

LITERATURE REVIEW

CHARACTERISTICS, SERVICE NEEDS AND SERVICE PREFERENCES OF YOUNGER ADULTS WITH SEVERE PHYSICAL DISABILITIES

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1.0 INTRODUCTION

1.1. BACKGROUND AND PURPOSE OF THE REVIEW

In Spring, 1994, as an aid to strategic planning in the Capital Regional District of British Columbia, the Simon Fraser University Gerontology Research Centre was commissioned to undertake a literature review and study focussed on younger adults with severe physical disabilities. For purposes of the project, "younger adults" were defined as persons aged 19-55.

The main objectives of the project were to a) clarify the characteristics and service needs and preferences of the client group and b) to estimate the extent to which current policies and programs in the Capital Regional District were meeting the needs of clients and their families.

An earlier literature review and study had focussed on a sub-set of the clients - those requiring facility care (Gutman, 1989; Gutman & Killam, 1989). Their characteristics and environmental design, staffing and programming needs had been examined. The literature review conducted for this project was broader, encompassing clients living in facilities, in group homes and in other forms of non-institutional collective accommodation, and in conventional accommodation in the community. The range of topics covered was also broader, including the history of the Independent Living Movement, issues surrounding attendant care (e.g. the comparative benefits of a consumer vs. an agency model for hiring and training), etc. A major goal of the literature review was to identify new trends in the philosophy of care and in the shelter and services available to clients and their families.

1.2. ORGANIZATION OF THE REVIEW

The review begins (Section 2) with an examination of the available information concerning the socio-demographic, health and functional characteristics of the client group, its current and its projected size. Section 3 identifies several recurrent themes in the contemporary literature concerned with younger adults with severe physical disabilities. In the process, some changes are described in the Independent Living Movement over the past several decades. The focus in Section 4 is on recommended client services. Section 5 reviews literature dealing with staff training. Section 6 examines family caregivers' tasks and needs. Section 7 reviews the limited literature on the financial costs of care that has relevance for the Canadian context. Section 8 deals with the need for program evaluation and more generally, for greater accountability with respect to services that are delivered to clients. Some criteria for evaluating goal achievement with respect to programs and services developed for younger adults with severe physical disabilities are described.

2. CHARACTERISTICS AND SIZE OF THE CLIENT GROUP

2.1. CLIENT CHARACTERISTICS

The earlier review of the literature (Gutman, 1989) suggested that although residents of units specialized for continuing care of younger adults with severe physical disabilities may range in age from 18-64, they tended, on average, to be middle-aged at time of admission. The sex distribution tended to be about equal. Multiple sclerosis was the single most common diagnosis. The category "other neuro-muscular disorders" accounted for the next largest group of residents.

Of 155 younger adults with severe physical disabilities identified in a population study by Currey, Barton and Dansie (1987), 46% were found to be between ages 18 and 45 and 54% between 46 and 65. The distribution of diagnoses was as follows: multiple sclerosis (50%), congenital neurological disorders (14%), spinal injury (9%), other neurological complaints (20%), and rheumatoid arthritis (8%).

In one of the very few other population studies to be located to date, Castree and Barnes (1993) provide a summary of clients' functional problems. Data derive from a screening questionnaire based on the OPCS Disability Scale (Martin, Meltzer & Elliot, 1988). As shown in Table 1, the most common problems were with personal care, locomotion, communication and intellectual functioning. The latter is not surprising given that only 66 of the 164 (40.2%) in this sample were described as having predominantly physical problems. Of the remainder, 10 (6.1%) were described as having additional psychiatric illness and 88 (53.7%) as having additional learning difficulties.

TABLE 1

CLIENTS' FUNCTIONAL PROBLEMS (CASTREE AND BARNES, 1993)

	%
Personal care	96
Locomotion	95
Communication	73
Intellectual functioning	73
Bladder continence	49
Reaching and stretching	44
Dexterity	43
Seeing	43
Mental illness	43
Bowel continence	42
Disfigurement	36
Hearing	34
Consciousness (epilepsy)	33
Behaviour	30
Eating, drinking and digestion	27
Pain	16

2.2. PREVALENCE ESTIMATES

Several researchers provide data on the proportion of nursing home residents who are non-geriatric. For example, Richmond, Bonita, Broad and Baskett (1991) report 9% under age 65 among nursing home residents in Auckland, N.Z. In the U.S.A., the Advocacy Centre for the Elderly and Disabled (1986) report 4.5% under age 55 in the nursing home population of Louisiana. Approximately three-quarters were described as "developmentally disabled". The definition included persons with one or more physical and/or mental impairments which began before age 22 and are likely to continue indefinitely, and which result in limitations in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic sufficiency. Of a sample of 373 for whom detailed information was obtained, 25% had a diagnosis of mental illness, 25% mental retardation, and 6% mental illness and mental retardation. An additional approximately 36% had physical disabilities the most common of which were cerebral palsy, multiple sclerosis, spinal cord injury and stroke. The Centre also noted that although overall about half of the non-geriatric adult population were males, the younger the age the more likely the resident was to be male.

In British Columbia in fiscal year 1991/92, persons aged 20-54 constituted 2.98% of the population in residential facilities (i.e. unique clients) and 13.21% of the clients using community services (Hollander, 1994). Tables 2 and 3 present an age breakdown of clients receiving residential care, including extended care, and various types of community services in British Columbia in 1991/1992. Although proportions are not additive as some clients may have received more than one service, as can be seen, persons aged 20-54 constituted 5.52% of the clients in extended care units in public hospitals, 1.54% of the clients in personal and intermediate care facilities, 1.74% of the clients in licensed private hospitals, 1.71% of clients in acute hospitals and 11.48% of clients in family care homes. While their representation in these types of residential settings was small they were the major occupants (79.37%) of group homes.

Also available are prevalence rates for the individual disabling conditions found among younger adults with severe physical disabilities. For example, Mathews (1983) estimates the worldwide prevalence of multiple sclerosis at 50 per 100,000 total population; O'Brien (1993) places the rate at 57.9. Appendix 1 describes a number of the factors which must be considered in discussing the prevalence rate and risk factors for multiple sclerosis (e.g. sex, race, geographic distribution). Appendix 2 summarizes prevalence rates for muscular dystrophy and other neuro-muscular disease commonly found among younger adults with severe physical disabilities. Very few prevalence estimates are available however, for the client group as a whole. Following is a summary of those identified to date.

TABLE 2
Age¹ Breakdown of Clients² Receiving Residential Care
Including Extended Care:
British Columbia, 1991/1992

Type of Residence	Age Category						Total
	0-19	20-54	55-64	65-74	75-84	85+	
Personal and Intermediate Care Facilities	0 0.00%	301 1.54%	668 3.43%	2,635 13.52%	7,461 38.27%	8,431 43.24%	19,496 100%
Acute Hospitals	0 0.00%	3 1.74%	9 5.23%	28 16.28%	74 43.02%	58 33.72%	172 100%
Licensed Private Hospital	0 0.00%	49 1.71%	113 3.93%	387 13.47%	1,096 38.16%	1,227 42.72%	2,872 100%
Family Care Homes	3 1.64%	21 11.48%	16 8.74%	25 13.66%	66 36.07%	52 28.42%	183 100%
Extended Care Public Hospitals	26 0.25%	576 5.52%	479 4.59%	1,416 13.58%	3,500 33.56%	4,432 42.50%	10,429 100%

¹ Age as of April 1, 1991

² Each client is counted once for each type of residence from which care was received. Numbers are not additive as some clients may have received service from more than one residence

Source: B.C. Ministry of Health and Ministry Responsible for Seniors (1993). Ministry of Health 1991/1992 Annual Report. Victoria: Ministry of Health, p. 117.

TABLE 3
Age ¹ Breakdown of Clients² Receiving Community Services:
British Columbia, 1991/1992

Type of Community Service	Age Category						Total
	0-19	20-54	55-64	65-74	75-84	85+	
LONG TERM CARE							
Homemakers	20 0.03%	4,129 6.97%	4,200 7.09%	15,504 26.19%	24,898 42.05%	10,458 17.66%	59,209 100%
Adult Day Care	0 0.00%	219 3.79%	335 5.80%	1,237 21.43%	2,626 45.50%	1,355 23.48%	286 100%
Group Homes	3 1.05%	227 79.37%	32 11.19%	12 4.20%	8 2.80%	4 1.40%	5,772 100%
DIRECT CARE							
Community Home Care Nursing	1,385 3.53%	7,987 20.34%	4,988 12.70%	9,802 24.96%	10,912 27.79%	4,189 10.67%	39,263 100%
Physiotherapy & Occupational Therapy	407 3.21%	1,561 12.31%	1,179 9.30%	3,052 24.06%	4,431 34.93%	2,054 16.19%	12,684 100%

¹ Age as of April 1, 1991

² Each client is counted once for each type of service from which care was received. Numbers are not additive as some clients may have received Care from more than one service.

Source: B.C. Ministry of Health and Ministry Responsible for Seniors (1993). Ministry of Health 1991/1992 Annual Report. Victoria: Ministry of Health, p. 118.

Perlman and Giele (1982) estimated that there were 5.8 "severely dependent" non-institutionalized persons per 1,000 aged 18-64 in the United States in 1975. This rate was based on the U.S. Census Bureau's 1976 Survey of Income and Education (SIE). Persons classified as "severely dependent" were those who indicated in the survey that they usually or frequently "need help from others in looking after personal needs, such as eating, dressing, undressing, or personal hygiene" or who frequently "need help from others to go outdoors or to get around outside their home." Perlman and Giele state that their definition of a severely dependent person corresponds to scores of less than 61 out of 100 on the Barthel Index (Mahoney & Barthel, 1965).

Self-report data from Statistics Canada's 1986 Health and Activities Limitation Survey show 29,960 non-institutionalized British Columbians aged 15-64 as having a "severe disability". There were a further 4620 in this age group in institutions, yielding a rate of 2098 per 100,000 in a population of 1,648,450 aged 15-64. The severity scale for adults was developed using responses to screening questions concerned with mobility, agility, vision, hearing and speaking. Additionally, there was an "other" category which included limitations due to "a learning disability, a mental health condition, a mental handicap, or because of labelling by others" (Statistics Canada, 1992, p.13). One point was assigned for partial loss of function and two points for total loss of function. A person with a total score, across disability categories, of less than 5 was classified as having a mild disability; scores of 5-10 were classified as moderate and 11 or more as severe. The severe category was further divided for persons living in institutions into Level 1 (11-17 points); level 2 (18-22 points) and level 3 (26-42 points).

Professional case-finding yields much lower prevalence rates. For example, Currey, Barton and Dansie (1987) asked general practitioners and district nurses to identify all patients in the East Hertfordshire Health District aged 18-64 with significant physical disabilities. In a total population of 287,600 (195,300 aged 15-64), 165 were reported. From these data the researchers calculated a prevalence rate of 57.4 per 100,000 total population. An additional seven were identified when the survey was extended to include hospital wards in the district.

In another British study, conducted in the Newcastle region, Castree and Barnes (1993) calculated a rate of 59 per 100,000. The rate was based on the identification of 164 clients living in hospitals and residential care settings in a population of 280,000. The types of facilities in which these individuals were located is shown in Table 4. Castree and Barnes report that discharges were planned for seven of the 104 currently in hospitals. The remaining 97, they state, "lived" in the hospital.

TABLE 4

LOCATION OF CLIENTS IDENTIFIED IN THE CASTREE AND BARNES (1993) STUDY

Hospitals	n
Mental handicap hospitals	62
Regional rehabilitation centre	24
Psychiatric hospitals	10
Acute hospitals	4
Geriatric hospitals	3
Psycho-geriatric unit	<u>1</u>
	104 (63%)

Residential Homes	
Homes for adults with physical disabilities	20
Homes for the elderly	15
Homes for people with learning difficulty	<u>25</u>
	60 (37%)

Obviously, the criteria used to define clients (some researchers include persons with significant psychiatric problems or learning disabilities while others do not) affects prevalence estimates. As Denson (1987) notes, there is no universally agreed upon data collection method to count the disabled nor a standardized operational definition of what constitutes disability. Some studies rely on the Barthel Index others do not.

Inclusion criteria also determine estimates of service need. For example, Gloag (1985b) notes that the officially recommended number of long-term care beds for younger adults with severe physical disabilities is six per 100,000 in England and Wales. She feels this is "about right" if persons with severe brain damage are included. Prouse, Ross-Smith, Brill, Singh, Brennan and Frank (1991) recommend four beds per 100,000 in areas where night nursing service is available for clients living in the community.

3. RECURRENT THEMES IN THE CONTEMPORARY LITERATURE

3.1. THE UNDESIRABILITY OF PLACEMENT IN GERIATRIC INSTITUTIONS

Castree and Barnes (1993) note that among participants in their study without psychiatric illness or learning difficulties, no statistically significant differences were found in level of disability between those living in a hospital and those living in a more home-like residential facility. "This raises the question of whether those in hospital really needed to be there" (p.144).

The unsuitability of hospitals and other institutional settings for most younger adults with severe physical disabilities is a recurrent theme in the literature. There is

consensus that in particular, placement in geriatric facilities should be avoided. Castree and Barnes (1993) note with some dismay that:

... Previous authors have commented on the unsuitability of hospitals and establishments for the elderly as homes for younger adults with physical disabilities (MacLennan, 1972; McAndrew, 1978; Swithinbank et al, 1984; Harrison, 1988). Echoing these comments in 1992 suggests that little progress has been made in improving this aspect of services for individuals with physical disabilities (p.146).

Lewis (1992) summarizes a number of the issues surrounding placement in geriatric facilities identified by various authors (cf. Advocacy Center for the Elderly and Disabled, 1986; Cunningham & Hanson, 1991; Wineman, Donohoe & O'Brien, 1992). These include that:

- 1) younger adults with severe physical disabilities have very few (if any) persons with whom to interact.
- 2) generally, they are cognitively intact although they may have communication impediments due to their particular disease.
- 3) they experience challenges and difficulties appropriate to life stages not common to the geriatric population.
- 4) they may be married (or want to marry) and "therefore experience multivaried and often profound emotional trauma related to separation from spouse, children and family life" (p.10).
- 5) most of the services, programs and activities commonly available in geriatric facilities do not necessarily or adequately address the unique needs and interests of younger adults.

3.2. THE HETEROGENEITY OF THE CLIENT POPULATION

Another recurrent theme in the literature concerns the heterogeneity of the population of younger adults with severe physical disabilities. Currey, Barton and Dansie (1987), for example, divide the population into the following four groups:

- * those with congenital or acquired static disability,
- * those with progressive disability,
- * those with accompanying dementia, and
- * those with behavioural problems in addition to their physical disability.

Gloag (1985b) notes that different sub-groups have different needs and capability of living without assistance in community-based settings:

...disabled people are not a homogeneous group and there are very different needs and capabilities. There may be medical, social, or psychological problems, or all three. Some have no medical problems (notably many with spinal injuries) and these people on the whole should be living in the community. At the other extreme are patients severely affected by stroke and multiple sclerosis, for example, with difficult medical afflictions requiring 24 hour nursing care that is usually impracticable at home (p.368).

McCuaig and Frank (1991) distinguish between persons with medically stable conditions and those on the downward slope of the so-called "disability trajectory" (Kaufert & Kaufert, 1984) or "chronic illness trajectory" (Corbin & Strauss, 1988; Glaser & Strauss, 1967, 1968). These authors note that clients with stable medical conditions such as cerebral palsy or spinal cord injury can expect to attain acceptable levels of independence in the community provided they are able to access reliable employment, income subsidies and supportive services as needed. McCuaig and Frank reinforce the theme that the needs of clients change over time both in response to medical and to socioeconomic conditions.

3.3. THE INTEGRATED VS. SEPARATE SERVICES DEBATE

A number of writers comment on the dramatic impact the Independent Living/Disability Rights Movement has had since the 1960s both on the collective conscience of the general population and on social welfare legislation in the United States (Asher, Asher, Hobbs & Kelley, 1988; Crewe & Zola, 1983; McCuaig & Frank, 1991; Pelletier, Rogers & Thurer, 1985; Spencer, 1991) and in Canada (Cooper & Hasselkus, 1992). Several writers draw parallels between the Independent Living Movement movement and other social movements of the time (eg. women's rights, civil rights, gay rights), noting that persons with disabilities wished an end to the paternalistic protectionism implicit in the medical model in exchange for the right to risk and to control their own destiny (Cooper & Hasselkus, 1992; Crewe & Zola, 1983).

Very early on in the literature review it became apparent, that there have been major changes over the past several decades in the focus of the Independent Living Movement. Asher, Asher, Hobbs and Kelley (1988) note that prior to 1970, vocational rehabilitation services were focussed primarily on increasing the employability of disabled persons. During the early 1970s, it was recognized that severely disabled persons for whom the goal of employment was not realistic were being under-served and the focus of human services began to shift toward deinstitutionalization. Centers for Independent Living (CILS) began to emerge in the mid-1970s. As well as playing an advocacy role these offered such services as training, peer counselling, transportation and referral. During the 1980s the focus changed again. Proponents of the independent living philosophy, the core of whom are persons with spinal cord injury (De Jong, 1979), became increasingly

critical of group homes and other living arrangements, work and recreation settings that segregated persons with disabilities from mainstream society. One major theme of the Independent Living Movement in the 1990s has been the integration of persons with disabilities into the day-to-day life of the community rather than segregating them de facto by providing special facilities and programs.

3.4. EMPHASIS ON CLIENT SELF-DIRECTION AND CONTROL

Castree and Barnes (1993) were distressed at finding that only 20% of the clients they interviewed had some choice in deciding the type of institution to enter. Their concern reflects a second major theme of the contemporary Independent Living Movement -- that of a strong stress on client self-direction and control (Asher et al., 1988; Budde, 1986; Cole, 1979; De Jong, 1979).

Asher et al., (1988) contend that both client self-direction and agency direction are means to the end of increasing day-to-day community participation of persons with disabilities. They caution though, that by allowing client self-choice, progress towards assimilation may be slower, especially when the individual's self-management skills are not well developed.

Gloag (1985a) also adds a note of caution:

...many people severely disabled by neurological conditions are in no position to exercise autonomy; some others do not really want to, and many feel threatened by all the talk about independent living. Staff used to traditional concepts of care may also have a sense of confusion and conflict about their roles. A further conflict may arise as workers in rehabilitation become more aware of how much improvement is possible even in irreversible conditions, while social workers and sociologists on the other hand eschew the "medical model" and any paternalistic approach. At the same time many people live in residential homes, and for that matter their own homes, quite untouched by ideas of either rehabilitation or autonomy (p.301).

She argues that different models and philosophies have a place in catering for the needs of different individuals. The problem, she contends, is that too often the right resources don't get to the right people at the right time due to inadequate resources or thought.

Cooper and Hasselkus (1992) add an interesting perspective when, venturing into the personality theory and social-psychological literature, they posit that independent living allows four types of control to be exercised: behavioural (direct action on the environment), cognitive (the interpretation of

events), decisional (having a choice among alternatives) and retrospective (enabling coping and mastery over past events).

Burwash and Warren (1990) remind us that perceived control is not dependent on physical status. Several very disabled respondents in their study of institutionalized multiple sclerosis patients perceived themselves as having control despite high Incapacity Status Scale (Kurtzke, 1981) scores. Control embodies not only the ability to perform tasks oneself, but also to influence/train others to complete tasks in a manner than meets one's personal standards and expectations. Nosek, Parker and Larsen (1987) make a similar point.

3.5. EMPHASIS ON ABILITIES RATHER THAN DISABILITIES

A number of authors draw attention to the World Health Organization (1980) distinction between impairments, disabilities and handicaps. According to the WHO definitions:

An **impairment** is any loss or abnormality of psychological, physiological or anatomical structure or function.

A **disability** is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

A **handicap** is a disadvantage for an individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and cultural factors) for that individual (p. 143).

Brown, Gordon and Ragnarsson (1987) describe "handicapping conditions" as anything external to an impairment that increases its negative impact. Examples include, within a societal context, architectural barriers and restrictive legislation; within an individual's immediate environment, the lack of an accessible vehicle; and internally, beliefs that narrow a person's goals. They report a study which found minimal differences between spinal cord injured and able-bodied men when both groups had access to resources.

Condie (1991) notes that it is not always possible to cure or even improve a person's underlying impairment but it may be possible to improve his/her functional capacity. Attention is drawn to the importance of recognizing that "the prospective level of handicap caused by disability can be greatly reduced by correct therapeutic intervention" (p.74).

Throughout the rehabilitation literature there are exhortations to build on the existing strengths of the client rather than emphasizing his/her disabilities (e.g. Gloag, 1985a).

McCuaig and Frank (1991) used an ethnographic approach to study the adaptation to independent living of Meghan, a 53-year old woman with cerebral palsy. In their report, they highlight the importance to her of being considered not only physically capable, but also mentally and socially competent. She often commented, they note, "on her struggle against what she saw as people's perception of her as "mental" or "like a child." McCuaig and Frank refer to Wright's (1983) concept of "spread" to explain this phenomena. "Spread", the opposite of the "halo effect", is where an observer ascribes more pervasive disabilities to the person than are actually present. The McCuaig and Frank article stands out not only for its use of ethnographic methodology and strong emphasis on psycho-social factors in the adaptation process, but also because it is one of a small number of articles that makes an attempt to link hypotheses and findings to theory. In the bulk of articles reviewed theory was noticeably absent.

3.6. APPROPRIATE TIMING OF SERVICE DELIVERY

Citing research by Woodrich and Patterson (1983) which, they state, supports the concept that the longer one is disabled the easier it is to accept the disability, Braun, Goto and Lenzer (1987) recommend that services be adjusted to the client's stage of disability acceptance and be provided in accordance with changing psycho-social as well as physio-functional needs.

That the timing of service delivery is not always optimal is underscored in an article by Burnett and Yerxa (1980). These researchers report that 26 of 61 students with disabilities attending a community college in California (42.6%) indicated that some rehabilitation services had not been offered to them at the most appropriate time. Of these 26 students, 31% said the service was offered "too early", 31% "too late" and 38% "not at all". At the time they were interviewed, 67% of the total sample thought that they could benefit from rehabilitation services.

Gloag (1985a) exhorts workers to prevent "cost disaster" which, she states, is the term used to describe "the extra money which you have to spend because you didn't spend a much smaller sum in the first place" (p.301).

3.7. THE NEED FOR INFORMATION, COORDINATION OF SERVICES AND CASE MANAGEMENT

Gloag (1985b), Williams and Bowie (1993) and others consider the lack of information about available services and financial assistance and the lack of coordination of services to be among the chief impediments to younger disabled adults living in the community. In arguing for special centres which provide a range of services in one location, Gloag (1985a) emphasizes the importance of a rehabilitation facility that is "always there", to which the patient can turn for support and practical help as

needed. She notes the advantages to aggregating several services in one location. Gloag also argues that the client's total needs are more likely to be met where the centre is jointly run by Health and Social Services departments. "The common practice of isolated planning by the two services is thought to create one of the greatest barriers to adequate provision for people with disabilities" (p.301).

4. RECOMMENDED SERVICES

The philosophical shift in the Independent Living Movement, referred to in Section 3.3. as well as the other recurrent themes described above are reflected in the types of services currently being recommended for younger adults with severe physical disabilities. These services are reviewed below under the following headings:

- Counselling
- Education
- Housing
- Respite
- Day Centres
- Transportation
- Attendant Care
- Rehabilitation

4.1. COUNSELLING

Gloag 1985b notes that depression is common among younger adults with severe physical disabilities (40% in a study by Cantrell, Dawson and Glastonbury, 1983) and that counselling, often neglected in the community, is needed by many clients. Pelletier, Rogers and Thurer (1985) note that many clients become seclusive, inactive and housebound. When they asked client advocates what types of mental health services severely disabled people require, need was perceived to be greatest for peer counselling, rehabilitation counselling, and respite care followed by individual therapy, family therapy, and social skills training. Braun, Goto and Lenzer (1987) recommend grief counselling as younger adults suddenly faced with multiple changes in body image and role may find the experience overwhelming. Florian (1983), Gloag (1985b) and others suggest a need for sex counselling. Gloag (1985a) also recommends vocational counselling.

It would appear that traditional face-to-face individual or group counselling is preferable to telephone counselling. Evans, Halar & Smith (1985) evaluated a short-term cognitive group therapy program conducted over the telephone. Clients consisted of disabled adults with a mean age of 53.1 years; 29% had suffered a stroke; 29% had a CNS disorder; 21% had spinal lesions and 22% a variety of other disorders. Only 7.9% reported even

minimal goal achievement and only 19.0% partial goal achievement as a result of the telephone counselling. The goals achieved included: gaining rehabilitation information, lessening anxiety, obtaining referral for individual counselling, increasing energy level, becoming more independent, not letting others' reactions bother them as much and getting along better with family.

A study by Florian (1983) suggests that the preferred age to begin sex counselling may be later for persons with disabilities than for those without and that there may be differences in the topics it is most important to covered. For example, non-disabled respondents gave more emphasis than disabled respondents to counselling on sexual functioning and establishing a family. The groups were similar however, in preferring sex counselling by a physician rather than a psychologist, nurse or nonprofessionals such as their parents, friends or partner. Florian also notes that whether clients are disabled or not, their cultural background must be carefully considered when providing sex counselling. Rieve (1989) cautions that not all professionals are adequately prepared to deal directly with the sexual concerns of younger adults with acquired physical disability. She recommends that in counselling, staff use the PLISSIT model which describes progressive levels of intervention with disabled clients. She also identifies disability-specific information regarding sexuality that should be provided when counselling younger adults with severe arthritis, traumatic brain injury, and spinal cord injury. This includes information about penile prostheses when counselling males and about pregnancy and how to achieve or avoid it when counselling females. Additionally, Rieve recommends discussion of strategies that minimize vulnerability so that when screening and hiring personal care attendants and selecting independent living environments, disabled persons do not place themselves at risk for sexual abuse. Another important point she makes is that relationships cannot be understood solely from the perspective of the disabled client. Surprisingly, she identifies a lack of studies concerned with the profiles, perceptions and reactions of partners of persons with disabilities in relation to sexuality.

Gloag (1985b) predicts that peer counselling will become more widespread with growth of the Independent Living Movement. Jenkins (1993) draws attention to the special needs of adolescents with severe physical disability. Citing the work of various authors, he notes for example that:

- adolescents with spinal cord injuries often experience loss of control and dignity (associated with use of a wheelchair and lack of bowel and bladder control), feelings of being an imposition on their family, fears about medical care and being perceived as different (Mulcahey, 1992).
- substance abuse has been extensively documented in this population (Heinemann, Doll, Armstrong, Schnoll & Yarkony, 1991) and suicide rates are two to six times higher than in

the general population of comparable age (Charlifue & Gerhart, 1991).

- as they mature, adolescents with disabilities may harbour resentments against or have difficulty coping with the achievements of their non-disabled siblings (Stiff, 1985).

- many experience prolonged adolescence because they tend to be over protected, lack role models and the social and emotional growth that comes from interacting extensively with peers (Strax, 1991).

Jenkins (1993) identifies a need for transition counselling for adolescent clients and their families (a) to deal with psycho-social issues and (b) to assist them in coping with the bureaucratic and other challenges that are associated with moving from pediatric to adult care service. Bureaucratic challenges include inconsistent organizational patterns across agencies and differences in geographic boundaries, service application procedures and planning cycles. Additionally, there are changes to adapt to in the level and type of support provided, the decision-making and consent process, the extent to which family input is expected and accepted, and in staffs' sensitivity to the psycho-social needs of clients and their families.

Victor, McCarthy and Palmer (1986) review a number of theories and concepts which may be useful in counselling physically disabled youth with respect to career development.

4.2. EDUCATION

Several types of education are recommended in the literature including independent living skills training; advocacy skills training; computer training as a means both of communicating with the broader community and of earning a living; and training in hiring and managing staff.

A) Independent Living Skills Training

Burnett and Yerxa (1980) gave a 30 item check-list called the "Index of Confidence in Independent Living Skills" to disabled current and potential Santa Monica Community College students. Table 5 shows the content of the check-list. Respondents were asked to indicate: (1) the activities they felt confident doing without the help of others (2) the activities they would like to develop more confidence in doing and (3) the items that did not apply to them.

TABLE 5

CONTENT OF INDEX OF CONFIDENCE IN INDEPENDENT LIVING SKILLS

Basic ADLs

Grooming, dressing, using the bathroom, feeding, using telephone

Cognitive Problem-solving Skills

Managing money, conserving physical energy, finding a place to live, solving problems/making decisions

Social/Recreational Skills

Eat at a restaurant, meet new people, have friends, date, take a trip, enjoy spare time

School/Vocational Skills

Go on a job interview, fill out forms, find a job, plan a school program, talk to employers/teachers

Home Skills

Prepare a simple meal, shop, hire/train help, clean your house, clean/iron clothes, sew/mend clothes

Community Mobility

Drive a car/take a driver's test, use public transportation

Burnett & Yerxa (1980) report that the disabled sample was significantly less confident than non-disabled controls in all except basic ADLs. They also found that disabled non-students were significantly less confident in home and community skills than disabled and non-disabled students. The latter was interpreted as suggesting that persons with disabilities may need to achieve some mastery of home and community skills before attempting to attend a community college. McCuaig and Frank (1991) claim that training in home and community skills is the most deficient and under-addressed form of occupational therapy provided to younger adults with severe physical disabilities.

Burwash and Warren (1990) recommend that in addition to basic ADLs and physical performance skills training, occupational therapists need to offer persons with disabilities choices and challenging and age appropriate daily activities and tasks. They also need training in how to be competent managers of staff and/or family caregivers and training in self-advocating for personal space and preferences. With respect to ADLs and IADLs, Gloag (1985b) makes the interesting observation that in developing countries most residential facilities encourage residents to be as self-sufficient as possible and to contribute as they can to the home's administration and financing. In developed countries, on the other hand, persons with disabilities often have to fight to be allowed to engage in "real" work.

Neistadt and Marques (1984) describe an Independent Living Skills Training Program that uses a psychoeducational model that recognizes the diversity of the client group. The model classifies clients into three psycho-social groups according to the onset of their disability:

- a) the "psychosocially deprived" group comprises individuals with severe congenital disabilities, such as cerebral palsy and spina bifida;
- b) the "psychosocially delayed" group consists of those under age 25 who were disabled during adolescence; and
- c) the "psychosocially disrupted" group comprises those injured or disabled as adults.

The model relates the life skills deficits and educational needs of each group directly to the psychosocial developmental tasks interrupted by their disability. Neistadt and Marques (1984) report that after counselling based on the model, of 17 multiply handicapped adults whose average length of institutionalization was 11.9 years, 58.8% returned to community living and 23.5% were waiting for openings in accessible housing units.

B) Advocacy Skills Training

Balcazar, Seekins, Fawcett and Hopkins (1990) argue for and describe an advocacy skills training program offered to six members of an advocacy organization for people with disabilities. Training focussed on identifying and reporting issues. Additionally, two chairpersons were trained on how to lead action-oriented meetings. Retrospective interviews and permanent records (e.g. meeting minutes; newspaper articles) showed that advocacy activities increased after training.

C) Computer training

Gloag (1985b) strongly advocates for computer training for clients living in both institutional and community settings. She considers computers to provide the chief way ahead, serving as aids, providing entertainment, and most importantly, providing the possibility of a career and source of income.

On the topic of work, she notes however, that disincentives are built into the system. The threat of loss of Social Security benefits tends to prevent some younger adults with severe physical disabilities from taking full time jobs when they are offered them. Gloag (1985a) asked, "Would it be a great drain on the exchequer if partial earnings and allowances became possible?"

Kenny and Murray (1993) describe a home-delivered information technology computer training program for people with severe physical disabilities who often are prevented from attending courses in conventional training centres by transportation problems, timing problems or because the centre is inaccessible.

Kuhlman (1988) followed-up 14 persons who completed a word-processing training and employment program for community-based persons with severe disabilities. After two years, 13 had been employed and 12 reported that the overall quality of their lives had improved as a consequence of their training. After four years, 55% perceived a continuing improvement in quality of life over the prior two years. After two years, graduates' mean increase in monthly income was \$353. After four years, 63% reported continuing improvement in their financial situation. One of the two companies participating in the program found that off-site clerical staff were economically viable and cost-effective. The other company underutilized its three home workers. A number of factors account for the difficulties encountered by the graduates placed with it.

Steimke, VanNingen and Clark (1982) caution, however, that although computer terminals for the homebound have been successfully experimented with, this form of employment lacks the stimulation of leaving the home to go to work.

...The psychological effect of leaving the home and having the opportunity to relate to and interact with co-workers, the opportunity of receiving praise and a pat on the back from a supervisor, and the many other positive aspects of the work environment are of immeasurable importance to the worker's self-concept and motivation to achieve (p.28).

4.3. HOUSING

Cooper and Hasselkus (1992) argue that three fundamental assumptions underlie the Independent Living paradigm:

- 1) a person has the right to live in the least restrictive environment;
- 2) a person has the right to autonomy; and
- 3) a person has the right to support for competency in daily living tasks.

Frankel (1984) points out that Independent Living Programs consist of policies, services and programs that are designed to assist persons with severe disabilities to achieve these goals. These services and programs can include: transportation, advocacy, peer counselling, equipment repair, attendant referral, attendant training, housing referral, permanent residential, transitional residential and temporary housing but most often, they are non-residential. The underlying philosophy is that consumers with disabilities are responsible for directing their own care. They are expected to seek out and secure accessible housing, hire and train their own attendants and act on their own behalf in securing benefits and entitlements. Still, some specialized housing does exist. For example, Nosek, Roth and Zhu (1990) found that 15% of the 163 Independent Living Programs

responding to their survey offered permanent residential facilities and 20% had transitional living programs.

A) Speciality Centres

Lewis (1992) estimated that overall, in the United States, there were about 36 residential "specialty centres". The recently published Complete Directory of Nursing Facilities for Younger Adults with Chronic Physical Disabilities (Buchanan and Lewis, 1994) contains over 270 listings. These include: facilities with a primary mission to care for younger adults with severe physical disabilities; facilities with special care units for younger adults; facilities with special programs and services for these clients; and facilities with five percent or more of their residents who are younger adults. Specialty centres such as those described below provide clients with care, community and a wide range of services.

Inglis House is a "wheelchair community" in Philadelphia. According to Lewis (1992), over 290 persons have lived there since it was established in 1977. It offers barrier-free apartments, a shopping court (containing a general store, launderette, beauty parlor/barber shop, library, and family dining area), a day care program and closed circuit TV. It also offers a comprehensive on-campus education service through which residents can earn a diploma or degree in General Studies, or learn data processing, creative writing, math, English literature, etc. It also offers a very broad range of therapeutic/recreational programs including HAM radio, photography, a greenhouse, poetry, music therapy and vocational counselling.

Frankel (1984) describes Winning Wheels, a barrier-free residence located in Prophetstown, Illinois. Constructed in 1978, it is home to 63 residents whose average age is 30. Services include 24-hour attendant care, medical support, an activity program and physical therapy. Many residents are students in local high schools and colleges. Residents leave for vacation and week-end visits.

Cheshire Homes are another example. Developed in England after World War II, but found now around the world, these homes offer medical and personal care and active recreation and activity programs to persons with disabilities aged 18-50 at admission. A key feature of these homes is that residents are expected to play a role in their management.

Self-management is even more strongly emphasized at 48 Boundary Road, in North London. In this arrangement clients live in groups of four in six self-contained flats to which their own care staff are attached. According to Gloag (1985b) "...if they do not arrange for shopping and cooking to be done they will go hungry" (p.370). She relates one criticism of this arrangement, voiced by a former resident, which is that it results in "endless meetings and group discussions to thrash things out democrati-

cally." This individual found the process tedious and moved on to even more independent living. (See Dartington, Miller and Gwynne, 1981 for more details about 48 Boundary Road.)

B) Transition Units

Several authors (Braun, Goto & Lenzer, 1987; Gloag, 1985a) identify a need for transition homes or "assessment flats". In such units, Gloag notes, people can have a "realistic trial run" either alone or with those they would normally be living with, prior to independent living. Such units, which currently exist in several locations in the United Kingdom, also provide a trial venue for disabled couples wanting to live together.

Inglis House includes an 11-bed "Transitioning to Independent Lifestyles" Unit. According to Lewis (1992) services offered by the unit include assistance in increasing ADL skills, use of public transportation, finding ways to continue education goals, budgeting limited resources, accessing the health care system and developing vocational skills.

C) Adapted Housing

In the United States, four pieces of federal legislation address the housing needs of persons with disabilities:

- * Section 202 of the 1959 Housing Act,
- * the Fair Housing Amendment Acts of 1968,
- * Section 504 of the 1973 Rehabilitation Act, and
- * the 1988 Fair Housing Amendment Act.

The latter is particularly important because in addition to ensuring that persons with disabilities are not discriminated against in the sale and rental of housing, for the first time, standards were set for accessibility of new construction of multi-family housing (Fanning, Judge, Weibe & Emener, 1991).

Despite the passage of this, state and municipal legislation, acquisition of appropriately designed and affordable housing is still a problem in many jurisdictions. For example, Fanning, Judge, Weibe & Emener (1991) surveyed persons with mobility problems due to multiple sclerosis, cerebral palsy, spinal cord injuries, etc. and service providers in Florida. Although the response rate of clients to their mailed questionnaire was disappointing (only 20% usable responses), of those who did respond 67% reported having difficulty obtaining information about the availability of affordable barrier-free housing. Sixty-eight percent of service providers said they had difficulty making housing placements or referrals.

Even where barrier-free housing can be found it often is not as accessible as it might be. Cooper and Hasselkaus (1992) and Reizensenstein and Ostrander (1981), for example, note that many units for persons with disabilities have been designed for use of a manual wheelchair. The dimensions of the unit are inadequate for the larger, less easily maneuvered power-driven chairs.

Problems are exacerbated by the lack of motor control of many clients. Reizensenstein and Ostrander (1981) add that one should not assume that wheelchair quadriplegics have the same mobility patterns and needs as paraplegics or that all quads are alike.

...since the extent of spinal cord damage and related muscular ability differ with each quadriplegic, the capabilities of each also vary widely.... For example, quads may be right or left handed either as a result of paralysis or in the traditional sense (p.639).

Another assumption that should not automatically be made is that assisted living means able-bodied people rather than residents will operate kitchen equipment. Reizensenstein and Ostrander (1981) also note residents' discomfort with the lack of visual privacy that is common in units designed for younger adults with severe physical disabilities.

Cooper and Hasselkaus (1992) call attention to a number of electronic technologies that facilitate independent living and/or provide clients with the security of knowing they can summon help if they need it (e.g. centralized remote control units, emergency links to hospitals, automatic door openers, hoists and microwave ovens). Both they and Reizensenstein and Ostrander (1981) note, however, that clients frequently voice concern over a possible failure of their power supply. It is recommended that an auxiliary source be provided.

Cooper and Hasselkaus (1992) also comment on the location of adapted housing. They remind readers that suburban sites often lack sidewalks and are isolated from shops and other services. In urban settings, there are hazards to using a motorized wheelchair in areas of heavy pedestrian traffic. Risk of victimization also increases.

Reflecting again the heterogeneity of the client population, Fanning, Judge, Weibe & Emener (1991) report that although 80% of their respondents (persons with a mobility impairment requiring permanent use of a wheelchair or scooter) believed that persons with disabilities should live in integrated housing, 20% preferred specialized housing projects. When asked what size housing project they preferred 19% said 5-10 units, 28% said 10-20, 19% said 20-30, 7% said 30-40, and 28% said 40+.

The Datahr Rehabilitation Institute (1991) reports that multiple sclerosis patients who are dissatisfied with their housing and willing to move tend to be younger and more functional in ADLs.

4.4. PLANNED SHORT-STAY ADMISSIONS/RESPITE

Currey, Barton and Dansie (1987) report that the Danesbury Young Disabled Unit offers both in-patient continuing care and planned short-stay admissions for persons who dwell the remainder of the time in the community. During these admissions, assessment, rehabilitation and social activities are provided. In most jurisdictions, there are only two alternatives available to provide caregiver respite: someone coming into the home or admission of the client to an acute or 'GP hospital'. These alternatives, Currey, Barton and Dansie claim, rarely confer any positive benefit on the patient. Also, the admission date cannot be guaranteed and may be cancelled by the hospital on short notice. A planned short-stay admission in a Young Disabled Unit also solves the problem for caregivers who do not want or have room for a volunteer or paid worker to come into their home.

Gloag (1985a) argues for facilities which are able to offer short or medium term rehabilitation in the early stages of disease or damage, and after that, periodic in-patient stays backed up by regular review, and respite and emergency beds.

Roy (1991) presents data from a study of patients with progressive neurological disease conducted in New Zealand which shows that in spite of physical decline, most patients in a short, intermittent planned admission program improved or maintained their social and psychological status.

4.5. DAY CENTRES

Gloag (1985a) recommends that more day centres be established for clients who are unable to work. Such centres provide regular outside activity for persons living in residential care settings "and a lifeline for some at home - and perhaps their relatives" (p.303). She cautions, however, that day centres must provide more than just activities for passing the time.

4.6. TRANSPORTATION

Fanning, Judge, Weibe and Emener (1991) asked 12 agencies providing service to younger adults to identify support services necessary for individuals to live independently. Ninety-six percent of the providers indicated that transportation is needed for independent living to even be possible. Lack of available affordable transportation was perceived by 29% as limiting clients' socialization and enjoyment of life; by 21% as hindering their ability to work; by 21% as reinforcing dependency on family and friends; and by 13% as creating a financial strain.

4.7. ATTENDANT CARE

Miller and Opie (1987) identify personal care attendants as the single most important factor in enabling clients to achieve independence and control of their lives. Attendant care and financial aid were second only to transportation in the Fanning, Judge, Weibe and Emener (1991) study (both were identified as a needed services by 88% of providers).

Advocates note that independence requires more than simply having access to a personal care attendant. To be truly independent, clients need to have responsibility for hiring, training and paying their attendants. This model, referred to as a consumer model, is contrasted (Asher, Asher, Hobbs & Kelley, 1988) with an agency model where some or all of these functions are carried out by others on behalf of the client.

It is interesting to note that 71% of the severely mobility impaired clients surveyed in the Fanning, Judge, Weibe and Emener (1991) study said they would have "no problem" living independently with a personal care attendant. Finding an attendant was, however, a problem for 92% of the respondents; for 91% the cost of attendant care was problematic.

It is also interesting that when asked their preference with respect to the selection of their care attendant only 16% of clients in the Asher, Asher, Hobbs & Kelley (1988) study indicated that they would prefer to advertise for and interview attendants themselves. More than half (55%) preferred to select from an agency list and 27.5% preferred that the agency have sole responsibility. A similar distribution was obtained in response to a question concerned with who should have responsibility for the training of attendants. In interpreting the findings Asher et al. (1988) suggest that persons who have been disabled/dependent most of their lives may be fearful of taking on the responsibility for complete control of their attendants. In contrast, newly disabled trauma victims may view it as a means of regaining their independence. Asher et al. (1988) also suggest that as clients gain more experience with independent living they may wish to take on more of the decision-making. Their recommendation therefore is that a continuum of options for the control of attendant care services be provided.

4.8. REHABILITATION

Symington (1984) makes a strong plea for increased attention to the rehabilitation needs of younger adults with severe physical disabilities. He describes two cases in which years after the accident which disabled them, appropriate rehabilitation and vocational services enabled quasi-independent living outside an institutional setting and a major improvement in their quality of life. Reflecting on the Canadian situation, he cites the report of a study of the rehabilitation system in

Canada (Brown, 1977). The report was entitled A Hit or Miss Affair which, he felt, aptly described the state of services in this country. He also refers to the Parliamentary Committee on the Disabled and Handicapped (Canada - Department of the Secretary of State, 1981; Canada - Special Committee on the Disabled and The Handicapped, 1981, 1982 a&b) which provided an important vehicle for Canadians with disabilities to voice their concerns and preferences. These largely reflected the concerns and preferences of the Independent Living Movement in the United States.

A recent study, conducted in the United Kingdom by Williams and Bowie (1993), underscores the important and on-going role of occupational therapists (and speech therapists) with respect to assessment and treatment of persons with progressive disorders. The study showed considerable unmet need among severely physically disabled younger adults seen solely in general practice, as well as in clients receiving outpatient consultation and/or in regular contact with district nurses. Unmet need was defined as a situation in which interventions were acceptable to the client and the following applied:

- (a) for ADLs, the client was dependent on a caregiver and this dependency could be reversed by provision of an assistive device
- (b) for communication disorders, the client had not been assessed by a speech therapist
- (c) for services (day care, respite), a referral had not been made to the appropriate agency and subsequent referral proved successful; and
- (d) for benefits, the client or caregiver was unaware of eligibility, an application had not been made, and subsequent application was successful.

The study showed that 43% of clients with progressive disorders (chorea/ataxia, motor neurone disease, multiple sclerosis, muscular dystrophy, rheumatoid arthritis) and 12% with non-progressive disorders (congenital, head injury, paraplegia, tetraplegia, stroke, other) achieved independence in at least one ADL with the provision of assistive devices. Among those with communication disorders, only 32% (including half whose speech caregivers found impossible to understand), had ever received assessment by a speech therapist. As the authors point out (p.96): "Communication disorders are a source of considerable frustration and undoubtedly interfere with quality of life. In addition, help is required for motor neurone disease patients with swallowing disorders. The results highlight deficits in the use of speech therapists in their assessment and treatment capacities" (only 2 of 5 persons with motor neurone disease suffering from swallowing disorders had been assessed). There was also a pronounced increase in use of services among clients solely in contact with physicians and nurses - in the case of

respite from 48% to 92% of clients; day care from 55% to 89%; mobility allowance from 56% to 91%, and attendant allowance from 55% to 93%.

5. STAFF TRAINING

Training programs for home support workers and personal care aides have tended to focus on care of frail elders since they constitute the majority of the continuing care population. Many case managers and professional direct care staff (eg. nurses, occupational and physiotherapists, social workers) lack specific training in care of younger adults with severe physical disabilities. A number of authors recommend that training modules be developed and made available for inservice and/or initial education of persons working or planning to work with this client group. Recommendations concerning the content of these training modules include material on:

- the psycho-social needs of traumatically disabled adults (Braun, Goto & Lenzer, 1987)
- the psycho-social needs of multiple sclerosis patients (Burwash & Warren, 1990).
- two types of case-management (1) "intensive" case management for more confused elderly clients and (2) "primary" case management for alert clients who can manage their own services and personal care aides (Braun, Goto & Lenzer, 1987).
- clients with multiple disabilities (Condie, 1991).

With respect to the latter, Condie (1991) argues that the current model of under-graduate education in core areas such as orthopaedics or neurology or paediatrics may be inappropriate when considering the management of younger adults with severe physical disabilities. She uses as an example, the case of a young adult spastic quadriplegic who has problems that are neurological in origin but which have led to structural and functional problems that are orthopaedic. As a result this individual has difficulties with mobility, seating and even footwear which in turn, have led to considerable social and economic handicap. Condie contends that:

...the average therapist will be quite ill-equipped to offer appropriate help to this type of patient. Ironically, physiotherapists who specialize in paediatrics will probably have gained considerable insight into this multifactorial type of problem. However, patients over the age of 18 or 19, and frequently younger, are usually obliged to leave the care of the paediatric services (p.75).

6. INFORMAL CAREGIVERS' TASKS AND NEEDS

The Castree and Barnes (1993) study referred to at the outset of this report (see Table 1, page 2) indicated that almost all younger adults with severe physical disabilities have functional difficulties with ADLs. Surprisingly, although families are expected to keep their relatives at home, relatively little has been written about the nature of the personal care and nursing service they provide. To fill the gap, Atkinson (1992) asked 64 informal caregivers (mostly spouse and parents of clients attending a day centre) to indicate which, from a list of eight activities, they either helped with or did for their dependents. Dependents were mainly persons suffering from neurological disorders including stroke, multiple sclerosis, Huntington's chorea and head injuries. The eight activities enquired about were: eating, washing/bathing, mobility, transfer, using the toilet, dressing, changing surgical dressings and giving medicines. For each activity performed, respondents were asked to describe in detail what they did for their relative, whether the activity posed either physical or emotional difficulties for them, if they had received any instruction in performance of the task and, if they would like outside help with it. Table 6 summarizes the findings. As can be seen, bathing was both the most frequent type of assistance provided and the activity that posed physical problems for the greatest number of respondents.

TABLE 6

ASSISTANCE PROVIDED, DIFFICULTY EXPERIENCED AND TRAINING RECEIVED BY INFORMAL CAREGIVERS (N=64, ATKINSON, 1992)

Activity	Provide Help n	Physical Difficulty n	Emotional Difficulty n	Received Instruction n
Eating	32	3	3	3
Bathing	45	22	2	6
Mobility	38	15	2	3
Transfer	24	7	1	5
Bowel/bladder management	24	8	8	2
Dressing	41	14	1	5
Other	40	3	2	7

Three caregivers were unable to bath their spouses because of back injuries caused by lifting. Others described difficult and potentially hazardous situations resulting from a combination of the weight of the person being bathed and the lack of strength of both parties. Instruction on how to bath had been received by only six of the 45 caregivers providing this service. For two of these, it had been part of their training when they had previously been employed as an auxiliary nurse.

The task most often found to be emotionally upsetting was bowel and bladder management. While for eight respondents

assistance was confined to assisting the client to get to the toilet, unfasten clothing and transfer, for other caregivers it included cleaning up after bowel movements, emptying drainage bags, bladder washouts, administering suppositories and/or manual bowel evacuation.

Thirty-two caregivers assisted with eating. Clearing spillage and assisting persons who choke (multiple sclerosis and Huntington's chorea patients) posed special difficulties for caregivers.

Two male caregivers found bathing to be emotionally upsetting. Both felt this aspect of care of their wives was too personal a task for a man to perform.

Atkinson notes that most of the persons being cared for were in the middle stages of their "career of disablement" and that the care they required would get heavier. She strongly recommends that more equipment be supplied (e.g. hoists for bathing; wheelchair showers), and that informal caregivers receive basic instruction on the skills they needed to perform their caregiving duties.

Caregiver training programs are also called for by Kulkarni, Chamberlain and Porritt (1992). These researchers compared the time spent on assistance with ADLs when rehabilitation patients were on weekend leave at home compared to when they were in hospital. They found that dependency was two to six times higher at home. The findings are attributed to the home caregivers being essentially untrained, to unadapted home environments, lack of space and equipment, and a shortage of caregivers.

7. FINANCIAL COSTS OF CARE

Prouse et al., (1991) examined the costs of caring for clients living in the London borough of Harrow. They report, as one would expect, that inpatient and respite are the most expensive types of care. The most expensive clients to support were those with multiple sclerosis and with cerebral palsy -- but for different reasons. With multiple sclerosis there were high domiciliary service costs; with cerebral palsy, high schooling costs. The researchers note that although it is extremely important in terms of quality of life, to respect clients' wish to remain at home, there are often large and underestimated financial implications. Examined in this study were costs associated with health (community nursing, inpatient and medical costs); domiciliary care (Meals-on Wheels, home care, care attendants, day care, home visits) and education (school, university). Costs were found to be mostly incurred by persons with a Barthel score of less than 50 and to be independent of the number of unpaid caregivers.

8. NEED FOR PROGRAM EVALUATION/GREATER ACCOUNTABILITY

Patrick, Scrivens & Charlton (1983) provide three reasons for conducting client satisfaction surveys in health care:

- (1) to ascertain the extent to which satisfaction influences compliance and continued contact with the care provider,
- (2) as an indicator of the quality of care delivered (including satisfaction with providers' technical competence, providers' personableness, access and cost of service), and
- (3) to better understand the client's perspective, gain feedback for planning and increase providers' accountability.

Budde, Petty and Nelson (1989) echo the latter point noting that Independent Living Centre's perceptions of clients' needs often differ from clients' perceptions. Further, they note, consumer satisfaction evaluation offers a means of complying with the requirement for "substantial consumer involvement" called for in the 1978 amendment to the U.S. Rehabilitation Act.

Several national surveys have been conducted in the United States which describe the operating characteristics of Independent Living Programs (e.g. Veerkamp, 1984; Nosek, Roth & Zhu, 1990). There is a paucity of studies, however, evaluating the impact of these programs on clients and communities. Nosek (1987) argues that evaluation of Independent Living Programs has been hampered by the absence of an adequately defined concept of independence. Iceman and Dunlap (1984), in a national survey of U.S. programs, reported a dearth of standardized assessment tools and effective instructional materials. Braun, Goto and Lenzer (1987) noted that although the concepts and mandate for programs have been established, education and rehabilitation centres have been left largely on their own to decide how independent living skills should be presented and taught to severely disabled clients. The majority of programs have been developed, these authors state, on a trial and error basis and their impact is unknown. Budde, Petty and Nelson (1989) make a similar point but note that the lack of standardized training and evaluation instruments is not unique to the rehabilitation field and also occurs in the mental health and educational counselling fields. "As a result", they note "psychometric practices and experimental designs are often ignored. Instruments are developed and used without understanding their inherent problems" (p.63).

A Canadian study (Hutcheon, McCallion & Kolodziel, 1993) evaluating a life skills program offered in a Young Disabled Unit in Calgary provides an example. It suffers from a number of methodological flaws including lack of a control group. Several other of the small number of evaluation studies located to date have structural flaws and/or a very small response rate (e.g. 20%

in the study by Fanning, Judge, Weibe & Emener, 1991). This raises uncomfortable questions with respect to the meaningfulness and generalizability of findings from these studies.

A final point that should be mentioned concerns who is being studied. Fourteen years ago, Burnett and Yerxa (1980) reported that most follow-up studies of discharged rehabilitation patients have been conducted with persons with spinal cord injuries "probably because of the predictability of type and extent of disability and the relative ease in controlling for those variables" (p.201). Florian (1983) made a similar observation with respect to information about sexual problems of disabled persons. The paucity of research on the service needs of community-based persons with other types of disabilities observed by these authors seems still to hold true today.

8.1. RECOMMENDED OUTCOME MEASURES

In an article focussed on evaluating the impact of Independent Living Centres on communities and individuals, Budde, Petty, Nelson and Couch (1986) argue that what should be compared are: a) common consumer goals with what has been achieved and b) changes in the options that are used at intake and at subsequent time intervals. Asher, Asher, Hobbs and Kelley (1988) also emphasize the importance of ascertaining if the client engages in different activities subsequent to participating in an independent living program.

Budde, Petty and Nelson (1989) indicate that cutting across most services are the following dimensions that commonly tend to be evaluated: accessibility, availability, the physical environment, information resources, interpersonal quality of client-staff exchanges, the technical skills of providers, service relevance and the outcome or effectiveness of services. They argue that a specific subcomponent of Independent Living Centres that should be evaluated is satisfaction with community options.

...ILCs spend a great deal of time advocating for and developing options for independent living, e.g., accessible housing, accessible transportation, funds for personal care attendants, legal rights. Results illustrating satisfaction with such options could be used to target needed options and determine commitment levels to develop those options (p.63).

Another dimension they think should be evaluated is clients' satisfaction with their degree of input, relative to staffs', into the decision-making process, up to and including decisions with respect to overall service delivery policy.

Budde, Petty, Nelson and Couch (1986) remind us that:

...individuals who receive services.... do not always set goals that enable them to reach higher levels of independence. In a few cases, particularly when there is progressive illness, an individual may choose to use more dependent options as goals. In other cases, particularly where there is loss of resources (e.g. arbitrary social security cuts), an individual might desire to maintain current options as a goal. In any event, ILCs should be given credit when they enable an individual to attain his or her own goals (p.69).

8.2. INDEPENDENT VARIABLES TO CONSIDER

Braun, Goto and Lenzer (1987) present a brief review of the literature on the relationship between age and client satisfaction with health care. Citing the work of various authors (e.g. Linn & Greenfield, 1982; Linn, Linn & Stein, 1982; Hulka, Kupper, Daly, Cassel, & Schoen, 1975) they note that in general, patient satisfaction with care tends to be greater among older than among younger clients. The same finding held in their own study evaluating Honolulu's Nursing Home Without Walls program. While the finding is not surprising, given that the program is described by the authors as a medical model home care program originally developed for geriatric patients, there is a trend in both the younger disabled adult and the geriatric/gerontological literature to attribute age differences in client satisfaction to older persons giving more socially desirable answers (c.f. Linn, Linn & Stein, 1987). It is important to remember, however, that there are other differences between young and old clients that could explain the difference. For example, as Braun, Goto and Lenzer (1987) point out, there are differences in the reasons younger and older persons are receiving home care service. Whereas most younger home care clients have been disabled through accidents or degenerative neurological disease most older clients require this service because of multiple chronic conditions. Age differences in client satisfaction may also reflect differences in the way services are delivered to the two groups (i.e. reflect provider characteristics and behaviour patterns).

Beside age, Linn, Linn and Stein (1982) found that severity of patient's condition was a good predictor of client satisfaction among younger adults. (This variable accounted for half the explained variance among younger patients at a VA clinic compared with only 11% among older patients). Severity of disability was also found to be an important predictor of patient satisfaction with doctors in a population survey (n=1,245) conducted in the United Kingdom (Patrick, Scrivens and Charlton, 1983). Respondents with higher levels of physical disability (as measured by a British version of the Sickness Impact Profile) were found to be less likely to be dissatisfied with doctors in general but more likely to be dissatisfied with their own doctor. An implication of this finding, the authors suggest, is that "attempts to use satisfaction measures for evaluating specific

services or providers should distinguish between patient groups with different physical and psychosocial disabilities" (p.1062).

Duration of disability is another variable various writers in the younger disabled adult literature suggest should be taken into consideration (Asher, Asher, Hobbs & Kelley, 1988; Braun, Goto and Lenzer, 1987).

Budde, Petty and Nelson (1989) suggest sampling clients who have dropped out of programs, those who receive different services since not everyone will use all the services a particular agency offers, as well as those who are at different stages of service delivery. With respect to the latter, they note that clients of Independent Living Centres have different needs at intake than later.

...Their needs might include transportation to the ILC, understanding about or attention to their problem, or orientation to the intake process. At the service delivery stage, consumers might be concerned about their opportunities to make decisions, their relationship with the provider, or their progress. At the post-service delivery stage, consumers might be concerned about final outcome, their overall view of the program, or follow-along relationships (p.64).

These authors note that in evaluating psycho-therapy, Mann (1973) has proposed a model that uses different criteria to assess impact at different stages. They suggest that the same approach might be useful in evaluating Independent Living Centres and, it could be argued, other human services developed for younger adults with severe physical disabilities.

Consumer bias also needs to be considered. Budde, Petty and Nelson (1989) state that services tend to be evaluated on the positive side even without evidence of progress towards people's intended goals. Possible reasons might be to please the social service agency, make a good impression, because the client fears loss of service or simply because of the Hawthorne effect -- ie. being paid attention to. There are measurement tools and techniques from other fields however, that can be used to "weed out" respondents with very high social desirability response tendencies. Use of multiple outcome measures, some objective and some subjective, is another way of dealing with the consumer bias problem.

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APPENDIX 1

PREVALENCE RATES FOR MULTIPLE SCLEROSIS

Multiple sclerosis is a disease of unknown aetiology characterized by myelin destruction. Survival is only rarely shortened, but disability to the point of requiring ambulation aids occurs in 30-70% of patients by 15 years from onset of symptoms (Weinshenker & Ebers, 1987). For example, in a population study where the median duration from onset was 15.4 years and patients had a median age of 47.5 years, Rodriguez, Siva, Ward & Stolp-Smith (1994) report that approximately one-third had marked paraparesis, paraplegia or quadriplegia. One-fourth needed intermittent or almost constant catheterization for bladder dysfunction. However, and as is typical, few patients (3.7%) reported severe decrease in mentation or dementia requiring supervision. It should further be noted that more than half (53.1%) were working full-time. Approximately three-quarters (72.2%) maintained their usual financial standard without external support.

PREVALENCE:

There are a number of factors which must be taken into consideration in discussing prevalence rate.

a) Gender

There is a preponderance of women in both early and late onset cases. For example, Sweeney, Sadovnick & Brandejs (1986) report a definite/probable overall rate for British Columbia of 93.3/100,000 (females - 126.4/100,000; males - 59.8/100,000). (Data source: the major portion of the study was a review of all files of neurologists practicing in B.C. Other sources used for identifying patients included the MS Clinic, GPs, ophthalmologists, urologists, LTC facilities and rehabilitation centres and patient self-referral.)

Svensen, Woodhead & Platt, 1994 report an overall rate for Alberta of 216.7/100,000 (females 260.3/100,000; males 173.1/100,000). Prevalence for Alberta is among the highest reported in the world indicating the province is an excess risk area. (Data source: Alberta Health Care Insurance Plan records.)

Duquette et al (1992) suggest the skewed sex distribution could be attributed to known hormonal and gender influences on the immune response as well as to genetic influences.

b) Race

Multiple sclerosis is more common in white than non-white populations (Louis, 1988). Oger and Lai (1994) report a rate for whites in British Columbia of 64.7/100,000 compared to

14.6/100,000 for non-whites. (Data source: MS clinic patients with clinically definite MS.)

c) Geographic Distribution

Prevalence is higher in northern latitudes (Visscher, Detels, Coulson et al., 1977). Sweeney, Sadovnick & Brandejs (1986) report that Canada is considered a high risk zone as are the northern states of the USA. However, prevalence rates vary across the country (see Table A-1) . A west-east gradient also exists in the USA (Ebers & Sadovnick, 1993).

Migration studies and the demonstration of clusters suggest that an environmental factor, likely infectious, is involved in the etiology of MS. Genetic predisposition is probably also a factor (Kurtzke, 1993; McDonald 1983 cited in Sweeney, Sadovnick & Brandejs, 1986). In high risk areas, MS is acquired by about age 15; moves from high to low risk areas suggest susceptibility is limited to ages 11-45. Kurtzke (1993) believes that clinical MS "is the rare late outcome of a specific, but unknown, infectious disease of adolescence and young adulthood and that this infection could well be caused by a thus-far-unidentified (retro) virus" (Abstract).

Clinical pattern differs geographically. For example, Lana-Peixoto and Lana-Peixoto (1992) report that high prevalence of visual and spinal abnormalities at onset and during course of illness, less common involvement of cerebellum, and relative frequency of Devic's disease seen in their Brazilian sample greater similarities between MS in Brazil and Eastern countries than with the USA and Europe.

d) Physical trauma

Two major prospective cohort studies of MS indicate that physical trauma is not responsible for onset or exacerbation (Kurland, 1994)

TABLE A-1

REPORTED PREVALENCE OF MULTIPLE SCLEROSIS

	Rate per 100,000	Source
World-wide	57.9	O'Brien (1993)
Australia		McLeod, Hammond & Hallpike(1994)
New South Wales	36.6 (age standardized)	
South Australia	28.8 (age standardixed)	
Canada		
NFLD & Labrador	42.2	Pryse-Phillips, Cook & Galway (1983)
Halifax County, N.S.	21.2 (32.4)	Alter, Allison, Talbert et al (1960)
Kingston, ON	57.0 (77.0)	White & Wheelan, (1959)
Ottawa, ON	67.0	Bennett, Hamilton, Neutel et al (1977)
Winnipeg, MAN	35.4	Stazio, Kurland, Bells et al (1964)
Saskatoon, SASK	111.0(134.0)	Ebers, Bulman, Sadovnick et al (1984)
Alberta	216.7	Svensen, Woodhead & Platt (1994)
British Columbia	93.3 (130.5)	Sweeney, Sadovick & Brandejs (1986)
South Estonia	51	Gross, Kokk & Kaasik (1993)
Berne Switzerland	110	Beer & Kesselring (1994)
Minnesota	167.5 (age & sex adjusted)	Rodriguez, Siva, Ward, Stolp-Smith et al (1994)

Note: Where two rates are given, the first refers to definite/probable MS and the second to possible MS (e.g. the overall rate for British Columbia increases to 130.5/100,000 if possible MS and optic neuritis are included).

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APPENDIX 2

PREVALENCE RATES FOR MUSCULAR DYSTROPHY AND OTHER PROGRESSIVE NEURO-MUSCULAR DISEASE

1. Spinal Muscular Atrophy (SMA)

Acute Childhood SMA (Type 1 or Werdnig-Hoffman or infantile SMA or severe SMA)

Incidence: 1/20,000 live births (Brzustowicz et al,1990)

Prevalence:

Carrier Frequency: 1/60-1/80 (Brzustowicz et al,1990)

Age of onset: infancy (Brzustowicz et al,1990)

Age of death: often in first year and usually by age 4
(Brzustowicz et al,1990)

Transmission pattern: recessive

Chronic childhood SMA (Type 2 and Kugelberg-Welander or Type 3)

Incidence: 1/24,000 live births (Brzustowicz et al,1990)

Prevalence:

Carrier Frequency: 1/60-1/80

Age of onset: 6 mo. to 17 years (Brzustowicz et al,1990)

Age of death: adolescence -

Cause of death:

Transmission pattern: recessive

Adult-onset SMA

Incidence:

Prevalence:

Carrier Frequency:

Age of onset: 17-55 years (Brzustowicz et al,1990)

Age of death:

Cause of death:

Transmission pattern: recessive or dominant

2. Amyotrophic Lateral Sclerosis (ALS) - also known as Lou Gehrig's Disease.

Incidence: 1-2/100,000

Prevalence: 7/100,000 (Connections, 1995)

Carrier Frequency: Not applicable. In 90% of cases, there is no family history of the disease.

Age of onset: 50-55 years (Connection, 1995).

Age of death: on average, 2-3 years post-diagnosis

Cause of death: Respiratory failure

3. Muscular Dystrophy

Duchenne MD

Duchenne (DMD) and Duchenne-type muscular dystrophies are x-linked recessive hereditary disorders characterized by diffuse skeletal and cardiac muscle involvement.

Incidence: 1/4,000 live male births according to the National Organization for Rare Disorders (1994); 1/5,618 according to Bushby, Thambayayah & Garner-Medwin, 1991)

Prevalence: 2.48/100,000 (Brooke, 1986; Bushby, Thambayayah & Garner-Medwin, 1991)

Carrier Frequency: 1/2500

Age of onset:

Age of death:

Prior to ventilation therapy, life expectancy was 18-21 years (e.g. Baydur, Gilgoff, Prentice et al, 1990 place age at death at 20 or slightly older; they report a mean life span of 17 years. Mohr and Hill (1990) describe the disease as "leading inexorably to quadraparesis in the pre-teen years and death due to respiratory failure at an average age of 20 or slightly older for the more slowly progressive Duchenne type dystrophies.) Currently in Canada, with ventilation people are living into their 40s.

Cause of death: respiratory failure (Baydur, Gilgoff, Prentice et al., 1990)

Transmission pattern: affects males exclusively; X-linked recessive

Becker Muscular Dystrophy

Incidence: 1/18,450 male live births (Bushby, Thambayayah & Garner-Medwin, 1991)

Prevalence: 2.38/100,000 - 2.61/100,000 (Bushby, Thambayayah & Garner-Medwin, 1991)

Carrier Frequency:

Age of onset: mean age 11 years (Bushby, Thambayayah & Garner-Medwin, 1991)

Age of death:

Cause of death: respiratory failure

Transmission pattern: X-linked recessive

Becker muscular dystrophy (BMD) shows the same pattern of muscular involvement as DMD but with a more slowly progressive clinical course.

Note: The National Organization for Rare Disorders (1994) estimate that currently all muscular dystrophies combined affect 40,000 in the USA.

4. Freidrich's Ataxia

Incidence: 1/50,000

Prevalence:

Carrier Frequency: 1/110

Age of onset:

Age of death:

Cause of death:

Transmission pattern:

5. Facioscapulohumeral Muscular Dystrophy

Incidence:
Prevalence: 1/20,000
Carrier Frequency: Not applicable
Age of onset:
Age of death:
Cause of death:
Transmission pattern: Not applicable
Reference:

6. Myotonic Dystrophy

Incidence: 1/8000 live births
Prevalence: 1/100,000
Carrier Frequency: Not applicable
Age of onset:
Age of death:
Cause of death:
Transmission pattern: Not applicable

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