



Intellectual and Developmental Disabilities and Covid-19: Health Research and Practice

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#ddprimarycare

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Disclosure

- **Sponsor relation**

- Executive Committee member, IASSIDD Health SIRG and Ethics SIRG
- Family Physician & Clinical Lead, DDPCP, Surrey Place
- Associate Professor, Dept. of Family & Community Medicine, University of Toronto, & St. Michael's Hospital Academic Family Health Team

- **Conflict of interest**

- None

- **Avoiding potential bias**

- Based on recent, peer-reviewed, evidence-informed sources

I'm interested in this topic primarily because I'm a/an

- self-advocate with IDD
- family member
- support worker
- family (GP) physician or nurse
- medical specialist
- allied healthcare provider
- ethicist
- spiritual care provider

Objectives

After actively engaging in this webinar, participants will be able to...

1. **Analyze and apply research** on Covid-19 and describe knowledge gaps.
2. **Develop care plans and adapt** them to changes in patient needs, services, and healthcare provider roles.
3. Promote **decision-making capabilities** of adults with IDD.

Vulnerabilities of people with IDD

- High prevalence of co-existing **high-risk physical health conditions**
- High risk of significant exposures to “**super-transmitters**”
- High prevalence of **mental health conditions**
- **Changed or decreased supports**
- Challenges **adjusting to change or loss**
- High prevalence of **neglect or abuse**
- Limited prior involvement in **healthcare decision making**

Courtenay K, Perera B. COVID-19 and people with intellectual disability: impacts of a pandemic. *Irish Journal of Psychological Medicine* 2020 [preprint]

Case: Fatimah



- 17 years old
- mild intellectual disability
- Down syndrome
- Lives with mother & frail grandmother
- Hyperthyroidism and poor immune regulation
- Some ASD-associated behaviours
- Recently experiencing fatigue
(COVID-19? Thyroid? Other?)

Case: Fatimah



Mother makes appointment for Fatimah with endocrinologist for a long-overdue annual assessment and review of medications at the hospital clinic. **Should Fatimah's mother take her to the appointment?**

- Yes
- No
- Unsure
- Ask Fatimah

1. Research

“Not everything that can be counted counts, and not everything that counts can be counted.” - William Bruce Cameron

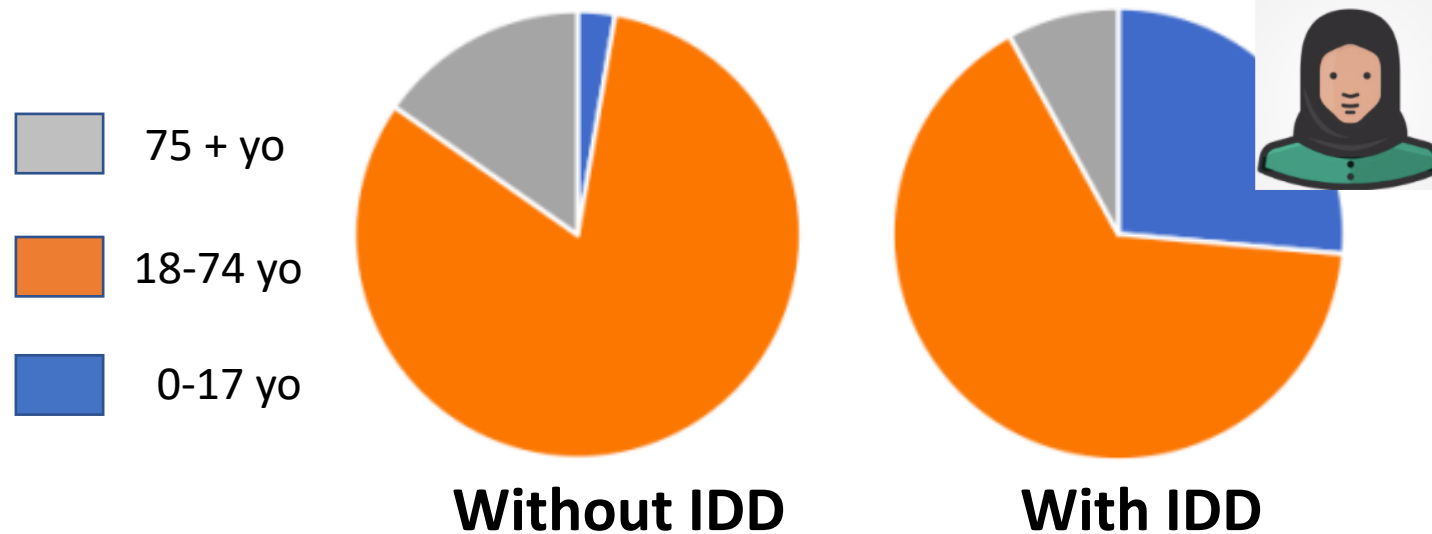
Knowledge Gaps

- Limited specific empirical research (still early; prior knowledge gap)
 - COVID-19 open research dataset (259/26,055) - Tummers J, et al. Coronaviruses and people with intellectual disability: an exploratory data analysis. JIDR 2020 July; 64(7): 475-481
 - Oxford COVID-19 Evidence Service (0/230)
- Generic empirical studies might be useful but require review considering issues for people with IDD
- Need for various types of knowledge: experiential, expert, ecosystem, framing

Empirical knowledge

Age effect

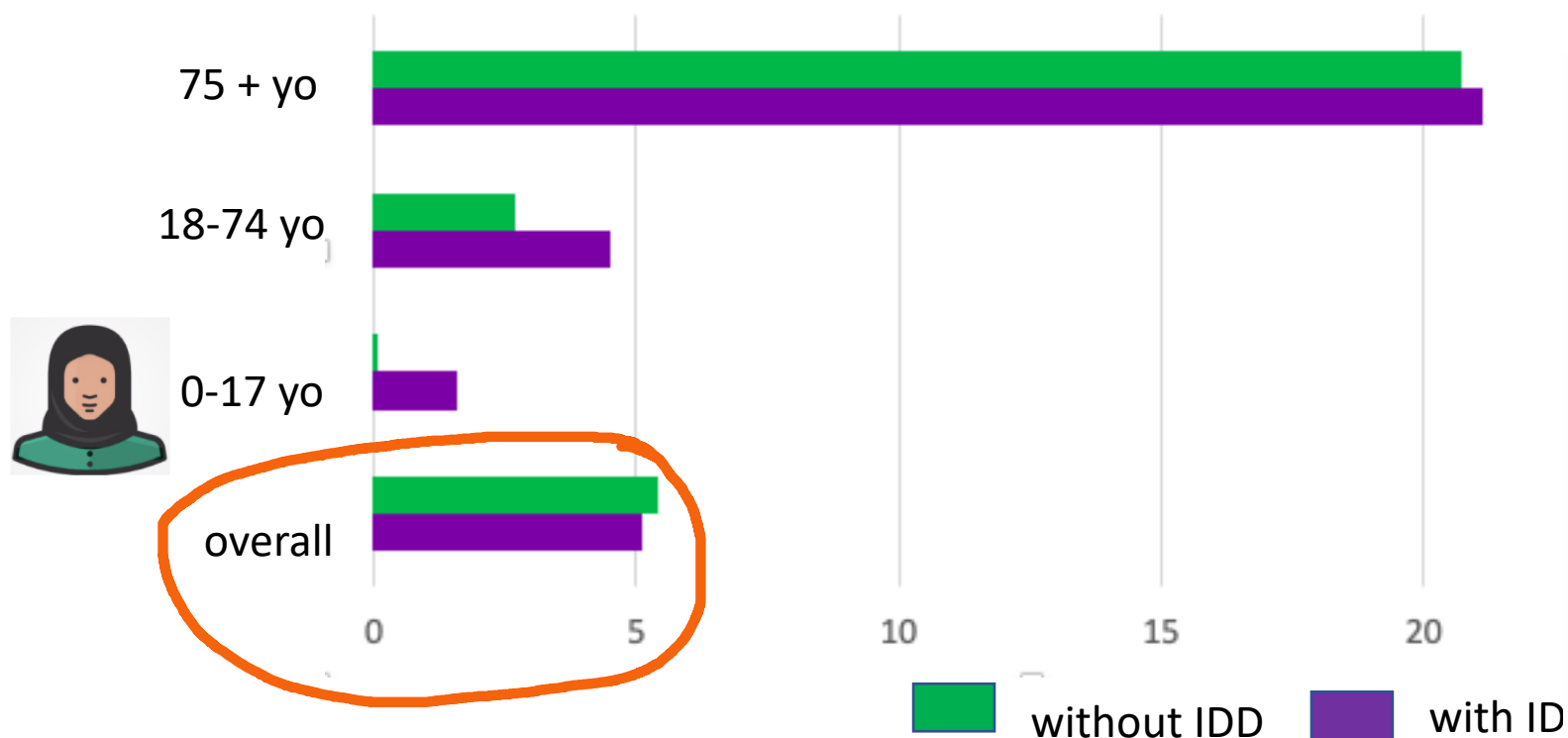
Distribution of COVID-19 cases by age group



Turk MA et al. (2020), Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis, Disability and Health Journal [pre-print]

Empirical knowledge

Death rates (%) among cases



Possible causes?

Earlier frailty and aging?

Higher rates of high-risk physical & social conditions?

Ecosystem considerations?

Turk MA et al. (2020), Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis, Disability and Health Journal [pre-print]

Empirical knowledge


Acta Neurologica Belgica

<https://doi.org/10.1007/s13760-020-01373-8>

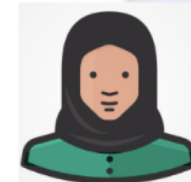
ORIGINAL ARTICLE



Are patients with Down syndrome vulnerable to life-threatening COVID-19?

Harald De Cauwer^{1,2,3}  · Ann Spaepen³

Received: 6 May 2020 / Accepted: 12 May 2020
© Belgian Neurological Society 2020



- DS-specific
- Limited case series
- Immune dysregulation and increased cytokine production renders patients with DS vulnerable to succumbing to both RSV and Covid-19 infections

Expert knowledge

- IDD-specific guidance
- integrated approach
- being prepared
 - Info for hospital
 - adapted care plan
 - advance care plan
- Tools to implement?



Journal of Policy and Practice in Intellectual Disabilities

Journal of Policy and Practice in Intellectual Disabilities

doi: 10.1111/jppi.12352

Guidance for the Treatment and Management of COVID-19 Among People with Intellectual Disabilities

Regi Alexander^{*,†} , Ambiga Ravi[‡], Helene Barclay^{*}, Indermeet Sawhney[§], Verity Chester^{* }, Vicki Malcolm^{*}, Kate Brolly^{*}, Kamalika Mukherji[¶], Asif Zia[¶], Reena Tharian^{||}, Andreana Howell^{**}, Tadhgh Lane^{**}, Vivien Cooper^{††}, and Peter F. Lanodon^{‡‡,§§,¶¶ }

Experiential knowledge



cmaj BLOGS



HOME ALL POSTS COVID-19 EDITORS' BLOG STUDENT HUMANITIES BLOG MEDICAL DISPATCHES

May
19
2020

COVID-19, REFLECTIONS

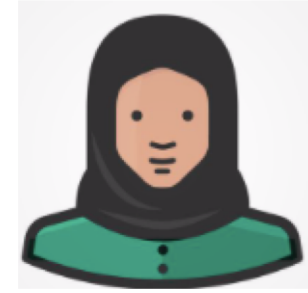
A SISTER'S REFLECTIONS

10 Comments

[Yona Lunsky](#) is *Director of the Azrieli Adult Neurodevelopmental Centre at the Centre for Addiction and Mental Health's Access and Developmental Disabilities Program*. She is a *Professor in Psychiatry at the University of Toronto*, and

- Families struggle with the balance between preventing infection and other issues
- Will people with IDD be valued? Will their needs be recognized and accommodated?





Applying the knowledge

- **In assessing risk of infection:**
 - consider factors not generally considered (younger age; cause)
 - additional risks of infection now that public measures are being relaxed?
- **Plan to manage overall health**
 - What is urgent, what is not?
 - What can be managed at home?
 - By whom? Who coordinates?
- **Communicate and address needs to be accommodated**
- **Be prepared**
 - Is there a hospital transfer package
 - advance care plan?



Applying the knowledge

- Good care involves not only clinical but also **ethical considerations**:
 - How to be person- and family-centred for each patient
 - How to involve patient in decision making
 - What are benefits relative to risks and burdens?
 - Where do people with IDD stand in queue for resources?
- Consider also **existential and spiritual questions**:
 - Adjusting to change
 - Coping with different kinds of losses
 - Fears about death and dying
- **Think long term!**

2. COVID-19 Care Plan

PLANNING FOR COMPREHENSIVE AND INTEGRATED HEALTH CARE

Why is a care plan important?

Implementation of Health Links coordinated care plans for adults with intellectual and developmental disabilities

Cross-sectoral pilot program

Mary I. Martin MSc Elizabeth Grier MD CCFP Nicole Bobbette MSc OTReg(Ont)

Ian Casson MD MSc CCFP FCFP Janet Durbin PhD Meg Gemmill MD CCFP

Yona Lunsky PhD CPsych Hélène Ouellette-Kuntz PhD

.Can Fam Physician. 2019;65(Suppl 1):S41-S46.

Example of a template for care plan

		COORDINATION and INTEGRATION			
		NEEDS, TASKS, and OVERSIGHT →			
		Health habits	Health management		Preventing illnesses
			new	ongoing	
SUPPORTS and INPUTS ↓	Person and caregivers				
	Primary care provider and team				
	Specialist inputs (medical and developmental)				
	Systems				

St Michael's
Hospital/Surrey
Place Transition
Youth with IDD
Clinic

Adapting health care plans during the pandemic

- Addressing changing needs, services, roles (caregiver, family physician, support professional)
- Telehealth – merits and difficulties
- Maintaining health habits during lockdown
- Being prepared for contingencies

3. Promoting decision-making capabilities

TOOLS FOR HEALTH CARE DECISIONS AND ADVANCE CARE PLANNING

Promoting decision-making capabilities

- Trend towards paternalism during pandemic?
- Identifying and engaging decision-making supports
- Advance care planning

DOWNLOAD TOOLS FROM
ddprimarycare.surreyplace.ca

Search for Guidelines or Tools 

Primary Care Tools
Approaches to Care & General Considerations

About My Health ●

Communicate CARE ●

Decision-Making Checklist ●

My Health Care Visit ●



Health Check ●

Genetic Assessment Frequently Asked Questions ●

Adaptive Functioning and Communication ●

Psychological Assessment ●

Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities UPDATED 2019

Promoting Capabilities

INTRODUCTION

This tool provides practical steps to help healthcare providers meet their obligation to respect the decision-making rights of people with intellectual and developmental disabilities. This information is not intended as legal advice. Always consider provincial laws and regulations when using this tool.

RELATED TOOLS

[About My Health](#)

[Adaptive Functioning and Communication](#)

[Communicate CARE](#)

RELATED GUIDELINES

[Capacity for Decision-Making](#)

COVID-19 Advance Care Plan: A Guide for Caregivers of Adults with Intellectual and Developmental Disabilities

DOWNLOAD TOOLS FROM
ddprimarycare.surreyplace.ca

Introduction

This tool guides care providers of adults with intellectual and developmental disabilities (IDD) through the process of advance care planning regarding possible medical treatments for COVID-19. Advance care planning is a process that promotes person-centred care, by clarifying the individual's present goals and values along with his or her preferences regarding future health care. For adults with IDD, this process involves the adult's substitute decision-maker, a healthcare provider (ideally the family physician), and others who know the adult well, whom the adult trusts, and who are willing to support this process. Adults with IDD should be engaged, with supports as needed, to participate as much as they can and wish to. They do not need to pass a legal capacity test to contribute to this process.

How to use this tool

What is an Advance Care Plan?

- ▶ An Advance Care Plan is a document that outlines the outcome of discussions in the advance care planning process.

COVID-19 Advance Care Plan

- A. Identify the person's **substitute decision maker** and a **backup**
- B. Discuss a person's **present values and goals**
- C. Discuss a person's **preferences for future care** in the COVID-19 context
- D. **Share the plan** with the patient, substitute decision maker(s) and other relevant persons

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