



# Shedding Light on Research and Advocacy Opportunities for Individuals with Intellectual and Developmental Disabilities (IDD)

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# Overview

- Introduction
- Why is the resource needed?
- Who is the resource for?
- Methodology
- Review of selected guide pages
- Closing Remarks



# Library Guide on Intellectual and Developmental Disabilities

<https://guides.library.duq.edu/idd>

# Why is this resource needed?

- 1 in 6 children are diagnosed with IDD, or 17%<sup>1</sup>
  - This is a sizable portion of our communities!
- Professionals in any field will meet individuals with IDD
  - Health sciences
  - Social sciences
  - Education
  - And many more!
- In order to work with and serve IDD populations, we need to know more
  - What is IDD?
  - How does IDD impact a person's life?
- Once we have a basic understanding of IDD, we can direct users to research resources

# Who is this resource for?

- Students
- Staff
- Faculty
- Professionals interested in/working with IDD
- Budding or aspiring professionals
- Members of the general public
  - Self-advocates
  - Advocates

# Methodology

- Standard guide elements
  - E.g. books, databases, getting help, related guides
- Compiled resources I was aware of from my own professional experience as well as others I found through research
  - Resources and organizations, most notably
- Sought and incorporated feedback from selected faculty in:
  - Occupational Therapy
  - School Psychology
  - Nursing
  - Office of Civic Engagement
  - Library



- Definitions from several reputable organizations
  - Advocacy
  - Education
  - Health Sciences
- The goal is to show that several disciplines engage with individuals with IDD
  - But the definitions don't always align well!
- Quiz helps readers identify inconsistencies



## Intellectual and Developmental Disabilities

### What are Intellectual and Developmental Disabilities?

Intellectual and Developmental Disabilities (commonly shortened to IDD) are defined in many different contexts, depending on many different factors. There can be several different causes for intellectual and developmental disabilities, and the vast majority of individuals impacted by IDD don't know the direct cause of their condition (CDC, 2021).

Depending on the organization you ask, there are different (and sometimes competing) understandings in how we define and approach IDD. Take a look at some example definitions below.

[AAIDD](#)   [The Arc](#)   [IDEA](#)   [NICHD](#)   [CDC](#)

"Intellectual disability is a condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22."

"Assessments must also assume that **limitations often coexist with strengths** in a person, and that an individual's level of life functioning will improve if appropriate, personalized supports are provided over a sustained period."

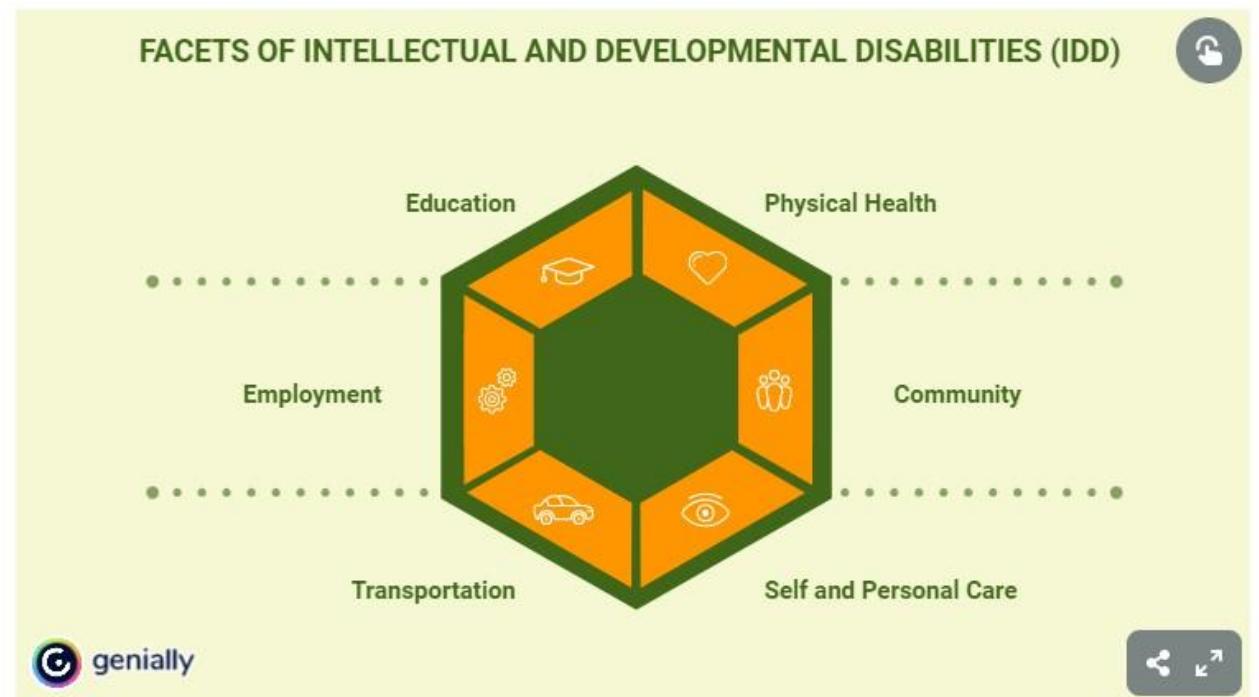
American Association on Intellectual and Developmental Disabilities

- Interactive, clickable diagram of 6 areas of life
- Clicking on the orange buttons pops out a text window
  - Context-dependent examples of IDD needs
- IDD impacts many areas of life, sometimes in unexpected ways

## The Many Facets of IDD

As several definitions describe, intellectually and developmentally disabilities are characterized by a pervasiveness in every aspect of life: including cognitively, physically, emotionally, and socially. In all people, there are dimensions to our functioning and abilities: this is also true for individuals with IDD. By no means are disabled people a monolith.

Interact with the infographic provided below (click on the orange buttons) to learn more about how each area of life can be impacted.



<https://guides.library.duq.edu/idd/facets>

- Emphasizes key diagnoses associated with IDD
- IDD is an abstract concept, but individuals impacted are not a monolith
- Concrete examples to clarify how IDD can manifest

## Health Conditions Related to IDD

Every individual's background is different, and there are numerous known causes to intellectual and developmental disabilities. Several of these known conditions are listed below. Click through the tabs to learn more about each diagnosis, as well as to find support resources/organizations affiliated with each condition.

Note: this is not a comprehensive list.

Cerebral Palsy

Down Syndrome

Fragile X Syndrome

Klinefelter Syndrome

Phenylketonuria (PKU)

Prader-Willi Syndrome

Rett Syndrome

Traumatic Brain Injury

Turner Syndrome

Williams Syndrome

### Down Syndrome

Down Syndrome, also referred to as Trisomy-21, is a genetic disorder that develops in the presence of an extra chromosome 21 (or additional piece of the 21st chromosome). This is the most common chromosomal cause of IDD (NICHD, 2018).

Recently, the National Institutes of Health began an initiative to conduct more research on Down syndrome and comorbidities with other medical conditions, including Alzheimer's/dementia, autism, cataracts, celiac disease, congenital heart disease, and diabetes (NIH, 2018). This research effort, known as the INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) Project, is ongoing.

- NICHD - Down Syndrome
- NIH - INCLUDE Project
- National Down Syndrome Congress

- Miscellaneous resources on...
  - Historical context
  - Legislation
  - Advocacy
    - Firsthand accounts
- Organizations affiliated with advocacy and research
  - Nationally
  - Statewide
  - At the county level



Image Source: Pexels

## Resources

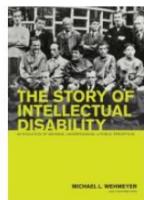
The following resources are available free to the public relating to the history, legislation, and advocacy surrounding intellectual and developmental disabilities.

- The Americans with Disabilities Act - National Archives [i](#)
- CDC - Intellectual and Developmental Disabilities Resources [i](#)
- Council for Exceptional Children [i](#)
- Disability History Museum [i](#)
- Disability Law in the United States - Library of Congress [i](#)
- Disability Voices - An Oral History Project [i](#)
- National Center on Birth Defects and Developmental Disabilities (NCBDDD) - List of IDD Websites [i](#)
- Rooted in Rights [i](#)

- Orienting users to library resources to help direct research on IDD

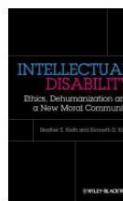
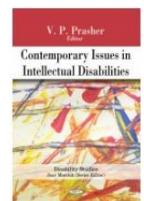
### Books in our Collection

Click the covers below to find some of the print books available in our library catalog relating to intellectual and developmental disabilities!



### eBooks in our Collection

Click the covers below to find some of the available eBooks available in our library catalog relating to intellectual and developmental disabilities!



### Tips for Searching Databases

When looking for research materials, a common issue one may run into is knowing which search terms to use. For general help on how to conduct a search, see the [DUQSearch library guide](#).

#### Search Terms

Historically, individuals with intellectual and developmental disabilities have been mistreated and disregarded in several harmful ways, including poor healthcare practices, inhumane living conditions, institutionalization, and a lot of harmful stigma. Some of that stigma is perpetuated by antiquated diagnostic language.

The medical standard for labeling and diagnosing IDD previously involved several derogatory terms, including mental retardation, idiocy, and countless others. These terms have since been removed from diagnostic materials, but may pervade in the literature depending on publication date.

As a professional in any field, it is important to know the harm that this history connotes, and to address this population throughout your research with respect. Please consider using these terms:

- Intellectual Disability
- Intellectual Development Disorder
- If you are working specifically with a given diagnosis that falls under the category of IDD, use it instead.
  - Fragile X Syndrome
  - Down Syndrome
  - Rett Syndrome
  - Prader-Willi Syndrome
  - Williams Syndrome

# Closing Remarks



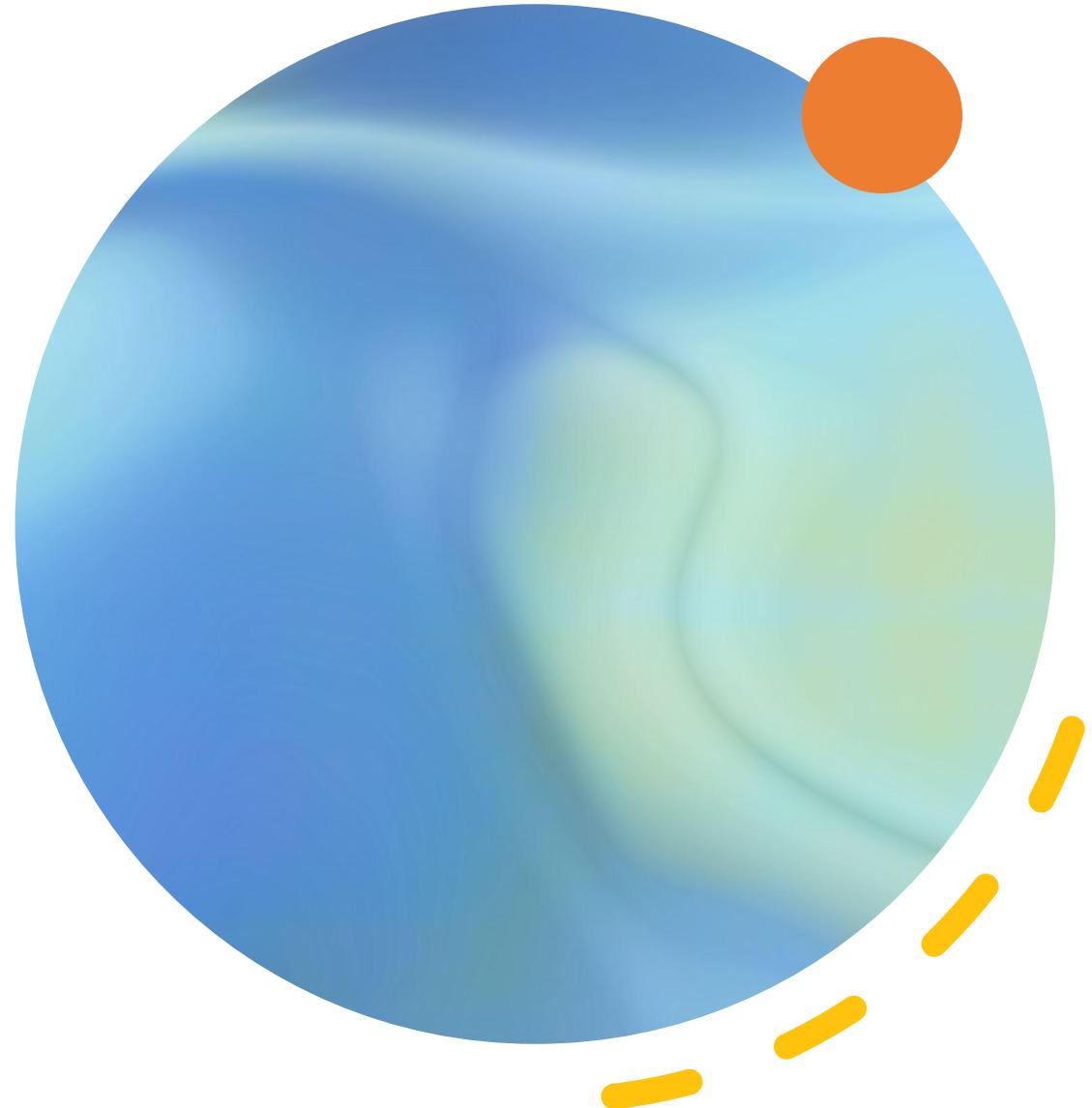
Showing the various contexts that IDD issues manifest in helps build a holistic understanding of IDD.



This can be facilitated with research strategies, orientation to library resources, and connection to advocacy resources.



A multifaceted understanding of IDD equips users to serve their communities in multiple contexts.





Questions?

# References

1. Zablotsky, B., Black, L.I., Maenner, M.J., Schieve, L.A., Danielson, M.L., Bitsko, R.H., Blumberg, S.J., Kogan, M.D., Boyle, C.A. (2019). Prevalence and trends of developmental disabilities among children in the U.S.: 2009–2017. *Pediatrics*, 144(4), e20190811. <https://doi.org/10.1542/peds.2019-0811>.
2. American Association on Intellectual and Developmental Disabilities. (n.d.). *American Association on Intellectual and Developmental Disabilities*. Retrieved February 21, 2022, from <https://www.aaidd.org/>.

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