

Podcast – Paul-Claude Bérubé

This year we are celebrating the 35th anniversary of the independent living movement.

We want to revisit some of the Canada 150 stories and update people's journeys as much as possible.

And ask them the question, what does the Independent Living movement mean to you as you continue your journey?

Did you know that there are 24 Independent Living Centres across Canada?

Indeed, our Centres are dedicated to promoting the full participation of people living with disabilities in society.

In this episode, we speak with Paul-Claude Bérubé from Saint-Jean-sur-Richelieu, Quebec, to discuss the concept of independent living.

Hello everyone and welcome to our first episode of the Independent Living Podcast where we talk about independent living as we celebrate the 35th anniversary of the movement. I'm Mikael Charrette and my guest today is Paul-Claude Bérubé.

Mr. Bérubé is a lawyer from Saint-Jean-sur-Richelieu, Quebec.

He was the first Vice-President of the Canadian Association of Independent Living Centres in 1986 and National President of the Board of Directors of Independent Living Canada from 1999 to 2008. He also has extensive experience in municipal politics and in the education and health sectors.

Mr. Bérubé welcome to the show!

Hello, it is a great pleasure for me!

I'd like to talk a little about independent living to start. What is the concept of independent living for you?

The concept of independent living initially responds to individual needs rather than collective needs. For many years, we have known about the movement to demand the rights of people with disabilities, which has materialized in various organizations. But when the concept of independent living was introduced in Canada, it was not so much to claim rights as to respond to individual needs. So, the independent living movement responds to individual needs as opposed to the collective advocacy movement, which promotes the rights of people with disabilities. The second element, which is very important in the concept of independent living, is the English concept of "nothing about

us without us", in other words, "nothing for us without us", which means that the people concerned, the people with disabilities, are the ones who must in all circumstances make the decisions that concern them. The third element of the concept of independent living, which I consider to be one of the most important, is "peer counseling". Peer counselling meets needs because people with disabilities need to be able to refer to people who have had the same experiences as they have in the past so that they can learn from them exactly what they need to do to meet their needs because the medical model and their social model being one thing, but the peer counselling model is much more effective if you have people who can immediately give you relevant information rather than playing musical chairs with officials in different institutions, in different departments to always come back to solutions that don't meet your needs. And the last element of the independent living concept is information. The person with a disability must be an informed and trained person, that is to say that this person can receive an appropriate education, appropriate instructions and that eventually, if we want him to be able to integrate into society, that we can use his abilities to meet social needs, that's where these four elements lead us to what we call the concept of independent living, but even broader, inclusion and integration. So, the integration of a person with a disability in society. His or her inclusion in daily life in Canada goes through the concept of independent living necessarily, in my opinion.

So, if I understand correctly, when it comes to independent living, we respond to individual needs, so the concept of independent living is only for the individual for the individual. So, he is in the best position to know what is good for him.

Absolutely, there are many organizations that promote the rights of people with disabilities. That is their mandate, but in the concept of independent living, the primary mandate is not to promote rights, but rather to meet the needs of people with disabilities.

Perfect and how has this concept of independent living impacted your life?

It had a huge impact on my life because, at the beginning, obviously, when I had my disability at the age of 19, and at 19 I wanted to continue my studies, the only image I had of a person with a disability was that of a person who belonged to an association for people with disabilities, which was dedicated to leisure activities and which organized activities a bit like those done for the elderly at the Golden Age Club. And it was not this concept of life that I wanted, it did not meet my needs. I wanted to be an active person, I wanted to be able to live an independent life, or if you prefer an ordinary life, that is to say, to have a family, a wife, children, to work, to earn an income, eventually to buy a house and to travel, to enjoy life, even in spite of my disability. So, I had to turn to something that would better suit my needs and that's when I discovered the concept of Independent Living, which was in its infancy, my disability came in 1978 and the concept of Independent Living in Canada started in 1985, so for real, It took a few years for this concept to be put in place, but I already

had the principles that were put in place by Independent Living, I was already applying them in my own life, so it had an influence in the sense of confirming me in the path that I had chosen and I would even say to go further in this regard.

OK. You just mentioned that you have principles that you adopt in your daily life, rules of life, I think, basically.

Yes, that's right. I have several at least a dozen that I apply, but I think for the purposes of today's podcast, I'd like to share five with you.

Yes, perfect!

So the first one, would it be necessary that the person, and I speak for myself obviously, these are my rules of life and the others will always be able to adapt them to their needs if they want to, but having said that, for me, what is important is to show, to always show my abilities first and not to show my incapacities. So, yes, I have been in a wheelchair for many years, now it is not that people notice when I talk to them for the first time. Yes, they may see my wheelchair for a few seconds, but people quickly forget about the wheelchair because we are able to hold a conversation on all sorts of subjects that will interest them and even advise them if necessary on certain other aspects of their lives. The second rule of life that I follow continuously is the fact that I make all the decisions that concern myself, that doesn't mean of course that I don't talk with my spouse, with my children, but I wouldn't accept that a third person comes and dictates to me what I should do in life. So, for years, I would even say for decades, this was the case for people with disabilities in Quebec, where they were taken care of by others and decisions were made for them; this is the medical model, the institutional model and it must stop and it has stopped for a few years, but it is still present for many people in their lives and these people must be able to make decisions for themselves in all circumstances. The other thing I like to do is surround myself with positive people. In fact, when you look at how a magnet works, the negative attracts the positive, and in everyday life, it is exactly the opposite that happens. The positive attracts and the negative attracts. And I realized very quickly that when you are around negative people, it has a negative influence on your life, it has an influence on your mood, it has an influence on your ability to adapt because people who are negative at the beginning are people who only see the difficulties, they do not see the solutions. Whereas in my life, it is always to see from an analytical point of view, to look at the situation, to make the analysis and to find a solution and not to stop at the problem. So that's why positive people react that way. And when you are around positive people, you grow as a person much faster. So, I say: apply this rule of life. If there are people around you who are negative people, you can always try to help them, you can always try to make them better, but if they don't want to and stay in negativity, that's not the kind of person you should keep in your circle of friends. Another thing, being generous to others in all circumstances means receiving, but also giving a lot. I have been spoiled by life. I had the opportunity to go to graduate school

and since then, I've gained knowledge and it's not always about money, it's often about meeting needs and often people come to me for all kinds of things, whether it's related to a physical disability, whether it's related to my professional skills or even my way of life, and it's always a pleasure to advise and help. What people do with it afterwards is none of my business, but one thing is for sure, I am always available for people in need. So, and generosity is first of all to listen to others too. You know, it is very easy for a person like me in a party where there is a group of people to be a center of attraction, well I move in a wheelchair, I am a person who expresses himself easily, I have the interpersonal skills towards others. So, I can become the center of attraction very quickly, but you don't always have to do that, you have to give room to others, you have to be generous to others and then you have to value them too. You have to make sure that other people who may not have as much facility are valued as much as the people who do have facility. So, generosity is also that. So being empathetic and being able to listen too, not just talk and express yourself, but listen to others.

Perfect! So, show your abilities and not your inabilities, make all the decisions that affect you, surround yourself with positive and not negative people, be generous to others, give, be empathetic and listen.

Absolutely.

Perfect! And in your opinion, what is different about the Independent Living movement today compared to twenty years ago?

I may surprise you a bit with the answer, but I would say that people with disabilities themselves are the first ones concerned. That is to say that the people with the independent living movement, as it is now known in Canada and in the whole world, but more particularly in Canada here in Quebec, we can always claim that the Canadian population, the Quebec population is much more sensitive to the issues that concern people with disabilities. We can always say that they have more sensitivity and less pity, because that used to be the case. Look, I'll give you an example, when I was younger and I was walking around a mall, with my spouse and well, I was waiting in the corner of the mall for her to go shopping, there were people walking by me saying, "Are you collecting money?" or "Do you want a donation?" or "Are you lost? Is there something wrong with you?" People back then because you were in a wheelchair felt more sorry for you. Today, it's not like that at all. The population understands that there are people with disabilities now who are very independent and who are integrated into society and who do their things naturally like any other person. And that comes from people with disabilities themselves first. So, obviously, 25 years ago, a person with a disability who needed a grocery store, what did he do? Either they would send someone else to do their grocery shopping for them, or they would do their grocery shopping by phone and have it delivered to their home. There was no internet at the time to order online. So, but later on, with the independent living movement, we saw more and more people like me, but who like others, go to the grocery store and do

like other customers, take a basket, push the basket and put things in it and pay for their groceries at the exit, take it to the car, put it in the trunk of the car and drive home, and there are others who go with paratransit and have the groceries they bought delivered to their home. So, people have become more autonomous, have become more involved, more integrated in the social movement and that makes other people who are observing, see a social change in the people with disabilities themselves.

So the independent living movement has changed over the past 20 years, but it is the behaviour of the individuals who are most concerned in the first place. These people want to integrate, they want to be respected, but they also want to contribute to the development of Canadian or Quebec society. So, we see these people on the benches of schools, we see them at university, we see them in CEGEPs, we even see them teaching, we see them as lawyers, we see some who are doctors, we see others who are researchers, we see others who are social workers. So, there are people with disabilities, now we see them everywhere, in all professional fields or almost. Well, where the disability is not an obstacle, for example, to practicing their profession. As a blind person could not be an airplane pilot, we agree. Well, but a blind person can do many other things in the field of aviation that are not necessarily related to driving a plane or moving a plane. So, that's why I'm trying to tell you that people have reacted, society has also put in place measures that allow them to study, that allow them to integrate socially. So it is certain that everything is not perfect, it does not mean that there is no more poverty for people with disabilities, far from it, there is still a very large majority of these people who are in a situation of extreme poverty, but gradually, it starts to change and people want to contribute. That's what I remember the most about the disabled person today: they want to integrate into society and participate actively in society in all its forms. But I was mayor of a municipality, people voted for me in spite of my disability, but why? Because they voted first for the capacities that I offered to be a good mayor, and that's the movement today, it's to know how to make the commitment, but the society 40 years ago would not have elected me as mayor, but today it's possible, there has been an opening of mind that has changed enormously compared to today, regarding the integration of minorities. We look at our government leaders who are adjusting, Mr. Legault in Quebec City, Mr. Trudeau in Ottawa. I am not playing politics when I say this, but I simply want to mention that these people are sensitive to the condition of people with disabilities as no other government leader has been before them.

OK so basically it's an evolution that will have more change more open-mindedness.

Yes, but there are things that are done now that were not done in the past, for example, when the Montreal metro was built in the 1960s to be ready for Expo 67 in 1967, there were about fifty stations at the time, none of which were accessible, and it took years before some were accessible. Finally there were 3, there are 5, there are 7 since the current mayor is in position in Montreal. There have been more metro stations that have been adapted, I think they are up to 16 or 17, if my figures are

correct, and there is a plan to make all metro stations accessible by 2035. But if we look at the metropolitan express network that is currently under construction, which will have 26 stations and will begin operations in 2022, all the stations are already planned to be fully accessible to all forms of disability. So, we can see that things are changing. There have been many mistakes made in the past in transportation, especially in the services, but I am optimistic for the future that it will improve and the more people with disabilities will participate themselves in the development of society, the more they will influence others and will help these changes to happen quickly. When I was mayor of a municipality, the municipality where I was, there were no ramps to access the town hall office. There were no ramps to access the office of the MRC du Haut-Richelieu and I can tell you that after I was elected mayor, the accesses were made and they realized thereafter that there were people in situation of handicap, who could not only sit as mayor, or as municipal councillor, but who could simply come to attend a meeting of the city council, and therefore to see what is going on with the city council or to make certain claims before the council, but they could not even do that because the rooms were not accessible. Today it is more and more.

And what advice would you give to people who are facing barriers or obstacles?

I don't want to be presumptuous in giving advice to others, however, I could add a piece of advice by saying: if you don't know about the independent living movement, find out about it and hurry! Because the independent living movement will help you enormously to make your life a success because if you don't know where to start, they know, they will help you. They won't tell you what decision to make, that's not it, but they will tell you what exists, what you could do, what the possibilities are, what the solutions are. So, through their duty of information where they will have you meet such and such a person and he is going to be a great help to you, he is located not far from you in the same municipality, he will go and meet you, you will be able to talk together and you will see that it is going to be very useful for you, that is what the independent living movement is doing via its independent living centers all over Canada. And this is what I tell people, apart from the advice that I mentioned earlier, which is rather personal, if you want advice as a person with a disability, how to develop yourself quickly? And to make sure that you are proud of who you are. I think you need to know about the independent living movement, it will help you progress quickly.

Yes, perfect! The independent living movement that has all the resources for the individual to find solutions. Mr. Berubé, thank you very much for being on the show.

It is a great pleasure for me and my greetings to all the people of Independent Living Canada and all the Independent Living Centers in Canada, it is always a pleasure to discuss with them. I wish you a nice end of day!

To you too Mr. Bérubé, thank you very much! That was Paul-Claude Bérubé, the very first vice-president of the Canadian Association of Independent Living Centres and national president of the board of directors of Independent Living from 1999 to 2008.

Dear listeners, stay tuned for more content and stories from Independent Living Canada. On that note, thank you all and see you next time!