

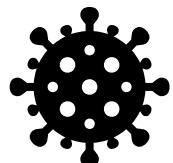
Self-Advocates' Reflections on Research about COVID-19 and Persons with Intellectual Disabilities

Introduction

1. We know that persons with **intellectual and developmental disabilities** (ID or IDD) are often left out of many areas of life, including important policy discussions.



2. We also know less about how persons with ID have experienced the **COVID-19 pandemic** than other groups.



3. We wanted to explore what **research studies** say about the experiences of persons with ID during the COVID-19 pandemic and to better understand what these studies are like.

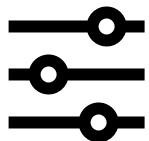


Methods

1. A group of 6 **self-advocates** reviewed the abstracts of 9 research studies on the topic of COVID-19 and persons with ID. “Abstracts” is another word for summaries.



2. The group’s supporter used **selective sampling** to choose 9 research studies on COVID-19 and persons with ID from different parts of the world that used different approaches. “Selective sampling” means that the supporter chose studies that would likely be interesting to the group of self-advocates, but that there are other studies on this topic that were not included.



3. We read these 9 abstracts and discussed them as a group. We discussed the studies' **focus, methods, participants, and findings.**



If we thought a part of the abstract was unclear, then we also read portions of the studies themselves.

4. We also **reflected** on if the studies were what we expected to find, if the researchers identified as persons with ID, what attitudes the researchers might have about persons with ID, and what gaps we think there are in the research.



Findings

1. Early in the pandemic, researchers were **less likely to speak to persons with ID directly** about their COVID-19 experiences.



Instead, researchers focused more on the experiences of people around persons with ID or what other people thought about the experiences of persons with ID.

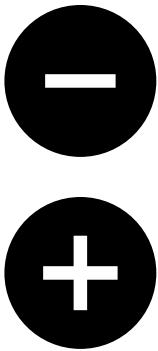
2. Researchers also did not always seem to choose **methods that make it easier for persons with ID** to participate in the studies, such as open-ended interviews.



3. Researchers identified **important themes** about the experiences of persons with ID, including the negative effects of social isolation or changes in services. But other important themes were less explored, including how information about COVID-19 and safety measures was shared.



4. Researchers focused more on the negative effects of COVID-19 on the lives of persons with ID than on how persons with ID handled these challenges. Even though COVID-19 did have many negative effects on the lives of persons with ID, too often **researchers and others overlook the strengths** of persons with ID. Even though COVID-19 posed greater health risks to persons with ID, it is also important to talk about the strategies that persons with ID used to protect themselves and others from these risks.



5. Researchers focused more on the experiences of persons with ID **who lived either with their family members or on their own** during the pandemic, and less on persons with ID living in other settings, like group homes.



6. None of the researchers appeared to identify as having ID themselves, nor did they appear to **include self-advocates in planning or doing their research.**



Recommendations

1. Researchers should **be aware** of any assumptions they make about the vulnerability of persons with ID and try to **avoid** talking about persons with ID only as receivers of support.
2. Researchers should do more to **include persons with ID in their studies as researchers**, to make sure their research methods are



appropriate for persons with ID, and to include in their studies persons with ID who live in diverse settings.

3. Researchers should include **more in-depth interviews directly with persons with ID** because this method is more likely to help us better understand their experiences during the pandemic.



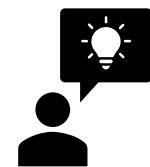
4. Researchers should **share their findings** with persons with ID to get their feedback on what they have learned and also to educate persons with ID about the experiences of others like them.



5. Journals should make sure that researchers give summaries of their studies about persons with ID in **simple language** that persons with ID can easily understand.



6. Other self-advocates should try to learn more about this area of research because it is important to know how researchers view persons with ID. These views might influence policies that affect the lives of persons with ID in the future and self-advocates should **make sure that their voices are heard**, too.



Acknowledgments

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Table of Research Studies

Title (Date)	Subjects & Methods	Positive Aspects	Concerns
1. Experiences and needs of direct support staff working with people with ID during the COVID-19 pandemic: A thematic analysis (Sept. 2020)	Field audio recordings from 11 direct support staff in the Netherlands	<ul style="list-style-type: none"> Provides insights on experiences in group homes from the early days of the pandemic 	<ul style="list-style-type: none"> Does not focus on persons with ID themselves
2. COVID-19 outcomes among people with IDD living in residential group homes in New York State (Oct. 2020)	Analysis of case, case fatality, and mortality rates in New York, USA	<ul style="list-style-type: none"> Focuses on the effects of COVID-19 on persons with ID living in group homes 	<ul style="list-style-type: none"> Supports idea that persons with ID are vulnerable
3. Priority concerns for people with IDD during the COVID-19 pandemic (Oct. 2020)	Survey and follow-on video conferences of 26 service provider representatives in the United Kingdom	<ul style="list-style-type: none"> Highlights issues important to persons with ID 	<ul style="list-style-type: none"> Does not include perspectives of persons with ID themselves
4. Supports for people with intellectual and developmental disabilities during the COVID-19 pandemic from their own perspective (Nov. 2020)	Online survey of 582 persons with ID or supporters in Spain	<ul style="list-style-type: none"> Describes a wide variety of perspectives, including different types of residences Describes how persons with ID provided support to others 	<ul style="list-style-type: none"> Uses less accessible close-ended, written questions Limits participants' open-ended answers to 20 words each

Title (Date)	Subjects & Methods	Positive Aspects	Concerns
5. The wellbeing and mental health care experiences of adults with IDD during COVID-19 (Mar. 2021)	Remote interviews with 9 persons with ID in Ontario, Canada	<ul style="list-style-type: none"> Describes persons with ID as active members in their community Focuses on the perspectives of persons with ID themselves 	<ul style="list-style-type: none"> Does not consider the impact of wheelchair use Does not focus on persons with ID living in group settings
6. Assessing the quality of support and discovering sources of resilience during COVID-19 measures in people with ID by professional carers (Apr. 2021)	Online survey of 290 direct support staff in the Netherlands	<ul style="list-style-type: none"> Describes some persons with ID as a source of support to others Includes a plain language summary 	<ul style="list-style-type: none"> Does not focus on persons with ID themselves
7. The experiences of carers of adults with ID during the first COVID-19 lockdown period (May 2021)	Remote interviews with 8 parents of persons with ID in the United Kingdom	<ul style="list-style-type: none"> Describes important gaps in services that affected both persons with ID and their supporters 	<ul style="list-style-type: none"> Does not focus on persons with ID themselves
8. Homeward bound: Exploring the motives of mothers who brought their offspring with ID home from residential settings during the COVID-19 pandemic (July 2021)	Remote interviews with 7 mothers of persons with ID in the Netherlands	<ul style="list-style-type: none"> Describes the unique challenges faced by persons with ID living in group settings Describes tensions that persons with ID might have had with family members 	<ul style="list-style-type: none"> Focuses only on the perspectives of family members Describes how family members decided for persons with ID about where they would live

Title (Date)	Subjects & Methods	Positive Aspects	Concerns
9. Changes in life experiences of adults with ID in the COVID-19 pandemics in South Korea (Oct. 2021)	Remote and in-person interviews with 15 persons with ID in South Korea	<ul style="list-style-type: none"> • Focuses on the perspectives of persons with ID • Describes how persons with ID adapted by spending time with family and exploring new activities 	<ul style="list-style-type: none"> • Includes only persons with ID living either with family members or on their own