

Addressing Bias in Health Care

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Advocate
Medical
Group

Adult Down
Syndrome Center
1610 Luther Lane



Agenda

- Describe bias in health care and define ableism.
- Share clinical examples.
- Discuss strategies to overcome bias

Bias

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graph TD; Bias((Bias)) --- LPT[Lack of provider training]; Bias --- LDC[Lack of DS clinics]; Bias --- IMHS[Inadequate mental health services]; Bias --- Transplants[Transplants]; Bias --- DO[Diagnostic overshadowing]; Bias --- AD[Advance directives (DNR)];
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Lack of provider training

Lack of DS clinics

Inadequate mental health services

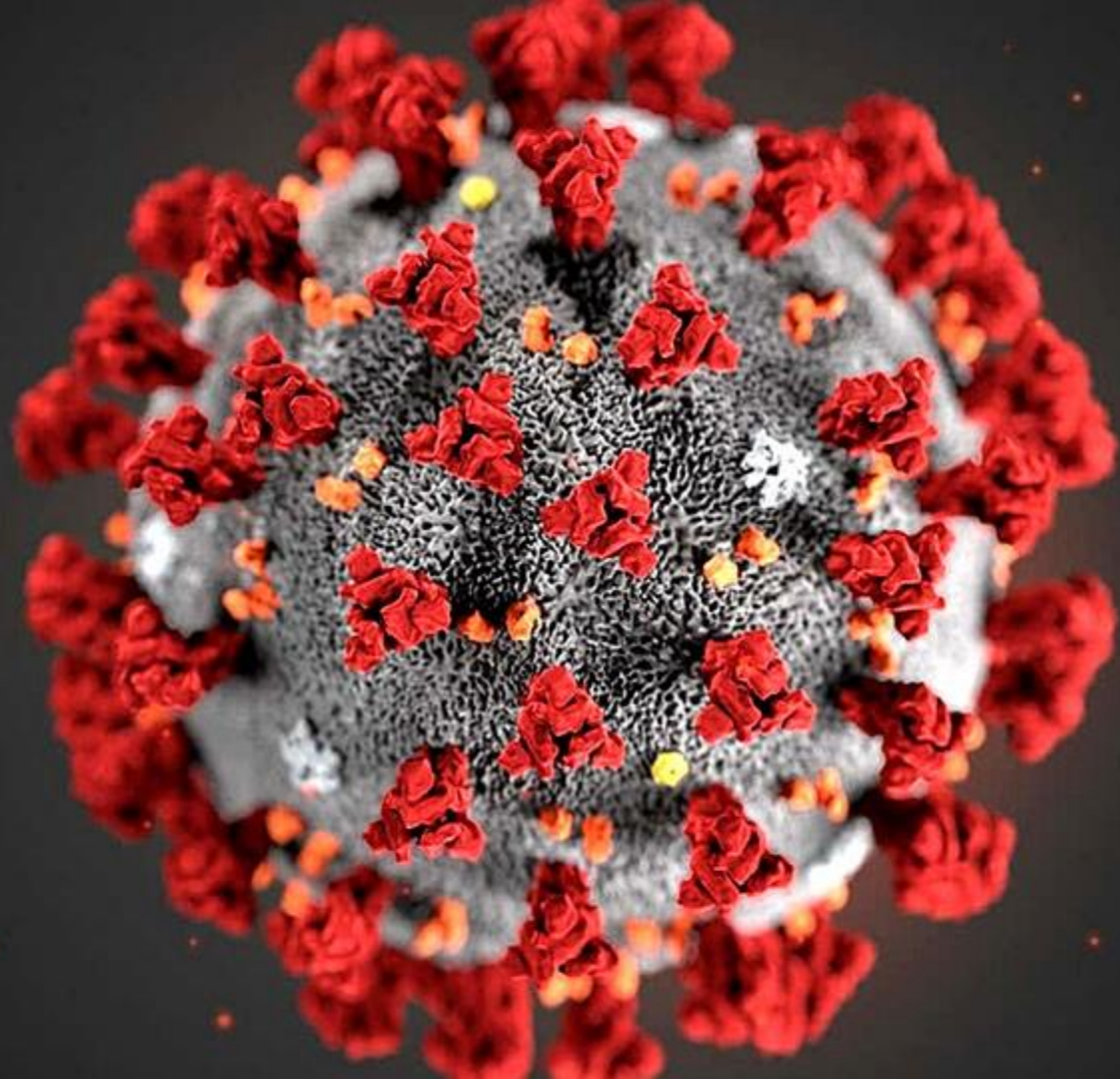
Transplants

Diagnostic overshadowing

Advance directives (DNR)

The Three Prong Approach

- Legislative
- Bedside advocacy
- Education





HHS Office for Civil Rights in Action



March 28, 2020

BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)

In light of the Public Health Emergency concerning the [coronavirus disease 2019 \(COVID-19\)](#), the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) is providing this bulletin to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.¹

In this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.

The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

"HHS is committed to leaving no one behind during an emergency, and this guidance is designed to help health care providers meet that goal," said Roger Severino, OCR Director. "Persons with disabilities, with limited English skills, or needing religious accommodations should not be put at the end of the line for health services during emergencies. Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism," Severino added.

Health care is at the bedside.



Ableism/disability bias

“The belief that the quality of life or worth of a person with a disability (PWD) is inherently less than that of a nondisabled person”

Ableism at the Bedside: People with Intellectual Disabilities and COVID-19

Caitlin Chicoine, MD, Erin E. Hickey, MD, Kristi L. Kirschner, MD, and Brian A. Chicoine, MD


People with intellectual and developmental disabilities have a higher risk of mortality from COVID-19 than the general population. Providers may assume that this is due to the burden of comorbidities for this population; however, the disparity in mortality persists even when controlling for comorbidities. We review the current policies and practices that may be contributing to this higher level of mortality. We contend that pervasive ableism among medical providers leads to a variation in the medical care options that are provided to people with intellectual disabilities and their families. Due to this bias, poor outcomes for people with intellectual disabilities may become a self-fulfilling prophecy. We make recommendations to address the modifiable factors that are contributing to the higher level of mortality for people with intellectual disabilities who are infected with COVID-19, provide strategies to combat ableism within the medical field, and discuss the unique role of the primary care physician as an advocate. (*J Am Board Fam Med* 2022;35:390–393.)

Keywords: Ableism, COVID-19, Down Syndrome, Intellectual Disability

DNR bias

- Down syndrome and COVID pneumonia
- 6.3 odds ratio of DNR status ordered at admission compared to those with COVID pneumonia without Down syndrome

Retrospective review of the code status of individuals with Down syndrome during the COVID-19 era

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Abstract

Code status is a label in the medical record indicating a patient's wishes for end-of-life (EOL) care in the event of a cardiopulmonary arrest. People with intellectual disabilities had a higher risk of both diagnosis and mortality from coronavirus infections (COVID-19) than the general population. Clinicians and disability advocates raised concerns that bias, diagnostic overshadowing, and ableism could impact the allocation of code status and treatment options, for patients with intellectual disabilities, including Down syndrome (DS). To study this, retrospective claims data from the Vizient[®] Clinical Data Base (used with permission of Vizient, all rights reserved.) of inpatient encounters with pneumonia (PNA) and/or COVID-19 at 825 hospitals from January 2019 to June 2022 were included. Claims data was analyzed for risk of mortality and risk of "Do Not Resuscitate" (DNR) status upon admission, considering patient age, admission source, Elixhauser comorbidities (excluding behavioral health), and DS. Logistic regression models with backward selection were created. In total, 1,739,549 inpatient encounters with diagnoses of COVID-19, PNA, or both were included. After controlling for other risk factors, a person with a diagnosis of DS and a diagnosis of COVID-19 PNA had 6.321 odds ratio of having a DNR status ordered at admission to the hospital compared with those with COVID-19 PNA without DS. The diagnosis of DS had the strongest association with DNR status after controlling for other risk factors. Open and honest discussions among healthcare professionals to foster equitable approaches to EOL care and code status are needed.

Physician perceptions

82.4%

- People with significant disability have worse quality of life than nondisabled people

18.1%

- Strongly agreed that the health care system often treats patients with a disability unfairly

56.5%

- Strongly agreed that they welcomed patients with disabilities into their practices.

**“I think you need a lot more care,
and I am not the doctor for you.”**

Lack of Down syndrome clinics and Lack of training

- 5% of adults
 - Down syndrome specialty clinics
- 95% of adults
 - Family physicians
 - Internists
 - Geriatricians
 - Other primary care providers

Diagnostic overshadowing

- "It isn't all Down syndrome."
- Pneumonia story
- "My 18-year-old son has been diagnosed with Alzheimer's disease."

Other forms of overshadowing

- Diagnosing mental illness without assessing physical health
- Assuming Alzheimer's disease for any decline
- Assuming all common conditions are inevitable
- Not considering possible underlying causes

Promoting health equity

Strategies

- Identify providers.
- Increase awareness in medical settings.
- Provide critical medical and functional information to providers.
- Share resources.

H My Health Passport H

! If you are a *health care professional* who will be helping me, **PLEASE READ THIS** **!**
before you try to help me with my care or treatment.

<p>My full name is: _____</p> <p>I like to be called: _____</p> <p>Date of birth: ____ / ____ / ____</p> <p>My primary care physician: _____</p> <p>Physician's phone number: _____</p>	<p>Attach your picture here!</p>
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This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

_____ may be easily referenced.

_____ completed: ____ / ____ / ____


Relationship: _____

_____ preferred language, sign language, _____
_____ ds, also state if extra time!


Advocate Medical Group
Adult Down Syndrome Center

I'm looking for...


Resource Library | All Resources




People with Down Syndrome




Families & Caregivers




Health Care Professionals




Events, Classes & Programs
[See the Schedule](#)




Video Gallery
[View All](#)



Related Organizations
[See Listing of Links](#)



Projects
[See Our Latest Projects](#)



News
[View News Articles](#)

Finding a provider

- **Down syndrome clinics**

- [NDSS](#)
- [NDSC](#)
- [GLOBAL](#)

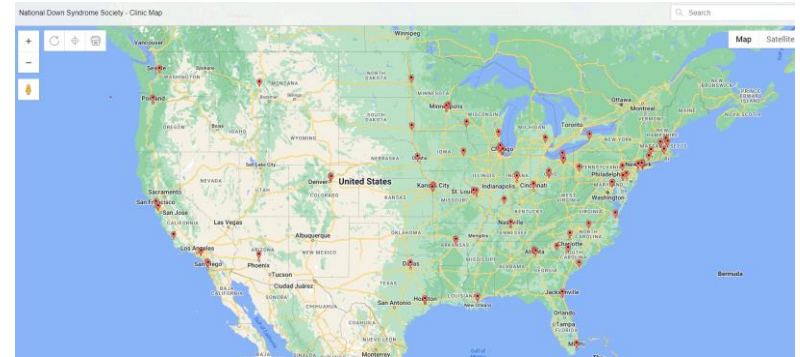
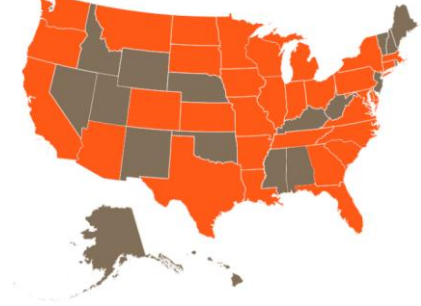
- **Down syndrome organizations**

- [NDSS](#)
- [NDSC](#)
- [GLOBAL](#)

See if there is a Down syndrome medical care center in your area by clicking on a state:

Alabama	Illinois	Montana	Rhode Island
Alaska	Indiana	Nebraska	South Carolina
Arizona	Iowa	Nevada	South Dakota
Arkansas	Kansas	New Hampshire	Tennessee
California	Kentucky	New Jersey	Texas
Colorado	Louisiana	New Mexico	Utah
Connecticut	Maine	New York	Vermont
Delaware	Maryland	North Carolina	Virginia
District of Columbia	Massachusetts	North Dakota	Washington
Florida	Michigan	Ohio	West Virginia
Georgia	Minnesota	Oklahoma	Wisconsin
Hawaii	Mississippi	Oregon	Wyoming
Idaho	Missouri	Pennsylvania	

States in orange have at least one Down syndrome medical care center, while states in brown currently have none.



Finding a provider

- **The Arc**
 - [Find a Chapter](#)
- **Mental health**
 - [Find a therapist](#)
- **University resources**
 - [University of Illinois Developmental Disabilities Family Clinic](#)
- **State resources**
 - [Department of Human Services in Illinois](#)

Finding a provider

- Qualities
 - A belief that all people with DS deserve the same respect and care provided to any patient
 - A willingness to listen to and learn from individuals with DS, families, care providers, and other health professionals
 - An understanding that problems that occur are not necessarily “just DS” (diagnostic overshadowing)

"I realized my real hopes for Josephine are that she feels loved ... and that she feels valued and respected... I realized that none of those things are dependent on specific abilities or disabilities. They are dependent on who she is as a person, and how we treat her as a person."

-K. Jane Lee, MD. *Catastrophic Rupture: A Memoir of Healing*

H

My Health Passport

H



If you are a **health care professional** who will be helping me,

PLEASE READ THIS

before you try to help me with my care or treatment.



My full name is: _____

I like to be called: _____

Date of birth: ____/____/____

My primary care physician: _____

Physician's phone number: _____



This passport has important information so you can better support me when I visit/stay in your hospital or clinic.

Please keep this with my other notes, and where it may be easily referenced.

My signature: _____ Date completed: ____/____/____

You can talk to this person about my health: _____

Phone number: _____ Relationship: _____



I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)



My brief medical history: (include other conditions (e.g. visual impairment, hearing impairment, diabetes, epilepsy) past operations, illnesses, and other medical issues)



My current medications are:

- _____
- _____
- _____
- _____



When I take my medication, I prefer to take it: (e.g. with water, with food)



I am allergic to: (list medications or foods, e.g. penicillin, peanuts)



If I am in pain, I show it by: (also note if I have a low/high pain tolerance)



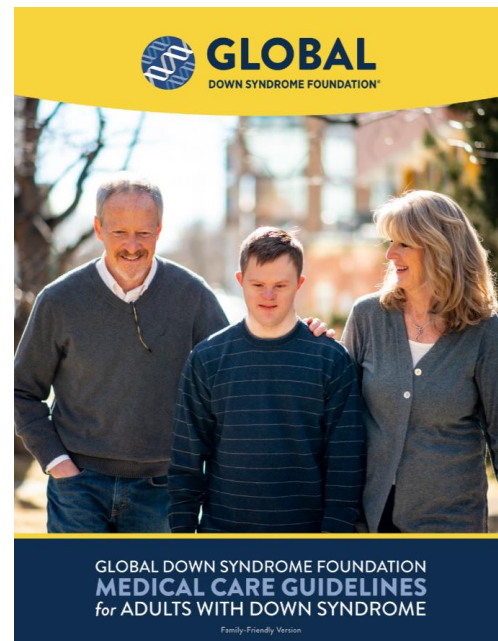
If I get upset or distressed, the best way you can help is by: (e.g. play my favorite music)



Supporting health care providers

Medical care guidelines and recommendations

- [Health Supervision for Children and Adolescents with Down Syndrome](#)
- [GLOBAL Medical Care Guidelines for Adults with Down Syndrome](#)
- [Down Syndrome Clinic to You \(DSC2U\)](#)



Professional organizations

- [Down Syndrome Medical Interest Group \(DSMIG-USA\)](#)
 - Membership
 - Annual Symposium
 - Free continuing education opportunities
 - Project ECHO



DSMIG-USA
Down Syndrome Medical Interest Group

FREE RESOURCES

SHARE WITH YOUR HEALTH CARE PROVIDER

- Down Syndrome Project ECHO is a monthly virtual meeting for health care providers to learn and seek input from expert providers.
- The DSMIG Speaker Series consists of webinars and enduring materials designed to share knowledge and experience related to the care of people with Down syndrome and clinical research related to Down syndrome.
- DSMIG vetted resources including articles and important guidelines related to child and adult health issues, and health utilization by people with Down syndrome.

find out more at:
DSMIG-USA.ORG

The graphic features a blue background with a megaphone icon on the right and a 'FREE RESOURCES' badge in the top left corner.



LATEST NEWS

DSMIG-USA wins award for Project ECHO program!

The graphic includes a photo of an award plaque on the right side.

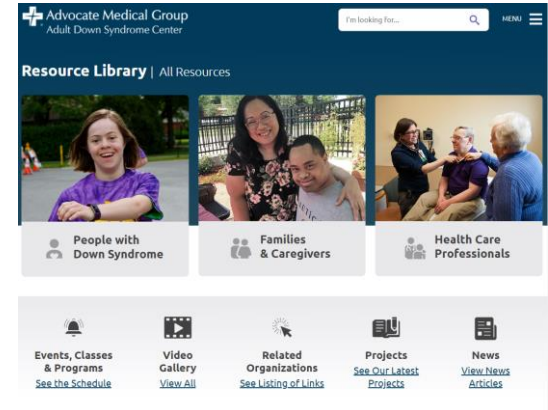
Professional organizations



- [National Task Group on Intellectual Disabilities and Dementia Practices \(NTG\)](#)
- [American Academy of Developmental Medicine and Dentistry \(AADMD\)](#)
- [American Association on Intellectual and Developmental Disabilities \(AAIDD\)](#)

Family resources

- [Adult Down Syndrome Center Resource Library](#)
- [NDSS Resources](#)
- [NTG Family Caregiver Resources](#)
- [Special Olympics Inclusive Health](#)



Resources

Health Adulthood



Alzheimer's Disease & Down Syndrome

ADULTHOOD, AGING
AGING, CAREGIVING, HEALTH



Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers

ADOLESCENCE, ADULTHOOD, AGING

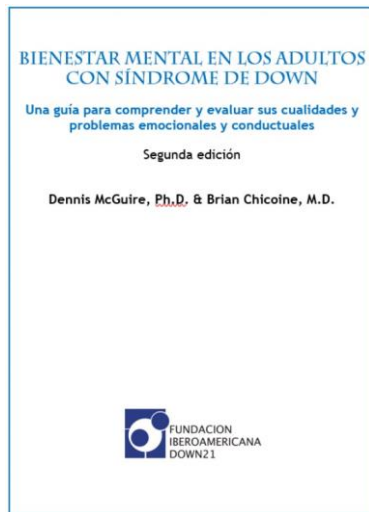
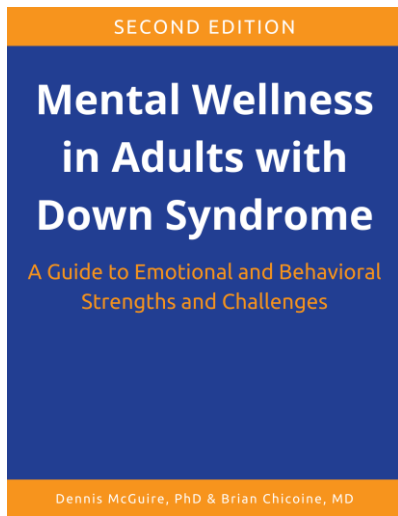


Behavior Challenges

ADULTHOOD, CHILDHOOD, SCHOOL-AGE
AGING, CAREGIVING, EDUCATION



Mental Wellness book



**Available as a free
PDF in English and
Spanish**

[Mental Wellness in Adults with Down Syndrome](#)

Keep in mind

- Observation
- Good concise history
 - **Limitations of appointment time**
- Understanding the differential

Takeaways

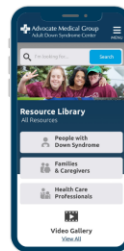
- Many people with DS do not have access to quality healthcare.
- Individuals with DS and their families can form a partnership with their healthcare providers by sharing information and resources.
- There are organizations that seek to support healthcare providers of people with DS.

Questions? Comments?

- [Resource Library](#)
- [Email List](#)
- [Facebook](#)
- [Instagram](#)

FREE HEALTH RESOURCES

*for people with Down syndrome, families
and caregivers, and professionals*



Resource Library



Find information on aging, puberty, mental health, self-talk, weight management, Alzheimer's disease, social skills, and more.

adscresources.advocatehealth.com

Facebook & Instagram



[@adultdownsyndromecenter](https://www.facebook.com/adultdownsyndromecenter)

Email List



www.eepurl.com/c7uV1v

 Advocate Medical Group
Adult Down Syndrome Center

Resources – Down syndrome

- **Specialty clinics for adults with Down syndrome (article)**
 - <https://doi.org/10.1002/ajmg.a.62169>
- **List of clinics (GLOBAL)**
 - <https://www.globaldownsyndrome.org/research-medical-care/medical-care-providers/>
- **List of clinics (NDSC)**
 - <https://www.ndsccenter.org/programs-resources/health-care/down-syndrome-clinics/>
- **List of DS organizations (GLOBAL)**
 - <https://www.globaldownsyndrome.org/about-down-syndrome/resources/local-organizations/>
- **List of DS organizations (NDSC)**
 - <https://www.ndsccenter.org/programs-resources/affiliate-organizations/local-and-national-support-networks/>

Resources – Finding a provider

- **The Arc**
 - <https://thearc.org/find-a-chapter/>
- **Find a mental health provider**
 - <https://www.psychologytoday.com/us/therapists?search>
- **List of DS organizations (NDSC)**
 - <https://www.ndsccenter.org/programs-resources/affiliate-organizations/local-and-national-support-networks/>

Resources – Sharing information

- **My Health Passports**
 - <https://adsresources.advocatehealth.com/information-forms-to-share-with-hospitals-and-clinics/>
- **Diagnostic overshadowing (article)**
 - <https://adsresources.advocatehealth.com/diagnostic-overshadowing-all-is-not-down-syndrome/>
- **Health care guidelines for children and adolescents with Down syndrome**
 - <https://adsresources.advocatehealth.com/health-supervision-for-children-and-adolescents-with-down-syndrome/>
- **Health care guidelines for adults with Down syndrome**
 - <https://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/>
- **Down Syndrome Clinic to You (DSC2U)**
 - <https://www.dsc2u.org/>

Resources – Organizations

- **Down Syndrome Medical Interest Group-USA (DSMIG)**
 - <https://www.dsmig-usa.org/>
- **DSMIG Project ECHO**
 - <https://www.dsmig-usa.org/Project-Echo>
- **GLOBAL Down Syndrome Foundation**
 - <https://www.globaldownsyndrome.org/>
- **LuMind IDSC Foundation**
 - <https://lumindidsc.org/>
- **National Down Syndrome Society**
 - <https://ndss.org/>
- **National Down Syndrome Congress**
 - <https://www.ndscenter.org/>

Resources – Organizations

- **National Task Group on Intellectual Disabilities and Dementia Practices (NTG)**
 - <https://www.the-ntg.org/>
- **American Academy of Developmental Medicine and Dentistry (AADMD)**
 - <https://www.aadmd.org/>
- **American Association on Intellectual and Developmental Disabilities (AAIDD)**
 - <https://www.aaid.org/home>
- **NTG Family Caregiver Resources**
 - <https://www.the-ntg.org/family-caregiver-resources>
- **Special Olympics Inclusive Health**
 - <https://www.specialolympics.org/what-we-do/inclusive-health?locale=en>