Empowering People with Developmental Disabilities

An Overview of Clinical, Familial, Provider, and Caregiver perspectives.

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Objectives and Purpose

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- To provide a broad overview of I/DD from a clinical and humanistic perspective.

- To provide a baseline education that instills an empathic approach to the I/DD population.

- To provide an opportunity for members of the audience to enhance their own abilities when working with an I/DD member or their caregiver/support.

- To normalize discussions about improving the healthcare and lives of people living with I/DD.

- To increase overall understanding of the population to improve how we may serve them best

Disclaimer and Speaker Bio

- Clinical background

- There are several "real-life" anecdotes contained within this presentation.

- Utilizing real-life stories is purposefully done to capture your attention and to provide context to what is being taught.

- All details of the actual people receiving treatment have ben changed to protect their identity.

- The contents of the presentation are for educational purposes only and do not provide any specific treatment nor diagnostic directions.

- Follow up questions can be directed to me at jrechtman@performcare.org or your direct supervisor/people manager.

The Journey of Human Development

Start Here

2 MONTHS
- Looks at your face
- Reacts to loud sounds
- Smiles when you talk to or smile at her
- Holds head up when on tummy

6 MONTHS
- Knows familiar people
- Takes turns making sounds with you
- Reaches to grab a toy he wants
- Rolls from tummy to back

12 MONTHS
- Plays games with you, like pat-a-cake
- Calls a parent "mama" or "dada"
- Puts something in a container, like a block in a cup
- Pulls up to stand

18 MONTHS
- Copies you doing chores, like sweeping with a broom
- Tries to use a spoon
- Points to show you something interesting
- Tries to say three or more words besides "mama" or "dada"

2 YEARS
- Tries to use switches, knobs, or buttons on a toy
- Kicks a ball
- Looks at your face to see how to react in a new situation
- Says at least two words together, like "More milk."

30 MONTHS
- Says about 50 words
- Uses things to pretend, like feeding a block to a doll as if it were food
- Shows you what she can do by saying, "Look at me!"
- Jumps off the ground with both feet

3 YEARS
- Talks with you in conversation
- Draws a circle, when you show him how
- Notices other children and joins them to play
- Uses a fork

4 YEARS
- Answers simple questions like "What is a coat for?"
- Names a few colors of items
- Unbuttons some buttons
- Likes to be a "helper"

5 YEARS
- Follows rules or takes turns when playing games with other children
- Uses or recognizes simple rhymes
- Writes some letters in her name
- Hops on one foot

Ages and Categories of Developmental Milestones

Birth to 1 Year

- 2 months
- 4 months
- 6 months
- 9 months
- 12 months

1 to 3 years

- 15 months
- 18 months
- 2 years
- 30 months

3 to 5 years

- 3 years
- 4 years
- 5 years

Social and Emotional

Language and Communication

Cognition/Thinking/ Problem Solving

Physical/Movement

Social/Emotional:

Laughs

Looks in mirror

Knows familiar people

Language and Communication:

Blows "raspberries"

Makes squealing noises

Takes turns making sounds

Cognition:

Puts things in mouth to explore

Reaches for preferred items

Closes mouth when done eating

Movement/Physical:

Rolls from tummy to back

Pushes up with straight arms when on tummy

Leans on hands for support when sitting

Environmental stimulation

Social/Emotional:

Plays "games"

Language and Communication:

Waves hello/goodbye

Calls a parent by special name

Understands "No!" (receptive)

1 Year - Pulls up to stand

Cognition:

Will look for hidden objects

Places objects in a container

Movement/Physical:

Pulls up to stand

Walks while holding on

Picks up small objects with thumb and pointer finger

Social/Emotional:

Reacts when others cry

Looks at parent's face to see how to react in a new situation

Language and Communication:

Says two-word phrases

Uses non-verbal gestures (nodding yes)

Can point to two body parts when asked

Cognition:

Uses switches/buttons on toy

Plays with more than one toy at a time together

Movement/Physical:

Uses a spoon

Kicks a ball

Runs

Age 3 Years

Social/Emotional:

Calms after 10 minutes of being left in unfamiliar area

Acknowledges and plays with other children

Language and Communication:

Asks W ?s

Expresses first name

Parent understands most of what is verbalized

Cognition:

Draws a circle when shown

Avoids touching objects when warned — stove, oven, electric wires, etc.

Movement/Physical:

Strings items together

Puts on clothing alone (not shoes)

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Social/Emotional:

Comforts others

Pretend play

Language and Communication:

4-word sentences at min.

Articulates events in their day

Answers simple questions

Cognition:

Draws a person with three parts

Names a few colors

Movement/Physical:

Catches large ball

Unbuttons with challenges

Holds crayon between fingers and thumb (pincer)

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Social/Emotional:

Follows game rules when playing with others

Helps with simple chores — clearing the table

Language and Communication:

Tells stories with two events ("A dog got loose and ran down the street")

Can carry on a conversation with four responses

Cognition:

Counts to 10

Can point to numbers 1 – 5

Writes and names a few letters

Movement/Physical:

Buttons several buttons

Hops on one foot

Monitoring Versus Screenings

- Developmental screenings by a pediatrician:
  - Formalized and standardized tools
  - Typically used every few months in the first few years
  - Completed during well visits
  - Routinely conducted

- Developmental monitoring by caregivers:
  - Milestone moments checklists
  - Milestone Tracker app
  - Settings for caregivers and professionals

What To Do With Concerns

Monitoring by caregivers

Developmental screening (MD)

Referral to:

Developmental Assessment

EI/IEP

Developmental Disabilities Defined

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Developmental Disability

Intellectual Disability
"Learning Disability" in the United Kingdom

IDD

Physical disability
Autism
Blindness
Deafnesss
Epilepsy
ADHD

And other developmental conditions

(Fischer et al, 2022)
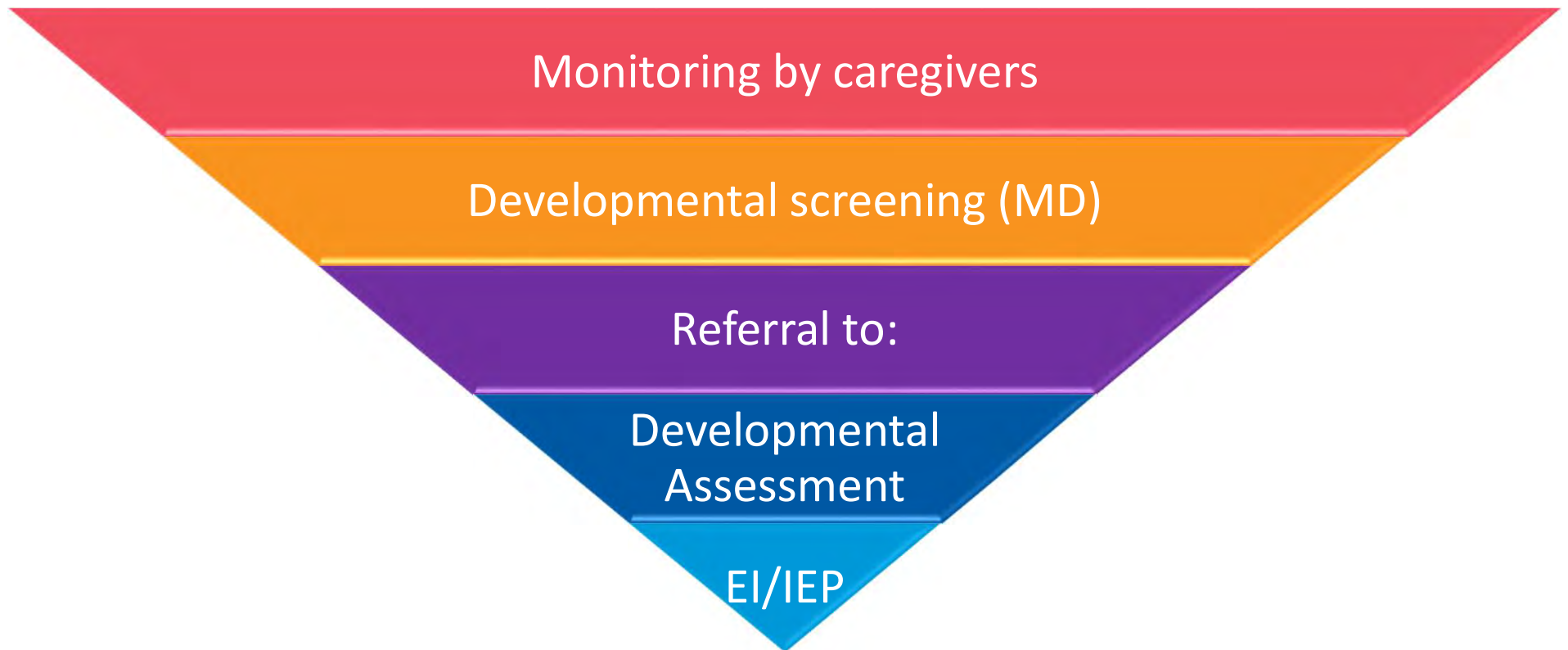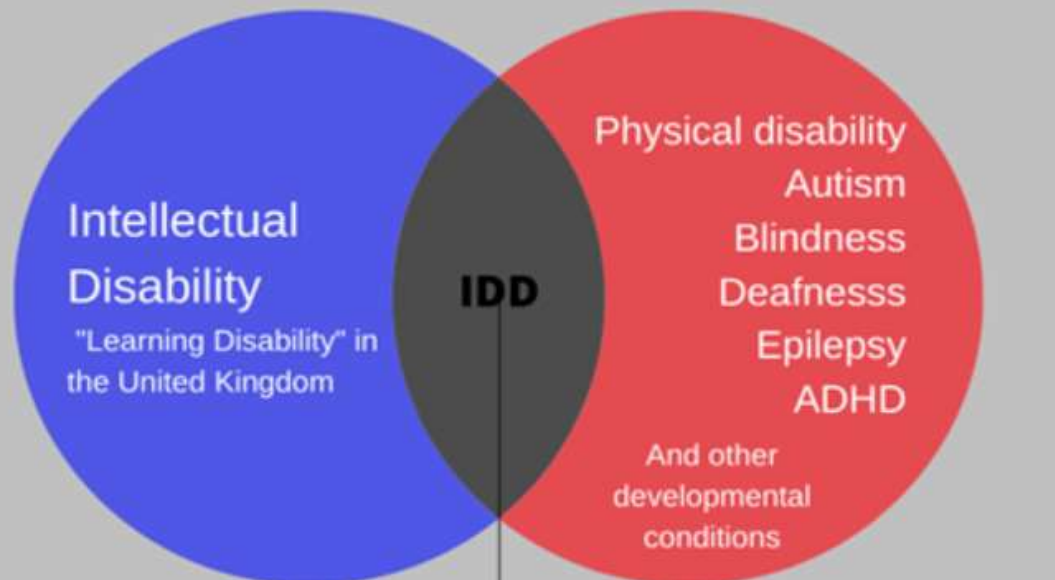
- ***Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime (CDC, 2024).***

- Disability is present before turning age 22.

- Is an umbrella classification.

- Includes autism.

- Does not equate to intellectual disability.

Intellectual Disability Defined

Intellectual Disability is diagnosed when all the following are present:

- The individual exhibits significant deficits in intellectual functions involving reasoning, problem solving, planning, judgement and more.
  - Confirmed via cognitive, developmental, and other testing. IQ<70.

- **AND**: The individual has significant needs regarding adaptive functioning abilities compared to same aged peers.

- **AND**: The onset of intellectual and adaptive deficits occur during the developmental period (APA, 2022).
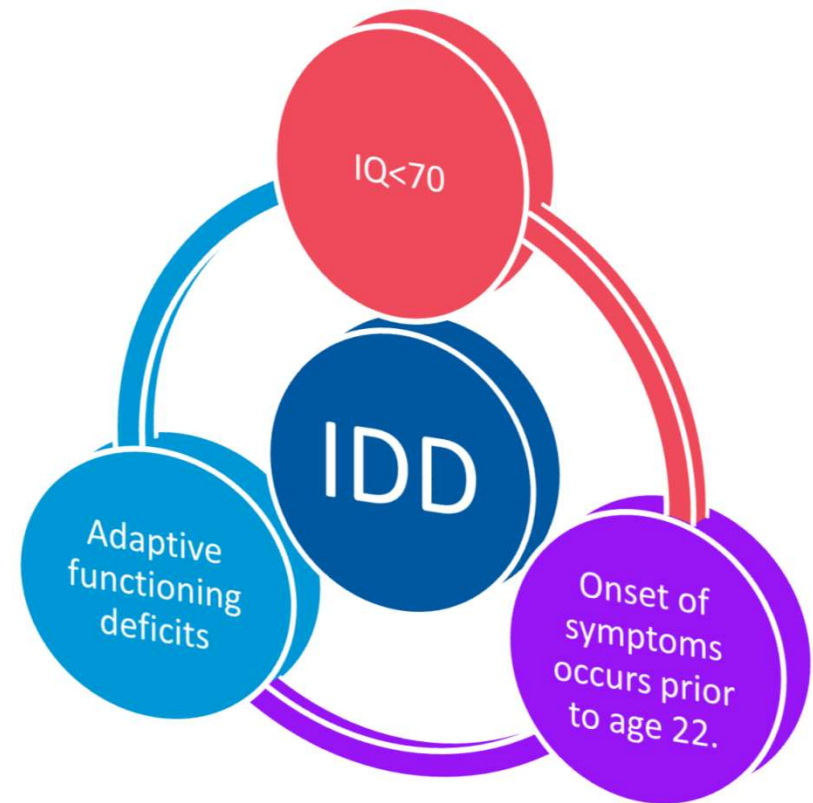
Classification of Intellectual Disability

Mild ~ 85%

Moderate ~ 10%

Severe ~ 4%

Profound 1%

IQ Score Bell Curve

Frequency of IQ scores

IQ SCORES	55	70	85	100	115	130	145
PERCENTILE	0.1%	2.3%	15.9%	50%	84.1%	97.7%	99.9%
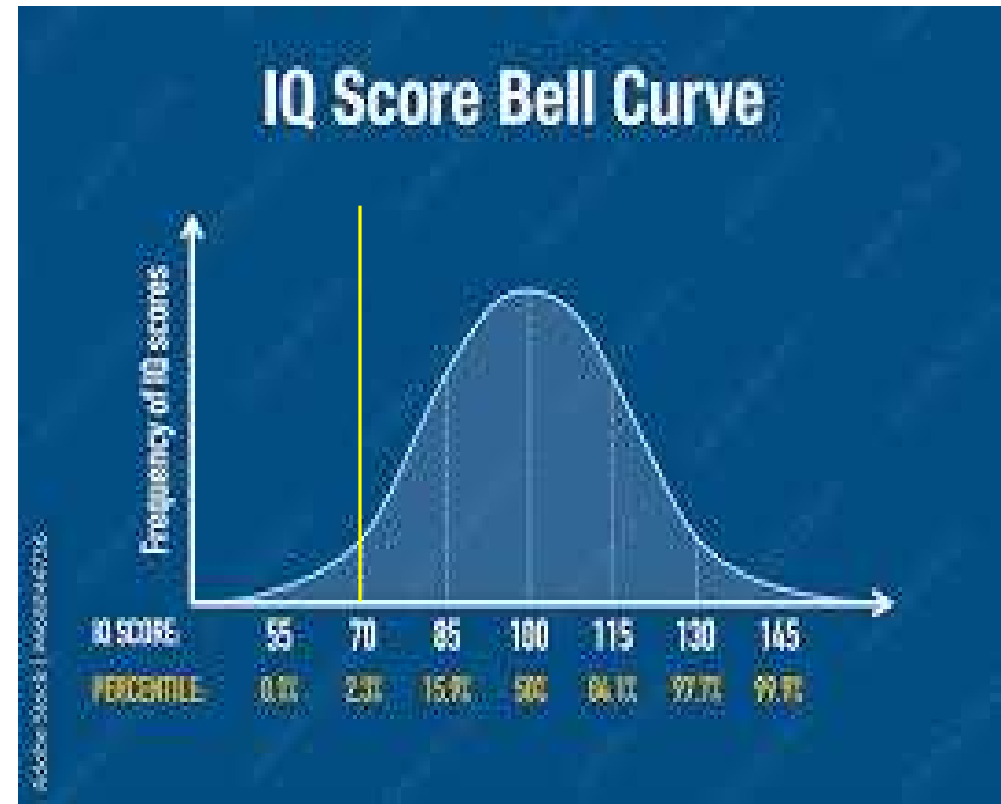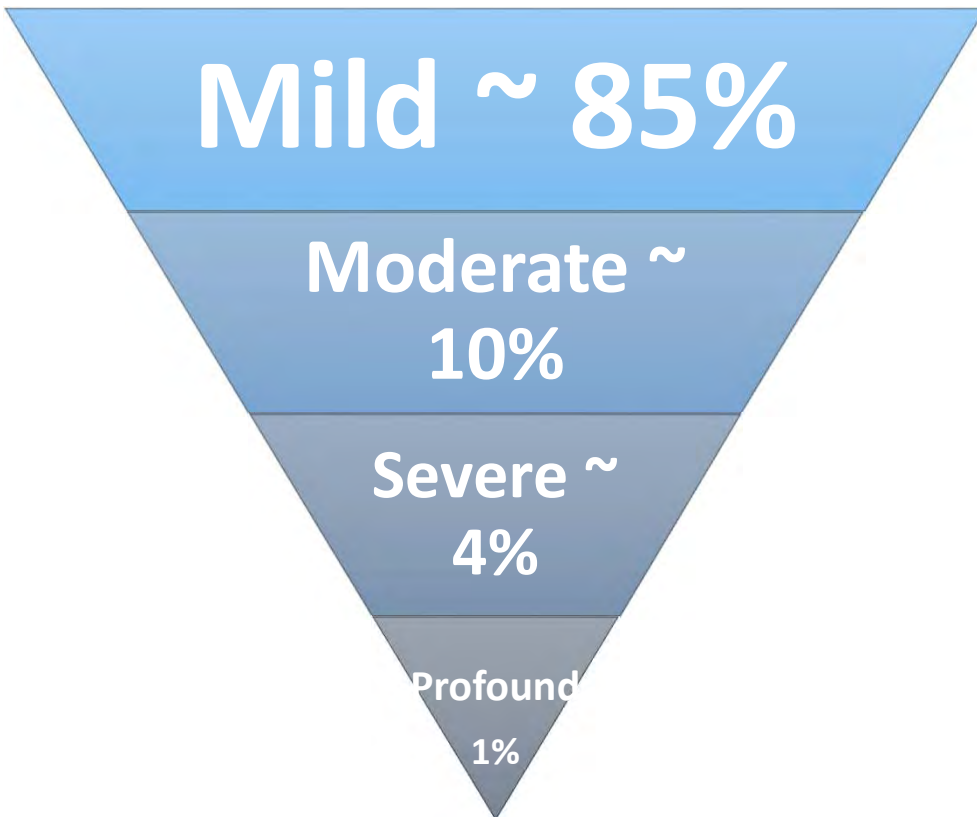
Pinals, 2021

How Common are Intellectual and Developmental Disabilities?

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- Estimated number of people with a Developmental Disability in the US- ~8 million.
  - An estimated 6.99% of children and 0.78% of adults in the United States have intellectual or developmental disabilities.
  - Based on those estimates, there were 7.3 (~2.4%) million people with IDD in the United States in 2019.
- Of the people with IDD in the US, an estimated 22% or 1.58 million people are known to state IDD agencies (RISP, 2019).
- During 2019–2021, the prevalence of any diagnosed developmental disability in children aged 3–17 years increased from 7.40% in 2019 to 8.56% in 2021.
- Prevalence numbers are constantly being updated
  - New research emerges/post-Covid world.
- Difficulty in research= difficulty to fund treatment.

Issues and Advocacy in ID/DD Research-"Nothing About Us, Without Us"

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- AAIDD's journal devoted the September 2023 volume, to the inequity and poor representation of IDD in research
  - Reliance on the medical model that utilizes categorical diagnoses that are not equal and should not be compared.
    - Autism Spectrum Disorder (ASD) is a spectrum with a wide range of abilities making people with the same dx categorically homogenous.
    - Intellectual Disability-Mild, moderate, severe, profound- Research tends to categorize together.
    - Down Syndrome v the presence of mosaicism- represents a potential spectrum but research does not tease out.
    - Cancer v no cancer, Pregnant v not pregnant, diabetic v not; either you are positive or negative for a dx.
  - Lack of diversity among recruitment for research AND researchers.
    - "Inequitable practices in research in IDD, not only fail to reduce disparities in healthcare or education for people with IDD, but may actually exacerbate those healthcare and education disparities, which is clearly counter to the goal of improving wellbeing in intellectually disabled people" (Kover & Abbeduto, 2023)
    - **"Dominant Culture"- often race and ethnicity is not reported in IDD research and uses potentially bias measurement tools.**
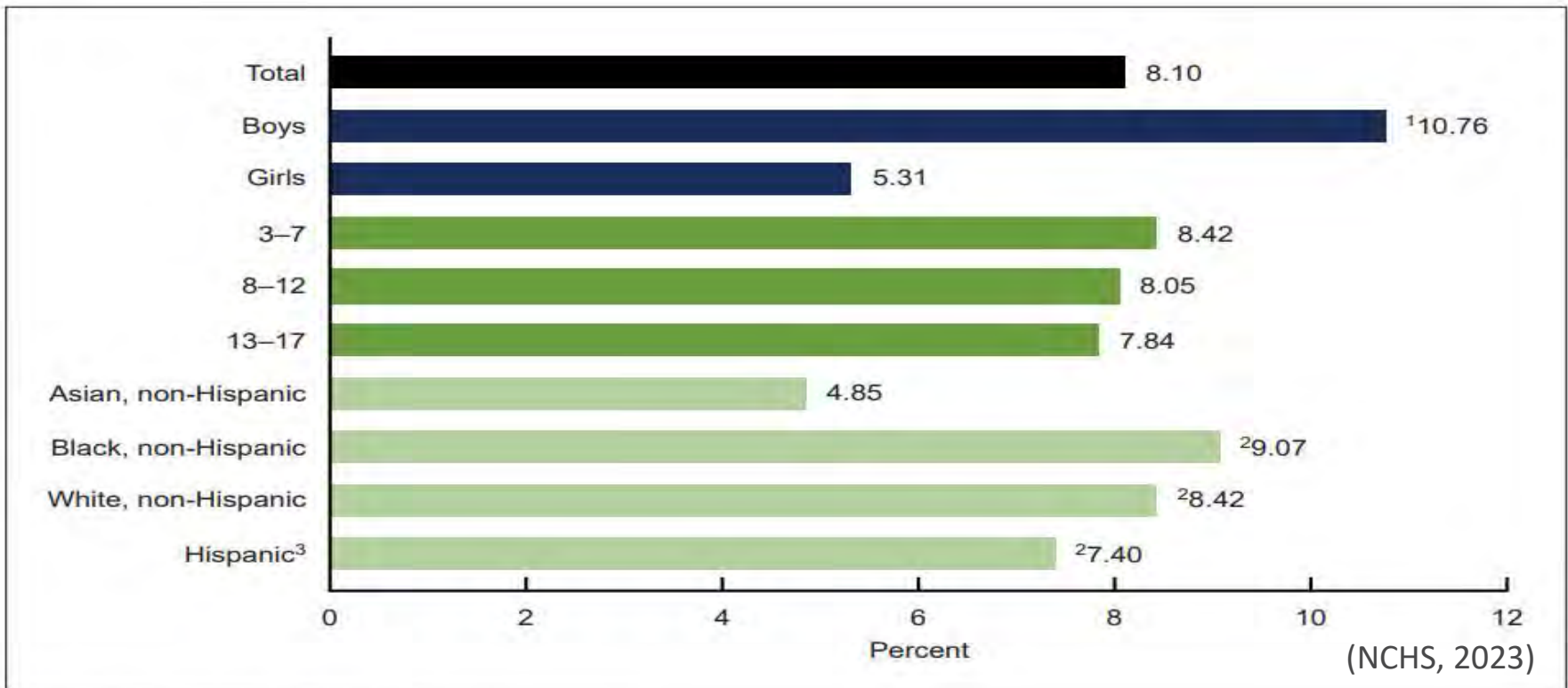
Representation in Research is Vital to Change Outcomes

Figure 1: Percentages of Health Outcomes by Ethnicity among Adults with IDD
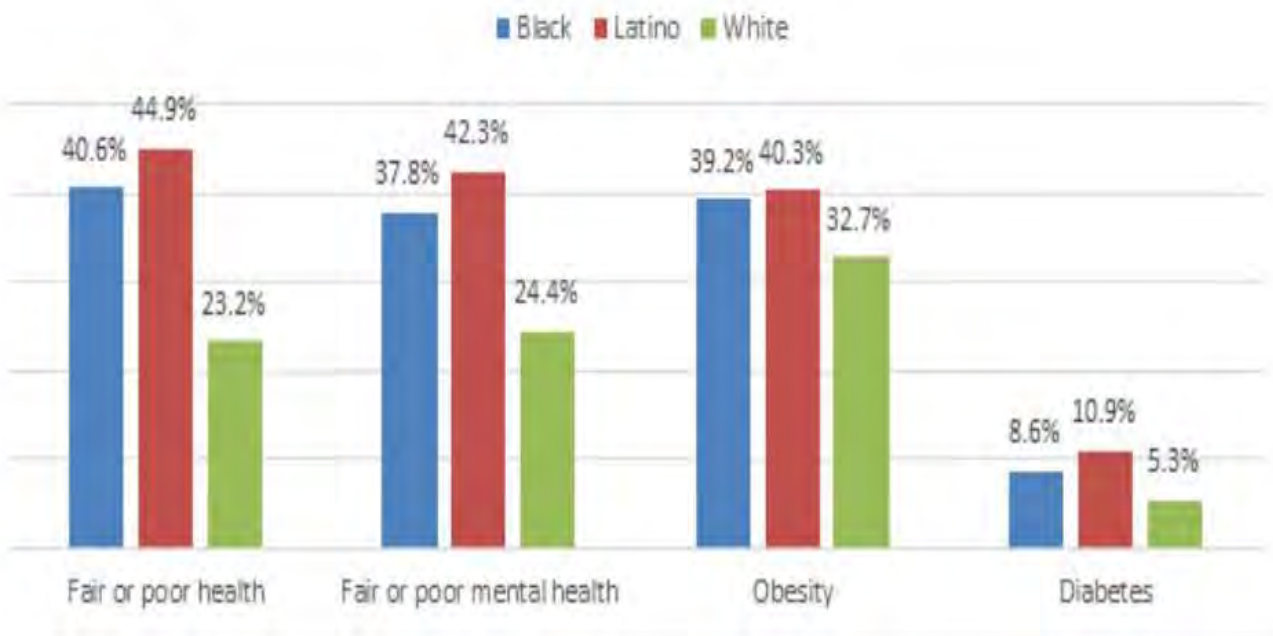
- The table shows research findings that indicate poorer outcomes for minorities with IDD.
- Some health research shows a turn toward better health outcomes for minorities. Per NIH(2019), Black and Latino women with IDD had higher rates of mammography versus white women with IDD.
- Progress made in general- Women with IDD are receiving mammography at higher rates than women that do not have IDD (76% v72% nationally)

Prevalence of Children 3-17 Diagnosed with a Developmental Disability

(NCHS, 2023)

[1]Significantly different from girls ($p < 0.05$).
[2]Significantly different from Asian, non-Hispanic children ($p < 0.05$).
[3]Children of Hispanic origin may be of any race.
NOTES: Developmental disability includes autism spectrum disorder, intellectual disability, and any other developmental delay. Estimates are based on household interviews of a sample of the U.S. civilian noninstitutionalized population. Access data table for Figure 2 at: https://www.cdc.gov/nchs/data/databriefs/db473-tables.pdf#2.

Prevalence of Children 3-17 Diagnosed with an Intellectual Disability

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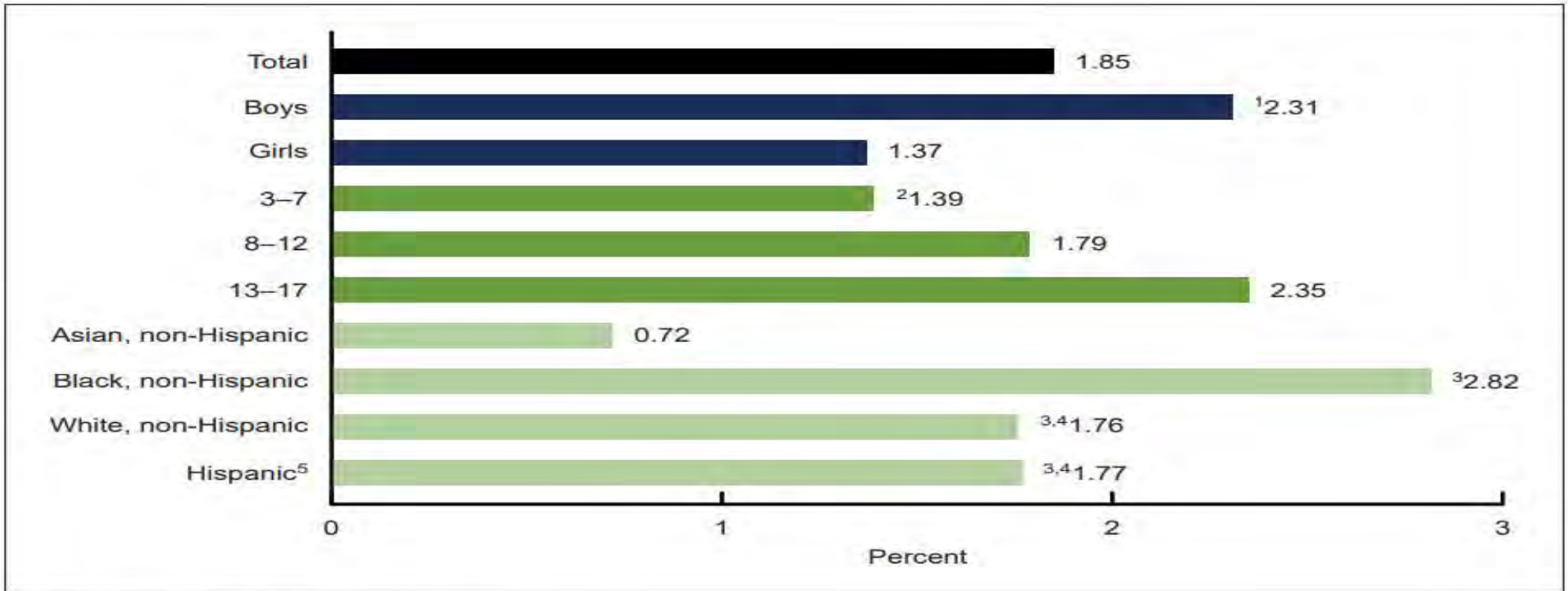
¹Significantly different from girls ($p < 0.05$).
²Significant linear trend by age group ($p < 0.05$).
³Significantly different from Asian, non-Hispanic children ($p < 0.05$).
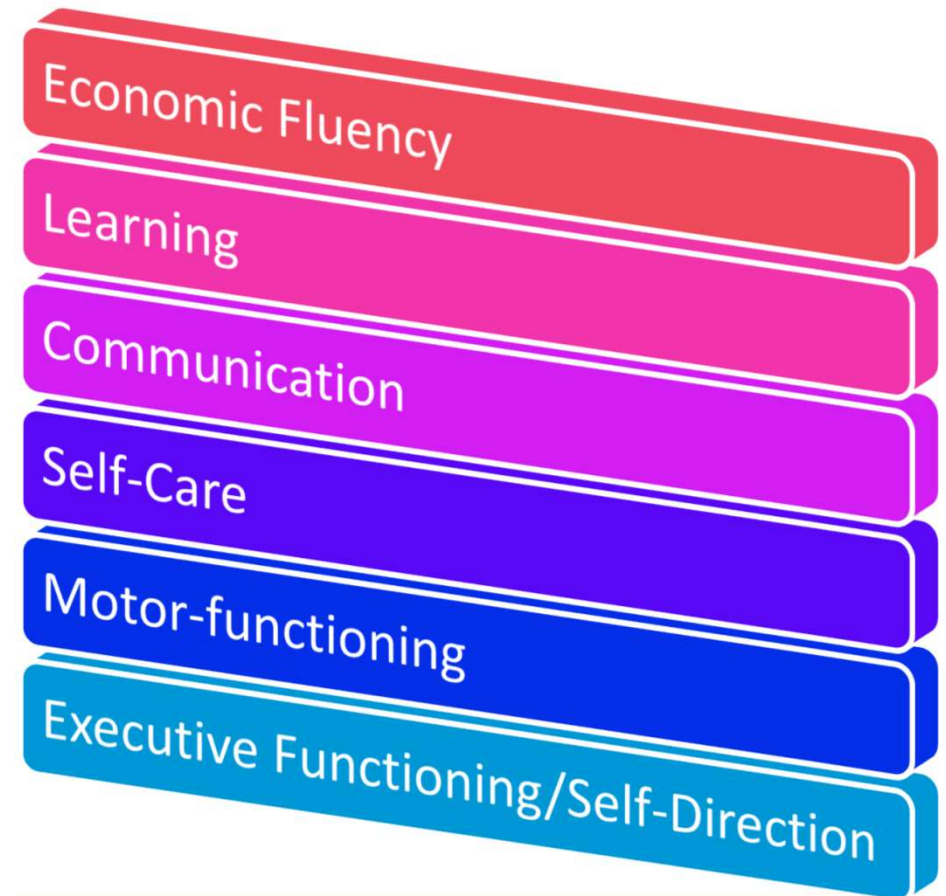⁴Significantly different from Black, non-Hispanic children ($p < 0.05$).
⁵Children of Hispanic origin may be of any race.
NOTES: Estimates are based on household interviews of a sample of the U.S. civilian noninstitutionalized population. Access data table for Figure 3 at:
https://www.cdc.gov/nchs/data/databriefs/db473-tables.pdf#3.

Most Common Diagnoses and Areas of Need

DEVELOPMENTAL DISABILITIES

- Intellectual Disability
- Down Syndrome
- Fragile X Syndrome
- Cerebral Palsy
- Attention Deficit Hyperactivity Disorder
- Autism Spectrum Disorder
- Fetal Alcohol Syndrome
- Epilepsy

- Economic Fluency
- Learning
- Communication
- Self-Care
- Motor-functioning
- Executive Functioning/Self-Direction

Risk Factors and Causes

Pre-natal
- Genetics
- Infection
- Exposure to substances

Labor/Delivery
- Exposure to Herpes
- Hyperbilirubinemia
- Hypoxia

Post-natal
- Failure to Thrive
- Lead Poisoning
- Malnutrition
- Impoverished/abusive environment
- Exposure to toxins

Unaware of pregnancy/dangers/ positive self-care

Parental blame/guilt

Burden of pathology on caregiver

Physical Health Co-Morbidities of I/DD

- Life expectancy increased into the 60s generally speaking(Pimlott, 2019).
    - Aging with I/DD is a relatively new concept
- Chronic Health diagnoses compared to non-I/DD population (Krahn & Fox, 2014)
    - Diabetes 5X
    - Arthritis almost 2X
    - Asthma 2x
    - Cardiovascular disease 2X
    - Health behaviors are the likely cause, not I/DD.
- Engage the individual with healthy lifestyle choices.
- Make them the center of the discussions.
- They make their own decisions; we can shape healthy habits and model positive behaviors/lifestyle.
- Diagnostic overshadowing- Diabetic psych/IDD patient in the

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Aspiration

Bowel Obstruction

Dehydration

Seizures

Infection/Sepsis

(King, 2023)

Physician and Nurse Training

- Lack of trained physicians, specialists, and supports. A study surveyed physicians on their knowledge of ADA and care of those with IDD (NIH, 2022).

  - 36% reported little to no knowledge of ADA

  - 41% attributed this to lack of formal education.

  - 68% of the physicians then believed they were liable for lawsuits due to non-compliance with ADA (passed in 1990).

  - Nurses in the US have historically no foundational education.

    - Developmental Disability Nurses Association (DDNA) founded in 1992- post-education/RN certification.

  - Lack of formal education leads to misperception, diagnostic overshadowing, poor treatment outcomes.

    - "Nurses must be aware that PWIDD may have differing presentation modes which may be interpreted as simply behavior challenges" (Fischer, 2022).

Co-occurring Behavioral Health Prevalence Data

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- "START (**Systemic, Therapeutic, Assessment Resources and Treatment**) a mental health crisis intervention tertiary care program provided across the U.S. The individuals are clinically referred and are young on average (27), identified as having mental health crisis service needs."

- Charlot et al, (2021) studied over 4000 people with IDD along with a sample of people with Down Syndrome report:

Mental Health Diagnosis	Population Group		
	IDD with DS (Charlot, 2021)	No DS with IDD (Charlot, 2021)	United States (NAMI, 2024)
Anxiety Disorders	18.8%	15.1%	19.1%
ADHD	11.9%	27.5%	Dev. Disability
Autism Spectrum Disorder	18.8%	39.7%	Dev. Disability
Bipolar/Related Disorders	6.9%	16.4%	2.8%
Depressive Disorders	26.7%	21.6%	8.3%
Disruptive Impulse Control	10.9%	19.8%	N/A
Trauma and Stressor Disorder	5.9%	10.6%	3.6%
Schizophrenia Disorders	5.9%	14.8%	<1%

Additional Findings from Charlot, (2021)

Service/ Diagnosis	IDD with Down Syndrome	No DS with IDD
Psychiatric inpatient within 1 year		
Yes	15.8%	34.9%
No	84.2%	65.1%
ED Visit within 1 year		
Yes	26.7%	42.8%
No	73.3%	57.2
Psychotropic Medications		
Yes	65.3%	83.5%
Average number of meds rx	2.4	3.2

Medical Condition	IDD with Down Syndrome	No DS with IDD
Neurologic	16.8%	21.9%
Gastrointestinal	17.8%	14.0%
Endocrine	25.7%	11.7%
Cardiovascular	16.8%	9.6%
Obesity	7.9%	6.7%
Pulmonary	9.9%	6.4%
Immunology/Allergy	7.9%	6.2%

Aging and Dementia Associated with Down Syndrome

- Common aged-related medical conditions (NDSS.org, 2024):

- Vision loss

- Hearing Loss

- Hypothyroidism

- Obstructive Sleep Apnea

- Osteoarthritis

- Cervical Spine Disease

- Osteoporosis

- Celiac Disease

- Alzheimer's Disease

- 50% born with congenital heart defect

- Experience "accelerated aging" in 40s and 50s

- Lifespan reaching into the 60s

- Seeing rising rates of Alzheimer's Disease
  - Due to a gene carried by the 21st chromosome
    - Produces amyloid protein thought to be responsible for Alzheimer's Disease.
    - Build-up of protein seen in almost all over 40 with DS.
    - 30% with DS have AD in their 50s.
    - 50% with DS have AD by the time they reach 60.
    - 0.68% have dementia in the general world population (WHO, 2024).

Purple Alert/MVP Alert

When things go as they should

- Florida- Signed by Gov. DeSantis in 2023:

- 255 Purple alerts issued
  - 250 developmentally disabled adults were successfully found
  - Very similar to better known amber/silver alert systems
  - Allows local LE to broadcast via cell/smart phones, radio, and other multimedia means of mass communication

When they do not

- New Jersey- Established Missing Vulnerable Person Alert System: 2016

- Per nj.com- 3 preventable deaths occurred in winter of 2019 alone as the alert system was never activated nor had it been inception
  - Public data could not be located

- NJ.gov webpage only provides the criteria for the alert to be issued- does not explain how/when it would be done

Public Venues- Magic with Thomas

Community and Home Safety Areas

- Elopement/Wandering/Darting

- Hypersensitivity to lights/noise

- Understanding social norms in public
  - Restrooms/etiquette
  - Standing in line
  - Paying for items
  - Social cues
  - Large travel venues-airports, bus, etc.
    - TSA/Immigration/Security

- Romantic Relationships
  - Varies state to state
  - Uses vague language

- Poor assumptions lead to poor outcomes
  - The firepit story

Safety in a Home Environment

MAKING MODIFICATIONS TO YOUR HOME CAN HELP:

Improve Quality of Life

Enhance Safety

Promote Independence

Reduce Costs

- All settings are unique

- Rural/Suburban/Urban- differences in dangers and culture- San Antonio story

- Group home/private home/supported housing

- All settings contain dangers
    - Natural Gas, Hot water Heater, electrical, plumbing, chemicals/poisons, tools, the entire kitchen, stairs, locked doors, unlocked doors, medications, food allergies, pools, etc.

- Safety versus Human Rights- alarms, locks, cameras, etc.

Disability in the Criminal Justice System

Victimization of People with Disabilities by Type of Disability and Victimization[B1]
rate per 1,000 people with disabilities age 12 or older
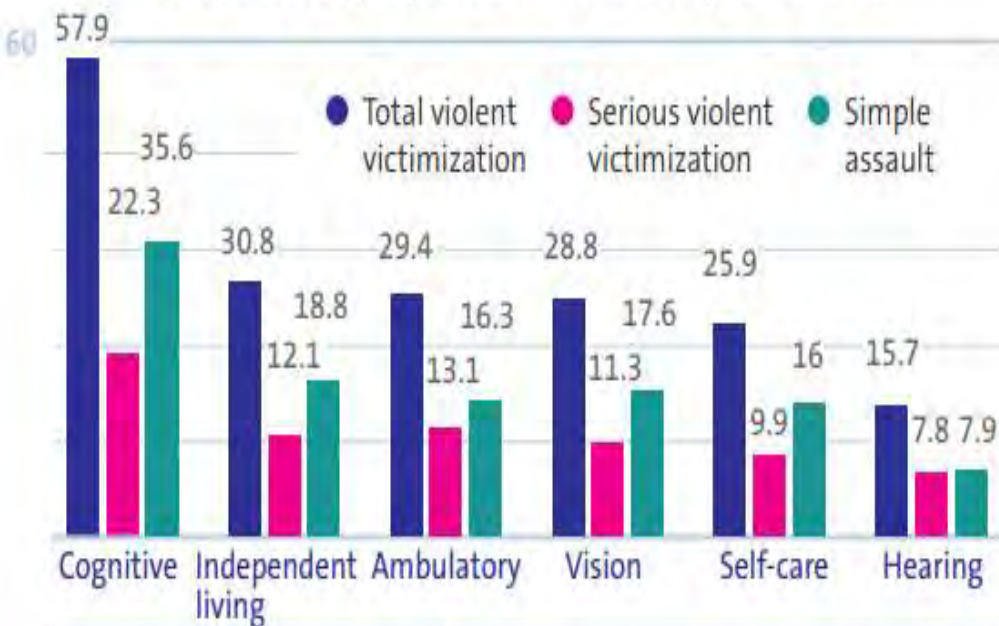
- People with disabilities can be easy targets to be victims of crime
- **Organized crime** utilizes people with intellectual disabilities to commit certain offenses as they are unaware, they are committing a criminal offense
- Is a sworn testimony valid for a jury?

Violent Victimization by Crime and Number of Disabilities[B]
rate per 1,000 people age 12 or older

Special Needs Registries
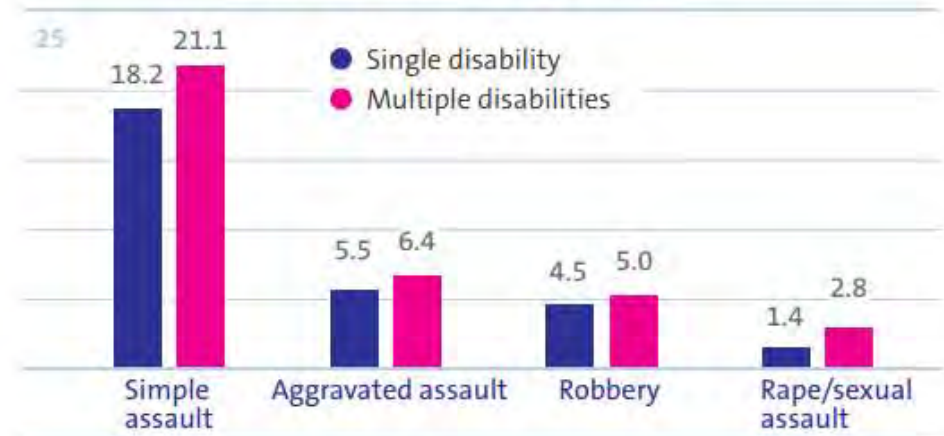
Disaster Planning

First Responder/Emergency Services

Trainings for Government Agencies

- Provide free trainings to local/county/state agencies

- Identified a need for knowledge of IDD/ASD

- Currently collaborating with:
  - Office of Emergency Management
  - County Medical Reserve Corps
  - County-level mental health agency
  - Prosecutor's office/Law enforcement

- Provides an opportunity for ACFC and PerformCare to provide a tangible service at no cost while improving the community and assisting community helpers all in one partnership

- Open for suggestions for additional partnerships and collaboratives

Educating and Exposing

Meet with your building manager about fire drills to make sure you are included.

FEMA

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Choose to live in a fully fire-sprinklered building for the best fire protection.

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ANCOR

ASAN — AUTISTIC SELF ADVOCACY NETWORK

NADD — An association for persons with developmental disabilities and mental health needs.

aaidd — American Association on Intellectual and Developmental Disabilities

NACDD — National Association of Councils on Developmental Disabilities

The Arc.

- "Each and every person in the United States has certain rights, not just those who make a threshold showing sufficient intellectual ability. When medical professionals and others fail to accept the rule of law, there is a dissonance between clinical practice and individual rights(Smith et al, 2012)."
  - Responding to emergency protocols calling for triage based on intellectual ability with comparisons made to end stage dementia patients.
  - Fett et al (2021) found many states violated federal law in their conduct during the public health emergency.
  - Non-verbal individuals had no ability to communicate their medical hx/current needs.
  - Medical and residential centers did not allow caregivers/family to visit creating intense isolation and mental health issues among this population.
  - Without access to medical hx during an emergency, physicians were tasked with making subjective decisions.
    - The authors conclude, "If a decision is to be made between 2 patients with similar presentations of symptoms, some triage protocols direct that an abled life is more worthy than a life with a disability."
  - Kuypers et al(2023) stated people with ID were 5 time more likely to die in the first 2 years of the pandemic.
    - Vaccinations were not prioritized for this population.
    - Many lived in communal residential settings, may have poor hygiene, etc creating a situation that has highlighted the global mistreatment of people with ID.

Technology

Communication

Tablets, PECS, predictive text

Home/Community
Safety

Monitoring equipment, telehealth monitoring

"Assistive technology promotes continuity and security, helps people exercise and realize their rights, increases relationships, and is a source of empowerment...as a result of these benefits, as well as the increased health, independence, and employment benefits associated with AT, assistive technology is not only cost-effective but also has a return on investment (ROI) of $9 for every $1 spent on AT" (WHO, 2022).

Movement

Wheelchair, tripod grip for writing, elevator

Self-Care

Use of reminder apps, physical fitness, adaptive toothbrush

Emerging Technologies

- AI-enabled cameras in South Korea to predict challenging behaviors before they happen (Ang, 2023)

- AI-enabled wearable sensors for children in educational settings to tailor education to the individual needs, not dx.

- Apple's Assistive Access simplifies iOS 16 for people with cognitive, and physical disabilities-
    - Think about Siri, Alexa, emoji only menus, etc.
    - Project Eurphoria/Parraton- Synthesizing your speech without you.

- Creation of learning opportunities- Virtual and Augmented Reality is now a reality.
    - 2-way learning- ADL skill building for those with ID/DD
    - Simulators being developed for professionals to experience life as someone with ID/DD.

Support System/Care Giver Challenges

- Family-is there any support in place?

- Specialized Healthcare/Dental
  - Major lack of providers

- Navigating Early Intervention/School
  - IEP/504 planning, testing, applying for DD services

- Socialization/sports/clubs/religious orgs-acceptance in general socialization programs.

- Behavioral/Mental health needs-dual-diagnosis

- Transition to adulthood/puberty/living situation/romantic relationships/new DD services application process

- End of Life issues

- Overall Theme- Very little control in own life

Bronfenbrenner's Bioecological Model of Human Development
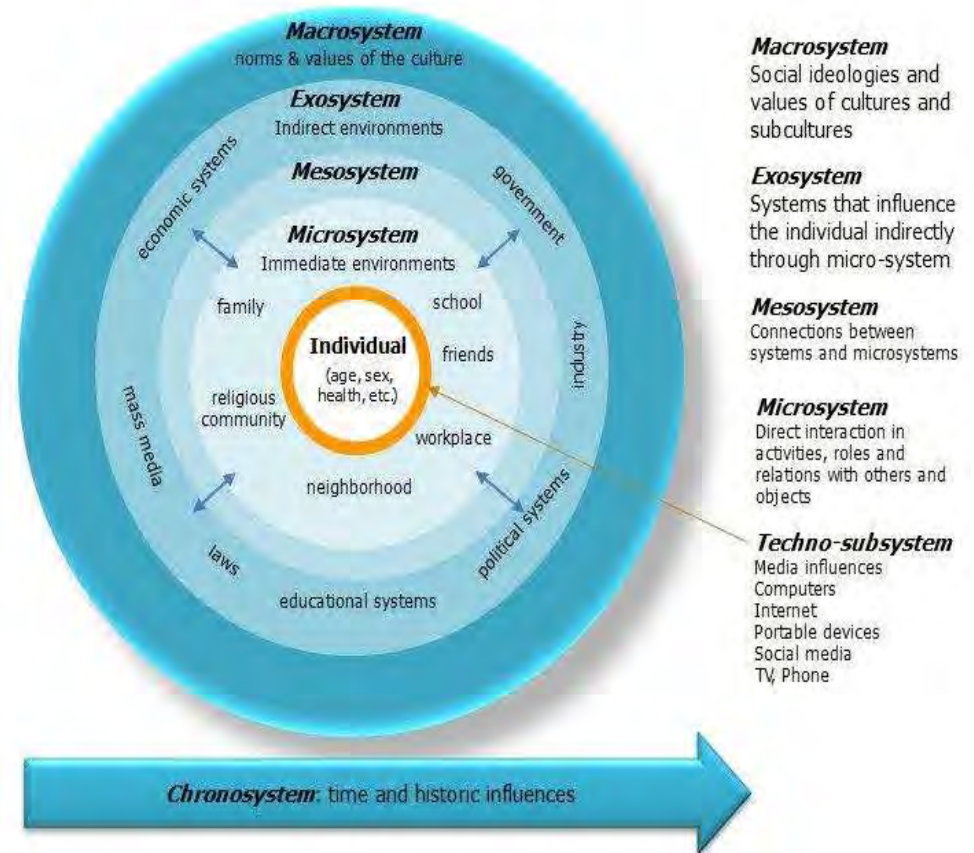
Questions, Comments, Concerns?

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Thank you for participating!

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