

CHECK AGAINST DELIVERY

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Speaking Truth to Power: Finding the Disability Boson

Hundreds of thousands of people with disabilities live behind closed doors. Closed locked doors in situations that by any standard of decency are abysmal. The legacy of institutional confinement continues to haunt people with disabilities particularly those labeled with an intellectual or psycho-social disability. The majority of the 650 million people throughout the World who live with a disability are languishing in segregated settings, profound poverty and suffer the pervasive impact of the discrimination and disadvantage associated with having a disability. Even for those who are no longer languishing in institutional settings, people with disabilities continue to be out of sight because of stigma, prejudice, poverty and ignorance. These are lives that have yet to benefit from the promise the majority of States Parties in the *UN Convention on the Rights of Persons with Disabilities* ["*UN Convention*"].

The World has largely been designed without the needs of people with disabilities in mind. Disabled people's unique needs have been systematically ignored in the design of services, supports and societal infrastructure. Burdened by the enormity of living in inaccessible communities where hundreds of thousands have no access to housing, community services and employment, people are looking for real solutions. New hope lives in the hearts of people with disabilities because of the advent of an international instrument designed by and for them entrenching all their rights - economic, social, cultural, civil and political. People with disabilities for the first time in history are looking for real remedies. Real and tangible solutions will be welcomed but will require States Parties to address the wrongs the *UN Convention* highlights and seeks to rectify.

This *UN Convention* has already enjoyed a magical life. It is the first international human rights document to be born in the new millennium. It was the first *UN Convention* to be drafted at the UN largely on the instructions of the intended beneficiaries – nothing about us, without us. It was drafted and completed in record time at the United Nations. At the time the *UN Convention* was first opened for signature, an historic record number of States Parties signed on. And the rate of nations ratifying continues to astound. It is the first human rights document that touches on all aspects of the lives of a person – health,

work, justice, transportation, housing, family, electoral, education, rehabilitation, social security – encompassing a holistic approach to economic, social, cultural and civil and political rights in one *UN Convention*. The Chair of the drafting committee Ambassador Don McKay of New Zealand referred to the *UN Convention* as a document that has constructed a major paradigm shift in how the world views the rights of disabled persons. This dynamic document gives real and tangible definition and meaning to the rights of persons with disabilities.

But the surge of energy so obvious during its illustrious beginnings during the drafting and signing periods seems to have reached a plateau. This is because we have reached the summit of the most difficult of efforts – the implementation phase. The excitement of the birth is now over and the *UN Convention* needs to grow, flourish and find meaning in the lives of people with disabilities.

Meaningful implementation will require existing structures within society to be totally revamped. Ways in which we design services and resources may require extensive reconfiguration. Mere tinkering will not put Braille on all doorways and elevators. Simple modification will not put elevators into all buildings old and new. Good faith will not redesign how people make decisions for themselves at banks, schools, places of employment and as entrepreneurs. Semantics will not enable people to make choices of where to live and with whom. But most importantly decision makers – politicians and bureaucrats and business leaders – will all need to convert their way of thinking about supporting and including all people with disabilities.

Finding the formula for what goes into making a community truly inclusive for all may seem to many of us gathered here as elusive as the Higgs boson [attributed to Indian scientist Bose and Scottish scientist Higgs] seemed to scientists in the 1960s. But like 5,000 researchers who have worked tirelessly for the last five decades, we can take comfort and find purpose in the fact that their tenacity paid off with the discovery in July of this year of the so-called God particle.

Like those scientists, we are looking for a new particle or element that creates a “sticky” field that binds other particles together to create matter itself. Building on the analogy, we see the answer to the singular question – what is the sticky that binds members of community together to be truly inclusive and integrated? It is in this context that we introduce the Ombudsman as one or the only oversight mechanism under Art 33 of the *UN Convention*. Can we demonstrate the same doggedness in pursuit of the disability boson?

Questions pop to mind when considering the traditional role of the Ombudsman and this newly established oversight role. Will the power to make findings and recommendations be enough to motivate State Parties to make the kind of change needed? Will the duty to consult with civil society under Art 33

create a perception of bias, a criticism that can strike at the heart of the impartial independent modus operandi of an Ombudsman? Is the oversight role under a *UN Convention* compatible with the statutory powers and duties under Ombudsman legislation?

What I intend to do for the remainder of my time is propose a list of factors you can use as a guide when looking at the world through your Ombudsman Disability lens. I will use the letters that make up the word DISABILITY as our guide.

D – DISABILITY LITERACY: Disability Wisdom

Understanding the world from the perspective of being disabled is key. “Walking in the shoes” or more appropriately “rolling in the chair” will require acquiring new intelligence. For many of us this will be like learning a new language. Becoming fluent in the language of disability will require that we confront and set aside our own biases. Ways to achieve this competency may include hiring persons with disabilities in your Ombudsman office or calling disability expert witnesses during investigations or allowing or inviting non-government advocacy organizations to intervene in investigations.

Art 33(3) states:

*Civil society, in particular persons with disabilities and their representative organizations, **shall be involved and participate fully** in the monitoring process.*

What does this duty require of the designated Ombudsman oversight mechanism? It is abundantly clear on a literal reading of this section that civil society must be an integral part – ***involved and participate fully*** – in the monitoring process.

I – IN-PERSON: In-person complaint procedure

Something as simple as how we receive complaints highlights the need for us to examine our own procedures to ensure they are accessible and available to all persons with all kinds of disabilities. Ordinarily complaints need to be made by the complainant. They need to be in writing or made by telephone to intake. These requirements could amount to insurmountable barriers for some individuals seeking access to an Ombudsman. The first step in addressing the Ombudsman role under the *UN Convention* is to do a thorough audit of all internal processes and procedures to ensure accessibility and set the standard as a role model to governments.

With the technological advances and the changes in how we do our work resulting from the birth of the internet, we have to examine and explore real and

tangible AND ACCESSIBLE ways in which to receive complaints and conduct oversight.

S – SYSTEMIC: Systemic Approach versus Individual Complaints

An example from my own experience as the Ombudsman for the Province of British Columbia is the investigation conducted into all the administrative practices and policies of Riverview Hospital, the largest psychiatric facility in BC, resulting in the *Listening Report*. Undertaking a systemic investigation can be extremely helpful in cases:

- where the discriminatory practices are entrenched in the way in which the service is provided,
- where a large number of people with disabilities are impacted and
- where Recommendations can address a myriad of contraventions of the *UN Convention*.

One Ombudsman from Quebec used to refer to many of the complaints coming to his office as the \$2.00 specials. Complaints about personal seemingly trivial matters may not be the way to approach oversight under the *UN Convention*. In a time where many countries worldwide are struggling economically, we must be prudent in how we manage our own resources. Systemic investigations, which can be labour intensive for a significant period of time, they can serve to ameliorate the disadvantages on a larger scale and serve to prevent ongoing discrimination for a greater population.

A – ABILITY: Focusing on Ability not Disability

Article 12 of the *UN Convention* is clear. Everyone has the will and intention to make their own decisions. This was purposefully not designed as a presumption as that would be seen as something that is rebuttable. The Article was designed with that in mind. The right to recognition everywhere as persons before the law is at the heart of exercising and enjoying all the other rights under the *UN Convention*.

In addition, Article 5 recognizes that all persons are equal before and under the law without discrimination. Individuals or groups seeking redress under the *UN Convention* through the Ombudsman are entitled to reasonable accommodation. The burden is on the Ombudsman to treat everyone equally regardless of her/his ability, of their method or mode of communication, of any medical labels or diagnoses attached by third party professionals. This includes communicating non-verbally, through electronic devices and making their complaint or evidence known through a third party/advocate/family or friend supporter. With the advent of technological advances, we must triple our efforts to find ways that will enable everyone to make their wishes known.

Canada had the lead on Article 12 during the proceedings at the United Nations. We introduced the concept of supported decision making. It is based on the premise that those labeled intellectually disabled can make decisions for themselves but they require accommodation in the same way as a person who relies on a wheelchair needs a ramp to get into buildings. Since the conclusion of the Ad Hoc Committee work, the Canadian Association for Community Living has established a special committee to work on the details of what Art 12(3) means when it states:

States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

These provisions essentially displace guardianship law that is not to be used except when absolutely necessary and then with all the safeguards to avoid a return to relying full board on guardianship. These safeguards require the measures to be free of undue influence, proportional and tailored to the person's circumstances, applied for the shortest period of time and subject to regular review.

Let's be clear. It is legal constructs that have disenfranchised people with mental and other disabilities – those being guardianship and mental health legislation. By way of analogy there was a time when aboriginal people were marginalized and not considered full persons – because, in the case of Canada, provisions in the *Indian Act* and other legislation such as the *Elections Act*. Similarly women were not considered persons and were unable to vote – all because the law disenfranchised them. This formal of legally sanctioned apartheid has excluded aboriginals, women, people of colour. It continues to do so for many people with disabilities. The new way of seeing supported decision making as the full realization of the right to decide entrenched in the *UN Convention* is essential for the enjoyment of all the other rights for those previously excluded from their own decision-making.

B – BOLD: Bold and Courageous in our Approach

Mining out the most egregious contraventions of the *UN Convention* by States Parties will not be work for the faint of heart. What goes on behind locked institutional doors can be anywhere from distasteful to disturbing to abhorrent. Ombudsmans and their representatives will have to be bold and courageous in going down the investigative road, many of which have not previously been traveled. I conducted an administrative investigation of an institution for people labeled intellectually disabled when allegations of abuse surfaced even though the facility itself had been shut down. This investigation of Woodlands School resulted in a public report *The Need to Know*. I conducted this review for

government shortly after leaving office as Ombudsman. The report and its findings bear the fingerprint of an Ombudsman because of its bold approach. This is where speaking truth to power is key. Sometimes the message will be difficult and will require courage.

I – ILLEGAL: Recommending Change where Discrimination has Legal Sanction

Much of the discriminatory treatment of people with disabilities has been done without legal sanction and indeed in some instances with legal authority. The discriminatory treatment is embedded in the laws without recourse. This is why the provision in most Ombudsmans' Acts empowering Ombudsman to make findings that the subject of the investigation has been based wholly or partly on a mistake of law is of critical importance. That section places Ombudsman in a prime position to address the heart of the discrimination – legally permitted either explicitly or implicitly – that other oversight bodies may not have.

Recommendations, therefore, can include proposing amendments where the law itself requires change, where without those amendments to the domestic legislation, contravention of the protections within the *UN Convention* will continue. This may be *the paramount power of the Ombudsman* - to target changes to laws to give realization to the full implementation of the *UN Convention*. And this capacity to be broad sweeping in our approach may lead to significant legal reform that will reflect the paradigm shift structured by the *UN Convention* and in fact emerge as our God particle or disability boson.

L – LISTENING

Serving populations of people who are vulnerable requires ingenuity and sensitivity. We need to recognize that people who are disabled are not vulnerable because they are disabled. They are vulnerable because of the situation in which they find themselves. They are often out of sight, impoverished, or something as simple as not registered to vote. This is a result of society's failure to include them or to reach out to them to understand how their lives could be improved.

By way of example. While Ombudsman in BC there were a record number of deaths of children and youth in care that resulted in Public Report No 22. Thereafter my office had been charged with the oversight of children and youth. While we were happy to be the focal point for these issues in the short term, the role was not sustainable in the long term. We approached this in a twofold way. First I issued an Ombudsman Discussion Paper entitled *Advocacy for Children and Youth in British Columbia* in October 1993. This paper was widely circulated particularly to youth still in care of the state or those who had formed a network after coming out of care and other advocacy organizations. This was followed by a province wide tour to meet with hundreds of youth and

not for profit societies. The result was a report *Children Should be Seen and Heard* issued in June 1994, which stated in part:

The advice provided to the Ombudsman by young people and their experiences with education, child welfare, social service, correctional and mental health systems, have strongly reinforced Ombudsman impressions from complaint investigations about the need for major reform of how we plan to organize children's services.

The outcome of that work was the establishment of a stand-alone Office of the Child Advocate as an officer of the Legislature and the Children's Commissioner to investigate all deaths of children in the province. While time does not permit me to provide all the details, those reports remain available on-line. The principal point is that by listening to those closest to a problem – that is by being inclusive and listening as part of the monitoring role – real and viable solutions can be found that bring meaningful and valuable reform.

I – INCUSIVE: New Principles of Administrative Fairness

All Ombudsmans tackle their statutory duties in a principled way. In other words, in investigating complaints, Ombudsmans measure the conduct complained of through the lens of principles such as the right to be heard, the right to know, the right to be treated fairly. The principles of administrative fairness include that public information is available and understandable, those affected by a decision have a chance to speak on their own behalf, decisions are timely and there are reasons given for decisions. Many of the Ombudsmans throughout the World have their own unique way of articulating the principles they use to unearth maladministration. In this new work as the oversight under the *UN Convention*, perhaps those principles need to be revisited and see if new ones should be added:

The best example to demonstrate this point is to consider adding the principle of inclusiveness. Is the service or facility, or the appeal or complaint procedure inclusive of people with disabilities, regardless of the nature of that disability? This goes beyond what a human rights commission may address where someone is denied access to a service because of disability. This infiltrates and examines the intricacies of a service – the fine points of how a procedure is administered and whether it has appropriately taken the unique requirements of a person with a particular disability into account.

T – TRUST: Trusting of the Real Experts

The real experts are the people with disabilities. The *UN Convention* is what it is today because of the enormous contribution made by civil society. At the closing session of the Ad Hoc Committee there were over 400 registered NGOs in attendance at the United Nations. Day in and day out over four years

the self advocates poured their hearts and minds into the intense lobby they tirelessly pursued in making the *UN Convention* meaningful. One of the ways in which their contribution has been recognized is the provision in Art 33 that States Parties must consult with civil society. So too must we in our role as the Ombudsman oversight keep this tradition alive. Listening to and truly hearing from the disability community will be key to our success as the Ombudsman oversight.

Y – YELLOW: Yellow Alert

Given the historic and pervasive disadvantage suffered by the majority of the 650 Million people with disabilities throughout the World, is the Ombudsman oversight role sufficient to address the breadth of the problem? Is recommendation power sufficient for the most egregious of contraventions of the *UN Convention*? In answer to these questions I would answer with a resounding Yes! I think the respect Ombudsmans around the world enjoy place them in an ideal position to be proactive and creative because they can! By that I mean because Ombudsman cannot force Parliament to do anything, cannot require states parties through injunction or Order, our greatest authority is based on our credibility and the faith the public has in the word of the office.

So for my final letter – the Y in DISABILITY – I am proposing but one example of how we can use the two basic tenets of the authority of the Ombudsman – one, the power to make Recommendations public and two, the tremendous credibility of the office – in a creative and relevant way.

I propose a Yellow Alert, similar in kind to the Amber Alert used for reporting the abduction of a child in many countries now. The Yellow Alert would be issued – as a recommendation – when an Ombudsman discovers a situation so problematic, where the abuse or suffering is so egregious as to justify the issuing of a Yellow Alert. This incitement would be used judiciously and prudently but it would sent a clear signal that the State Party must take immediate action.

Conclusion

Through your role as one or the only monitoring oversight body under the *UN Convention*, you can play a concrete role is nudging, persuading or forcing governments into action. Your role is to shine a light – even a Yellow Alert – shine that light on the atrocities faced by people with disabilities and force those in power, through persuasion and public airing, out of their complacency.

Taking up your monitoring role with courage and wisdom to contribute to the change required to finally enable all of us to reject any notion of “them” and “us”. Using the DISABILITY lens to view the problems and what needs to be done to reach full equality, Ombudsman can aid in making ours a fully inclusive

World where there is no light shining between people with and without disabilities.

I want to sincerely thank Ombudsman Beverley Wakem for her kind invitation to travel to this beautiful country and be able to speak to you today. Along with the other panelists, I look forward to opening it up for questions and discussion.

Thank you.

- **tēnā koutou**

hello! (speaking to three or more people), thank you.
(*Te Kāhano* Textbook (Ed. 2): 1;)