# **Community Inclusions**

Building the Case for Increased Residential Supports





Wayne Oulton, a Community Inclusions client works in the workshop at Maple House in O'Leary, Prince Edward Island.

Community Inclusions recently embarked on a research and strategic planning effort to verify the needs of their current and future clientele. The end result is a community responsive strategy and recommendations for increased residential supports.



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# Community Inclusions

Building the Case for Increased Residential Supports



# 1.0 Executive Summary

For the past number of years, Community Inclusions Ltd. has recognized that parents of clients accessing their various services were aging, and that their adult sons and daughters would need future residential options. As well, the housing supply\resources in the region have remained relatively static and have not grown to meet that need. One home was built in the Tignish Region and currently it houses five residents - one individual whom is in transition and has yet to find a suitable housing placement in the community.

As well, there are a limited number of resource providers taking people into their homes in Western PEI.

# 1.1 Purpose

In the summer of 2004, a parent of a client of Community Inclusions fell seriously ill. At the time, she was unable to take care of her adult son thus escalating the situation into a crisis. Shortly afterwards, Community Inclusions was asked to attend a Parents' Meeting, and the question was asked:

"What residential plans does this organization have in place for those taking advantages of services, and for future clients?"

~ Parents' Meeting

At that time, it was acknowledged that:

- we had a population of parents that were aging;
- that persons with intellectual disabilities were living longer;
- there was no formal plan in place to address these changing factors.

In order to aid in the development of a formal plan, a survey was undertaken to determine the needs and plan support services that would be responsive to those needs.

Thus, in 2004, a Housing Survey was conducted with the objective of finding out from parents what their current and future needs would be for their son(s) or daughter(s). The results illustrated that very few families had any type of plan in place and that they were not aware of current resources, or thought them inadequate. The results also confirmed that the population was indeed an aging one.

The goal of the 2007 Housing Survey was to update the November 2004 efforts, and to add two new groups, Resource Providers (individual(s) in the community taking people into their homes) and clients themselves (self-advocates), asking them the same questions (see Appendix A) as the parents, and further developing a plan based on needs identified in the updated survey.

# 1.2 Community Inclusions

Community Inclusions is a Non Governmental Organization that provides supports and services to adults with intellectual disabilities. Services range from residential supports and vocational day-programs to employment and recreational opportunities. Services cover the geographical areas from North Cape to Northam.

The organization is governed by a volunteer Board of Directors, and has a staff complement of 18, including relief and part-time staff.

# 1.3 Objectives

The objectives of this research and planning process were identified as follows:

- To re-interview original interviewees of the 2004 Survey to see if their situation has changed.
- To add two new target groups: Respite\Resource Providers and some selected, existing clients of Community Inclusions asking them the same questions.
- 3. To create awareness concerning residential options for adults with intellectual disabilities in PEI.
- Based on the results, make recommendations to the Department of Social Services and Seniors.
- 5. To garner financial support from the province to further develop residential options in Western PEI.

"I want my 48 year old son who is legally blind to live where he is not lonelu."

~ Parent of a Client

# 1.4 Research Efforts

All original interviewees from the 2004 survey were also re-interviewed and, as stated above, two new target groups were interviewed. Two techniques were used for this: contacts made by phone, and one-on-one interviews conducted in-person. The majority of the interviewees from the 2004 survey participated by phone, while the two groups added were mainly interviewed in person. In total, 50 people were interviewed from the three above-mentioned groups.

As well some of the existing research\information on the subject was reviewed, this included:

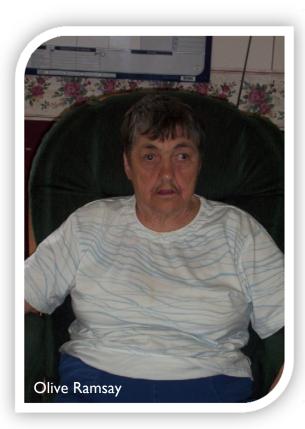
- Aging Parents Caring for Children with Developmental Disabilities on PEI - This report was carried out through the PEI Centre for the Study of Health and Aging in November, 2003.
- Various correspondence with the PEI
  Association of Community Living, an
  advocacy organization based out of
  Charlottetown (umbrella for groups
  throughout the province), regarding
  data they have collected in the past,
  particularly around the number of
  aging parents in the province.
- Lost Connections A report about Islanders with an intellectual challenge living in long-term care and community care facilities. This report was completed in May, 2006.

 Various internet related research, including the definition of an Intellectual Disability obtained from the British Columbia Special Olympics website. This definition is used by the World Health Organization.



# 1.5 Summary of Findings

After interviewing the three groups it was found that the issues are very similar to what they were in 2004. There is little to no planning being done by families with regards to future housing for their son(s)/daughter(s)/relative(s). Because of the lack of resources, families are being forced to use manors or community care facilities for respite. In many cases, however, families are unable to get a break. Because of the lack of resources, families are suffering from fatigue and feeling discouraged in their present situations.



Resource Providers feel that there needs to be more incentives for people to take an individual with disabilities into their home. Some made reference to the Provincial Disability Support Program, pointing out that assessments are done through that program and resulting dollars allotted are not meeting the needs. Clients are seeking more support as far as budgeting, transportation and also assistance with opportunities to get out into the community to socialize. Clients want to live in their communities and live in age-appropriate settings.

# 2.0 Introduction

The 1996 Canadian General Social Survey showed that there are approximately 20,000 parents aged 65 or more caring for their adult children with long-term health problems, and an additional 40,000 parents in the 45-64 age group. Unlike caring for older adults, caring for a child with a developmental disability can span 4 or 5 decades. (Weeks, Bryanton, Nilsson, Kozma, & Richards, 2003)

In 2004\05 the Prince Edward Island
Association for Community Living collected
data from across PEI that indicated that
there were close to 400 aging parents across
PEI at that time still caring for their adult
aged son or daughter with an intellectual
disability. For the purpose of this study, a
total of 50 interviews were conducted
representing the three identified groups
throughout West Prince – 2004

interviewees, Respite/Resource Providers and selected Community Inclusions clients.

It is important to first clarify what is meant by the term intellectual disability. According to the World Health Organization, an intellectual disability is defined as (www.bcso.bc.ca, 2007):

"An intellectual disability is a condition of arrested or incomplete development of the mind characterized by impairment of skills and overall intelligence in areas such as cognition, language, and motor and social abilities.

An intellectual disability can occur with or without any other physical or mental disorders.

Although reduced level of intellectual functioning is the characteristic feature of this disorder, the diagnosis is made only if it is associated with a diminished ability to adapt to the daily demands of the normal social environment."

# 3.0 Primary Research

In February and March of 2007, a survey was conducted to determine the extent of the housing needs for individuals with intellectual disabilities currently living in the West Prince region. Accepting that there currently exists a chronic shortage of housing options for this population, it was deemed important to update this information and determine if it had changed

since the November 2004 survey. The focus of the study was on individuals with intellectual disabilities, parents who have a son(s) or daughter(s) with an intellectual disability, siblings of these individuals and resource providers. The research consisted mainly of telephone and one-on-one interviews, along with literature review.

# 3.1 Methodology

The focus of the study was to identify individuals with intellectual disabilities through their families in order to determine the current and future housing needs of this population. Areas for investigation included:

- Age of person with intellectual disability;
- Range of ability of the person with the intellectual disability;
- Current living arrangement;
- Age of care-giver;
- Relationship of care-giver to person with intellectual disability;
- External supports currently in place;
- Awareness of services in the area;
- Future housing plans in place;
- Additional supports and or services required.

39 telephone surveys were conducted with families and resource providers and 11 face-to-face interviews were completed (see Appendix A).

# 3.2 Summary of Findings

From interviews conducted and comments collected a number of themes emerged. Please refer to Appendix B to see a more complete listing of comments from the three target groups.

# Aging Families

There is a dire need for housing options for people with intellectual disabilities, especially those from aging families who are caring for their aging sons, daughters, and siblings. As captured in the interviews there are many parents in their seventies and eighties who are caring for their sons and daughters whom have a variety of needs and levels of care. There are cases where both parent and family member are at risk.

Most of the population requires a supervised setting, where the individual will not be alone and will receive support such as personal care, daily life skills, transportation and meal preparation. Parents are tired and frustrated and don't know where to turn for help. They worry about what will happen to their loved ones when they are no longer able to provide care, for example will they be treated well, will they be comfortable, have companionship and have their basic needs met? One family feels that their senior family member is discriminated against because of her disability and not being accepted in Community Care.

# Lack of Resources in the Community

The number of residential resource providers in the community has diminished over the past few years mainly due to a sentiment that they are not compensated adequately for what is expected of them - in terms of room and board, supervision, transportation and respite care, especially with the increased cost of living. Existing resource providers feel that the financial compensation is not equal across the province. There is the question of how to recruit more placements and the associated challenges of screening, accountability and responsibility. There is a lack of financial support to make associate resource homes accessible in the areas of ramps, doors and grab bars.

"I want to live in
Alberton, probably share
a place because I need
help with budgeting,
transportation and
company so I won't be
lonely."

~ Client

# Clients

Clients who were interviewed want to live in the community where their families and friends are, where they are familiar with the area and close to their day programs/work. It may be with associate families, independent or semi-independent living, apartment with supports, or living with their families without losing eligibility for supports. People in their early 50's are asking to move to community care facilities because they feel they do not have other options to explore. They do not realize that this is not an appropriate environment given their age and abilities.

Overall the research continues to point toward the need for more appropriate options to suit individual needs. There is currently just one group home in Tignish that provides support to four full-time individuals. More help for families to assist with future planning is needed as most do not have any type of plan in place.

The research calls for the revitalization of the Residential Resource Committee, a committee fronted by the former West Prince Health that advertised and screened potential Resource Providers for the region. Finally, there needs to be a local housing plan put in place going forward. This could fit into a larger provincial plan as housing is a concern right across Prince Edward Island.

# 4.0 SWOT Analysis

A SWOT analysis provides an assessment of the relative strengths, weaknesses, opportunities and threats of an organization or entity. In this case we are analyzing the availability of housing for persons with intellectual disabilities and the ability of the West Prince Community to provide the needed housing for this segment of our population.

# 4.1 Strengths

- Community Inclusions is the recognized leader in the area of professional services for adults with intellectual disabilities in Western PEI.
- Community Inclusions Board of Directors has set the pursuit of additional housing to meet the needs of their client population as a priority.
- Existing infrastructure of the organization can support further housing units. The necessary expertise has been gained from operating a residence in the Tignish area for the past 20 years.

# 4.2 Weaknesses

- Individuals requiring appropriate, alternate housing options are often represented by aging parents and care-givers who are not well organized and unable to lobby government effectively to put the necessary funding in place.
- Community Inclusions is seen as selfserving when lobbying for more dollars for new services.

 Community Inclusions costs continue to rise (wages, etc.), however the current funding process does not reflect this.

# 4.3 Opportunities

- The current appropriate housing stock for this population is centered with family, resource providers and one group home located in Tignish. The opportunity exists to increase capacity for this much needed service.
- A very small percentage of parents have plans for their son's and daughter's after they can no longer provide care. There is an opportunity for Community Inclusions to aid in that planning process.
- Parents are aging and soon will no longer be able to care for their adult sons and daughters. Community Inclusions can be a partner in offering solutions to finding and or providing appropriate care.
- The Coordinator position created in 2006 for Disability and Social Programs is currently a new dedicated position within government for this target population. This should allow the issue of appropriate housing for this population to be higher on the list of priorities for the Province.

# 4.4 Threats

- The acute side of Health spending still dominates as a budgetary item as compared to Social Services and Seniors where funding for appropriate housing would come from. Although creating two separate departments in 2005 is a step in the right direction.
- This organization is funded mainly through the Provincial Government and with only so many funding dollars to go around, housing for people with intellectual disabilities has not been a priority until this point.
- Because there is currently a severe lack of housing, clients of this population are being housed in inappropriate facilities such as Community Care facilities and manors (PEI Citizen Advocacy, 2006).

"What will happen to my son goes through my mind all the time, but I have no answers."

~ Parent

# 5.0 Recommendations

Based on the research in 2004, the 2007 Housing Survey and various other research efforts, Community Inclusions has developed a list of four primary recommendations which address the short to medium term needs of the region.

- Revival of Residential Resource Committee
- Development of a Western Housing Strategy
- Communications and Liaison Officer
- Immediate Improved Housing Options

# Residential Resource Committee

At one time a Residential Resource Committee advertised, screened and approved potential resource providers (individuals/families that provide private housing) in the region. This Committee has been dormant since around 2004 and has it is recommended that it be revitalized immediately or a new one formed by the fall of 2007.

# Development of a Western Housing Strategy

While Community Inclusions has identified some very specific short term needs and action items (such as the revival of the Residential Resource Committee, the Communications and Liaison Officer and some tactical and immediate housing enhancements), it is recognized that there is

a need for an overall housing strategy that brings all the necessary stakeholders together with regards to the current and future housing situation in Western PEI.



This strategy needs to involve both medium and long term planning with a built in mechanism for ongoing re-evaluation over the course of time. It is recommended that the Community Inclusions Housing Committee facilitate this process, with an initial meeting to be held no later than the fall of 2007.

It is also recommended that the following groups be an integral part of this process:

- Department of Social Services and Seniors
- Parents
- Self-advocates
- Private businesspeople

Community Inclusions recognizes that housing is not just bricks and mortar.

Additional housing supports/planning needs to occur to further enhance existing housing options in the region. Some immediate recommendations in this respect are included under the Immediate Improved Housing Options recommendation section on this page.

"I spent a few nights in a seniors' home which is a good place to visit but not to stay. The people there were older than my parents and every day there was somebody dying. It was a depressing place for me."

# Communications and Liaison Officer

Community Inclusions recommends the immediate creation of a Communications and Liaison Officer within their staff complement to address the following needs within the western region:

- To broker/share information and act as a liaison between clients and their parents or families, resource providers, government and government representatives, etc.;
- To provide residential supports;
- To assist in planning such as housing/respite options and estate

- planning issues of concern and relevance for clients and families, as well as resource providers;
- To communicate with resource providers regarding government and community services;
- To facilitate training such as First Aid/CPR and peer networking;
- To work with the revitalized Residential Resource Committee.

# Immediate Improved Housing Options

While the proposed Western Housing Strategy will begin to address the medium term needs of the community and some of the larger issues uncovered by the research such as the aging parent population, it is clear that the following immediate needs should be addressed:

- It is recommended that a new residence/group home be pursued.
- It is recommended that additional supports be established for clients to live at home such as financial incentives to address inequalities in the funding to families versus resource providers.
- It is recommended that additional monitoring be put in place to assist those who live independently or semi-independently such as meal preparation, budgeting and cleaning.

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# **Appendix A**Interview Questionnaire

# Interview Questions

١.	Family	Age Range
	Address	
2.	Family Member	Age
3.	Current environment	
4.	Range of abilities, needs, supervision require	red, etc.
5.	What plans do you have in place for the fu	ture?
6.	What supports to you have in place? ie. far	mily, extended family
7.	What services are you aware of in the We	
8.		to see for your family member in the future?
9.	Would you be willing to participate in a fun	
	Additional:	

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**Appendix B**Target Population Comments

# Comments from Parents

- "We try not to burden family so we get no help from them."
- "We lack respite care and we have no family on PEI."
- "I only have my 76 year old mother to help with my son who is hemophiliac, hepatitis C and has an intellectual disability. I can't get anyone to do respite care with him. I'm discouraged."
- "I want my 48 year old son who is legally blind to live where is not lonely."
- Eighty-six year old mom says, "My son has always lived with me and will continue to live with me for as long as possible. Since my heart attack six months ago he worries about me but soon will need to live in a place where he is supported i.e. Group Home or supported apt."
- Seventy-eight year old mom, "I
  wouldn't mind if my daughter found a
  good supervised home now, but she
  is reluctant to go since she feels that
  she has to look out for me since I
  broke my hip."
- Seventy nine year old sibling, "Not able to do this forever, talked to politicians, community care will not accept my 76 year old sister, feel discriminated against, don't know what to do next, 86 year old husband needs a rest now, my sister deserves to have a good home where she is safe and well taken care of like everyone else."

- Mother of two mentally and physically disabled adult daughters, "Our family is stressed out, we worry every day, stress resulted in me getting chicken pox, respite workers come in to our home because there is no accessible place in the community to go."
- Parents of 47 year old daughter, "She will not sleep any where but home but she will have no choice but to go somewhere when we are gone."
- Parents ages 83 and 86, "We take one day at a time, don't want to think about what will happen to our daughter when we go, her Parkinson's Disease is getting worst, wants to be home, can't travel anymore, home care comes in to do her baths, but like her to go to Community Care but she is not old enough."
- Mother of 39 year old son who has an intellectual disability and has no mobility, "We have no extra care at home, he goes to the manor for respite when I have to go out of province, only positive thing in his life his going to the workshop twenty hours a week, risk of going to a nursing home or an institution."
- Mother of three daughters in their forties, "I want the girls to live in the community where they grew up, all need supervision (day & night), would like to see one of them move now."
- "What's going to happen to my son goes through my mind all the time but I have no answers."

- "I'm 86 years old and I'm tired, he's too much care but it's so hard to let him go. I worry a lot."
- "Wouldn't want to impose on family, but if worse comes to worse they will have to take him in and look after him."



 "I want my son to move from Hillsborough Hospital close to home but I'm not getting anywhere, not getting any help."

# Comments from Resource Providers

- "I am caring for four people with disabilities besides my daughter who has Down Syndrome. I am 60 years old and will do this as long as I am able, however, I do not have enough help or respite."
- "We care for two gentlemen age 63 & 65 and we are looking for a nursing home for one of them."
- "There should be more supports for care givers, respite dollars should be equal across the province, and we need more training and information sessions. The DSP assessment scale needs to be revised to adequately meet clients' needs."
- "My sister lives with us only because she was in the hospital for two months with no place to live. She wants to live in Alberton close to her day program and transportation costs are using up most of her allowable DSP dollars."

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# Comments from Clients

- "I spent a few nights in a seniors home which is a good place to visit but not to stay. The people there were older than my parents and every day there was somebody dying. It was a depressing place for me."
- "I want to live in Alberton, probably share a place because I need help with budgeting, transportation and company so that I won't be lonely."
- "I like living with my sister and they are good to me but I feel that I am in the way. I called Minister Gail Shea to find me a place to live."
- "I'd be sad, lonely, and miss my friends if I had to leave my community but I'll soon have to move because my two sisters (also with intellectual disabilities) get on my nerves."
- "I can't stay alone because of my nerves and I don't feel comfortable living where there are men because of the past."

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**Appendix C**Profile of Survey Respondents

# Profile of Survey Respondents

The survey was conducted with a total of 38 families throughout the region, addressing both family care-givers (31) and resource providers (7) for insights. This translates into 46 clients who were represented by either their family member(s) or resource providers. To further expand the scope of the research and provide a well-rounded perspective, 12 clients of Community Inclusions were directly interviewed and asked for their insights on the questions outline in Appendix A, Interview Questionnaire.

The survey program experienced a high rate of participation with only seven mail-outs going unanswered from the initial target list. This is a very high response rate, in any case.

The following chart shows the responses by region of the west, as well as the proportion of families versus resource providers interviewed to gain the representative sample. The proportion was relatively consistent across the region, reflecting the target population.

Figure 1: Respondents by Residence Area and Category



In the preceding chart, the areas depicted are defined as follows:

**Tignish Area** – including Nail Pond, St. Roch, St. Louis

**Alberton Area** – including Elmsdale, Bloomfield

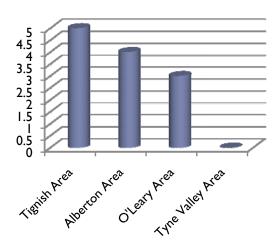
O'Leary Area – including Coleman, Campbellton, Cascumpec

**Tyne Valley Area** – including Ellerslie

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Figure 2: Client Respondents by Resident Area

# ■ Client Respondent



For quick reference the following table summarizes the origin and respondent categories:

	Respondent Category							
		Total Clients						
Residence			Represented					
	Family	Resource	(Family/Resource					
Area	Member	Provider	Provider)					
Tignish Area	11	2	16					
Alberton	7	1	11					
Area								
O'Leary Area	7	2	10					
Tyne Valley	6	2	9					
Area								
Total	31	7	46					

# Sub-Population Profiles

Due to the nature of the survey and the stated objectives, it was deemed appropriate to provide profiles of several subpopulations of the survey respondents in order to better understand the issues as they relate to those particular age

categories, especially those with the greatest need.

# Parents/Guardians Aged 73 to 86

The first sub-profile is the 73 to 86 year age range. There are fifteen (15) families of those surveyed where the parent interviewed was between the ages of 73 and 86. These parents provide care to 17 adults with intellectual disabilities in their homes.

The average age in this sub-population is 79 for Mothers and 80 for Fathers.

Of these 15 families, their family members with an intellectual disability range from age 33 to 76.

Client Age	Family Members
33-39	6
41-49	5
55-59	3
60-76	3

In particular, a closer look at the last age category above (age 60 to 76 years of age) reveals:

# Situation #1

Parents ages are 75 and 78. They have three daughters with an intellectual disability ages 39, 41 and 43. They have no future plans in place and are prepared to have one of them move as soon as a suitable placement is available.

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# Situation #2

Parents ages are 79 and 86. They are providing care to their 76 year old sister who requires 24 hour supervision and does not fit the criteria for community care.

# Situation #3

An 86 year old parent is caring for her 60 year old son who requires 24 hour care and supervision. In this, case they are both at risk given the health and disability situation.

# Parents/Guardians Aged 60 to 69

There are 8 families where the parents range from age 60 to 69 years of age who care for their family members who range in age from 21 to 45.

The average age in this sub-population is 63 for Fathers and 63 for Mothers.

A closer look at this age category reveals:

## Situation #4

One of those families have two daughters, ages 31 and 36 who have intellectual disabilities and have no mobility. The 31 year old daughter has a profound disability and they both require 24 hour care and supervision.

# Parents/Guardians Aged 50 to 59

The average age of this sub-population is 55 for Fathers and 55 for Mothers.

A closer look at this age category reveals:

## Situation #5

There are 12 families where the parents range from 50 to 59 years of age who care for their family members with an intellectual disability who range in age from 21 to 36.

# Resource Providers

A closer look at the resource providers subpopulation reveals:

# Situation #6

Resource Providers who provide room, board and supervision to people with intellectual disabilities range in age from 36 to 60. Some resources provide care in their homes to two or more individuals who range in age from 37 to 67.

# Clients

A closer look at the 12 clients interviewed directly (representing a fifth sub-population) reveals:

# Situation #7

The 12 individuals with intellectual disabilities that were interviewed range in age from 24 to 54 with an average age of 35 and live at home, with a sibling, or with a resource provider. Six of those individuals are requesting appropriate housing as soon as possible to suit their needs which range from 24 hour supervision, accessibility, or semi-independent.

# Appendix D

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- PEI Citizen Advocacy (2006). Lost Connections. A report about Islanders with an
  intellectual challenge living in long-term care and community care facilities. This report
  was commissioned by the PEI Association for Community Living.
- Various correspondence and phone conversations with the Prince Edward Island
  Association for Community Living, an advocacy organization based out of
  Charlottetown with umbrella organizations throughout the province. These took place
  between February-April, 2007.

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# **Appendix E**Organizational Overview

# **Community Inclusions**

Community Inclusions is a nonprofit organization in West Prince that provides supports to adults aged 18-65 with intellectual disabilities. Services range from residential, employment, supportive, recreational, and include the following divisions.

- O'Leary (Maple House) Clients attend day services and participate in a variety of
  employment related opportunities, such as furniture refinishing, promotional buttons, bakery
  work, school lunch programs, and packaging magazines. Other services provided at this location
  include life skills training as well as recreational and social opportunities for clients.
- **Tignish (Workshop)** Clients attend day services at this location. The main focus is integration into the community and clients take part in a variety of community-based opportunities which include employment activities such as packaging magazines and lunch programs, as well as volunteer work, recreational and social opportunities.
- **Tignish (Residential Service)** The Haywood Residence provides housing and supports to the four individuals living there. The residence is staffed on a 24-hour basis. Supports include: vocational, recreational, social, living, and employment.
- Bloomfield (Administration Office) Both the Executive Director and Residential
  Coordinator are located at this office. The Residential Coordinator is responsible for
  overseeing operations at the Group Home and is also responsible for coordinating Community
  Based Residential Services which can include respite care, supported apartment living,
  independent living, room and board options and in-home care providers.
- Employment\Outreach (West Prince Region) The Employment\Outreach Worker(s)' office is located in Bloomfield, however there are satellite office hours in O'Leary and Tignish. These positions are responsible for working with clients of the organization (including outreach), in the

areas of employment, and training. Presently there is an Employment Counselor and an Assistant Employment Counselor\Job Coach.

An Executive Director through direction from a 9 person volunteer Board of Directors administers the organization. The goal of the Community Inclusions Ltd. is to ensure that every individual has the opportunity to participate in the activities and the strong community life of West Prince.

