

“LOST CONNECTIONS”

A report about Islanders with an intellectual disabilities living in long-term care and community care facilities

May 2006

researched and written by PEI Citizen Advocacy for the
PEI Association of Community Living

Background

In the Fall of 2004 organizations involved in advocating for adults with intellectual disabilities had become extremely concerned about the numbers of people they knew living in institutional-like settings with little prospect of ever gaining more independence. There was no statistical information available and no-one knew exactly how widespread the phenomenon was. As a result the PEI Association of Community Living funded PEI Citizen Advocacy to do province-wide research on the issue and also to find volunteer advocates for a few individuals living in institutions or in community care facilities.

This document is the report provided to the PEI Association of Community Living by PEI Citizen Advocacy at the end of the project.

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PEI Citizen Advocacy Inc. is a non-profit organization which matches volunteers from the community (advocates) with adults who have an intellectual disabilities on a one-on-one basis. An advocate becomes not only a friend to the person with whom they are matched, but also someone who can make sure that their voice is heard and who can advocate for them when necessary.

Acknowledgements

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Rosalind Waters wrote the report and **Barbara Fanning-Keaveny** travelled with her all over the province to help with the research.

Grant Curtis provided editing guidance.

Finally, we would like to thank all the **facility staff and residents** whom we met along the way. Many took an interest in what we were doing and provided valuable insights.

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A report about Islanders with an intellectual disabilities living in long-term care and community care facilities made to the PEI Association of Community Living by PEI Citizen Advocacy

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The purpose of this project was to establish the extent to which Islanders with intellectual disabilities are living in institutional settings and to develop an understanding of the texture of the lives they lead in these settings. We also aimed to match a few of those individuals with an advocate through the Citizen Advocacy program.

APPROACH TO GATHERING INFORMATION

Barbara Fanning, who is a member of People First and a Citizen Advocacy board member worked with me on this project. Together we visited thirty facilities over the course of the project. We also surveyed an additional eight facilities by telephone. The facilities included manors, public and private nursing homes and community care facilities.

Prior to each visit we phoned the facility to obtain permission and to arrange a time suitable to staff. During our visits we spoke to staff and residents. In the case of manors and nursing homes our visits often started with a meeting with the Director of Nursing. In community care facilities we usually met with the operator, or in the case of the larger facilities, the head nurse.

At the outset of the project we decided to gather our information through informal visits, rather than formally approaching government officials for statistics. We felt that this approach would give us greater understanding of the characteristics and individuality of each facility and an opportunity to meet residents.

Any numbers in the report were gathered through conversations with staff, with the exception of one instance where we did the counting ourselves.

COMMUNITY CARE FACILITIES

Community care facilities are establishments governed by the *Community Care Facilities and Nursing Homes Act* of Prince Edward Island. Their original purpose was to provide accommodation to seniors who needed some day to day support such as the provision of meals, housekeeping and some assistance with daily living. At the outset of the project there were 37 licensed community care facilities. Currently there are 36. They vary greatly in size and also with respect to whom they house. Some community care facilities, especially those in urban areas, now house people of all ages with a variety of disabilities including mental illness and intellectual disabilities. In five instances the community care beds are combined with nursing home beds in one institution.

At the outset of the project the Department of Health and Social Services (now the Department of Health) helped us with basic research regarding the network of community care facilities and private nursing homes on Prince Edward Island and the legislation which governs them. The Department of Health noted that these facilities were designed to meet the needs of the seniors' population rather than individuals with intellectual disabilities who have been placed in them.

We were informed that 17 of the 37 community care facilities house individuals with intellectual disabilities. We surveyed by telephone all 17 with the following questions:

1. Do you have residents who have intellectual disabilities?
2. If so, how many?
3. Are there any younger than 60 years of age?
4. If so, is there any special programming or special way which you go about meeting their social, recreational and vocational needs?

We visited 14 of the 17. These visits gave us a chance to talk further with staff and residents and to see the physical set up of the facility. One operator who owned two facilities would not give us any information saying the "Privacy Act" prohibited her from doing this.

Our research showed us that there are approximately 56 individuals with intellectual disabilities living in community-care facilities. Three quarters (42) are not seniors. Our numbers can not be exact because in the course of the project people moved in and out of several facilities. In addition, there were some operators who were not clear about the distinction between an intellectual disabilities, conditions which are considered mental illness issues and head injuries and struggled to give us exact figures.

Community care facilities fall, very roughly, into three categories:

1. Those which are large (accommodate over 20 residents) and cater primarily to seniors;
2. Those which are small (accommodate fewer than 20 residents) and cater primarily to seniors; and
3. Those, mostly in Charlottetown, which cater to individuals of all ages with:
 - intellectual disabilities
 - a history of mental illness or
 - other conditions which have disadvantaged them in the community.

The Larger Community Care Facilities (6)

These facilities cater primarily to seniors. Some look like, and are designed like, nursing homes. One or two are in converted old houses. On the whole the operators of these facilities welcomed visitors and in some cases it was clear that they were conscious of the lack of stimulation available to their younger residents. Ironically, the lack of staff around to provide residents with any program or stimulation also meant that they were very open to visitors and didn't attempt to monitor visitors in any substantial way.

Younger residents of these facilities with intellectual disabilities are not eligible for the Disability Support Program. This means that they basically receive no services, no one-on-one support for any activity, no age appropriate programs and often have no social worker from outside of the institution to ensure that their needs are being met. Boredom is the most common complaint. At one facility there were movies shown sometimes. As one young resident told us "I feel like I'm in a manor...we never go out anywhere".

Lack of physical exercise is also evident. For those living in facilities out in the country a few miles from the nearest town, there is no "town" to walk to. There is often very little privacy. A few residents who had a girlfriend or boyfriend living in the same facility talked about having to share a room and having no privacy. In one case a young man had a girl friend who lived in the community but he felt that he was not permitted to have her in his room.

In these larger facilities meals are routine and served at a set time every day. Baths and showers also tend to be scheduled according to staff schedules and availability of the wash facilities.

We talked to one or two very pleasant staff in these facilities and one operator who very clearly understood the lack of quality of life of her younger residents.

The Small Facility Catering to Seniors (1)

We visited one small facility which served seniors. It was in a rural setting. The resident we talked to there who had an intellectual disabilities was a senior. She was extremely bored but she appreciated the relative degree of flexibility in the facility and the personal freedoms she enjoyed. For example, she could make herself a snack whenever she wanted, she had her own phone in her room and felt she had the freedom to organize her room however she wanted. She liked the operator and considered her a friend. She did say however, that the boredom made her “nutty” sometimes.

Since we visited this facility we have talked with placement workers who were considering placing a much younger resident here, simply because they could not find any other place to house her. It is in a very isolated location, primarily serves seniors and can offer very little in the way of activities for someone in their 30's. This situation is a symptom of the lack of appropriate homes for adults with intellectual disabilities.

Facilities Catering to Residents of all Ages (9)

These facilities tended to be smaller. All but one is licensed for fewer than 20 residents. The residents of these homes are diverse in terms of age and disabilities. The degree of control over residents' lives varies. Some have curfews and in others people feel free to come and go as they please. In some the residents decide when they go out and where, and in others the operator exerts some control over these types of decisions including when to nap and bed times. In some the residents can make their own snacks and in others snacks and meals are very routine and requests for flexibility are met with resistance.

These facilities also vary physically. Some have a few quiet spots in the premises where people can spend time alone, while others are tighter for space and only offer communal space.

Except for a few exceptions these residents have no access to the Disability Support Program. There are a few residents who attended a vocational training center prior to the introduction of the Disability Support Program. They continue to receive Disability Support Program funds to pay for this service. Overall, boredom and a lack of any meaningful day-time activity are evident.

One operator whose residents all have intellectual disabilities commented to us that there are fewer options for her residents than in the 1970's. She said “It's as if the government has forgotten about them”.

For those living in facilities in Charlottetown watching television and walking into town to the mall appear to be the main daytime activities . While those with a connection to the mental health system have the Fitzroy Center to meet friends and pass time, those with intellectual disabilities do not even have this connection. The residents who used to receive supports and get out each day to Tremploy expressed a desire for a day-time activity through which they can feel productive.

The operators we talked to said they couldn't afford the number of staff needed to provide individualized programming for residents. In the meanwhile, government representatives have told us that they feel that the operators have a duty to do this. The residents are therefore caught in limbo. No one is assuming responsibility for providing them with meaningful occupations which recognize their need to develop skills and interests and contribute to the community.

Table 1: Community Care Facilities and the Number of Residents with Intellectual Disabilities

Type of facility	Total number of residents with an intellectual disabilities	Number of residents under 60 years of age	Number of residents over 60 years of age
Larger facilities catering primarily to seniors	16	10	6
Smaller facilities catering primarily to seniors	1	0	1
Facilities catering to individuals of all ages	39	32	7
Total	56	42	14

Issues confronting a significant number of these residents include:

- boredom
- lack of one-on-one support for any kind of activity
- lack of control over day-to-day decisions
- curfews
- regimentation
- lack of privacy

However, one resident's anecdote reminded us that a sense of dignity and freedom depends on many aspects of a person's environment, and that a housing placement which appears, on the surface, to be closer to community living may have many characteristics of an institution. She had previously lived with a family in the community. She told us that, in the community care facility she experienced considerably more freedom to come and go as she pleased, to have her boyfriend over and felt altogether more in control of her life. In her case, the attitudes and training of the individual housing providers she encountered played a decisive role in determining which housing option she preferred. This anecdote points to the need for training for all persons playing a role as a housing support to people with intellectual disabilities.

MANORS

Manors are government run and are long-term care facilities intended for seniors. Normally, someone moves into a manor when independent living has become difficult and their nursing needs have been assessed at level 4 or 5. There are seven manors across the province excluding the Prince Edward Home. The Prince Edward Home has a unit known as the “Under 60’s unit” which has been set aside to accommodate younger persons with nursing needs. There are approximately 13 individuals with intellectual disabilities under the age of 60 living in manors, including the "Under 60's unit" at the Prince Edward Home.

Table 2: Manors and the Number of Residents with Intellectual Disabilities

Facility	Total number of residents with an intellectual disabilities	Number of residents under 60 years of age	Number of residents over 60 years of age
Summerset Manor - Summerside	2	1	1
Wedgewood Manor - Summerside	6	2	4
Stewart Memorial Hospital - Tyne Valley	1	0	1
Riverview Manor - Montague	2	1	1
Beach Grove Home - Charlottetown	1	0	1
Colville Manor - Souris	4	2	2
Maplewood Manor - Alberton	1	0	1
Prince Edward Home - Charlottetown	7(?)*	7(?)*	0
Total	24	13	11

* These numbers are estimated.

We were told both by staff of manors and by staff of the Department of Health and Social Services that younger people with intellectual disabilities end up living in manors because there are no community living options for them if their nursing needs are assessed at level 4 or 5. We have to ask two questions: “Is a manor the appropriate place for them to be living and having their nursing needs met?” and “Why are supports not provided to enable them to receive nursing care while living in the community?”

This situation puts all young people who have significant personal care needs and/or nursing needs at risk of being put in a manor once their families are no longer able to take care of them.

Three of the larger long-term care facilities we visited run recreational programs for their residents. They include indoor bowling modified for those with disabilities, bingo, crafts and sing alongs. The activities are geared towards seniors and are used primarily by seniors. On the whole they are not age appropriate activities for the younger residents. One of the residents whom we met one day in a sing along expressed clearly, despite her communication disabilities, a dislike at being there and asked us to wheel her back to her unit. She expressed a similar dislike of the children's toys which show up in her room and are sometimes put on the tray of her wheel-chair for her to play with.

Residents of manors are not eligible for The Disability Support Program. And one-on-one support from within the institution is not normally possible given the staffing levels. In any case, the facilities are run on a medical model and don't hire human services workers to provide support to these residents.

In one of the smaller manors the head of nursing was very aware of how difficult it was for her facility to meet the needs of the younger residents with intellectual disabilities. She cited firstly that her staff are not trained in the area of human services and commented on how difficult it was to meet the needs of two specific populations within the one facility. She also referred to the cultural gap between the younger residents and the senior residents, many of whom had had no exposure to individuals with intellectual disabilities during their life and could be very awkward and sometimes upset at having them in their environment.

Some staff we talked to in one of the larger facilities were not as insightful and their comments indicated that they felt that any suggestion that the quality of life of their younger residents might be lacking was misguided. We would argue that their attitudes reflect a lack of vision about the rights of individuals with intellectual disabilities to live meaningful lives and to develop themselves personally, and a lack of belief in what is possible.

Issues facing a significant number of these residents include:

- little contact with people their own age
- isolation
- lack of age appropriate activities
- being viewed in light of their medical needs, rather than from a community living point of view
- lack of possibility to develop personally and a lack of belief in the community at large in what is possible for their lives

PRIVATE NURSING HOMES

There are nine privately owned nursing homes on Prince Edward Island which are licensed pursuant to the *Community Care Facilities and Nursing Homes Act*. Five also have community-care beds. At present there are six individuals with intellectual disabilities who are either presently under the age of 60, or who were under 60 at the time they were admitted, housed in private nursing homes. These six are spread only three homes.

Table 3: Number of Individuals with Intellectual Disabilities admitted to Nursing Homes before they reach 60

Kings	Queens	Prince
1	5	0

Private nursing homes vary in size from accommodating 5 to 103 residents. In several of the larger facilities the managers were clear that their mandate was to care for people over the age of 65 and believed that it was not an appropriate home for people in their 40's or 50's.

Although there are only a few people with intellectual disabilities who are under 60 living in private nursing homes at present there are signs that this may change. One of the Directors of Nursing whom we spoke to talked about the apparent growing demand for nursing home beds from Islanders under the age of 65. Staff from several nursing homes mentioned that their owners were considering developing their own under 60's "wing" or "service". This, they said, was a response to the current 2 or 3 year waiting list for the "Under 60's" unit at the Prince Edward Home. They mentioned that people living on this unit at the Prince Edward Home were young and likely to live long lives so the waiting list was not moving. It is a sad commentary on the status quo on Prince Edward Island that the only response to the dilemma of inadequate supports for people to live in the community with disabilities, is to create spaces for them in nursing homes.

We know through one of Citizen Advocacy's matches that a transfer to a nursing home was proposed to a woman in her 40's with a mild intellectual disabilities and very few nursing needs.

SHERWOOD HOME

Sherwood Home is a long-term care facility with 13 residents. Many are in their late 20's and 30's. All have significant intellectual and physical disabilities. Historically, Sherwood Home has differed from other long-term care facilities due to its developmental focus. Its management was experienced in providing developmental support to adults with intellectual disabilities and it ran a day program provided by human service workers. In recent years, the management of Sherwood Home has been passed to nursing staff. This has led to some fear in the community that the developmental focus of its service will get lost over time.

Sherwood Home is also used for respite for young adults with intellectual disabilities.

HILLSBOROUGH HOSPITAL

We visited all four units at Hillsborough Hospital which house individuals with intellectual disabilities. There were approximately 24 individuals with intellectual disabilities on Units 5, 7 and 8 and there are always a few in Unit 3 (the unit for the “short stays”).

Although Unit 8 is considered a rehabilitation unit staff told us that about 50% of the patients are “permanent” while the remaining 50% would eventually leave the hospital. At the time of our visit there were nine individuals on unit 8 with intellectual disabilities.

Unit 7 is considered to be the unit for individuals with long-term physical and intellectual disabilities. Of the 17 individuals living on Unit 7, 12 or 13 had an intellectual disabilities. The remaining patients had head injuries or mental illnesses. Many of the residents with intellectual disabilities had challenging behaviours and require considerable support on a daily basis. We were told that only four individuals on the unit received regular visits from friends and family and only two patients had a possibility of moving out over the next 6 months. We were told that Unit 7 has a higher staff / “patient” ratio than other hospital units in the province. As a result group outings are possible and staff appear to have a bit more time to spend with the “patients”.

Unit 5 is the psycho geriatric and assessment unit. However, the head nurse described it as a “bit of a mixture”. Most of the patients have Alzheimers . There are 5 or 6 beds which are for seniors being assessed before placement to a nursing home or manor. There are two individuals with intellectual disabilities who are both in their 40's. One is there because her family wishes her to stay there. The second has lived there for over 20 years, and has severe physical disabilities.

CITIZEN ADVOCACY PROGRAM MATCHES

During the course of this project we have been able to make three matches involving individuals living in institutions. This is very encouraging because it can often take six or nine months to match one person. The matches involve a woman in her 30's who has lived in the Prince Edward Home for more than six years, a 49 year old woman who is in Unit 7 of Hillsborough Hospital and a woman in her forties who lives in a community care facility. Through these matches our understanding of the issues facing those living in institutions is greatly increased.

CONCLUSION

There are approximately 89 individuals with intellectual disabilities now living in community care facilities, manors and nursing homes. 60 of these are under the age of 60 and suffer from a lack of resources, lack of support and a lack of age-appropriate programming. They tend to be bored, isolated and in some cases have lost control over very basic decisions in their daily life. They are at risk of depression and ill health. Among staff and operators of all types of institutions there is a wide range of attitude, some understanding these problems only too well, while others see nothing wrong with the status quo. In addition there are approximately 37 individuals with intellectual disabilities living in Sherwood Home and Hillsborough Hospital.

Table 4: Total number of adults with intellectual disabilities living in institutions.

Type of facility	Total number of residents with an intellectual disabilities	Number of residents under 60 years of age	Number of residents over 60 years of age
Manors including Prince Edward Home	24	13*	11
Community Care Facilities	56	42	14
Private nursing homes	9**	5	4**
Sub Total	89	60	29
Sherwood Home	13		
Hillsborough Hospital	24		
Total	126		

* This number is estimated

** This number is a minimum. In one nursing home we only obtained the number of residents under the age of 60. This number also includes one resident who was under 60 at the time of admission, but is now over 60.

Public policies concerning Islanders with intellectual disabilities such as:

- the lack of access to disability supports for those in certain living arrangements,
- lack of access to the ongoing support of a social or human services worker to ensure that their need for personal development and community participation is met,
- the lack of investment in the development of supportive housing options, and
- medicalization of the care of individuals with intellectual disabilities once they live in a long-term care facility,
- reflect the attitudes of policy and decision makers within the provincial government.
- They may also reflect a lack of concern among the general public for the quality of life of adults with intellectual disabilities.

There is clearly much work to be done to promote changes to these policies and attitudes. There are other community organizations which have committed to working on these issues. These include P.E.I. People First and the coalition group “Partners for Change”. In the case of PEI People First a three-year project is already underway entitled “The Road to Inclusion: Working Together towards Healthy Public Policies for Persons with Intellectual Disabilities.” This project has collected stories of people with intellectual disabilities living in institutionalized settings and is training citizens in both Queens County and West Prince to understand issues relating to institutionalization and how to influence public policy. In the third year the project will focus on educating decision-makers and developing dialogue with politicians.

Partners for Change is a coalition of PEI Citizen Advocacy, PEI People First, the Association for Community Living, non-governmental organizations (non-profit agencies governed by community-based boards) and for-profit service providers and human services instructors. This group is interested in partnering with the Association for Community Living to work on these issues.

Given the variety of organizations interested in the issue we would recommend that they are brought together to determine how best we can work together to provide an effective push for change. If the efforts of each group are co-ordinated to complement one another our influence will be the greatest.