

# MAKING SURE THAT ARTICLE 12 IS, TRULY, FOR ALL OF US!

## A 30-Year Personal Reflection

CLAIMING FULL CITIZENSHIP  
2015 International Conference  
Vancouver, October 15-17, 2015  
Centre for Inclusion and Citizenship, UBC

### Notes for Visual Presentation

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#### Summary

A personal reflection on over 30 years of effort towards equality in decision making. As envisaged from the beginning, what we now call supported decision making is for all of us. The law alone can only provide the legal ramps. Are we falling behind in providing the social ramps?

#### Slides and Text

**Slide 1 (Title)** "Making Sure that Article 12 is, truly, for all of us! A 30-year personal reflection.

Actually it is 46 years of reflection, 30 of them more actively!

#### Slide 2 Why this title?

Why this title?

- Because no-one should be subject to "replacement" in the decision making context
- Supported Decision Making – conceived initially as an alternative to guardianship for people with severe intellectual disabilities
- assumed it would also be attractive to seniors

No-one should be "replaced" in the decision making context: not people with severe or profound intellectual or physical disabilities; not people who need occasional or life-long assistance with decision making to whatever degree; not people whose former cognitive capabilities have diminished through age or infirmity; no-one! Guardianship is not truly a "need"! Rather, guardianship is a legal

"construct" devised hundreds of years ago primarily as a means of protecting the property (initially by the King) of people whose capacity to manage it themselves had diminished, in effect, people who for various reasons were unable to make decisions alone and unsupported. Guardianship, in essence, replaces the person in the decision making context. Supported decision making was devised as a less demeaning and more enhancing way of assuring that necessary decisions could be made without destroying the person's legal status and social identity. Its foundation was the natural way in which most people make decisions.

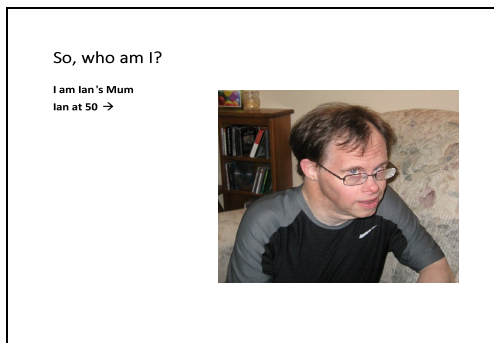
This Conference alone indicates the high level of interest in the subject of legal capacity and supported decision making. Yet it is also noticeable that, around the world, the

current focus with respect to people with intellectual disabilities appears, mostly, to be on devising ways of providing the necessary support to enable them to make their own decisions or to assist in that process.

I am concerned that this apparent narrowing of focus could eventually squeeze out those people with severe and profound intellectual disabilities for whom the concept of supported decision making was originally conceived. They are people who, intellectually, would never be able to understand what a decision was, why it had to be made or what its reasonably foreseeable consequences would be yet, ironically, they (my son included) make dozens of personal decisions every day of their lives solely from their experiential knowledge of life as they know it. Just watch them!

Perhaps now is the time to look back to those early days whilst those of us who were there are still here! Finding it difficult as the years go by to devise new ways to say the same thing, I will look back by using quotes from briefs and other pieces I have written about supported decision making during the past 30 years.

### Slide 3 So, who am I?



I am Ian's Mum! My qualification to speak about supported decision making comes not from my academic interests. It is gratifying to note at this Conference the role played by lived experience. In earlier days, that was rarely the case in Conferences that attracted people in academic and professional fields of endeavour. I well recall my surprise a few years ago, in a casual corridor conversation just prior to speaking at a Human Rights Conference on the subject of "genetic screening," when I was asked by a

psychologist what qualifications I had to speak on the topic. I responded that my qualifications came naturally; my son's future well-being and social image was threatened by the drive to eliminate certain causes of disability - Ian has Down syndrome.

My qualification to speak of my extensive work on alternatives to guardianship over these many years comes from that same source, Ian, who – quite unknowingly, I believe – is the greatest teacher I have ever had! (I did have an different identity before Ian – as a technical illustrator in the aircraft industry).

### Slides 4-7 Who is Ian?

- Ian (photos)
- as a child with his Dad;
- as a cool teenager;
- at work; and
- opening the door of his own home for the first time.

Re. "At work":

Ian worked weekday mornings at the video store for nine years before he was "fired" because of a disagreement

between his support worker and the store manager! But that is another story!

### Slide 8 Ian is.....

- Gentle, sensitive, warm and caring
- as a child, described by clinicians as “profoundly intellectually disabled”
- denied access to public school system until age 15
- as of today his disability has not diminished
- neither has his innate dignity and value as a human being and as a Canadian citizen

When eventually accepted into the local School system at the age of 15, Ian was placed in a special “developmental” class of five students, segregated from the other hundred or so students in the also segregated school for “trainable m... r...” students!!! But he had a very talented teacher! (Yet another story!).

### Slide 9 Ian ....

- Ian’s future well-being –
- depends on legal recognition of supported decision making
  - such law must be fully inclusive
  - no such assurance at this point in Ontario (relevant legislation under provincial or territorial jurisdiction)

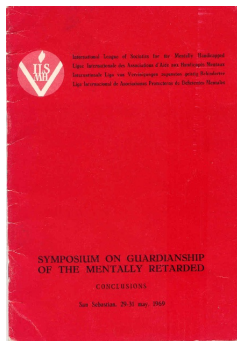
### Slide 10 Where it all began for us

1969

Inclusion International  
(then ILSMH)

*Conclusions of the*  
**Symposium on**  
**Guardianship...**

San Sebastian, Spain  
May, 1969



**Quote** (Reflections on a long journey, Coming Together, CACL Spring 2010):

“It seems a bit ridiculous that I would have been worrying about adult guardianship when Ian was only five but it wasn’t Ian, himself, who got me hooked on my long anti-guardianship crusade: it was something I read. Ian’s dad was a former senior Librarian in the Library of Canada’s Department of National Health and Welfare. Fred was a whizz at

finding written materials relating to disability and to people with disabilities. I have spoken elsewhere of arriving home from the hospital with a newborn Ian to find the coffee table already loaded with “must read” books, learned papers and leaflets! Fred was the eternal information “finder!” ... It was my job to be the “reader and absorber!” ..... It was in late 1969 that a little red booklet appeared on the coffee table. Published by International League of Societies for the Mentally Handicapped (now Inclusion International), it

contained the conclusions of the Symposium on Guardianship of the Mentally Retarded, held in San Sebastian, Spain. ...

What caught my attention in the San Sebastian findings was the clear recognition by organizations such as ours that guardianship did not serve people with intellectual disabilities well, that it needed "revitalization." What I took from the deliberations was that we required mechanisms that, literally, would keep the options open for people with disabilities as they gained confidence from new experiences in the broader and gradually more welcoming community. Guardianship, as we knew it, could not do that. Obviously, there had to be a more fluid approach to protection. Always a bit of a radical, that sounded good to me! .....(There being more immediate battles to fight) the perils of guardianship went onto my emotional and functional back burners; they simmered, there, nevertheless."

### Slide 11 Looking back ...

1982

Justin Clark "mental incompetency" trial

- Institutionalised as an infant
- Successfully challenged father's attempt to have him declared mentally incompetent

1987

"Leaked" copy of draft Report of government Advisory Committee

### 1982 -- The "Justin Clarke" case

**Quote** (Reflections on a long journey, Coming Together, CACL Spring 2010):

"(Those simmering thoughts)... boiled over at the trial of the issue of the mental incompetency of Justin Clark, in November 1982, in the County Court House in Perth, Ontario. Ian was 17. At the request of CACL and as a member of CACL's Advocacy

Committee, I had agreed to attend.

During one of the many recesses in the six-day trial, I was chatting to a well-known psychiatrist, an expert witness, there to give evidence of his professional opinion that Justin Clark was, indeed, mentally incompetent. As you probably know, Judge Matheson, rightly, found otherwise! The psychiatrist and I had met on occasions in the past, had even shared conference panels although I do not believe that we had ever spoken on the same side of an issue. As we chatted, he noted that Ian must be about the same age as Justin Clark. "I suppose you will be going through this process with Ian, soon, Audrey," he said. My reply, as I recall, was, "Over my dead body!" From that moment, I was hooked on finding alternatives to guardianship...!"

In **1987**, I received an unofficial copy of a draft Report by the Ontario government Committee considering changes to guardianship legislation in light of Canada's Charter of Rights and Freedoms.

Despite many well thought out improvements, I saw nothing in the proposed legislation that would safeguard people such as Ian from ultimately inevitable guardianship. Knowing the Association had representation on the Committee. I wrote a "strong" letter of protest to my provincial Association.

**(Quote Reflections on a long journey.....):** "One thing I have noticed over my many years in the Association is that it takes little more than expressing an opinion to plunge one into responsibility for action. I was asked to chair a provincial Association Task Force on Advocacy and Alternatives to Guardianship which gave me the opportunity to express some of those long simmering notions."

### **Slides 12 and 13 1989 - First brief to Ontario Government**

(Brief of the Ontario Association for Community Living to the Ontario Guardianship and Advocacy Review Committee May, **1989**)

1989 – OACL first Brief  
Recommendations –**(quote):**

"1. That any legislative changes relating to protection and substitute decision making honour the personal supportive networks within which the wishes and preferences of a vulnerable person are most likely to be determined with the most possible accuracy."

1989 Recommendations cont'd – (quote):

"9. That lesser levels of consent such as clear desire, however expressed, be recognized as valid consent."

"10. That clinical assessments of competence be replaced by processes that expose vulnerability and that response be in terms of support rather than guardianship in the first resort."

### **Quotations from the text (1989):**

Page 19 para 5: "The strongest safeguards against the hazards of extreme vulnerability are those that arise from the sharing of natural supportive relationships in a spirit of equality within the broader community."

Page 9 para 1: "... experience indicates that the capacity of a person with an extremely disabling condition, for decision making or indicating preference, is more likely to increase than diminish. The more one knows such a person and the more challenged and supported that person is, the more competent that person becomes and the more able the partner (or supporter) is to understand what preferences are being expressed. Presumption of capacity is not simply a legal concept. It also has significant developmental and social implications."

Page 15 para 1: Because most people initiate their own search for whatever resources they require in reaching a decision they are rarely called upon to account for how the decision has been made. OACL believes that given the necessary support all people irrespective of disability can participate to indefinable degrees in the decision making process. OACL would take the principles underlying the Fram recommendations on presumption of capacity and carry them through into new and different levels and kinds of decision-making that will validate the process not just the product. (This latter statement, like Recommendation #1 (slide 12) was an early reference to the quickly growing recognition in OACL that the question should never be "Is this person capable?" but, rather, "What

personalised and committed support and capable and accountable process can be put in place in this person's life to ensure that only the best decisions to the benefit of the person would be made, and that those decisions would reflect, to the greatest extent possible, the will and preferences of the person").

Page 20 para 1 (Arguing for OACL's stated need for a mandated advocacy system in Ontario)... "It must be recognised that not only do some people have no immediate family support but also that families have no natural immunity to making bad decisions. It is probable that the most vulnerable of all are those people whose personal support networks produce decisions that are not for the benefit of the vulnerable person. (A mandatory Advocacy system is necessary) ... to advocate directly on behalf of individuals for whom no personal support exists at present or where the personal network is not acting for the benefit of the vulnerable person or to provide back-up support to personal networks where they do exist and to support and enhance the development of networks for all vulnerable people."

### Slide 14 1992

Looking back...

**1992 February**  
Brief to Standing committee

**1992 August**  
Brief to Standing Committee

**1992 OACL (AC) appearing before the Ontario Parliamentary Standing Committee on Administration of Justice 12 February, 1992.**

#### **Quote:**

"... When we start by assuming that certain people are unable to exercise their right to self-determination because of their incapacity, we inevitably look for solutions

in the appointment of others to make decisions for them. Mindful of the intrusiveness of that process, we seek to temper it by imposing the least restrictive of a known series of confining alternatives, such as full or limited guardianship, all of which take away rights to some degree or other.

Had we asked how decisions are made rather than who decides, we would perhaps have recognized that the road to self-determination is rarely travelled in solitude. Typically, we make that journey interdependently, in the company of those who care about us. It is not usual for us to make decisions alone and unaided. We make decisions with the affection and support of people we trust -- family, friends or others whose opinions we respect. When we enjoy the presumption of competence or capacity, we are never asked to reveal that we had support in making our decisions, nor are we required to prove our capacity to make them independently. To subject others to such requirements on the basis of disability is discriminatory.

Had we not concentrated on who decides, we would have seen the need to provide for everyone the same opportunities for support in decision-making that most of us take for granted. In the spirit of equality, we would have recognized the need to validate decisions

resulting from such support in the name of the person at the centre of it. Perhaps then we would have looked for the most enabling solutions in an infinite and untapped reservoir of alternatives for empowering those of us who are disadvantaged. Rather than competence, we would have been thinking about accommodation.

The disadvantage for people with intellectual disabilities is that their decision-making capacity is doubted or denied. Guardianship law cannot accommodate to that disadvantage. To place people under the control of others can, instead, contribute to greater vulnerability.

We must design enabling legislation that validates the decision-making process of those people whose decision-making is discredited, without diminishing either their personal rights or their human identity. Such legislation must be based on clear principles which assert the inviolability of the rights to self-determination and presumption of competence. Such legislation must recognize not only entitlement to support in decision-making, but also that the amount of support that goes into interdependent decision-making is not a ground for either discrediting decisions or compromising autonomy. It does not do it for those of us who we presume to be competent. Why should it do it for people who we suspect are not?

Such legislation must recognize that decision-making can, and usually does, take place within chosen and trusted relationships, that choices and wishes can be made known with or without assistance, through typical and non-typical means of communication, and that some of those non-typical means of communication may only have evolved and may only be expressed within those trusting relationships. It must also recognize that it is the duty of the state to accommodate to disability by enabling the necessary support to be built around people who have severe intellectual disabilities. Only by such principles can the presumption of competence and the right to self-determination be ensured for everybody."

AC

([http://www.ontla.on.ca/web/committee-proceedings/committee\\_transcripts\\_details.do?locale=en&Date=1992-02-12&ParlCommID=79&BillID=&Business=Bill+74%2C+Advocacy+Act%2C+1992%2C+and+Companion+Legislation&DocumentID=17111#P69\\_3351](http://www.ontla.on.ca/web/committee-proceedings/committee_transcripts_details.do?locale=en&Date=1992-02-12&ParlCommID=79&BillID=&Business=Bill+74%2C+Advocacy+Act%2C+1992%2C+and+Companion+Legislation&DocumentID=17111#P69_3351)).

### **Slide 14 (cont'd) 1992**

OACL (AC) appearing before the Ontario Parliamentary Standing Committee on Administration of Justice August 11, 1992 (Ref. Submission to the Standing Committee on Administration of Justice on Government Amendments to Bills 74, 108, 109 & 110. OACL. August, 1992)

#### **Quote:**

Page 1 para 3 "... The handicapping effects of the traditional legal guardianship paradigm are particularly damaging to people with intellectual disabilities.... Guardianship is discriminatory and unjust because it removes the fundamental right to self-determination, classifies and stigmatizes the person on the basis of disability, reduces his or her status to

that of a legal non-person for all official purposes and offers no commensurate benefit in return. In fact, guardianship increases rather than reduces the person's vulnerability."

Page 2, para 3 "The Minister said he was looking for ways to "extend supportive, consensual decision-making" to respond to our concerns. OACL has been given to understand that the amendments related to powers of attorney for personal care represent the Attorney General's solution. With all due respect, OACL submits that the amendments do not remove the discriminatory and unjust effects of the proposed legislation."

Page 2, para 4 "The fundamental purpose is still 'substitute' decision-making. In that model, a competent or capable decision-maker makes decisions for the person presumed to be or determined to be incompetent or incapable. A process designed to legally replace a person in this way inherently jeopardizes people with severe intellectual disabilities. Replacement is not an equitable substitute for empowerment. Third-party interests are legitimate and real. It is both unnecessary and morally repugnant to provide this security for professionals and other non-disabled persons at the expense of declaring people to be mentally incapable and assigning their decision-making rights to other persons. The same protection can be built into the consensual or supported decision-making model as is presently built into the substitute decision-making model."

Page 3, para 2 "OACL's concerns can't be addressed by loosening some of the rules in the traditional legal paradigm of guardianship, as these amendments do with respect to granting powers of attorney. Powers of attorney increase the empowerment only if people already exert control over their own lives. Powers of attorney, validated or unvalidated, are, in effect, guardianship. They should be an option only for people who fully understand their implications."

Page 3, para 4 "When OACL suggested looking to powers of attorney as an avenue for change, it saw them as a way of stepping into a new and different paradigm. It saw some form of power of attorney as a potential vehicle for sanctioning partnerships in supportive decision-making. In this different way of thinking, there is no such legal fiction as incapacity or incompetency, since the necessary support is provided to enable people with intellectual disabilities, and others, to be regarded as capable of self-determination. That's the way it typically is for most of us. We are all free to accept support in our decision-making. We do so. We are never called upon to declare the extent of that support. That principle of presumption of capacity must be maintained for all people."

Page 4, para 3: "We believe these (alternatives) will be helpful not only to people who always need support in making decisions, but also to those of us who would really like to retain our natural status as presumed decision-makers in our own right, rather than eventually being replaced in the decision-making process at the very time we need the most support.

Rather than assessments of capacity, people must be enabled to identify the supportive decision-makers by whatever means they choose; by identifying them actually in writing, if



that's possible, by indicating choice by any other means, or by demonstrating even the existence of a trusting relationship with certain other people in which choices and wishes can be determined and interpreted."

## Slide 15

We spoke consistently in those early days about recognising "trust" in relationships, particularly in those relationships in which there was little if any verbal communication on the part of the person being supported. My son does not speak or vocalise. It is not always easy to communicate with him. It is particularly distressing when he is ill as he has no way to describe his discomfort.

He is not demanding in any way but clearly he has his likes and dislikes. He finds often surprising ways to make them known and he expects them to be respected.

Looking back.....

No matter how severe the disability all human beings have "will."

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

Canada, have talked about that "clear desire" in terms of 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! It is certainly not enough for the Peter Singers of the world but it is there.

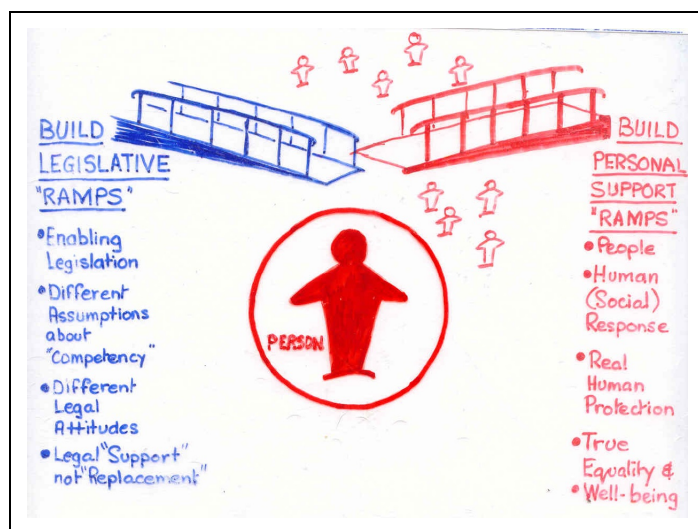
Ian has it! It is what makes him stop, suddenly, and listen to the sounds of the birds or of the wind blowing through the trees. I am sure it is what makes him sensitive to music. It is also what makes him instinctively draw back or resist things he doesn't understand (an unfamiliar medical procedure,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

## Slide 16 - 1992

We also talked in those days about the need to build some different kinds of "ramps." Just as the building of ramps contributed significantly to expanding access to equality for people whose disabilities affected their mobility, we saw the need for different kinds of "ramps" to ensure access to equality in decision making control for people whose disabilities affected the typical presumption of legal capacity. As you may know, Inclusion International, in its negotiations with UNESCO on the matter of legal capacity leading eventually to Article 12, used amongst other instruments the 1992 Report of the CACL Task Force on Alternatives to Guardianship to the CACL Board of Directors. Slide 16 consists of a copy of one of the transparent "overheads" I used in presenting that Report in 1992 to the CACL Board as Chair of the CACL Task Force.



Now, these many years later, I know that we have put much of our energy into (hopefully) convincing governments to bring in new legislation or make the necessary amendments to existing legislation.

Critical as that activity is, I worry that, perhaps, we have neglected the equally important building of the personal support ramps (I know that is a fact in my province). Around the world, there are thousands of people who need those ramps, desperately, if they are ever to be considered equal citizens of

their countries. Sadly, many of them don't have families or friends, or others who care enough about their future to ensure those ramps will be built.

## 1996 (Quote):

"People who do not usually have their capacity questioned in everyday life, feel no imminent threat from guardianship. They probably see it as a practical and beneficial solution to a problem someone else might have - a natural kind of responsibility they would assume if necessary were a family member or friend to "need" it. People do not usually give much thought to their own possible incapacity or, if they do, it is as something that might only happen in the far distant future. Even when people make arrangements for such an eventuality, it is usually with intentions similar to those of making a will - to maintain control over their own lives by making their wishes known.

It is unlikely that the majority of people consider the less enhancing and less dignifying aspects of guardianship, of undergoing a major change in legal and human status; of losing legal identity and social image; of being deprived of the rights to self-determination and to be regarded as equal; and of being under the control of another person, possibly a complete stranger." ("The potential impact on persons with intellectual disabilities of BILL 19, The Advocacy, Consent and Substitute Decisions Statute Law Amendment Act 1995: Submission to the Standing Committee on Administration of Justice", OACL February 1996)

## **Slide 17 The Essence of Supported Decision Making**

Looking back.....

A fundamental principle:-

"Every person, no matter how severe his or her disability, can maintain control over his or her life solely by means of the commitment that other people are willing to make to that person's well-being: people should be enabled and supported to maintain that control." (A Cole)

The essence of supported decision making!

# Thank you!

Audrey Cole

October 2015