current housing better, recommendations offered by community-based respondents focussed on specific renovations that were needed. The most common recommendations of facility-based respondents were to increase their personal space, increase staff and increase decision-making opportunities.

3.3.4. STAFF ASSISTANCE RECEIVED AND NEEDED (Facility and Group Home respondents only).

Facility and group home residents were asked what type of staff assisted them. Responses included: nurses aides/care aides/home support workers (mentioned by 93.0% of respondents), nurses (82.1%), physiotherapists (32.1%), occupational therapists (28.6%) and recreation aides (25.0%). Additionally, a small number (3.4%-7.1%) mentioned a dietician, life skills worker, volunteer, housekeeper or maintenance worker. When asked if they were receiving the amount and type of help they needed, 82.1% said "yes". The final question in this set asked respondents whether, in their opinion, the staff in their residence had the right kind and amount of training to work with them and if not, to suggest the type of additional training staff should acquire. A very strong majority of the facility and group home respondents (92.9%) were satisfied with the staffs' qualifications.

3.3.5. USE AND SATISFACTION WITH HOME HELP (Community-dwelling respondents only)

Community-based respondents were asked a parallel series of questions about home help including the type and amount they received, whether the staff have the right kind and amount of training and if not, what type of training they should receive.

Two (9%) of the 22 respondents living in the community had 24-hour live-in attendant care; 77.3% received 8 to 60 hours of homemaker service per week (mean = 25.8 hours per week, s.d.=15.0), 13.6% received home nursing care and 18.1% received home physiotherapy. Over two-thirds (68.1%) said that generally they were receiving the amount and type of home help that they needed. Dissatisfied respondents expressed a desire for more control over the choice of home support workers, the availability of child care, the availability of a relief worker should the regular worker be unable to come, payment for a family member or the opportunity to hire someone to occasionally "take over her hours", and better trained home support workers since "often", one individual stated, they are unwilling to perform tasks "the way we would like them done."

In response to an explicit question about the adequacy of training of home care staff, respondents were divided: 50.0% thought staff have the right kind of training to work with them, 40.9% thought they do not and 9.1% refused to answer the question.

When **dissatisfied respondents** were asked to explain their response some commented that homemakers "are basically off the street. They seem to have no idea what they are getting into." Others commented that "Homecare Course grads are inadequate", that "The Continuing Care Certificate doesn't mean they're well equipped to do the job" and that some of those with formal training come in with a "know everything attitude".

Explicit concern was expressed about some workers' lack of interpersonal skills, reflected in comments such as "homemakers don't seem to know how to work with people", "some have attitude problems" and "homemakers need to have the 'right' attitude in working with special needs persons."

Another area of concern had to do with adapting to clients' individual needs, reflected in comments such as "they are taught transfers but how they are taught is not applicable to my needs." "Every quad is different. They don't know the routine. They come and watch once then are expected to do it. Transfers, bowel care, etc. are all client-specific. It takes time to learn."

Additionally, several respondents felt that workers needed more disability-specific training. Working with blind persons and with quadriplegics were two specific examples mentioned.

One of those who **was satisfied** with the training of the staff who worked with her summed up the qualities that most seemed to be looking for: "You either have to have a trained person or a very experienced 'in tune' person to recognize my needs." Her "best" homemaker was described as very spontaneous, showing empathy, allowing her flexibility and recognizing that her needs are different from those of older adults.

3.3.6. SATISFACTION WITH PHYSICAL DESIGN OF CURRENT ACCOMMODATION

Respondents were asked: "Does the physical design of your home meet your needs and if not, why not? ", "What adaptations, if any, have been made to your home?" and "Are there some other adaptations that need to be made?" Two-thirds (66%) said that their home's physical design met their needs, 40% had made adaptations to it and 38% said that further adaptations were needed.

Dissatisfied respondents living in facilities commented that their personal space (bedroom; bathroom) was too small and that they lacked adequate storage space. Other comments focussed on the lack of accessibility of some public areas (grounds, patios, elevators). Residents of one group home identified a need for sensitivity in the placement of public washrooms: "Currently, you have to go through the centre of things to get to the bathroom."

Dissatisfied community-dwelling respondents noted that kitchens and bathrooms were too small, that cupboards, countertops and closets were too high and/or inaccessible and that lever-type faucets were required in kitchen and bathroom. Some wished more extensive bathroom renovations including larger bathtubs and the installation of wheelchair showers. Several also suggested renovations that would improve their mobility (wider doors and hallways; "flush" door sills; fewer corners; lever door handles). Better access to the outside (patios; balconies; yards) and better design and accessibility of gardens and paths were desired by some. Fire safety was also a concern.

Among adaptations that respondents had made to **bathrooms** were: enlargement of bathroom door and installation of wheelchair shower, grab bars and transfer devices (e.g. hydraulic lift). Adaptations in the **kitchen** included adjusting the height of counters, sink and oven (note: appropriate height may vary depending on whether the wheelchair is manual or electric); removing cupboard doors to enable wheelchair access to sink; and replacing cupboard door handles. **Mobility and access** was improved by removing carpets and adding handrails, ramps, and lifts and pouring concrete outside. More extensive renovations ranged from adding a bathroom or bedroom to an entire specially designed house. As one respondent ruefully noted, however, providing an example of a conflicting policy: "We added a room for me - we got a grant from the government to do it but then they raised the taxes due to the expansion."

Few of those whose homes need further adaptation had immediate plans to make them. Several said they would be made "when I can afford it", one person adding "if the landlord will allow it" and another "if the landlord will make a sufficiently long commitment to make it worthwhile." These latter comments illustrate a particular problem faced by disabled renters.

3.3.7. PRIVACY AND PRIVATE SPACE IN CURRENT ACCOMMODATION

Respondents' were asked whether they had enough privacy and private space for the seven activities shown in Table 3.8. Approximately three-quarters responded "yes" with respect to personal care (76%), visiting with their family (76%), hobbies (74%) and time to themselves (76%). Over two-thirds (68%) felt they had enough privacy/private space for visiting with friends. On the other hand, only 60% of those who chose to answer felt they had adequate privacy for sexual activity.

TABLE 3.8

SATISFACTION WITH PRIVACY/PRIVATE SPACE FOR SELECTED ACTIVITIES (N=50)

	Yes	No	N/A
	n	n	n
Personal care (e.g. bathing, toileting)	38	11	1
Visiting with your family	38	9	3
Visiting/entertaining friends	34	11	5
Sexual opportunities	24	16	10
Hobbies	37	6	7
Studies/homework	15	3	32
Time to yourself	38	10	2

Dissatisfied facility-based respondents had three major recommendations for improvement: private bedrooms, private and/or bigger bathrooms, and the addition of "cosy", "private", "small" rooms analogous to a den or living room in a private home. The latter recommendation was echoed by more than half of the group home respondents, particularly with reference to entertaining friends. As one person put it: "The bedroom isn't set up for entertaining."

Several of the respondents living in the community would like to have larger space or additional rooms for the activities enquired about. Additionally, they identified a need for space in which they could occasionally distance themselves from their children and/or caregiver, noting that "As a parent, the family takes up a lot of time. I'm not able to just pick up and go out in the car to get time to myself" and "This house is too small - the caregiver is always around (and my children)."

3.3.8. SATISFACTION WITH DEGREE OF INDEPENDENCE

Respondents were asked whether they had too much independence, not enough or about the right amount. One person (2%) said "too much", 28% said "not enough", 66% said "about right" and 4% chose not to answer the question.

Recommendations for improvement suggested by facility-based respondents included a device to answer the phone and turn on the TV and lights. Another "would like the staff to ask me more about what I want to do and give me more choices." Respondents living in the community wished more money to allow greater choice (eg. of recreational activities). They also wished more services "on demand", that is, available without a long planning time. HandyDART was explicitly mentioned as an example.

3.3.9. OVERALL SATISFACTION WITH CURRENT ACCOMMODATION (Facility and community-based respondents only)

Three questions were used to assess facility and community-based respondents' overall satisfaction with their current accommodation. The first asked: "Which of the following best describes your feelings about your living situation during the last six months?". Respondents chose one of the four alternatives shown in Table 3.9. As can be seen, 86% living in the community and 62% living in facilities reported comfort with their current accommodation.[4]

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[4] Group home respondents were deleted from the analysis of questions in this section since by definition, the Anscomb House residents, who constituted 57% of the sample, were required to move.

TABLE 3.9

SATISFACTION WITH PRESENT RESIDENCE AND PLANS TO MOVE

	Facility (n=21) %	Community (n=22) %
During the last 6 months: I have been comfortable in my current living situation.	62	86
I have been increasingly dissatisfied with my current living situation, but I have not made any plans for a change.	19	5
I have begun to make plans to move.	9	5
I have definite plans to move.	9	5

A second question asked: "How much does this feel like a real home (a place you really belong) or just a place you happen to live?" The vast majority (86.4%) of community-dwelling respondents perceived their current accommodation to be a real home. In contrast, the vast majority of institutionalized respondents (85.7%) saw their residence as just a place to live.

A third question asked whether respondents would prefer to live somewhere else. Proportions saying "yes" were respectively 47.6% for the facility-based and 40.1% for the community-dwelling groups. Responses of facility-based respondents reflected a preference for living "in my own home." Community-dwelling respondents generally wished to have larger and/or better designed and more accessible homes.

3.4. SERVICE UTILIZATION AND SATISFACTION

3.4.1. USE OF EXISTING SERVICES

Respondents' were asked whether they currently or in the past had used any of the 13 categories of services shown in Table 3.10, all of which are available to disabled persons living in the CRD. Satisfaction ratings for those used and suggestions for improvement were also solicited.

TABLE 3.10

PAST AND PRESENT UTILIZATION OF SERVICES AVAILABLE TO PEOPLE WITH DISABILITIES IN CRD (N=50)

	Uses now	Used before	Never Used
	n	n	n
Transportation	41	6	3
Recreation	29	4	17
Continuing Care	26	7	17
Associations for specific conditions	20	10	20
Home support	16	19	15
Loan cupboards	9	13	28
Housing	14	2	34
Education	10	6	34
Counselling	7	7	36
Information/public ed.	6	2	42
Vocational	5	2	43
Meals-on-Wheels	1	3	46
Advocacy	1	3	46

A) Transportation

As can be seen in Table 4.10, virtually all respondents (47 or 94%) had or were using specialized transportation. HandyDART was the most frequently used transportation service. Of the 46 reporting experience with it, 19 (41.3%) were satisfied with the service, 25 (54.3%) were dissatisfied and 2 (4.3%) gave no rating. Several satisfied respondents specifically praised the drivers describing them as "very willing to help." In order of their frequency of mention (see numbers in brackets), the following complaints were expressed by 10% or more of the dissatisfied HandyDART users:

* Inflexibility imposed by reservation system (13 persons)
* Poor/unreliable service (7)
* Problems with dispatchers/office (4)
* Lack of consideration of users (4)

The need to book rides well in advance makes its use impractical, respondents noted, for anything but scheduled appointments, allowing "no room for flexibility or spontaneity." Examples of poor service include: late pick-ups, forgotten pick-ups, and insufficient supply of buses to provide needed service. Comments regarding the dispatch office include: "the office is pathetic - the dispatchers don't know what is going on (but the drivers are great)" and "the dispatchers have an 'inconsistent' attitude - they can be condescending." This perceived poor attitude was reflected in other comments such as "they're not concerned about the clients", "no consideration for users' needs", and "you're not treated as a human being." One person, commented on safety issues, having fallen over in the van when it rounded a corner.

Ten (20%) of the respondents used accessible taxis but 7 (14%) said they were too expensive to be practical. Only one person mentioned the government sponsored "taxi-saver program."

Six respondents (12%) reported satisfaction with accessible public buses. Three others use the service but have some difficulty getting to the bus stop and noted a lack of sufficient wheelchair spaces on the buses.

Of those having their own vehicle, three complained of the cost of purchase, maintenance and adaptations. Another stated it was only possible to afford the vehicle because a friend did all the maintenance at no cost. Another cannot get his electric wheelchair in his van and is in the process of acquiring a more suitable vehicle from Social Services. He/she expects it will take two years "to get through the system."

Finally, two clients reported drives by their home support worker as an important transportation service.

B) Recreation

In total, 33 (66%) of the respondents had used recreation services. Of the 17 who were facility-based, nine had used only the facility recreation program, five used outside services and three used both facility and community recreational services. All but one expressed satisfaction with the services (this individual found a community pool to be too noisy and crowded). A recently discharged resident reported that he returns to the facility every week to participate in a recreation program.

Community recreation activities engaged in by respondents included: recreation centre and pool activities (6 persons), wheelchair sports (5 persons), horseback riding (2), Disabled Sailing (1), a church youth group (1) and various voluntary organizations assisting them (2) (e.g. Epileptic Society and Citizens Advocacy).

Four respondents mentioned using the services of Recreation Integration Victoria including the Leisure Assistant Pass which allows free entry for an attendant to many regional recreation programs.

Positive comments related to friendly and helpful staff at recreation centres and pools. Three dissatisfied respondents would like better access to pools. Pools vary greatly in accessibility, they noted (e.g. in the availability and placement of lifts, design of changing rooms, help available). One respondent has had difficulty finding reliable and knowledgeable volunteer assistants when he wishes to use a pool.

Two respondents were averse to "group disabled activities." One individual had found a "disabled" class to be "very degrading" and non-stimulating when she was grouped with mentally retarded people. Respondents reported that they can participate in "regular" activities only if they have someone to attend with them.

Two respondents have found "good" programs but the cost prevents them from participating to the extent they would like. One person did not know what is available nor how to find out.

C) Continuing Care

While all respondents would have had contact with the Continuing Care Division of the Ministry of Health at some time, only 33 (66%) indicated awareness of service from this source. Among "satisfied" respondents, four specifically mentioned an able case manager or social worker. Positive comments included: "more than willing to listen and offer suggestions and come up with ideas to help client" and "good, positive assessment." Dissatisfied respondents most often complained of infrequent contact with the case managers: "they only come once every two years", "we never hear from them - we have to run around finding them." Policies were mentioned which seem "geared more to the elderly." An example given was the prohibition against home support workers toileting clients outside of the home thus, in effect, confining clients to their homes. Another respondent felt more hours of home support were needed than were being allowed.

D) Associations for Specific Conditions

Thirty respondents (60%) reported accessing services provided by 10 different associations for specific conditions. The associations mentioned most frequently were: the Multiple Sclerosis Society (mentioned by 12 respondents), the Muscular Dystrophy Association (7) and the B.C. Paraplegic Association (5). Services obtained from these organizations included:

- direct care (e.g. physiotherapy)
- counselling
- equipment loan
- information
- discount on cellular telephone costs
- support group

Suggestions for improvment included: offering services over longer hours, providing more practical information (e.g. concerning housing options) rather than educational materials about the disease, and directing more funds to client services and less to research.

E) Home Support

Thirty-five respondents (70%) reported using home support services delivered by 14 different agencies. Fourteen expressed satisfaction, five dissatisfaction, eight a mixed reaction (either with one or several agencies) and six didn't answer the satisfation part of the question.

Positive comments regarding home support workers included "friendly", "reliable", and "good, consistent workers." Several respondents commented favourably about the agency itself. For example, one individual stated: "They try to keep continuity of staff whenever possible." Two clients were pleased that the agency arranged to hire people they had found themselves and one commented "the office people are nice" and "the administrators tried to be helpful."

The complaints of less satisfied respondents also included both home support workers and agency operations. Examples of the latter included:

> "At times there is confusion over scheduling the homemakers. Communication is poor."
>
> "I have no input into who will come to care for me."
>
> "They don't screen caregivers properly."
>
> " The agency should be doing a better job matching the client to the home support worker."
>
> "The person leaving should train the new staff coming on the job."
>
> "The organization doesn't seem to know how cleaning should be done."
>
> "The office blames you for difficulties."
>
> "They need adequately trained 'on-call' workers."
>
> "They had no male workers so I switched to another agency."
>
> "The administrators are intrusive in the home regarding decision-making and services to be provided. They are unsympathetic and have a poor attitude with clients. They tend to go by the book and forget they are dealing with people."
>
> "Home support workers are not trained or skilled in caring for children."

Three respondents commented on the need for home support workers to learn the client's system and routine and two stated that they would prefer to be given the money and hire and pay their own attendants.

F) Loan Cupboards

Twenty-two respondents (44%) reported experience with a Loan Cupboard and all were satisfied with the service. The sponsoring organizations mentioned were:

* Multiple Sclerosis Society
* Kinsmen
* Muscular Dystrophy Society
* Red Cross
* "Commercial"

Particular interest was expressed in the "Kin Control" - an environmental control unit. Those who had had it in the past but not longer did, would like to have it again.

G) Housing

Sixteen respondents (32%) had used a housing service and most were satisfied with the service provided. Three specifically lauded the Vancouver Island Housing Association for the Physically Disabled which had found and arranged for their current accommodation. Two spoke positively about assistance received from the Capital Regional Housing Corporation. Other agencies mentioned as helpful included: B.C. Housing, the Rotary Club, and the Ministry of Health's Services for Community Living.

H) Education

Sixteen respondents (32%), most of them satisfied, had used the following educational services: libraries (city and University of Victoria), secondary schools, the Open Learning Institute, Camosun College, and the University of Victoria. One person suggested that high school counsellors should be more adequately trained to assist students with physical disabilities, both in coping as an adolescent and in referring them to appropriate resources.

I) Counselling

Fourteen respondents (28%), all but one satisfied, had used a counselling service. Three had obtained counselling through private sources. Other providers included: Hospice Victoria, the Multiple Sclerosis Society, B.C. Paraplegic Association, Family Violence Project, Island Loss Clinic, University of Victoria, facility staff, and friends. The value of including family members in counselling was mentioned by several respondents.

J) Information/Public Education

Eight respondents (16%) had used information or public education services provided by the Handicapped Action Committee, associations for specific conditions (e.g. Cancer and ALS Societies), the Resource Centre for Independent Living, Kinsmen, or the Disabled Women's Association. All but one was satisfied with the service provided.

K) Vocational Services

Seven respondents (14%) had accessed some form of vocational service, the majority of which were government programs. Three dissatisfied respondents mentioned the Spectrum Job Search Centre, all commenting that it provided less than adequate counselling and job choices. One noted, however, that for a vocational program to prove its value it must continue for more than the one year Spectrum had existed. "It takes time to educate the employers and you need a long term commitment so employers can count on them." Two respondents were very satisfied with the guidance they had received from Canada Employment and Manpower and from the Ministry of Advanced Education, Job Search, and Assistive Technology Services in obtaining employment and in appropriately furnishing their workplace.

L) Meals-on-Wheels

Only four respondents (8%) reported ever using Meals-on-Wheels; one was still doing so. The current user stated: "It is a great idea! The food is not great but the volunteers come in and chat and see you are all right."

M) Advocacy

Only four respondents (8%) had used an advocacy service. Services respondents were satisfied with included: the Law Center, the Ombudsman's Office, B.C. Paraplegic Association, "Disabled Advocacy", and an MLA's constituency office. Dissatisfaction was expressed with advocacy services provided by the University of Victoria Ombudsman and the Resource Centre for Independent Living, on the basis that staff were not as well informed or as helpful as they might have been.

N) Other

Eight respondents volunteered their satisfaction with several services not specifically enquired about in the interviews. These included: Legal Aid, "Social Services", physiotherapy at Cedar Hill Centre, the Quick Response Team, and the swing-bed program at Gorge Road Hospital.

In order of their frequency of mention, the most commonly perceived barriers to use of existing services were: transportation problems, cost, and having no one to accompany them.

3.4.2. UNMET SERVICE NEEDS

As a means of estimating unmet service needs, respondents were shown the list of services in Table 3.11 and asked to indicate all they would like to have. Nine respondents (18%) did not want any of the services listed; others chose from 1 to 16. Those most desired were: help locating improved housing, help finding a place to meet people, help finding an attendant, information about where to get help and help with equipment purchase, repair or modification.

TABLE 3.11

NUMBER AND PERCENT DESIRING ASSISTANCE WITH SELECTED ACTIVITIES (N=49)

	n*	%
Help in finding a new place to live.	21	43
Help in improving my housing situation.	14	29
Help in dealing with my landlord.	1	2
Help in finding an attendant.	14	29
Help in training or relating to an attendant.	6	12
A place to meet people.	17	35
A place to talk to people with similar problems.	13	27
Advice from a counsellor.	11	22
Information about other places to get help.	14	29
Help in dealing with an agency.	10	20
Legal help.	9	18
Help in finding a job or job training.	8	16
Help in dealing with an employer.	1	2
A special device or piece of equipment (eg.wheelchair, eating aid, ramp)	14	29
Repair or modification of equipment.	14	29
Ride service.	13	27
Help in finding a reader or interpreter.	3	6
Other communication assistance (e.g. message relay service)	3	6
Mobility training.	0	0
None	9	18

* Columns cannot be summed as multiple responses were allowed.

3.4.3. OTHER DESIRED EDUCATIONAL, VOCATIONAL, REHABILITATION AND THERAPEUTIC SERVICES

Respondents were asked if there other services they would like to have, in the areas of: education, vocational training or rehabilitation, physiotherapy, occupational therapy, speech therapy and counselling. As shown in Table 3.12, they were most vocal about educational services, physiotherapy and counselling.

TABLE 3.12

NUMBER OF RESPONDENTS DESIRING OTHER EDUCATIONAL, VOCATIONAL, REHABILITATION AND THERAPEUTIC SERVICES (N=50)

	n	%
Educational	15	30
Physiotherapy	12	24
Counselling	12	24
Vocational training or rehabilitation	9	18
Occupational Therapy	7	14
Speech Therapy	2	4
Other	9	18

The types of educational service desired ranged widely. Some of the community-dwelling respondents spoke about access/ admission to specific educational programs or courses (e.g. computer; veterinary), others were concerned about the physical accessibility of classrooms and college and university campuses. Several respondents living in care facilities said they would attend if classes were held on site.

Virtually all of the 24% of respondents who spoke about physiotherapy stated that it was beneficial in maintaining function and wanted more. Several stated emphatically that more physiotherapy (and occupational and speech therapy) was needed for clients living at home.

Most respondents who spoke about counselling identified a need for general rather than for specific types (e.g.,grief, support or sexual health). Several mentioned a shortage of counsellors for community-dwelling younger adults with severe physical disabilities. One respondent poignantly noted that early in his illness his physical needs were adequately met but he would have benefitted from psychological help. "My reaction was to close the door and watch TV for two years. I needed somebody to 'pull me out by my hair'."

Several individuals used this point in the interview to comment about municipal services. For example, two individuals living in the community commented about curb cuts. One noted that in some parts of the CRD these are lacking making these areas inaccessible to persons in wheelchairs. Another person stated that "curbs are not flushed to the street smoothly enough. Even the smallest lip of a curb jars my head." Other respondents mentioned the need for an ombudsman service for persons with disabilities and a centralized place to find out about available resources. Several pointed out that each individual must go out and find his/her own information about housing alternatives, recreation and leisure activities and employment.

3.4.4. INTEREST IN RESPITE CARE, DAY PROGRAMS AND SHARED/GROUP HOMES

A) Respite

Community-dwelling respondents were asked whether they were interested in "respite care" which was defined as "where someone may come in while your primary helper goes away, say for two weeks, or you may go somewhere else for care while your helper stays home." Fifteen of the 22 respondents in the community sample (68.2%) indicated that they were interested in respite care. Of these 15, eight preferred having someone come to their home, four preferred to go somewhere else, one would like to take advantage of both alternatives and two had no opinion.

B) Day Programs

Respondents in all three groups were asked whether, if it were available, they personally would use a "day program or centre" which was defined as "a place where people can receive care and participate in activities during all or part of the day and then return home at night." It is interesting to note that 76.2% of those in facilities expressed interest in day programs. Positive responses in the community-dwelling and group home groups were, respectively, 40.9% and 28.6%.

C) Shared Housing/Group Homes

Respondents in all groups were asked a series of questions about a living arrangement in which "a small number of people share a house with a caregiver." The first question asked what they considered to be the ideal number of residents in such homes. Responses ranged from 2-20 persons (mean=5.8, s.d.=3.7).

The second question explored their preference with respect to housemates offering four choices: "similar disabilities to yours", "different disabilities to yours", "no disabilities" or "doesn't matter". Twenty percent preferred housemates with disabilities similar to their own, 18% preferred living among persons with different disabilities, 4% wished to live with persons with no disabilities, 8% stated emphatically that they wished to live among persons who were intelligent or at least mentally alert and half said it didn't matter or gave no answer.

The third question asked what type of neighbourhood respondents would like a shared/group home to be in. They were told that "some answers others had given include: in a residential neighbourhood, close to downtown, near transportation." As shown in Table 3.13 just over half who answered the question preferred a residential neighbourhood. Being near public transportation and shopping was also viewed as important.

TABLE 3.13

PREFERRED LOCATION FOR A SHARED/GROUP HOME (N=44)

	n*	%
Residential neighbourhood	23	52
Near downtown	12	27
Near stores, etc.	10	23
Near transportation	15	34
Park-type setting	2	5
Rural area	4	9
Other	5	11

* Columns cannot be summed as multiple responses were permitted.

3.5. EQUIPMENT USED AND DESIRED

In this section of the interview respondents were asked to describe the equipment they have now that assists them in living with their disability and to identify other equipment that would help them and how it might help. Additionally, they were asked how they travelled in the community.

Table 3.14 shows that mobility and transfer aids constituted the most common equipment used by respondents. Equipment most frequently desired consisted of environmental control devices, computer assisted communication devices and motorized wheelchairs.

TABLE 3.14

EQUIPMENT USED AND DESIRED (N=50)

	Have Now	**Would Like**
Bathing and Toileting Aids	**n***	**n**
Shower chair	22	0
Hand rail	20	1
Commode	19	1
Adapted toilet seats	8	0
Mobility and Transfer Aids		
Motorized wheelchair	30	4
Manual wheelchair	29	0
Mechanical lifts	25	0
Transfer devices/boards	18	0
Ramps	9	0
Walker/cane	4	0
Bath seat/lift	2	0
Scooter	2	0
Wheelchair van	2	0
Sip and puff controlled chair	1	1
Communication Aids		
Bliss board	2	0
Computer assisted communication devices	5	4
Voice activated telephone	2	0
Environmental Aids		
Remote control for lights, door etc.	5	8
Eating Aids		
Aids and adaptations	12	1
Medical Equipment		
Ventilator	4	0
Electric bed	4	0
Suction	2	0
Liquid oxygen	1	0
Stairglide	1	0

* Columns cannot be summed as multiple responses were permitted.

As shown in Table 3.15, few respondents (only 16%) own or operate a motor vehicle. While 24% use a powerchair or scooter, most get to places in the community via HandyDART (62%) or rides provided by others (32%).

TABLE 3.15

METHOD OF TRAVEL IN THE COMMUNITY (N=50)

	n*	%
Uses HandyDART	31	62
Depends on others for a ride	16	32
Uses powerchair/scooter	12	24
Owns or operates a vehicle	8	16
Takes taxi	8	16
Uses buses	6	12
Facility van	5	10
Other	3	6

* Columns cannot be summed as multiple responses were permitted.

3.6. CONTROL AND DECISION-MAKING

3.6.1. AMOUNT OF CLIENT VS. STAFF INPUT (GROUP HOME AND FACILITY-BASED CLIENTS ONLY)

This section of the interview began for group home and for facility-based respondents with a set of questions asking who made decisions concerning each of the eight activities shown in Table 3.16. Four response categories were provided:

(1) Staff/administration decide by themselves
(2) Staff/administration decide but clients have input
(3) Clients decide by themselves
(4) Clients decide but staff have input.

As can be seen, staff decision-making was perceived to be primary in all areas enquired about except bedroom privacy. The same was true when respondents were asked if they had any say in who provided their care: only 7 said "yes" and 20 said "no".

TABLE 3.16

LOCUS OF DECISION-MAKING FOR SELECTED ACTIVITIES (N=28)

	S/A	S/A+C	C	C+S	NA
	n	n	n	n	n
Planning entertainment	9	9	8	1	1
Deciding what kinds of new activities/programs will occur	9	10	6	1	2
Planning daily or weekly menus	14	6	4	3	1
Setting meal times	18	1	2	6	1
Dealing with residents' complaints	13	5	4	3	3
Changes in staff (hiring or firing)	22	2	0	2	2
Who decides on how much privacy you are allowed in your bedroom (e.g. locking your door)?	9	3	14	1	1
Who decides when you get up in the morning and when you go to bed at night?	11	4	7	5	1

S/A = Staff/administration decide by themselves
S/A+C = Staff/administration decide but clients have input
C = Clients decide by themselves
C+S = Clients decide but staff have input
NA = No answer

3.6.2. IN-PUT INTO HIRING OF ATTENDANTS (COMMUNITY-BASED RESPONDENTS ONLY)

The control and decision-making part of the interview began for community-dwelling respondents with questions focussed on the hiring of attendants. The first question asked: "Do you have any say in the hiring of your attendants?" 15 of the 22 (68.2%) community-dwelling residents said "yes". When asked "Would you like more or less say in the hiring of your attendants?" 17 (77.3%) said "more". Question 3 asked, "Are you <u>consulted</u> regarding who will care for you?" Ten respondents (45.1%) replied "yes". When those answering "yes" were asked how they were consulted the following examples were given: "the agency takes my preferences regarding home support workers into consideration", "the agency tries - they call and tell me who will be coming and the supervisor will come by and consult" and "I have the right to refuse an attendant but would like more proactive input." Additionally, two respondents reported that when they had located their own attendants in the community, the agency had cooperated by hiring them.

Three of those not consulted noted that they have the right to fire someone whom they feel is not suitable but would prefer to have more input prior to the hiring/assignment of home support workers. Seventy-five percent of those not consulted said "yes" when asked if they would like to be consulted.

3.6.3. ATTENDANT TURN-OVER RATE

Community-based respondents were asked whether they experienced a high turnover in attendants/home support workers. Seven (31.8%) said "yes", 13 (51.9%) said "no" and two (9.1%) did not answer the question.

3.6.4. SYSTEM RESPONSIVENESS

Respondents in all three groups were asked: "Do you believe the health and social services systems you use are responsive to your needs? Those answering "yes" were asked to give examples. Those answering "no" were asked: "In what way are they not responsive?"

Thirty one (62%) of the respondents said "yes" the system was responsive to their needs. However, three qualified their answer with the observations "only if you continually bug them", "they meet my needs because I am assertive and therefore go after what I want" and "there is give and take - you have to know how to function in the system and deal with the bureaucracy."

Examples of system responsiveness included: receiving help in finding an appropriate place to live (3 respondents); providing power wheelchairs (2); and rapid response by Continuing Care (restarting service after a two year hiatus and immediate care for skin break down)(2). Two respondents commented on the good quality of home support workers and two praised a specific agency (Canadian National Institute for the Blind; Canadian Paraplegic Association). A resident of Gorge Road Hospital observed "they listen to patient's concerns here - things get changed even if not right away." One community-residing respondent observed "generally I have had no problems so far and my needs have been met."

Examples of lack of responsiveness were varied but several centered on the complexity and rigidity of bureaucracies, reflected in statements such as: "too much paperwork and passing the buck", "we get the run around" and "you have to play games to get what you need because of policies that block the road." Respondents identified the need to be an active self-advocate and wished for more "openness" to clients' feelings and opinions.

Other examples of lack of responsiveness revolved around equipment and finances. One respondent noted: "They won't share the cost of equipment - either you take what they provide or pay it all on your own." He went on to explain that he had been offered a second hand power chair. He asked to be given the amount allotted for that chair and make up the difference to buy the chair he wanted. His request was refused. Another respondent commented that there were unrealistic expectations for client contributions to the cost of services and equipment. A third person observed that there is no financial assistance available for the installation and/or maintenance of hand controls on a car.

Other comments regarding the lack of system responsiveness included:

> "We were assigned a social worker we never met until she was forced to come. Then she insisted that I sign for the welfare cheque in spite of being a tetraplegic."
>
> "Physical needs are well met but emotionally the system has been totally inadequate."
>
> "The transition from childhood to adulthood was difficult. I lost many services and had to start all over again with a new system and build rapport with new agencies and workers. No one prepared us for or helped with the transitions."

Among facility-residing clients, four expressed dissatisfaction with their living situation. "Well, I live here, therefore they aren't responsive to my needs" and "the government system and administration don't understand what it is like to be in a hospital."

When asked whether they had ever complained to a service agency, 22 (44%) of the respondents said "yes". Most positive outcomes occurred when the complaint was made directly to home support agencies. Complaints regarding "bad" home support workers, too many different caregivers, and poor communication between workers, the client and the agency office were reported by four respondents to have been resolved to their satisfaction. However, five other respondents reported experiencing inadequate response from the home support agency, and in at least two cases, the client changed agencies. Two of the unresolved complaints concerned suspected theft by home support workers. In both cases the agency stated that the only recourse was for the client to involve the police. In one case the worker continued to be employed by the agency. Another situation involved a home support worker the respondent claimed over-represented hours worked "by a factor of 100%". Another unresolved complaint was that an agency sent a worker for more hours than approved by the Continuing Care assessor and continued to do so even after the client informed the agency.

Examples of other negative outcomes to complaints concerned:

- housing and accessibility. In response to a question about accommodation one respondent stated he/she was just told "you are on the waiting list" and another encountered "fixed and inflexible rules" precluding assistance with adaptations to the home;

- HandyDART. One respondent complained about reckless driving and another, about being left waiting for 2 1/2 hours. Both complaints "fell on deaf ears" and nothing was done about it.

Three clients specifically mentioned having to resort to "Tribunal" - two to achieve their aims as to where they wished to live and another to obtain a piece of equipment (all were ultimately successful).

Several clients stressed the importance of knowing "how to complain."

> "It is hard to complain 'properly'. The squeaky wheel gets service but if it is too squeaky you are seen as a 'problem' and it backfires."

One person stated, however that "many clients fear complaining to an agency because of fear of possible retribution."

3.7. CLIENT MORALE

Respondents in all three sub-groups were asked the following two questions in an attempt to assess their morale:

Which of the following best describes your feelings about your daily activities?

1) You are bored a lot of the time.
2) You spend some time in activities you like but would like to do more.
3) Most of your time is spent in interesting activities. You are seldom bored.

About how much of the time do you feel down or depressed?

1) Most of the time.
2) More often than not.
3) About half the time.
4) Sometimes.
5) Seldom.

As shown in Table 3.17, in total, almost one-quarter (24%) of the respondents reported being bored a lot of the time, 34% reported engaging in some interesting activities and 40% said they spent most of their time in interesting activities. Twelve percent of the sample reported that they felt depressed most of the time, 10% were "down" more often than not and 6% about half the time. The majority, however, reported feeling depressed only sometimes (41%) or seldom (31%).

TABLE 3.17

CLIENT MORALE

	Facility	Group Home	Community	Total
	(n=20)	(n=7)	(n=22)	(n=49)
	%	%	%	%
Feelings about daily activities				
Bored a lot	35	14	18	24
Some interesting activities	35	29	36	34
Mostly interesting activities	30	57	46	40
Time spent feeling "down"				
Most of the time	15	0	14	12
More often than not	20	0	5	10
About half the time	15	0	0	6
Sometimes	20	57	55	41
Seldom	30	43	27	31

To place these findings in context, they should be compared with responses to two similar questions included in Statistics Canada's 1991 Health and Activity Limitations Survey (HALS). As can be seen in Table 3.18 rates of boredom and depression among severely disabled HALS participants were highly similar to those obtained in the CRD study.

TABLE 3.18

MORALE, DISABLED PERSONS AGED 15-54: CANADA, HEALTH AND ACTIVITY LIMITATIONS SURVEY, 1991 (Community Sample, scaled and weighted frequencies)

	All Disabled	Severely Disabled
Feel bored	%	%
Often	17	30
Sometimes	41	40
Never	42	30
Feel depressed		
Often	11	21
Sometimes	37	41
Never	52	38

3.8. USE OF GORGE ROAD HOSPITAL VACANT SPACE

Respondents were asked if they were aware that the Gorge Road Hospital will have vacant space in the Rehabilitation Unit available for other uses. Sixteen (32%) said "yes" they were aware of it. Of these 16, nine were in the facility sub-sample, one was in the group home sub-sample and six were community-dwelling. The interviewer then went on to state: "Nothing has been planned for this space but one suggested use for the old Rehabilitation Unit would be to convert it to a residence for younger adults with physical disabilities. If this were to happen, who do you think might want to live there?" As shown in Table 3.19, seven (14%) of the respondents said that younger adults currently living at Gorge Road Hospital would like to live there with other younger adults, ten (20%) said it would appeal to younger adults with severe physical disabilities, and three (6%) said it would appeal to younger adults in transition. The remaining 60% of the sample were far less enthusiastic. Five persons (10%) explicitly said "not me", three (6%) thought no one would be interested in such a residence and more than one-third (36%) did not know who might be interested. Respondents were not asked directly whether they themselves would want to live there.

TABLE 3.19

WHO WOULD LIVE IN GORGE ROAD HOSPITAL REHABILITATION UNIT

	Facility	**Group Home**	**Community**
	(n=21)	**(n=7)**	**(n=22)**
	n	**n**	**n**
Any younger adults with severe physical disabilities	8	0	2
YAs currently in GRH	4	1	2
YAs in transition	0	1	2
No one	1	1	1
Not me	1	0	4
Don't know	6	4	8
Other	1	0	3

Respondents who suggested that a residence for younger adults with severe physical disabilities might be particularly appealing to current residents of Gorge Road Hospital mentioned the advantages of living with other young adults stating: "it gets depressing living with older people" and "it would be great to be around people who we could relate to mentally and age wise." They also assumed all the current services of the hospital would be available there.

Several respondents who stated "no one would be interested" or "not me" cited, as reasons for their answer: the physical limitations of the space (e.g. the rooms are too small, it is too small for wheelchairs, bathing facilities are not adequate); a lack of privacy; and a general dislike of institutional settings.

The idea of using the space as a transitional unit was volunteered by three different community-based respondents. One noted that by grouping younger adults with severe physical disabilities together at an early stage "they have a chance to talk to others with similar injuries and meet new friends who are really unique. These friendships last a lifetime and give strength to those who have a disability." The other two respondents noted that it would facilitate the transition of moving from community to facility, facility to community or, for those moving from living with their parents to living on their own.

When asked if they could suggest any other uses for the space at Gorge Road Hospital, almost half the respondents (48%) said "yes". Suggested uses included:

- day program/drop-in centre/recreation/pool (6 persons)
- respite/swing-bed unit (5)
- in and out-patient rehabilitation services, including physiotherapy and occupational therapy (4)
- vocational/computer training (3)
- extended care hospital for the elderly (3)
- hospice (2)
- resource/information centre (2)
- residence for younger adults with severe physical disabilities with private rooms (2)
- chapel (1)
- a site for functions/fund-raising (1)

3.9. SUMMARY

This chapter has presented information from personal interviews conducted with 50 younger adults with severe physical disabilities living in the Capital Regional District (34 males, 16 females; age range 18-54). In addition to providing information on clients' self-care abilities, unavailable in the LTC-1 study due to missing data, the interview data expands and personalizes the client profile in other ways. For example, it shows that some clients are parents (30% of the sample); that although few (only 14% of the sample) engage in paid work, a substantial proportion (one-third) contribute voluntary service, in some cases involving a very considerable commitment of time and energy; and that while some have limited education (44% did not graduate from high school), others are highly educated (20% hold one or more university degrees).

The interviews also yielded information concerning clients' satisfaction with their housing and care, about the services they used and their satisfaction with these, the equipment they used and wished to acquire, and about the degree of control and involvement in decision-making they had with respect to their living environment and every-day activities.

Concerning their accommodation, community-based respondents answered the question "What do you like best about your current residence?" with answers that paralleled their reasons for choosing it: affordability, accessibility and reasonable size. The most common complaints were the mirror image, i.e., that what they could afford was poorly designed/not accessible and/or too small for their needs and equipment (e.g. power wheel chairs require more room than manual chairs). When asked what could be done to improve their current housing, community-based clients focussed on specific renovations (generally to improve accessibility of the kitchen and/or bathroom and access to the outside). The most common design recommendations offered by facility-based respondents were to increase their personal space (bedroom, bathroom, storage), improve the accessibility of some public areas and provide space, other than in their bedrooms, where they could entertain friends.

Over 80% in facilities and group homes were satisfied with the amount and type of care they received, and over 90% were satisfied with their staffs' qualifications. In contrast, approximately one-third of the community-based respondents were **dissatisfied** with their amount/type of care and half, with the qualifications of their staff. They felt that home care/support staff, trained primarily in meeting the needs of the elderly, frequently lacked the appropriate attitudes, knowledge and skills to meet their needs.

Specialized transportation, recreation, Continuing Care, associations for specific conditions, home support and loan cupboards were among the services clients most frequently used. Dissatisfaction was greatest with HandyDART and home support. Clients complained about the inflexibility of the HandyDART reservation system and about poor/unreliable service. Complaints about home support included both agencies and workers.

Additional services clients most desired were help locating improved housing, help finding a place to meet people, help finding an attendant, information about where to get help and assistance with equipment purchase, repair and modification. From one-quarter to one-third of respondents were also interested in more education, physiotherapy and counselling. Over two-thirds expressed interest in respite services, half preferring to have someone come to their home. Interestingly, the sub-group most interested in attending day programs/centres were facility residents.

Mobility and transfer aids were the most common types of equipment used by respondents. Equipment most frequently desired consisted of environmental control devices, computer-assisted communication devices and motorized wheelchairs. Financial aid in general, and for equipment purchase in particular, were two areas in which respondents felt "the system" was less responsive than in might be. Other sources of irritation centred on the complexity and rigidity of the bureaucracy. Three-quarters of the community-based clients also wished more input/control over their attendants. Unfortunately, while respondents in the institutional sample were asked who made decisions about a range of every day activities and most indicated that it was staff, they were not asked whether they desired more control.

Another key omission was in not asking respondents directly whether they themselves would be interested in living at Gorge Road Hospital if the vacant space was dedicated for use by younger adults with severe physical disabilities. Response to the indirect questions about recommended use of the space suggest that the answer would have been "yes" for a substantial proportion of those currently in facilities but it is not possible to be certain of this without having asked the question.

4.0.THE FAMILY FOCUS GROUP STUDY

This chapter describes findings from three focus groups held with family members of younger adults with severe physical disabilities living in the CRD. Participants numbered 24. For the most part:

- Group I (n=10), consisted of families of residents of the Gorge Road Hospital

- Group II (n=11), consisted of families with relatives who are unable to speak for themselves due to cognitive and/or communication impairments

- Group III (n=3), consisted of families of clients residing in the community.[5]

As with the client interviews, the chapter begins with a brief description of the research method (how participants were recruited, the clients they represented, when and for how long the focus groups met). This is followed by the family members' response to the following six questions that were used to guide discussion:

1. Can you think of an experience that you can share with us that made you feel pleased or gratified with the systems and services that you and your family member require?

2. Can you think of an experience or incident that you can share with us that made you feel angry, disappointed or frustrated in the services and systems that you and your family member require?

3. What are the major concerns or gaps in services that you and your family member experience?

4. What other issues are of importance to you and to your family member who has a significant physical disability?

5 What residential options do you and your family require now, or in the future? What is important to you?

6. What do you feel the role of the Gorge Road Hospital should be?

There was a high degree of congruence in the response of the three focus groups to these purposefully general questions. In the presentation of findings, unless otherwise noted, points described came spontaneously from at least two of the three groups and, for the vast majority, from all three.

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[5] Due to scheduling difficulties, the groups were not totally homogeneous.

4.1. METHOD

4.1.1. SELECTION OF PARTICIPANTS

Members of Group I were recruited from among family members identified by the staff of Gorge Road Hospital as being sufficiently involved with their relative to be able to participate meaningfully in the study. Two members of Groups II were suggested by the CRD. The remainder and majority of family participants in Groups II and III were selected using information from the clients' LTC-1 forms.

An attempt was made to choose participants representative of both male and female clients, clients of different age and diagnostic groups, clients living in institutions, group homes and conventional single family dwellings as well as a mix of family relationships (spouses, parents and adult children). While a broad cross-section of clients was represented in the focus groups (see Table 4.1) there were some limitations on the sample selection. These included that:

1. there was a family member sufficiently involved with their relative with a disability to be familiar with the services delivered to him/her;

2. if the client was cognitively competent, he/she gave permission to invite the family member to participate; and

3. the selected family member was willing to participate and was available at the time the focus groups were scheduled.

Potential participants were initially contacted by telephone, most having been informed that they would be invited to take part in the study by their interviewed relative. Within five days of the telephone call each received a letter of invitation from the Project Coordinator (see Appendix 5 for a copy) accompanied by the same letter from the Regional Medical Health Officer and copy of the SFU Ethics Review Committee certificate sent to interviewed clients.

Two of the family members approached refused to participate, two were prevented from doing so by the lack of an alternative caregiver to stay with the client, one could not participate due to a family crisis while two cancelled due to unforeseen circumstances (hence the small n for Group III).

4.1.2. CLIENTS REPRESENTED BY FOCUS GROUP PARTICIPANTS

Twenty-one clients, 13 of whom were interviewed in Phase 3 of the study, were represented in the focus groups by one or more of their family members. As shown in Table 4.1, 61.9% of the clients represented were male and 38.1% were female; they ranged in age from 21-53; 57.1% were residents of Gorge Road Hospital, 38.1% lived in conventional community-based housing and 4.8%

lived in a group home. The most common primary diagnosis among those represented was degenerative neurological disease (38.1%) followed by head injury (28.6%). Most commonly, clients were represented in the focus groups by their mother.

TABLE 4.1

CHARACTERISTICS OF THE 21 CLIENTS REPRESENTED BY FOCUS GROUP RESPONDENTS

	n	%
Client's Gender		
Male	13	61.9
Female	8	38.1
Age Range	21-53	
Living Arrangement		
Gorge Road Hospital	12	57.1
Conventional Community-based Housing	8	38.1
Group Home	1	4.8
Primary Diagnosis		
Degenerative neurological disease	8	38.1
Head injury	6	28.6
Cerebral Palsy	3	14.3
Quadriplegia	3	14.3
CVA	1	4.8
Relationship of Respondent to Client		
Parent	16	66.7
Spouse	7	29.2
Adult Child	1	4.2

4.1.3. LOCATION AND DURATION OF FOCUS GROUPS

The three focus groups were held June 7-9, 1994. Each was of 2 hours duration. Group I met at Gorge Road Hospital; Groups II and III met at the CRD Health Department offices. One of the Principal Investigators, a male, served as moderator for all three groups. The Project Coordinator, a female, was an on-site observer. With the participants' permission, the proceedings of the focus groups were audio-taped.

4.2. RESPONSE TO QUESTIONS 1 & 2 : POSITIVE AND NEGATIVE EXPERIENCE WITH EXISTING SYSTEMS AND SERVICES

Some examples were provided of when "the system" works. One participant was delighted with the response of the CRD Continuing Care program to her request for help when her daughter came home from the hospital. "They did it all for me" she reported, "including providing home support workers, equipment and necessary adaptations to the house." Another participant stated: "Without the Ministry of Social Services and Housing and Continuing Care neither my nor my husband's lives would be as good - we do appreciate it." Another reported: "The CRD was very responsive. Everything was provided. The nurse was compassionate and the CRD staff worked well as a team."

Unfortunately, however, this was not the typical experience. Most focus group participants reported having encountered many frustrations and obstacles in seeking services for their relative and for themselves. These included finding that their relative did not qualify for services because he/she was "too old for Queen Alexandra" or "too young for private extended care" or "too disabled for a group home." They reported that "so many things fall between the cracks" and that they have to "fight for everything." They also reported that interpretation of policies varies between agencies. Specific examples were that different answers were provided by financial affairs workers and home support agencies, with the client/family "caught in the middle." Additionally, large variations were reported in the policies and in the quality of different home support agencies.

4.2.1. COMPLEXITY OF "THE SYSTEM"

The participating families felt that the sheer number of ministries and agencies involved in providing services to younger adults with severe physical disabilities is very difficult for families to cope with. Some participants reported having had to deal simultaneously with: the Ministry of Social Services and Housing, the Ministry of Health, the CRD, the Insurance Corporation of British Columbia and often other agencies as well. The prevalent perception was that these ministries and agencies do not work together and further, that the same policies can be interpreted in different ways by workers from each.

The participants tended to be very involved and active advocates for their relative with a disability but they reported frequently feeling defeated by the system. They expressed concern for clients who have no advocate to assist them in securing services and described two overriding needs: (a) for a central source of information and (b) for more effective service coordination/case management.

With respect to the former, participants noted that:

"There are excellent services out there BUT families need to find them."

"When we were in that traumatic state of where to put him - we felt lost - we had to dig for information."

While several participants had encountered professionals able and willing to provide guidance, the majority felt that they had wasted vast amounts of energy pursuing information about what services were available. Some participants, in all three groups, believed information was purposely withheld from them so that a service or benefit would not have to be provided. Typical comments included:

> "There is a reluctance to share information."
>
> "They don't want to tell you what's available unless you ask for it and how can you ask for it if you don't know about it?"

Examples of information respondents felt was grudgingly provided included the availability of special homeowner's grants for households of disabled persons and the availability of Leisure Assistant's passes.

Participants recommended the appointment of an inter-ministerial resource person and/or establishment of a centre that would provide all needed information at one location or telephone number. For this service to be effective, they noted, <u>every</u> professional dealing with the disabled should have and give out the telephone number. Some participants would prefer a more active service -- that is, one providing practical assistance in obtaining services in addition to simply dispensing information.

The need for improved coordination/case management was reflected in comments such as:

> "It is so draining emotionally, physically, and mentally having a relative with a disability that fighting the 'system' is exhausting...a patient/family advocate is essential."

4.2.2. LACK OF CONTROL AND INVOLVEMENT IN DECISION-MAKING

The families reported often feeling that they and their disabled relative had very little control over the situation and that "you have to fight all the time to maintain independence." The commonly held perception was that "the system controls you." This perception appeared to arise, generally, from the problems associated with dealing with a complex health and social service system, but some specific examples were provided. These included:

- Being told that if they didn't cooperate with the service delivery plan or if they complained too much, their family member would have to return to a living situation not wanted by the family (i.e. return to Gorge Road Hospital). This "threat" was reported by at least three families in two of the three focus groups.

- Being "bounced " between Ministries, each claiming that it was not their responsibility. This was most frequently reported (but not exclusively) in the context of describing their difficulties in obtaining needed equipment for their relative.

- Having had to hire a lawyer in their "fight" to be allowed to bring their family member home from a facility.

- Having had to "get him into the Gorge through the back door" via an admission to the G.F. Strong Rehabilitation Unit in Vancouver when the doctor wanted their disabled relative to be admitted to another extended care hospital rather than Gorge Road Hospital.

A number of family members reported having experienced financial difficulties and the loss of control that accompanies having to rely on support from the public purse. For example, one respondent reported that when the client portion of the per diem charge was raised to match that paid by Old Age Pension recipients (from $1 to $7), they could no longer afford it, and as a result were forced to accept Social Assistance. Their experience was: "Once you go under the Social Security system, they call the shots." Another example was of a wife who was working but not making enough money to pay for all the client's care and equipment needs. She reported being told that if she went on Social Assistance "they would provide homemakers and all his needs." Since doing so, however, "you wouldn't believe all the hoops we have to go through to prove he needs things. We can't expect it the first time." As a solution to the problem several family respondents stated "give us the money and we'll manage it."

4.2.3. HOME SUPPORT POLICY

One participant was impressed by the cooperation of Gorge Road Hospital in allowing her to arrange alternate forms of care, such as acupuncture and faith healing, in an attempt to help her family member. This helped her, she reported, to come to terms with the reality of the client's situation. However, such flexibility was rare in most families' experience, particularly as regards home support. Among concerns expressed were that:

- Rules regarding permitted activities of home support workers appear to be based on the needs of geriatric clients. For example, allowing vacuuming only every two weeks is not appropriate in a home with young children.

- Workers' lacked training in caring for young children. "The quality of care of kids, if available, is awful. One home support worker smacked them."

- Some home support agencies prohibit their workers from driving clients places. This policy has forced some families to change agencies because getting out "to do chores" or for a "change of scene" was viewed as vital to the psychological well-being of their disabled relative.

- Frequently, families and clients experienced great difficulty in accessing home support in the evening or at any time beyond "normal working hours." The family caregiver may want to go out and/or the client may want to attend a sporting event, concert or other community event but they are precluded from doing so by the lack of an alternative caregiver, the lack of appropriate affordable transportation or both.

- Agencies and workers are reluctant to stay alone with a ventilator-dependent client. Although they "fought to get them home" the families involved greatly appreciate an opportunity to spend some time away from their disabled relative -- for example, to take their children out or to attend to other responsibilities.

- In one situation, "the system" had paid a worker for four hours to drive the children to a summer program rather than provide the grandmother with the price of gas.

- The family is invited to participate in annual assessment meetings but the meetings are always held during the day thus preventing working family members from attending.

- Being told that the policy is that home support workers may only care for the client, for example, cleaning only his/her room and cooking only his/her meals. There are times when the family would prefer the worker to do housework beyond the client's room (e.g., vacuum the rest of the house, clean the bathroom) thus freeing them to spend time with the client. In a few cases the case manager has made it possible for this to happen, but this was not the experience of the majority. Again, families complained of having to "fight for everything."

- The policy that a home support worker cannot become a "friend." Because of the long term nature and the severity of the disabilities in this population, focus group respondents noted that an effective caregiver often becomes a friend of the client/family and serves as a source of support and contact with the community. Clients and home support workers are forced to "hide" their friendship so the worker will not be removed.

- Some families expressed a preference for the home support worker to spend time playing cards or conversing with the client while the family member does the housework. It is seen as enriching the client's life and providing relief by giving the family and client a needed break from each other's company. "We want friends with skills more than a professional."

4.3. RESPONSE TO QUESTION 3: SERVICE CONCERNS AND GAPS

4.3.1. STAFFING LEVELS, STAFF TRAINING, STAFF ATTITUDES AND CONTINUITY

In addition to the above, several other issues relating to staff, both in facility and community, came up repeatedly in the focus group discussions.

A) Staffing Levels

There was a strong perception of staff shortage in facilities, both at the professional and at the care worker level. Time constraints on staff were seen to result in increased dependence, loss of function and increased care need. For example, several respondents pointed out that shortage of direct care staff mean "doing for" the client rather than allowing time for them to do as much as possible for themselves. Specific examples given were that residents are neither able to be out of bed as often as they should and would like to be nor are they able to routinely stand and walk. As a result, these abilities are lost.

Several participants questioned whether staffing levels designed for a geriatric population are adequate for younger adults with severe disabilities. Many believe their relative has greater care needs than geriatric patients.

A lack of sufficient rehabilitation staff (physiotherapy, occupational therapy, and speech therapy) was acutely felt both by respondents with relatives in facilities and by those with relatives in the community. Maintenance therapies are perceived to be very important for this population, again to prevent loss of function and increase dependency.

Concern was also expressed that there is often no relief home support worker so that if the regular worker cannot come "the family is left in the lurch."

B) Staff Training and Qualifications

In both facility and community situations, most care workers were seen by focus group participants as having been trained to work with the elderly and not adequately prepared to care for a younger population. "They do not know how to deal psychologically with younger people", respondents noted. Lack of training specific to the disabilities encountered in this population was also a concern.

C) Staff Attitudes

On the positive side, some families expressed delight at the number of caring workers involved with their family member. This was reflected in general statements such as: "Staff are very helpful, compassionate and caring." As well, some specific examples were given. The family of a Gorge Road Hospital resident reported that when their relative was in the Victoria General Hospital for an extended period, the Gorge Road Hospital staff had sent cards, flowers and a different staff person came to see him nearly every day. "He felt that people really, truly care for him. This is important when he is separated from us for a large part of the day."

Several participants reported that some staff make a special effort to find the time to do such things for residents as put on makeup, fix their hair and do manicures in preparation for visits or outings. Others concurred that many staff have a very positive attitude and make a real effort to keep residents involved whatever their functional level. "Staff go out of their way to maintain self-esteem regardless of level." One participant appreciated the willingness of Gorge Road Hospital nurses to learn ventilator care which allowed her relative to move to Victoria and be closer to his family.

Unfortunately many examples of less positive actions and relationships were also cited. Several families commented that "Staff is poorly trained. They send people out who can't do things - not even make a bed." Several reported overhearing conversations held in the presence of clients who were nonverbal or comatose thus showing a distinct lack of sensitivity. "If you don't want them to hear it, don't say it in front of them." Others found staff lacked tact in their conversations with families. For example, one family reported being told by a staff person, "He'll always be a vegetable - you are wasting your time taking him to the pool." 2 Participants felt that "the attitudes of workers make a tremendous difference." In particular, there was criticism of financial assistance workers. "They have been in the system many, many years and they're so hard core that they think you're out to get them and they'll tell you so." While acknowledging that it is an extremely stressful job, they felt financial assistance workers should be more sensitive to the fact that "families and clients have needs and feelings too."

D) Staff Continuity

Clients with high care needs often want their caregivers to know and follow a specific routine. Frequent rotation of staff at Gorge Road Hospital makes this difficult. One focus group participant complained that "at Gorge Road Hospital all the RNs are part time and the aides are switched around." Compounding the problem, was a perceived lack of communication among staff members. "They may write it down but no one reads it." It was argued that if clients are expected to spend many hours every day with a care worker, they should have a say in the hiring process.

4.3.2. REHABILITATION SERVICES

Most participants believe insufficient rehabilitation services are offered both in facilities and in the community. This was seen to result from the low priority put on rehabilitation by the system, a shortage of rehabilitation staff and the lack of care staff time. Health benefits, maintenance of function and quality of life issues were raised in this context. For example, lack of adequate physiotherapy was believed to result in loss of function (e.g. ability to stand on crutches), loss of strength (e.g. can't help with transfers), and weight gain. Respondents believe that range of motion exercises confer health benefits to quadriplegics.

Considerable concern was expressed over a purported transfer of community physiotherapy and occupational therapy services from the Ministry of Health to the Ministry of Social Services and Housing which, they anticipated, might result in a reduction in service. Respondents also noted that there appeared to be unequal access to rehabilitation services depending on whether the client lived in the community or a facility and whether he/she was connected with a voluntary association such as the Multiple Sclerosis Society or the Paraplegic Association.

Speech therapy was also seen to be undersupplied.

4.3.3. PSYCHOLOGICAL SERVICES

It was perceived that insufficient attention is paid to mental or psychological health. "Mental health or quality of life is as important as health and safety but LTC does not consider them relevant." Dreams, aspirations and hopes were seen as the entitlement of all people including those with severe disabilities. Participants commented: "They provide housekeeping and shopping but she has nothing to look forward to - she is not being trained for anything"; "He was very depressed when he first came into the facility." Significant time was spent discussing quality of life issues.

4.3.4. RECREATIONAL/EDUCATIONAL OPPORTUNITIES

Recreation was seen as having "... great value to these young people - almost as much as medical. It gives them a purpose and is a part of being someone." The recreation program at Gorge Road Hospital was generally considered to be excellent given the limited number of staff, and many residents' families felt recreation was the most positive thing in their relative's life, offering him/her stimulation, opportunities for community involvement, choices and enhanced self-esteem. "They wouldn't be who they are without it -- otherwise they would be more institutionalized."

The pool was seen as a major asset but, because of heavy demand, residents sometime have their times cancelled. This was described as being "devastating to someone who has looked forward to it all week." Participants commented that continuity and predictability of programs is essential.

Family barbecues, special dinners and outings were described as an appreciated venue for family interaction.

Respondents commented that recreation opportunities for community-based clients were neither as available nor as appropriate as those at Gorge Road Hospital. They noted that it is left up to the individual and the family to locate recreational resources. Some "good" programs (e.g., computers) were mentioned but the families had to "dig" to find them. Recreation Integration Victoria was mentioned as a resource, but most participants felt the activities it offers are beyond the capabilities of their relative. Recreation centers were perceived not to offer activities for those in wheelchairs. It was noted that if the client needs to be accompanied, there is no one but the family to do it.

Some families reported that their relative has had excellent educational opportunities. For example, one individual completed a Masters Degree while living at Gorge Road Hospital. Another took courses through Camosun College. However, other families complained that opportunities were lacking.

Discussion of vocational counselling and training elicited mixed comments and there was a difference of opinion on the value of sheltered workshops. The view of some was that to be valuable an activity must be intrinsically worthwhile and challenging to the individual's abilities while others felt that just being paid something made people feel valued.

4.3.5. EQUIPMENT ACQUISITION AND MAINTENANCE

The view that the process of obtaining and maintaining equipment can deplete family energies was emphatically proclaimed by many focus group respondents. "No one accepts responsibility" was a frequent refrain. While most requests for equipment tend eventually to be approved, it was reported that families can expect to have to "fight" for things as simple as the bearings for a wheelchair.

Stories about the difficulties of obtaining a suitable wheelchair came from a number of families and in several cases, involved "going to Tribunal." One family reported that a

Respiratory Technician had identified a part needed for their relative's ventilator. The request for the part was routed to the George Pearson Centre Ventilator Outreach Program in Vancouver and then back to Victoria at which point it was refused and the whole process had to be repeated.

Major problems were described in obtaining communication devices. It was reported that neither the Ministry of Health nor the Ministry of Social Services and Housing will fund them. The sentiment was expressed that: "Many of those now adult who were disabled as children were deprived of an education - we should compensate for that by helping them with communication now." Additionally, respondents believed that equipment can save money as in the case of a cellular phone enabling a head injured man to take public transit into town thus dispensing with the need for an accompanying attendant.

In contrast to the above anecdotes, one participant was delighted with the way all needed equipment had been readily provided to her relative, including an electric bed and necessary home adaptations.

4.4. RESPONSE TO QUESTION 4: OTHER ISSUES

4.4.1. ATTENTION TO THE NEEDS OF YOUNGER ADULTS

At various times during the discussions, comments were made about younger adults having needs different from the elderly and yet, they are being grouped with and cared for in a system geared to delivering services to the elderly. Family respondents noted that more frequent baths, hair washing, teeth brushing etc. may be needed by younger people. For example, young women, during menstruation, need more than the allotted one bath per week. Also, social interaction with peers is important to many young people and "it is not easy to make friends when you are surrounded by older people who aren't communicating." Further, some elderly individuals are noisy and disturb sleep and "it is hard having roommates always dying." While an intergenerational facility was considered to offer some advantages, most of the participants would prefer that their relatives live in a separate area with other younger adults.

4.4.2. SUPPORT FOR THE CAREGIVER

"Being the primary caregiver/advocate is a very lonely position", "I don't dare get sick" and "the caregiver needs to learn to let go, give yourself permission for free time " were ways in which the caregivers expressed their need for relief and for counselling. Respondents believed that currently, the system does not provide caregivers with respite nor does it assist them in understanding and accepting their own needs.

Support groups composed of families of younger adults with severe physical disabilities were seen as potentially advantageous and one focus group was followed by an informal exchange of information preliminary to forming such a group. However, opinions varied regarding the role of a support group. Some saw it as offering mutual support and exchange of information while others perceived it to have predominantly an advocacy role.

Families from out of town would welcome overnight accommodation in or near their relative's facility. Some reported that the frequency of their visits had been curtailed due to distance and costs.

Respite programs, both regular and occasional, were wanted but with the proviso that they must be affordable.

4.4.3. FINANCIAL SUPPORT

Several participants believed that far too much money is going to highly paid administrators and too little to front line services. Others believed some services could be provided at lower cost. Hospitals were seen as the most expensive way of delivering services. One participant complained of a "double standard" with a lot of money going to some places at the expense of others. "Money was thrown at group homes for transition of Glendale residents because they wanted it to be a success."

On the more personal level, several participants complained that their support allowance was inadequate - "it doesn't cover enough for food, let alone clothing and incidentals." Another client stated that the "hardest part of the whole thing has been financial - the years when we had to go through Social Services. People put in this position are labelled." Several participants referred to how "awful" they felt when going to "those offices" stating: You "feel like crawling under a table" and "When caring for him at home by myself we were made to feel like leeches. Living in poverty with our son got too much and that was one reason why he came to Gorge Road Hospital."

4.5. RESPONSE TO QUESTION 5: RESIDENTIAL OPTIONS

4.5.1. ENVIRONMENTAL DESIGN

Most family members felt passionately that the current residential situation of their relative was the best for him/her, whether it was community or facility-based. However, suggestions were forthcoming regarding improvements to both settings.

Families of clients living in facilities thought these should be more homelike with more space allotted to each resident and freedom to individualize it. Since their room is their home, they argued, more counter and storage space is needed. Currently there is little room for personal belongings, few outlets for computers, television sets, etc.

More private and semi-private rooms were recommended. Respondents whose relatives had been moved into a private room reported that they were happier now than when in a shared room. Several respondents described how they were required to fight to obtain a private room -- in one case having to go to Tribunal. One focus group member reported that her relative was strongly counselled against a private room by a social worker who asked, "Why do you want a private room? Don't you like people?". The family and client's response was "how many strangers live in your bedroom?"

More areas for private visiting would be appreciated. For example, families with young children have difficulty finding space in a care facility where they can interact in a "normal" fashion, including having a meal together. The availability of private space is particularly important, respondents stated, where the family lives out of town and taking the resident home for holidays and birthdays is logistically difficult or impossible.

Families of group home residents were not well represented in the focus groups but those who participated mentioned that homes with only four-residents can result in isolation, boredom and a restricted choice of associates. Respondents believed that although residents like the privacy that small scale homes provide, the stimulation of interacting with other residents, activation programs, opportunities to make choices and the general level of activity of a larger place may be more important.

Most of those with relatives living in the community, believe a community location to be the only acceptable option for their family member. However, most also recognize that it was their involvement that had allowed this to happened. "If I weren't here he would need a lot more help to live in the community. Probably a live-in person would be needed."

The advantage of having a self-contained suite within the family home was discussed in one group. In some situations the client could do more for himself if such an arrangement were provided and it would give both family and client more privacy. Financial help for such renovations was seen as money well spent.

4.5.2. SWING-BEDS AND ASSISTED LIVING PROGRAMS

Swing beds were considered extremely valuable by those whose relatives used them. Some saw them as the only way their family member could remain at home. One client was told of the program when discharged from Gorge Road Hospital and didn't believe it would be needed. However, once the family settled into their "new life" the value of such a service became evident and now is considered vital to the success of their living arrangement.

In the focus groups, the discussion leader shared information about several new residential care options which participants expressed considerable interest in. One was a Part-Time Resident Program, which operates within a large Extended Care facility in the Lower Mainland. Clients in the Part-Time Resident Program live at home for three or four days a week and in the care unit for the balance of the week. While they are at home with their spouse or family, another client occupies their facility bed. Currently, four beds serve eight clients. The community's response to this new initiative has been very positive and there is a waiting list of clients whose only remaining option is full-time facility placement and resulting separation from their family.

Some respondents also favoured Supportive Care Housing defined as a large homelike setting for about twelve residents with staffing at the Extended Care level. Such housing could be constructed adjacent to an Extended Care facility to permit access to services and staff expertise and would be less isolating than a group home. As an example, the discussion leader described William Rudd House, a 12-bed (11 permanent and one respite) project for younger adults with Multiple Sclerosis, currently under development on the grounds of Queen's Park Hospital in New Westminster. Fully funded by the Ministry of Health and the Greater Vancouver Regional Hospital District, with operating funds provided by the Ministry of Health, residents will direct their own care and will be partners in decision-making at all levels of operation. Each will have a separate bedroom with access to a private patio. Rooms will be large, allowing for computer equipment, personal furniture and belongings. Residents will have access to the therapeutic programs and services, including hydrotherapy, offered at the adjacent Queen's Park Extended Care hospital (Anderson, 1993; Hutchinson, 1994). While the facility is "multi-level", in reality most clients will be at the Extended Care level at admission, or will progress to that level due to the nature of their disease. The model of residential care to be offered is increasingly being referred to as Assisted Independent Living. The Ministry of Health is watching this particular project closely to determine whether it meets the objectives of being non-institutional, cost effective and positively impacting the quality of life of residents.

4.5.3. SELF-DIRECTED AND BROKERED CARE

The concepts of self-managed care and brokered care were also discussed. Self-managed care was described as assuming that the person with disabilities should determine what services he/she receives and involving a process whereby funding is attached to the person, giving him/her control and ownership of resources rather than a service agency. Brokered-care was described as being based on the same principles but recognizing that the person with disabilities may require information, support and assistance to make informed decisions. Service brokerage is the means by which the information and assistance is provided. A broker may be a non-profit society or some other person(s) appointed in cooperation with the individual to oversee his/her affairs. Families indicated a keen desire to be allowed to play the role of broker on behalf of their relative.

4.6 RESPONSE TO QUESTION 6: USE OF GORGE ROAD HOSPITAL VACANT SPACE

Most families saw a future role for the Gorge Road Hospital, but what it might be varied with the living situation of their relative. Those with community-dwelling relatives were more likely to see it providing day programming, out-patient rehabilitation, and respite. Families with relatives in Gorge Road Hospital recommended that it be used to house a separate residential wing or pod for younger adults with severe physical disabilities.

4.7 SUMMARY

A considerable number of the issues and problems identified in the family focus groups reflected difficulties respondents had experienced in dealing with the different "systems" such as the Ministry of Social Services, the Ministry of Health, and various home support agencies, sometimes with quite different results from other families and frequently, with frustration. Most respondents expressed great difficulty in navigating the bureaucracy. Their ability to obtain successful resolution to a particular problem often appeared to be more a reflection of their persistence and creativity than of the responsiveness of the system.

Some of the issues raised by the respondents are matters of policy and of inter-ministerial jurisdiction; others seem to reflect the interpretation of individual case managers or workers. Many families have become veterans, having fought the system for many years. "Newer" families learn from these more "experienced" families. Suggestions and ideas on how to "work the system" were frequently shared in the focus groups.

Some families reported feeling vulnerable and were reluctant to "make waves" lest the client receive less care or some form of retribution. Others expressed deep appreciation for their case manager, financial assistance worker, social worker or specific home support worker. Many of these staff appeared willing to stretch the limits of their authority in order to help clients and their families. But the overall impression was that respondents felt exasperated and frustrated in their attempt to achieve both the quantity and quality of service that they needed.

Specific concerns included the range of tasks home support workers are permitted to perform for the client. Focus group participants felt these needed to be expanded beyond those appropriate for the geriatric population in order to meet the psycho-social/recreational needs of clients and to support the family care-givers.

Focus group participants also expressed concern about the training afforded to home support workers. Some felt staff lacked sufficient knowledge about the medical conditions and specific care needs of the younger adults with severe physical disabilities with whom they worked. Child care was another area in which their knowledge base was felt to be lacking. Staff turnover, sometimes deliberately initiated by home support agencies to prevent attachments, was also decried.

There was considerable discussion about the difficulty of obtaining financial assistance for equipment purchase or repair. Communication devices and power wheelchairs were singled out for special mention. Participants also identified inequities between facility-based clients and those living in the community which they found particularly irritating given the effort they were expending to keep their relative at home.

5.0 SUMMARY AND RECOMMENDATIONS

5.1. SUMMARY

5.1.1. BACKGROUND

In the Capital Regional District there are younger adults with severe physical disabilities who require considerable assistance to live as independently as possible. This population includes persons between the ages of 19 and 55 years of age with primary diagnosis of a chronic illness such as multiple sclerosis, cerebral palsy, muscular dystrophy, amyotrophic lateral sclerosis, etc., or with a disability as a result of spinal cord or brain stem injury.

Their current places of residence include conventional accommodations either owned or rented, specially designed units in non-profit housing projects (i.e., integrated with non-disabled individuals), small group homes (licensed and unlicensed), long term care facilities and extended care units.

Some of this population receives services from the same programs that provide care to the much larger, geriatric population. The standards applied to these services, the levels and types of care provided, the maximum amounts of service, and the available residential options are not always appropriate or relevant for this younger client group. As a result, satisfactory living conditions and appropriate levels of vocational and rehabilitation programming may not be available.

To establish a clearer understanding of this group and its current and projected service needs, a study was commissioned in Spring of 1994 by the Capital Regional District Health Planning Division. The study was conducted by the Simon Fraser University Gerontology Research Centre.

5.1.2. PURPOSE OF THE STUDY

The purpose of the study was fourfold:

(1) To define the pertinent characteristics of the population of younger adults with physical disabilities (e.g., age, sex, diagnosis, education, marital status, current living situation, etc.).

(2) To conduct surveys and focus groups of representatives of the population (consumers and their families) to determine their preferences as to the type and location of services they require.

(3) To analyze specific programs and policies within the current health and human service system including comments on their ability to respond to consumer preferences.

(4) To recommend the type and level of resources required to meet consumer preferences.

5.1.3. SCOPE OF THE STUDY

The individuals chosen for this study represent most but not all of the younger severely disabled adult population in the CRD. The study selection criteria included individuals between the ages of 19 and 55, who were eligible to receive services under the CRD Long Term Care Program, and who were assessed at the Intermediate Care III or Extended Care Level.

The study does not include a small number of severely physically disabled adults who fall into one of the following four categories:

1. Multiply handicapped adults receiving services through the Ministry of Social Services, Services for Community Living.
2. Mentally handicapped adults receiving services through the Ministry of Social Services, Services for Community Living.
3. Adults with psychiatric illnesses receiving services through the Ministry of Health, Mental Health Services.
4. Adults receiving services through the Ministry of Health provincial Head Injury Program and Organic Brain Syndrome Program.

5.1.4. METHODOLOGY

The study was conducted in five phases.

Phase 1: Literature Review

An electronic literature search and review was conducted beginning with Gutman's (1989) review of the characteristics, service and staffing needs of institutionalized younger adults with severe physical disabilities. Unpublished material obtained from the Ministry of Health and other contacts was also reviewed.

Phase 2: Review of LTC Client Assessment Forms

Assuming that most younger adults with severe physical disabilities living in the CRD were known to the regional Long Term Care Program, a client profile was constructed using information from the LTC client assessment forms for existing clients. In some cases, the lack of currency and completeness of the information on these forms prevented the collection of consistent and accurate information for all sample clients.

Phase 3: Individual Client Interviews

Semi-structured personal interviews were conducted with a sample of 50 younger adults with severe physical disabilities: 21 living in facilities, 7 living in group homes, and 22 living in the community in conventional housing.

Phase 4: Family Focus Groups

Three focus groups were conducted with relatives of the subject client group: Group 1 with families of persons who could not speak for themselves due to cognitive or communication impairments; Group 2 with families of individuals living in the community; and Group 3 with families of individuals living in institutions.

Phase 5: Sub-Study of Residents of Queen Alexandra Centre for Children's Health

A profile was constructed of 10 of the eldest residents of Queen Alexandra Centre for Children's Health to facilitate planning for persons who will become part of the CRD's population of younger disabled. The profile was based on information from LTC assessment forms which were specially completed for the study.

5.1.5. SUMMARY OF THE FINDINGS

A. CLIENT PROFILE

The report describes the characteristics of 153 younger (19-55) physically disabled adults who were clients of the Continuing Care Program in June, 1994. Half of the clients are male; half female. The average age of the group is 41.5 years. About one-third are married. Sixty-eight percent live in conventional housing in the community, 28% live in care facilities, and 5% live in group or private family homes.

Four diagnostic groupings account for 71% of the clients: degenerative neurological condition (31%); head injury (15%); spinal injury (13%); and cerebral palsy (12%). Three-quarters have no cognitive impairment.

Although small in number this group has levels of disability which generate considerable service needs. For example:

- 18% are completely dependent for all movement;
- 31% have a significant communication problem;
- 50% require significant continued assistance with ambulation;
- 50% receive some form of regular treatment, most commonly concerned with bladder or bowel function;
- 52% must be dressed;

- 61% require continued assistance with transfer;
- 71% require continued assistance with bathing; and
- on average, each client uses four medications.

The data from the personal interviews helped to highlight client diversity. For example:

- 30% of the younger disabled group are parents;
- 14% engage in paid work, while 32% contribute voluntary service;
- 36% have at least some college or university training, and 12% are currently taking college or university courses.

In summary, the findings describe a diverse client group composed, in roughly equal proportions, of persons with degenerative conditions that will render them progressively more disabled (e.g., multiple sclerosis, amyotrophic lateral sclerosis) and persons having suffered injuries (e.g., head and spinal cord) whose conditions are more stable. Some of the clients are young adults with habilitation and education needs and aspirations; others are middle aged person who have had careers terminated by illness or injury.

B. SERVICE ISSUES AND SYSTEM DEFICIENCIES

While 62% of respondents felt that the system was generally responsive to their needs (see Section 3.6.4), both clients and families identified a number of service issues and system deficiencies. The issues arose from the survey of clients and the family focus groups. They have been sorted into twelve general areas. The issues are not listed in any priority order.

(i) Availability of Accurate and Comprehensive Service Information

Respondents reported that accurate and comprehensive information concerning services and entitlements for younger adults with severe physical disabilities and their families was not readily available. In the focus groups some families reported receiving services of which other families were unaware. Some clients and families felt that information on available services and resources was purposely withheld from them. Some reported expending inordinate amounts of time, energy and resources seeking information and services from various ministries and community services (see Sections 3.6.4 and 4.2.1).

(ii) Program Coordination

Clients and their families rarely have all their needs addressed by one profession, service organization or government ministry. Respondents reported frustration in having to deal with multiple programs and services each with differing mandates and funding mechanisms (see Sections 3.6.4, 4.2 and 4.2.1).

(iii) Case Management

The majority of clients under LTC case management are the elderly. Clients and their families thought that dedicated case managers who are more aware of the greater service and coordination needs of the younger disabled population would be preferable.

In addition, respondents felt that an "advocate" would be helpful in dealing with the many professionals, service organizations and government ministries with whom the clients and families must interact (see Sections 3.6.4 and 4.2.1).

(iv) Client Control Over Resources and Decision Making

Approximately three-quarters of the home-based clients (see Sections 3.3.5 and 3.6.2) and most families (see Section 4.2.2) expressed a desire to have increased control over those delivering their services. They would like the system to be more consumer driven, and to participate more in care planning. The perception that the system controls them, rather than that they control the system, made families feel devalued. Frequently, families stated that they felt that they were at the mercy of professional staff, hospitals, financial assistance workers and social workers.

The Choices in Supports for Independent Living pilot project (B.C. Ministry of Health, 1994) which provides clients with funds to hire their own home support worker drew considerable interest from respondents.

(v) Optional Living Arrangements

The majority of clients interviewed were satisfied with their current accommodation. However, over one-third (37%) in facilities and 15% in home-based housing said they were dissatisfied and/or had plans to move (see Section 3.3.9).

Responses to questions about best and least like features of their current accommodation (Section 3.3.3), satisfaction with its physical design (Section 3.3.6), and satisfaction with its degree of privacy (Section 3.3.7) indicated that:

Home-based clients want accommodation that is more spacious; has an accessible interior design and is well-located with respect to transportation, facilities and services. Specially designed handicapped units are available (mainly non-profit, subsidized housing) and are adequate for those who use manual wheelchairs. However, they are not adequate for the larger, less maneuverable motorized wheelchairs which 60% of the respondents use. Forty percent of the clients living in conventional housing had made adaptations to their homes; 38% said that further adaptations were needed. Barriers to making them included cost and obtaining landlord permission.

Facility-based and group-home clients want larger bedrooms and bathrooms, increased space for storage of personal belongings, and space, other than in their bedrooms, in which to entertain friends. They also mention lack of accessibility of some public spaces (e.g., grounds, patios, elevators) and some design flaws (e.g., in location of washrooms).

Group homes are the only Ministry of Health program designed specifically for younger adults with severe physical disabilities. Waiting lists are long and some facilities are very small. Some families thought four-person group homes were desirable, others considered them too small. The reasons cited by the latter included the potential for social isolation, boredom and restricted choice of programs and services (see Section 4.5.1).

In the focus groups, the consultants shared information about several new residential initiatives that are being developed in other regions. These included a Part-time Resident Program and a 12-bed Assisted Living project (Anderson, 1993; Hutchison, 1994). Families were very interested in these options (see Section 4.5.2 and 4.5.3).

(vi) Flexibility in Home Support Services

Policies and procedures governing home support services were seen by clients and families as tailored primarily towards the elderly LTC client. They are less effective in meeting the needs of the subject population. For example, clients with young families may need more assistance than seniors with house cleaning, transportation, supervision of children and evening help. A minority of clients (32%) reported difficulty in remaining in the community within the current maximum allowance of 120 hours per month. The CRD LTC manager can authorize in excess of the 120 hour limit and this occurs in some cases but not others.

Clients and families also reported that some home support agencies actively discourage their staff from becoming "friends" of the client and where this has occurred, have replaced them with new home support workers (see Section 4.2.3).

(vii) Specialized Training for Home Support and Facility Staff

Clients and families raised the following staffing concerns:

- inadequate staffing levels in Extended Care facilities, particularly in rehabilitation services (4.3.1.A, 4.3.2);
- inadequate home support staff training (3.3.5, 4.3.1.A);
- poor attitudes and insensitivity on the part of some staff (3.3.5, 3.4.1.E, 4.3.1.C);

- lack of continuity of staffing (3.4.1.E, 4.3.1.D) and
- lack of recognition that the skills to serve the needs of younger adults differ from those needed for the geriatric population (see Sections 3.3.5, 3.4.1.E, 4.3.1.B).

Some suggestions to improve services included:

- instructing direct care staff not to "do for" clients, but rather to encourage clients to do as much as possible for themselves;
- modifying routines, for example, bed time, to accommodate a younger client group who may wish to be more active in the evening; and
- being more sensitive to younger adults' needs for privacy and for recreation and leisure activities.

(viii) Access to Rehabilitation Services

Both clients and families mentioned the need for more activation and rehabilitation to enable clients to maintain optimal levels of functioning and independence (see Sections 3.4.3 and 4.3.2). Rehabilitation staffing levels (physiotherapy, occupational therapy, speech therapy) in Extended Care facilities do not meet the meet the needs of younger adults. In Intermediate Care facilities rehabilitation programs are often non-existent.

The Community Rehabilitation Program provides physiotherapy and occupational therapy services to clients in their own homes, but the service does not extend to clients residing in group homes.

(ix) Specialized Transportation Services

Virtually all clients used specialized transportation, most commonly, HandyDART. Half of the clients interviewed were dissatisfied with the service claiming that it lacked flexibility and reliability, and that staff were not always sensitive to the needs and feelings of clients (see Sections 3.4.1.A and 3.6.4).

(x) Acquisition of Specialized Medical Equipment

Clients and their families expressed frustration in obtaining and maintaining specialized medical equipment, e.g., customized motorized wheelchairs and computer-assisted communication devices (see Sections 3.6.4 and 4.3.5). Clients and families reported that when dealing with different agencies and jurisdictions, it was difficult to find one that would assume funding responsibility. Obtaining each needed piece of equipment was a protracted and stressful process.

Facilities receive funding in their budget for purchase of standard medical equipment for residents. However, the Ministry of Health does not provide sufficient funds for purchase of specialized equipment. Only clients living in the community are eligible for assistance in purchasing specialized equipment under the Ministry of Social Service's Medical Equipment Program. Therefore, inequities exist between clients living in facilities and those living in the community.

Respondents also perceived that both the Ministry of Health and the Ministry of Social Services have been slow to recognize and fund the purchase of communication devices (see Sections 3.4.2 and 3.5).

(xi) Respite and Other Caregiver Support Services

Family caregivers frequently reported feeling physically and emotionally exhausted (see Section 4.4.2), and some clients expressed concern about the "load" they placed on their families.

Family respondents expressed interest in the establishment of family support groups. They requested more information about respite services, in particular the swing-bed program at Gorge Road Hospital (see Sections 4.4.2 and 4.5.2). Home-based clients expressed considerable interest in respite services (see Section 3.4.4.A), and facility-based clients expressed interest in a day program or centre (see Section 3.4.4.B).

(xii) Educational, Vocational and Recreational Services

Between 18% to 30% of clients (see Section 3.4.3) identified a need for expanded recreational, educational and vocational choices that would enable them to achieve their personal goals and aspirations. Those living in facilities seem to have richer recreational opportunities than clients residing in the community. For the latter, recreational opportunities are left up to the individual and the family to locate and access.

The rapid expansion of computer-assisted communication and other "high-tech" devices for the physically disabled, creates new opportunities for clients to exercise independence and control over their lives. Clients who would like to take advantage of these new technologies may be prevented from doing so by lack of information, lack of coordination among agencies and lack of financial support.

5.2. RECOMMENDATIONS

Based on the literature review, the consultant's experience, and the service issues and system deficiencies identified by the respondents, the following 15 recommendations are proposed:

Recommendation 1: Extend Mandate of Working Group

Most of the recommendations are quite general and will need more review and analysis. There are no cost implications attached to the recommendations and they are not prioritized. It is not always clear who has the responsibility and authority to act in a given area. The current system is quite complex and partitioned such that no one provider or government ministry or department will be able to independently determine the next steps or implement the recommendations.

Also, while the report draws its findings and recommendations from a survey and discussions with clients and their families, these people have not been involved in the production of the report. Consumers and providers will need to work more closely together to pursue the interests of the consumer through changing times and conditions.

These follow-up and ongoing requirements might best be served by the formation of a permanent Working Group made up of consumers and providers. This group would fit into the larger Advisory/Standing committee structure currently being discussed by the Capital Health Board. Depending on the policies to be established by the Capital Health Board, the composition of the Working Group could involve representatives from some of the ministries, program and service providers involved in the production of this report, as well as persons nominated by consumers, families, and non-governmental agencies which support the interests of the severely physically disabled younger adult population.

Recommendation 2: Develop and Maintain Comprehensive Information on Programs and Services Available for Younger Severely Disabled Persons

Develop and maintain an information package on available programs and services provided by the Ministry of Health, other ministries, non-profit societies and private sector organizations. Detailed information on how to access each service should be included. The information package should be distributed to all clients and their families (see Recommendation 3).

Recommendation 3: Establish a Resource and Information Centre

Clients and their families and friends should be able to access information at a single point. A Resource and Information Centre would store information on existing and pilot programs/services, equipment and technology (see Recommendation 2); and provide client assistance in appeal procedures.

The Centre should be developed in cooperation with the Office for Disability Issues, the Capital Regional District, the Ministries of Health and Social Services, and the Resource Centre for Independent Living. Centre staffing and budget would be determined in conjunction with the sponsoring agencies.

Recommendation 4: Improve Policy and System Coordination

Establish an Interministerial Coordinating Committee with the responsibility and authority to co-ordinate mandate and resource issues and to effect timely responses to client requests.

Recommendation 5: Assign Specialized Long Term Care Case Manager(s)

Assign specially trained case manager(s) to the younger client caseload instead of having this caseload distributed amongst all case managers. This may involve a need for more case management resources due to the additional workload associated with this client group, i.e., their extensive network of service requirements, and their need for greater program coordination. The case manager(s) must be able to work across disciplines (e.g., Social Work, Physiotherapy, Nursing, Psychology), across jurisdictional boundaries, and be responsible for the coordination of all services required by clients, including contracting for services from community social work, mental health, and vocational and life skills training programs.

Recommendation 6: Increase Client Control over Service Planning and Decision Making

Greater opportunities for client control over service planning and decision making should be provided. For example, if the Choices in Supports for Independent Living Pilot Project is found to be effective in terms of cost and improved client health, then the means should be found to extend it to other eligible clients. Where clients are unable (or not always able) to direct their own home support services, the program should be expanded to allow families to control funds on the client's behalf. Clients and families would require training in advertising, interviewing, screening, reference checking, training, supervising and evaluating staff.

Recommendation 7: Revise Home Support Guidelines and Policies to Reflect the Needs of the Younger Disabled Population

Home Support guidelines and policies should distinguish between the needs of the younger severely disabled population and the elderly. Ministry of Health and Capital Regional District Home Support guidelines, and the policy and procedures of the various providing agencies should be reviewed and revised to better reflect the needs of this younger client group.

Recommendation 8: Introduce Specialized Training Programs

Facilities and home support agencies should ensure that staff serving young adult clients have appropriate knowledge, skills and attitudes. Currently, no formal training programs exist. Action should be taken including a request to the Community Advisory Committee of Camosun College. Other ways of providing training including the use of clients to teach providers should be considered. Education initiatives should include initial training, continuing education and inservice modules.

Recommendation 9: Improve Rehabilitation Services

Younger disabled clients require opportunities to participate in activation and rehabilitation programs in order to maintain optimal levels of functioning and independence. The Ministry of Health should review its rehabilitation policies and staffing models as they pertain to facilities, group homes and the Community Rehabilitation Program.

Recommendation 10: Review HandyDART Policy and Procedures

The current HandyDART service is not meeting clients' needs. B.C. Transit should review the priority given to this client group and increase service levels, if necessary, to facilitate client access to the fullest possible range of community resources and services.

Recommendation 11: Review Equipment Acquisition Policy and Procedures

Inequities in the acquisition of specialized medical equipment is a major concern of clients and families. The Office for Disability Issues in conjunction with the Ministries of Health and Social Services and other involved community agencies should review the related guidelines and policies in an effort to establish consistent access and funding support.

Recommendation 12: Publicize and Enhance Respite and Other Caregiver Support Services

Clients and their families reported that they were not adequately informed about existing respite services. While Recommendations 2 and 3 should help to address this concern, it is also suggested that:

(a) clients and their families be informed of all existing respite services including the swing bed at the Gorge Road Hospital.

(b) the Gorge Road Hospital expand its service to include accommodation for out of town family stay-overs.

(c) the Ministry of Health and local service providers develop a wider range of respite options, including planned short-stay and emergency placement services.

(d) the Ministry of Health subsidize Extended Care respite user fees where they present a financial hardship for the family.

(e) advocacy and support groups for families be established and supported.

Recommendation 13: Expand Educational, Vocational and Recreational Services

Clients identified a need for expanded educational, vocational and recreational opportunities. The Office for Disability Issues should encourage development of the widest possible range of affordable and accessible programs, including computer-linked training opportunities and services.

Recommendation 14: Explore Optional Living Arrangements

The younger severely disabled population have varied housing needs and preferences and no one option will meet all of their needs. Development of a broader range of options should be examined including part-time resident programs and assisted independent living, etc..

When new beds are approved for the CRD, high priority should be given to the creation of alternatives to the extended care unit accommodation in which most facility residents now live.

Recommendation 15: Maintaining Gorge Road Hospital Current Services and Consider the Introduction of New Programs Aimed at the Younger Disabled Client Group

The Gorge Road Hospital has traditionally provided services to the younger disabled client group. It is suggested that, in the short term, the Hospital continue to offer these services. Specifically, it is recommended that the Gorge Road Hospital:

(a) Become an Integral Component in a Comprehensive System of Care for Younger Adults with Severe Physical Disabilities

Gorge Road Hospital is well positioned to establish itself as an important resource for this client group. The Hospital could provide training and development of care providers (in conjunction with other training programs suggested in Recommendation 7), as well as quality residential care, rehabilitation, and community outreach programs designed to support the independence of the younger disabled client group.

(b) Establish a Dedicated Residential Care Unit

No special "podding" or staffing for younger adults is provided at Gorge Road Hospital. Clients indicated a desire for more space and more privacy. While some respondents acknowledged that value exists in intergenerational living, most believed that grouping younger people together was more desirable. It is suggested that, in the short term, a dedicated Residential Care Unit be established at Gorge Road Hospital for clients unable/unwilling to consider supported independent community living or a group home.

The suggestion to establish a dedicated residential care unit at Gorge Road Hospital must recognize the limitations of this extended care facility in meeting the spatial and environmental requirements of this client group. In the long term, these beds could be relocated to a purpose-built facility dedicated to the younger disabled client group.

(c) Consider the Need for a Transitional Living Unit and/or a Rehabilitation-Oriented Day Health Program

Some clients identified a need for a Transitional Living Unit that would provide life skills training and rehabilitation. Interest was also expressed in a Day Health Program that would promote and maximize independence.

Both services are recognized in other jurisdictions as important components of the range of services to this client group. Their primary purpose is to prepare clients for more independent living. The need for them in the Capital Regional is not certain and therefore, should be the subject of a more detailed assessment.

6.0. REFERENCES

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APPENDIX 1

SERVICES FOR PHYSICALLY DISABLED ADULTS IN THE CRD

SERVICES FOR PHYSICALLY DISABLED ADULTS IN THE CAPITAL REGION*

Bus Buddies

c/o Resource Centre for Independent Living
610 - 620 View Street
Victoria, B.C. V8W 1J6
Phone: 360-1500

Services:
- one-to-one volunteer program accompanying disabled people on the bus and teaching them how to use the bus themselves
- funded by B.C. Transit

Camosun College - Special Programs

3100 Foul Bay Road
Victoria, B.C. V8P 5J2
Phone: 592-1556 **Fax**: 360-3662
Hours: 8:30 a.m. - 4:30 p.m. Monday, Tuesday, Thursday, Friday;
12:30 a.m. - 7:30 p.m. Wednesday

Adult Special Education:
General Office: Room 202, Ewing Building, 370-3312
Access Resource Centre: 370-3323
- provides information for students with special needs who require assistance with registration, assessment, goal planning, use of ramps, elevators, handicapped parking
- provides learning material, such as talking books, visual-tek enlargers, tape recorders
- arranges for interpreters and learning partners
- provides information on disabilities and community agencies.

Student Mentor Program:
Room 202, Ewing Building, 370-3321
- provides mentors (free of charge) to help special needs students with a variety of tasks including mobility assistance, typing assignments, individual tutoring in course materials, reading or taping for visually impaired students, note-taking for visual or hearing impaired students, reviewing basic skills in reading, writing and math

Basic Employment Readiness Training (B.E.R.T.):
Room 200, Ewing Building, 370-3325
- combines in-class course work with on-the-job work experience to prepare students with special needs for employment
- goal is for students to establish a realistic understanding of their skills and abilities and where they fit into the job market
- support is provided when students are ready for a job search

Cost: tuition fees
Area Served: South Vancouver Island

*Source:
CRD Health (1994). Directory of Services

Disabled Women's Network of Victoria (D.A.W.N)

c/o 506 Lone Tree Place
RR #6, Victoria, B.C. V9B 5T9
Phone: 474-5939, answering machine

Services:
- provides support for women with disabilities
- addresses the issues of poverty, accessible housing, violence, isolation, parenting, health, sexuality, and the enpowerment of disabled women
- communicates with the non-disabled community about the concerns of all physically, mentally, and emotionally disabled women; works in coalition with other groups and individuals who share the same concerns
- tries to make all women's services available and accessible
- gathers and dispenses information from all sources to establish a network and to assist our membership

Garth Homer Society for the Handicapped

813 Darwin Road
Victoria, B.C. V8X 2X7
Phone: 388-4244
Hours: 8:30 a.m. - 4:30 p.m. Monday to Friday

Services:
- pre-vocational training for adults with disabilities
- offers a variety of remunerative work situations
- provides counseling to assist disabled individuals in achieving their highest level of social, economic and life skills development
- provides training in crafts for rehabilitation and recreation
- offers chair caning and rush repair, labour intensive assembly, woodwork manufacturing, mail handling service

Area Served: Capital Regional District

Goodwill Enterprises for the Handicapped

220 Bay Street
Victoria B.C. V9A 3K5
Phone: 385-5756 **Fax**: 389-6791
Hours: 8:00 a.m. - 4:00 p.m. Monday to Friday

Services:
- non-profit society sponsored by the Rotary Clubs of Victoria, Duncan, Nanaimo, and Courtenay
- offers vocational rehabilitation of handicapped persons through work assessment, work adjustment, specific individual on-the-job training programs and assistance with independent job search
- rehabilitation is carried out by professional staff
- also sponsored by the Ministry of Advanced Education and Job Training and Canada Employment
- continuing employment is provided for approximately 200 individuals
- internships, work experience, and volunteer opportunities are ongoing

Costs: tuition for the rehabilitation program is usually provided by the Skill Development Department of the Ministry of Advanced Education or Canada Employment
Area Served: British Columbia

Handicapped Action Committee

926 View Street
Victoria, B.C. V8V 3L5
Phone: 383-4105
Hours: 9:00 a.m. - 4:00 p.m. Monday to Friday

Services:
- promotes integration of people with various disabilities into the community; helps build awareness of disabled persons' abilities and needs; offers information, referral, advocacy, and counseling
- consumer card discount for disabled consumers; sells handicapped parking decals

Costs: $10.00/year for membership and HACTION subscription
Area Served: Greater Victoria

Home Support Agencies

Alpha Home Care
1037 Cloverdale Road
Victoria, B.C. V8X 2T4
383-4423

Fairfield Homecare Services
2 - 380 Cook Street
Victoria, B.C. V8V 3X7
386-9222

Fernwood Home Support
109 - 1026 Johnson Street
Victoria, B.C. V8V 3N7
386-0521

Helping Hand Services Ltd.
1834 Oak Bay Avenue
Victoria, B.C. V8R 1C2
592-1511

Island Community Home Support
470 - 1105 Pandora Avenue
Victoria, B.C. V8V 3P9
382-5135

James Bay Home Community Homemaker
547 Michigan Street
Victoria, B.C. V8V 1S5
388-7566

Medox Health Care Services
302 - 510 Yates Street
Victoria, B.C. V8X 1K8
388-7388

Metchosin Homemaker Service
202 - 814 Goldstream Avenue
Victoria, B.C. V9B 7X3
474-4541

Nisika Enterprises
1133 Fort Street
Victoria, B.C. V8V 3K9
380-7055

Olsten Health Care
202 - 2187 Oak Bay Avenue
Victoria, B.C. V8R 1G1
595-2133

Paramed
220 - 1175 Cook Street
Victoria, B.C. V8V 4A1
383-4668

Pender Island Homemaker
R.R. #1, Pender Island, B.C. V0N 2M0
629-3313

Peninsula Community Association
9751 - 3rd Street
Sidney, B.C. V8L 3A5
656-0134

Salt Spring Homemaker Service
Box 98 Ganges, B.C. V0S 1E0
537-9955

Victoria Home Support
205 - 895 Fort Street
Victoria, B.C. V8W 1H7
384-1113

Housing Association for the Physically Disabled (1976), Vancouver Island

303 - 2294 Douglas Street
Victoria, B.C. V8T 4N4
Phone: 384-8837 Fax: 384-8819

Services:
- establishes and maintains cost-effective, accessible homes for adults whose primary disabilities are physical
- provides a continuum of housing options and holistic, multi-level support services (housekeeping, food services, life skills teaching, recreating and leisure activities, support care, counseling, nursing, medical intervention)

Nigel House
846 Nigel Avenue
provides accommodation for 35 residents in both single and double rooms

Sutton House
106 Medana Street
accommodation for 6 residents

Hazeland House
2130 Florence Avenue
5 - bedroom to accommodate five

Paskin Way
761 Paskin Way
accommodation for 4 residents

Costs: shared by residents, government and donations, individual cost based on income
Area Served: British Columbia

Apartment Support Services:
- provides support to adults living in apartments throughout the community, a limited number of rentals have subsidies

Residential Services:

McKenzie Home
112 McKenzie Avenue
Victoria, B.C. V8V 2W2
382-8310

Maplewood Home
3290 Maplewood Road
Victoria, B.C. V8P 3M5
381-4557

Wilcox Home
2476 Wilcox Terrace
Victoria, B.C. V8Z 2H7
652-9877

Mariposa Home
4133 Mariposa Heights
Victoria, B.C. V8Z 6P5
727-9784

Jeffree Home
1867 Jeffree Road
Saanichton, B.C. V0S 1A0

McRae House
1512 McRae Avenue
Victoria, B.C. V8V 2W2
382-8310

Lindsay Home
754 Lindsay Street
Victoria, B.C. V8Z 3E1
479-2478

Redfern Home
937 Redfern Street
Victoria, B.C. V8S 4E7
595-8615

Marin Park Home
1166 Marin Park Drive
Brentwood Bay, B.C. V0S 1A0
652-9996

Area Served: Capital Regional District

Independent Living Housing Society of Greater Victoria

2571 B Quadra Street
Victoria, B.C. V8T 4E1
Phone: 383-2524 **Fax**: 383-9431
Hours: 8:30 a.m. - 4:30 p.m. Monday to Friday
Contact: Lynn Knight, Executive Director

Services:
- provides full personal care, residential housing, group homes, apartments and private care for the developmentally and physically challenged

Costs: based on income
Area Served: Greater Victoria

Loan Cupboards - For the Handicapped

Amyotrophic Lateral Sclerosis Society
Phone: 479-0738

Mount Newton Centre
2158 Mount Newton X Road, Saanichton, B.C.
Phone: 652-3432

Red Cross House
909 Fairfield Road, Victoria, B.C.
Phone: 382-3159

Sooke Loan Cupboard
Phone: 642-4607, 642-3045

Sidney Legion
1660 Mills Road, Sidney, B.C.
Phone: 656-2428, 656-3152

Ministry of Advanced Education, Training and Technology - Vocational Rehabilitation Services

1st Floor, 838 Fort Street
Victoria, B.C. V8V 2Y5
Phone: 387-3645 **Fax**: 356-0008
Hours: 8:30 a.m. - 4:30 p.m. Monday to Friday

Services:
- assists individuals who want to re-enter the workforce by offering a comprehensive vocational rehabilitation program
- referrals to the program are made by various health and welfare agencies, self, or professional persons
- provides needs assessment, development of a rehabilitation plan and assistance in obtaining skills for employment
- eligible individuals must be B.C. residents, 16 years of age or older, and must have a permanent physical or mental disability which hinders them from obtaining gainful employment

Costs: funding dependent upon need
Area Served: Capital Regional District

Ministry of Health - Services to the Handicapped Branch

Regional Services
#1 - 1810 Blanshard Street
Victoria, B.C. V8V 1X4
Phone: 952-0850 **Resource Line**: 1-800-465-4911

Services:
- assists individuals with multiple disabilities to integrate into community settings
- toll-free resource line provides information on services and resources available to individuals and their families
- Associate Family Program provides individualized, home-based living arrangements, services and supports for children with multiple disabilities who reside in long-term care facilities
- Provincial Head Injury program provides support for adults with a traumatic head injury
- provides coordination of admissions to the At Home Program for children with severe disabilities

Neil Squire Foundation

#1 - 2130 Central Avenue
Victoria, B.C. V8S 2R3
Phone: 595-7442 **Fax**: 595-7474
Hours: 9:00 a.m. - 5:00 p.m. Monday to Friday

Services:
- part of national organization identifying and responding to the needs of adults with severe physical disabilities
- aim is to create opportunities for greater independence
- area of expertise is access to computers
- offers consultation and assessment services to meet the needs of clients
- includes alternative computer access, client case management, home and office accessibility evaluation, computer and technical systems training, workshops and presentations about alternative computer access

Costs: consulting fee: $75.00/hour; instructional fee: $35.00/hour; workshops and presentations: negotiable; non profit organization
Area Served: Vancouver Island

Recreation Integration Victoria

4135 Lambrick Way
Victoria, B.C. V8N 5R3
Phone: 477-6314 **Fax**: 477-6046
Hours: 8:30 a.m. - 4:30 p.m.

Services:
- provides information regarding community recreation and leisure opportunities for individuals with disabilities
- Leisure Assistance - a one-to-one volunteer service that assists people with disabilities in accessing community recreation and leisure opportunities
- services focused on the needs of children and families during Spring Break, summer vacation and Christmas holidays
- provides training and orientation for community organizations
- acts as recreation integration advisors, consultants, and provides liaison between people with disabilities, recreation professionals, agencies, and all levels of government

Area Served: Greater Victoria

Resource Centre for Independent Living

610 - 620 View Street
Victoria, B.C. V8V 1J6
Phone: 360-1500 **Fax**: 360-2702
Hours: 10:00 a.m. - 4:30 p.m. Monday to Friday

Services:
- provide information and referral, individual advocacy, peer support, and service development to people with all types of disabilities
- offers "BUS BUDDY" transportation assistance program for people with disabilities who are physically able to board the public transit buses (bus passes are provided for volunteers)
- publishes "Independent Living" newsletter bi-monthly; contains issues of concern and information regarding people with disabilities (distributed free, subscriptions available)
- provides parking placards for use in handicapped parking spaces; application form available at office, doctor must complete and sign the form, processing fee $10.00

Costs: non-profit organization
Area Served: Southern Vancouver Island

Victoria Association for Community Living

3861 Cedar Hill Cross Road
Victoria, B.C. V8P 2M7
Phone: 477-7231 **Fax**: 477-6944
Hours: 8:30 a.m. - 4:30 p.m. Monday to Friday

Services:
Advocacy Services:
- offers family and personal advocacy support - group and individual counseling, information sharing, referral and networking
- educational, residential, vocational, recreational, and respite information is available

Community Services:
- family and personal support is provided regarding residential, vocational, recreational, respite and school placement
- people who have previously been working in sheltered workshops are supported in finding employment in the community
- talks with community groups are held to increase awareness regarding the capacity of people with disabilities
- individualized training in parenting and life skills is provided as well as integrating individuals into existing community and support services

Day Services:
- offers various day programs providing support to adults in a small group or on one-to-one basis

Community Access Program:
- focuses on accessing the community through social/leisure opportunities, work skills, recycling, garden maintenance, and small industries; supported employment is offered

Work Crews:
- operates work crews providing grounds keeping and landscaping services

APPENDIX 2

QUEEN ALEXANDRA HEALTH CENTRE FOR CHILDREN ANSCOMB HOUSE SUB-STUDY

INTRODUCTION

This appendix describes the characteristics of 10 of the eldest clients of Victoria's Queen Alexandra Health Centre for Children. In April/May, 1994, when this sub-study was conducted, eight of the 10 were residents of Anscomb House; the other two were living in the community but accessed respite beds at Anscomb House.

Anscomb House (AH) is an eight bed group home unit located in a wing of one of the buildings at Queen Alexandra Health Centre for Children. It provides residential habilitative, palliative and respite services to adolescents with muscular diseases such as Duchenne muscular dystrophy and spinal muscular atrophy and their families. This provincial resource has a full multi-disciplinary team consisting of a physician, nurses, child and youth care workers, social worker, psychologist, physiotherapist, occupational therapist, seating and orthotics expert and nutritionist. A speech and language therapist is accessed from the community as needed. The unit works collaboratively with other provincial service providers such as the Muscular Dystrophy Association of Canada, B.C. Rehab and Children's Hospital.

Data reported here derive from the LTC-1 Form, the Continuing Care Program's standard client assessment form which was specially completed for these 10 clients for purposes of this study.

In addition to the fact that they are living in a group home, these clients are of special interest because they suffer from disorders (predominantly Duchenne muscular dystrophy) with which children are living longer than ever before. As a result, they will in the near future become part of the population of younger adults with severe physical disabilities living in the CRD. It is important to understand their care needs as in future individuals with their diagnoses will likely constitute a larger proportion of the Continuing Care case load than is currently the case. (There were 5/131 individuals with similar diagnoses among the sample of Continuing Care clients described in Chapter 2).

A2.1 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF ANSCOMB HOUSE (AH) CLIENTS

Nine of the 10 AH clients were male. As can be seen in Table A2.1 they ranged in aged from 14-21 (mean age=18.4; s.d.=2.07); none had ever been married.

TABLE A2.1

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF AH CLIENTS (N=10)

	n
Sex	
Male	9
Female	1
Current Age	
(as at June 1, 1994)	
14	1
16	2
18	1
19	4
20	1
21	1
Mean age (in years)	**18.4**
s.d.	2.0
Range	14.5-21.3
Living Arrangement	
Group Home (Anscomb House)	8
Parent's Home/Respite	2
Single Marital Status	10

A2.2 PRIMARY DIAGNOSIS AND LEVEL OF CARE

Eight had a primary diagnosis of Duchenne muscular dystrophy, one of spinal muscular atrophy and one of Werdnig-Hoffmann muscular dystrophy. Table A2.2 shows the incidence and prevalence of these disorders.

With respect to level of care, seven of the 10 AH clients were described as "clearly extended care eligible".

A2.3 MEDICATION USAGE

The number of prescription and non-prescription medications used ranged from 0-10. As a group, this sample averaged five drugs per person (mean=5.30, s.d.=3.34). Only one individual (10% of sample) was reported to use no medication. This individual was one of those with a diagnosis of Duchenne muscular dystrophy.

Table A2.3 shows the types of medication used by the AH clients. As can be seen, those most commonly used were: skin preparations (used by 60% of the sample), analgesics (used by 50%), laxatives (used by 40%), vitamins and minerals (40%), and anti-asthmatics (40%).

TABLE A2.3

TYPES OF MEDICATION USED BY AH SAMPLE (N=10)

	n
No medications	1
Analgesics	5
Laxatives	4
Vitamins/minerals	4
Muscle relaxants	1
Antidepressants	1
Anti-biotics/anti-infectives	1
Skin preparations	6
Anti-inflamatory agents	1
Steroids	1
Anti-hypertensives	1
Anti-coagulants	1
Anti-histamines	2
Anti-asthmatics	4
Anti-emetics	1

Note: Columns cannot be summed as multiple medication groups were recorded for each person. Regardless of the number of drugs consumed, a category was recorded only once per client.

A2.4 TREATMENTS

All of the clients in the AH sample received physiotherapy. Other treatments, as shown in Table A2.4, most commonly included manual coughing and esophogeal breathing.

TABLE A2.4

TREATMENTS ADMINISTERED TO AH CLIENTS (N=10)

	n
Physiotherapy/exercise	10
Manual coughing	10
Esophogeal breathing	9
Night time ventilation (non-invasive)	4

Note: Columns cannot be summed as all clients receive more than one treatment

A2.5 MENTAL HEALTH

Since 1990, mental health has been reflected on the LTC-1 form via a set of 10 measures. The measures and their response categories are shown in Table A3.5. As can be seen none of the 10 AH clients is cognitively impaired and all are described as having insight. Nine of the ten are rated as cooperative, behaving normally, showing appropriate affect, and having normal thought content and perceptions. Fewer, but still a majority (6/10), are described as well groomed, self-directing, and showing good judgment.

TABLE A2.5

MENTAL HEALTH OF AH CLIENTS (N=10)

Attitude	n
Cooperative	9
Indifferent	1
Resistive	0
Demanding	0
Suspicious	0
Hostile	0
Appearance	
Well groomed	7
Adequate	3
Dishevelled	0
Inappropriately dressed	0
Ill - not dressed	0
Self-direction	
Independent	6
Needs motivation	2
Needs direction	2
Dependent	0
Behaviours	
Normal	9
Aggressive (physical or verbal)	0
Restless	0
Withdrawn	1
Self-destructive	0
Affect	
Appropriate	9
Anxious	1
Labile	0
Inappropriate	0
Blunted	0
Depressed	0

Angry	0
Thought content	
Normal	9
Obsessions/delusions	0
Preoccupation	0
Other	1
Perceptions	
Normal	9
Other	1
Cognition	
Normal	10
Mild impairment	0
Moderate impairment	0
Severe impairment	0
Insight	
Good	10
Partial	0
None	0
Judgement	
Good	6
Adequate	4
Poor	0

A2.6 COMMUNICATION ABILITIES

Six of the 10 AH clients wears glasses. Table A2.6 shows that with the use of these, all 10 clients are rated as having a level of vision that is at least adequate for personal safety. All are also rated as having unimpaired hearing and unimpaired communication ability.

TABLE A2.6

COMMUNICATION ABILITIES OF AH CLIENTS (N=10)

Vision	**n**
Unimpaired	3
Adequate for safety	7
Hearing	
Unimpaired	10
Speech	
Unimpaired	10
Understanding	
Unimpaired	10

A2.7 LEVEL OF PERFORMANCE OF ACTIVITIES OF DAILY LIVING

Table A2.7 shows the AH client's level of performance of activities of daily living. As can be seen, all ten are completely dependent for transfer, require continued assistance with bathing, require significant or continuous assistance with ambulation and must be dressed. Nine of the ten require total assistance for grooming. Most, however, are able to eat independently with aids. Also all are totally continent of bowel and nine of bladder, with one requiring routine toileting or reminders, although total assistance in toileting is required by all ten.

TABLE A2.7

LEVEL OF PERFORMANCE OF ACTIVITIES OF DAILY LIVING OF AH CLIENTS (N=10)

	n
Ambulation	
Independent - normal emvironment	0
Independent - specific environment	0
Requires supervision	0
Requires minor assistance	0
Requires sig./continued assistance	10
Mobility aids	
Uses cane	1
Uses wheelchair	9
Ankle-foot orthosis	6
Transfer to/from bed, chair & toilet	
Independent	0
Requires supervision	0
Requires intermittent assistance	0
Requires continued assistance	0
Completely dependent for all movement	10
Bathing	
Independent	0
Independent with aids	0
Requires minor assistance/supervision	0
Requires continued assistance	10
Dressing	
Independent	0
Requires supervision	0
Requires periodic or partial help	0
Must be dressed	10

TABLE A2.8

SELF CARE ABILITIES OF AH CLIENTS (N=10)

	n
Food Preparation	
Independent	0
Adequate if ingredients supplied	0
Can make/buy meals but diet inadequate	0
Physically or mentally unable	9
No opportunity or does not participate by choice	1
Housekeeping	
Independent w/help for heavy tasks	0
Can perform light tasks adequately	0
Performs light tasks inadequately	0
Needs regular help and supervision	8
Physically or mentally unable	0
No opportunity or does not participate by choice	2
Shopping	
Independent	7
Independent only for small items	1
Must be accompanied	2
Travelling	
Independent	6
No public transport, uses private vehicle or taxi	2
Can travel only if accompanied	2
Telephone	
Independent	9
Physically or mentally unable	1
Medications and Treatments	
Completely responsible for self	0
Requires reminder or assistance	10

Grooming/hygiene	
Independent	0
Requires reminder/direction	0
Requires some assistance	1
Requires total assistance	9
Eating	
Independent	0
Independent with aids	8
Requires intermittent help	0
Must be fed	2
Bladder Control	
Totally continent	9
Routine toileting or reminder	1
Bowel Control	
Totally continent	10

A2.8 DIET

Six of the AH clients eat a regular diet, one a regular diet with increased fibre and one with increased calories, one eats a regular but blended diet and one, a regular diet with increased calories and blended.

A2.9 SELF CARE ABILITIES OF AH CLIENTS

Table A2.8 shows that none of the AH clients prepares their own food although one could prepare some foods in an appropriate environment. Nine can use the telephone independently, eight can undertake some housekeeping duties with regular help and supervision, seven can shop independently, and six can travel independently.

A2.10 SUMMARY AND DISCUSSION

This appendix has presented detailed information on the socio-demographic, clinical and functional characteristics of 8 full-time residents of Anscomb House and 2 individuals who access its respite beds. These clients are of special interest because they are among the oldest patients at Queen Alexandra Health Centre for Children (age range of sample 14-21 years; mean age=18.4) and they suffer from disorders (predominantly Duchenne muscular dystrophy) with which children are living longer than ever before (Jenkins, 1993). As a result, they will in the near future become part of the population of younger adults with severe physical disabilities living in the CRD and will constitute a greater proportion than currently of the Continuing Care case load.

Among key characteristics to note is that consistent with their diagnosis, this group is predominantly male. For example, Duchenne muscular dystrophy, one of the most prevalent forms affects males exclusively. The estimated incidence is 1/5,618 male live births; prevalence is estimated at 2.48/100,000 (Bushby, Thambayayah & Garner-Medwin, 1991). Duchenne and related muscular dystrophies are characterized by diffuse skeletal and cardiac muscle involvement. They are described as "leading inexorably to quadraparesis" in the pre-teen years and to death due to respiratory failure in young adulthood. Mohr and Hill (1990) estimate average age at death as 20 years. Iannaccone (1992) indicates however, that with the advent of molecular genetic technology, the definition and treatment of these diseases are being modified. The discovery of genetic markers is leading to earlier detection. Iannaccone suggests that treatment "may soon mean the routine use of steroids and later include direct injection of an artifical gene". Jenkins (1993) cites a number of recent studies demonstrating that assisted ventilation therapy can result in a prolongation of life into the 40s. "Furthermore", he adds "research has indicated that people whose lives have been extended through the use of technology can live active lives in the community with typical family lives, involvement in recreational and educational activities and satisfying interpersonal relationships..." (p.15).

APPENDIX 3

DESCRIPTION OF FACILITIES AND GROUP HOMES FROM WHICH INTERVIEWED CLIENTS WERE DRAWN

A) GORGE ROAD HOSPITAL

B) NIGEL HOUSE

C) ANSCOMB HOUSE

A) GORGE ROAD HOSPITAL

Gorge Road Hospital, located in Victoria, B.C. consists of two units: a rehabilitation unit and an extended care unit. Both have been in operation since the hospital opened in 1973. Of the 388 beds in the hospital, 288 are for Extended Care, 55 are out of service and designated to become a hospice/palliative care unit in December, 1994 and 45 are currently used for active rehabilitation.

In September, 1994, there were 286 individuals in the hospital's Extended Care beds. As shown in Table A3.1, 48 (16.8%) were aged 19-54.

TABLE A3.1

AGE DISTRIBUTION OF EXTENDED CARE POPULATION, GRH, September, 1994 (N=286)

	n	%
<20	0	0
20-24	0	0
25-34	16	5.6
35-44	18	6.3
45-54	14	4.9
55-64	21	7.3
65+	217	75.9

The 45 beds currently used for active rehabilitation are scheduled to be relocated at Royal Jubilee Hospital when its redevelopment goes ahead. This will leave the "empty rehabilitation space" for which opinions were solicited in the present study (see Sections 4.8 and 6.13).

B) NIGEL HOUSE

Located in Saanich, B.C., Nigel House is one of four residences for adults with physical disabilitites that is operated by the Vancouver Island Housing Association for the Physically Disabled (VIHPD). Nigel House provides accommodation for 35 residents in both single and double rooms. Direct care is provided by support care workers who provide 24-hour service and nurses who work six and one-half hours per day, seven days per week. In addition, housekeeping, activity and lifeskills training are provided. The dining room is staffed by trained cooks who are supervised by a Registered Dietician who is also the Manager of Client Care. Counselling, in the form of individual and regular group work, is provided by a Registered Social Worker who is also the Manager of Client Services (K. Macmurchie, 1994 - personal communication)

An Independent Living Support (i.e. Transition Unit) program is also available at Nigel House for persons aged 19 and over "who have a desire to live as independently as possible in the community". Clients in the Program live for three months in a private training apartment. While there the client works intensively one-on-one with the Program's Lifeskills Worker. This individual provides instruction in financial management, consumer shopping, housekeeping, personal hygiene, cooking and baking, problem solving and decision making. The Lifeskills Worker also assists the client to move to suitable accommodation in the community and maintains contact with the client for a minimum of six months after community relocation. (Note: one of the three clients from Nigel House interviewed in the present study was in the Independent Living Support Program).

The other three homes operated by the VIHAP are all smaller and are located in residential neighbourhoods within the City of Victoria. Sutton House in James Bay, is a spacious heritage home accommodating six residents. Hazeland House, located in Oak Bay, is a five-bedroom house able to accommodate five residents. Paskin Way House in Royal Oak is a newly-built home for four residents.

Services offered include: housekeeping, meals, life skills training, recreation and leisure activities, support care, counselling, nursing and medical intervention.

As with Nigel House, admission is open to persons aged 19 and over with physical disabilities. In all four homes the cost is shared by residents, government and donations, with individual cost based on income.

C) ANSCOMB HOUSE

Anscomb House is an eight bed group home unit located in Victoria, B.C. in a wing of one of the buildings at Queen Alexandra Health Centre for Children. It provides residential habilitative, palliative and respite services to adolescents with muscular diseases such as Duchenne's muscular dystrophy and spinal muscular atrophy and their families. This provincial resource has a full multi-disciplinary team consisting of a physician, nurses, child and youth care workers, social worker, psychologist, physiotherapist, occupational therapist, seating and orthotics expert and nutritionist. A speech and language therapist is accessed from the community as needed. The unit works collaboratively with other provincial service providers such as the Muscular Dystrophy Association of Canada, B.C. Rehab and Children's Hospital.

APPENDIX 4

A) LETTERS OF INVITATION TO PARTICIPATE IN THE CLIENT INTERVIEWS.

B) CLIENT INTERVIEW INFORMATION AND CONSENT FORMS.

C) CLIENT INTERVIEW SCHEDULE.

SIMON FRASER UNIVERSITY
AT HARBOUR CENTRE

Gerontology Research Centre
Gerontology Diploma Program

2800 515 West Hastings Street
Vancouver, British Columbia
Canada V6B 5K3

Centre Tel: 604/291.5062
Program Tel: 604/291.5065
Fax: 604/291.5066

SERVICE PREFERENCES OF YOUNGER ADULTS WITH PHYSICAL DISABILITIES STUDY

This study is being carried out to assist the Capital Regional District and SFU Gerontology Research Centre to better understand the needs and preferences of younger adults with severe physical disabilities and their families. This information will be considered in planning future services. The term "younger adult" refers to persons between the ages of 19-55.

The interview you are being asked to take part in will take between one and one and one half hours of your time. You will be asked questions about yourself, where you live, about services and programs you use, and your opinions of these services. You will also be asked about other services you would like to have provided.

All information that you provide will be confidential. Respondents will not be named or otherwise identified in reports of the study. You may refuse to answer any question you don't want to answer or stop the interview at any point. Refusal to participate will have no effect on the care you receive.

If you would like further information or a summary of the findings from the study, please contact Dr. Gloria Gutman, Director of the Gerontology Research Centre at the above address.

SIMON FRASER
UNIVERSITY
AT HARBOUR CENTRE

Gerontology Research Centre
Gerontology Diploma Program

2800· 515 West Hastings Street
Vancouver, British Columbia
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Centre Tel: 604/291.5062
Program Tel: 604/291.5065
Fax: 604/291.5066

16 May, 1994

You are being asked to give from 1 to 1 1/2 hours of your time to take part in an interview with a researcher from Simon Fraser University in Vancouver. As you will see from the attached letter from Dr. Shaun Peck, we are going directly to the consumers of services to find out your experiences with, and preferences regarding, the services you use and those you would like to have available.

We will be in Victoria for a week starting Tuesday, May 24 and hope very much that you will agree to meet with one of us during that time. Without the help of those who need and use the services, we cannot conduct the study and much valuable information would be lost.

We want to stress that your particpation is voluntary, whether or not you take part will have no effect on your care, you can refuse to answer any questions and you can stop the interview at any time. However, we do hope you will help us with this study - your input is valuable to us.

We look forward to meeting with you next week.

Sincerely,

Monica Bischoff
Judy Killam
Maureen MacLachlan
Diane Sawicki

SIMON FRASER UNIVERSITY

VICE PRESIDENT, RESEARCH

BURNABY, BRITISH COLUMBIA
CANADA V5A 1S6
Telephone: (604) 291-4152
FAX: (604) 291-4370

May 16, 1994

Dr. Gloria Gutman
Gerontology
Simon Fraser University

Dear Dr. Gutman:

Re: **Proposal to Ascertain Key Characteristics and Determine the Service Preferences of Younger Adults with Severe Physical Disabilities**
Capital Regional District

I am pleased to inform you that the above referenced application has been approved on behalf of the University Ethics Review Committee.

Best wishes for success in this research.

Sincerely,

for Bruce P. Clayman, Chair
University Ethics Review Committee

c: Keith Anderson, Co-Investigator
Judy Killam, Co-Investigator

BR/hme

CRD

Capital Regional District

524 YATES STREET P.O. BOX 1000 VICTORIA B.C. V8W 2S6 TELEPHONE (604) 360-3000

Please note the Medical Health Officer's telephone number: 360-3116; fax number: 360-3120

April 21, 1994

To Whom it May Concern:

This is to advise that the Gerontology Research Centre of Simon Fraser University has been commissioned to undertake a review of the needs and preferences of younger adults with severe physical disabilities in the Capital Region.

Funding sources include the Capital Regional District, the Greater Victoria Hospital Society, the Ministry of Health and the Queen Alexander Centre. The contract with the Gerontology Research Centre is being administered by the Capital Regional District with support from a seven person Working Group made up of representatives of the funding agencies.

The purpose of the study is to:

1. Define and examine pertinent characteristics of the population of younger adult (age 19-55) severely disabled individuals.
2. To obtain information from individuals and their families on their current and preferred living arrangements.
3. To examine existing Health and Social Services policies/programs for their ability to respond to consumer preference, and provide suggestions and recommendations for improvement.
4. To determine the type and level of resources required to meet consumer preference.

As part of the study, the consultant will be conducting personal interviews with a representative sample of 50 younger adults with severe physical disabilities and three focus groups involving families/ advocates of the younger adults with severe physical disabilities.

The consultant will be directly undertaking the arrangements for the interviews and focus groups. I have reviewed the implications of this study on the rights and welfare of the individuals reviewed. The research is sponsored by a competent, reliable organization (Simon Fraser University) and supervised by qualified personnel (Dr. Gloria Gutman). The consultant has agreed that those interviewed will be fully informed of the purpose and procedures and may decline to participate without loss of service or other costs to them. Individuals may withdraw if and when they choose and their confidentiality will be preserved by the researchers. No information gathered by the researchers will be used to adversely affect the individuals, their care, or subsequent decisions about their care and placement.

We look forward to co-operation of those involved in this study. If there are any questions pertaining to this study, they should be directed to Mr. Jeremy Tate, Director of Planning and Information Services at the Capital Regional District, at 360-3146.

Yours sincerely,

Shaun Peck

Shaun H.S. Peck, M.B., M.Sc., F.R.C.P.(C)
Regional Medical Health Officer

JT:SP/mw
cc: Simon Fraser University
Younger Adults Working Group Members

MUNICIPALITIES AND ELECTORAL AREAS

CENTRAL SAANICH • COLWOOD • ESQUIMALT • LANGFORD • METCHOSIN • NORTH SAANICH • OAK BAY

SIMON FRASER
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2800 515 West Hastings Street
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Program Tel: 604/291.5065
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May 18, 1994

The Simon Fraser University Gerontology Research Centre is conducting a study on behalf of the Capital Regional District with the goal of learning from individuals with physical disabilities about their service needs and preferences. In this study we are going directly to the consumer of such services to conduct individual interviews.

Please read the enclosed material and give serious consideration to our request that you take part in an interview. If you agree to participate you will meet with an experienced interviewer from the Research Centre at a time and place convenient to you.

We will be in Victoria from Tuesday, May 24 to Saturday, May 28 and early in that period I will telephone you in order to answer any questions and, if you agree to participate, to set up an interview time. The interview will take from 1 to 1 1/2 hours, all information will remain completely confidential, and no names will appear in the report.

We would like to stress that your participation will be strictly voluntary and your decision whether to participate will have no impact on the cost or delivery of care and services. You will be free to refuse to answer any questions and can stop the interview at any time. If you find you are getting tired and wish a break, we will schedule a convenient time to come back to complete the interview. Also, if you would like to have someone of your choice present during the interview, they would be most welcome.

If you have any questions or concerns, please feel free to call your Long Term Care case manager, or the main office (388-2300).

This is a very exciting study and can produce worthwhile results only if we have the cooperation and input of those most affected by the services - the consumers such as you. Please seriously consider participating in this study. I look forward to talking to you early in the week and arranging a time for an interviewer to meet with you.

Sincerely,

Judy Killam

Judy Killam
Project Coordinator

INFORMED CONSENT TO PARTICIPATE IN A STUDY OF YOUNGER DISABLED ADULTS' PREFERENCES

Note:

The university and those conducting this project subscribe to the ethical conduct of research and to the protection at all times of the interests, and anonymity of the participants. This form and the information it contains are given to you for your own protection and full understanding of the procedures involved. Your signature on this form will signify that you have received the document described below regarding this project, that you have received an adequate opportunity to consider the information in the document, and that you voluntarily agree to participate in the project.

Having been asked by ______________________________ of the Gerontology Research Centre at Simon Fraser University to participate in this survey, I have read the procedures specified in the document entitled: SERVICE PREFERENCES OF YOUNGER ADULTS WITH PHYSICAL DISABILITIES STUDY.

I understand that I will be asked a series of questions about my needs and about services I receive or would like to receive.

I understand that I may withdraw my participation at any time.

I also understand that I may register any complaint I might have about the study with Dr. Evan Alderson, the Dean of Arts at Simon Fraser University.

I agree to be interviewed on the matters described in the document SERVICE PREFERENCES OF YOUNGER ADULTS WITH PHYSICAL DISABILITIES STUDY referred to above.

NAME____

ADDRESS____

____

SIGNATURE ______________________________

DATE ______________________________

WITNESS ______________________________

YOUNG ADULTS
WITH
SEVERE PHYSICAL DISABILITIES
STUDY FOR THE CAPITAL REGIONAL DISTRICT

Gerontology Research Centre
Simon Fraser University

CLIENT NAME:________________________________

CLIENT ID #:________________________________

CLIENT LTC #:________________________________

AGE:________________________________

SEX:________________________________

PRIMARY DIAGNOSIS:________________________________

ADDRESS:________________________________

COMMUNITY WHERE LIVES:________________________________

Client I.D. Number ________

YOUNG ADULTS WITH SEVERE PHYSICAL DISABILITIES

INTRODUCTION

During this interview we will be referring to "younger adults". I'd like to explain that this refers to those between 19 and 55 years old and we are specifically interested in those whose physical disabilities require them to have assistance to live as independently as possible.

It is important to note that although we will be talking about various services and facilities, it does not necessarily mean they will be available. The information we are gathering is intended to help in planning, but funding realities will determine whether a service can be provided. We say this now to avoid raising false hopes. We are interested in what you say, but can offer no promises other than that your opinions will be listened to and documented.

We want to remind you that you are free to decline to take part in the interview, to refuse to answer any question or to stop the interview at any time. This will have no effect on the services you receive or their cost to you. All information will be held in strict confidence and no names will appear in the final report.

The interview will take from 45 minutes to 1 1/2 hours, and you may find it tiring. If, at any point, you feel you are too tired to continue, please tell me and we will try to schedule a time to complete the interview at a later time or day.

PART I - CLIENT PROFILE (Circle number of answer)

1. **(Interviewer to complete if knows answer, otherwise ask)** Who lives with you here?

   1. Lives independently alone in community
   2. Lives independently with spouse/family
   3. Lives independently with paid live-in caregiver
   4. Lives in group home with other individuals with disabilities
   5. Lives in facility setting (specify name of facility________________________)
   6. Other (specify)________________________

2. What is your current marital status?

   1. married
   2. common-law
   3. divorced
   4. widowed
   5. have never married

3. Do you have any children?

   1. yes 2. no

   (If yes) How many?________________________

   What are their ages?________________________

4. What is the highest level of education you completed?

   1. some high school
   2. high school graduation
   3. some college or university
   4. university graduation
   5. post-graduate university diploma or degree

5a. Do you do any paid work now?

1. yes 2. no

(If yes) What kind of work do you do?____________________

How many hours each week?____________________

5b. Do you do any voluntary work now?

1. yes 2. no

(If yes) What kind of volunteer work do you do?____________________

5c. Do you attend school/college?

1. yes 2. no

(If yes) Where?____________________

How many hours each week?____________________

PART II - HOUSING AND CARE SATISFACTION

6. How long have you lived here? **(If less than one year - give months, otherwise years)**

__________ months __________ years

7. **(If under 5 years in current residence)** Where did you live before moving here?

____

8. **(If not in own/family home)** Who made the decision that you would come here to live? **(Ask open ended and circle number of all that apply)**

1. you alone
2. you and family members
3. you and professionals
4. you were not involved in the decision
5. other (specify)____________________

9(a) Why was this place chosen? **(Ask open ended and circle number of all that apply. If need prompting, say "Some of the answers given have been . . . ." and choose 2 examples which might fit their situation.**

1. have always lived here/no need to move
2. all on one level
3. close to family
4. close to public transportation
5. familiar neighbourhood
6. close to needed services (e.g. health, shopping)
7. friends live here
8. wanted to be with other younger adults
9. range of programs and services available
10. feel safe here
11. other (specify)____________________

9(b) **(If more than one answer is given ask):** Which of the things you mentioned was the most important reason for choosing this place?

____

10. Overall, what do you like most about your current housing?

____

____

____

11. Overall, what do you like least about your current housing?

____

____

____

12. What could be done to make your current housing better and more satisfying for you?

____

____

____

13. Which of the following best describes your feelings about your living situation during the last six months. **(Read list and circle number of answer).**

1. I have been comfortable in my current living situation.
2. I have been increasingly dissatisfied with my current living situation, but I have not made any plans for a change.
3. I have begun to make plans to move.
4. I have definite plans to move.

(If answers 1 or 2) Do you think in the future you might move?

1. yes 2. no

(If yes) Why?______________________________________

____

____

To what sort of place?________________________________

____

(<u>If answers 3 or 4</u> choose appropriate phrase and ask) Why are you dissatisfied/planning on moving?

____

____

____

I am now going to ask some questions about specific aspects of your current housing. (<u>Ask questions 14 - 17 of group home and facility residents only</u>)

14a. How many people live here?____________________________

14b. Is this about the right number, too many, or too few? **(Circle number)**

1. About right number
2. Too many
3. Too few

14c. Why do you say that?____________________________

15. What kinds of staff help you here?

1. Nurses
2. Nurses Aide/Care Aide/Home Support Worker
3. Physiotherapist
4. Occupational Therapist
5. Dietician
6. Recreation (Activation) Therapist/Aide
7. Housekeeping
8. Maintenance
9. Other (specify)____________________________

16. Are you getting the amount and type of help you need?

1. yes 2. no

(If no) Why do you say that?____________________________

____

____

17. Do you think the staff here have the right kind and amount of training to work with you?

1. yes 2. no

(If yes) Why do you say that?____________________________

____

(If no) What additional training should they have?____________________________

____

____

(Ask Questions 18-20 of home dwelling clients only)

18. What type of home help are you getting now? (Fill-in where appropriate)

SERVICE	HOURS (per day/week/month specify)
1. Homemaker (Home Support Worker)	
2. Home Nursing Care	
3. Physiotherapy	
4. Occupational Therapy	
5. Speech Therapy	
6. Other Therapies (specify)__________ ____________________	
7. Other help (specify type)__________ ____________________	
8. None	

Comments:____

____

____

19. Are you getting the amount and type of home help that you need?

1. yes 2. no

(If no) Why do you say that?

____

____

20. Do you think the staff have the right kind and amount of training to work with you?

1. yes 2. no

(If yes) Why do you say that?________________________________

____

____

(If no) What additional training should they have?__________________

____

____

(Resume asking everyone)

21. Does the physical design of (insert name of residence or "your home") meet your needs?

1. yes 2. no

(If no) Why not:

22a. **(Ask only if in own home)** What adaptations, if any, have you made to your home? For example, added a ramp; grab bars; wheelchair shower.

22b. Are there some other adaptations that need to be made?

1. yes 2. no

(If yes) What are they?

22c. What are your plans for this?

23a. Now we are going to talk about privacy and private space. I am going to read you a list of items and for each tell me if you have enough privacy or private space.

1. personal care (e.g. bathing, toiletting)	1	yes	2	no	3 n/a
2. visiting with your family	1	yes	2	no	3 n/a
3. visiting or entertaining friends	1	yes	2	no	3 n/a
4. sexual opportunities	1	yes	2	no	3 n/a
5. hobbies	1	yes	2	no	3 n/a
6. studies/homework	1	yes	2	no	3 n/a
7. time to yourself	1	yes	2	no	3 n/a

8. any other (specify)
9. comments (if any)

23b. What would you recommend to improve the situation?

____

____

24a. Now we want to talk about the amount of independence you have. Would you say it is:

1. too much
2. not enough
3. about right

24b. Can you tell me why you say that? **(Probe for specific reasons for the response)**

____

____

____

(If 1 or 2 ask)

24c. What would you recommend to improve the situation?____________________

____

____

____

____

____

25. How would you rate the social atmosphere here?

a) 1. pleasant 2. unpleasant

b) 1. stimulating 2. dull or boring

26. How much does this feel like a real home (a place you really belong) or just a place you happen to live?

1. my real home
2. just where I live

27. Would you prefer to live somewhere else?

1. yes 2. no

(If yes) Where?____________________________________

PART III - SERVICE UTILIZATION AND SATISFACTION

28. We are now going to talk about services for the physically disabled that are available in the Victoria area. We are particularly interested in knowing what services and agencies you have used or had contact with. **(Read list and record response on next page)**

1. Transportation
2. Recreation
3. Home Support
4. Housing
5. Loan Cupboards
6. Meals on Wheels
7. Continuing Care
8. Education
9. Advocacy - **(explain if necessary)**
10. Counselling
11. Information/Public Education
12. Associations for specific conditions
13. Vocational
14. Other

(For each service ask)

1. Have you personally used this service (agency)?
2. **(If specifies a service but not an agency)** Who provided this service?
3. Are you still using this service?
4. Are (were) you satisfied with the service?
   - a) Why do you say that?
   - b) Do you have any suggestions for improvement?

(CONTINUE COMMENTS ON BACK OF PAGE, IF NECESSARY)

Service	Ever Used		Agency Providing Service	Uses Now		Satisfaction		Why & How Improve?
	Yes	No		Yes	No	Sat	Unsat	

Service	Ever Used		Agency Providing Service	Uses Now		Satisfaction		Why & How Improve?
	Yes	No		Yes	No	Sat	Unsat	

29. Are there obstacles or barriers that prevent you from using any of these resources? The kinds of answers people have given include: **(Read the first four and circle all that apply).**

1. problems with transportation
2. cost
3. not having someone to accompany you
4. physical barriers (specify)____
5. other (specify)____

30. **I am going to show you a list of specific services some people need. Take your time to look over the list and tell me the number of any that you would like assistance with. (Circle all that apply).**

1. **Help in finding a new place to live.**
2. **Help in improving my housing situation.**
3. **Help in dealing with my landlord.**
4. **Help in finding an attendant.**
5. **Help in training or relating to an attendant.**
6. **A place to meet people.**
7. **A place to talk to people with similar problems.**
8. **Advice from a counsellor (ask "What kinds of things would you like to talk to a counsellor about?")**____
9. **Information about other places to get help.**
10. **Help in dealing with an agency.**
11. **Legal help.**
12. **Help in finding a job or job training.**
13. **Help in dealing with an employer.**
14. **A special device or piece of equipment (example: wheelchair, eating aid, ramp, etc.)**
15. **Repair or modification of a piece of equipment.**
16. **Ride service.**
17. **Help in finding a reader or interpreter**
18. **Other communication assistance (example: message relay service)**
19. **Mobility training.**
20. **None**

31. Are there other kinds of services you would like to have in any of the areas I am going to name? ***(Read headings only and use subheadings only for recording and prompting, circle all that apply).***

(If yes to any, ask) Tell me what you would like.

1. Educational (Specify)____
2. Vocational Training or Rehabilitation (specify)____

3. Rehabilitation Services

a) Physiotherapy____

b) Occupational Therapy__________________________________

c) Speech Therapy______________________________________

d) Counselling____

i - general counselling____________________________
ii - grief counselling_____________________________
iii - support group______________________________
iv - life skills________________________________
v - sexual health/counselling________________________
vi - spiritual counselling__________________________
vii - other counselling (specify)______________________

d) Other (specify)______________________________________

4. Other types of services that have not been mentioned (specify). (Continue on back if not enough room).

Certain services for disabled adults are offered in some communities. I am now going to ask you about such services even though they may not be readily available in the Victoria area.

32. One such service available some places is "respite care". This is where someone may come in while your primary helper goes away, say for 2 weeks, or you may go somewhere else for care while your helper stays home. Would you yourself be interested in either of these types?

1. yes 2. no 3. don't know

(If yes) Which one or both? (Circle all that apply).

1. someone comes to you
2. you go somewhere else
3. both

33. Another service sometimes offered is a "day program or centre". This is a place where people can receive care and participate in activities during all or part of the day and then return home at night. If such a day program were available to you, would you use it?

1. yes 2. no 3. don't know

(<u>Read only to those in own homes</u>).

Sometimes the housing arrangements of people with disabilities may change. While we realize that most people prefer to stay in their own homes, sometimes a person needs to consider alternative housing arrangement. Various residential options are offered in some communities.

To assist in planning for the future we are going to ask you about your preferences regarding housing arrangements.

(<u>Read to those in group homes or facilities</u>).

Various housing arrangements are provided to people with disabilities in some communities. We are interested in your preferences for housing.

(<u>To everyone</u>).

I will start by asking you some questions about shared housing, or group homes. This is when a small number of people share a house with caregivers.

34. First, what would you consider the ideal number of residents in such a home?

____

35. Would you prefer that your housemates or neighbours have: (Circle number).

1. similar disabilities to yours
2. different disabilities than yours
3. no disabilities
4. dosen't matter

36. What type of neighbourhood would you like it to be in? Some answers others have given, include: in a residential neighbourhood, close to downtown, near transportation.

____

____

37. What type of people would you like to help you in your care?

____

____

____

38. Do you have suggestions to ensure you have enough privacy?

____

____

____

____

____

39. Do you have suggestions to ensure you have more control over your life and decisions?

____

____

____

____

____

PART IV - EQUIPMENT

40. Next we are going to talk about equipment that assists you in living with your disability. Please tell me:

1. What equipment you have now.
2. If there is any other equipment that would help you, and how it would help.

(Probe as necessary with appropriate questions regarding activities such as getting out of bed, the bathroom, eating, communicating, etc. Do not ask each item but tick all that apply).

EQUIPMENT	HAVE NOW	WOULD LIKE	WHY & COMMENTS
1) CLOTHING & TOILETTING AIDS			
a) Commode			
b) Shower Chair			
c) Hand Rail			
d) Adapted Toilet Seats			
e) Other (Specify)			
2) MOBILITY & TRANSFER			
a) Scooter			
b) Motorized Wheelchair			
c) Sip and Puff Controlled Chair			
d) Manual Wheelchair			
e) Mechanical Lifts			
f) Transfer Devices			
g) Transfer Boards			
h) Ramps			
i) Other (Specify)			
3) COMMUNICATION			
a) Bliss Board			
b) Computer Assisted Communication Devices			
c) Other (Specify)			
4) ENVIRONMENTAL AIDS			
a) Remote control for such things as: lights, doors, security			
b) Other (Specify)			

EQUIPMENT	HAVE NOW	WOULD LIKE	WHY & COMMENTS
5) EATING			
a) Aids and Adaptations			
b) Other (Specify)			
6) ADDITIONAL MEDICAL EQUIPMENT			
a) Ventilator			
b) Suction			
c) Other			

41. How do you travel in the community? **(Circle all that apply).**

1. You own or operate a vehicle.
2. You depend on friends, family or support group for rides.
3. You use buses.
4. You use Handi-Dart.
5. You take taxis.
6. You use power chair/scooter.
7. You seldom or never travel because you have no reliable sources of transportation.
8. Other (specify)____

____

PART V - CONTROL AND DECISION MAKING

(Questions 42 and 43 to be asked of those living in a facility or group home).

42. We are now going to talk about how much say you have in making decisions that affect you. For each question, please tell me which of the categories on this paper most applies in your situation. **(Read the 4 categories while showing the card).**

(Note: categories are:

1. Staff/administration decide by themselves.
2. Staff/administration decide, but we have input.
3. We decide by ourselves.
4. We decide, but staff have input).

Topics to be addressed:

1. planning Entertainment
2. deciding what kinds of new activities or programs will occur
3. planning daily or weekly menus
4. setting meal times
5. dealing with residents' complaints
6. changes in staff (hiring or firing)
7. who decides on how much privacy you are allowed in your bedroom e.g. locking your door
8. who decides when you get up in the morning and when you go to bed at night

CATEGORIES	(1) STAFF/ADMIN DECIDE BY THEMSELVES	(2) STAFF/ADMIN DECIDE BUT WE HAVE INPUT	(3) WE DECIDE BY OURSELVES	(4) WE DECIDE BUT STAFF HAVE INPUT
1. PLANNING ENTERTAINMENT				
2. DECIDING WHAT KINDS OF NEW ACTIVITIES OR PROGRAMS WILL OCCUR				
3. PLANNING DAILY OR WEEKLY MENUS				
4. SETTING MEAL TIMES				
5. DEALING WITH RESIDENTS' COMPLAINTS				
6. CHANGES IN STAFF (HIRING OR FIRING)				
7. WHO DECIDES ON HOW MUCH PRIVACY YOU ARE ALLOWED IN YOUR BEDROOM E.G. LOCKING YOUR DOOR				
8. WHO DECIDES WHEN YOU GET UP IN THE MORNING AND WHEN YOU GO TO BED AT NIGHT				

43. Do you have any say in who will provide your care?

1. yes 2. no

(If yes) What kind of say do you have? ______________________________

____

(Questions 44 and 45 to be asked only of those living in the community.)

44a. Do you have any say in the hiring of your attendants?

1. yes 2. no

44b. Would you like more or less say in the hiring of your attendants?

1. more 2. less

44c. **(If no say in hiring).** Are you consulted regarding who will care for you?

1. yes 2. no

(If yes) How are you consulted?______________________________

____

(If no) Would you like to be consulted?______________________________

____

45. Do you experience a high turnover in attendants/home support workers?

1. yes 2. no

Resume Asking Everyone

46. Do you believe that the health and social services systems you use are responsive to your needs?

1. yes 2. no

(If yes) Please give an example. ______________________________

____

(If no) In what ways are they not responsive?______________________________

____

47. Have you ever complained to a service agency?

1. yes 2. no

(If yes) Please give an example.________________________________

____

____

How did the agency respond to your complaints?________________________

____

____

We will end with some general questions.

48. Which of the following best describes your feelings about your daily activities? **(Circle 1)**

1. You are bored a lot of the time.
2. You spend some time in activities you like but would like to do more.
3. Most of your time is spent in interesting activities. You are seldom bored.

49. About how much of the time do you feel down or depressed: **(Chose one only)**

1. Most of the time
2. More often than not
3. About half of the time
4. Sometimes
5. Seldom

50a. Are you aware that the Gorge Road Hospital will have vacant space in the Rehabilitation Unit available for other uses?

1. yes 2 no

50b. Nothing has been planned for this space but one suggested use for the old Rehabilitation Unit would be to convert it to a residence for younger adults with physical disabilities. If this were to happen, who do you think might want to live there?

____

____

Why do you say that?____

____

____

52c. Can you suggest any other uses for this space?

____

____

____

53. DEGREE OF DISABILITY. Interviewer will complete Page 3, Section F and Page 4 Section B (ADL's and Self-Care) of LTC-1 Form, if not done in 1993 or 1994.

THANK YOU . . .

NOTE: **COMPLETE NEXT PAGE**

To be completed if Ltc done 1992 or earlier. (Complete using information gained during interview, supplemented by direct questions as necessary.

F ACTIVITIES OF DAILY LIVING	1 ☐ USES CANE	2 ☐ USES WALKER	3 ☐ USES CRUTCHES	4 ☐ USES WHEELCHAIR	5 ☐ OTHER PROSTHES
1 AMBULATION	1 ☐ INDEPENDENT IN NORMAL ENVIRONMENTS LIMITATIONS:	2 ☐ INDEPENDENT ONLY IN ENVIRONMENT SPECIFIED BELOW	3 ☐ REQUIRES SUPERVISION	4 ☐ REQUIRES OCCASIONAL OR MINOR ASSISTANCE	5 ☐ REQUIRES S OR CONTIN ASSISTANC
2 TRANSFER	1 ☐ INDEPENDENT	2 ☐ SUPERVISION FOR: ☐ BED ☐ CHAIR ☐ TOILET	3 ☐ INTERMITTENT ASSIST. ☐ BED ☐ CHAIR ☐ TOILET	4 ☐ CONTINUED ASSIST ☐ BED ☐ CHAIR ☐ TOILET	5 ☐ COMPLETEL FOR ALL MOVEMENT
3 BATHING	1 ☐ INDEPENDENT IN BATH OR SHOWER	2 ☐ INDEPENDENT WITH MECHANICAL AIDS	3 ☐ REQUIRES MINOR ASSISTANCE OR SUPERVISION	4 ☐ REQUIRES CONTINUED ASSISTANCE	5 ☐ RESISTS
4 DRESSING	1 ☐ INDEPENDENT	2 ☐ SUPERVISION AND/OR CHOOSING OF CLOTHING	3 ☐ PERIODIC OR DAILY PARTIAL HELP	4 ☐ MUST BE DRESSED	5 ☐ RESISTS
5 GROOMING/HYGIENE	1 ☐ INDEPENDENT	2 ☐ REQUIRES REMINDER MOTIVATION AND/OR DIRECTION	3 ☐ REQUIRES ASSIST. WITH SOME ITEMS	4 ☐ REQUIRES TOTAL ASSISTANCE	5 ☐ RESISTS
6 EATING	1 ☐ INDEPENDENT	2 ☐ INDEPENDENT WITH SPECIAL PROVISION FOR DISABILITY	3 ☐ REQUIRES INTERMITTENT HELP	4 ☐ MUST BE FED	5 ☐ RESISTS
7 BLADDER CONTROL	1 ☐ TOTALLY CONTINENT	2 ☐ ROUTINE TOILETING OR REMINDER	3 ☐ INCONTINENCE DUE TO IDENTIFIABLE FACTORS	4 ☐ INCONTINENT—LESS THAN ONCE PER DAY	5 ☐ INCONTINENT MORE THAN ONCE PER DA
8 BOWEL CONTROL	1 ☐ TOTALLY CONTINENT	2 ☐ ROUTINE TOILETTING OR REMINDER	3 ☐ INCONTINENCE DUE TO IDENTIFIABLE FACTORS	4 ☐ INCONTINENT—LESS THAN ONCE PER DAY	5 ☐ INCONTINENT MORE THAN ONCE PER DA

B SELF CARE INDICATE CLIENT'S CAPABILITY ON MOST DAYS

1 FOOD PREPARATION	1 ☐ INDEPENDENT	2 ☐ ADEQUATE IF INGREDIENTS SUPPLIED	3 ☐ CAN MAKE OR BUY MEALS BUT DIET INADEQUATE	4 ☐ PHYSICALLY OR MENTALLY UNABLE	5 ☐ NO OPPORT DOES NOT PARTICIPAT CHOICE
2 HOUSEKEEPING	1 ☐ INDEPENDENT WITH HELP FOR HEAVY TASKS	2 ☐ CAN PERFORM ONLY LIGHT TASKS ADEQUATELY	3 ☐ PERFORMS LIGHT TASKS BUT NOT ADEQUATELY	4 ☐ NEEDS REGULAR HELP AND SUPERVISION	5 ☐ NO OPPORT DOES NOT PARTICIPAT CHOICE
3 SHOPPING	1 ☐ INDEPENDENT	2 ☐ INDEPENDENT ONLY FOR SMALL ITEMS	3 ☐ MUST BE ACCOMPANIED	4 ☐ PHYSICALLY OR MENTALLY UNABLE	5 ☐ NO OPPORT DOES NOT PARTICIPAT CHOICE
4 TRAVELLING	1 ☐ INDEPENDENT	2 ☐ NO PUBLIC TRANSPORT USES PRIVATE VEHICLE OR TAXI	3 ☐ CAN TRAVEL ONLY IF ACCOMPANIED	4 ☐ PHYSICALLY OR MENTALLY UNABLE	5 ☐ REQUIRES AMBULANCE FACILITIES
5 TELEPHONE	1 ☐ INDEPENDENT	2 ☐ DIALS WELL KNOWN NUMBERS	3 ☐ ANSWERS TELEPHONE ONLY	4 ☐ PHYSICALLY OR MENTALLY UNABLE	5 ☐ NO OPPORT DOES NOT U PHONE
6 MEDICATIONS AND TREATMENTS	1 ☐ COMPLETELY RESPONSIBLE FOR SELF	2 ☐ REQUIRES REMINDER OR ASSISTANCE	3 ☐ RESPONSIBLE IF MEDICATIONS PRE—PARED IN ADVANCE	4 ☐ PHYSICALLY OR MENTALLY UNABLE	5 ☐ RESISTS

APPENDIX 5

A) LETTERS OF INVITATION TO FAMILY FOCUS GROUP PARTICIPANTS.

B) FOCUS GROUP INFORMATION AND PARTICIPANT CONSENT FORMS.

SIMON FRASER
UNIVERSITY
AT HARBOUR CENTRE

Gerontology Research Centre
Gerontology Diploma Program

2800 - 515 West Hastings Street
Vancouver, British Columbia
Canada V6B 5K3

Centre Tel: 604/291.5062
Program Tel: 604/291.5065
Fax: 604/291.5066

June 3, 1994

Mr. and Mrs. Abbott
733 Dalkeith
Sideny, B.C.
V8L 5G7

Dear Mr. and Mrs. Abbott,

As we discussed in our telephone call, the Simon Fraser University Gerontology Research Centre is conducting a study on behalf of the Capital Regional District with the goal of learning from younger adults with physical disabilities (ages 19-55) and their families about their service needs and preferences.

There are several phases to the study, one of which involves meeting with families of clients in focus groups to explore their point of view. In our telephone conversation you agreed to participate in the group being held Thursday, June 9 from 7:30 to 9:30 p.m. at the Health Department at 1947 Cook Street in the Conference Room on the second floor (please take the elevator). Those attending this group will be relatives of younger adults living in the community.

As you can see from the enclosed, this study has the approval of the Capital Regional District and the Simon Fraser University Ethics Committee. Your participation is strictly voluntary and your decision whether to participate will have no impact on the cost or delivery of care and services to you or your family member. The identity of participants will be held in strict confidence with only the overall results of the group discussion being reported. The only people present, other than family members, will be two researchers from Simon Fraser University.

We appreciate your willingness to help with this project. If you have any questions, please do not hesitate to call me at 291-5175. This is a very exciting study and can produce worthwhile results only if we have the cooperation and input of those most affected by the services. I look forward to meeting you next Thursday.

Sincerely,

Judy Killam
Project Coordinator

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SERVICE PREFERENCES OF YOUNGER ADULTS WITH PHYSICAL DISABILITIES STUDY

This study is being carried out to assist the Capital Regional District and SFU Gerontology Research Centre to better understand the needs and preferences of younger adults with severe physical disabilities and their families. This information will be considered in planning future services. The term "younger adult" refers to persons between the ages of 19-55.

The focus group discussion you are being asked to participate in will take approximately 2 hours of your time. Questions will be posed regarding your perceptions of the service needs and preferences of the young adult you are representing as well as your own needs as a family member.

All information that you provide will be confidential. Respondents will not be named or otherwise identified in reports of the study. You may refuse to answer any question and are free to leave at any point. Refusal to participate will have no effect on the care you or your family member receives.

If you would like further information or a summary of the findings from the study, please contact Dr. Gloria Gutman, Director of the Gerontology Research Centre at the above address.

APPENDIX 6

POPULATION AGED 20-54, BY SEX: CAPITAL REGION 1994, 2001,2011 AND 2021

Population Aged 20 - 54, by Sex:
Capital Region, 1994, 2001, 2011 and 2021.*

	1994			2001			2011			2021		
	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
20 - 24	11,543	11,274	22,817	11,055	10,592	21,647	11,901	11,654	23,555	12,832	12,345	25,177
25 - 29	12,242	11,738	23,980	12,281	11,892	24,173	13,302	12,887	26,189	14,199	13,550	27,749
30 - 34	13,257	13,171	26,428	13,374	13,344	26,718	13,147	12,966	26,113	14,196	14,237	28,433
35 - 39	12,875	13,793	26,668	14,053	13,949	28,002	13,820	14,031	27,851	15,168	15,345	30,513
40 - 44	12,555	13,167	25,722	14,228	15,434	29,662	15,029	15,444	30,475	15,059	15,338	30,397
45 - 49	11,294	11,417	22,711	13,371	14,368	27,739	15,242	15,379	30,621	15,006	15,543	30,549
50 - 54	8,052	8,508	16,560	12,862	13,156	26,018	14,807	15,974	30,781	15,511	16,282	31,793
Total	81,818	83,068	164,886	91,224	92,735	183,959	97,248	98,335	195,585	101,971	102,640	204,611
All ages	156,227	168,359	324,586	171,475	183,039	354,514	195,999	206,400	402,399	218,242	228,557	446,799

Source: BC Stats (1994, 19 May).
*P.E.O.P.L.E. Projection Model, Projection 19.