InFocus: Building a More Inclusive Community for People with Disabilities

April 11th, 2013
Murphy's Community Centre, Charlottetown

REPORT

Participants: Over 80 people took part in this forum. The participants were people with disabilities, service providers, people who work for advocacy and other community organizations, social workers, people who work for government and politicians.

1. Welcome and Introductions: To start with, **Josie Baker**, facilitator for the forum, welcomed everyone and introduced **Denice MacNeill**, who would be doing American Sign Language interpretation.

Josie also introduced **Dianne Crowell**, a representative of DAWN Canada in the Atlantic Region. Dianne talked about how the project called InFocus is taking place in each province and territory of Canada. She said the forums are part of an effort to create awareness in communities about the issues of health and safety for people with disabilities. The organizers hope that the forums will lead to more action on these issues. The forums in New Brunswick and Nova Scotia have already led to some new activities. She talked about the importance of everyone supporting one another and working together to make sure people with disabilities are included in their communities.

Josie went over the agenda. She read the three **goals** for the afternoon:

- To become more aware of the issues people with disabilities face getting access to health care
- To better understand the challenges people with disabilities face getting access to services and supports to help them deal with violence
- To come up with strategies to support Islanders with disabilities to be safe and healthy in their communities

Josie then asked people to suggest some **ground rules** for the afternoon, to make it easier for everyone to communicate with each other. Ann wrote on flipcharts some of the ground rules that people suggested:

- ✓ Listen to people when they are speaking, without interrupting,
- ✓ Speak slowly please,
- ✓ Respect the interpreters and anyone who is hard of the hearing,
- ✓ Treat each other like human beings and be respectful.

2. Panel Presentations: Josie introduced **Anne MacPhee**, who was going to be the chairperson for the panel discussion. Anne introduced each person before he or she started to speak, and after each presentation, she summarized what she had heard.

Eleanor's Story – Eleanor's first husband abused her. One day he hit her and broke her ribs. She called a friend, who came and got her, took her to a women's shelter in Charlottetown. She went to the police. They charged her husband. She had to find a new apartment. Her advocate helped her to get her things from her old place. When she got her apartment, her partner followed her and she needed to get a restraining order so that he would stay away from her.

She went to a women's support group, which was helpful. Eleanor says she has trouble with reading, and it was hard to participate so she left the group.

She got divorced and in another relationship her partner also abused her. She got help from a neighbour who called the police. She went to Anderson house again, and police became involved the second time with the other partner. She did not have to go to court; it was dealt with outside of the court system, so that was good for Eleanor. Victim Services helped out. Her partner went to an anger management course and doesn't abuse her anymore.

About health, Eleanor said: Part of being healthy is having good teeth. Social Assistance does not pay for getting your teeth cleaned. They only pay for pulling rotten teeth.

There is very little coverage for transportation so she has to rely on friends to volunteer to take her to appointments. Having to ask for friends all the time is hard.

When she was asked if there were any other challenges Eleanor said some of her medications are not covered by the provincial plan. Counselling is another challenge; she felt uncomfortable with a counsellor but her social worker would not let her see a different one.

Anne thanked Eleanor for her honesty and sharing her story; it is powerful and helps us to better understand the challenges of dealing with violence and keeping healthy.

Highlights:

- Having someone to call – someone you trust – is important
- It's good to have someone who can help get you to a shelter and talk to police
- Support Groups should be open to everyone even if you can't read
- People need more money from Social Services, to stay healthy – better coverage for dental care and medications
- When you need counselling, you should be able to choose your counsellor

Jake's Story – Jake has an advocate, Pat, and she made the presentation with him. Kendra from PEI Citizen Advocacy also helped to make sure Jake's voice was heard.

Jake said he enjoys spending time with friends, going downtown and watching the Montreal Canadians. Jake has lived at different community care facilities. Right now he lives at Hillsborough Hospital. Jake has a lot of experience fighting for his rights, and getting his voice heard.

At the hospital, Jake has his own room, and pictures up and a big TV to watch hockey, and they (Montreal Canadians) are going to win the Stanley cup. He goes to church and activities, rides and dances. But Jake said he doesn't like living there. "They watch me, and I don't like that. It's not good. I can only go for walks to the gazebo if a staff takes me. Can't sit on a bench without someone taking me. **I have no freedom**; I don't get to make my own decisions. But I should be able to."

Jake was told that he ended up in Hillsborough Hospital (HH)because he had too many trips to the hospital by ambulance in one year (he was admitted to HH after being taken to the QEH by ambulance when he had the flu) and that meant he could no longer live at the community care facility. He had no choice in the matter.

He has been very close to being able to get out of HH and moving into his own apartment with a person he knows, but a local service provider thought he would be too aggressive if he lived with another person, so he was not allowed to leave.

Jake said that he got angry when they tied his arms and legs in his room. When he feels his freedom is taken away and when people don't take the time to listen or ask questions and give him the time to process and get his answers out, he will get frustrated, and then he ends up getting hurt.

Jake said his physical health is good, but he gets sad. Pat noted that doctors and others have told Jake that he should stop talking about getting out, and that he should "behave".

Anne summarized what she had heard. She said it is sad that he is not living where he wants to, and that his voice is not being heard. It's sad that he can't go outside without someone with him, and that the chance to be alone is taken away. The reasons people gave for Jake's situation are not good enough. It is understandable that he feels frustrated and angry. Restraints should never be used. We need to treat each other with respect and kindness.

Highlights:

- Freedom can be taken away
- People have their choices taken away
- Communication is important
- Other people sometimes make decisions for you
- People are using restraints
- Having a good advocate is important
- Look beyond the behaviour – at why people behave the way they do

Kathy's Story – Kathy is deaf. She has a cochlear implant which means she can hear a little and speak. She talked about challenges people who are deaf face in getting access to health care, as well as the challenges of being deaf in a province where services are not adequate. Denice is an ASL interpreter, and supported Kathy; she also interpreted (American Sign Language) for those in the audience that needed it.

Kathy was born deaf and at 2 was taught to lip-read and when she was 16, she learned to talk. She said some of her friends have moved away from PEI because there is not a large community for persons who are deaf and there are not enough services.

Kathy said there are no interpreters at most events. People who are deaf need to pay out of their pockets for interpreters. It is hard to get an interpreter for doctors' appointments. If you need one you may need to pay for someone to come from off Island or hope that a family member can come. You have to pay them by the hour, even when you are sitting in a doctor's waiting room.

She was in the hospital after having a stroke and it was difficult to understand the doctors. The interpreter had to force her way in to the Emergency Room. Kathy would like to see better health care for persons who are deaf. They need to have access to an interpreter every time they go into the hospitals. **PEI is the only province in Canada where an interpreter is not present in the hospital at all times**. You have to pay for it yourself! They are breaking the law and the basic right of people to be understood.

Kathy said, in the hospital there are times when she needs to remove her implant and she is totally deaf. She has to make sure that the nurses or doctors know she is deaf, and that they are speaking clearly and slowly, looking directly at her. She also has to keep pushing for Denice to be allowed in.

Privacy is an issue – in order for her to see who is coming and what they may be saying, she has to keep asking for them to leave the curtain open, which is another example of having to fight for the awareness of the health care providers.

The lack of Interpreters is the most important thing that limits access to health care. It is a very isolating feeling to not have interpreter there. It feels like her safety is not important to people in the system. She can't always rely on family when Denice is not available.

Anne summarized some of Kathy's issues and challenges. For a person who is deaf or hard of hearing, an interpreter is as necessary as a wheelchair is to someone who cannot walk, and to not have it provided is wrong.

Highlights:

- We need interpreters in the hospital
- An Interpreter is as important as a wheelchair
- People don't know enough about the communication needs of people who are deaf and hard of hearing

Bernie's Story – Bernie started by saying that society is judged by how we treat our most vulnerable people, and considering where we live, society does not treat us well, and society MUST do better. He said he appreciated the chance to talk and felt that for persons living with disabilities, as they get older, it is getting harder.

Health care to Bernie means "getting what I need when I need it, and being part of the world, just like everyone else". He said, "Independence means I can do what I want when I want to, because I have the equipment and care I need". Bernie is living at the Prince Edward Home and he is happy with his decision about that. Although, it is noisy there, and it can be difficult to share and have your belongings be respected.

It makes you crazy sometimes, and he needs to get out and shake off the 'cabin fever'. He sees a lot of depression with persons with disabilities, and for good reason. He sees some people living at the home who have never left, or spoken, and who are lonely. Bernie sees that every day.

With the financial cutbacks that have happened and are happening, he feels that people with disabilities become a "list of things to do for staff". Bernie gets the care that he needs and he appreciates it, but would love a house or home of his own.

Bernie expressed his frustration with the fact that when you live in long term care facility or institution, you can't get DSP funding. Equipment, such as wheelchairs, doesn't last forever! He gets what he needs because he has a loud voice, and has contacted the PEI Council of People with Disabilities, but he is very concerned about the people who don't have a voice, an advocate or the ability to say what they need to the people who need to hear it.

The longer he lives at the Prince Edward Home the worse he feels. People die, and it's hard to deal with that. No wonder he feels depressed or sees other with depression issues. He worries about his future. Depression is a very real issue for persons with disabilities.

Bernie said children don't judge, and he really liked working with them; they accept him at face value. He can go anywhere and children will talk to him ask about the wheelchair and see it as part of him, and not be scared. He closed by saying, "Let's push for some changes."

Anne summarized: Bernie thinks we need to look at the positive in life, as well as the negative and work together for positive change. Everyone needs independence and privacy. She noted that people with disabilities are more vulnerable because they often are living in close quarters, and sickness spreads, and depression is an issue that needs to be addressed.

Highlights:

- Look at the positive as well as the negative – to make change
- Independence is important
- In institutions there is not much privacy, and it's too noisy
- Institutions are costly
- Institutions can lead to depression – you are always around death
- You can easily feel like someone's "To Do List" instead of a person

3. Questions for the Panel – People said they appreciated the stories the panellists had shared. We need to raise our voices and say it is not OK to be in Hillsborough Hospital. Here are some other questions and comments:

Who do we talk to about discrimination that is taking place? What can we do? Bernie answered that the people who can do something about it (government), are often too far away. We want them to pay attention to us but we also need to listen to what we are being told. He sees that questions are starting to be asked of people with disabilities. If you are smart enough to know that things need improving, then you need to take the time to LISTEN to the answers and DO something about it (when you are not happy with what you hear). Make changes! Do better.

Are there any other challenges for persons who are hard of hearing or deaf, when they try to get help after they are hurt? Kathy said that sometimes when she asks for help, she is turned down. You have to keep asking, "Who can I ask for help when I need it?" There is only one interpreter and family members are not always available.

The rights of people who are deaf or hard of hearing in PEI are being denied – in Canada all hospitals are supposed to have ASL interpretation services. This needs to change.

Because services are limited, people who are deaf or hard of hearing tend to rely on family and friends for interpreting. If you are in a violent situation, and it is a family member who is hurting you, this means you have no access to proper treatment or counselling.

4. Small group/ table discussions and report back:

After hearing from the panellists about the challenges they face being healthy and safe, everyone worked together at their tables to answer the following questions:

1. ***What are the barriers?***
2. ***What would make things better?***

4.1. Barriers

*a) **Health** Care*

Not enough doctors – you don't have the same doctor every time – they don't know you
Doctors and other health care providers use language that's hard to understand
Some women do not feel safe with a male doctor
Most dental care is not covered (if you are on Social Assistance)
Not all medications are covered by the provincial plan
Mental Health services are limited
Specialists are often far away and you have to take time off work to go to see them

*b) Specific barriers for **people who are deaf or hard of hearing***

Hearing aids are expensive
It's hard to find communication devices or interpreters for people who are deaf
The alarm system in hospital doesn't work for people who are deaf or hard of hearing
You don't have access to counselling when there are no interpretation services

*c) **Transportation***

Transportation is expensive, not always accessible and lacking especially in rural areas

*d) Other **Services***
Speech therapy is not available everywhere and families often have to cover the costs
Not enough training for service providers to work with people with disabilities
Getting what you need depends on “who you know” – lack of accessibility

*e) **Housing***
The “System” puts people in institutions instead of supported, independent living
Lack of housing options- not enough choices for independent living
Some buildings are not physically accessible – including government buildings

*f) Getting **Help***
Some people can’t speak for themselves
Some people are afraid to call someone
There aren’t enough advocates
It’s tricky sometimes, getting support from advocates without losing independence
When people are put in institutions they stop trusting people

*g) **Safety***
Violators get off too easily
Victims are blamed
Victims are not believed
There is not enough safe housing in PEI
Police don’t always understand
People don’t trust the police
People in the community don’t know what abuse looks like for people with disabilities

*h) **Knowledge** and Skills*
Not enough job opportunities
Literacy is an issue for many people
Not knowing how to prepare healthy food

*i) **Money***
People don’t have enough money to get healthy food
Lack of funding for programs & services
Not enough money! Financial freedom does not exist for people with disabilities.
DSP limits – things don’t get covered – cut-offs seem arbitrary (i.e. speech therapy)
Social Assistance rates are not enough for good food, housing, clothing, medicine, dental

*j) Lack of **Awareness** in the Community*
People don’t understand about disabilities - they have ideas about who (or what) people with disabilities are and what they can or can’t do - stereotypes
Lack of visibility of people with disabilities in the community
Assumptions about what persons with disabilities can’t do
Decision-makers seem to lack empathy

*k) Lack of Respect for **Rights***
PEI is not following national laws and agreements
It can be frustrating and tiring always fighting for your rights
You have to ask for help and that makes you dependent on other people

4.2. What would make things better?

a) Increase people's ***income***

Guaranteed Annual Income – a basic income that you can live on, and be healthy
More money through Disability Support Program
Raise Social Assistance Rates to a livable income
Complete coverage of dental care and get all medications covered

b) Promote the ***rights*** *of people with disabilities*

Create a position of Ombudsperson to advocate for the rights of persons with disabilities
Have an Ombudsperson at the hospital

c) Increase Public ***Awareness***

Create awareness of the issues and of how to support people with disabilities to be equal participants in society – focus on human rights – events and activities
More VOICES!

d) Build awareness and make plans for ***safety***

Organize support groups for women and men
Work with service providers to make them more aware of communication needs and issues – talk to Victim Services, Police and Anderson House, etc.
Develop a social awareness program that violence is not acceptable – use MADD as a model
Educate people about what violence and abuse looks like for people with disabilities – it's not just about hitting
Make more information available about services such as Anderson House, Rape and Sexual Assault Centre
Create safety plans
Stay away from people who are using drugs/alcohol
Have a cellphone
Identify a safe person to talk to

e) Use ***Information*** *to empower people*

Distribute information about supports (government as well as advocacy groups)
Create awareness around community organizations that offer support and advocacy
Get service providers together to share what they do and get information out by having meetings, making a directory and putting things in the paper
Encourage use of Plain Language
Recognize limits of written information – people want to get information from other people

f) Build ***Skills***

Exercise or walking groups
Cooking groups (community kitchens) to develop skills
Literacy – need programs

g) Health Care

Health Care Providers should use plain language, and speak slowly
Make presentations to health care providers
More attention to addictions and mental health
Lobby for more Nurse Practitioners
Patient registry – ask for monitoring and targets for time people can stay on it
Emergency services should all have some capacity to communicate using ASL

h) Lobby for better services for people who are deaf or hard of hearing
Interpreter, videophone and appropriate phones for all,
More funds for hearing aids (if you are deaf, you are covered if just hard of hearing it is not!) and other technologies
Bring hospital alarm systems up to standard for persons who are hard of hearing & deaf
Talk to counsellors
Increase awareness about sign language.

i) Demand better housing options
More accessible homes!

j) Transportation
Transportation! Better accessibility in rural communities, and affordable
Rural public transportation system
Audit transit system for accessibility including stability issues
Awareness program/information sessions with bus drivers

k) Speak up!
Get elected officials involved
Offer the solutions to the problems –we have to **ask the questions** to get the answers from people who know. They, and we, must make society better and fully accessible to everyone. Demand that they spend the money on what is needed. WE BELONG AND WE MATTER!!

5. Next Steps – Julie Smith, from the PEI Association for Community Living talked about the next steps in the InFocus project. There will be 3 focus groups – for men with disabilities, women with disabilities, and service providers. Julie invited anyone who wanted to help plan the focus groups or take part in one of them to contact Ann at Cooper Institute or Julie at PEI ACL.

Julie thanked the organizers of the forum – Ann Wheatley, Cooper Institute; Teresa McKinnon, PEI Council of People with Disabilities; Joni Miner and Heidi Mallett, PEI People First; Shelly Breau, DAWN Canada board member. She also recognized national project partners CACL, IRIS, and DAWN Canada and the support of the PEI Interministerial Women's Secretariat.

6. Evaluation – Participants filled out evaluation forms. Here's what they said:

- The purpose and the goals of the forum were clear.
- The place was comfortable and accessible.
- The forum was well organized.
- People agreed they had a chance to participate and share their ideas.
- Most learned new things about access to health care for people with disabilities.
- 2/3 of participants said the forum gave them new ideas about actions to improve access to health care for people with disabilities.
- 2/3 of people said they learned new things about violence prevention and safety for people with disabilities and that the forum gave them new ideas about actions to improve violence prevention and safety for people with disabilities
- The stories of the people with disabilities (panel discussion),the large group discussions and the small group discussions were useful.

What were 3 important things you learned at the forum?

The lack of trust that results from people's experience in institutions

The extent to which people are stripped of their voices and independence

PEI is harmful to its disabled residents

How far behind PEI is in terms of meeting human rights – we can challenge this

There is a long way to go to correct the issues

Need for advocacy – a strong need for an ombudsperson

Need for more housing options for people with disabilities

People are not alone – the same issues are Island-Wide

More money is being spent on putting people where they do not belong

We have a VOICE. There is HOPE!

The hospital has violated peoples' rights - there are places in PEI that use restraints

Finances are a huge concern and lack of resources is a huge issue

Disempowerment of people with disabilities – decisions are made for them

Rights on paper aren't rights in practice

People with disabilities experience injustice

There are more people who are worse off than I am

We have work to do – we need to change things – it will take different ideas and actions

Institutionalized discrimination and the lack of decency

Shocking and moving personal stories

That other people have the same thoughts that I have

Lack of value placed on people with disabilities

I have a role to play in making change – it's important to stand up for yourself

Understanding giving a hand up rather than a hand out to make a positive difference

Speech language pathology stops at Grade 3

If you don't "behave" you can have your decision-making powers taken away

There are many safety risks that are even more risky for people with disabilities

Important for me to hear how people with disabilities feel not listened to, and excluded

The lack of services for people who are deaf or hard of hearing – need for interpreters

People in positions of power need to listen

You need to not quit - You have to keep pushing the issues

People have important stories – we need to hear them – listening is important

If you warehouse people you see will them as things in a warehouse

What would you like to learn more about?

Advocacy –

How to implement ideals
More things a person with a disability can do – how to advocate!
Where to get help and supports for people with disabilities
How to do more advocacy in rural areas
How do we get what we want without sounding negative?
We need more telling of the truth as difficult as it is.
More about solutions that exist
Social organizing and how our groups can work together

Getting Help -

Steps to take after violence happens
Are there lawyers for people with disabilities?
More about what services exist to help people find jobs
Would like to receive newsletters, updates from groups such as COPD
Is there is a list of organizations that offer assistance to people with different disabilities?

Other comments:

I was surprised by how overcome I was by the panellists' personal stories. Please thank them again and let them how much I learned from their courage.
It was a very good session – and a big thank-you to the people who put it on
Loved the suggestion of the ombudsperson to keep the needs of people in the media and help focus pressure on government.
Everybody did a good job - Excellent Forum!
It was life changing
It was interesting and there was lots of good information and also, good, healthy food!
Thank-You!