Champions for Inclusive Health Stakeholder Coalition – Collective Action to Advance Health Outcomes for Individuals with Intellectual Disabilities

Despite making valuable contributions to our communities, individuals with intellectual disabilities continue to experience marginalization, and alarming health outcomes as a result. Across almost all commonly accepted health indicators, individuals with intellectual disabilities experience significant disparities compared to the general population. Recent findings concerning the health of individuals with intellectual disabilities include:

Prevalence:

- Intellectual disability – 0.78% (HCARDD, N.D.).
- Occurrence of Autism Spectrum Disorder in individuals with ID – 18.04%, which compares to 0.6-1.11% in the general population (Tonnsen, et al., 2016).

Mental Health:

- In Ontario, researchers found that over a two year period, 44% of adults with ID had a mental illness diagnosis (Lin, et al., 2016B).
- Children with ID are particularly at risk, with a prevalence of psychiatric disorders estimated at 36%, compared to 8% of children without (Emerson & Hatton, 2007).
- 26% of psychiatric diagnosis' are classified as 'severe' in individuals with ID, compared to only 8% in those with psychiatric diagnosis but no ID (Lunsky, et al., 2012B)

Sexual Health:

- An Ontario study found that only 34.3% of women with ID were screened for cervical cancer, compared to 66.8% of their peers (H, Plourde, et al., 2016). The same study cited the perception by physicians that individuals with ID were sexually inactive as the primary barrier to increased screenings.
- Between 39-68% of female children and 16-30% of male children with an intellectual disability will be sexually abused" before their 18th birthday (Mahoney & Poling, 2011).

Nutrition, Physical Activity and Obesity:

- Only 7-8% of adults with ID eat balanced diets (Robertson, et al., 2000).
- 13.5% of adults with ID meet the recommended daily physical activity guidelines (Stancliffe & Anderson, 2017), while 50% report more than 4 hours of screen time per day (Melville, et al., 2018).
- Obesity is found in children with ID at rates 2-3 times that observed in typically developing children (Rimmer J., Yamaki, Lowry, Wang, & Vogel, 2010).

Drug and Alcohol Use:

- A recent Ontario-based study found that over a two year period, individuals with ID had a prevalence of Substance-Related and Addictive Disorders (SSRD) of 6.4% (Lin, et al., 2016A).
- In the UK, children with ID comprised 9% of all children with potentially harmful drinking habits (Emerson, et al., 2016).

Access to Quality Care:

- An Ontario study found that individuals with ID were 2-3 times more likely to be hospitalized for an ACS condition (potentially preventable hospitalization). ACS hospitalizations rates are used as an indicator of access to quality care (Balogh & Ouellette-Kuntz, 2005).
- The proportion of women with ID in Canada who are not screened for breast cancer is 1.5 times greater than it is for women without ID (Cobigo, et al., 2013).

Pharmacology:

- By analysing the Ontario Drugs Benefits claims database, researchers found that 50% of individuals with ID are dispensed multiple medications concurrently, with 22% being dispensed five or more concurrently (Lunsky, et al., 2013). Of individuals prescribed 5 or more medications concurrently, 32% did not have regular follow-up visits with the same physician, making discontinuation unlikely.
- Researchers in the Netherlands found that in individuals with ID taking a psychotropic drug, 80% had a drug-related problem (Scheifes, et al., 2016).
- Dutch researchers found that 69% of prescriptions for antipsychotics were issued to deal with problem behaviours, while only 5% were issued as a result of a chronic psychotic disorder (Kuijper & Hoekstra, 2017).
- In Ontario, 39.2% of individuals with ID filled at least one antipsychotic prescription over a six year period, with rates jumping to 56% for adults living in a group home setting (Lunsky, et al., 2018). Of these individuals, 29% had no psychiatric diagnosis.

Practitioners and Health Care Providers:

- Canadian universities do not generally include substantial training in intellectual disabilities during undergraduate medical programs; however, the University of Toronto and Queens University have both implemented some form of training. A survey of undergraduate medical students at these institutions found that while 85.6% of respondents had received some specialized ID training, 93.3% felt that more patient exposure and curriculum development was needed (Burge, et al., 2008).
- 51.8% of practitioners who work with individuals with ID will be exposed to aggressive behaviour over a 12 month period (Crocker, et al., 2006).
- Little guidance has been provided concerning the Medical Aid in Dying Act and individuals with ID, which is troubling given the risk of inducement and a population that is ageing.

Oral Health:

- Individuals with ID have a higher proportion of filled teeth, extracted teeth, less preventive care and an increased prevalence of traumatic dental injuries (Gallagher & Fiske, 2007; Anders & Davis, 2010; Waldman et al., 2001, Pezzementi & Fisher, 2005).
- As a result of anxiety and behavioural concerns, many adults with ID cannot receive any dental treatment, including dental hygiene, unless they are under general anesthesia (GA) (Miyawaki, et al., 2004). Procedures involving GA are often riskier for individuals with ID, who may not be able to adequately respond if complications arise and are at risk for delayed emergence times (Higuchi, et al., 2017).

Cumulatively, these health disparities result in an expected lifespan for individuals with intellectual disabilities in Canada that is twenty years shorter than their peers in the general population. While there is cause for concern, there is also reason for optimism. Achieving health equity is simply a matter of:

1. Promoting more active lifestyles
2. Empowering individuals with intellectual disabilities to eat more nutritious diets
3. Fostering the social inclusion of individuals with intellectual disabilities in our communities.
4. Developing a health service system that is responsive to the needs of individuals with intellectual disabilities.

Collective Action for Inclusive Health

Spurred by the growing recognition that collective action is needed to address the unacceptable health outcomes faced by individuals with intellectual disabilities in BC, a diverse group of stakeholders met to establish a roadmap for collaboration. Together, they formed the Champions for Inclusive Health Stakeholder Coalition, which is unified by the following Mission Statement:

"The elimination of health disparities faced by individuals with intellectual disabilities in B.C. and the establishment of resources, expertise and best-practices that can encourage and inform efforts in other jurisdictions and position B.C. as the global leader in inclusive health."

Guided by a Steering Committee, the Champions for Inclusive Health Stakeholder Coalition is comprised of six thematic Working Groups, each of which is currently engaging in meaningful discussions and initiatives. To learn more about the work of the Coalition, you are encouraged to reach out to Scott Howe, the Coalition Director, at showe@howeinternational.consulting.

Finding Your Role in the Solution

Regardless of your professional background or organizational mandate, there are countless ways that you can support our efforts to advance the health outcomes faced by individuals with intellectual disabilities. Ask yourself the following:

1. Do I know somebody with an intellectual disability?
2. Do members of my profession or professional network serve individuals with intellectual disabilities?

3. Does my organization make or adhere to policies that affect individuals with intellectual disabilities?
4. Do I have a skillset that can contribute to efforts to eliminate the health disparities faced by individuals with intellectual disabilities?
5. Do I believe that individuals with intellectual disabilities are valuable members of my community and deserve the same health outcomes and access to services as everybody else?

If you answered 'yes' to ANY of those questions, then you have a role to play! Remember, empowering somebody to live a healthier, happier, and more fulfilling life is perhaps the greatest gift you can give. We sincerely hope that you take the time to consider your role in building a more inclusive British Columbia. If you're still stuck for ideas, consider these suggestions:

- Raising awareness within your personal and professional networks of the health disparities faced by individuals with ID. Very few stakeholders we meet with have any idea that the current situation is so dismal. If they don't know, they can't make change. This is not an issue that can be solved only through medical interventions, it will require society as a whole to rethink the way it views and interacts with people with ID.
- Connecting with individuals with ID on a social level, you might learn a thing or two!
- Including individuals with ID in recreation activities in your community.
- Partnering with the coalition to implement a joint project or initiative.
- Creating professional learning/networking opportunities that aim to provide the skills needed to better serve the population.
- Consider the resources available at your disposal, could they be used by groups outside of your organization?

Please remember, these are only ideas for how we can work together to achieve health equity. There are countless ways that you can contribute to this meaningful cause. When you're ready, we're here to work with you!

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Champions for Inclusive Health Stakeholder Coalition

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