Connecting on Disability and Abuse

S'engager contre l'abus envers les personnes ayant un handicap

Communicative Disabilities & Abuse Workshop

Understanding, Empowerment and Action

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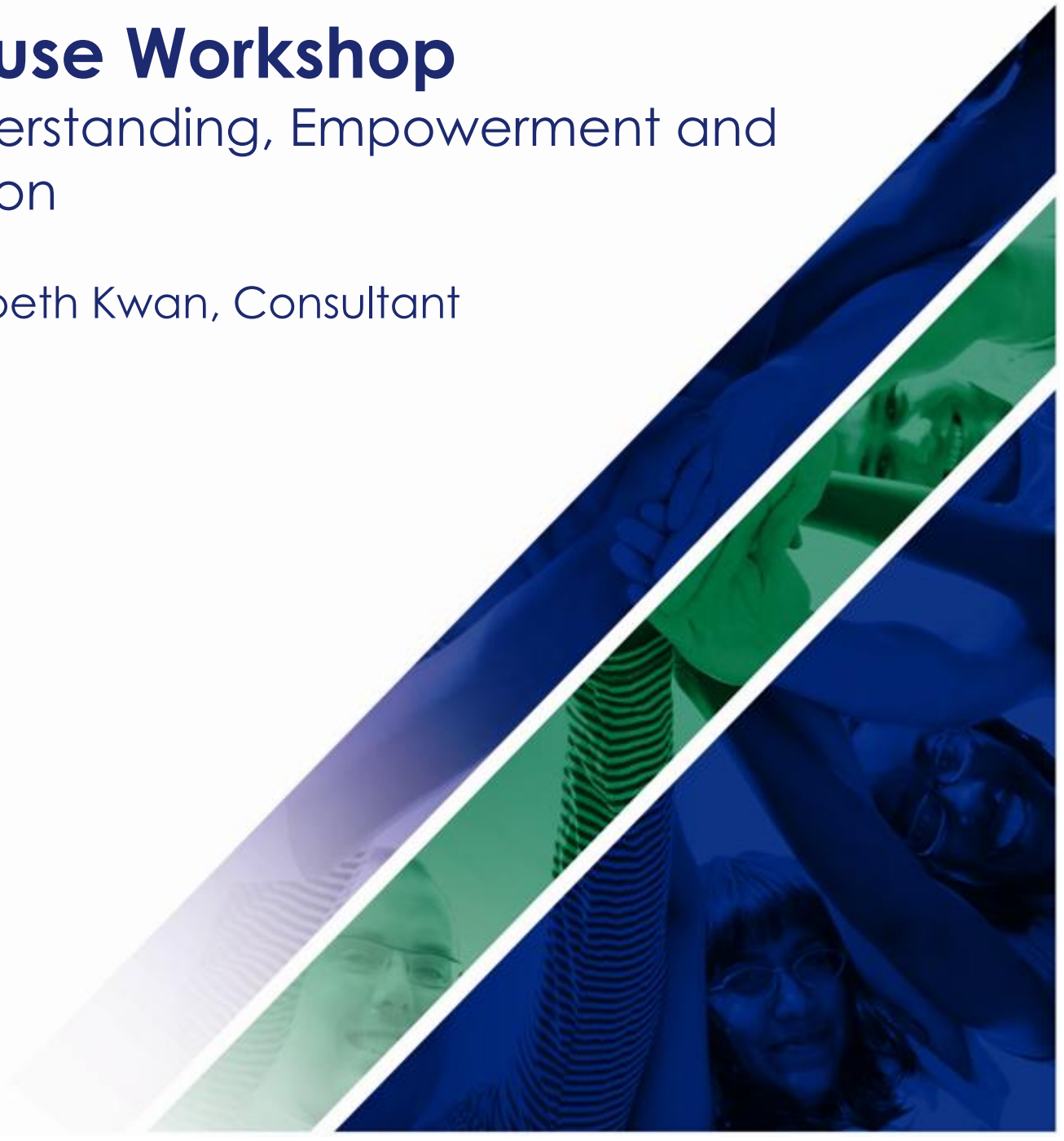

Table of Contents

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Background

The Communicative Disabilities and Abuse: Understanding, Empowerment and Action workshop took place on May, 4th, 2012. This event was hosted by Connecting on Disabilities and Abuse (CODA) in partnership with the Canadian Hearing Society, Crime Prevention Ottawa, Aphasia Centre of Ottawa, and the Learning Disabilities Association of Ottawa-Carleton.

This workshop explored the abuse issues facing people with communicative disabilities and identified towards prevention and solutions.

Welcome and Introduction

Gail Carroll emceed the workshop. Gail's thirty year career spans a history of accomplishments that include the development of successful public awareness programs and the execution of effective strategic communications, cause marketing and fundraising campaigns, strategic partnerships, project and event management, media training, legislative affairs and journalism. Recently, she lead the OutCare Foundation in supporting community based healthcare, including the Aphasia Centre of Ottawa and raising $1Million for a group of hospice palliative care programs in the region.

Nancy Worsfold, the Executive Director of Crime Prevention Ottawa started the workshop with a brief history of CODA, the workshop host. CODA is a community-based initiative dedicated to developing awareness and understanding of the abuse of people with disabilities and working towards prevention. CODA was created as a result of a town hall forum on April 30, 2009 entitled "Rising Strong: Disability, Abuse and Prevention".

CODA secured a federal government grant to develop and deliver workshops for service providers on abuse and persons with disabilities. After a year of delivering these workshops, one of the recommendations on this complex issue was to focus the work, that is look at abuse in terms of the different groupings of disabilities as the issues and actions vary with different disabilities. As a result, we have this workshop on Communicative Disabilities and Abuse.

Dr. Alexandra Carling-Rowland Ph.D. Reg CASLPO, the key note speaker, shared some knowledge and provided insights on the communicative disabilities and abuse.

Highlights from Keynote Speaker

Dr. Alexandra Carling-Rowland has recently joined the College of Audiologists and Speech Language Pathologists (CASLPO) as the Director of Professional Practice and Quality Assurance. Alexandra has completed a CHIR post-doctoral fellowship at Health Care Technology and Place at the University of Toronto where she investigated communication barriers and access to psychosocial oncology research trials. In 2010 she completed her doctorate from the Institute of Medical Science at the University of Toronto. Her research focused on the consent and capacity process for people living with aphasia and other communication barriers. As part of her doctoral studies she developed and successfully tested a tool, the Communication Aid to Capacity Evaluation (CACE).

Dr. Carling-Rowland's informative presentation about the different types of communication barriers that many people live with focused on the law and ethics, rights and abuse.

Law and Ethics

Every Canadian is protected by the Canadian Charter of Rights and Freedoms, and there are many laws and legislation to protect the rights of those living in the province of Ontario. Everyone has the right not to be discriminated against based on race, national or ethnic origin, colour, religion, sex, age, mental or physical disability.

Then there is the Department of Justice in Canada that has a Criminal Code that outlines crime in terms of:

- Physical abuse
- Sexual abuse and exploitation where someone uses another person for a sexual act without their consent
- Abuse of neglect, that is failing to provide what we need to sustain life
- Psychological and emotional abuse
- Economic and financial abuse.

Aside from the protections provided by the law, there are also these four incredibly important medical ethical principles first introduced by Beauchamp and Childress:

- Patient autonomy - the right of patients to decide, to make choices
- Beneficence - that we must do good
- Non-maleficence – that we must not do bad or harm
- Justice

For Dr. Carling-Rowland, the principle of autonomy is the most overt expression of human rights.

Abuse

In the Oxford English Dictionary, abuse is defined as "to use something to bad effect" or to do something to bad effect, or for a bad purpose. Aside from abuse outlined in the Criminal Code, there is the abuse of power or using power for a bad purpose - to take away someone's legal rights, to ignore those fundamental ethical principles, to take away someone's choice to decide about where they are going to live, what medical treatment, how they're going to manage their bank account. People who live with a communication barrier are extremely vulnerable to this power imbalance.

The way to have balance in the relationship is by conversation. And, when this conversation is taken away, there is an imbalance of power in a relationship and it is not equal. This imbalance could be between you and anyone you have a relationship with, and this can lead to abuse. In abusive situations, the person who holds the power in a relationship can say and act to take away the rights and ethics of the individual living with a communication barrier.

Communication Barriers

Dr. Carling-Rowland spoke about several groups of people with communication barriers, their vulnerability and difficulty in explaining emotional and complicated issues in a situation of abuse.

People living with aphasia are one of the groups with communication barriers. Aphasia is when there is a disruption in understanding spoken language. It can also affect the way someone talks, the ability to read and write, difficulty finding the right word, or putting those words together in a sentence but it does not necessarily affect the ability to think. Research has shown that 33% of every Canadian has a head injury or a brain injury will have aphasia.

Another group who live with a communication barrier is people with dysarthria that is when someone's speech is hard to understand because the muscles or the nerves of their mouth and voice have been affected. People with dysarthria include those who have had a stroke, people living with multiple sclerosis, cerebral palsy, Parkinson's disease, Lou Gehrig's disease, cancer of the voice box, tongue, lips, palate and larynx, and maybe a syndrome such as Down Syndrome. People with dysarthria feel very vulnerable and find it exhausting to have to keep repeating themselves until they are understood.

People whose subsequent or acquired language is French or English also face communication barriers. There are now nearly 7 million people living in Canada

for whom English or French is a subsequent language or one of the many languages or dialects that they speak. In Ontario, 20 per cent of people speak another language other than English or French at home.

Yet, another group living with communication barriers is older people. One quarter of Canadians who are 65 years of age or approaching 65 years are hearing impaired. But, only one quarter of those people will have a hearing aid. In Canada, there are approximately 310,000 individuals who are profoundly deaf and deafened.

Finally, low health literacy and low literacy of the complicated language of law used in the justice system are communication barriers for many individuals. In terms of low health literacy, 22% of Canadians are unable to read a medicine label and follow the instructions.

Communication barriers often stop individuals from receiving the same rights as others.

Capacity

The legal definition of capacity to decide is based on these two factors: an individual can understand relevant information, and can appreciate the consequences of their decision. How do we determine the capacity of an individual living with a communication barrier in these circumstances:

- Understanding written material if they cannot read
- Having a low level of literacy
- Communicating that that they understand if they live with aphasia
- Not being able to hear the question
- Being understood by other people when the individual has a speech problem.

In Ontario, there is no legal construct of global capacity or incapacity, and applies in this regard only to finances. For every other decision, you have to assume that they can make that decision. Everyone assumes people in abusive situations cannot make any decision if they have a significant communication barrier, and that is absolutely not the case.

Suggestions

Dr. Carling-Rowland suggested these solutions to workshop participants:

- Get educated about the law
- Get educated about the different communication barriers
- Learn simple techniques to overcome communication barriers

- Advocate for individuals living with a communication barrier
- Consider becoming a communication intermediary, a translator or an interpreter

Interpreters for people with communication barriers who are victims of abuse are needed. If someone can help them communicate what is happening and painful to them, then maybe they will have the courage to pursue a way of getting out of their abusive situation.

Some tips to communicate in easier ways include:

- Talking in the present tense
- Speaking in the active and not in a passive voice
- Keeping sentences short
- Not using contractions, especially in written materials (e.g. don't, can't)
- Enlarging the size of the font
- Highlighting key words in bold
- Using pictures but make sure they are gender neutral, culturally representative and age-balanced
- Not having too much on a page – balance the white space

With the supports mentioned above, people living with a communication barrier can get the information to either report a crime or show that they have the capacity to make a decision. The biggest barrier is the system as there are materials or supports available for people to just gather and use, for example if they could just have a quick sheet on each type of abuse with clear pictures at the police station, a lawyer's office or a court.

It also gives the abused person with a communication barrier the confidence to get information out. Unfortunately, people with communication barriers will give up because it is too difficult to get their message across. And in a case of abuse, we cannot let that happen.

After Dr. Carling-Rowland's presentation, the audience had a chance to participate in the question-and answer period. The first question to Dr. Carling-Rowland was about the age groups targeted in her presentation. According to Dr. Carling-Rowland, the Criminal Code has provisions for families and then specifically for children. She thought that there were more supports for children, and wanted to see the same amount of support for adults as well.

The next question to Dr. Carling-Rowland was if there is a kit that could be purchased like little cards, or did people have to create the materials themselves. Dr. Carling-Rowland suggested some on-line resources that are

available from the aphasia organization in Toronto. People were welcomed to look for pictures in a large binder at the Aphasia Centre of Ottawa. Also, there are many icons available publicly on Google that can be used.

Lastly, Dr. Carling-Rowland, asked to comment on the power of attorney stated that it is a substitute decision maker. Just because an individual has given someone the power of attorney does not mean that they cannot make a decision. In fact, everyone should be going to the person with a communication barrier first. And with abuse, this is very important.

Small Group Discussions

When participants went into their small groups, they shared some personal experiences of abuse that some specifically did not want in the report back to the large group. There were others who gave many examples of discrimination and abuse that they were willing to share with the larger group.

In the small groups, participants shared and discussed both the experiences or discrimination and abuse. Although discrimination and abuse are different, the basis of both lies in the power imbalance in the relationship with the person with a communicative disability.

In addition, during the report back to the larger group, some small groups acknowledged that it was immensely difficult for participants to speak of their abuses, and it was very difficult to engage in that discussion when this was the first time, for most, that people with communicative disabilities have had a chance to gather and focus on abuse.

The following sections highlight the discussions in the four small groups. Participants in each small group were asked to discuss these questions:

1. What experiences of abuse exist for people with communicative disabilities?
2. How can we overcome barriers and make it possible for people with communicative disabilities to get help?
3. What actions need to be taken next?

Deaf Group

Many deaf people do not identify as having a disability as they have their own culture and communicate using sign language. This group agreed to change the question by substituting "communicative disabilities" with "deaf".

For the deaf group, some shared experiences of abuse included:

- Service and health care providers not directly interacting with the deaf person but with the hearing people who are with them
    - Addressing the hearing children and not their deaf parents in public places, at the doctor's offices, in restaurants and at offices
    - At the doctor's office, handing the deaf patient's prescription to the hearing person accompanying them
- Deaf people's negative and embarrassing experiences in stores that has a huge impact
- An encounter with the police where the deaf person was handcuffed because the police thought that the individual was trying to hit them when they were trying to communicate using sign language

Hard of Hearing Group

For the hard of hearing group, some shared experiences of abuse included:

- People's prevalent, condescending attitude and their stereotypes of people who have communicative disabilities
    - Assuming that someone living with cerebral palsy is not intelligent and cannot make decisions because of their speech difficulty
    - People are sometimes surprised that a hearing impaired person can drive a car
    - People are surprised that a hearing impaired person went to university
- Workers' impatience takes away the autonomy from the person with communicative disabilities who can speak for themselves
- Denial of professional training opportunities because people assume they cannot hear

Aphasia Groups

The summary of this section is a combination of the Aphasia small group discussion at the workshop, and two additional groups of people who were unable to attend the workshop.

For the aphasia groups, some shared experiences of abuse included:

- Being interrupted often and neglected as people assume that the person with aphasia does not want to participate, and as a result, they are left out, treated as though they do not exist or communicatively isolated in personal and systemic ways
- A woman who used a communication board, not having the right to personal privacy in an institution because her male social worker would

enter her room unannounced, often when she was doing something very personal such as toileting. She seemed to have no support from the institution because she was unable to communicate and advocate for herself
- Being overmedicated and nearly dying in a medical establishment because the service and health care providers did not listen to the person with aphasia
- Being ignored at the doctor's offices
- Being financially abused

Learning Disabilities (1)

For the first learning disabilities group, some shared experiences of abuse included:

- Systematic abuse of students with learning disabilities in the education system
- A child with a severe learning disability who now has a grade 3 level of education because of the work that the parent did to promote the right of the child to mainstream education
- The risk for potential abuse by not requiring police record checks for everyone who comes into contact with children with learning disabilities, for example Educational Assistants, or people at work placements
- The high percentage of persons in prison with learning disabilities who do not have the ability to advocate for themselves, for example informing police of their disability. People with communicative disabilities in prisons are vulnerable to bullying and financial abuse
- People with spectrum syndrome disorders, such as FASD (fetal alcohol syndrome disorder), who have behavioral problems, are often suspended from school and rejected by mainstream society
- Being denied services for example, a professional providing an amplifier to a deaf client
- Individuals with learning disabilities living in poverty, feeling disenfranchised and not receiving opportunities and protections under the law

Learning Disabilities (2)

For the second learning disabilities group, some shared experiences of abuse included:

- People making fun of their disability or ignoring them
- Being dismissed as stupid or lazy
- Being embarrassed by communication breakdown
- Being bullied

- Impatience by people who give enough time to the person with learning disabilities to express themselves and/or they are very hard to understand
- Inherent systemic problems in education and institutions
- Being labelled as "pushy" when they request for additional accommodation for their disability

Actions Recommendations

There was mention that now that people with communicative disabilities have had an initial engagement in focusing on abuse, that a follow-up event may help them to truly "drill down" more on the abuse aspect.

In this event, their initial response the discrimination and abuse they experienced and continue to experience, participants made these action recommendations that were identified in the small group discussions at the workshop.

1. Provide more outreach and education on both visible and invisible disabilities (e.g. aphasia, dysarthria) to promote awareness and increase the understanding of disabilities in order to change the prevailing attitude towards people living with disabilities that includes:
    - Public presentations at elementary, junior, high schools; hospitals and other institutions
    - More information provided by service providers in the disability field to their clients living with communicative disabilities about their limitations
    - More promotion of existing events such as the Canadian Hearing Society (CHS) annual "Deaf for a Day" held each May about the culturally deaf, hard of hearing, late deafened and oral deaf, in English and French
    - The CHS could produce different kits for various service providers about different groups – deaf, deafened and hard of hearing
    - Sharing stories from deaf and hard of hearing people with the public through the newspaper, special events such as the CHS "Deaf for a Day" or on television
    - Engaging the media in playing a bigger role in changing attitudes towards people living with communicative disabilities
    - Using various communication strategies through the internet, web pages and websites on how to overcome barriers for people living with communicative disabilities
    - Promoting the interests of people living with communicative disabilities through the City of Ottawa 2-1-1 community bulletin board

- Participation of people living with communicative disabilities in community associations
- Encouraging more role models who have learning disabilities such as Jacques Demers

2. Self-advocacy training that will increase the skills, knowledge and confidence of:
    - People with learning disabilities by further understanding their disability, encouraging self-identify and teaching them to articulate their limitations to others
    - People with communicative disabilities to keep advocating for their right to services and equal opportunities.

3. Training more advocates:
    - To help individuals with communicative disabilities through the legal system
    - Including speech pathologists, intermediaries and mediators to be on contact lists for organizations that deal with individuals with communicative disabilities such as the police, community centres, schools, etc.
    - For a more organized lobby regarding communicative disabilities
    - To more actively engage speech pathologists in hospitals working with people living with communicative disabilities especially aphasia

4. Provide more funding, resources and supports for:
    - Education and training for the police, victim services, front line staff, school personnel and volunteer advocates
    - To increase services and agencies serving people living with aphasia
    - "Invisible" communicative disabilities

5. Find and develop different tools to communicate with people living with aphasia such as using single words or pictures/ visual information that convey the information accurately to people from different cultures, of different genders, socio-economic backgrounds, and ages.

6. Ensure that Accessibility for Ontarians with Disabilities Act (AODA) is implemented in terms of making public places, businesses, organizations and communities more accessible and inclusive of people with disabilities.

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