ENVIRONMENTAL DESIGN, STAFFING AND PROGRAMMING NEEDS OF YOUNGER ADULTS IN LONG-TERM CARE FACILITIES: RESIDENTS’ AND STAFF’S PERCEPTIONS

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SIMON FRASER UNIVERSITY
The Gerontology Research Centre
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Environmental Design, Staffing and Programming Needs of Younger Adults in Long-Term Care Facilities: Residents' and Staff's Perceptions

Report of a Study conducted for the Pacific Health Care Society by

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Thanks also go to Annie Ciok who assisted with data processing and to Mary Cooper, Gerontology Research Centre Administrative Assistant/Secretary, who handled the computer analysis and typed and provided valuable input into the questionnaires and manuscript.

Finally, we wish to acknowledge the financial support and encouragement of the Pacific Health Care Society for whom the study and the literature review that preceded it (Gutman, 1989) were conducted.

We trust the information gathered will prove useful to the Society in evaluating the need for and feasibility of expanding its services to include a special unit for younger adults (i.e. persons aged 20-64) requiring extended care as well as in understanding this client group’s environmental design, programming and staffing needs.

We hope the information will also prove useful to other facilities providing long-term care to younger adults.
While small in comparison to the geriatric long-term care facility population, younger adults constitute an important sub-group, whose special needs and interests must be recognized and met.

Gloria M. Gutman
Judy Killam

November, 1989
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<th>Page</th>
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</thead>
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<tr>
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<td>Age Distribution of Total Inpatient Population at Hospital A (May 1989)</td>
<td>3</td>
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<td>4</td>
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<td>5</td>
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1. INTRODUCTION

1.1 Background and Rationale for the Study

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 type of care. In British Columbia as of the quarter ending September 30, 1989, there were 7799 individuals in Extended Care hospital beds. As shown in Table 1, 41 (0.5%) were under age 20 and 847 (10.9%) were between the ages of 20-64.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-19</td>
<td>41</td>
<td>0.5</td>
</tr>
<tr>
<td>20-44</td>
<td>272</td>
<td>3.5</td>
</tr>
<tr>
<td>45-54</td>
<td>196</td>
<td>2.5</td>
</tr>
<tr>
<td>55-64</td>
<td>379</td>
<td>4.9</td>
</tr>
<tr>
<td>65-69</td>
<td>371</td>
<td>4.8</td>
</tr>
<tr>
<td>70-74</td>
<td>589</td>
<td>7.6</td>
</tr>
<tr>
<td>75-79</td>
<td>1003</td>
<td>12.9</td>
</tr>
<tr>
<td>80-84</td>
<td>1357</td>
<td>17.4</td>
</tr>
<tr>
<td>85-89</td>
<td>1536</td>
<td>19.7</td>
</tr>
<tr>
<td>90+</td>
<td>2055</td>
<td>26.3</td>
</tr>
<tr>
<td></td>
<td>7799</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Source: Extended Care Inpatient Quarterly Report #8, Information Resources, Institutional Management Resources Division, Ministry of Health, Victoria, BC.

How do individuals between the ages of 20-64, who are the focus of this report, feel about living in close proximity to mostly very old (i.e. age 75 or over) persons?

In an attempt to answer this and other questions concerning the characteristics and care needs of the younger adult long-term care facility
population, an extensive search of the literature was undertaken. As indicated in the report (Gutman, 1989) summarizing findings from this search, the bulk of what little data are available concerning this client group derive from units specializing in their care (i.e. so-called Younger Disabled Units).

To ascertain the extent to which findings from these units are generalizable to British Columbia, and to obtain answers to questions concerning environmental design, staffing and programming needs that have not heretofore been addressed in the literature, a study was conducted, in Spring 1989, in two hospitals in BC.

Hospital A specializes in care of younger disabled adults. Hospital B represents the more usual situation in which younger adults constitute a small minority within a mostly geriatric population.

In the study, interviews were carried out with three groups of respondents: with representatives of the Administration of each hospital, with a sample of other staff regularly in contact with younger adult residents, and with a sample of residents themselves.

As indicated in Section 1.3 below, the focus of the interviews was on ascertaining respondents' views concerning separate facilities for younger adults and their opinions about the environmental design, programming and staffing needs of this client group.
1.2 Characteristics of the Participating Hospitals

1.2.1 Hospital A

1.2.1.1 Sex and age distribution of patient population

Hospital A, a 197-bed Extended Care Unit, located in Vancouver BC, was originally opened in 1952 as a T.B. sanitarium. Later, it became specialized in caring for polio victims. In 1975, it opened its first ward specifically for younger adults requiring Extended Care*. Since that time, it has become specialized in the care of the younger adult physically disabled. In May, 1989 when the study was conducted, there were 183 individuals in residence there, 89 males and 94 females. As shown in Table 2, more than two-thirds (67.8%) were aged 45 or older, a not atypical finding (Gutman, 1989) in Young Disabled Units.

Table 2

<table>
<thead>
<tr>
<th>Age Group</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>2</td>
<td>1.1</td>
</tr>
<tr>
<td>25-34</td>
<td>23</td>
<td>12.6</td>
</tr>
<tr>
<td>35-44</td>
<td>34</td>
<td>18.6</td>
</tr>
<tr>
<td>45-54</td>
<td>52</td>
<td>28.4</td>
</tr>
<tr>
<td>55-64</td>
<td>49</td>
<td>26.8</td>
</tr>
<tr>
<td>65+</td>
<td>23</td>
<td>12.6</td>
</tr>
<tr>
<td></td>
<td>183</td>
<td>100.0</td>
</tr>
</tbody>
</table>

1.2.1.2 Case mix

Table 3 shows the primary diagnosis of the population in residence in Hospital A. As can be seen, the two neuromuscular conditions, multiple sclerosis and cerebral palsy, accounted for nearly half (48.1%) of the disabilities.

* See Appendix I for a description of the classification criteria for admission to Extended Care and the other levels of long term care recognized in British Columbia.
represented. This too, is similar to what is found in most of the Young Disabled Units described in the literature.

<table>
<thead>
<tr>
<th>Table 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Diagnosis of Total Inpatient Population</td>
</tr>
<tr>
<td>At Hospital A (May, 1989)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>N</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>63</td>
</tr>
<tr>
<td>25</td>
</tr>
<tr>
<td>21</td>
</tr>
<tr>
<td>17</td>
</tr>
<tr>
<td>16</td>
</tr>
<tr>
<td>13</td>
</tr>
<tr>
<td>12</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>10</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>183</td>
</tr>
</tbody>
</table>

1.2.2 Hospital B

1.2.2.1 Sex and age distribution of patient population

Hospital B, located in Victoria, BC, consists of two units: a rehabilitation unit and an extended care unit. Both have been in operation since the hospital opened in 1973. Of the 388 beds in the hospital, 100 are for active rehabilitation and 288 are for extended care.

In May 1989, when the study was conducted, there were 283 individuals in extended care at Hospital B. As shown in Table 4, 51 or 21.6% were aged 20-64. Of those in this age category, as in Hospital A, there was an approximately equal sex distribution (32 males and 29 females). Among those aged 65 and over, females predominated (64 males and 158 females).
Table 4
Age Distribution of Total Extended Care Inpatient Population at Hospital B (May 1989)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>2</td>
<td>0.7</td>
</tr>
<tr>
<td>25-34</td>
<td>14</td>
<td>4.9</td>
</tr>
<tr>
<td>35-44</td>
<td>12</td>
<td>4.2</td>
</tr>
<tr>
<td>45-54</td>
<td>13</td>
<td>4.6</td>
</tr>
<tr>
<td>55-64</td>
<td>20</td>
<td>7.1</td>
</tr>
<tr>
<td>65+</td>
<td>222</td>
<td>78.4</td>
</tr>
<tr>
<td></td>
<td>283</td>
<td>100.0</td>
</tr>
</tbody>
</table>

1.2.2.2 Case mix

Table 5 shows the primary diagnosis of individuals in extended care at Hospital B. As one would expect, given the age distribution of its population, a high proportion of the disabilities represented are those more prevalent among elderly persons (e.g. cerebrovascular accident, rheumatoid arthritis, Alzheimer's disease and other dementias, osteoporosis).
Table 5
Primary Diagnosis of Total Extended Care Inpatient Population at Hospital B (May 1989)

<table>
<thead>
<tr>
<th>Condition</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebrovascular accident</td>
<td>33</td>
<td>17.8</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>17</td>
<td>9.2</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>17</td>
<td>9.2</td>
</tr>
<tr>
<td>Parkinson's</td>
<td>16</td>
<td>8.6</td>
</tr>
<tr>
<td>Other neurological conditions</td>
<td>16</td>
<td>8.6</td>
</tr>
<tr>
<td>Alzheimer’s disease/other dementias</td>
<td>16</td>
<td>8.6</td>
</tr>
<tr>
<td>Brain injury</td>
<td>14</td>
<td>7.6</td>
</tr>
<tr>
<td>Cervical spine injury</td>
<td>9</td>
<td>4.9</td>
</tr>
<tr>
<td>Other spine injury</td>
<td>8</td>
<td>4.3</td>
</tr>
<tr>
<td>Diabetes</td>
<td>8</td>
<td>4.3</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>6</td>
<td>3.2</td>
</tr>
<tr>
<td>Fractured hip</td>
<td>6</td>
<td>3.2</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>5</td>
<td>2.7</td>
</tr>
<tr>
<td>Cancer</td>
<td>4</td>
<td>2.2</td>
</tr>
<tr>
<td>Cerebral tumour</td>
<td>2</td>
<td>1.1</td>
</tr>
<tr>
<td>Renal failure</td>
<td>2</td>
<td>1.1</td>
</tr>
<tr>
<td>CHF</td>
<td>2</td>
<td>1.1</td>
</tr>
<tr>
<td>Blind</td>
<td>2</td>
<td>1.1</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>1.1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>185</td>
<td>100.0</td>
</tr>
</tbody>
</table>

1.3 **Outline of the Interviews**

1.3.1 Administrators

The administrators' interview was designed to provide information concerning: the hospitals' admission and discharge criteria and philosophy of care as regards younger adult residents; the most common precipitating factors leading to their admission; the number and type of staff regularly in contact with them; the extent and nature of any special environmental design features and/or special equipment provided to meet their needs, and the programs and activities provided for them and their families and their views on the issue of segregating vs. integrating younger adults with older residents.
1.3.2 Other Staff
The interviews conducted with staff other than the administrators included a series of questions designed to ascertain the extent of their contact with younger adult residents, whether they planned to continue working with this client group, and what special education they had had that prepared them for working with younger adults or would like to have. They were asked to describe the major management problems presented by younger disabled adults. As with the administrators, the major focus of the interview, however, was on ascertaining their views concerning the segregation-integration issue and their experience with, and opinions about, special environmental design features, equipment, and programs that might be of benefit to younger adult residents.

1.3.3 Residents
The purpose of the residents' interview was to ascertain their views concerning the advantages and disadvantages of having separate units for younger disabled adults. Also of key interest was their satisfaction with the physical space, equipment and programs currently available to them and, in particular, how these might be changed or expanded to better meet their needs and interests.

1.4 Organization of This Report
This report describes findings from all three sets of interviews. Data are presented topically. Where applicable, information from the three sets of interviews are presented together and compared and contrasted.
2. METHOD

2.1 Respondents

As indicated in the Introduction, in both hospitals three groups of respondents were interviewed: representatives of the Administrative staff, a sample of other staff regularly in contact with younger adult residents and a sample of residents. The rationale for interviewing all three groups was that it was felt that each would bring a unique perspective that, when considered together, would provide a more comprehensive picture of the needs of younger adult residents than would be provided by any one group alone. Additionally, we were interested in identifying the needs of both residents and staff in the areas of environmental design and education.

In the case of staff other than administrative, each hospital was asked to provide a range of respondents representing nursing and the other professional groups regularly in contact with younger adult residents.

Residents who participated in the study were also recruited by the administration, with the request that those asked to participate reflect the major disabling conditions leading to admission of younger adults to the hospital.

2.1.1 Administrators

The administrators interviewed in Hospital A consisted of the Director and Assistant Director of Nursing and the Director of Activation. In Hospital B, respondents consisted of the Assistant Executive Director of Patient Care and the Clinical Education Coordinator.
2.1.2 Other Staff

As shown in Table 6, of the 15 other staff who participated in the study (eight from Hospital A and seven from Hospital B), five were nurses, nine were other professional staff (Occupational Therapist, Physiotherapist, Social Worker, Therapeutic Recreation Coordinator, Dietician, Chaplain) while one was a care aide (Health Care Worker II).

<table>
<thead>
<tr>
<th></th>
<th>Hospital A</th>
<th>Hospital B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Recreation Therapist</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Care Aide</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Dietician</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Chaplain</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>8</strong></td>
<td><strong>7</strong></td>
</tr>
</tbody>
</table>

All from Hospital A and five of the seven from Hospital B worked full-time. Both of the two from Hospital B who worked part-time worked four days per week.

All from Hospital A had six or more years of experience in working with younger adult disabled persons. Among respondents from Hospital B, five had worked from three to five years with this client group; the remaining two had six or more years of experience.
2.1.3 Residents

Eight residents from each hospital were interviewed. As shown in Table 7, seven residents from Hospital A and five from Hospital B were female; most were between the ages of 45 and 54.

<table>
<thead>
<tr>
<th></th>
<th>Hospital A (n = 8)</th>
<th>Hospital B (n = 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-34</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>35-44</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>45-54</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>55-64</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Primary Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Post polio</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Cerebral tumour</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Three from Hospital A had a primary diagnosis of multiple sclerosis, two of post-polio, two of quadriplegia and one of cerebral palsy. Multiple sclerosis (n = 5) was the most common diagnosis among respondents from Hospital B. As shown in Table 8, all were severely disabled.
### Table 8
Functional Abilities of Resident Respondents

<table>
<thead>
<tr>
<th></th>
<th>Hospital A (n=8)</th>
<th>Hospital B (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can walk unaided</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Can walk with aid</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Can use self-propelled wheelchair</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Can use motorized wheelchair</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Can sit unsupported</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Can transfer from chair to bed</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Can feed self</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Can wash self properly</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Can wash hands and face only</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Can comb hair</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Can write</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Can speak clearly</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Can use telephone</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Can read</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Can watch TV</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Is catheterized</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Needs manual removal of faeces</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Is ventilator-dependent</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

As shown in Table 9, five respondents from Hospital A had lived there more than ten years; the modal length of residence among Hospital B respondents was 3-5 years.

### Table 9
Duration of Residence in Hospital

<table>
<thead>
<tr>
<th></th>
<th>Hospital A (n=8)</th>
<th>Hospital B (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>1-2 years</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>3-5 years</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>6-10 years</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>5</td>
<td>1</td>
</tr>
</tbody>
</table>

Seven from Hospital A and six from Hospital B had been residents of other care facilities prior to moving to their present residence.
As shown in Table 10, the most common reason respondents gave for choosing to move to Hospitals A and B was because of the facilities, services and programs available there.

<table>
<thead>
<tr>
<th>Reasons for Choosing Their Current Residence (Multiple response permitted)</th>
<th>Hospital A (n = 8)</th>
<th>Hospital B (n = 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The facilities, services and programs available</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Friends there</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>To be with other younger adults</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Close to family</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Best for own needs</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Heard it was the best</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>It had a vacancy</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Food was better there</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Doctor chose/recommended it</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Foster mother chose it</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

2.2 Procedure

All administrators and other staff interviews were conducted by the junior author, a nurse (B.Sc.N.) and graduate of SFU's Diploma Program in Gerontology. The interviews with residents were conducted by two individuals, one male and one female, trained by the junior author.

The administrators' interviews ranged in duration from one to one and three quarter hours; the interviews with other staff and with residents took from 50 minutes to one and one half hours.
The administrators' and the staff interviews were conducted at the hospital in which they worked, 94% during working hours. Residents were interviewed in their rooms or elsewhere in the hospital, if greater privacy was possible.

3. FINDINGS

3.1 Admission and Discharge Policies

3.1.1 Admission Criteria

Hospital A offers three types of service: an extended care program, a sustained rehabilitation head injury program and a therapeutic day program.

There are six criteria for admission to the extended care program:*

1. Eligible for extended care
2. Able to understand the spoken word and able to communicate needs and wishes expressively
3. Desire to interact with persons in a younger adult social milieu
4. Able to practice acceptable social behaviour
5. Absence of severe psychiatric problems, profound mental retardation or brain damage
6. Able to benefit from an enriched program whereby the maintenance or growth of physical, mental and/or social functioning is maximized (The Hospital, September 1986).

The only criterion for admission to Hospital B's extended care program is that the client has been assessed as at the extended care level.

* See section 3.8.3 for a description of the therapeutic day program. Admission criteria for the Sustained Rehabilitation Head Injury Program are included in Appendix II.
3.1.2 Factors Precipitating Admission

When asked to describe the most common precipitating factors leading to admission, in descending order of importance, administrators from Hospital A mentioned:

1) increasing physical disability
2) no caregiver available
3) burnout of caregiver
4) marriage breakdown

Administrators at Hospital B mentioned the same factors except they omitted marriage breakdown and added death or illness of caregiver.

3.1.3 Ward Assignment

When asked about the factors considered in choosing the ward a person is assigned to, the administrators at Hospital A replied "suitability; compatibility". They went on to note that "If the person is a management problem, we look at who [i.e. which staff] can handle it best, who has resources, who has fewer similar problems to deal with". While a new admission is placed in whatever bed is available, often patients already in the hospital will be moved when a more appropriate bed becomes available.

At Hospital B, the administrators reported that ward assignments are made on the basis of level of care required, workload involved, special needs (e.g. ventilator dependency, history of wandering and other risk factors), age and sex, behaviour history (e.g. noisy; suitability for roommates) as well as the incoming resident's and his/her family's wishes.
3.1.4 Trial Admission

At Hospital A, if either the Admissions Coordinator or the client has any doubts about the advisability of admission, the client can be admitted on a trial basis, using one of the two beds in the hospital designated for respite and assessment.

Trial admissions also occur at Hospital A in the case of a person who is a behaviour problem. "It allows us to see if the behaviour is manageable in the hospital. If in doubt, the person will be admitted for a six week period on the basis that, if necessary, the facility in which he/she resided previously, will take the client back into their first available bed."

3.1.5 Discharge Criteria

Hospital A strongly encourages residents to return to the community. Where this seems feasible and the move is desired by the resident, a discharge needs assessment is conducted which includes examination of the individual's medical history, social history, ability to perform activities of daily living, nursing, occupational therapy, physical therapy, recreation, social service and medical needs, as well as safety concerns. The administrators at Hospital A stressed, however, that once people are admitted to the extended care program, unless they wish to leave, the Hospital is their home, even after they reach age 65.

Discharge criteria described by the administrators interviewed at Hospital B were as follows:

- where resident and family are able to make plans for adequate care, using support systems
- where resident chooses to move to another Extended Care facility
- where the resident is reassessed as at the Intermediate Care level.

As one would expect, given its age distribution and policy of admitting persons of any adult age, no change occurs when residents at Hospital B reach age 65.

3.2 Segregation vs. Integration

In all three sets of interviews, respondents were asked to describe what they perceived to be the advantages and disadvantages of having separate facilities for younger disabled adults. They were asked to consider the issue from each of three points of view: the needs of residents, the needs of families and the needs of staff. Table 11 presents a summary of findings. These are described in detail in the text that follows.
Table 11
Advantages And Disadvantages Of Separate Facilities
For Younger Disabled Adults

<table>
<thead>
<tr>
<th>Advantages For Residents</th>
<th>As Perceived By</th>
<th>Administrators</th>
<th>Staff</th>
<th>Residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Resident-resident communication/friendship formation easier</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td>- Economies of scale in purchase of supplies, equipment, special design features</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td>- Specialized staff</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td>- Don’t have to mix with elderly</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td>- Sole focus of staff’s attention</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td>- Greater number/variety of age-appropriate activities, services, programs</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td>- Staff more knowledgeable of relevant community-based services and programs</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td>- No danger of old being overstimulated/facility being &quot;taken over&quot; by young</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
<tr>
<td>- More mental stimulation</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disadvantages For Residents</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Mixed-age facilities more &quot;family-like&quot;</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- May need to relocate at age 65</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Young lose opportunity to learn from old</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Old lose opportunity for stimulation/help from young</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Young-only environment may be very competitive</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Residents may be remote from family/home community because YDU’s usually located in large urban centres</td>
<td>***</td>
<td>***</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advantages For Families</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Reassured by presence of specialized staff their relative is getting best possible care</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Can relate more easily to the other residents</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Availability of relevant support groups</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Not faced with old people at low functioning level</td>
<td>***</td>
<td>***</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disadvantages For Families</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Residents may be remote from family/home community</td>
<td>***</td>
<td>***</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advantages for Staff</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Satisfying to work with residents who can communicate/appreciation</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Opportunity to specialize</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Work with preferred age group</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Easier to form friendships/relationships with residents</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Easier to work with only one age group</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- More stimulating disabilities to work with</td>
<td>***</td>
<td>***</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disadvantages for Staff</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>- May become over-involved with residents</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Heavier physical and emotional demands</td>
<td>***</td>
<td>***</td>
</tr>
<tr>
<td>- Less stimulating than a mixed age group</td>
<td>***</td>
<td>***</td>
</tr>
</tbody>
</table>
3.2.1 Advantages and Disadvantages for Residents

3.2.1.1 Administrators' Opinions

In describing advantages for residents, the administrators at Hospital A pointed out that where younger adults are grouped together, they have people in proximity with whom they can communicate and to whom they can relate. They mentioned opportunities for cost savings in purchasing equipment, supplies and furnishings, and in construction of physical space with the point noted that "it's much more expensive to supply small numbers". A further perceived advantage was that staff with specialized knowledge could be attracted. The administrators of Hospital B pointed out that some younger adult residents do not like being mixed with the elderly.

Regarding disadvantages of separate facilities, the administrators at Hospital A felt mixed-age facilities might be more "family-like". The administrators at Hospital B elaborated on this point, suggesting that mixed age facilities offer opportunities for younger adults to form relationships with elderly residents, similar to those of grandparent/grandchild. They observed that many younger adult residents have no family involvement and, therefore, such relationships can be particularly valuable. Another perceived advantage of mixed-age facilities, noted by the administrators at Hospital B, was that when residents, originally admitted as younger adults, reach old age, they do not have to face a potentially disruptive move. They also spoke about residents in mixed-age facilities helping one another, giving the example of a younger adult resident who sits with dying patients, thus relieving family members. It should be noted, however, as the administrators at Hospital B pointed out, that many younger adult residents have little or no hand function and therefore are limited in the ways they can physically assist others.
3.2.1.2 Other staff’s opinions

Among the advantages of segregated facilities perceived by other staff of the two hospitals was an opportunity for enhanced care. This, they felt, occurred as staff developed expertise in caring for the types of complex disabilities often found in this population. In segregated facilities, staff are also able to focus on younger adults’ needs without having to deal with conflicting demands placed on them by another population. Another frequently perceived advantage was the occurrence of bonding among residents arising from their common struggles to overcome their disabilities. Staff also mentioned the opportunities available in segregated facilities for residents to support and learn from one another and to build a "community of age peers". The most frequently cited advantage, however, related to how larger numbers and common interests enhance a hospital’s ability to provide activities, services and training relevant to younger adults, in particular, computer access and training, and pre-vocational training. With a sufficient population in a given age range, appropriate social and recreational programming can also be planned, with enough variety offered to permit choice. Further, as one respondent from Hospital B observed, in a segregated facility staff tend to be more familiar with the full range of resources (educational, recreational and occupational) available in the community for this particular client group and therefore are better equipped to assist residents in getting out of the facility more frequently.

Another major theme emerging from the staff’s discussion of the advantages of age segregation concerned areas of potential incompatibility between the elderly and young. Some saw the high energy level of the younger residents
being too stimulating for their elderly co-residents and feared the frail elderly could suffer from younger residents "taking over the facility" and not having respect for the old. A staff member from Hospital B noted that younger adults tend to be more demanding than the old; this, she felt, could result in staff time being taken away from the elderly. Conversely, a respondent from Hospital A feared that older residents could be very frustrating to the young.

Most of the disadvantages of age segregation mentioned by staff related to the loss of potential interpersonal benefits. For example, one staff member from Hospital A observed that age-integrated environments are more family-like; another that they offer more opportunity for socialization. Three respondents from Facility B commented that the young can learn from older residents. Conversely, one respondent noted that older people "keep young by virtue of being around the young"; another said the elderly may feel needed when there are younger residents around. Another respondent from Hospital B expressed the opinion that mixed ages provide "more satisfaction and stimulation of growth". In her experience when only young adults are together, they tend to get "too busy and competitive". Some younger residents, she stated, after mixing for a while with their own age group, like to come back to their own ward and its older people, where they feel less competitive threat.

A further disadvantage of age segregation, noted by one staff member from Hospital A, is that younger adult facilities are usually located in large urban centres necessitating some residents moving away from their family and home community.
A final point to be noted is that during the discussion of age segregation vs. integration, staff respondents from both facilities offered spontaneous comments regarding age being a less important factor for grouping residents than disability and condition. In elaborating on this theme, one respondent from Hospital A stated that mixing those with widely differing energy levels (often low in those with MS and high in those with brain injuries) causes problems. Four from Hospital B believe that mixing the confused with the alert produces more difficulties than age mixing. One of these respondents also recommended taking psychosocial considerations into account in grouping, giving the example of the head injured often not wanting to associate with young adults who have been institutionalized all their lives. This reluctance, she believes, is partly a reflection of their difficulty in accepting their condition.

3.2.1.3 Residents' Opinions

A number of the residents' views of the advantages for themselves of age-segregated facilities were similar to those of the administrators and staff. For example, one resident from Hospital A reiterated the belief that age segregation facilitates the acquisition of specially trained staff resulting in enhanced care; one from Hospital B suggested it enabled tailoring of services to the needs and interests of younger adults; several from each hospital noted that while they enjoyed talking to other younger people they found it difficult to talk to older people. Additionally, four respondents from Hospital B expressed the view that grouping younger adults together resulted in more mental stimulation, facilitating "sharing of ideas on the same level".
As regards disadvantages, in similarity to staff, five residents (two from Hospital A and three from Hospital B) commented on the loss, in age segregated facilities, of the opportunity to experience the positive aspects of age mixing. Typical comments were "younger adults make the older lively" and "a mix of young and old contribute to each other".

Also as with staff, several residents volunteered the view that there were criteria other than age on which segregation could be based, including mental ability and type or degree of disability. For example, one resident from Hospital B remarked that living with others with the same disability (more likely to occur in an age-segregated facility) could be a source of support. Another resident, from Hospital A, noted that younger adults are not usually in a facility unless their care needs are very great. As a result, there is a lower average level of functioning in a YDU compared with the average extended care facility. This resident believes grouping similarly functioning residents avoids staff bias against the more disabled. He/she also believes that higher functioning individuals may feel uncomfortable being around those functioning at a lower level. On the other hand, this resident recognized that a mixture of disabilities could result in the more able helping those with greater needs.

3.2.2 Advantages and Disadvantages for Families

3.2.2.1 Administrators' opinions

When asked the advantages of age-segregated facilities from the point of view of the relatives of younger adult residents, the administrators from Hospital A observed that families tend to believe their relative gets better care in a specialized facility. In the experience of Hospital B’s administrators,
families do not like having their younger adult relative mixed in with the elderly. They added "families seem to have greater difficulty accepting age mixing than residents do". No disadvantages for family were mentioned by the administrators.

3.2.2.2 Other staff's opinions

When the same questions were posed to the other staff, several stated that most families are not very involved with their relative and, as a result, they had difficulty offering an opinion on how relatives are affected by age segregation. Among those who did give an opinion, two believed families feel reassured by staff expertise, two believed that families are upset by a young relative living with cognitively impaired elderly, while one felt families could relate more easily to other residents the same age as their relative.

Only two staff respondents (both from Hospital B) mentioned any disadvantages of YDU's for families. Both referred to the difficulties created by having the resident away from his/her home community because YDU's tend to be constructed in large urban areas.

3.2.2.3 Residents' opinions

Residents could think of no disadvantages of YDU's for families. Among advantages mentioned were: the "good" environment and "not having to be faced with older people at a low level of functioning".
3.2.3 Advantages and Disadvantages for Staff

3.2.3.1 Administrators' opinions

Hospital A’s administrators reported that staff derive satisfaction from working with residents who can communicate and express appreciation. They also appreciate having the opportunity to develop specific skills. The administrators at Hospital B commented that age segregation enables staff with age preferences to choose an appropriate work environment. Both hospitals' administrators noted the opportunity for staff to form friendships with the residents, many of whom do not have involved families. However, one administrator cautioned that such friendships can lead to over-involvement, with staff experiencing difficulty in separating roles. Other disadvantages for staff noted by this administrator centred on the physical and emotional demands placed on staff by younger adult residents, which are often heavier than in regular extended care units. For example, more lifting is required and feeding is more difficult as many residents are prone to choking. She also noted that "young, motivated, alert residents can be very negative, critical and cynical. They're observant and see everything and are not afraid to speak up." For these reasons, she felt staff may experience burnout.

3.2.3.2 Other staff's opinions

A number of what the other staff perceived to be the advantages and disadvantages of working in an age segregated facility reflected the administrators' comments. For example, the most commonly cited advantage was the opportunity to develop expertise in a specific area and therefore "deal more effectively and efficiently with residents." Staff also mentioned appreciating the opportunity to work with the age group they enjoy most. They
also noted that program planning and staff development was easier where one could "focus on one age group and not have to balance divergent interests".

When it came to disadvantages, respondents echoed the administrators' comments about the work being physically heavy and younger adult patients being "demanding and fussy". Families being very demanding of staff and a possible lack of stimulation from working with only one age group were also mentioned. Two staff from Hospital A also remarked that age segregation or integration is not important because staff tend to adjust to where they are and to develop the requisite skills. One gave as an example the way staff have adapted to the aging of Hospital A's population. One respondent also commented on the danger of closing one's mind to alternatives and thinking that hospitals are the only way to care for residents.

3.2.3.3 Resident's opinions
Residents saw separate facilities for younger people as enabling staff to communicate with residents "at a meaningful level", develop expertise and be challenged by the variety of disabilities presented. One resident noted, however, that the level of care demanded is higher than for most elderly and that staff burnout could be a problem.

3.3 Recommended Room Type, Ward and Unit Size
The first of a series of questions dealing with environmental design issues concerned what respondents considered the ideal room type for younger adults. The ideal ward size and the ideal unit size were also discussed
3.3.1 Room Type

At Hospital A, residents in the extended care program are distributed among five wards, one respiratory and four general. Each of the general wards accommodates approximately 40 people, in eight private rooms; six two-bed rooms and five four-bed rooms. The respiratory ward is an open ward with a small number of private rooms attached. Wards are larger at Hospital B, accommodating approximately 75 persons. There are four in total, one on each of the four floors of the building. Each consists of eight private rooms, six double rooms and 14-17 three- or four-bed rooms.

When asked "Ideally, how many residents should there be per room in a hospital for younger disabled adults?", the response given by the administrators at Hospital A was "one per room". When asked the basis for their answer, reasons given included:

- they need privacy when getting care
- to permit private conversations between the resident and staff or between the resident and his/her family
- all have different preferences e.g. for music, TV programs, room temperature, bed-time
- should have privacy for BM routines
- need lots of space for their clothes and other belongings
- need space around the beds so wheelchairs can be easily manoeuvred

The administrators at Hospital B felt that higher functioning younger adults with families should be accommodated in private rooms. Those with few family and/or friends were thought to need/prefer two or more per room.

Among the eight other staff from Hospital A who participated in the study, only one recommended only single rooms. Of the others, one recommended only double rooms; three recommended both single and double rooms; one recommended
single and four-bed rooms; one recommended the existing combination of some singles, some doubles and some four-bed rooms; while one recommended an open-ward arrangement.

Those recommending at least some single rooms did so because they felt:

- some residents prefer to be alone/would like more privacy
- residents would have more room for their things. "Some have a large number of belongings e.g. computers; typewriters".
- so they could watch/listen to tapes, radio, TV shows they prefer
- so they can make their room more home-like
- as a means of reducing friction. "Often little things can get on each others' nerves e.g. ringing call bell too often; which TV channel to watch; who gets care first; if one gets more care than the other."

Double rooms were recommended "because some people like company".

Where four-bed rooms were recommended, it was because they were thought to make nursing easier and/or to provide company for the severely disabled for some of whom their roommates may provide their only social interaction.

The staff member who recommended an open ward works mainly with post-polio patients and high level quadriplegics who are respirator dependent. In this individual's opinion, such patients feel safer in an open ward where they can be seen by and can see staff. An open ward was also felt to be more efficient for staff who often have to move quickly between patients when there is a problem with a respirator; a patient needs suction, etc. As evidence in support of this recommendation, it was noted that currently a single room was available on the respiratory ward and none of the residents there seemed to want it.
At Hospital B, as at Hospital A, the most common response given by the other staff respondents (three people) was "single rooms plus a few doubles". Of the remaining four respondents, one said "singles only", two said "a mixture of 1, 2 and 4 bed-rooms" and one gave no response.

The reasons given for recommending more single rooms generally echoed those given at Hospital A (i.e. "privacy"; "space for one's things around them -- makes it more home-like"; "have privacy while getting care"; privacy for personal hygiene/family visits"; "avoid being bothered by roommate's noise"). Additionally, two respondents at Hospital B noted that some younger adult residents are married and that, if relationships are to be maintained, privacy was needed. One respondent also stated "it's particularly important that cognitively intact people have privacy".

Reasons for recommending double rooms were similar to those given at Hospital A (i.e. "some want company"). One respondent cautioned, however, that there is more chance of personality conflict in a double room than in a three- or four-bed room. This argument is countered, however, by the point made by another respondent, that it is hard to find three or four compatible people to share a room.

Table 12 shows residents' responses to the question "How do you feel about the number of persons living in your room: is it the right number, too many or too few?" Responses are cross-tabulated by the type of room they currently occupy. As can be seen, except in the case of single rooms, responses were
mixed, with some respondents feeling the number in their room was the right number and others feeling there were too many in their room.

Table 12
Feeling About Number in their Room by Type of Room Currently Occupying

<table>
<thead>
<tr>
<th>Type of Room Currently Occupying</th>
<th>Single (n=2)</th>
<th>Double (n=5)</th>
<th>4-bed (n=7)</th>
<th>18-bed (n=2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right number</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Too many</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>

Among those feeling there were too many in their room, the following comments were volunteered:

* by persons in two-bed rooms
  - too crowded, especially when hoist is in the room to lift people out of bed
  - would like single room but I can't afford it

* by persons in four-bed rooms
  - although I get along with my roommates, room (and closets) are too small
  - no privacy, too noisy, too crowded. Room often has four staff as well as four residents in it, along with a hoist

* by person in 18-bed room
  - too crowded

It should also be noted that one person in a four-bed room, even though saying it had the right number of residents, said he/she would prefer a semi-private room but couldn't afford it. Another, in a four-bed room, said there was enough space but barely. A third, in a two-bed room, said it was good to have company but four in a room is too many. On the other hand, one occupant of a four-bed room noted that it allows for company and diversity of individuals and that staff or visiting relatives provide company for all.
3.3.2 Ward Size

When asked how many persons there should be on a ward, the range given by the administrators at Hospital A was from 24 to 30. The administrators added "We're looking at the smallest number feasible which would still be approved for one nurse per unit." Numbers this size not only would reduce the current staff workload but also, they felt, would create a more home-like environment.

For the administrators at Hospital B, 35-40 was considered the ideal ward size because on a 75-bed ward:

- it takes longer/is hard for the head nurse to get to know all the residents and their families and relate to them
- a person can see themselves as part of a group of 35 but not of 75.

Of the six other staff from Hospital A responding to this question, two said from 30-40; two said from 20-25 while two said from 8-12.

One justification staff gave for an upper limit of 40 was that 40 was considered the maximum number of residents manageable. This size was also considered:

...large enough so nearly everyone can find someone to be compatible with. Residents can visit other wards but for many there seems to be a psychological barrier to this. In fact, they rarely go off the ward.

One of the staff recommending between 20 and 25 said this number was most effective from the point of view of programming. One of the two staff recommending a grouping of from 8-12 said that in groups of this size "residents know all the group but still have some choice of who to socialize
with". The other staff member felt it was about the size of a large extended family and therefore was more "normal". She felt it also provided a good therapist-client ratio.

The ideal ward size was larger at Hospital B. One respondent said "75" because the current arrangement at Hospital B "worked well"; two felt 30 should be the maximum. Another respondent would not give a number but said the size should be large enough to provide some choice of who to become friends with. "This would not be so important", she added, "if they got out of the facility more to meet other people".

Table 13 shows residents' feelings about the number of people living in their ward cross-tabulated by their ward size. Interestingly, although there are more per ward at Hospital B, there were fewer respondents from Hospital B than Hospital A who felt their ward was too large.

<table>
<thead>
<tr>
<th>Size of Ward Currently Occupying</th>
<th>Hospital A</th>
<th>Hospital B</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24 (n=2)</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>30-50 (n=6)</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>62-75 (n=8)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Among those feeling their ward was too large, comments were as follows:

* Hospital A
  - too crowded for staff and residents
  - the space was built for walking people, not those using wheelchairs
  - crowded, especially in the bedrooms
* Hospital B
- 95% geriatrics - not enough young people
- too many residents for staffing levels
- residents all at different levels with different disabilities; creates confusion in dining room and all over when noise level is high

3.3.3 Unit Size
When asked the total number that should be accommodated in any one hospital, the administrators at Hospital A replied 150. This large a number, they felt, would allow the hospital to attract good staff and to purchase needed services and equipment at reasonable cost.

No specific size was given in response to the question at Hospital B. Rather, the administrators noted that "the milieu for interaction is the floor not the whole facility." They also pointed out that in estimating size, one needs to consider providing sufficient beds to ensure adequate medical care and to support the cost of the physical plant, equipment and staff.

3.4 Special Design Features
In all three sets of interviews, two types of special design features were enquired about: those that compensated for residents' physical disabilities and those that took special account of residents' age.

3.4.1 Design Features That Compensate For Physical Disabilities
In the administrators' interviews, respondents were asked to describe any special design features their hospital currently had that compensated for residents' physical disabilities and to comment on how effective these were.

In the staff interviews, the topic was approached as follows:
Some facilities have special design features, such as sound-activated doors, that compensate for patients' physical disabilities. Please tell me about any such design features you've seen used and for each, whether you'd recommend it to others and why.

In the residents' interview, the instructions were to describe any design features they'd had experience with or heard about and whether they'd recommend them and why.

3.4.1.1 The administrators' responses

The administrators from Hospital B stated that their hospital had no special design features to compensate for residents' physical disabilities. The administrators from Hospital A mentioned the following:

- automatic front doors - which they would like to have to residents' rooms as well
- large open areas which are used for parties, Pub nights, etc.
- homey, non-institutional colour scheme
- a family visiting area with a fridge, etc.
- wheelchair accessible toilets which are located off corridors but which, they felt, should be off the residents' rooms
- curtains instead of doors to the lavatories for easy access by persons in wheelchairs. However, it was noted that these decrease privacy
- bumper rails to decrease damage to the walls by electric wheelchairs
- railings along corridors and ramps which, they noted, residents who can't wheel themselves use to pull themselves along
- a variety of lifting devices
- high and low bathtubs and wheelchair showers

In terms of environmental design features that could be improved, noting that most residents have both a manual and an electric wheelchair, the administrators at Hospital A mentioned a need for more space for storing wheelchairs and for recharging electric ones; also, for storing residents' off-season clothes. Additionally, they felt a pool with a wheelchair
accessible ramp and water immersible chairs would be better than the current one, which is equipped only with lifts.

They also recommended expansion of dining areas to include one per ward (40 people), about the size of two four-bed rooms. Even though only about half the residents eat in the dining room, they felt the current dining areas was too small, noting that wheelchairs bump and that there are a lot of spills with this population -- both creating safety hazards and many problems. Further, they'd like to have room to be able to include families at mealtimes. In speaking about meal service, they also noted that currently trays are delivered, sometimes with spillage in the corridors. They'd like to try the idea of meals being served right in the dining room which they felt would be safer and more homelike.

Finally, they mentioned that hospitals for younger disabled adults should be built as theirs was, all on one level with access to outdoor patios or at least with all patient areas at ground level; services, administrative offices, etc. could be located on higher floors with elevator access.

3.4.1.2 Other staff

Like the administrators, a number of the staff from Hospital A recommended automatic doors, open areas for parties, the need for larger dining areas and single level construction which allowed easy access to the outdoors. Also recommended by staff, from one or both hospitals, were:

- wide hallways
- a room in which residents could make tea, coffee
- elevators manageable from a wheelchair
- "built in" shelves for residents' stereo, TV, computer
- more room in bedrooms
- wheelchair accessible sinks so residents who are able to, can wash their hands, face
- wheelchair accessible kitchen so residents can do some meal preparation
- wheelchair accessible laundry equipment and supplies - some could do their own laundry

The need for more space in the bedrooms and for more wheelchair accessible fixtures and equipment is underscored by the following comments:

..When they come here some residents can no longer do for themselves things they want to do because of lack of room e.g. can’t access sink with wheelchair; can’t dress selves because no room to manoeuvre wheelchair [Hospital A]

..We should be optimizing independence. Often the current setup and physical space doesn’t permit this e.g. non-accessible sinks; bathrooms. Therefore ADL training can’t be carried out. [Hospital B]

3.4.1.3 Residents

Virtually all of the residents found automatic doors to be helpful. Several recommended better design of elevators (bigger; doors that open front and back and/or stay open longer; buttons lower, larger, or on a cable that could be brought towards the resident). Other design recommendations included lever-type tap handles, windows that can be adjusted more easily and sound activated doors.

3.4.2 Design Features That Take Into Account The Residents’ Age

3.4.2.1 Administrators

In the administrators’ interview, respondents were asked whether their hospital’s design took into account the age of their residents such as by having extra soundproofing of residents’ rooms/lounges to allow for loud music, or having rooms for conjugal visits.
Staff and residents were asked if there were any such design features they knew about or would recommend.

The only response given by the administrators at Hospital A was that their hospital had big canteens and a social centre (i.e. a large area where residents could get together, for example for Pub nights or in which live entertainment could be presented).

The administrators at Hospital B responded to the question by reiterating that their hospital had a mixed age population and by noting that there were no rooms available for conjugal visits. They added that generally, there was insufficient space for privacy and for residents to have their own territory.

3.4.2.2 Other staff
The need for more personal privacy and for conjugal visiting space was reiterated by the staff of both hospitals. For the latter purpose, one respondent suggested a self-contained suite with kitchen, lounge and bedroom. Such space would also be useful for residents with children as it is difficult, for example, for a teenage son to maintain a relationship with his father when they cannot speak privately; young children may find the general hospital atmosphere distressing. As one respondent noted:

..There is not much here [Hospital A] in the way of physical design for the young. We’re working within the constraints of a building designed for another purpose.

On a similar note, one staff member recommended a music room - exclusively for the purpose of enabling young adults to play loud music if they wished.
As will be evident from reading the next section, such a room should be given serious consideration in constructing new YDU's.

3.4.2.3 Residents

More than half (56%) of the residents recommended one or more soundproofed rooms for people who like loud music. Some recommended it because they recognized loud music may be disturbing to other residents; one because "why should disabled young have to behave differently from non-disabled young?"

The second most frequently mentioned special feature (4 respondents) was a room for conjugal visits. Also mentioned by residents of Hospital B was the need for a social lounge and a computer room.

3.5 Architectural/Administrative Barriers

In the section of the interview dealing with environmental design, residents were asked whether there were any architectural or administrative barriers that prevented them from (a) getting around inside the hospital or in accessing the grounds around it and (b) getting around in the neighbourhood. No administrative barriers were mentioned in response to either question. Architectural barriers were as follows:

3.5.1 In Buildings or Grounds

The administration area at Hospital A is not wheelchair accessible. Residents from Hospital A also commented on the grounds - one stating that they were too rough for her to push herself on; another saying that more paved walkways were needed.
At Hospital B, residents mentioned that the elevator was limiting, one commenting that the buttons were not accessible to his/her particular disability. Another resident found the doors at Hospital B limiting. A third found the length of the halls to get to various areas too great for him/her to travel comfortably.

Common to both hospitals were complaints about inclined ramps which, the residents pointed out, created a barrier to manually operated wheelchair users.

When asked if there was anything else about the physical aspects of the hospital they'd like to comment on, several other barriers were noted. These included, at Hospital A, that windows and paper towel dispensers were too high for the wheelchair bound and, at Hospital B, that ashtrays were not high enough, that access to the refrigerator was not convenient, and that larger rooms with "proper" height tables were needed for activities.

3.5.2 In Neighbourhood

As regards accessibility of the neighbourhood, comments of the residents of the two hospitals were similar. These centered around curbs and sidewalks. Curbs, even those modified for wheelchairs, were found to be too steep. Sidewalks were not level or smooth enough for wheelchair users.
3.6 **Locational Considerations**

3.6.1 **Satisfaction with Location of Hospital**

Hospital A is located in a residential area on the west side of the city of Vancouver and is easily accessible by public transportation. Some shops and services are located on the ground floor of the apartment complex across the street; a major shopping centre is approximately ten blocks away. Hospital B is located in a residential area of Victoria, close to the downtown centre. When asked how they felt about the location of their hospital within the city and whether it met their needs, six of the eight residents from Hospital A and seven of the eight from Hospital B responded favourably.

3.6.2 **Recommended Location for a YDU**

When asked "If you were advising an architect, what type of neighbourhood would you recommend for locating a new hospital for younger adults?", the most common response was that it be in a residential area, close to movies, shopping, coffee shops, etc. Several residents also commented that it should have good access to public transportation, be reasonably quiet (not too close to a school or heavy traffic) and that the site should be flat. Two residents from Hospital B added that it should be close to where young people live and/or where there were social activities for young adults.

3.7 **Special Equipment**

In all three sets of interviews respondents were asked about special equipment in the hospital or that they'd had experience with or heard about.
3.7.1 Administrators

The administrators at Hospital A, indicated the following items were available to residents:

- talking books and large print books in the library. They felt, however, that these should be available in the lounges not in a physically separate room
- electric wheelchairs and computer systems which operate the lights, TV, telephone, etc. These, they noted are, however, very expensive (an electrical wheelchair costs about $14,000; communication devices about $12,000)
- a Technology Independence Centre in which residents can type messages, letters, etc., which has Technology Access programs and where a speech pathologist and occupational therapist assess an individual’s problems with communication and mobility and help the resident to maximize what he/she can do independently.

Hospital B’s administrators mentioned only two items: computerized environmental control devices and computers for communication and education. They noted that one of their occupational therapists specialized in assisting residents with these.

In terms of equipment that was needed, only one item was mentioned by the administrators. Those from Hospital A recommended bigger bedside tables or alternatively, two of the existing size, one for use by staff and one for use by the resident.

3.7.2 Other staff

The staff recommended a variety of special equipment including:

- tongue operated systems; "sip and puff" switches; computers with large keyboards to communicate/control the environment
- specially adapted electric wheelchairs
- portable suction equipment and more compact, reliable ventilators that allow people to get around and out
- mechanical hoists -- which one respondent noted are used mostly by female staff. "Most male staff", he stated, "prefer two or three man lifts; most patients feel more secure when lifted by several staff they know rather than by a hoist."
Hoists are good for less experienced staff and will also be used more as regular staff get older."
- accessible, barrier-free telephones e.g. head phone; large number pads; no coins to deal with
- such low-tech devices as large faced cards, card holders, reading stands, page turners, tables of adjustable height. "Now, much of eating/activities is done on individual wheelchair trays. Sharing tables might promote interaction."

Several respondents noted that it is essential to have technical support staff available to keep equipment in order and/or adapt it to users' special needs. "There is a tendency not to recognize the need for a specialist in this area. It is a separate field from rehabilitation." One respondent [from Hospital A] noted that some residents find it hard to accept technology and need education and support before they can/will use it. Another respondent said that nursing staff sometimes need educating about equipment. "They don't always understand what is available. Often, they opt for the least expensive alternative without understanding the advantages of the more expensive model." As an example, he/she mentioned commodes that could enable quadriplegics to do bowel self-care.

3.7.3 Residents
Besides experience with electric wheelchairs and remote controls for TV, some residents had experience with:
- specially adapted grooming aids (hairbrush, toothbrush, etc.)
- Kinsman Environmental Control equipment to turn on radio, light, answer phone
- computer with special adaptation for the disabled (e.g. computer key guard)
- speaker phone

Devices some had heard of but not tried included:
- self-feeding aids ("dish that stays still", support for wrist to hold spoon, leak-proof cup)
- talking books
- electric wheelchair with control to open and close door
- wrist computer for non-verbal communication
- breath controlled wheelchairs

3.8 Programming
3.8.1 For Residents
3.8.1.1 Programs offered

In exploring the area of programming, the interviewer began by asking what types of recreational programs or activities the hospital offered for younger disabled residents. The responses of the administrators and/or the Recreation Coordinator are shown in Table 14.

<table>
<thead>
<tr>
<th>Recreational Programs Available at Hospitals A and B</th>
<th>Hospital A</th>
<th>Hospital B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arts and crafts</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Cards and games</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Exercise</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Makeup and manicure</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Monthly gourmet dinners</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Movie club</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Music</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Outings</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Pet visitors</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Photography club</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Plant therapy/gardening program</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Pub night/special meals</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Residential pets</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Swimming</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Volunteer visitors</td>
<td>Yes</td>
<td></td>
</tr>
</tbody>
</table>

3.8.1.2 Goals and planning considerations

When asked what factors are taken into consideration in planning/delivering programs, the following answers were given by staff:
- functional level/disability type (3)*
- emotional state/psychosocial needs (2)
- interests (2)
- resources/finances available (2)
- availability of staff (1)
- accessibility of community resources (1)
- group dynamics (1)
- age (1)

The two respondents directly involved in recreation and leisure services expanded on these answers. One described how a resident and the recreation professional, when planning activities, go through a process of joint goal setting, using programming as a form of leisure education in developing attitudes and values. The other outlined how priorities for recreation are set, based on a resident’s needs classification. For example, younger age, lack of family, and lack of interest in other programs, such as pastoral, result in a higher needs classification.

Respondents were also asked how they deal with the various types of disabilities of residents. One reported using adapted equipment such as card holders and large print cards. Another stressed the need to consider each person individually, and one suggested that mental abilities are more relevant than physical abilities. Additionally, one respondent recommended offering bedside programs to some residents, such as MS sufferers, who are very easily fatigued and "too weary to go places once out of bed".

Regarding accommodating individual differences in preferences and interests, the most frequent responses were that residents are actively involved in planning activities and choose what they wish to do. Respondents at each hospital also pointed out that at intake, they do a "recreation assessment" on

* Numbers in brackets indicate number of respondents.
all residents, which includes a series of questions enquiring about their interests.

3.8.1.3 Residents' input

In response to the question "Do residents have a voice in programming?", all staff responded affirmatively. When asked how this is done, respondents from both hospitals indicated residents provide ideas, are involved in program planning and preparation, and choose what they wish to participate in. As an example, at Hospital A, in planning an outing, one resident becomes the "key client". He/she decides where the group will go, when, and who will be invited. He/she invites the other residents and makes arrangements such as phoning for reservations and finding attendants. "The staff member does only what the resident is unable to do, and then usually under his/her direction."

At Hospital A, other input comes from regular Resident Council or Ward Representative meetings and monthly Resident-Management team meetings. Additionally, individual needs assessments, general surveys and program evaluations are conducted. The philosophies of both hospitals are strongly supportive of residents' involvement in program planning. Ideas are encouraged and are utilized whenever feasible.

As further examples of resident involvement at Hospital A, the Residents' Social Centre is managed by a residents' committee and recently, day program clients were involved in hiring a temporary social worker.
3.8.1.4 Residents’ reactions to the programs offered

In the residents’ interviews, respondents were asked which programs and activities offered by the hospital they especially enjoyed or benefitted from and which they did not particularly like. They were asked whether the programs and activities offered took their individual needs, preferences and interests into account, whether there were any programs or activities not currently offered that they would like to see offered and whether they had as much input as they would like into the programming that was offered.

All but one of the sixteen residents said the programs and activities offered at their hospital took their individual needs, preference and interests into account. All but two said they had enough input into the programs that were offered.

Of the various programs and activities offered at Hospital A, the three most frequently mentioned as pleasing were: the arts and crafts program and, in particular, the ceramics program; the computer facilities and associated programs; and the outings program. Outings and card games were clearly the preferred activities at Hospital B.

On the whole, there were few negative comments about programs. At Hospital A, the programs or activities some respondents did not like included Pub nights, which one resident found offensive because of the noise and smoke, and the crafts programs which one resident disliked. Additionally, one resident stated that he/she skips bingo and some movies because their timing is inconvenient. Another said staff used to present entertainment on the ward, which residents had to watch even if they did not want to.
At Hospital B, disliked programs and activities included tea parties, which one resident described as "ridiculous," old time music which one resident found unappealing, and birthday parties which one resident described as "just an excuse to eat cake." One resident explicitly stated the opinion that too many of the activities at Hospital B were centred on the geriatric population.

Suggestions for additional programming that were forthcoming were that:

**Hospital A**
- consideration be given to providing a woodworking shop
- more activities be available on weekends

**Hospital B**
- more social programs be provided
- consideration be given to enabling residents to swim in a cool water pool
- there be more cultural activities
- there be an opportunity for "special dinners", where residents would eat in small groups in the lounge on "real" china and plan their own menu
- more outings take place during the daytime hours rather than as currently, when most are scheduled at night

### 3.8.2 Programming for Families

According to the administrators at Hospital A, residents' families are offered counselling as well as information on how to care for their relative in the hospital or when they are home for a visit. Family involvement with residents is promoted by inviting them to activities (e.g. barbecues, Pub Nights, parties) and to team conferences. They also are involved in discussions concerning a "living will" for the resident.
There is no formal family support group at Hospital B. Rather, families are invited to social events at which the Social Worker makes a concerted effort to ensure they get to know one another on an informal basis. She also reported providing counseling to families at the time of admission and if and when they come to see her "for instrumental things".

When residents were asked whether their family participated in any of the special programs and services available to them, only two from Hospital A and one from Hospital B answered in the affirmative. Two of the three found them useful.

The only comments that were forthcoming to the question "Are there any other services or programs that would be helpful to your family?" were:

- more staff would be useful [Hospital A]
- counseling services [Hospital B]

One resident also volunteered the information that an MS clinic and family support group exist outside the hospital.

3.8.3 Programming For Younger Disabled Adults Living in the Community

Hospital A offers a regular, organized day program for younger physically disabled adults. Clients attend one day a week and are provided with lunch. Available services include:

Nursing - Program staff liaise with referring agency; monitor health status including medications, nursing care and treatments; provide client education, liaise with family physician and refer to health resources

Occupational Therapy - offers information regarding activities of daily living, functional aids and adaptations, energy conservation and compensation techniques; assessment and training in use of
electric mobility aids and positioning aids; a stress management program; individual computer instruction and home visits as required.

**Physiotherapy** - offers exercises to improve strength, coordination and balance; re-education of functional mobility such as transfers and gait; education re: loss of sensation, management of spasticity, home exercise, pain management; pool class; stress management program and assessment for mobility aids.

**Recreation** - offers individual projects, group sessions and guest speakers; leisure education; referral to appropriate community recreation resources.

**Social Services** - offers support, adjustment, crisis and transition counselling to clients and their families; liaises with community agencies, support and education groups; provides resource information, home visits and referrals.

In addition, a therapeutic pool program and/or individual computer instruction is available for those assessed as appropriate for such training. According to printed material provided by the hospital, the goal of the program is to:

- maintain or improve functional abilities
- provide support for clients and their families
- promote responsibility through independent decision-making
- foster social and independence skills

The family physician's consent is necessary for admission to the day program and all applicants are pre-assessed for suitability. In May 1989, when this study was conducted 50 clients were registered in the program.

Hospital B does not have a regular, on-going day program but does occasionally provide an opportunity for individuals to spend time in the facility in preparation for moving into it.

Both hospitals provide respite beds. Hospital A has two which are fully used. A proposal to the Ministry of Health for an additional 8-13 respite and
assessment beds is planned. Hospital B has two respite beds for high quadriplegics and two swing beds. Its' respite beds are also fully used.

3.9 Counselling and Related Services

As indicated in the literature review that preceded this report (Gutman, 1989), a number of different types of counselling are felt to be needed by younger disabled adults requiring long-term care. These include occupational and educational counselling, sexual, marital and family counselling, as well as counselling focussed on assisting the individual to deal with his/her disability and the limitations it imposes.

According to the administrators, at both Hospitals A and B residents and/or their families are offered emotional, marital, family, sexual and educational counselling. Hospital B also provides occupational and financial counselling. Individuals providing the counselling include social workers, nurses and staff of Pastoral Services. Additionally, Hospital A employs a part-time Sexual Health Clinician to assist residents in meeting their sexual needs.

When asked "In what ways besides counselling, are residents assisted in meeting their sexual needs?", the administrators at Hospital A indicated that residents are encouraged to go home for visits if at all possible. Hospital B refers clients to a sexual therapy clinic, if needed. One example of the services provided at the clinic is artificial insemination which enabled one resident to father a child which he subsequently watched being born.

When staff were asked a similar question about giving residents assistance vis-a-vis sexuality, most responded that nothing but counselling is offered,
with several remarking "there are no easy answers." Lack of privacy was identified as a common problem for residents. As an example, one staff member noted "even a visit with the Sexual Health Clinician is noted and commented on by staff and residents". Several staff stated, however, that staff try to respect privacy as much as possible, for example, by knocking before entering a room and asking permission to enter the curtained area around a bed, whether the resident is alone or with visitors. Several also remarked that education of staff and family regarding sexual needs and behaviour would be helpful.

As regards educational needs, the administrators reported that these are addressed by encouraging and facilitating residents' attendance at local educational institutions (most frequently community colleges), making them aware of correspondence courses and, at one of the hospitals, organizing a volunteer tutor's program. The administrators at both hospitals also stressed the value of computer adaptations and training in enabling residents to complete courses and/or to be gainfully employed.

The administrators at both hospitals noted that most residents are too disabled to be employed in regular work settings. As an alternative, they are encouraged to engage in productive activities within the hospital, for example, publishing an in-house newsletter and planning activities. Staff at Hospital A also indicated that some residents are employed in sheltered workshops while others operate small businesses (e.g. selling their pottery). Wherever possible, encouragement and assistance is provided in finding courses and work situations. A number of staff remarked, however, that this was an area in which much more could be done.
When asked "Other than what’s provided here, what types of counselling do you think would benefit residents?", additional needs identified included assertiveness training, in particular, to encourage more independence. Training in social and communication skills was also mentioned.

Respondents also noted a general need for more counselling (all types); for more counselling professionals (e.g. social workers; psychologists) and for more time to be made available to existing staff for counselling purposes.

3.10 Techniques For Assisting Residents To Maintain Contact With The Community

The administrators were asked how residents are helped to establish/maintain contact with people living in the community. Replies included: "encourage/facilitate residents going out into the community" and "plan activities including families (e.g. barbecues)". Staff were more specific, stating they:

- encourage/assist residents with outings (7)
- encourage outside groups to come in/take out residents (most commonly church groups) (6)
- encourage/assist residents to make contacts and arrangements with outside groups e.g. community centres, community colleges (5)
- utilize/encourage volunteers in and out of the facility (5)
- assist with/provide transportation for residents (3)
- try to make visitors feel welcome and part of the team (1)
- work on residents' social skills to facilitate acceptance by community members (1)
3.11 Staffing Patterns and Staff Education Needs

3.11.1 Type of Staff Employed

The administrators of both hospitals noted that, as a result of the emphasis on keeping people at home for as long as possible, the needs of younger adult residents have increased greatly over the years, and most now require "very complex care by the time they come in".

To meet their needs, both hospitals have nearly all the health care professions represented. These include, either on staff or on a consultant basis, RN’s/RPN’s, Care Aides (Health Care Workers), Occupational and Physiotherapists, Recreation Programmers, Social Workers, Dieticians, Speech Therapists and Psychologists. Hospital A also has a Pharmacist on staff and a part-time Sexual Health Clinician; while Hospital B employs therapy aides (occupational and physio). Both hospitals have chaplains on staff (one part-time at Hospital A and three full-time equivalents at Hospital B). While neither has a music therapist on staff, Hospital A utilizes music therapy students. Volunteers are viewed as an essential component of resident care and programming by both hospitals.

3.11.2 Staff’s Perception of the Adequacy of Current Staffing Ratios and Staff Mix

When asked whether, in their opinion, the number and type of staff in the hospital was sufficient for adequate care of residents, three of the eight (37.5%) respondents at Hospital A perceived the number of staff to be sufficient and four (50%) the type of staff. Two qualified their answers, however, stating that numbers were sufficient only if all scheduled staff were on duty i.e. if anyone off sick was replaced. Another said they manage "as
is" but more staff would allow them to spend more time with residents. At Hospital B, none of the staff respondents believed either the number or type of staff to be adequate.

When asked "What additional staff (type and number) are needed?", the most common answer was for more nursing and/or direct care staff (8 respondents).

Reasons given included:

- "usual extended care staffing is not enough because residents are so dependent in ADL's"
- "residents could be given more independence and choice if the staff had more time"
- "needs of residents coming into the hospital are more complex now because people are staying in the community longer and medical science is keeping people alive longer (e.g. advanced ALS patients who are at high risk of choking)"
- "staff are really pushed to get the work done - this decreases job satisfaction"

Examples of specific types of additional staff needed included:

- "LPN’s to relieve RN’s of some duties e.g. catheter changes, some dressings, so that the RN’s have more time to carry out nursing assessments and supervise Health Care Workers"
- "More RN’s on 3 to 11 shift because one per unit can be unsafe"
- "One more Health Care Worker on each of the day and evening shifts or remove non-nursing duties such as filling water jugs and cleaning up spills by having housekeeping staff on duty in the evenings"
- "(More) RPN’s are needed because many emotional and psychosocial needs are not being met. They could help staff by providing teaching and information sharing right on the unit"
- "Nursing specialists or clinicians are needed. Much of the Head Nurse’s time is taken up by administration and there is a need for expert clinicians out on the units dealing with problems as they arise and giving on-the-spot teaching"

One reason for desiring a greater presence of staff other than nursing/care staff during the 3 pm-11 pm shift was because residents have more free time in the evening. One respondent felt they would benefit if Recreation Therapists
were regularly available. Another suggested this would be a good time for counselling and meeting psychosocial needs.

A need for better trained Recreation Therapists was also identified. Currently, only a two-year diploma program is offered in British Columbia and two respondents believe a university degree is necessary to provide adequate preparation and to allow Recreation Therapists to "work with the team as an equal".

Other responses included a perceived need for more:

- OT's and PT's (one respondent believed the need for the former is greater for Younger Adults; another suggested therapist staffing "should be more like Rehabilitation than Extended Care")
- Social Workers to provide for more counselling, community developments and finding funding
- Psychologists
- Technical staff e.g. experts in seating, computer access, communication systems
- Barbers and hairdressers - "Many of the men are very difficult to shave. They can't move their face to help and special skills are needed. A good appearance is important for self esteem."

3.11.3 Inservice Education

Inservice education at Hospital A is directed toward care and management of specific conditions rather than for Younger Adults per se. For example, the physiology of the bowel and bowel regimes in different conditions are taught. Instruction is provided by both hospital personnel and outside experts. Sessions are offered three times a week and repeated two to three times to enable as many staff as possible to attend. Staff also attend presentations given by student nurses at the completion of their training. A nursing instructor is employed by the hospital.
At Hospital B, reflecting the age distribution of the residents, formal inservice education is predominantly oriented toward geriatric care. However, the head nurses and psychiatric nurses provide education in the work situation relevant to specific resident needs. Assistance in the organization of inservice is provided by the Greater Victoria Hospital Society's Clinical Education Coordinator. There is a clinical nurse specialist in geriatrics on staff.

When asked "What type of staff usually attends inservice programs?", the administrators from both hospitals replied that all team members are welcome. They added that staff generally come when a topic is relevant or of interest to them. However, although they are given leave from work to attend, staffing constraints often prevent attendance. At Hospital A, for example, senior nursing, OT’s and PT’s attend about once per week, RN’s about every two weeks and health care workers about once per month.

3.11.4 Staff Training and Educational Needs

When staff were asked what topics they would like information about, some responded regarding their own needs, but most offered opinions regarding the needs of direct care staff. The most frequently suggested topics (6 respondents) related to psychosocial needs - spiritual, vocational, sexual and concerning emotional reactions to disability. Other perceived needs included:

- communication/negotiating/motivating skills or therapeutic approaches (4)
- family dynamics/communicating with family (3)
- facilitating teamwork by sharing information regarding varying disciplines' roles and activities (3)
- stress management (for staff and residents) (3)
- self-awareness/ego strengthening (2)
- promoting residents' independence/control of their life (2)
- information about specific conditions/disease processes (2)
- help accepting and perceiving residents as individuals (2)
- strategies for dealing with residents and their behaviours (1)
- medications and their effects (1)

Two respondents commented on the need to tailor the method of education to the recipient. It was suggested that for non-professional staff, "more relaxed, low profile presentations" by in-house staff are the most effective. An example given was to have a social worker meet over coffee with care aides in the evening after most residents are in bed, to provide them with a specific resident's background.

Although not asked about, three staff suggested that education for residents and/or their families is also needed. Topics proposed included stress management, transition between community and facility (in both directions), assertiveness training, negotiating skills and skills needed now that clients and/or families are given the role of case managers.

3.12 Control and Decision Making

The concept of residents having control over their lives is central to the philosophies and approaches of both hospitals. This was reflected in staff response to the question: "In what areas do you feel younger disabled residents could or should have control?" More than half (53%) answered that they should have choices in all areas/as much choice as possible. Specific areas mentioned included: schedules (e.g. the hours they keep, mealtimes, going and coming from the hospital); planning and choosing recreation activities; planning/choosing education, vocation, or to live in the community; and concerning their own care (including attending/having family
attend care planning meetings). Involvement in resident-management committees and providing input into hospital policy (e.g. regarding alcohol consumption) were other ways mentioned of returning control to residents.

Two staff members noted that along with control goes responsibility. They believed residents should be encouraged to take responsibility for themselves wherever possible. Examples given were arranging their own transportation or for a new battery for their wheelchair. It was also stressed that residents must be listened to. If a suggestion cannot be implemented, the resident must be told why. It was also observed that freedom of choice includes allowing residents to take risks (e.g. choosing a food which could cause them to choke).

That more than just lip service is given to this philosophy is reflected in residents' responses to the following question: "Many facilities feel it is important for residents to maintain, as far as possible, control over their lives. This includes making small and large decisions. How is the situation here for you?"

As indicated below, while not unanimous, a majority of the residents at both hospitals were satisfied with the degree of control they exercise.

**Hospital A**

01) - resident decides when to go out and where to go, what activities to choose

02) - getting out of bed, when to do it should be decided by resident - has to pressure staff at times to get things done - does this by refusing to get out of bed - feels she is bullied by staff

03) - health care worker exercises too much control over residents for the convenience of staff
04) - gets to make his own decisions
05) - enjoys having control over her own life and being independent
06) - feels she has control over life
   - planning to move to community living this fall
   - has worked on jobs outside of hospital
   - enjoys own phone and being able to call when desired
07) - of "sound mind and body" and capable of making own decisions
08) - living in an institution but doesn’t feel like institution
   - able to control her life, does not want to live in community

Hospital B
09) - private room provides control over own environment
   - limited control result of institutional schedules
10) - staff may suggest but resident has ultimate control over decisions
11) - pretty good control
   - has control over activities, courses at college, etc.
   - would like more control over menu choices
   - not enough control over interruptions of other residents - noise
12) - control of personal activities when able
   - more input into type of food served and way it is prepared - would
     probably need more money to change food system and increase
     training of staff
13) - control - is assertive, is head of Residents Council for floor
   - would like to change quality of food and menu choices
14) - is able to be part of major decisions on own behalf
15) - has control of all necessary areas
16) - has control in most areas
   - give younger people more say over matters vs. older people
   - not dictated by nurses and doctor

3.13 Management Problems and Staff Morale

A final portion of the interviews that should be reported on concerns what
staff perceive to be the major management problems posed by younger disabled
adults and the effect these, and the workload such residents present, have on
staff morale.

3.13.1 Major Management Problems

When asked to describe the major management problems they had encountered in
working with younger disabled adults, the following were mentioned:

- manipulative/selfish/demanding behaviour
- verbal/physical aggression
- lack of realistic expectations and life skills (Many have been
  sheltered a long time; they don’t know how to deal with
  other adults.)
- conflict between right to self-determination and diminished judgment
- resistance to providing self-care/taking responsibility for own needs (e.g. phoning for Handi-dart; arranging for batteries for wheelchair)
- depression/residents' difficulty in developing a sense of self-worth or dignity
- specific aspects of physical care (e.g. bowel and bladder management; transfers; maintaining adequate nutrition)

3.13.2 Staff Morale

Despite the above, staff morale appeared to be high with all of the respondents from Hospital A and all but one from Hospital B, indicating that they planned to continue working with younger disabled adults.

Staff also demonstrated a high level of understanding and compassion for the residents. This is illustrated in the following comment made by one individual in describing manipulative behaviour as a management problem.

...They have experienced loss of power and control over their lives; they have little personal autonomy. They must do things the way the institution wants and must wait for everything. Staff must get their work done. They therefore don't always give residents as much attention as they (and staff) would like. Sometimes the result is that residents play 'head games'. This is particularly true of those who are not able to enjoy external things (e.g. recreation). We are trying to allow residents more choice in what they do.

Several respondents also recognized their own difficulty in allowing residents "to be adults", in resisting the temptation to "do for" and in being flexible.

Also telling were staff's responses to a question asking about aspects of the hospital or its programs that were especially pleasing or displeasing to them. The most frequently mentioned pleasing aspects related to the philosophy of the hospitals, in particular the open-mindedness of the administration and the
fact that residents are central and viewed as having rights and responsibilities. Staff from both hospitals also commented on the "family-like" atmosphere of the wards in which staff and residents relate as friends. Other responses included "the excellent recreation therapy" and "the marvelous volunteer corps".

The most frequently mentioned displeasing aspects were the need for more staff and the tendency of some individuals to view institutionalization as "the answer". One respondent commented that extensive staff education was necessary to counteract this attitude. Others commented on the need for staffing at levels sufficient to allow residents the time they required to do things for themselves. Another noted that over time both staff and residents age, care needs and demands change, and both staff and residents need assistance in coping.

4. DISCUSSION

This report has presented findings from a study focused on ascertaining opinions concerning separate facilities for younger adults requiring long-term care, as well as the environmental design, programming and staffing needs of this client group. Respondents consisted of a sample of administrators, other staff and residents from two British Columbia hospitals providing Extended Care. Hospital A specializes in care of younger disabled adults. Hospital B represents the more usual situation in which younger adults are a distinct minority in a predominantly geriatric population.

As indicated in Section 3.2, in general, reactions to separate units for younger disabled adults were favourable. Respondents saw them as having a
number of advantages for residents, for families and for staff. Chief amongst these were the opportunities they present for staff specialization which all three groups of respondents felt would result in enhanced care of residents, provide reassurance to families and provide job satisfaction to staff. Easier and more satisfying resident-resident and resident-staff communication and interaction were also frequently mentioned as advantages. Also very important was the residents' perception that such units would provide them with greater mental stimulation.

It should be noted, however, that several disadvantages were also commonly noted. These included that some residents may be rendered remote from their family and home community as YDU's tend to be located in large urban centres, that the old would be deprived of the stimulation (and sometimes the help) that younger persons provide and, conversely, that the young would be deprived of the benefits of interacting with older persons, some of whom may function as surrogate grandparents.

What the latter argument fails to take into account, however, is that YDU's are not the exclusive purview of the young adult. Rather, a fairly broad age range (20-64+) is represented, within which all of the "family-type" benefits of age-mixing alluded to by respondents should be readily accommodated. In fact, with the change in facility admission policies that we have witnessed in recent years, such that it is only the oldest and most disabled of the old who are being institutionalized, many with severe cognitive impairment (e.g. Alzheimer's and other dementias), there are real questions as to the extent to which these individuals could provide younger adults with the type of relationships people tend to envision when they think about age-mixed
settings. Even if those old with the most severe cognitive impairments or who are most disturbed/disturbing were to be separated into Special Care Units for dementia, questions would still remain given the very advanced age (see Table 1) of most Extended Care residents. Among these questions are: what does the average 80 or 90 year old have in common with young or middle-aged adults? To what extent can the very old, most of whom have been institutionalized as a result of age-related disorders, serve as role models for individuals incapacitated at much younger ages by such diseases as multiple sclerosis?

As regards the issue of geographic separation of younger adults from their families and home communities, the primary answer that comes to mind is that YDUs do not have to be constructed only in large urban centres. Rather, there could and probably should be regional centres providing specialized care for younger disabled adults. In fact, several of the administrators and staff explicitly stated "the last thing needed is another large institution". Their recommendation, in calculating the number of beds needed, was to work from the bottom up. That is, begin with the ideal ward size (estimated by respondents as no more than 30-40) and add wards until a sufficient number of beds are in place to justify the costs involved in hiring staff with the necessary expertise and interest in working with younger disabled adults.

Another alternative would be to consider constructing a unit on the grounds of an existing facility, such as is proposed by the Pacific Health Care Society, or attaching it to or designating one ward of an existing facility as specifically for younger disabled adults. Any of these arrangements would enable construction of a small unit while achieving cost savings in terms of the physical plant (e.g. heating, dietary services), supplies and equipment.
Another means of having a sufficient client population to justify staff and other costs, and one which should be very seriously considered by the Society, is to plan for both an inpatient unit and an outreach program.

Today, the trend is to encourage younger disabled adults to remain in the community for as long as it is possible for them to do so or, to return to it after a period in hospital. This is surely a laudatory policy so long as the necessary support services are in place to meet their needs. Often, however, this is not the case. For example, there may not be sufficient expertise among community-based health care professionals to provide younger disabled adults with the depth and variety of counselling they may require. Younger disabled adults living at home may be deprived of the mental and social stimulation and the support and encouragement that others of similar age and with similar disabilities can provide. Even if in a group home, they may be deprived of the type of educational, vocational and recreational programs and activities provided in specialized inpatient units.

If a new unit were to be built, as we would strongly recommend, with an explicit mandate for outreach, many of these needs could be met through a combination of an active, vital day program and home-delivered consultation. The expertise of the inpatient unit staff could also be utilized to educate and support family caregivers, staff of group homes and staff of other facilities providing care to younger disabled adults.

A new inpatient unit could also serve as a model in the area of environmental design. As indicated in Section 3.4, there are few special design features in
the two hospitals that participated in this study. Even some of the basics are lacking, such as wheelchair accessible sinks, lever-type tap handles and elevators that can be easily activated by persons with a variety of disabilities. The staff and residents at both hospitals had a number of suggestions as to how the environment might be altered/added to so as to make it more responsive to their needs. There is likely much more that can be done.

Brief consultation with members of SFU’s School of Engineering Science suggests that there are a number of existing technologies that could be applied to the long-term care setting. For this to happen, however, it is necessary for a group, such as the Pacific Health Care Society, to take the initiative and work with gerontologists, engineers, expert staff and younger disabled adults to develop improved living environments for this important client group.
Appendix I

Classification Criteria for Levels of Long-term Care in British Columbia
Levels of Care
The classification system used by the Long-Term Care Program to describe individuals with similar types of health care needs consists of three major groupings - Personal Care, Intermediate Care and Extended Care. Within these groupings, Intermediate Care has been further divided into levels I, II and III.

These care levels move in a progression from the lighter care requirements of Personal Care, through the Intermediate Care levels to the heavier care requirements of Extended Care. Briefly summarized, the care levels are:

Personal Care
This level of care recognizes the individual who is independently mobile, with or without mechanical aids, and whose primary need is for minimal non-professional supervision and/or assistance with the activities of daily living for the purpose of achieving or maintaining maximum personal independence in everyday activities.

Intermediate Care
The three Intermediate Care levels build on the Personal Care level and recognize a need for care planning and supervision under the direction of a health care professional by introducing a combination of professional and non-professional (lay) supervision. This professional supervision is required on a daily rather than a twenty-four hour basis. Individuals at the Intermediate Care levels are ambulant with or without mechanical aids.

Intermediate Care I
This level of care recognizes the individual who requires moderate assistance with the activities of daily living and minimal professional care and/or supervision.

Intermediate Care II
This level of care recognizes the individual who has more complex care needs, and who requires additional professional care and/or supervision.

Intermediate Care III
This level of care primarily recognizes the individual who exhibits severe behavioural disturbances on a continuing basis and who presents a significant management problem.

This level also recognizes the individual who has very heavy care requirements which require significant staff time to manage.

In both instances, this level of care requires considerable supervision and/or assistance under the direction of a health care professional.

Extended Care
This level of care recognizes the individual with a severe chronic disability who requires professional nursing services on a twenty-four hour basis and regular and continuous medical medical supervision, but who does not require all the resources of an acute care hospital. This individual may or may not be able to ambulate independently.
Appendix II

Criteria for Admission to Hospital A's Sustained Rehabilitation Head Injury Program
SUSTAINED REHABILITATION HEAD INJURY PROGRAM

ADMISSION CRITERIA

• Primary diagnosis - significant diffuse head injury.

• Age 19-50, others considered on an individual basis.

• Completion of acute rehabilitation process, where appropriate.

• Medically stable.

• Able to understand the spoken word and able to communicate needs and wishes.

• Moderate to severe deficits in the areas of:
  - independent living skills
  - cognitive and perceptual function
  - physical function

• Must demonstrate a potential for functional improvement in at least two of the following areas:
  - cognitive remediation
  - communication skills
  - independent living skills
  - psychosocial skills
  - physical conditioning

• Must demonstrate a potential for remediation of aggressive behaviours as well as a current clear record with regard to substance abuse.

• Individuals will be admitted for a six week assessment period. The referring agency must agree to readmit the individual to the first available bed if, during this time, the individual is assessed as being inappropriate for the program.

November 24, 1988