

## **An introduction to Supported Decision Making**

BDACI Community Workshop

June 26 2019.

Good afternoon!

I am not sure just how one covers 30 years of effort in 15 minutes but that seems to be my task. My name is Audrey Cole. I have been active in the Community Living movement for over 50 years. Since the mid 80s I have been involved in efforts to bring into law what has come to be known over time and around the world as "Supported Decision Making," a practical and accountable alternative to guardianship. Like most of my fellow members in the Association and as a parent of a son with a severe intellectual disability, I oppose the notion of guardianship which I see as archaic and discriminatory, an instrument of control that has no place in a modern society that says it believes in equality and rights.

Believe it or not, we almost had Supported Decision Making in Ontario law. Almost 27 years ago in the afternoon of September 25, 1992, I was sitting with colleagues in a room in the Toronto offices of the Attorney General of Ontario. We were there on behalf of Community Living Ontario (CLO), People First of Ontario (PFO), People First of Canada (PFC) and the Canadian Association for Community Living (CACL) which I represented. We were the spokespersons for the Coalition on Alternatives to

Guardianship. We were there to try to persuade the late Steve Fram – the senior legal bureaucrat responsible for Ontario’s then soon to be enacted Substitute Decisions Act (SDA) – to accept further amendments to the prohibition sections (22 and 55) of the Bill that we had already convinced the government to include<sup>1</sup>. Although our efforts had already had useful effect on Government thinking, subsequent rewording of those sections did not quite meet our needs. Literally, we were down to the wire! The deadline for amendments was the following day.

A demonstration on the grounds of Queen’s Park by Members of PFO and PFC earlier that week (September 21<sup>st</sup> ) and a meeting on that day with Steve Fram and the Political Assistant to the AG’s Parliamentary Assistant, to which I was invited, had concrete results. According to my Report of that Meeting, those results included assurances that both the Attorney General and his Parliamentary Assistant were “sympathetic” to supported decision making and “very open to seeing it come forward” as “complementary” to Bill 108 (the *Substitute Decisions Act*)." In a follow up letter, we asked why the principles underlying the “diversion” programme in the criminal justice system could not be applied to guardianship since “diversion” in effect, is an alternative to incarceration just as supported decision making is an alternative to guardianship. Since such

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<sup>1</sup>Prohibition

- (3) The court shall not appoint a guardian if it is satisfied that the need for decisions to be made will be met by an alternative course of action that,**
- (a) does not require the court to find the person to be incapable of managing property; and**
  - (b) is less restrictive of the person’s decision-making rights than the appointment of a guardian. 1992, c. 30, s. 22 (3).**

accommodation was in place for people who had committed crimes, surely there could be similar considerations for those who had committed no crime but would, in effect, serve a life-time sentence under guardianship law.

In another communication that week, Steve Fram clarified that although he was suggesting to the Attorney General that he make a statement to the effect that he would encourage development of a supported decision making model, it could not take place before the imminent 3<sup>rd</sup> Reading of the Bill. In the meantime, he said, "We will be working on building the ramp but it is too soon to tear down the stairs!" We typically used the concept of ramps to illustrate the issue but that was the first time I had heard an admission by a government spokesperson that, as we had always maintained, the issue of supported decision making with respect to people with intellectual disabilities was one of accommodation. No other group of citizens is threatened with the loss of rights inherent in guardianship from the age of majority throughout life.

We didn't get our final wording but the prohibitions were solidified! Steve Fram gave sound reasons why he couldn't support our suggestion for subsection (b) of Articles 22 and 55, which was "... alternative measures to guardianship that *"are more enhancing of the person's autonomy, inclusion and participation than the appointment of a guardian."* He suggested instead that the Act say, *"(b) is less restrictive of the person's decision-making rights than the appointment of a guardian."*

I now believe he was right in saying that although our suggested words were very clear to us as advocates, they would not be so clear in a judicial context and secondly, they might actually become barriers as a judge would want to see "evidence of that inclusion, participation and enhancement." He argued that proving something was less restrictive would be easier.

At least, we had succeeded in getting the prohibition into the Act. It is still there! We continued to work with Government and received grants for research, etc. as we developed the notion of supported decision making. I have in my files, encouraging correspondence from Ontario's Attorney General about a Supported Decision Making model. It was also recognised not only by us but by Government that the rights advice and other advocacy services available under the Advocacy Act were essential to the development of supported decision making. But the economic climate of the day was taking all the attention of government and further modernising of Guardianship legislation went onto the government's back burner. In 1995, the change in government spelled disaster for our efforts! One of the earliest actions by that new government was to repeal the Advocacy Act! Gone were the funded advocacy services and rights advice that were critical to development of a legal supported decision making model. That particular Government had little interest in our concerns!

For all the progress we did make all those years ago, little seems to have changed in Ontario. We are told that people with intellectual disabilities are still placed under guardianship for what many of us would consider

unacceptable reasons. For example, some families of relatively articulate sons and daughters with disabilities have felt obligated to use guardianship in order to protect an RDSP. To me that is too big a price to pay. We need to fix the problems, not take away people's rights!

Supported decision making has its origins in the natural way that most of us make our decisions. We use whatever help we can get in decision making, from family, friends, people we trust and respect. Those of us lucky enough to get the advice we need should we need it, go through life without ever having our capacity challenged. Only those whose capacity is challenged – people with intellectual disabilities, people with diminishing cognitive capacity, people with mental health problems, have to prove their ability to make decisions alone and unaided. There is something inherently wrong with that in a society that prides itself on fairness and equality.

Supported Decision Making is about "supporting" the decision making processes that affect a person's life, unlike substitute decision making which "replaces" the person in the decision making processes that affect his or her life. Supported Decision Making puts the focus on the quality of the decision making process rather than solely on the capacity of the person to make decisions independently.

I wonder if any of us in this room who look forward to being placed under guardianship?

I suspect none! No-one wants to be declared incapable! I have never met

anyone who wants to be under the control of a guardian! Have you noticed that we only ever talk about placing other people under guardianship? Even as we write our instructions in our powers of attorney documents, we are not thinking about guardianship. We think only of how we are controlling our own future, by telling someone what we want them to do. We are not thinking that, in effect, we are giving those others absolute control over our lives. If not in name, we are making them our future guardians. Once they assume that role we lose all control of those decisions, in effect any control over our human rights! Look at the decision making hierarchy in Ontario for medical consent. Who is at the top of the list? "A Guardian!" There can be no more powerful or controlling entity in our lives in Ontario than a guardian!

Why do we only think of guardianship as something other people need – as something that people like my son need? How can we carve out a small group of harmless and absolutely dependent people from society and say that unlike the rest of us, they need to have their rights removed and to be placed under the total control of some other person or persons?

I was already a senior when we started this work back in back in the 80s (I have been a senior quite a long time)! Back then, as we hashed through the pros and cons, the paths and the barriers, to a new concept of decision making, I was acutely aware that this was what I would want were I to be losing my cognitive capacity. I don't want to be declared "mentally incapable"! I don't want to have a guardian! I want the people who understand me and care about me to share with me that decision making

process that I would no longer be able to control. I trust those people! I trust them because I know that they know that with their support, I can still, in effect, control my life, solely by the commitment they will make to ensuring my safety and well-being. And the same should apply to my son Ian and his circle of support and to all the other Ians of the world.

We Canadians have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). Canada, with the interventions of Inclusion International and support from CACL, is given credit for introducing the concept of supported decision making now implicit in Article 12 of the Convention. The Report of CACL's Task Force on Alternatives to Guardianship to the CACL Board on supported decision making in the early 90s was one of the documents considered by the UN ad hoc Committee.

It is time we started living up to the implications of our success. We all have human will and preferences no matter the levels of our cognitive abilities. To quote from the *Legal Capacity Inclusion Standard\**:

*"The Office of the UN High Commissioner of Human Rights defines legal capacity as having power to make, modify and terminate legal relationships. Doing so does not necessarily require having the cognitive abilities on one's own to understand and retain information and appreciate consequences. A person's unique abilities can be enhanced with decision-making accommodations by other parties, and also by assistance from decision-making supporters who can assist in interpreting and translating a person's will and preferences in the making of particular decisions."*

We don't need guardianship! Guardianship has been a matter of concern in the Community Living movement almost from our beginnings.

In closing, I want to quote something about our innate will as human beings.

Discussing guardianship and limits on capacity in **1976**, Michael Kindred talked about the need to recognise expressions of "clear desire" in people with severe disabilities. (Ref. Kindred, Michael. *Guardianship and Limitations Upon Capacity*. President's Committee on Mental Retardation. *The Mentally Retarded Citizen and the Law*. N.Y. Free Press, 1976). Since those early days, we, in the Community Living movement, have talked about that "clear desire" in terms of our human "will" being inherent no matter how severe the disability.

I have been asked on occasion to describe what I understand as "will" in the context of decision making. I quote from one of my responses:

**Quote:**

*"I do know that I have talked many times about human will - that instinctive and inherently human imperative, that sense of being, that thing that tells us we are here, that we can feel. I honestly don't think it has anything to do with intellect. It's basic!*

*Ian has it! It is what makes him stop, suddenly, and listen to the sounds of the birds or of the wind blowing through the trees. I am sure it is what makes him sensitive to music. It is also what makes him instinctively draw back or resist things he doesn't understand (an unfamiliar medical procedure, for example). And it is certainly the thing that has prompted*



*him on a couple of occasions when his Dad, Fred has been in intensive care, to gently reach out and stroke Fred's arm - an intimacy that is not typical of Ian who, usually, would have to be prompted to make such personal contact.*

*I don't know what it is but I do know we all have it! And if we take the trouble to get to know people who do not communicate in typical ways, we become very conscious of it.*

*Now, all we need to do is to put it in terms that lawyers can understand!*

*After all, they, too, have it! (Ref. Personal response to request from Michael Bach [Audrey Cole to Michael Bach, October, 2010].)*

**Truly, we can do better for people than guardianship!**

**Thank you for listening!**

*\* Legal Capacity Inclusion Standard. 'Working Group for a Legal Capacity Inclusion Standard.'*

*October, 2017*