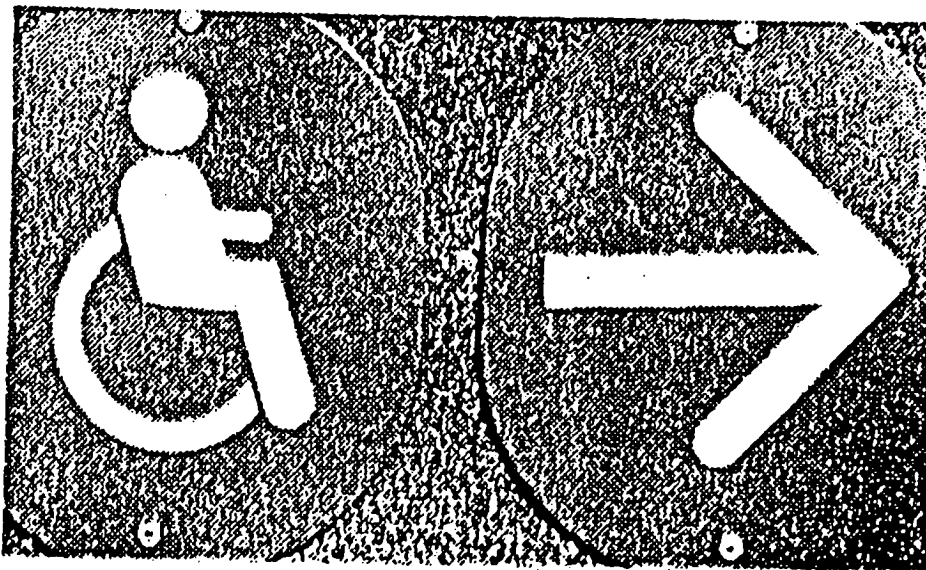


YOUNGER ADULTS IN LONG-TERM CARE FACILITIES:

**A REVIEW OF THE LITERATURE CONCERNING
THEIR CHARACTERISTICS AND
ENVIRONMENTAL DESIGN, STAFFING AND
PROGRAMMING NEEDS**

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Facilities: A Review of the Literature
Concerning Their Characteristics and
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and Programming Needs

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by

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I INTRODUCTION

Concern over provision of long-term care for an increasing seniors' population has tended to obscure the fact that younger persons may also require this level of care.

This report focuses on the non-geriatric population in long-term care: specifically, on adults between the aged of 20-64. Within this group, the emphasis is on those requiring facility care.

While there is general consensus (Ontario Medical Association Committee on Rehabilitation, 1980a and b; Reinecke, 1979; Nichols, 1978) that everything possible should be done to enable younger adult disabled persons to live out their lives in the community, it is recognized that for some individuals with severe congenital or accident-caused disabilities, community living is impossible. Others require periodic admission to an institution in order to continue to live most of the time in the community. Still others enter an institution at the late stages of a progressive deteriorating illness which they and/or their family caregivers can no longer manage in a community setting.

For all of these groups, the objective must be to construct institutions that will best meet their physical and psycho-social needs -- that is, that provide the best possible physical care in the least restrictive, most emotionally and intellectually satisfying environment possible.

A first step towards achieving this objective is to understand the characteristics of the non-geriatric, adult long-term care facility population. This report therefore begins with a description of their diagnoses, sex distribution, marital status and functional status. Attention is then directed towards their environmental design, staffing and programming needs.

The material presented on each of these topics is severely constrained by the general dearth of information on the non-geriatric long-term care population. For example, while younger adults are known to reside in both age-integrated and age-segregated long-term care facilities, the bulk of information about them comes from descriptive reports of hospital or care-facility units specifically designated for their care, hereafter termed Younger Disabled Units (YDU's).

II CHARACTERISTICS OF YOUNGER ADULTS IN LONG-TERM CARE

FACILITIES

Diagnosis

When grouped in terms of relative frequency and the proportion severely disabled, multiple sclerosis, cerebrovascular accident (stroke), Parkinsonism and rheumatoid arthritis emerge as the dominant problems in the younger adult population (Wood, 1978). These same disorders, and in particular multiple sclerosis, are also the commonest diseases leading to long-term residential care in this population as indicated by data presented by Wilson (1978), Currey, Barton and Dansie (1987) and Miller and Gwynne (1972).

Wilson (1978) describes a YDU in Whitehaven, England. The unit has 22 beds for patients aged 16-65. During 1975 and 1976, 54 patients were admitted to the unit, 16 for specific rehabilitation, 4 for terminal care, 1 for holiday relief and 33 for long-term care.

As shown in Table 1, cerebrovascular accident was the most common diagnosis among patients admitted for rehabilitation and discharged back into the community. Multiple sclerosis and cerebrovascular disease were the most common diagnoses of the long-stay patients.

TABLE 1

DIAGNOSES OF REHABILITATION AND LONG-STAY PATIENTS ADMITTED TO
WHITEHAVEN HOSPITAL'S YOUNG DISABLED UNIT, 1975 AND 1976

Patients Admitted For <u>Rehabilitation</u>		Patients Admitted For <u>Long-Term Care</u>	
	<u>n</u>		<u>n</u>
Cerebrovascular accident	5	Multiple sclerosis	10
Head injury	2	Cerebrovascular disease	9
Back injury	2	Tumours	6
Spina bifida	1	Parkinsonism	5
Hand injury	1	Paraplegia or tetraplegia	3
Epilepsy	1	Rheumatoid arthritis	2
Hypokalaemic periodic paralysis	1	Renal failure (TB)	1
Arteriovenous cerebral aneurysm	1	Syringomyelia	1
Ankylosing spondylitis	1	Cerebral palsy	1
Parkinsonism	1		--
	--		38
	16		

Source: Wilson (1978)

Currey, Barton and Dansie (1987) describe a 26-bed YDU, 20 beds of which are used for long stay patients. Located in Danesbury Hospital, Hertfordshire, England, the unit was established in 1957. From 1957-1971, patients admitted were between the ages of 18-45. With passage of the Chronically Sick and Disabled Persons Act in 1970, the upper age limit for admission was moved to 64. Over the period 1957-1986, 197 long-stay patients were admitted. As shown in Table 2, 67.5% had a diagnosis of multiple sclerosis.

TABLE 2

DIAGNOSES OF LONG-STAY PATIENTS ADMITTED TO DANESBURY HOSPITAL'S
YOUNG DISABLED UNIT, 1957-1986

	n	%
Multiple sclerosis	133	67.5
Cerebrovascular accident	12	6.1
Cervical spine injury	8	4.1
Muscular dystrophy	5	2.5
Cerebral tumour	4	2.0
Cerebral palsy	4	2.0
Other neurological conditions	26	13.2
Rheumatoid arthritis	2	1.0
Other/unknown	3	1.5
	---	-----
	197	100.0

Source: Currey, Barton and Dansie (1987)

Miller and Gwynne (1972) describe five institutions in Britain serving younger disabled adults. Two were voluntary homes; two were units run by Regional Hospital Boards, one consisting of a segregated ward for young chronic sick within a geriatric hospital; one was a purpose-built unit in the suburbs run by a local authority. As shown in Table 3, three neuromuscular conditions - multiple sclerosis, cerebral palsy and muscular dystrophy - account for nearly half the disabilities represented in these institutions.

TABLE 3

DIAGNOSES OF PATIENTS ADMITTED TO THE FIVE INSTITUTIONS
SERVING THE PHYSICALLY HANDICAPPED AND YOUNG CHRONIC SICK
STUDIED BY MILLER AND GWYNNE (1972)

	<u>N</u>	<u>%</u>
Multiple sclerosis	34	23.1
Cerebral palsy	20	13.6
Muscular dystrophy (and muscular atrophy)	16	10.9
Paralysis*	14	9.5
Rheumatoid and osteoarthritis; Still's Disease	13	8.8
Parkinsonism	6	4.1
Poliomyelitis	6	4.1
Freidreich's ataxia	5	3.4
Dual disabilities	15	10.2
Other	18	12.2
	---	----
	147	100.0

* hemiplegia, tetraplegia, quadriplegia, paraplegia

Age Distribution

The term "young" when used in the context of residential units for the handicapped and chronically ill is a relative one, generally meaning under age 60 or "pre-geriatric".

As shown in Table 4, in the five units surveyed by Miller and Gwynne (1972), almost three-quarters (72.1%) of the residents were over age 35 despite the fact that each unit had been established to care for the "young chronic sick" and in two, the upper age limit for admission was fixed at the mid-forties and late forties respectively.

TABLE 4

AGE DISTRIBUTION OF RESIDENTS IN THE FIVE INSTITUTIONS
STUDIED BY MILLER AND GWYNNE (1972)

	<u>n</u>	<u>%</u>
Under 21	7	4.8
21-35	34	23.1
36-50	77	52.3
Over 50	29	19.7
	---	----
	147	100.0

Data from Dansbury Hospital show a similar trend. As is evident in Table 5, even when admission was restricted to persons between the ages of 18-45, on average patients were middle-aged (mean age = 39) when they entered residential care.

TABLE 5

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF LONG-STAY PATIENTS ADMITTED
TO DANESBURY HOSPITAL'S YOUNG DISABLED UNIT,
BY PERIOD OF ADMISSION

	<u>1957-71</u> <u>(age 18-45)</u>	<u>1971-85</u> <u>(age 18-64)</u>
Number admitted	98	99
Mean age on admission	39	49
% male	58	58
% married	40	53
% died on unit	50	74

Source: Currey, Barton and Dansie (1987)

Sex and Marital Status

As in the geriatric long-term care institutionalized population, females appear to predominate in YDU's. Of the long-stay patients treated in the YDU at Whitehaven Hospital, 73% were female (Wilson, 1978). Currey, Barton and Dansie (1987) report that the current proportion of females among YDU patients at

Danesbury Hospital is 65%. However, as shown in Table 5, it appears that the Danesbury Unit admitted more males than females.

Table 5 also indicates that, at admission, from 40-53% of patients were married. It should be noted, however, that among current residents the proportion married is only 20%.

In the case of the sex distribution of patients, the apparent discrepancy between the current and the cumulative admission statistics from the Danesbury Unit could be due to the differential mortality rate of males and females.

In the case of marital status, the apparent discrepancy between the current and the cumulative admission statistics could be related to the nature of the diseases suffered by patients. For example, Currey, Barton and Dansie (1987) report that patients refer to multiple sclerosis as the "marriage splitter". Miller and Gwynne (1972) also comment on the high proportion of divorces and legal separations (45.2%) among their sample which contrasts with the situation of disabled persons living in the community.

Functional Abilities

Table 6 shows the functional abilities of 20 long-stay patients in residence at Danesbury Hospital's YDU in 1986. These patients ranged in age from 37-67 (mean age 53.8). Twelve had a diagnosis of multiple sclerosis. The diagnoses of the other eight patients were: cerebral palsy (2); cerebrovascular accident (2); cerebral

damage due to traffic accident (1); cerebral damage due to carbon monoxide poisoning (1); ependymoma of the cervical cord (1) and Klippel Feil syndrome (1).

As can be seen from Table 6, these patients were severely disabled. While approximately three-quarters could feed themselves, use a self-propelled or motorized wheelchair and speak clearly, only a third were described as able to wash themselves "properly", only a quarter could sit unsupported or transfer from chair to bed and more than two-thirds were catheterized and/or needed manual removal of faeces.

TABLE 6

FUNCTIONAL ABILITIES OF 20 LONG-STAY PATIENTS:
DANESBURY HOSPITAL YOUNG DISABLED UNIT, 1986

Walk unaided	1
Walk with aid	4 ^a
Use self-propelled wheelchair	4
Use motorized wheelchair	10
Unable to manage wheelchair	5
Sit unsupported	5
Transfer from chair to bed	5
Feed self	15
Wash self properly	6
Wash hands and face only	9
Comb hair	10
Write	3
Speak clearly	17
Use telephone	3
Read	7
Watch television	15
Catheterized	13
Need manual removal faeces	14

^a All use wheelchairs

Source: Currey, Barton and Dansie (1987)

Patients in the five institutions studied by Miller and Gwynne (1972) also show a high level of disability. For example, as can be seen in Table 7, while two-thirds could wash their face and hands in a handbasin, less than ten percent could bathe without assistance. Further, approximately half required help with eating and going to the lavatory and three-quarters with dressing. It should also be noted that while approximately one-fifth (18.4%) could walk with or without aids and two-thirds (63.9%) could use a manually or electrically operated wheelchair, one-fifth (17.7%) were immobile without assistance. Also, about half had defective speech and about a fifth had defective sight.

TABLE 7

ASSISTANCE WITH ACTIVITIES OF DAILY LIVING
 REQUIRED BY RESIDENTS OF THE FIVE INSTITUTIONS
 STUDIED BY MILLER AND GWYNNE (1972)

N = 147

	<u>Full</u> <u>Assistance</u> %	<u>Some</u> <u>Assistance</u> %	<u>No</u> <u>Assistance</u> %	<u>Total</u> %
Dressing	45.6	31.3	23.1	100.0
Washing hands and face	26.5	12.2	61.2	100.0
Bathing	70.1	23.1	6.8	100.0
Feeding	29.2	22.4	48.3	100.0
Going to lavatory	32.7	16.3	51.0	100.0

Age at Onset of Disability

Table 8 shows the age at onset of disability among residents of the five institutions studied by Miller and Gwynne (1972). As can be seen, one-quarter (24.5%) of the residents had congenital disabilities, one-fifth (20.5%) became disabled during childhood, while approximately one-third (29.3%) did not become disabled until after age 25.

TABLE 8

AGE AT ONSET OF DISABILITY AMONG RESIDENTS OF THE FIVE
 INSTITUTIONS STUDIED BY MILLER AND GWYNNE (1972)

	<u>n</u>	<u>%</u>
Congenital disability	36	24.5
Under age 15	30	20.5
15-25	26	17.7
Over 25	43	29.3
Insufficient information	12	8.2
	--	----
	147	100.0

As Miller and Gwynne (1972) note, the age at which a person becomes disabled has considerable implications for his/her life experiences.

...A severe congenital disability, for example, may prevent a child from attending an ordinary school and in some cases from obtaining an education at all. On the other hand, the individual who becomes affected later in life may have established a career, set up home, and founded a family... Another significant age appears to us to be about 15: below this, the child will not have completed his education; between 15 and 25 the young person may be expected to have left school and started work. Thus, an individual who becomes disabled at, say, 18 may have completed his education but have had little experience of a work role and the relative independence that accompanies it. (p. 65).

Differences in the age at onset of disability and, consequently, in life experiences, need, of course, to be taken in to consideration in designing programs for residents of YDU's, in providing appropriate counselling, etc.

III ADMISSION CRITERIA AND TURNOVER RATES IN YOUNG DISABLED UNITS

Age

YDU's vary from those restricting admission to young and middle aged adults to those admitting all adults under age 65. For example, ages 18-45 are the limits for a 50-bed YDU at Edmonton's Dickinsfield Extended Care Hospital (Lazaruk, 1987).

This was the original age range at both the Whitehaven and the Danesbury YDU's. Subsequent to passage in Britain, in 1970, of the Chronically Sick and Disabled Persons Act, however, both hospitals moved their upper age limit to 64.

Mental Status and Physical Condition

The emphasis in YDU's is on treatment of persons with physical disabilities. For example, the admission criteria for the Danesbury YDU specify that the patient have severe physical disability but that he/she be without significant dementia or behavioural disturbance (Currey, Barton and Dansie, 1987).

At the Dickinsfield Unit in Edmonton, admission is restricted to mentally alert persons having a chronic disabling disease or disability due to traumatic injury, who have been assessed at the Type III (auxiliary) level of care.

Turnover Rates

Currey, Barton and Dansie (1987) report that the annual turnover of patients per bed at Danesbury was only 0.25 during 1957-1971

when the unit admitted patients between the ages of 18-45. They also note that although the policy was that those with terminal diseases were to be sent back to the referring hospital, approximately half from the 1957-71 admission cohort and three-quarters from the 1972-85 cohort died in the YDU.

Average Length of Stay

Currey, Barton and Dansie (1987) report the median length of stay of multiple sclerosis patients to be 20 months (range 3-200 months). The median length of stay for other patients on the unit (with diagnoses including cerebral palsy, cerebrovascular accident, cerebral damage due to traffic accident/carbon monoxide poisoning) was more than double at 45 months (range 2-199 months).

IV GOALS AND OBJECTIVES OF YOUNG DISABLED UNITS

A recurrent theme in the literature on YDU's and one which clearly distinguishes it from the geriatric long-term care literature is an emphasis on rehabilitation, recovery and return to the community.

Also much more explicit in the YDU literature than in the geriatric long-term care literature is the recommendation that patients be granted as much control as possible over their lives and that they be involved in decision-making.

For example, Reinecke (1979) states:

...Once it is determined that the handicapped person needs the services provided by the long-term care facility, and hopefully when it is possible, it will be the determination of the affected individual, every emphasis should be placed on rehabilitation, recovery or attainment of maximum potential and where appropriate return to the community. (p. 49).

Similar themes are reflected in the objectives of the Edmonton YDU which, according to Lazaruk (1987) are to:

...create an atmosphere where the patient is able to maintain a lifestyle which is as normal and independent as possible; allow the patient to make as many individual choices as possible; care for each patient with kindness and respect for the dignity and worth of the individual; and promote rehabilitation and encourage movement back to the community whenever feasible (p.).

As a means of accomplishing this goal, patients in the Edmonton Unit are encouraged to make and carry out a contract with staff.

...we ask him to consider what his goals are and to prioritize them. In this way we also ask him to take responsibility to regain or take control of his life to the extent that it is feasible. Using the goals as outlined in the contract, the

individual disciplines assess and consult with the patient in order to delineate a plan of action. The team's plans and programs must fit into the patient's stated goals, thus the emphasis is on working with rather than for the patient. The contract functions well to coordinate efforts of all team members and provides a continuum thereby eliminating duplication or working at cross purposes. (Lazaruik, 1987, p. ; emphasis added).

V DESIGN RECOMMENDATIONS

Size of Unit

The YDU's described in the literature vary between 22-26 beds (the Whitehaven and Danesbury units respectively) and 50 beds (the Edmonton Unit). The Ontario Medical Association Committee on Rehabilitation (1980) recommends 50-75 beds but provides no rationale for their recommendation. Miller and Gwynne (1972) recommend against units of between 25 and 35 patients. They feel such units are too small to justify the cost of hiring both a director of care and an administrator but too large to allow the head of the institution to remain closely in touch with individual patients and staff members.

Location of Unit

The Whitehaven Hospital YDU is located on the second floor of a building of an unspecified number of stories. While accessible by elevator, Wilson (1978) feels this location is less than ideal. He indicates that "most people" believe such units should be on the ground floor.

Type of Rooms

The YDU literature contains no specific recommendations as to the type of rooms that should be provided. In discussing age-integrated facilities, Foxley-Norris (1978) notes, however, that the young seem to prefer to share rooms "for company". He goes on to describe a home in Lancashire which is building a single-story extension. Consisting largely of single bed-sitting rooms,

the home has included in its plan two double rooms designed for younger residents. These are to be located at the end of the building and will have double soundproofing. This is advisable, Foxley-Norris feels, because:

...the young, even the badly handicapped are often vivacious, alert, enterprising, talkative and noisy -- or at least like to be; their elders frequently find such attitudes unwelcome in a small and rather closed community. (p. 451).

Other Recommendations

Although the YDU literature contains no floor plans or specific design guidelines, several reports, including that of the Ontario Medical Association Committee on Rehabilitation (1980), point to the need to remove architectural (and administrative) barriers that prevent freedom of movement, both within the institution and between the institution, its surrounding neighbourhood and the broader community. In reference to architectural design, the need for privacy is also underscored (Ontario Medical Association Committee on Rehabilitation, 1980).

VI STAFFING OF YOUNG DISABLED UNITS

Type of Staff Needed

Various authors agree that in order to meet the objective of rehabilitating patients to their highest possible level of functioning, various disciplines need to be represented in the care team of long-term care facilities serving younger disabled patients.

According to Reinecke (1979), ideally these should include:

- rehabilitation nursing
- medical services
- pharmacological services
- dentistry
- podiatry
- physical and occupational therapy
- speech therapy
- medical social services
- at least consultant psychiatry, psychology and dietary specialists.

Wilson (1978) feels that physiotherapy and occupational therapy services are especially key in keeping patients mentally alert and stimulated.

Staff-to-Patient Ratio

Wilson (1978) recommends a nursing ratio of 1:1 per 24 hour period, with a fully qualified sister and staff nurse heading the nursing team.

In terms of other staff, he feels that requirements for a 22-bed unit should include:

- a part-time physiotherapist and a part-time helper
- a part-time occupational therapist with a full-time helper
- 1 full-time and 4 part-time domestic personnel

- the services of a speech therapist (time commitment unspecified)
- the services of a hospital-based social worker who can liaise with local authority social services and the local housing department on behalf of patients who are to be discharged from the unit (time commitment unspecified).

Currey, Barton and Dansie (1987) report that the 26-bed Danesbury YDU (20 beds for long-stay patients and 6 for planned short stays) is administered by a consultant in rheumatology and rehabilitation. A local general practitioner provides day-to-day medical services. Other staff include:

- 8 FTE trained nurses and 15 nursing auxiliaries
- 2 part-time physiotherapists (15 hours weekly)
- 1 occupational therapist
- 1 part-time social worker.

Miller and Gwynne (1972) report care staff/patient ratios ranging from 1:1.2 to 1:3.9 in the five institutions they studied.

Volunteers

Foxley-Norris (1978) underscores the importance of having young volunteers associated with a YDU. The young volunteer, he feels, is often a more acceptable attendant than an older person, who may be viewed as a parent-substitute.

...The young chronic sick want the company of someone with whom they can share contemporary tastes and interests, in music, humour, hobbies, education and so on; someone in front of whom they can swear or weep freely and without shame; someone who does not obviously represent the authority they instinctively represent. (p. 453).

Selection and Training of Staff and Volunteers

There is little mention in the literature as to what constitutes appropriate training and selection criteria for staff working with younger chronically ill adults. The few recommendations that are made are rather non-specific. For example, Miller and Gwynne (1972) recommend that administrators attend group relations training conferences and that courses be developed that will help them "to tease out the nature and implications of their task and find more effective ways of carrying it out". (p. 216).

VIII THERAPEUTIC PROGRAMS

General Recommendations

- Provide therapeutic services and modalities that meet the physical, psychological, emotional, spiritual and social needs of the residents (Reinecke, 1979).
- Treat the whole person, taking into account his family, the environment from which he came and his past history (Reinecke, 1979).
- Help the resident to do as much as he can, as well as he can, for as long as he can (Miller and Gwynne, 1972; Reinecke, 1979).
- Involve residents in program planning and decision making (Miller and Gwynne, 1972; Wilson, 1978; Reinecke, 1979).
- Involve the family where appropriate (Reinecke, 1979; Wilson, 1978).
- Foster continuation or the establishment of social contacts in the community (Lazaruk, 1987).
- Foster participation in leisure activities both inside and outside the care facility (Reinecke, 1979).
- Maximize physical mobility (Nichols, 1978).

As regards the latter two recommendations, an article in the American Health Care Association Journal (Anonymous, 1974) notes that among those under age 65 about half participate in activities outside the nursing home compared with only about a third of those aged 65 and over.

Nichols (1978) notes that loss of mobility is a major feature of and a key issue in management of physical handicaps. As Sharp (1974), whom he cites, points out:

...for the severely disabled even quite a little mobility can make all the difference between independence and dependence...Independence of mobility gives even the most severely disabled a choice of view, of conversation, and indeed a minor movement can be used as a gesture.

Recommendations Concerning Recreational/Leisure Programs

Both Reinecke (1979) and Wilson (1978) feel strongly that care and rehabilitation of patients is not enough and that recreational programming must be provided. Both feel residents should have input into the type of programs offered. Wilson (1978), in fact, recommends that a patient committee be established which, with the help of staff, has responsibility for planning and organizing outings and parties.

Reinecke (1979) emphasizes the importance of fostering participation in leisure activities both inside and outside the care facility. He also recommends providing special assistance devices, if necessary, so that residents can participate in activities they particularly enjoyed before being disabled.

Recommendations Concerning Counselling

A number of different types of counselling are felt to be needed by younger adult long-term care patients. These include occupational and educational counselling (Reinecke, 1979),

sexual, marital and family counselling (Gutman et al, 1982), as well as counselling focussed on assisting the patient to deal with his/her disability and the limitations it imposes.

a) Educational and occupational counselling

The Ontario Medical Association Committee on Rehabilitation (1980) note that the young physically disabled usually view their situation from the perspective of further personal and social development -- physically, intellectually, vocationally and avocationally. They note further that educational and vocational pursuits have traditionally been accorded relatively low priority in institutional settings.

Reinecke (1979) recommends that when occupational and educational counselling is undertaken, it involve the family and other agencies such as the local Division of Rehabilitation. Both have the potential to assist the patient in determining his/her future objectives as well as to provide enabling financial and other assistance. Reinecke also recommends establishing a facility-based work program in which residents are paid to perform such jobs as telephone operator, typist, secretary or counsellor. In addition to providing a means of earning money, such a program provides the resident, he claims, with an opportunity to develop and test his skills "in a relatively anxiety-free setting".

Miller and Gwynne (1972) note that where group work opportunities are provided, such as in one unit in Britain where patients

perform light assembly work under contract for local industry, the patients themselves need to be heavily involved in securing/organizing the work as well as in deciding on the disposition of the profits. Miller and Gwynne (1972) stress the importance of work and the income it provides in terms of giving patients the opportunity to be givers rather than receivers.

b) Sex counselling

Gutman et al (1982) point out that sexual habilitation is as crucial to the younger disabled person as other aspects of physical and psychological habilitation or rehabilitation. Counselling may be needed to assist the patient in expressing his/her sexuality. In addition, the need for and provision of birth control information should be considered.

c) Marital and Family Counselling

Younger persons who were married or cohabiting prior to entering institutional care may be in need of marital or related counselling. As Gutman et al (1982) note, sudden disability may significantly alter family relationships and assistance may be required to help spouses and children come to terms with the different physical appearance or mental status of the newly disabled patient. There may also be a need to assist the spouse in dealing with the parents of the disabled individual. Gutman et al (1982) illustrate these needs with the example of the wife of an accident victim, now working to support two small children, who was contemplating divorce. The proposal of divorce did not

seem to adversely affect her disabled husband but it did disturb his parents, who were putting great pressure on the woman to remain married. The man's children, on the other hand, were not only distressed by the possibility of the marriage break-up, but were actually frightened by the changed appearance of their father.

Marital or family counselling may also be needed by persons with progressive degenerative diseases. As noted earlier, patients refer to multiple sclerosis, a common diagnosis of younger adults in YDU's, as "the marriage splitter". According to Nichols (1978), this disease is characterized by a combination of problems which are difficult for the family to cope with, such as progressive immobility, incontinence, personality change and lack of insight into the problems of the condition.

To gain some perspective on the prevalence of marital problems, it should be noted that among the 20 patients currently at the Danesbury YDU, 50% are divorced or separated (Currey, Barton and Dansie, 1987). While no information is given as to the number of divorces or separations that took place subsequent to admission to the unit, the implication (Wilson, 1979) is that the proportion is considerable.

Gutman et al (1982) also note that family counselling may be required in situations where parents were the care-givers prior to institutionalization of the younger disabled adult. Parents

may feel guilty about "abandoning" their child to an institution. Their child, on the other hand, may view institutionalization as liberating, allowing him or her more independence than previously experienced in the home of overprotective parents. In these and other situations, counselling may moderate the stress and strain between the patient and his/her parents.

d) Counselling aimed at countering resentment and fostering acceptance of disability

Currey, Barton and Dansie (1987) point out that for most young adult patients their first sight of the YDU is when they are admitted for long-term care. At that point they may be angry and resentful at having had their dreams and aspirations cut short. As Foxley-Norris (1978) points out, they may also be bitterly resentful at having to return to the state of dependency on adults, which they have only recently left. Timely and appropriate counselling may assist them in dealing with their resentment and accepting their disability.

VIII DISCUSSION

In contrast to the large amount of information available on the characteristics and needs of geriatric long-term care facility patients, there is a dearth of information about patients under age 65.

Most of what is available comes from descriptive reports of what are termed "Young Chronic Sick Units" or "Young Disabled Units". As Miller and Gwynne (1972) note, these terms are to some extent misnomers.

... 'Chronic sick' is often attacked as misleading, since it tends to imply a requirement for medical and nursing resources rather than, as is often the case, for more straightforward help in getting dressed and going to the lavatory. (p. 57).

"Young" conveys the impression that residents are young adults. In fact, they may not be, since several of the units described in the YDU literature admit persons up to age 64. The Danesbury unit, in fact, reports that two of its current 20 long-stay patients are over age 65. One is described as awaiting assessment for a Social Services home. The other, Currey, Barton and Dansie (1987) report, could go to geriatric ward but they are reluctant to discharge her since she is still benefitting from being in the YDU.

This, of course, raises the whole question of aging in place and what one does with patients who "outgrow" the upper age limit.

Miller and Gwynne (1972) note that only two of the units they visited rigorously pursue a policy of transferring patients to a geriatric unit once they reach the upper age limit. Of the remainder with a specified age limit:

...Four institutions...had no clearly defined policy as to what happens to people when they reached the top of the range or, having previously decided that they should be exported, found the actual process too painful not only for inmates but also for staff. One was therefore building an extension to house those above the age limit, while two others were deferring decisions; the fourth has since capitulated and is now committed to keeping its inmates until death (p. 102).

The trauma of having to transfer to another unit when a patient ages past the upper limit of a YDU and the bureaucratic problems such as transfer could pose are cited by some as an argument against the establishment of such units. On the other hand, some of the same writers recognize the importance of young people having access, in their day-to-day environment, to age peers. Foxley-Norris (1987), for example, states that the Cheshire Homes are careful to avoid placing young people in homes where they will find no contemporaries. In a care-facility housing both geriatric and non-geriatric residents, a key question, of course, is how many young adult contemporaries is the right number. A related question is whether age contemporaries should be grouped or whether it is sufficient that they reside somewhere in the facility. The advantages and disadvantages of age as compared to other types of grouping (e.g. all multiple sclerosis victims in the same ward or wing) also need to be explored.

The implications of retaining patients until death also requires further consideration. As Miller and Gwynne (1972) note, the result of failing to establish and enforce a policy of restricting YDU's to a specific age range is that, over time, the population may change such that the YDU approximates the geriatric facility it was designed to replace.

Additionally, and even more important, we need to ask -- "Do YDU's work? Do they, in fact, provide the younger disabled person with a better quality of life than is possible in the usual care facility environment?" As with Special Care Units for dementia patients, YDU's seem to have been developed without sufficient consideration having been given to evaluating their efficacy. Much remains to be learned about them.

Towards this end, the SFU Gerontology Research Centre, with funding from the Pacific Health Care Society, has recently conducted a series of interviews with a sample of younger adult residents and the staff who care for them in two hospitals in British Columbia, one hospital specialized in care of the age group and the other having a higher than average proportion of younger adult residents. Preliminary examination of the data indicates that both groups of respondents perceive far more advantages than disadvantages of YDUs. The data also appear to contain a number of design and programming suggestions that would enhance residents' quality of life. Building on these, the Pacific Health Care Society would be in a position to develop a

higher quality physical and psycho-social environment than is currently available should it proceed with its plan to develop a YDU. Establishment of such a unit would also enable the Society to play a leadership role in Canada in researching and meeting the needs of this up-to-now seemingly neglected patient group.

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