

Health Care and Disability

in Prince Edward Island

A report about how people with disabilities in Prince Edward Island are or are not getting everything they need to be healthy.

Research Report

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What we learned

People with disabilities talk about how income affects their health and about their experiences with health care professionals.

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Gathering the information

How information was gathered for this report.

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Challenge #1: Income

Being healthy depends on how much money you have.

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The importance of getting information in a way you can understand.

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What did we learn?

The first title of this study was "Access to health care for people with disabilities". We wanted to know about the challenges people face when they try to get access to the formal health care system.

The challenges people talked about are:

- Attitudes about people with disabilities
- Communication

The people who took part in the interviews made it clear that there are other challenges to being healthy that may be just as important to them:

- Low income
- Lack of good housing options
- Transportation
- Isolation

Where did this information come from?

In 2011, we talked to nine people with disabilities who live in Prince Edward Island. We asked them questions about their experiences with the health care system and about what it takes for them to be healthy. Some of what they said is in this report, but we have not included any names.



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What effect does a person's income have on their health?

There are different ways in which having a low income affects a person's health. People with disabilities often **have** less money than other people, and they often **need** more money.

Sometimes they need money to pay for extra care and equipment, which can be expensive. Participants in this study said they could not afford: wheelchair accessories and repairs, extra home care visits, hearing aids, stockings, and special shampoos.

"For instance, my hearing aid . . . These hearing aids are \$1,900.00 each. There's no chance of them being covered. I need them so much. I can't do without them. They wear out and you need to get new ones."

Some people don't have enough money for some **medications** or **dental care**. Dental care is important for your health.

"The dentist won't clean your teeth - Income Support won't pay for it - they will pull a tooth if it is bad, but they won't fix it. I want to look after my teeth - they're important; I want to get them cleaned but I can't afford it."

Some people said when they have to pay for the dentist or medications they may not have enough money for other things, like food.

"Sometimes you can't buy the things you need because you have to pay for medication, pills - things like that. If there is something wrong with my teeth, I have to pay for that."

Another thing people said they had trouble paying for is **healthy food**.

"Once in a blue moon I can afford healthy food. I buy just canned stuff - I don't have a choice - they say cans aren't as good. I know how to cook a good meal - and bake things but I don't get the good things to make a good meal."

Having a **social life** is an important part of being healthy, but without enough money, you can't really afford to go out:

"If you need that money for food, your electric bill . . . then you just don't have a social life."

What difference does transportation make to your health?

Getting out, and going places – whether it's to shop for groceries, for a visit with friends or a trip to the doctor – can be expensive. Many people with disabilities rely on taxis or a wheelchair-accessible bus service.

"Social Services gives 25.00 a month for transportation - which people need to get out to the food bank or the store - and they will give you up to 31.00 a month for medical appointments - that's not very much if you have to go to the hospital every week for physiotherapy or something. Plus you can only get that if you have a plan written out by your doctor or other medical person. They expect you to ask neighbours for a ride."

Public transit is starting to grow in Prince Edward Island. It should be an affordable option for people but there are several challenges. The system in Charlottetown can be confusing:

"If you don't know your way around town, it's very hard to do - which place to go, which bus to take. So it's hard for me to understand that way."

It's easier to be healthy when you have enough money for:

- Special needs & equipment
- Medications
- Dental Care
- Healthy Food
- Transportation
- A Social Life

How does housing affect a person's health?

Where you live can have an impact on your health. People with disabilities are often grouped together in institutions, group homes, community care facilities or nursing homes, not because they have chosen this option, but because there is not enough support for them to live more independently. This can cause people to feel as if they have no power or control over their lives.

"I live with my husband and a roommate. We can't really afford it, but you can do more things, you can be out, doing things . . . around the community, walk around, go shopping. A lot of people in group homes have to have people with them. They treat you like a two year old kid, and I didn't like that."

"I'm 46. The average age in here is over 80. I came here because I needed a place, and there was no such thing. I wanted an apartment. I didn't want to live where I was, and I needed the care that I get here. And I don't need near as much care as some other do. They need to be able to breathe, to physically help them eat. I'm half their age, and I have twice as much energy as they do. Mentally I don't belong in this place."

Many of the housing options that are available have the effect of making people feel left out or excluded from their communities. When people are housed all together in one place, it may cause others to see them as "different" which makes things even worse, and can have a negative effect on self-esteem and mental health.

"The [supported housing building] was built with all the best intentions. It's an adapted apartment building for people with disabilities. It's full. The difference between that building and any other is that people with disabilities can live there. But on the outside of it, you don't notice. It's a home. But what it does, it ghettoises people that live there. You [become] one of THOSE people that live in THAT home. I came from there to this home, so now I'm one of these people that lives in this home . . . I'm just somebody that lives in a home."

Participation in the community/social inclusion:

Feeling included and participating in the community is something that helps people to be healthy. This can be a challenge for people with disabilities, because of low income, lack of transportation, inadequate housing and supports.



The feeling that you are cut off from the community can lead to depression. It can also make people feel afraid.

"It's made my depression even worse, much worse, because I'm homebound. I can't go anywhere. I can't do anything. And when you don't have support systems, it really hurts. If I have to go somewhere, I have to take a cab, and it eats into my budget. It's really scary. I'm scared. I'm (age), and it's happening to me and I'm like "Whoa!" Hopefully I'll get better, but it kind of shows that when I'm older and things start going. I'm really screwed. Like now, I can still do my upkeep, and housekeeping, but [what] if I couldn't do that? I'd be screwed."

Things people said were good for their health:

- Having a good place to live.
- Having support to live independently.
- Being connected to people - having a social life.
- Participating in your community.

How do attitudes about disability and people with disabilities affect health care?

When health care workers show a lack of respect or sensitivity: People want their health care providers to treat them with respect and with sensitivity. This doesn't always happen:

" . . . [the doctor] said, "Do you transfer? Do you get in an out of your chair?" and I said "no", and he said "Well, we're not going to bother with that...we'd get in trouble". And he turned his back."

This kind of experience is important because:

a) when you are in a vulnerable position and you are treated disrespectfully, at that moment you feel hurt and even afraid, and you may lose your confidence to share important information about your health with the health care provider, and
b) when you need to get health care some time in the future you may not feel comfortable enough to go to a doctor or nurse or other health care worker.

Assumptions about capacity: Physicians sometimes assume that people with intellectual disabilities are unable to make decisions surrounding their health care, and therefore they may choose to discuss those decisions with someone else in the person's life – such as a family member or a landlord. Many people with intellectual disabilities are aware of this, and would prefer to be talked to directly.

Individual patients have the right to decide with whom they share information about their health. When physicians choose not to respect that right, they may lose the trust of their patients.

"[Doctors] should talk to [us], not to the people who talk to us. When I lived in the group home, they treated you like a kid, and if you had to go to the doctor, they would talk to the people you live with and not to you. I got kind of mad, because we aren't kids . . . with a handicap or a disability, people think "Oh no, you can't do that", and talk to the person that [the person with the disability] lives with. People don't like that, they like to know themselves"

The importance of Good Communication

Several things can get in the way of people understanding their health care worker:

- the language the health care workers use is sometimes hard to understand
- sometimes people speak too fast
- instructions may be given in written form and hard to read

Why is this important?

- if you don't understand you might feel too uncomfortable to ask for things to be explained
- you might feel "stupid" and this can make you feel bad about yourself
- you might not be able to follow the treatment the health care worker is prescribing so your health won't improve
- you might not want to go back to the health care worker next time you have a problem

"You don't really know . . . what they're trying to say to you. If it's in small print, forget about it, because everyone can't read small print – some people can't even read or write so with medications you don't know which one to take at a certain time or what to take it with . . ."

"It would be better if . . . when they give us medication, to make sure that it is plain language and make sure that we can read it and understand what it's for and how it's supposed to help."

"They don't really explain it to you and you're afraid to ask questions, because you don't really want to say the wrong thing to the doctor because you don't know how to say it – they use these doctor terms . . ."

Using plain language and other tools to improve communication would help people to feel comfortable, confident and more empowered to ask questions. This would help them to get the most out of their appointments, and also afterwards, in following through with any treatment they are prescribed.