WHO DECIDES? A Workshop about Supported Decision-Making
Tuesday, May 30, 2017
Benevolent Irish Society Hall, Charlottetown

PURPOSE:

- To better understand supported decision-making and how it works;
- To learn about how a Supported Decision-Making law could make a difference in the lives of people living in Prince Edward Island.

REPORT

1. **Welcome** – Nathalie Walsh and Richard Gallant welcomed everyone, on behalf of the Supported Decision-Making Coalition (members include the PEI Council of People with Disabilities, Seniors United Network, the Alzheimer Society of PEI, Stars for Life, Autism Society of PEI, PEI Association for Community Living, Cooper Institute, PEI Citizen Advocacy and PEI People First, Special Olympics PEI and the Brain Injury Association of PEI.)

   They noted that the workshop was made possible by the Community Fund for Canada's 150th, a collaboration between the Prince Edward Island Community Foundation, the Government of Canada, and extraordinary leaders from coast to coast to coast. And by our member organizations and the Rotary Club of Charlottetown Royalty and the Parkdale Sherwood Lions Club and the Rodd Charlottetown Hotel.

2. **Our rights – worth fighting for!** Leo Garland and Eleanor Kelly of *PEI People First* made a presentation about rights: the right to live independently, in the community, the right to make decisions and the right to get support. They talked about ways in which People First has advocated for their rights over the years. Their presentation is at on page 10 of this report.

3. **The Right to Education** - Chris Mollins from *Stars for Life* made a presentation about the importance of realizing the right to education. See the whole presentation on page 11.

4. **Supported Decision-Making in PEI, A Brief History** – Rosalind Waters started by saying that Supported Decision-Making is something that people have been talking about for over 40 years. People with dementia, intellectual disabilities, and brain injuries were finding that other people were taking away their rights to make decisions, often applying for guardianship. Which is a total taking away of rights, the taking away of your legal personhood. People said, "I can make my own decisions. I may need help, someone to explain information or someone to make sure others understand me. But that's my way of making decisions and it should be recognized in law." This became known as Supported Decision-Making.

   In 1997, a Supported Decision Making Law was introduced in PEI, but it was never proclaimed. The Health Care Directives and Consent to Treatment Act did come into effect at that time, and it recognised right to have supporter or associate to help with treatment decisions. It also had provisions for a proxy to be appointed for treatment decisions (with a proxy, you wouldn't need a guardian or Power of Attorney).

Since then, there have been several other attempts to create a law. All along, community groups have come together to tell government what is important to the people they represent.

Most recently, between 2013 and 2015, a lot of work was done. There was a government-community working group. We talked about how a registry would work, and what kind of non-governmental organization we would need to help put a law into effect.

The only other places in Canada with supported decision-making legislation are Yukon and British Columbia.

5. **Joanne Taylor –** Rosalind introduced Joanne, the Executive Director of the Nidus Personal Planning Resource Centre and Registry in British Columbia. Nidus (http://www.nidus.ca/) is a Latin term for nest: a symbol of support and safety; to enable self-determination. Since the *Representation Agreement Act* came into effect in BC in 2000, Joanne has helped people to learn about Representation Agreements and supported decision-making. She has personally assisted thousands of people to make, register and use Representation Agreements. She has also been a support to community volunteers and healthcare providers so they can help numerous other individuals and families. Joanne has been invited to speak in the US, Australia and Germany – and now Prince Edward Island. Today she's going to tell us all about how it works in her province, and answer any of your questions about how it might help you.

   Joanne: In BC, a Representation Agreement under Section 7 of the *Representation Agreement Act* is a legal alternative to adult guardianship. In BC, we used the term supported or assisted decision making to describe the process of how an adult could make a legal document to be an alternative to guardianship. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (2008) is about "equal recognition before the law". It is based on the BC Representation Agreement Act.

   The law reform project for supported decision-making, funded by the Law Foundation of BC, was for three years (from 1989 to 1993) and four new and interrelated laws were passed unanimously in July 1993 to reform adult guardianship in BC. However, only parts of the new legal package were proclaimed in 2000. Thankfully the Representation Agreement Act was proclaimed (put into force). The law is there because the community kept pushing for it. The law in BC came from the people, and today, because there is a resource centre, it is accessible to people and it works for the people. A resource centre is essential.

   Supported Decision-Making is about self-determination – it's about our identity. The vision is that everyone has the right to direct their own lives. This requires that any law reform must provide a definition of capability that allows it to be an alternative to adult guardianship. Adult guardianship happens when someone is considered not capable of making a contract and then they lose their rights and civil personhood. A new law must say that adults can make an agreement even if they cannot make a contract.

   In BC, just prior to the legislation was being developed, two other things were happening – institutions were being closed and individualized funding was being implemented.

Joanne gave some examples of people who have Representation Agreements. The first one was **Frances**. She was living in a group home – she had no family. She ended up in hospital. She used non-traditional communication and was kind of neglected. She had cancer and needed treatment and tests. The doctors needed someone to give consent on her behalf. The staff at the group home called Joanne to ask if Frances could use a representation agreement. Frances' mother was reluctant to do it on her own but happily, an old childhood friend appeared on the scene, and the two of them agreed to act as a team of supporters. The Public Trustee would still look after money. The agreement helped to focus on Frances, and improved her quality of life.

Another example – **Josh** lived with an associate family and had a representation agreement with a family member. When his associate family moved away (they would have taken Josh but his representatives (who were also his family members) weren't sure if it was a good idea. Josh really missed the associate family but he was also very close to his own family members. Would Josh be happy to move so far away from his parents and siblings to be with the associate family? Later on Josh decided (with the support of his representatives) to join the associate family, which meant moving away from his family's hometown.

Joanne talked about a tool they use in BC. It's a Planning Circle and you can find out more here: http://www.nidus.ca/PDFs/Nidus_Tool_Planning_Circle_Exercise.pdf

Supported Decision-Making Laws need to include:

- ✓ Recognition of all forms of communication – but Joanne cautioned against making detailed lists – because if something isn't on the list, it may not be accepted by a third party such as a bank or hospital.
- ✓ A continuum of capability – that includes a new definition of capability that allows someone to make a legally enforceable document, even if they cannot make a contract.
- ✓ Procedures for signing/witnessing and helping people to understand that signing is making a voluntary mark. There are lots of creative ways to do this.

Supported decision-making, or in the case of BC, a representation agreements are documents designed for a third party; a doctor or banker, for example. They need to know who it's about, what it's about, and who to go to if they have trouble communicating with the person.

Supporting documents can go along with the agreement – a supporting document can describe how the person communicates. When you develop a supporting document, it helps to get input from lots of people who know the person. Supporting documents strengthen the agreement.

Joanne asked participants what they thought makes a good supporter or team member. They said it's important for supporters to:

- ✓ Listen
- ✓ Be objective (or acknowledge your bias – you might not always agree)
- ✓ Be open-minded
- ✓ Focus on the individual whose agreement it is
- ✓ Communicate Assertively
- ✓ Show empathy and kindness
- ✓ Be available

Supported Decision-Making is about getting the help you need to exercise your rights. It's very much about **relationships**.

Joanne gave another example. **Mary** was 93. She had dementia and memory problems. The person whom she had appointed to be her "enduring power of attorney", many years before, could not continue. But Mary was not capable of designating a new power of attorney. The bank suggested that someone apply for guardianship. But a representation agreement under section 7 was also looked at, and that's what happened. Once it was in place, the representatives helped Mary to do her banking and other financial things as well as make health care decisions. Due to the progression of Mary's dementia, her representatives helped Mary move to a care facility where she could get more personal care and support. The enduring power of attorney that Mary made before was still in place – Mary could not legally revoke (cancel) it because she was not considered capable of making a new one. However, the person named in it filled out a resignation form, which ended the enduring power of attorney. This was good because then there was not worry about it conflicting with the financial powers in Mary's new representation agreement.

And another example: **Bob** had cerebral palsy and was living in an extended care facility. He wanted to live in the community and get married. The Public Trustee looked after Bob's money. Bob made a representation agreement under section 7 for health and personal care – and then he had the support he needed to move out and get married. Bob's mission was to control his own money – the Public Trustee agreed to let go, as long as there was a representation agreement in place. Bob made a new representation agreement that covered all life areas: financial, legal, health and personal care.

It's important to note that in the BC Law, capability is a **continuum** – it says representatives can help, or (only when absolutely necessary) make decisions *on behalf of* the individual.

6. **Table Talks and Questions** – At their tables, participants talked about what they had heard, and came up with some questions for Joanne. Here are the questions, each one followed by Joanne's answer:

   Question: How does supported decision-making deal with the potential for abuse?
   While service systems need to focus on competency and use assessments to determine who gets services (the less competent you are the more support you are entitled to), in representation agreements, the assumption is that everyone is capable.

   Accountability is built into the law, for example the Public Guardian or Public Trustee can freeze a bank account if they suspect financial abuse.

   In BC, at the beginning, some people, especially lawyers and government staff, worried that the legislation was irresponsible, they were sure there would be abuse. But that has not happened.

   The process is really important. There are safeguards in the legislation, which include the signing/witnessing and the role of the monitor. Supported decision-making is about developing and strengthening relationships – *people* keep people safe. Representation agreements can't provide a solution for abuse or family conflict – but neither can guardianship.

Question: How do you get politicians to do this?
Keep connected and be vigilant. Find someone in government you can count on. Politicians don't do detail – it's easier to get their support for the *idea* of supported decision-making.

Question: Facilitated Communication?
NIDUS does everything they can to avoid "hand over hand" communication. The law doesn't forbid it. But you don't want third parties to be arguing about hand over hand communication.

Question: Have any agreements been challenged?
There have been no court challenges.

Question: We've been working on this for 20 years. What can we do?
One thing is to raise awareness to counter the idea of capability being a black and white issue. And make the point that this is about equality. And, having a coalition is important – bringing together all the people who are affected or would benefit from supported decision-making.

Question: Was it important to help people make agreements before the law was proclaimed?
Stories are really compelling – it helped. In BC the agreements that were developed before the law was proclaimed were eventually recognized.

Question: What is the process for conflict resolution if your supporters don't agree?
The roles of all of the supporters and the monitor are defined in the agreement. The monitor's role is important – that person can help with conflict resolution because they are not really involved in making decisions. The role is not fully described in the law itself – this is okay – it leaves it open for you to create a role that responds to the needs of the person/agreement. If necessary, you could go to someone outside of the circle – a mediator – to help with conflicts.

Joanne noted that you need to include in the legislation a process for revoking or cancelling the agreement, and for a representative to resign.

Question: Can someone use a stamp to sign an agreement?
The signature has to be a mark of some kind – it can't be a stamp alone.

Question: What happens if a type of communication is not recognized by the government?
BC recognizes all forms of communication – this needs to be written into the law. The law should not have a list of different types of communication because it may leave something out, and that could be a problem later on. It's sufficient to say "all forms of communication".

Question: What if the family disagrees with your choice of representative?
The monitor role is important here again – to buffer and to provide information.

Question: Where can I get more information?
The Nidus website has videos and stories and documents – http://www.nidus.ca.

Question: How to I start a People First group?
Talk to Melissa and Barb at the People First office. Their number is 902.892.8989 and their email address peipeoplefirst@eastlink.ca.

7. Small Group Discussions

The discussion groups were organized according to the following interests:

a) Seniors/Alzheimer;
b) Disabilities/Autism;
c) Intellectual Disabilities

Each group was given a scenario describing a person who would benefit from a Supported Decision-Making agreement. And they were given questions to guide their discussion:

- Why does the person want a supported decision-making agreement?
- What kinds of decisions would this person want help with?
- Where would you start/who would you ask to become a supporter?
- What kind of things would need to be included in their agreement about communication?
- What are some challenges people might encounter in trying to set up and use a supported decision-making agreement?
- What are some ways to get around those challenges?

Afterwards, the whole group gathered again and one person from each of the breakout groups reported one challenge & one solution that their group had talked about. Here are some of the challenges and solutions that were reported:

Challenges:
The changing conditions and needs of the individual
Differences in communication
Recognizing all forms of communication
Reactions of family members, parents
How the role of the proxy fits in
Finding and choosing the right supporter
Resistance by others in the community
Concerns about accountability
Questions about the legitimacy of the agreement
Language
Knowledge – education and understanding
Trust – too little or too much

Solutions:
Keep the focus on the individual
A Resource Centre
Early education
Media – public awareness – good news stories
Education – a website, best practices, information sessions
Documentation
Supporting documents (resource centre)
Clearly defined roles including for the monitor
Collaborating with the legal system

8. Wrap-up & Evaluation

Joanne made a few final comments. She said, it’s important that there is some kind of clearing house/resource centre for people looking to develop agreements.

There is tremendous pressure on parents when they are told their sons/daughters won’t be able to do things. They need to be advocates, and deal with the system from day one. In “the system” there is this need to concentrate on what sons/daughters *cannot do* in order to get services – the same thing happens at the other end of life, with seniors. It requires a shift – it’s hard for people to talk about capabilities, instead of the opposite.

We need to be looking for others, besides parents and caregivers, to be part of circles of support. (It’s not unusual for staff in care facilities to take on the role of parent or guardian.)

Joanne cautioned against using the language of “best interest” when it comes to helping people to make decisions. Best interest implies that you know what is best for that person.

She also noted that really, there is no such thing as “objective” – everybody has their own experience & knowledge - **we need to “own” our bias**.

Richard and Nathalie thanked everyone for participating, thanked Joanne once again, and promised to send a report of the workshop to everyone soon. People filled out a short evaluation form. (See page 8 for what was said in the evaluations.)

EVALUATION

1) One thing I really liked about today was:

The pace and how things were kept on time
The whole thing – I liked how clear the presentations were
How clear and informative the session was
The diversity of the participants and hearing different perspectives
Communication with people, networking within a diverse group
Joanne Taylor's talk on supported decision-making in BC
The breakout room allowed me to talk
It was very interesting to be part of the break-out group! It tied the information together.
Learning about how supported decision-making looks like in practical terms
Scenarios and the interactive activity - talking and working with others to solve the problems
The sample agreements
Getting to speak and hearing the words of other people - the chance to ask questions and talk
The people who are committed to this
Information about law
The real stories
It was my second time being in a conference with my supportive group of people and it was just as informative as the first one I was in
That it was really focused on the individual and how the community can support them
It allowed me to feel more confident about not getting guardianship over my son, but to continue to support him in decision-making
Having a common interest
Great food
Information and the cases help shift points of view

2) Today I felt:

Very informed
Hopeful to a point – wheels turn slowly
Accomplished
Encouraged by the number of organizations that were represented here today
Relaxed and content
Excited and happy to see the issue becoming so known and important
I was able to make contact with people who had things in common
Empowered!
Productive
Engaged
Enthusiastic and encouraged
Good to be able to be part of this
That I had a major decision in the outcome being presented to government
Good about being here, meeting people and hearing their stories – it felt worthwhile
That I want to create an agreement and that I was heard
Determined to create and get involved!

Informed and captivated
Hopeful for people with disabilities
Like some weight could be lifted off my shoulders, and others' shoulders (of people similar to me)
Hopeful about a way to ensure that my daughter's wishes and needs will be looked after when I'm gone
Antsie
Good to know that more people are being educated on disabilities
Informed, more knowledgeable and ready to move forward with supported decision making on PEI
New people are involved in the issue

3) Something I would like to learn more about is:

How to fill out a supported decision-making agreement – get some practice
Putting together an agreement for my son
Different supports available as my daughter reaches 18
How to get out on your own
Strategies – how other provinces and territories deal with this issue
How I can help make this a law - what more we can do with the government to ensure this law comes into play- does the coalition need to do something different?
Independence and self-advocacy
I would like to learn more about rights and wrongs about supported decision making
Different disabilities and how people deal with having them
Support in different environment without giving feeling of dependency and weakness
Alliance with others having the same issues
How we can spread our decision-making wisdom around and get people who might not care about or support our decisions to care more about and support our decisions without saying or doing hurtful things
Transitioning to supports and supported decision-making when my daughter is an adult
How to further spread awareness - how to let others know
How to help

4) Next time, let's:

Do the same but reach more people
Get Ron Kelly to sing a few songs
Hear local stories/experiences
Invite politicians and other influential members of society
Talk and join group to help to implement the law
Have a police officer in attendance that we can talk to about issues regarding that people with Aspergers/autism would like them to be more aware of
Have simple language
Have more movement - do more fun things
I would bring my 17 year old with me
Dive deeper into subject matter
Identify next steps and follow up - follow up can be as simple as email group to share next moves?
Introductions
More time

Rights Worth Fighting For

Leo Garland and Eleanor Kelly, PEI People First

PEI People First is an advocacy organization run by and for adults with intellectual disabilities. We have groups across the Island.

Things that People First help people do are:

- Be Involved, we have conferences and workshops about things that are important to us like affordable housing and knowing our rights.
- Have our Voice heard, we give different presentations and we help people that need help having their voices heard.
- Make our own decisions- we learn about our rights and say what we want and what we need.

Ways that we get our voice out are:

- We have an acting Troupe that put on plays about issues that we want people to know about. Like what it is like to live in an old age without having a choice when you're too young to be there.
- Conferences, we just had a conference about what PEI People First has done over the years to have control over our lives and make our own decisions. We had a really happy thing to celebrate when one of our members had her voice heard with her circle of support and finally got to live where she chose to live.
- We made our first newsletter in 1990 and it was about people living in the hospital because they had an intellectual disability. They didn't want to live there and told their stories; we met with politicians and wrote a lot of letters about it. Now in 2017 we are still talking about people living in places they shouldn't be. We are part of a National task force to live in the community.
- We have projects like The PEI People First Freedom tour where we took a bus around the Island holding forums to talk to communities about the rights of people to make their own decisions on where they live, and other decisions people make in their lives. We wanted people to know that this doesn't happen to all people with intellectual disabilities and how people are living in places that are not the right place for them to live.

We have met with a lot of politicians over the years to show them how we can make our own decisions and how with the rights support everyone can. We met with Robert Ghiz when he was premier to talk about stopping new admissions to institutions for people with intellectual disabilities. The meeting went well but there was no action on what we talked about.

We have worked very hard to be heard and to make sure that the government doesn't forget its promise it made when it ratified the UN convention for people with disabilities. Making our own decisions is the in the middle of all of the things we do and the key to all of our rights being heard.

We will always work and speak up and when we can't we will pass it on to the next generation. We all have the right to make our own decisions and anybody that needs support has that same right!

The Right to an Education

Chris Mollins

The right to an education has greatly impacted my life for the better. I graduated from Three Oaks in Summerside in 2014. After high school, I went to UPEI for two years and took a variety of arts courses. After UPEI, I was accepted into Fundamental Arts at Holland College. I graduated this past May and I am now enrolled in Graphic Design at Holland College for the next two years.

There are many benefits of having a post secondary education. The first is having the opportunity to meet new people who are enrolled in a program based on similar interests. Meeting other students with similar interests gave me the opportunity to develop lifelong friendships.

The second benefit is having the opportunity to develop critical thinking skills, an essential part of working in a professional career. Critical thinking skills are also necessary for everyday life, whether it is related to reading and watching the news, or in terms of making purchases. The ability to think critically not only develops evaluation skills, but it also the ability of one to do his or her own research and develop his or her own outlook on the world.

The third benefit of post secondary education is having the opportunity to gain professionalism, which will be necessary in the working world. Professionalism is important because it teaches one to abide by the different protocols, which vary between different working environments and to act according to the expectations which vary between different working environments. Post Secondary also gives students the opportunity to learn the skills they need to enter the workforce in a field of their choice.

If I did not have the support and accommodations that I currently have with Stars for Life, my educational journey may not be as successful as it is. At the beginning of post secondary, I would struggle with many challenges, which included anxiety and my inability to pay attention in class. When I started post secondary, I had full time support in my classes, which included having a worker take notes for me in class while I wrote my own to compare with his or her notes, which allowed me to develop note taking skills. I also wrote my tests and exams in a private room and was given extra time. This gave me the opportunity to show my professors my knowledge of the course material. I developed these skills with the support of Stars for Life and by the end of the Fundamental Arts program I was able to successfully attend classes independently and manage my own workload.

Without the right to education, I may have missed the opportunity to pursue post secondary education, and without a post secondary education would not have the opportunity to have a career in Graphic Design. In the worst case without an education, I would be working at a minimum wage job and most likely be in a lot of debt trying to pay off loans and living expenses. I would be under so much anxiety that I wouldn't even be able to maintain a job long-term and would not be able to afford to eat healthy, which would affect my ability to sleep and function. I would also be more isolated from the community and would not have the same opportunity to develop friendships. This would also negatively impact my mental health and self esteem. Having a post secondary education allows me to work towards a career, which I will be able to maintain and enjoy. It is important for all people to have the right to an education, so they are afforded the same opportunities as everyone else in the community. To me, the right to education has meant being part of a community, developing lifelong friendships, and the ability to pursue a career I am passionate about.

Participants:

Adam Robbins
Adam Arsenault
Amanda Birt
Ann Wheatley
Bethany Cousins
Billie MacKean
Brenda Oslawsky
Bridget Cairns
Bronwyn Rodd
C.J. Snyders-Coachman
Candy Wigmore
Charity Sheehan
Chris Mollins
Christine Beck
Colleen Bannon
Daniel Harris
Daniel Martens
David Ellis
Dorothy St. Jean
Doug Roper
Eboni Court
Eleanor Kelly
Heather Campbell
Helena Reeves
Jaclyn Borden
Jared MacNeill
Jeremy teRaa
Jillian McInnis
Jo-Anne Doiron
Joanne Taylor
Jordan Havenga
Judith Bayliss
Judy Hennessey
Julie Smith
Kerry Duggan
Kyle Wightman
Laura Sarlo
Leo Garland
Lloyd LeFurgey
Marie Burge
Mark Cameron
Mary Whitehead
Maude Desjardins
Melissa Good
Melissa MacDougall
Naghma
Nathalie Walsh
Nathalie Horne Gallant
Nicole Mooney
Richard Gallant
Ron Kelly
Rosalind Waters
Rosemary Matthews
Sheila Killorn
Shengzhi Zheng
Wendy Coles
Yanfang Li