



Data
Discovery
Better Health

ICES Research Forum Workshop #4: Inclusion of Disability in the Research Life Cycle

May 11, 2023

Dr. Amy Freier, Dr. Hilary Brown, and Dr. Yona Lunsky

Disability and Accessibility in the Research Process

Dr. Amy Freier

Inclusion, Diversity, Equity, and Accessibility Lead – HDRN Canada



Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

What is IDEA?

A set of concepts to help guide practice:

Inclusion

Diversity

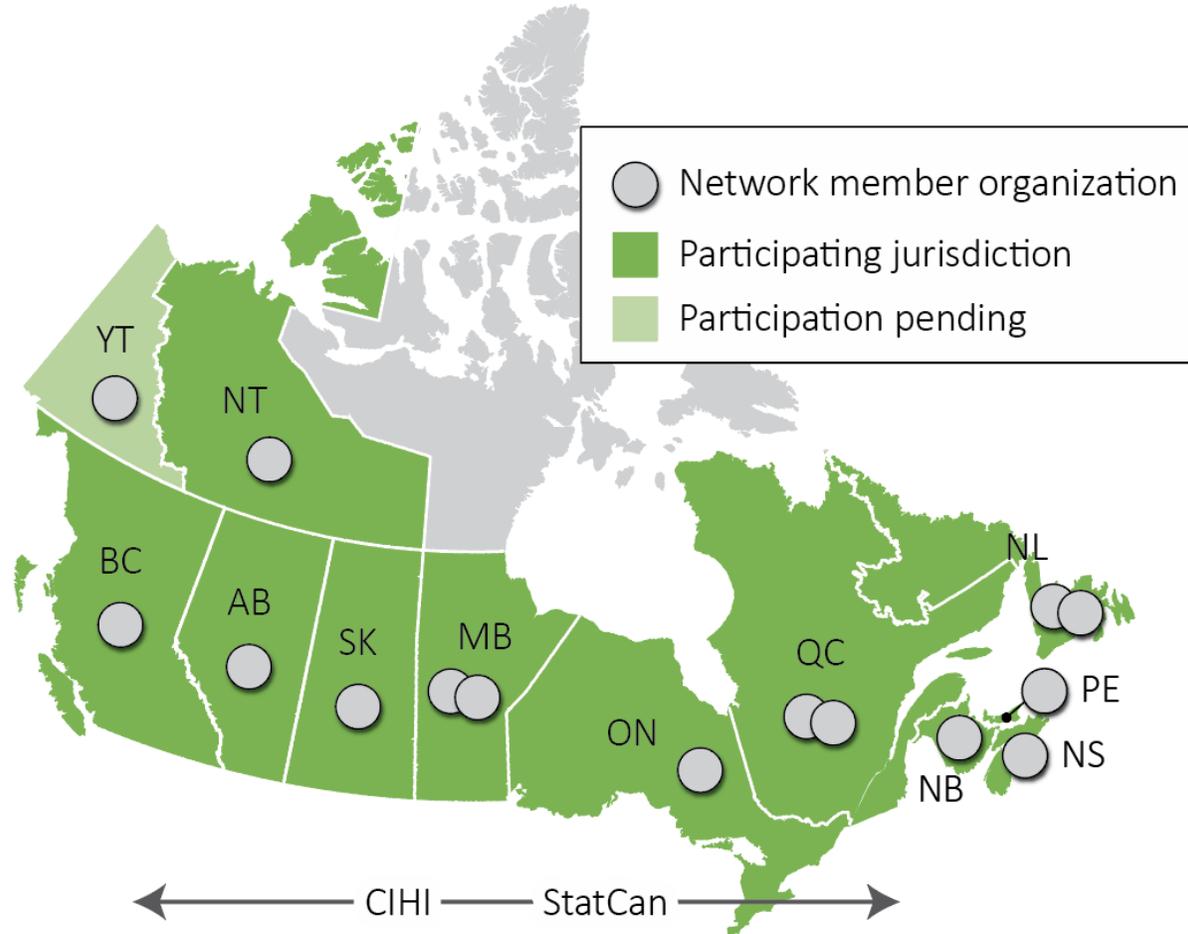
Equity

Accessibility

- Orients us towards justice and emphasizes action
- Purposefully includes accessibility
- Encompasses both operational and data research practices/processes

Where is this happening?

Health Data
Research
Network Canada
(HDRN)

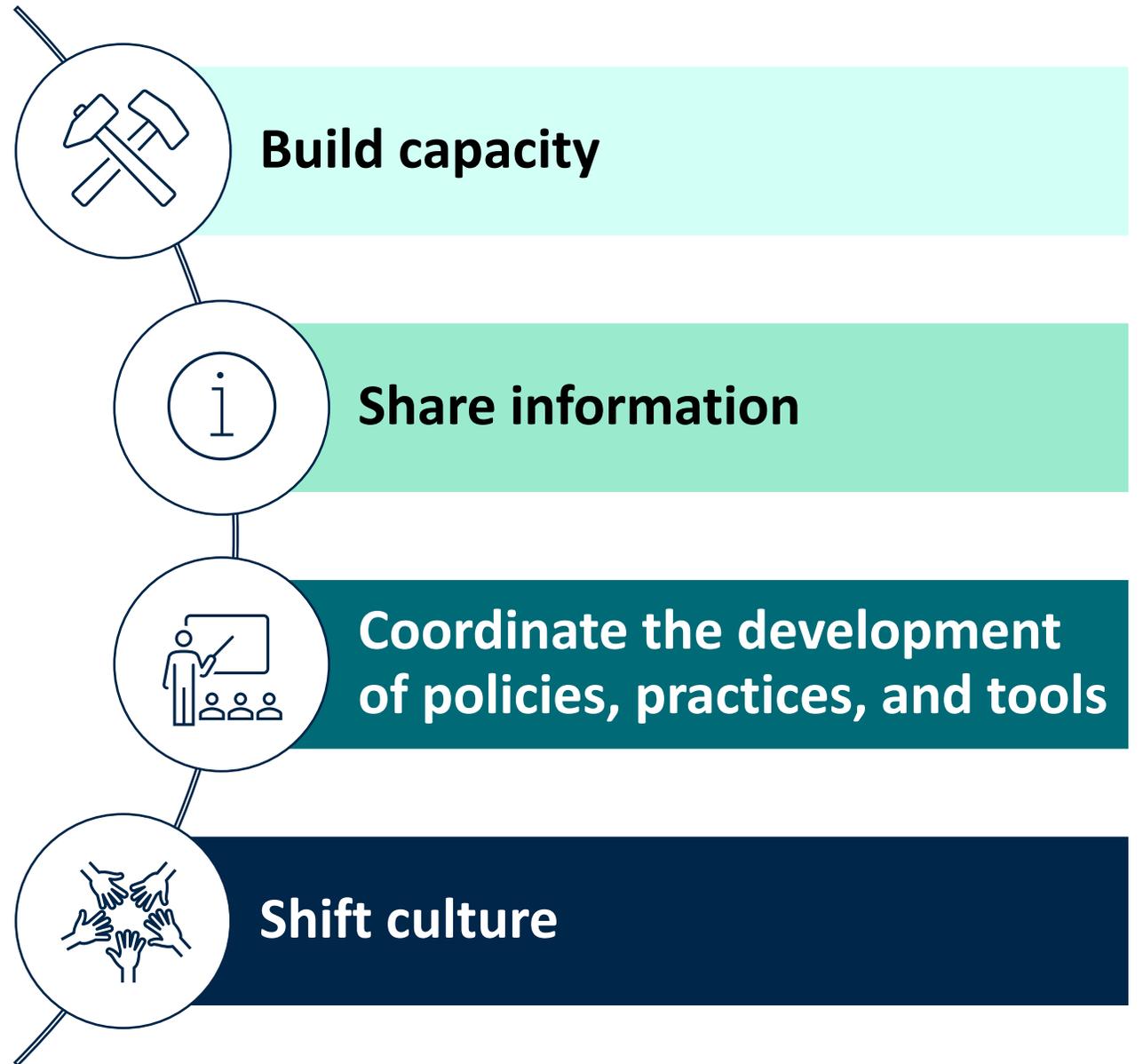


HDRN Member Organizations



IDEA Team

30 Team Members from HDRN Canada member organizations, working groups, and SPOR SUPPORT Units joining together to...



HDRN Canada: IDEA

Definitions & Principles for Working Together

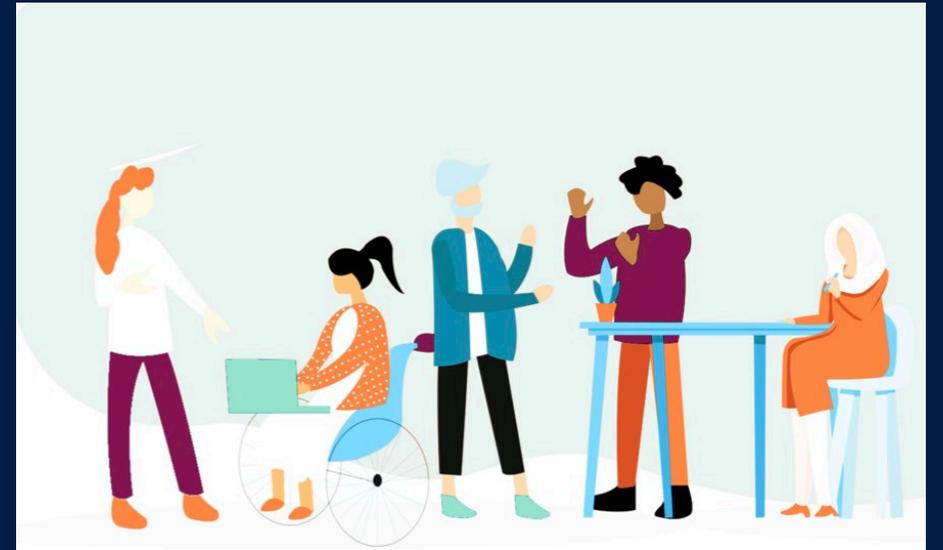


Accessibility

Accessibility refers to the design of products, devices, services or environments for people who experience disabilities, as well as the continuous commitment to the removal of political, social, economic, historical and systemic inequities that limit full experience in social space and life. To fully address accessibility, we must commit to addressing systemic ableism, oppression and historic inequities encoded in policies, practices and services.

Accessibility is Practiced by:

- ❖ **Working** to understand individuals' accessibility needs & recognizing needs may change.
- ❖ **Providing** confidentiality
- ❖ **Ensuring** technology and formats meet needs (i.e. closed captioning, accessible documents/ppt)
- ❖ **Avoiding** jargon or acronyms



Holistic accessibility policies consider permanent, temporary & situational disabilities, including:



Guidelines for accessible design

- Use at least 18 pt black, Calibri font (**Arial** Black for titles) and sufficient white space
- Limit the use of images including icons; any graphic that is included must be labeled with Alt text
 - When you do use an image, make sure it is an integral part of your presentation and/or describe it in your presentation
- When creating a new slide, use the built-in slide designs from the menu
- Hyperlinks should be described (e.g., Instead of “click here”, use the website’s name or URL itself)
- For tables, specify column header information and avoid the use of split or merged cells
- Review -> Check Accessibility in the menu bar should be used prior to slide submission
- Please visit Microsoft’s [Make your PowerPoint Presentations Accessible to People with Disabilities](#) website for further guidance



Colour Combinations

Use	Do Not Use
White	Black, Dark Teal, Light Teal
White	Black, Light Teal
Black	White, Dark Blue, Dark Teal
Black, Dark Blue	Dark Teal, Light Teal
White	Dark Teal, Light Teal

Unsure? Use a free online Contrast Checker:
<https://webaim.org/resources/contrastchecker/>

Considering Accessibility Throughout the Research Process

Team Formation

Grant application and funding

Data and Methods

Analysis and Interpretation

Knowledge Mobilization



IDEA Work to Date

- Engagement with data centres and HDRN working groups to understand needs, challenges, and capacity
- Forming of an IDEA Team
- Accessibility training and standards
- Creation of definitions and principles
- IDEA and the HDRN Data Asset Inventory
- Environmental Scan

Upcoming IDEA Initiatives

- Developing an IDEA Strategy
 - Implementation Science Approach
 - Facilitation towards HDRN priorities for IDEA, vision,
- Disaggregated data learning series
- Outcome measurements – KPIs, benchmarks
- Training and mentorship – HDRN Pragmatic Clinical Trials



Thank you!

Be in touch:

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Measurement of disability in health administrative data

Presented by:

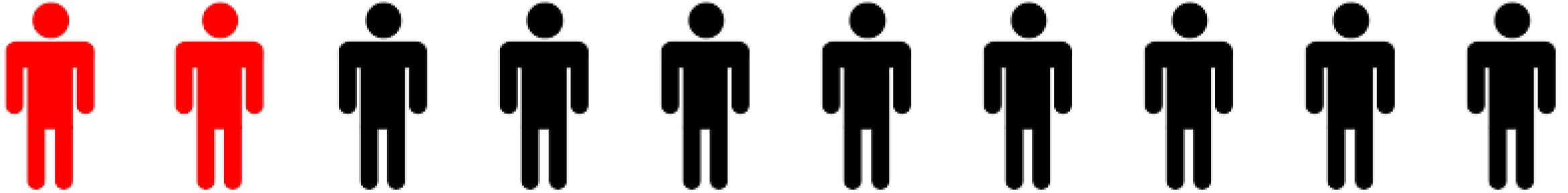
Dr. Hilary K. Brown, PhD

Assistant Professor, University of Toronto

May 11, 2023

Measurement of disability in administrative data

Frequency of disability in the population



Inclusion and measurement of disability is critical in population-based health research

Models of disability

Medical model of disability

- Views disability as a medical problem
- Focuses on prevention and/or treatment of disability as a health outcome
- Widely criticized for viewing disability as “pathological”

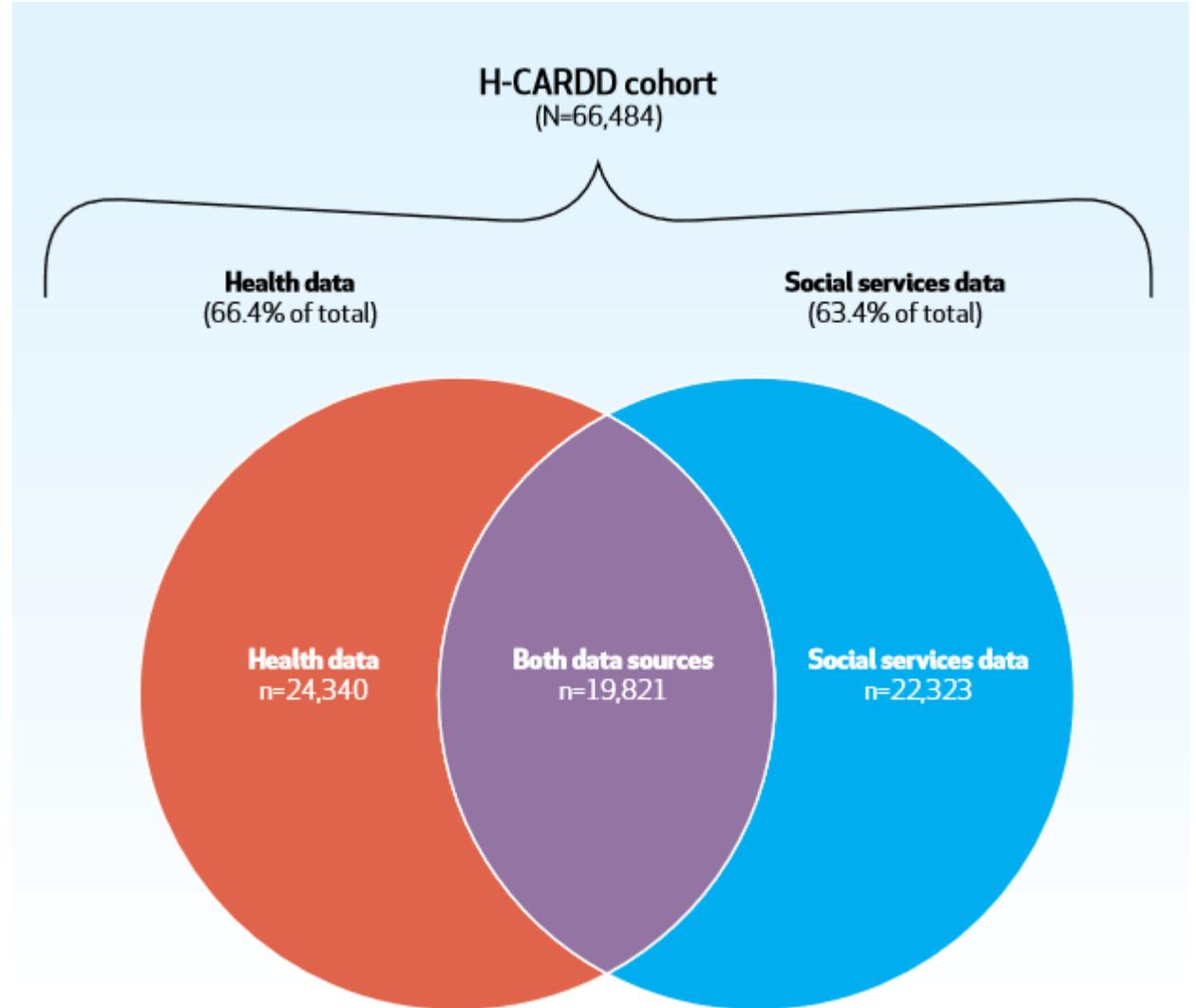
Social model of disability

- Recognizes that disability is independent of health and results from structural factors that limit participation in society
- People with disabilities may experience disparities in health and mortality, and these are driven by structural barriers

Measurement of disability in administrative data

Intellectual and developmental disabilities

- Diagnostic codes and receipt of disability supports



Measurement of disability in administrative data

Physical disabilities

- Diagnostic codes for musculoskeletal disorders, neurological disorders, permanent injuries, congenital anomalies (*+ measures of assistive device use*)
- Codes previously shown to be associated with functional limitations and need for accommodation when accessing care (Ben-Shalom et al., 2016; Khoury et al., 2013; Palsbo et al., 2008)

Sensory disabilities:

- Diagnostic codes for blindness/low vision, Deafness/hearing loss (Javitt et al., 2007; Mann et al., 2007)

Why not use other measures of ‘comorbidity’?

- E.g., Charlson Comorbidity Index, Elixhauser Index
- Use health care utilization patterns to reflect morbidity severity
- Health care patterns do not clearly or consistently reflect disability specifically
- ***Disability and health are distinct constructs***: Conflation of disability and illness falsely presupposes people with disabilities cannot be healthy and prevents public health attention to health disparities experienced by people with vs. without disabilities

Example application of algorithms: Outcomes of COVID-19 patients with IDD

Case rates of hospitalizations, admissions to the intensive care unit (ICU) and mortality within 30 days post COVID-19 positive test among adults (18+) who tested positive for COVID-19 with Down syndrome and without intellectual and developmental disabilities (Jan 15, 2020 to Jan 10, 2021), in Ontario, with incidence rate ratios and 95% confidence intervals.

	Adults with Down Syndrome N = 121		Adults without Intellectual and Developmental Disabilities N = 187,290		Incidence rate ratio (95% CI)	P value
	Frequency	Rate per 1000 cases (95% CI)	Frequency	Rate per 1000 cases (95% CI)		
Hospitalization	20	165.3 (101, 255.3)	8473	45.2 (44.3, 46.2)	3.65 (2.45, 5.46)	<0.0001
In those hospitalized, proportion in ICU	7	350 (140.7, 721.1)	2027	239.2 (228.9, 249.9)	1.46 (0.80, 2.66)	0.2463
Mortality	22	181.8 (113.9, 275.3)	5170	27.6 (26.9, 28.4)	6.59 (4.51, 9.62)	<0.0001

Lunsky et al. Disability and Health Journal 2022;15:10114.

Example application of algorithms:

Severe maternal morbidity & mortality in people with disabilities

Table 2. Risk of Severe Maternal Morbidity or Mortality Arising Between Conception and up to 42 Days Post Partum in Women With a Disability Compared With Women Without a Disability

Variable	Individuals with outcome, No. (%)	RR (95% CI)		
		Unadjusted	Model 1 ^a	Model 2 ^b
Disability type				
None (n = 1 601 363)	27 242 (1.7)	1 [Reference]	1 [Reference]	1 [Reference]
Physical only (n = 144 972)	3444 (2.4)	1.39 (1.34-1.44)	1.38 (1.33-1.43)	1.29 (1.25-1.34)
Sensory only (n = 45 249)	931 (2.1)	1.21 (1.13-1.29)	1.20 (1.12-1.28)	1.14 (1.06-1.21)
Intellectual/developmental only (n = 2227)	67 (3.0)	1.70 (1.33-2.18)	1.73 (1.35-2.21)	1.57 (1.23-2.01)
Multiple (n = 8883)	314 (3.5)	2.09 (1.86-2.34)	2.05 (1.83-2.30)	1.74 (1.55-1.95)

Brown et al. JAMA Network Open 2021;4(2):2034993.

Example application of algorithms:

Experiences of violence in pregnant people with disabilities

Table 2. Risk of Experiencing Interpersonal Violence During Pregnancy and Up to 365 Days After Delivery in Individuals With Disabilities Compared With Those Without Any Recognized Disability

Disability Status	n (%) With Outcome	Unadjusted RR (95% CI)	Model 1*	Model 2 [†]
No disability (n=1,594,441)	7,474 (0.5)	Ref	Ref	Ref
Physical disability only (n=147,414)	1,183 (0.8)	1.68 (1.57–1.81)	1.52 (1.42–1.63)	1.40 (1.31–1.50)
Sensory disability only (n=47,459)	311 (0.7)	1.39 (1.22–1.57)	1.13 (1.00–1.28)	1.06 (0.94–1.19)
Intellectual or developmental disability only (n=2,557)	135 (5.3)	11.08 (9.10–13.51)	3.05 (2.53–3.68)	2.39 (1.98–2.88)
Multiple disabilities (n=9,598)	173 (1.8)	3.84 (3.22–4.59)	2.38 (2.01–2.81)	1.96 (1.66–2.30)

RR, relative risk; Ref, referent.

Data are adjusted RR (95% CI) unless otherwise specified.

* Model 1 adjusts for age, parity, neighborhood income quintile, rurality, stable and unstable chronic conditions, mental illness, and substance use disorders.

[†] Model 2 adjusts for model 1 variables in addition to any history of interpersonal violence.

Brown et al. *Obstetrics & Gynecology* 2022;140:797-805.

Limitations of diagnostic algorithms

- Not all diagnoses allow for inferences about functional limitations (e.g., quadriplegia vs. multiple sclerosis)
- Not all individuals with disabilities have a diagnosis (e.g., chronic pain)
- Disabilities tend to be under-reported in health administrative data because the focus of most health care encounters is on acute problems (Iezzoni et al., 2022)
 - E.g., 57% of people with quadriplegia and 58% of people with multiple sclerosis have codes for these conditions in the year after diagnosis (Kronick et al., 2000)
- Diagnostic codes are limited in their accuracy and completeness

Recommendations

- Inclusion of measures of functional limitations (not just diagnoses) in health administrative data (e.g., ICF or Mini-ICF, which are already used in routine reporting in home care and rehabilitation services in several countries) (Baron & Linden, 2008; Bickenbach et al., 2003; Iezzoni et al., 2002)
- Inclusion of self-reported disability as one of several equity-related variables (e.g., along with race/ethnicity and gender identity) (Pinto et al., 2020)



Brief Report

Routine identification of patients with disabilities in primary care: A mixed-methods study

Andrew D. Pinto, MD CCFP FRCPC MSc ^{a, b, c, d, e, *}, Erica Shenfeld, BSc ^f,
Robert Lattanzio, BA LLB BCL ^g, Tatiana Aratangy, PhD ^h, Ri Wang, MMath ^h,
Rosane Nisenbaum, PhD ^{d, h, i}, Tara Kiran, MD CCFP MSc ^{b, c, d, h, j}



Until then... interim recommendations

- Linkage of records across time to ensure disability can be identified across multiple years (e.g., to capture diagnoses made in childhood)
- Linkage of health administrative data with other administrative data (e.g., disability support records) that better reflect participation restrictions (*still only captures people receiving services*)
- Linkage of health administrative data with other forms of data (e.g., Census, surveys, that might include disability measures, Washington Group Short Set)
(Washington Group, 2016)
- Machine learning to provide better classification of disabilities using existing data

Thank you!

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Accessibility considerations for inclusive administrative health data research

Yona Lunsky, PhD CPsych

May 11, 2023

We don't see them



We don't see them



Relationship building – it matters



Group of self advocates sitting at a meeting room table together with the research team including Yona Lunsky discussing H-CARDD research

Nothing about us without us (study planning)

- In person or virtual?
- Watch out for tokenism (value of multiple people)
- Separate groups or larger meetings with range of KU's?
- Materials for meetings (format, organization, paper/links)
- Liaison support role
- Do your homework about perspectives on the topic
- Language/terminology considerations

Nothing about us without us (interpreting data)

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Research

Risk prediction of covid-19 related death and hospital admission in adults after covid-19 vaccination: national prospective cohort study

BMJ 2021 ; 374 doi: <https://doi.org/10.1136/bmj.n2244> (Published 17 September 2021)

Cite this as: BMJ 2021;374:n2244

Abstract

Objectives To derive and validate risk prediction algorithms to estimate the risk of covid-19 related mortality and hospital admission in UK adults after one or two doses of covid-19 vaccination.

Conclusion This population based risk algorithm performed well showing high levels of discrimination for identifying those patients at highest risk of covid-19 related death and hospital admission after vaccination.

The BMJ:

<https://www.bmj.com/content/374/bmj.n2244>

Study: Among Vaccinated, Those With Down Syndrome Face Highest Risk From COVID-19

by Michelle Diament | September 24, 2021

People with Down syndrome are the most likely of all vaccinated adults to die from COVID-19, new research suggests.

DisabilityScoop:

<https://www.disabilityscoop.com/2021/09/24/study-among-vaccinated-down-syndrome-face-highest-risk-covid-19/29502/>

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Rapid response to:

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Risk prediction of covid-19 related death and hospital admission in adults after covid-19 vaccination: national prospective cohort study

BMJ 2021 ; 374 doi: <https://doi.org/10.1136/bmj.n2244> (Published 17 September 2021)

Cite this as: BMJ 2021;374:n2244

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Rapid Response:

Re: Risk prediction of covid-19 related death and hospital admission in adults after covid-19 vaccination: national prospective cohort study

10 October 2021

Andre Strydom

Professor in Intellectual Disabilities

The BMJ:

<https://www.bmj.com/content/374/bmj.n2244/rr-2>

Cross-outcome implications and guiding principles

1. Follow the rule of *Nothing about us without us*.¹⁰⁶ People with disabilities and their families and supporters should have full and meaningful involvement in the development of policies, programs and services that affect their lives.



This principle focuses on who should be involved in deciding how changes to the system occur. People with DD are not just recipients of care; they should be active participants in any efforts aimed at them. For them to understand and meaningfully contribute to the decision-making process, they do require more time. To help with this, family members and other supporters may also need to be involved since they are commonly important partners in the care and support of adults with DD.

“Doctors should make sure they talk to people with disabilities and not just with caregivers, because we know what we need the best.”

— Andrew, self-advocate

2. A range of proactive supports and health care services should be provided in the community that are appropriate for or accommodate the specific needs of people with DD.

This principle focuses on supporting the individual in his or her community and addresses one of the contributors to the five health outcomes discussed in this report. Specifically, it aims to prevent or delay the need for hospital-based and long-term care services by proactively addressing health service needs and social service needs (e.g., appropriate financial, residential, vocational and other support needs). This means that community health care providers must be equipped to properly care for adults with DD and that the social service supports they require must also be available and accessible.

Importantly, because of the reliance of many people with DD on either family or paid caregivers, proactive services and supports should also be available and accessible in a timely manner to caregivers.

“It does not matter if it is expensive. We want people to get the proper care they need.”

— Sarah, self-advocate

3. Appropriate supports and health care services should be available and accessible to people with DD in emergency department, hospital and long-term care settings.

This principle focuses on the provision of health care that addresses the unique needs of those with DD and particular types of DD once an individual has been admitted to an emergency department, inpatient hospital or long-term care setting. Specifically, it aims to prevent early return or lengthy stays in these settings through quality care, tailored to those with DD. These supports or accommodations include changes to the physical environment and communication approach, an allowance for additional people to support the person and an increase in time to carry out health care procedures.

“I would like doctors to have a little more time for people with disabilities, and be more understanding. We’re a little slower than other people are. We need more time to talk to them.”

— Michael, self-advocate

4. When adults with DD transition between different health care services or between health care and community settings, these transitions should be planned, well-coordinated and seamless.

This principle focuses on the interconnection and cooperation within and between sectors, programs and interventions. Specifically, it aims to make the journey across services and supports as seamless as possible and thus addresses one of the contributors to the five outcomes discussed in this report. Success requires that those involved in the transition process remain involved before, during and immediately after the transition period.

“They had to change my IV in the hospital, but then I needed it changed at home, too. A nurse came to my house.”

— Rachel, self-advocate

Nothing about us without us (dissemination)

- Accessibility of information
- Sensitivity in messaging
- Finding ways to share sharing



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30TH
ANNIVERSARY

ICES RESEARCH
FORUM

11
MAY
2023

WAY
FORWARD

ADVANCING
HEALTH EQUITY
THROUGH DATA

ALT [on.ca](https://alt.on.ca)



Ontario 
Ministry of HEALTH

ALT text (image description):

2023 ICES Research Forum: Way Forward Advancing Health Equity Through Data May 11, 2023

Partnerships in Knowledge Exchange

camh | Azrieli Adult
Neurodevelopmental Centre

Research Summary

A study about depression for Special Olympics athletes and people who do not do Special Olympics





[Click here for the research paper](#)

What did we do?

We looked at all the young adults with developmental disabilities from Ontario who were and who were not in Special Olympics.



Then, we looked to see how many people in Special Olympics had depression **and** how many people who were not in Special Olympics had depression.



We looked at information that was collected over 20 years.



What did we learn?

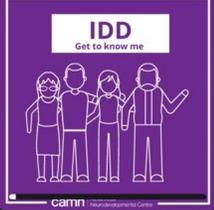


Young adults in Special Olympics were **diagnosed with depression less often** than people who did not go to Special Olympics

The people who did Special Olympics were **half** as likely to get depressed as the people who did not.



SCAN ME



April 12 · S3 E1 · 27 mins left

Special Olympics and Mental Health with Dr. Meghann Lloyd

IDD: Get to know me >

[▶ Resume](#)

Join us for the first episode of our third season on IDD Get to Know Me!

Podcast hosts Daniel and Victor interview Dr. Meghann Lloyd from Ontario Tech University. They talk about her journey with getting involved in Special Olympics and her exciting research about the benefits of participating in Special Olympics.

Lloyd M, Temple VA, Foley JT, Yeatman S, Lunsky Y, Huang A, Balogh R. Young adults with intellectual and developmental disabilities who participate in Special Olympics are less likely to be diagnosed with depression. Soc Psychiatry Psychiatr Epidemiol. 2022 Dec 22. doi: 10.1007/s00127-022-02406-8.

Learn to Be an **Ally**

Resources

- [Demystifying disability \(Emily Ladau\)](#)
- [Being Heumann \(Judy Heumann\)](#)
- [Disability Visibility \(Alice Wong\)](#)
- [Docs with disabilities podcast \(Canadian section\)](#)

- <https://healthydebate.ca/2021/05/topic/inclusive-health-research/>
- <https://www.w3.org/WAI/>
- <https://autisticadvocacy.org/resources/accessibility/easyread/>

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Thank You

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