

# **Karlen Communications**

## **UNICEF Forum on the Rights of Children and Youth with Disabilities**

### **Comments for Follow-up to September 24 meeting**

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## **Introduction**

The meeting at UNICEF Place on September 24, 2013 was a great second forum to promote discussion on the rights of children with disabilities. However, there are some items that I would like to comment on.

At the forum, each participant was given yellow Post-it notes to make comments or suggestions on for each topic and purple postcards for items they wanted follow-up on or that might be related to policy. Neither of these methods of contribution had an alternative accessible format for those of us with visual disabilities to make timely contributions so this is my “yellow Post-it” and “purple post card” contribution.

## **Task Force Activities**

There was much mention of the various task forces and the number of task forces being implemented. The time for task force activity is over. We have enough information to proceed with strategic planning committees and actual action plans.

What is the plan moving forward to ensure that education is accessible to all children with disabilities that day-care is available and that day-care facilities are accessible? What is the plan for ensuring that students in co-op programs, physical education classes and extracurricular activities have the opportunity to participate and that the venues for these activities are accessible?

Those of us who are advocates and are working in the trenches of disability rights need the process to move to the next level: strategic planning. We have been studied to the fullest extent and now need concrete action and strategies with accountability.

We do not need to spend more time talking among ourselves in task force committee meetings. We need solid action plans that include accountability for moving forward while we have the momentum provided by Secretary-General Ben Ki-Moon.

## **Approved Structure**

The percentage of involvement of people with disabilities in the approved structure is disproportionately lower than the involvement of organizations and “stakeholders” without disabilities. All levels of any structure of a mechanism on the rights of children, youth and adults with disabilities should have a two thirds membership of those of us with disabilities. If the mission is truly “nothing about us without us” then we must have the majority representation in any structure to achieve those goals. This includes preference given to organizations “of” people with disabilities over organizations “for” people with disabilities.

The “vision” which did read more like a “to do list” rather than a vision of the future began with the collection of data, metrics and rubrics.

The inclusion of those of us with disabilities in the vision and goals for inclusion appear to be secondary or tertiary in the vision. Equality and inclusion should be the focal point of any vision statement as it pertains to the goals and objectives of moving disability rights forward.

Data collection, metrics and rubrics should be a by-product and should not be the primary focus in the vision of communities and societies that are inclusive. Data collection should also not be the focus of funding opportunities. The funding of projects should focus on elevating the inclusion level of people with disabilities with any data or rubrics being a by-product.

## **Human Rights Law**

There was some discussion at the forum on the role of government with questions being raised on how to encourage governments to recognize value in people with disabilities.

Some participants had examples of where human rights law and the Convention on the Rights of People with Disabilities were enacted and ratified “in name only.”

A key component of any funding opportunity related to the implementation and adoption of the CRPD must be how the human rights laws are enforced and complied with in ratifying countries. Accountability is an essential element in moving toward an inclusive society. This is where data collection, monitoring and rubrics should be present.

For example, Ontario Canada has the following layers of human rights law and legislation, each building on the other:

1. Canada ratified the Convention on the Rights of People with Disabilities in 2010.
2. Canadian Charter of Rights and Freedoms which includes people with disabilities.
3. Ontario Human Rights Code which includes people with disabilities and has the following additional components:
  - a. Duty to Accommodate.
  - b. Section 11 which states that additional layers of discrimination cannot be added onto a group identified by the Ontario Human rights code.
4. Accessibility for Ontarians with Disabilities Act (2005) or AODA which has the following additional legislation relevant to the case study:
  - a. Integrated Accessibility Standards Regulations or IASR (Information Communication, Employment, Transportation, Open Spaces).

Yet in a current case study illustrating the violation of these laws, elected officials in one community/municipality near Toronto Ontario “decided” that the AODA “isn’t a real law, so we don’t have to follow it.”

Where monitoring and reporting are useful is in these types of cases where there is layers of human rights legislation yet no accountability or enforcement of those laws and legislation. The rights of people with disabilities appear to exist in rhetoric and paper only.

In this case, the municipality wants to eliminate specialized transportation or Para transit. Statements such as “people with disabilities are abusing the service by going shopping, to restaurants and visiting friends” were among the more benign comments made by Council members.

On the 20<sup>th</sup> anniversary of the International Day of People with Disabilities, December 3, 2013, the Community services Committee which is a committee of Council and is comprised of Council members, stated: “if a human rights complaint is filed, the service will stop immediately.”

Despite contacting every level of government to gain assistance and enforcement of the various human rights laws and legislation, the task was labeled the responsibility of the Accessibility Directorate of Ontario (responsible for the accountability of and enforcement of the AODA and its subsequent standards) and nothing was done. For each update on the situation in the municipality, the Accessibility Directorate of Ontario sent letters stating that “all questions have been answered and your feedback will be kept as data only.” The final letter, received in November 2012 stated that “we don’t need any more information.”

This case study doesn’t require more “metrics and data collection” as the discrimination is clear from the public documentation of the events, but does require a mechanism for accountability that works.

This is only one example of the situation and environment for those of us with disabilities in Ontario Canada. The AODA is not complaint based and is based solely on self-reporting. Random organizations and municipalities will be investigated but nothing is being enforced (despite the identification of \$100,000 per day fines for non-compliance).

There is an audit process, but that process only identifies what is in place now, not what is planned and what is currently being deprecated.

The Accessibility for Ontarians with Disabilities Act appears to be thorough and inclusive on paper but in practice, without accountability and the ability to enforce human rights law and legislation and to showcase the failure of such legislation, there can be a hundred layers of legislation promoting an inclusive society” with no advancement or inclusion actually being accomplished in the area of disability rights.

On January 1, 2013 all companies and organizations in Ontario of one employee or more had to submit an accessibility report on the progress they’ve made toward implementing the AODA and its subsequent standards. According to the Ontario government, only 20% have submitted their reports. Some companies and organizations don’t know this is now a requirement while many others are just waiting for the 2025 deadline for full implementation of AODA as there is no accountability or enforcement, several deadlines for

reporting levels of AODA compliance have passed and nothing has happened. Many organizations and municipalities believe that if they simply wait this thing out that after 2025 it will go away.

If we are looking at data collection and case studies on the failure of human rights law and legislation, then Ontario becomes a prime example of a developed country that seemingly has enough layers of human rights law and legislation, but one elected Council in one municipality can set human rights for people with disabilities back decades or centuries.

This is where data collection, monitoring, evaluation and rubrics should be used: to shine a light on the human rights violations and encourage change.

Core funding of projects must put people with disabilities first and data collection as a by-product.

## **Core Funding Revision**

If we are truly committed to the inclusion of people with disabilities in all levels and aspects of society, then any core funding projects that begin in 2014 or 2015 MUST include people with disabilities as a percentage of the population that the funding of a project includes.

For example if there is a project to improve or fund early childhood education, 25 percent of the funding must be used to include children with disabilities in the project. If a school is to be built, then the funding proposal MUST include ensuring that the building and learning material are accessible to students with disabilities. If fellowships and scholarships for educational opportunities are being provided, then students with disabilities must represent at least 15 percent of the fellowships and scholarships awarded.

This does not negate any projects or fellowships specific to the advancement of inclusion of children, youth and adults with disabilities. We have a lot of “catching up” to do.

As with the principles of inclusive and universal design, it is more cost effective to include accessibility and people with disabilities in the core development process than to “accommodate” or “add them on as needed.” An inclusive society is one where individual accommodation is the exception rather than the norm.

The principles of core funding must be reviewed and revised to be inclusive for people with disabilities. Until we have an inclusive society and the accessibility of education, employment, transportation and goods and services are “simply part of what we do,” we need the funding supports, program supports and truly inclusive design of everything the UN and its supportive organizations and governments do.

## **Families and Caregivers of People with Disabilities**

The inclusion of families and caregivers of people with disabilities is important to understanding some of the physical and program-based needs of those of us with

disabilities and where government and community support fall short. However, we must have our own voice that is heard above all others. We must have the larger segment of representation on all focus groups, task forces and strategic planning committees

If we don't, then the rallying call to action of "nothing about us without us" is meaningless.

## **Eliminating Disability**

One of the suggestions at the forum was to include funding and the promotion of eliminating disability as part of the "nothing about us without us" campaign. This is a small component of the disability rights movement. The focus on a mission that is "nothing about us without us" concentrates on including those of us who have disabilities into our own lives and communities.

For example, we currently have more people, including children, who are acquiring disabilities in developed nations due to nutritional issues. We have a large segment of the global population that are reaching "old age" and are acquiring disabilities as a natural progression of aging. We still have accidents, work based injuries and recreational based injuries. Disability is not going to go away! It is not going to be eliminated!

We can't "put off the development of an inclusive society while we are waiting to eradicate disability."

Those of us with disabilities **MUST** have access to the same rights and privileges as every other segment of the global population.

As we move toward supporting those who are aging in Ontario Canada with the provincial governments "Aging at Home" strategy we need to consider what is missing from those types of supportive programs. The Aging at Home strategy focuses on health care and facilitating the opportunity for those who are aging and require supportive care to remain in their homes. There are renovation tax credits and health care projects and initiatives.

Yet one of the glaringly missing components is the ability of those who are aging and acquire disabilities, especially in rural communities, to have access to accessible, affordable and sustainable transportation.

It is often too expensive to move into more urban areas, friends and community connections exist in the community people have either grown up in or moved to in retirement. Again pointing toward the actions of the municipality violating the AODA, statements were made such as "if they aren't living close to shopping and work, they need to move." The direct quote from the elected official is "People with disabilities need to learn how to budget their money like everyone else...If they can't afford the luxuries then they should consider moving and changing their lifestyle..."

It is not clear when accessible, affordable and sustainable transportation became a "luxury."

It is clear from policy and program development that accessible, affordable and sustainable transportation, especially in rural municipalities, is a huge part of independence and inclusion that is missing from funding initiatives.

We will always have or acquire disabilities and while moving toward eradicating diseases that cause disabilities, we must acknowledge that those of us with disabilities will always be part of society.

## **Accessible, Affordable and Sustainable Transportation**

As the population of what we affectionately call “Baby Boomers” ages and acquires disabilities and as children and youth acquire disabilities due to lifestyle choices, the ability of people with disabilities to move around their community has become a critical component of independence.

Of course, accessible, affordable and sustainable transportation has always been a critical component, however, as the population of those of us with disabilities increases and we gravitate away from urban areas to improve our lifestyle, the issue of accessible, affordable and sustainable transportation moves to the forefront of disability needs and rights.

Often rural municipalities and areas do not have conventional transportation services and either have no “Para transit” or the Para transit (specialized transportation service) is taxi-based. Taxi-based Para transit is the most efficient and cost effective type of specialized transportation service in all research and case studies examined for a formal report to the municipality attempting to eliminate Para transit.

As we move to an inclusive society post-2015 one of the areas of research, planning and project implementation must be the provision of accessible, affordable and sustainable transportation for those of us with disabilities in both developed and developing countries. This is a key component in getting to school, work, social and recreational activities and being independent.

## **Inclusive Education**

As with the statement at the end of most current job descriptions that says “equal opportunity employer” the implications of inclusive education may not have been thought through.

While we can advocate for the use of adaptive technology, an accessible built-environment and access to learning material by students with disabilities, this approach is still done on a customized or accommodation based basis.

Inclusive education often means the same thing to people with disabilities as “mainstreaming” does: we are thrown into inaccessible environments and have to ask for, advocate for and beg for the tools we need to be successful. In other words we have to fend for ourselves which is why we often balk at the word “mainstreaming.”

In 2013 students often get reading material at the end of the semester they needed it in.

The production of alternate format is still behind the timeframe needs of the students with disabilities. We know that alternate formats are needed yet the textbook publishers and the process for getting alternate format is chaotic at best and unavailable at worst.

Students aren't often notified when work is to be done on sidewalks, roads or parking lots on campus and arrive via Para transit only to find that they can't get to class and have to wait for the normally scheduled Para transit pick-up time, stranded on campus for hours.

Inclusive education means that universal design principles are evident in every aspect of every tool used in the learning environment, every deliverable or assignment whether they are created by students with disabilities or not, and in the overall identification by academic and training institutions as part of "who we are and what we do."

As we move forward past 2015 and think of how we want our global community to be inclusive for people with disabilities, we must include the ability of people without disabilities to seamlessly produce accessible multimedia, software, technology, and anything that would ensure that they too are employable after finishing their educational process.

There are many inventions and designs that were implemented to assist those of us with disabilities that have ended up assisting the population of people without disabilities. Inclusive, universal design is for everyone. In the educational environment it allows any student to access any content in any format they want or need. Those needs can change with the environment the student (or faculty member) is in. Being able to look at content as a student and say, "I don't understand this, but let me look at it this way, in this format" provides a powerful conduit to learning.

We can't continue graduating students with no concept of inclusive universal design. The fact that people with disabilities must be included in architectural design, software design, the design of any technology, open space design, the employment process and every aspect of every graduating category simply makes sense.

Employers shouldn't be responsible for re-educating graduates on inclusive universal design to meet human rights law and legislation and to maintain an inclusive community. Graduates should be job ready when they graduate.

If we are to be a truly inclusive society with inclusive education, accommodation will be a rare instance instead of the norm. Inclusive design in everything produced and created will be seamless and automatic.

## **Employment of Youth and Adults with Disabilities**

Pointing again to the Integrated Accessibility Standards Regulations which are part of the AODA here in Ontario, Section III – Employment continues to perpetuate accommodation in the workforce instead of inclusion.

As long as the focus of employment for people with disabilities is accommodation on a one-off basis, we will not be equal and have “the same” employment opportunities as people without disabilities.

There is an acknowledgement that in 2013 people with disabilities are not able to participate in some types of employment activities due to limitations of a specific disability. However, this does not negate the possibility that as we move toward a truly inclusive community, that this will not change. My comments around employment relate to ensuring that any workplace is as accessible and universally designed as possible.

In 2013 it is still not possible for someone with a disability to simply “get work” when they are unemployed. If they are laid off or their work moves, it is not as simple as going to another business and being employed again.

We can’t get work at the local fast food restaurant, grocery store or pharmacy. We must find an employer “willing to take a chance at hiring us” despite having a solid work history.

In terms of co-operative education opportunities, students with disabilities should be able to choose a workplace or work area that they are interested in rather than having teachers scour the community to find “something that can be accommodated” or “someone who is willing to take you.”

Toward that goal, and with the IASR in mind, job descriptions need to be revised to include information on the accessibility of the interview site and the built-environment.

Focus needs to shift from accommodating the disability to employing the person who can do the job.

Job descriptions should include at the bottom the following information:

We are an equal opportunity employer.

The interview site is accessible as per (building code, IASR or other standards).

The workplace is accessible as per (building code, IASR or other standards).

The adaptive technology supported and used by our organization is: name of screen reader, name of screen magnification software, name of Text-to-Speech software, name of voice recognition software, name of any other adaptive technologies available/supported.

Can anyone imagine how frustrating it is to apply for a job only to find that even before you start working, you are “creating a problem” for an employer who didn’t think through what an equal opportunity employer means?

Having to change the venue of an interview as an accommodation. Finding out the workplace isn’t accessible after you spend time applying for and hoping for the job that uses your skills and abilities. Having to justify your employment and spend time in an

interview talking about how your adaptive technology will work or not with the customized software of an organization instead of the skill you bring to the job is demoralizing.

We need to be able to take the focus off of disability and accommodation and put it on the person and their skills that we are hiring.

Most people do research on what an organization does and how they will benefit the organization as a potential employee. People with disabilities must often research the workplace accessibility issues, spending interview time troubleshooting IT issues and helping the organization accommodate them and answering questions on adaptive technology interviewers should already have answers to

Can anyone imagine how depressing it is to see a job you are qualified for and can do, apply for it and then find out that the interview site is not accessible, the workplace is not accessible, no one knows if the software used for the position is accessible, the interviewers have no idea what to do with you or an understanding of how you would do the work with adaptive technology? The level of feelings of rejection, disappointment, worthlessness and low self-esteem increase exponentially with each failed attempt to find work to be independent and financially independent.

This becomes a never ending cycle of “busy work” that appears to be systemically designed for people with disabilities to “fail in gaining meaningful employment.”

In order to truly be equal opportunity employers and to eliminate most of the need for individual accommodation, we need to think of employment of people with disabilities as being inclusive and not “special.”

## Resources

Karen McCall has written a [discussion paper on inclusive education](#)<sup>1</sup> which can be downloaded from the Karlen Communications web site.

The case study of discrimination in the County of Brant Ontario has been presented at an AODA/Accessibility conference and will be presented at other conferences on disability issues. The slides can be found on the [Accessibility for Ontarians with Disabilities web page on the Karlen Communications web site](#).<sup>2</sup> All blog articles and letters to the editor as well as the report from the Accessibility Advisory Committee to Council and the report researched and written by Karen McCall to Council can be found on the same page.

The Accessibility for Ontarians with Disabilities web page includes links to Canadian and provincial laws and legislation. The formal report to Council includes research papers and

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<sup>1</sup> AODA and Education in Ontario - A Discussion Paper: <http://www.karlencommunications.com/AODA.html>

<sup>2</sup> Accessibility for Ontarians with Disabilities page on the Karlen Communications web site: <http://www.karlencommunications.com/AODA.html>

reports on specialized transportation service in both rural and urban areas read for the report.

Karen McCall has provided technical comments on the refresh of section 508 in the US as well as for the Integrated Accessibility Standards Regulations in Ontario.

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