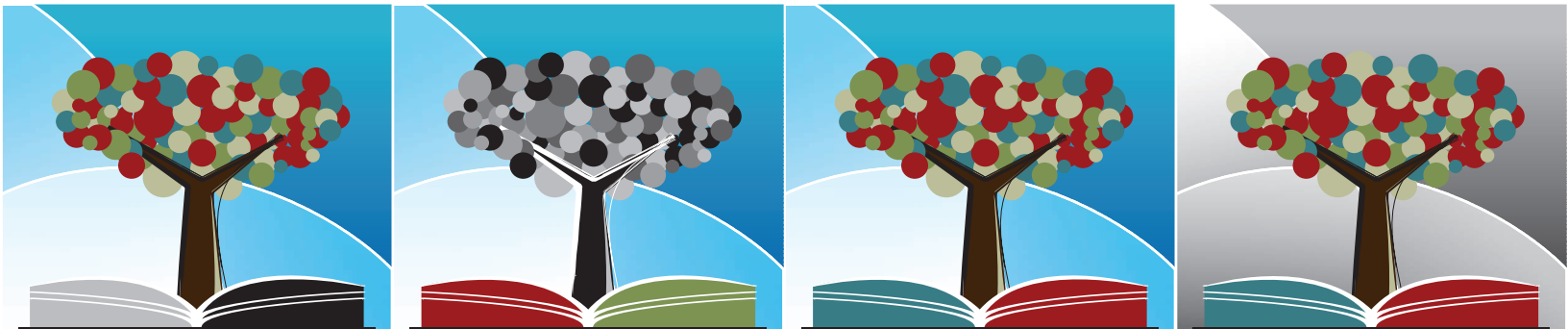


K N O W L E D G E   D E V E L O P M E N T   C E N T R E



# Stepping Forward: Including Volunteers with Intellectual Disabilities

Guide

Kelly Robinson and Barb Fanning  
PEI People First

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The logo for Canada, featuring the word "Canada" in a serif font with a small Canadian flag icon above the letter "a".

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PEI People First is a self-advocacy group for adults who have an intellectual disability. People First members help one other to learn about their rights and speak for themselves. The main goal of the group is to help people to live as independently as possible in their own communities.

Our address is 81 Prince Street, Charlottetown, PE C1A 4R3. Our phone number is 902-892-8989. Our e-mail address is [peifirst@isn.net](mailto:peifirst@isn.net)



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# Stepping Forward: Including Volunteers with Intellectual Disabilities

## Introduction

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Volunteers provide essential services in our communities and make an enormous contribution to the national economy. According to the 2000 National Survey of Giving, Volunteering and Participating (NSGVP), Canadian volunteers perform the equivalent of 549,000 full-time jobs each year.<sup>1</sup>

PEI People First, a self-advocacy group for people with intellectual disabilities or challenges, understands the important roles that volunteers play in the community and recognizes the importance of volunteer participation among its own membership.<sup>2</sup> For this reason, we undertook a research project in 2005 entitled “Stepping Forward” to demonstrate that men and women with intellectual disabilities<sup>3</sup> can be productive volunteers and that they have enthusiasm and an abundance of skills and talents to share. Although it is true that, historically, people with intellectual disabilities are more likely to have benefited from the services offered by charitable organizations than to have participated as volunteers, we know that there are many men and women with disabilities who are engaged in a broad range of volunteer activities organized by many different community groups. We wanted to find out what people with intellectual disabilities gain by being volunteers and what barriers they encounter as volunteers. Finally, we wanted to demonstrate to

community organizations the feasibility and benefits of including volunteers with intellectual disabilities and show how they could accommodate their specific needs.

In our research, we found that many clients of community service organizations (e.g., vocational training centres, residential services) were being supported to be volunteers in the community. Service providers saw volunteering as a way for clients to learn new things, develop social skills development, and participate in the community.

PEI People First interviewed 32 volunteers and staff representatives of six organizations. Some of the volunteers we interviewed had a “mild intellectual disability”; others had more limited literacy and communication skills. Some required no support whatsoever to carry out their voluntary responsibilities while others needed to have a one-on-one support person with them at all times. This booklet is based on what we learned from the successes and struggles of these volunteers.

What we learned was that volunteers gain knowledge, skills, confidence, and social connections and that organizations gain dedicated volunteers who make a difference. It is our hope that this booklet will encourage other organizations to consider involving volunteers with intellectual disabilities.

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<sup>1</sup> Hall, M., McKeown, L., & Roberts, K. (2001). *Caring Canadians, involved Canadians: Highlights from the 2000 National Survey of Giving, Volunteering and Participating*. Toronto ON: Canadian Centre for Philanthropy.

<sup>2</sup> The terms people with intellectual disabilities and people with intellectual challenges are both used often. For the remainder of this document, we have used the term people with intellectual disabilities.

<sup>3</sup> See Appendix 1 for more information about intellectual disabilities or challenges.

## Be inclusive: Involve volunteers with intellectual disabilities

*“(People) need to believe in themselves. It took a long time for me to believe in myself. Before I started volunteering, a lot of times people told me I couldn’t do this and I couldn’t do that. It took a long time for me to get that out of my system and to believe that I could do it – and I know I can do it – I’ve been doing it for three years!” ~ Susanne<sup>4</sup>*

## Where people with intellectual disabilities volunteer

People with intellectual disabilities volunteer in many different places and in almost every role imaginable. They are involved in many kinds of organizations and undertake many kinds of activities. Some of the types of organizations they volunteer with include:

- advocacy organizations for people with disabilities
- social justice groups
- youth groups
- food banks

**Susanne is 41 and lives in rural PEI with her parents and her school-aged son. She has always been going to the same workshop for adults with intellectual disabilities for the past 24 years.**

I work here at the workshop baking cinnamon rolls, squares, and pies – a little bit of everything. I work here every day and I’ve been here for 24 years. It’s paid work.

A few years ago, a worker asked me where I would like to volunteer. I had always wanted to go to the manor, so we made an appointment with the staff and the next week I was there! Since then, I’ve been going once a week, from 9 to 1 every Thursday. I set and clear tables, do dishes, and help get the meals ready for the next day.

When I go in, people smile and they’re happy. They say “Oh, she’s back!” and that makes me feel good, too. One lady, when she sees me coming, she runs up and gives me a hug. I think it makes a difference – I think they’d be pretty sad and lonely if no one was going in.

I like going – it gets me up in the morning, knowing on Thursdays that I’m going to the manor. It makes me happy. It’s time away from the workshop, and it’s good to



work with different groups of people, getting to know new people, other than the ones who are at the workshop. That’s important. I like to get to know other people.

I’ve learned a lot of things. Knowing I can do it makes it easier for me. It makes me happy and gives me reasons to set goals for where I want to go in life. I know I don’t always want to be here at the workshop. I want to work out in the community. Maybe someday they’ll hire me. I think I’ve learned some things that will help me get a job in the future.

If there are other people who want to volunteer, they should set their goals. They need to believe in themselves. It

took me a long time to believe in myself. Before I started volunteering, a lot of people told me I couldn’t do this or I couldn’t do that. It took me a long time to get that out of my system and believe that I can do it. And I know I can do it, because I’ve been doing it for three years! I keep going back.

<sup>4</sup> In this booklet, we have not used anyone’s real name. This is to protect the privacy of the people who told us their stories.

- sports teams
- churches
- animal shelters
- fire halls
- nursing homes
- blood donor clinics
- libraries
- schools and kindergartens

*“Be aware that you can get some very, very, very reliable people who are very outgoing [and] who can turn your organization in ways you would have never imagined if you are inclusive in who you choose and if you don’t put blinders on.” ~ Staff person*

*“I love doing it. I love it. I like volunteering. I like helping people.” ~Tonya*

*“I need it. I need a volunteering job. I want to be with people, with the residents. I know them.” ~ Lance*

*“It goes back to my childhood, because I came from a poor family. I know what it’s like when people suffer the issue of poverty. These days you see it more in the forefront than ever before. By growing up in it, I have a heart for other people – compassion, you know. I have the heart to help others in need...” ~ Mark*



## What people with intellectual disabilities can do as volunteers

Volunteers with intellectual disabilities contribute to their communities in many ways, including:

- serving as board or committee members; sharing their perspectives, making decisions and guiding policy;
- helping in the office by organizing books, photocopying, and answering the phone;
- advocating for political and social change;
- cleaning and helping in the kitchen; preparing and serving food;
- helping with fundraising activities;
- organizing events;
- caring for animals;
- helping senior citizens with activities such as bowling and bingo;
- doing crafts with children;
- greeting and serving refreshments to blood donors;
- making presentations;
- helping out at the fire hall; and
- working with youth groups.

Not all volunteers with intellectual disabilities have the same capabilities. Volunteer placements work best when activities or tasks match the skills of the volunteer.

*“I got to learn more about other people with disabilities. I like being around people my own age, my friends. I like volunteering for the board because I’ve learned a lot of things since I got on the board, like how to run the meetings. I had to bring people back on topic.” ~ Robert*



*"I learned how to speak up better and talk in front of people. It gets me out. I learn different things. I meet all new friends at these places." ~ Marie*



*"I volunteered at the public library for a little while and at the day care. I also volunteered at a seniors' home and with Allied Youth and 4-H and the church. We collected food for food banks, did yard clean-ups and beach clean-ups. We also helped seniors. We sang Christmas carols to old folks, and we went to the hospitals as well. I also helped my Mom teach Sunday School and serve meals at church suppers." ~ Jane*

**Frank is 41. He lives in the city with his sister and her husband. He is a client of a vocational training centre for adults with intellectual disabilities.**

I volunteered at a junior high school last year making the breakfast for the kids, buttering toast and bagels, pouring juice and chocolate milk for the kids. Plus I used to volunteer at cable station, for about four years. I used to sing over there and play the spoons. With a cowboy hat on and blue shirt, blue pants, blue denim pants. You'll have to hear me some time! At the school, I prepared food and cleaned up. I'd go out and sanitize the tables. They had to give us rubber gloves to wear when we were doing the food so we wouldn't cause bacteria and germs to grow on the food. One of the staff workers here goes with me.

I learned some new things. I learned how to get along with other people and talk to them when they talk to me and not avoid them and walk away from them. I got along great with that, but there were days that were off. I eventually turned it around and carried on with my day.

How did I get started? Well, one day when he picked me up, my worker, he said to me, "Frank, how would you like to go volunteer and make breakfast at the Junior High?" I said to him, "Well, I'll have to give it some thought." So I started in September and I carried it right on until June. I loved it. A worker asked me if I wanted to volunteer on the cable show. I just thought I'd try it on my own. I thought

I'd get to know new people. And my friends wanted me to try it. They said, "You won't know until you try it." I was kind of hesitating, but they said to me, "Just relax and open a new window and things will get easier." And that's what happened.

It was kind of hard to get transportation, so I had to start phoning people. And then I had to come up with the money. At first I didn't know if people were going to accept me or not for who I was. It helped by talking to people and asking questions.

Sometimes I get frustrated and can't handle situations. I might have to stop just for one day or maybe fifteen or twenty minutes to do some thinking about how am I going to handle this. "I've got a problem, what am I going to do."

Why I like volunteering is making good friends and getting to know people. It makes me feel good. I get thinking, "Hey, I did that and I'm glad I did that." Once I got a flashlight for volunteering with the breakfast program at the school. I'd have to say, just do what you can and try to avoid the problems you've got. Leave your problems at home. It's good to learn new things. You might get better and better as things go along.



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## How volunteering benefits people with intellectual disabilities

In recent years, the community living movement has made tremendous strides in raising public awareness of the rights of people with intellectual disabilities. Despite this, the experience of many people with intellectual disabilities today is characterized by isolation, under-employment, lack of autonomy, and limited opportunities to participate in making decisions that affect their own lives. In this context, some of the benefits of volunteering take on a deeper meaning in the lives of these individuals.

**Gerry lives in rural PEI with his mum. He is 48 and has for over 20 years attended the same workshop for adults with intellectual disabilities, where he sands and strips furniture. He volunteers mostly as a board member with several advocacy groups.**

I've been doing this for a long time, at least ten years. I served on the local committee for People First and I was on the provincial board at one time, including as president for while. Now I'm on a different committee that looks at issues in the community that need to be looked at: parking permits for the disabled and accessibility for people with disabilities in the community. I think some things have changed. Some people in the community didn't know we were there, but now they do know we are there. We give a helping hand; for example, when the brand new fitness centre went up in my town, they wanted a new elevator to be put in. We looked at it and found out the bathrooms weren't up to standards for accessibility. They changed things, but we had to lobby for those changes.

I have travelled a little and talked about the issues that come up. I've been on committees; I've made presentations on subjects like housing and transportation. I've met with people from all across Canada: local politicians, the Premier and MLA's. I feel pretty good about these meetings. They want to know who you represent and about the issues you are talking about. From our meetings I know at least they are looking at issues and understanding more.

When I started, I did not know what a steering committee was about. I learned about being on a board and representing your area. I had to learn my role on the board. It was new at first. I did not know how to run a meeting. But learning this in People First helped down the road when I was with other groups.

We have to pay \$2 to the van drivers to take us to meetings. If you want to volunteer you have to have a way to get to there.

What I like about volunteering is to get involved with other people, to keep in touch with people and neighbors. It can be more or less a social gathering. I have pride for doing something helpful. Also, you know when you're volunteering in a group, it's a chance to talk about issues that you really want to talk about. I wouldn't have a chance any other way.

I've learned how to listen to people and share some ideas. I've learned how to get along with people and how to chair meetings. It's good to volunteer. It's good to be out in the community. People should be volunteering to enjoy it. Volunteering is a good thing because it keeps your spirits up and it keeps you in contact with people you want to talk to – it keeps you connected.

Volunteering can have many positive effects on the lives of men and women with intellectual disabilities who have had limited opportunities to learn, to make decisions for themselves, or to participate in the paid work force. The positive effects of volunteering include:

- increased self-confidence and self-esteem;
- learning new skills (e.g., learning how to use technology);
- meeting new people, making new friends, and having a sense of belonging;
- opportunities to travel;
- learning work-related skills that can lead to paid employment;
- social networks and a sense of community;
- opportunities to have fun;
- a sense of satisfaction and achievement;
- an opportunity to get out of the house and do something;
- an opportunity to speak up;
- an opportunity to get involved in important issues; and
- a connection to the community.

*“Volunteering is a good thing because it keeps your spirits up and in contact with people that you want to talk to – it keeps you connected.” ~ Gerry*

*“I feel good about myself, very good about myself.” ~ Diana*

*“I enjoy it. I enjoy getting out for the day. I enjoy people. I enjoy making crafts. And also the birthdays for the residents every month.” ~ Olivia, on helping at a seniors’ residence*

*“I just like it. I get out of the house and everything. I just get to know all the players and coaches and everything.” ~ Shawn, on volunteering with a sports team*

*“What I like about it is meeting new people, new staff people. I would like to find a paid job like this, at a manor. Someone is going to help me with this.” ~ Karen*

*“The time I was elected to the board...I was kind of surprised and shocked at the same time, because I was never elected on a board in my life, period. That made me feel good, that night, when they elected me to the board. And the people clapped that night to show their recognition. They accepted me on the board and welcomed me as well. It was just extraordinary satisfaction I felt that night. You couldn’t put a price on it.” ~ Mark*

*“It’s the community connection between the firemen and me. And we all know each other and we all trust each other. It makes your reputation look good for the community – makes people realize that you’re doing something for the community that people really appreciate. It makes me feel good.” ~ Joseph*



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## How organizations can benefit from including volunteers with intellectual disabilities

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Volunteers can make a big difference in a community or an organization. Volunteers with intellectual disabilities can contribute in a variety of ways. Besides offering practical help such as caring for animals, putting away library books, and serving food, they can:

- share their perspectives on issues;
- educate others about the rights and abilities of people who have intellectual disabilities;
- help make decisions; and
- teach about diversity and inclusion.

In one community organization, volunteers with intellectual disabilities welcome the people who come to the clinic to donate blood. The volunteers serve refreshments and sit and chat with people as they get ready to give blood or afterwards as they prepare to leave. Their interaction with visitors to the clinic – some of whom might be neighbours or potential employers – plays an important role in dispelling myths and in raising awareness of the capacity of people with intellectual disabilities to contribute in their communities in very concrete ways. In this very simple way, these volunteers promote inclusion and respect for diversity.

Another organization included in its bylaws a requirement that at least two of its board members must be persons with intellectual disabilities. According to their spokesperson, *“It’s really important to get the perspective of people living with disabilities. It’s a really big role that people with intellectual disabilities play. We consult with them at the board*

*meetings all the time, about decisions that we make or about how we should go about talking to someone or doing something.”*

*“They bring their own personalities and their own ideas. They bring their own kind of person, a different dynamic to what we’re doing.” ~ Staff person*

*“We make better decisions because of the ideas of people with intellectual disabilities. We’re better connected to the community that we serve, which makes our work better. The main thing is that they speak with such authority on what it’s like to live with a challenge and can often have a very definite sense of what people’s advocacy needs are.” ~ Staff person*

*“He’s a great worker. I really depend a great deal on him. He’s always obliging, very helpful. I’d be lost without him, basically. When he doesn’t come in a day, I miss him a lot.” ~ Staff person, on the contribution made by a volunteer.*

*“I think it makes them happy – they don’t have many people in there to talk to.” ~ Laura, on making a difference by volunteering with senior citizens.*

*“I think it’s important that organizations are reflective of the community.” ~ Staff person*

*“Everybody wins. Our staff wins because volunteers are helping us. The volunteers win because they know that they’re doing an important job and it’s helping animals and it’s helping people. I think the animal shelter as a whole wins because it shows that we are a community organization that is inclusive, that includes everyone in our work to help animals.” ~ Staff person*



## How organizations can accommodate volunteers with intellectual disabilities

Some volunteers with intellectual disabilities may need a lot of extra support, others may need it only for a short time, and still others may need no extra support at all. In many cases, strategies for accommodating volunteers with intellectual disabilities are strategies that can improve overall volunteer relations. They include:

- providing a thorough volunteer orientation and a clear job description;
- assigning tasks according to ability, comfort level, and interest;
- breaking jobs down into clear steps;
- ensuring that transportation needs are met;
- recognizing the value of support people,<sup>5</sup> especially in the early stages;
- thinking about ways to increase the physical accessibility of your building or office; and
- talking to other organizations that have engaged volunteers with intellectual disabilities.



<sup>5</sup> Who are support people? Some agencies that provide training and vocational services to individuals with intellectual disabilities see volunteering as a good way to help people to develop skills and participate in the community. Because of this, they provide paid support people to accompany their clients with intellectual disabilities who participate in volunteer activities. Individuals may find volunteering easier if they have the assistance of this type of support person. Others may only need their support person to accompany them for the first few times they volunteer. Sometimes individuals may wish to have their support person with them every time they volunteer. Organizations interested in recruiting volunteers with intellectual disabilities may want to start by contacting a local vocational training centre.



Some accommodations have to be made with organizing tasks, for example:

*“Every day, Peter goes to volunteer at the kindergarten. At first, he brought a support worker with him. Now he goes alone. He knows when to go and how to get there. Peter does a lot of different tasks at the kindergarten. He cleans, and he helps with snacks. Peter is really good at organizing and he likes to organize the children’s shoes by colour and size. He will also organize the dishes by colour. Peter learns tasks very quickly and is very good at his work. To help Peter remember and keep track of his tasks, the kindergarten staff made Peter a chart with words and pictures. When he has completed a task, Peter turns the word or picture around on the chart. He likes to keep things organized and in order, so he likes the chart.”~ Representative of an organization*



Another organization found it helps to break the job down into clear steps:

*“Volunteers help to keep the dog park clean and tidy. We all know how to clean, right? And we know what tidy is. But do we all know what it takes to keep that dog park clean? First you have to get a bucket of warm water with soap in it and a bit of Javex [bleach]. Then you have to walk out to the dog park. Then you have to get the bowl for the dogs and clean it. Then you have to go to each station where the bags are for the poop and you have to clean those stations and then you have to dump the poop into another bag. So there are lots of steps and we have to make those steps clear to everybody. And when we have to make them clear and write them down for a volunteer who has an intellectual disability, it makes us think really hard about all the little things that have to be done. There are a lot of jobs here like that.” ~ Representative of an organization*

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Organizations that include people with intellectual disabilities on their board of directors or on committees can make accommodations by:

- using plain language;
- remembering that not everyone has access to a computer or e-mail;
- not relying on written information or assuming that everyone reads;
- pairing up an individual with an intellectual challenge with a ‘buddy’ for support; and
- balancing the desire for efficient and punctual meetings with the need to ensure that everyone understands the process and has a chance to participate.

**It is important to** take steps to ensure that your organization’s relationship with the volunteer is not exploitative. For example, if a volunteer with an intellectual challenge is not currently employed, do not assume she or he is always available. Remember that his or her time is just as valuable as yours. Volunteers should not be used to meet the ongoing labour needs of businesses or organizations. A situation may be seen as exploitative if a volunteer is providing assistance on a continuous basis with tasks that would normally be done by paid staff.

*“I’d advise other groups that they need to respect people with disabilities and not [see them as] just unpaid labour.” ~ Staff person*

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## Final points to consider

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Across Canada, men and women with intellectual disabilities and their supporters continue to advocate for their rights to be included – at home, at work, and at school. They fight for their right to make decisions, for opportunities to learn and grow, to live in real homes instead of institutions and to have access to meaningful jobs. On the surface, these are not extraordinary requests, but against the backdrop of centuries-old negative stereotypes and attitudes that have resulted in institutionalization, lack of respect and denial of basic human rights, these ordinary expectations take on a deeper meaning. Volunteering presents an opportunity for people to participate in and contribute to their communities, to develop skills and self-confidence, to dispel myths about intellectual disabilities, and to gain respect. Community organizations, and the volunteers and staff who make up those organizations have a role to play in the struggle for inclusion. By creating more opportunities for volunteers with intellectual disabilities, organizations not only facilitate relationships and inclusion within their own walls, but they also send a positive message to the rest of the community about the strengths and capabilities of individuals with intellectual disabilities.

*“It makes your reputation look good for the community. It makes people realize that you’re doing something for the community that people really appreciate. It helps me to do other things. If I go to other places to volunteer, everyone is going to talk to me and everyone is going to say, ‘If you need me, just call me.’ It’s just the connections with the community and with the people.”*  
~ Joseph, a volunteer with the community fire station



## Getting started

“My advice for groups that are looking for volunteers is to basically find out who is a good volunteer, and make sure place is accessible.” ~ Gerry

Here’s what you can do if your organization would like to include volunteers with intellectual disabilities:

1. Ask a self-advocacy organization for persons with intellectual disabilities to make a presentation to your group.
2. Work with organizations and individuals with intellectual disabilities to develop and distribute plain language information about your organization and your volunteer opportunities.
3. Contact local groups or services who can connect you with volunteers with intellectual disabilities. In Prince Edward Island, this includes:
  - **Citizen Advocacy’s** e-mail address ([peica@isn.net](mailto:peica@isn.net)) – contact them about their document *Having their say: Including persons with mental handicaps in our organizations*
  - **People First** of Canada ([www.peoplefirstofcanada.ca](http://www.peoplefirstofcanada.ca))
  - **Queens County Residential Services** (Charlottetown) – (902) 566-4470; [qcrs@pei.aibn.com](mailto:qcrs@pei.aibn.com)
  - **Tremploy** (Charlottetown) – 892-5338; [tremploy@auracom.com](mailto:tremploy@auracom.com)
  - **Community Connections** (Summerside) – (902) 436-7576; [commcon@pei.aibn.com](mailto:commcon@pei.aibn.com)
  - **PEI Association for Community Living** – 566-4844; [info@peiacl.ca](mailto:info@peiacl.ca)
  - **PEI Volunteer Network** – <http://www.volunteer.pe.ca/>
  - **Voluntary Resource Council** – Charlottetown, (902) 368-7337
  - **PEI Citizen Advocacy**. (1996) *Having our SAY; Including persons with mental handicaps in our organizations.*
  - **The Roeher Institute** ([www.roeher.ca](http://www.roeher.ca)).



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## Useful information resources

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Schmidl, B. (2005). *Simple solutions: How NGOs can eliminate barriers to volunteering by people with disabilities*. Toronto, ON: Knowledge Development Centre, Imagine Canada. Retrieved July 5, 2006, from: [http://www.kdc-cdc.ca/attachments/manual\\_pei\\_council\\_eng.pdf](http://www.kdc-cdc.ca/attachments/manual_pei_council_eng.pdf)

Volunteer Centre of Toronto. (2002). *Ready and able: Information for organizations – benefits of partnering with volunteers with disabilities; separating myth from fact; implication for volunteer management*. Webpage. Retrieved July 5, 2006 from: [http://www.e-volunteering.org/specialneeds/sn\\_organizations.asp](http://www.e-volunteering.org/specialneeds/sn_organizations.asp)

**Canadian Association for Community Living**  
<http://www.cacl.ca>

**People First of Canada**  
<http://www.peoplefirstofcanada.ca>

**Public Service Human Resource, Management Agency of Canada**  
[http://www.hrma-agrh.gc.ca/ee/ncfspd-cnehfpf/links\\_e.asp#link2](http://www.hrma-agrh.gc.ca/ee/ncfspd-cnehfpf/links_e.asp#link2)

**The Learning Disabilities Association of Canada**  
<http://www.ldac-taac.ca/>



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## Appendix 1: Intellectual disabilities

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An intellectual or developmental disability is a condition that starts early in childhood (making it distinct, for example, from a brain injury) and is marked by an impaired ability to learn. It is not the same as a mental or psychiatric illness. Individuals with intellectual disabilities sometimes say they are “slow learners.” They may have trouble with communication, social skills, or learning. Although some individuals might have quite profound disabilities and require a high level of support, others are quite capable of living and working independently. Men and women with intellectual disabilities are entitled to the same rights as everybody else. For more information, contact:

**PEI People First** – Charlottetown, (902) 892-8989

**PEI Citizen Advocacy** – Charlottetown, (902) 566-3523

**PEI Association for Community Living** – Charlottetown, (902) 566-4844

**People First of Canada** – <http://www.peoplefirstofcanada.ca/>

**Canadian Association for Community Living** – <http://www.cacl.ca/>



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# NOTES

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