

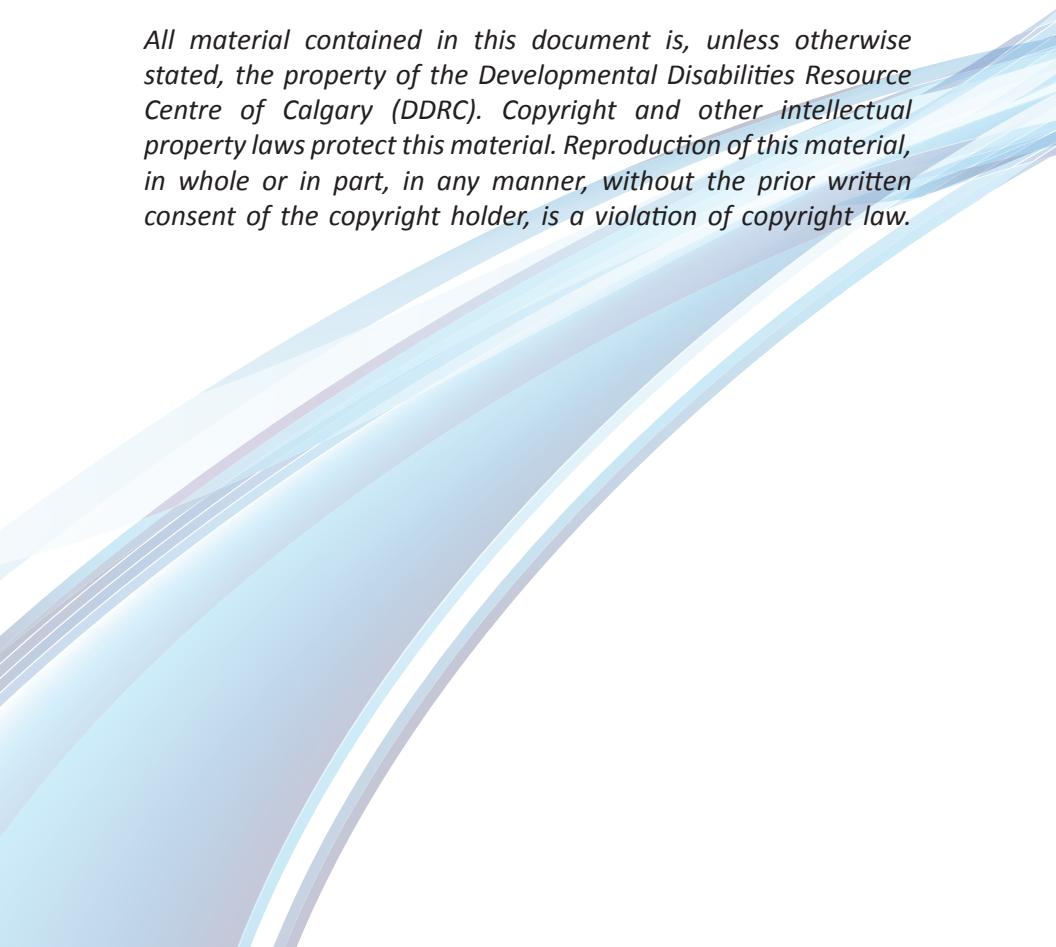
# Reporting on Developmental Disabilities

A Guide for Journalists



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# Introduction

The aim of this resource is to provide journalists in the Calgary-area with a comprehensive guide to respectful reporting on matters pertaining to people with developmental disabilities, and the developmental disabilities sector. A need for such a publication was recognized when it became apparent that many of the resources available today group all disabilities - physical disabilities, mental illness, chronic illness, and so forth - together. There were no resources that could be found which pertained solely to developmental disabilities.

The Canadian Association of Broadcasters has created an “Equitable Portrayal Code” which aims to prevent negative portrayals, stereotyping, and stigmatization. The code notes that “language and terminology evolve over time...” and thus “broadcasters shall remain vigilant with respect to the evolving appropriateness or inappropriateness of particular words and phrases, keeping in mind prevailing community standards.”<sup>1</sup> This concept can be difficult to put in to practice when there is a lack of resources available to journalists dealing specifically with developmental disabilities.

It is important for journalists to have a current, concise, and accessible resource available to them that reflects the state of the sector in Canada. In addition to this, we have created this in consultation with those who understand the sector better than anyone else: people who have developmental disabilities, and the staff that strive to support them.

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## What is a Developmental Disability?

A developmental disability is a permanent disability, present before age 18, that causes challenges with day-to-day living. A developmental disability may be mental, physical, or a combination of the two. People with developmental disabilities experience difficulty with things like personal care, language skills, learning, and independent living, and the difficulties may be mild or severe. People with developmental disabilities may also have challenging behaviours and are often at risk of social isolation.

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<sup>1</sup>“Recommended Guidelines on Language and Terminology – PERSONS WITH DISABILITIES: A Manual for News Professionals,” accessed September 19, 2014, [http://cab-acr.ca/english/social/diversity/disabilities/pwd\\_guidelines.htm](http://cab-acr.ca/english/social/diversity/disabilities/pwd_guidelines.htm).

Most people know at least one person with a developmental disability. People with developmental disabilities might have autism spectrum disorder (ASD), Down syndrome, cerebral palsy, or fetal alcohol syndrome disorder (FASD), for example. Other people may experience an illness or injury in childhood that leads to a developmental disability.

As is the case with numerous other forms of disabilities, it is vital to recognize that some developmental disabilities have physically identifiable characteristics, but many are considered non-visible. Never assume that someone does or does not have a disability based on their appearance. Likewise, do not assume the severity of an individual's disability from their appearance.

When a person has a dual diagnosis, he or she has a developmental disability as well as a mental health diagnosis (such as depression, or an anxiety disorder).

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## **What is the DDRC?**

The Developmental Disabilities Resource Centre of Calgary is a non-profit, registered, charitable organization that began in 1952. We offer programs and resources for children and adults with disabilities, their friends and family, and other people in the community. We believe that communities are stronger when people of all abilities are involved in activities that are meaningful to them.

Operating under the direction of a volunteer Board of Directors, the DDRC's activities are funded through government contracts, fees for services, fundraising events, corporate partnerships, and individual donations.

# Inclusive Language

Regardless of who you are or what you do, language is an extremely powerful tool. The use of inclusive language is important as it places an emphasis on equality and respect. Using inclusive language allows the representation of diverse groups without making differences the focal-point of the dialog, or having a developmental disability transform into an individual's entire identity. This includes "person-first" language, where the human comes before the disability (such as "person with a developmental disability" rather than "developmentally disabled person").

As is the case in many areas, language use in the developmental disabilities sector is constantly changing and evolving. Phrases that were commonplace decades ago may be considered incredibly offensive today. Even terms that may still be frequently used by society have grown out of favour, and have negative connotations associated with them.

Some examples of the drastic changes that language pertaining to developmental disabilities has undergone are the terms "idiot," "imbecile," and "moron." These three words are used today exclusively as insults, generally regarding an individual's intelligence. However, this was not always the case. The term "idiot" was originally used to describe a person with a perceived mental age of an infant, "imbecile" to describe a person with a perceived mental age between three and seven, and "moron" to describe a person with a perceived mental age between seven and 12.<sup>2</sup> It is highly unlikely that anyone would think to apply these outdated phrases to a person with a developmental disability, but these words were once considered appropriate scientific descriptors.

Phrases that are still commonly used include "special needs" (which is unpopular as it places undue emphasis on difference and can be considered condescending)<sup>3</sup> and "handicapped" (this word may originate from "cap-in-hand" beggars - often individuals with a disability - who were seen as unfit for work, and ostracized from their communities).<sup>4</sup>

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<sup>2</sup>"Etymology of Moron," *Online Etymology Dictionary*, accessed October 14, 2014. <http://www.etymonline.com>

<sup>3</sup>Kathie Snow, "The Case Against 'Special Needs,'" *Disability is Natural*, accessed October 14, 2014. <http://disabilityisnatural.com/images/PDF/specneed.pdf>

<sup>4</sup>"Inclusive Language: Healthy Diverse Populations and Aboriginal Health Program," *Calgary Health Region*, accessed September 19, 2014, [http://www.calgaryhealthregion.ca/programs/diversity/diversity\\_resources/research\\_publications/2007\\_inclusive\\_language.pdf](http://www.calgaryhealthregion.ca/programs/diversity/diversity_resources/research_publications/2007_inclusive_language.pdf).

Avoid invented phrases that attempt to put an overly positive spin on an existing word or phrase, as these can often come across as disingenuous at best, or patronizing and offensive at worst. Some examples of this include “handicapable,” “differently-abled,” or “temporarily able-bodied.”

The concept of repatriating a term has been embraced by numerous minorities, both visible and non-visible. This is when a group “takes back” a word or title that has negative connotations in an attempt to remove the stigma associated with it. While an individual with a developmental disability may decide to refer to themselves by what is considered to be a slur, that does not make it acceptable to use it in a news story.

It can be a challenge to keep abreast of changes to socially-accepted phrases, but it is a crucial part of responsible journalism. Some may view this focus on “political correctness” as being overly-sensitive, but not paying attention to it can result in discrimination, stereotyping, and insult.

The below table features some phrases to avoid, and suggested appropriate replacements for them<sup>5</sup>:

<b>Instead of...</b>	<b>Use...</b>
Able-bodied, normal	Non-disabled, person without a disability
Autistic	Has autism, person with autism spectrum disorder (ASD) or Asperger’s syndrome (when appropriate)
Developmentally disabled person	Person with a developmental disability
Fetal alcohol syndrome	Fetal alcohol spectrum disorder (FASD)
Handicapped parking Handicapped washroom	Accessible parking Accessible washroom
Has a mental handicap or mental challenge, is retarded	Person with a developmental disability
Mongoloid, Down’s	Person with Down syndrome
Seeing eye dog, guide dog	Service dog, service animal
Special needs	Complex needs
Suffers from, victim of	Has, diagnosed with
Wheelchair-bound, confined to a wheelchair	Wheelchair user, uses a wheelchair

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<sup>5</sup> Language suggestions in table are based on “Inclusive Language: Healthy Diverse Populations and Aboriginal Health Program.”

# Types of Media Portrayal

There are three predominant portrayal-types in stories pertaining to people with developmental disabilities. These are the “superhuman,” the “victim,” and the “average person.” The third is where we hope to steer portrayals of developmental disabilities in the future, and will be discussed shortly. First, here is an overview of the two portrayals that should be avoided:

## The Superhuman

**Key Terms:** *Overcome, heroic, courageous, incredible, despite the odds, extraordinary, etc.*

**Concerns:** The more out of the ordinary it seems for those with developmental disabilities to have accomplishments, the more “different” they will be viewed as being.<sup>6</sup> This risks further marginalization and disenfranchisement. In some instances, these types of portrayal can also be patronizing. This is especially the case when the activity or accomplishment is common such as having a job, or volunteering.

Stories falling into this category portray an individual with a developmental disability as heroically overcoming the odds to achieve something.<sup>7</sup> While there is nothing wrong with drawing attention to someone’s accomplishments, these stories tend to focus on the feat as being “in spite of” a disability rather than due to the individual’s effort.<sup>8</sup> This is problematic as those included in the story may ultimately be viewed as less capable of completing a specific task. As an example, an article about those with developmental disabilities competing in the Special Olympics may choose to feature a person with Down syndrome. Instead of mentioning the skills this person has, or the preparation they underwent to earn a spot on the team, the author may wind up focusing on the disability itself, and the difficulties they had training or competing with a disability. While this may increase the public’s awareness of developmental disabilities and the Special Olympics, ultimately it is emphasising the differences between this group, and those without disabilities.<sup>9</sup>

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<sup>6</sup> Carla Filomena Silva and P. David Howe, “The (In)validity of Supercrip Representation of Paralympian Athletes,” *Journal of Sport and Social Issues* 36: 174 (2012): 178.

<sup>7</sup> Beth A. Haller, *Representing Disability in an Ableist World: Essays on Mass Media* (Louisville, KY: The Advocate Press, 2012), 52.

<sup>8</sup> Silva and Howe, (In)validity, 175.

<sup>9</sup> Beth A. Haller et al, “The Place of News Media Analysis within Canadian Disability Studies,” *Canadian Journal of Disability Studies* 1.2 (2012): 51



## The Victim

**Key Terms:** *Victim, suffer, bound, confined, illness, handicap, invalid, defective, unwell, etc.*

**Concerns:** People with developmental disabilities are viewed as helpless invalids, or worthy of pity.<sup>10</sup> This sort of portrayal can make those with disabilities seem as though they are incapable of having a successful life, that disabilities are something that need to be cured,<sup>11</sup> and may even reinforce the idea that they should be institutionalized. This last point is especially concerning, as reasoning in support of institutionalisation generally falls into one of two categories: either the belief that it is in the interest of the health and safety of those with developmental disabilities, or the much more damaging belief that those in this group are a nuisance and/or do not have enough value to be included in society.<sup>12</sup>

Articles written from this perspective may discuss people with developmental disabilities without any actual input from an impacted individual. These stories may feature the voices of disability rights groups, service providers, healthcare specialists, educators, and politicians, as though no one with a developmental disability has the capability to speak for themselves.<sup>13</sup> The danger with this sort of portrayal is that the interests and rights of those with developmental disabilities may be swept aside in favour of the opinions of those perceived to be authoritative experts. This flies in the face of the ideal of “nothing about us without us.”<sup>14</sup>

## The Average Person

The best method to use while reporting on people with developmental disabilities is to portray them as an average person with likes, dislikes, hobbies, interests, families, and friends. Remembering that it is important to use person-first terminology, it is equally important to write a person-first article.

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<sup>10</sup> Haller, *Representing Disability*, 54.

<sup>11</sup> Charles A. Riley III, *Disability and the Media: Prescriptions for Change* (Lebanon, NH: University Press of New England, 2005), 53.

<sup>12</sup> Haller et al, “News Media Analysis”, 46.

<sup>13</sup> Haller et al, “News Media Analysis”, 49.

<sup>14</sup> Jerry Alan Winter, “The Development of the Disability Rights Movement as a Social Problem Solver,” *Disability Studies Quarterly* 23: 1 (2003), <http://dsq-sds.org/article/view/399/545>.

In many stories, mentioning that a person has a developmental disability is simply not a pertinent detail. Making the choice to identify that an interview subject has fetal alcohol spectrum disorder in an article about bowling is as logical as identifying that someone has depression, or is a Buddhist.

There are many cases where this fact is germane to the story, but it is vital to introduce it respectfully. Ask the individual you are interviewing how they wish to be identified; never make assumptions. One person may prefer to be identified specifically as having autism or Down syndrome, while many others would prefer to be identified by the more generic “developmental disability.”

In terms of referring to an individual with a developmental disability by their name, it is recommended that you follow the conventions set out in Canadian Press Style. Those aged 18 or under may be referred to by their first name on second reference in the majority of cases.<sup>15</sup> Adults should be referred to by their surname on second reference.<sup>16</sup> Referring to a person with a developmental disability by their first name throughout an article, while everyone else mentioned is referred to by their surname, portrays them as juvenile or childlike. An adult is an adult regardless of their disability.

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## Potential Story Ideas

Those who are interested in exploring and writing about the developmental disabilities sector have a multitude of options for story ideas.

We surveyed some of our clients to find out what they would prefer to see in the news. Here is what they had to say:

***I want to know what [the story] is about first. If my disability matters, then I will talk about it.*** - Theresa W.

***People [with developmental disabilities] need to be supported, but there aren't always enough resources for us. That should be in the paper.*** - Martin B.

***Children [with developmental disabilities] aren't getting the chance to learn like other kids. That's bad, and should be on the news.*** - Shelley H.

<sup>15</sup> James McCarten, ed., *The Canadian Press Stylebook: A Guide for Writers and Editors*, 17th edition (Toronto: The Canadian Press, 2013), 334.

<sup>16</sup> *Ibid.*

Below, we have listed some additional ideas compiled by DDRRC employees:

**The difficulties faced by individuals with developmental disabilities and/or their parents or guardians in obtaining government funding.**

**The move towards independent living and the challenges of finding affordable and accessible housing.**

**Finding meaningful employment that offers a living wage.**

**Equal opportunities to engage in political discussion, voting, and other forms of civic discourse.**

**Access to healthcare and the ability to make decisions regarding health.**

**Government policies regarding people with developmental disabilities.**

**Funding for agencies dedicated to assisting people with developmental disabilities, and what sort of programs are available through these agencies.**

**Access to education at all levels, whether public/separate board schools or post-secondary institutions.**

**Literacy levels in individuals with developmental disabilities, and appropriate ways to promote literacy.**

**The drive to build inclusive communities where all people are welcome.**

**Looking into how individuals with developmental disabilities interact with the law, and what happens to those who find themselves in the legal system.**

The above list is only a small sampling of potential story ideas, but they may be a jumping-off point for those who want to write about the sector in a way that provides value for those with developmental disabilities, allows them an opportunity to have a say, raises awareness of the real issues they encounter, and doesn't put undue emphasis on differences.

# Conducting a Successful Interview

For a person who has never previously had the opportunity to interview an individual with a developmental disability, the prospect may seem a bit intimidating. Here are a few things to bear in mind, and some tips to make the interview run smoothly<sup>17</sup>:

**Some people with developmental disabilities may have a companion or communication assistant with them. It is important to speak directly to the person you are interviewing. Never assume that the companion will speak on behalf of them. While they may be there to translate another form of communication (such as sign language), they are normally just there for support.**

**When introducing yourself, please feel free to offer a handshake if that is something you tend to do.**

**While it is perfectly fine to offer assistance to someone with a developmental disability, please do not start assisting them without their permission.**

**Remember that a wheelchair is an extension of its user. Never lean on a wheelchair, or use it to assist you when standing up.**

**Using plain language is a good rule when interviewing most people, and the same holds true for people with developmental disabilities. Speaking clearly and at a reasonable pace is also advised, but take care not to overdo it as you may sound patronizing.**

**Individuals with developmental disabilities may require additional time to answer any questions you pose to them. Be patient and courteous. Do not try to finish their sentences for them.**

**Some individuals with developmental disabilities may communicate using methods other than speaking. Some have communication devices, some use letterboards, and some may use a pen and paper. If a person communicates something you do not understand, ask for clarification.**

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<sup>17</sup> Based on "Recommended Guidelines on Language and Terminology," and "Communication Tips," Communication Disabilities Access Canada, accessed on October 24, 2014. <http://www.communication-access.org/make-your-service-accessible/communication-tips>

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# Notes



**We believe that inclusive  
communities are more  
vibrant, healthy, safe, strong  
and satisfying places for  
everyone.**



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