

COVID-19 and the Disability Community

Presented by The Arc of Pennsylvania



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Overview

- Barriers to Inclusion and Participation
- Health Care Access Challenges
- Health Risks for People with Disabilities
- Disparities in the COVID-19 Response
- Data Review
- Mitigation Efforts to Address Disparities



1 in 4 adults in the United States has a disability

A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).

- Centers for Disease Control and Prevention

CDC data to on disability status of U.S. adults shows that:

- 12.0% of adults have a cognitive disability
- 5.9% of adults have a hearing disability
- 12.8% of adults have a mobility disability
- 5.0% of adults have a vision disability
- 3.8% of adults have a self-care disability
- 7.0% of adults have an independent living disability

[Disability and Health Data System \(DHDS\) Data Guide Status and Types | CDC](#)

People with disabilities are a diverse group of individuals with a wide-range of healthcare and support needs.

40.9% of people with a disability
report **fair or poor** self-rated health
compared to
9.1% of people without a disability.

Individuals with disabilities experience poorer health compared to those without disabilities:

- **15.8%** of people with a disability have had diabetes compared to **7.2%** of those without a disability
- **6.6%** of people with a disability have had a stroke compared to **1.5%** of those without a disability
- **13.2%** of people with a disability have had COPD compared with **3.1%** of those without a disability
- **9.0%** of people with a disability have had cancer, compared with **5.3%** of those without a disability
- **42.0%** of those with a disability have had depression, compared to **11.6%** of those without a disability

Certain Medical Conditions and Risk for Severity of COVID-19

- **Cancer**
- Chronic kidney disease
- Chronic liver disease
- **Chronic lung diseases**
- Dementia or other neurological conditions
- **Diabetes (type 1 or type 2)**
- Down syndrome
- Heart conditions
- HIV infection
- Immunocompromised state (weakened immune system)
- **Mental health conditions**
- Overweight and obesity
- Pregnancy
- Sickle cell disease or thalassemia
- Smoking, current or former
- Solid organ or blood stem cell transplant
- **Stroke or cerebrovascular disease, which affects blood flow to the brain**
- Substance use disorders
- Tuberculosis

Barriers to Inclusion and Participation

The World Health Organization (WHO) describes barriers as factors in a person's environment that, through their absence or presence, limit functioning and create disability

Common Barriers to Disability Inclusion and Participation - WHO

- Attitudinal
 - Ableism, stereotyping, stigma, prejudice, and discrimination
- Communication
 - Experienced by people who have disabilities that affect hearing, speaking, reading, writing, and or understanding
- Physical
 - Obstacles that prevent access or block mobility, such as curbs and steps
 - Equipment designed without flexibility of needs (standing xrays, scales, examination rooms)
- Policy
 - Lack of enforcement or awareness of existing laws and regulations, e.g., the Americans with Disabilities Act (ADA)

Common Barriers to Disability Inclusion and Participation

- Programmatic
 - Factors that limit the effective delivery of healthcare programs, such as inconvenient scheduling and poor communication with patients
 - Provider's attitudes, knowledge, and understanding of people with disabilities
- Transportation
 - Lack of adequate and accessible transportation, interfering with a person's independence and participation
- Social Barriers
 - Social determinants of health, including lack of affordable and accessible housing, and lower rates of employment, education and income

Employment and Income as a Barrier

- The 2018 American Community Survey estimated that **37%** of working-age adults with disabilities are employed, compared with **76%** of people without disabilities (Winsor et al., 2020)
- **19.7%** of people with a disability have an income **under \$15,000** compared to **6.6%** of people without a disability (CDC DHDS)
- When people with disabilities are employed, they are more likely to **work part time (28%)** compared to people without disabilities (**15%**) (Bureau of Labor Statistics, 2020)
- For people with intellectual and developmental disabilities (IDD), the disparity in employment participation is even greater. Data from the National Core Indicators project suggest that in 2017–2018, only **18%** of working-age adults supported by state IDD agencies were **employed in a paid job** in the community (National Core Indicators, 2019)

Health Care Access Challenges

- People with disabilities have less access to adequate health care due to factors such as:
- Costs
 - **26.7%** of people with a disability could not see a doctor due to cost in the past 12 months compared to **10.1%** of people without a disability
- Health care provider stereotypes about disabilities
 - **82.4% of U.S. physicians** reported that people with significant disability have worse quality of life than nondisabled people
 - **Only 56.5% strongly agreed** that they welcomed patients with disability into their practice
- Lack of appropriate provider training
 - **Only 40.7%** of physicians were very confident about their ability to provide the same quality of care to patients with a disability

Health Care Access Challenges - Continued

- Lack of accessible medical facilities and equipment
 - Exam tables and chairs may not be adjustable
 - Scales may fail to accommodate wheelchairs or require a step up
 - People with visual disabilities or intellectual/developmental disabilities may not be able to access patient portals
- Communication barriers
 - Care after a medical visit may be hindered by materials that are not available in plain language or braille
 - Lack of accommodations, such as sign language interpreters

COVID-19 and People with Disabilities

People with disabilities have been differentially affected by COVID-19 because of three factors:

1. Increased risk of poor outcomes from the disease itself
2. Reduced access to routine health care and rehabilitation
3. Adverse social impacts of efforts to mitigate the pandemic.

➤ Increased Risk of Poor Outcomes from the Disease Itself

- [The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States | Catalyst non-issue content \(nejm.org\)](#)
- Study across 547 U.S. health care organizations found that individuals with intellectual disabilities are at substantially increased risk of dying from Covid-19.

“In this study, having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality.”

Patients with intellectual disabilities:

- Had higher rates of Covid-19 incidence than those without intellectual disabilities and with Covid-19 (3.1% vs 0.9%)
- Were more likely to be admitted to the hospital if diagnosed (63.1% vs. 29.1%)
- Who were diagnosed with Covid-19 had higher rates of ICU stay (14.5% vs. 6.3%)
- Were more likely to die following diagnosis of Covid-19 (8.2% vs. 3.8%)

Patients with intellectual disabilities (cont):

- Were less likely to be in a higher age group (1% over 80 and 18% from 60–80 compared with 5% and 25% in the general population, respectively)
- Were more likely to have a health care payer status associated with low socioeconomic status (44% vs. 28%)
- Had higher rates of all comorbidities other than cancer prior to Covid-19.

Certain Medical Conditions and Risk for Severity of COVID-19

- **Cancer** ← **All But**
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Risk of Poor Outcomes from COVID-19

- Individuals with intellectual and developmental disabilities are at a higher risk of severe disease and of dying from COVID-19 than those without such disabilities
- Psychological Distress: Activity restrictions can induce mental health stress - especially among those on the autism spectrum
 - [COVID-19 and people with intellectual disability: impacts of a pandemic \(nih.gov\)](#)

➤ Reduced access to routine health care and rehabilitation

- Telehealth provided opportunities to access care for some and posed additional challenges for others:
 - Blind/low vision: screen reader tools were not necessarily compatible
 - Cognitive disabilities: tools may be difficult to navigate
 - Deaf/hard of hearing: ASL interpreters or closed captioning unavailable
- Caregivers
 - Individuals have experienced disrupted access to caregivers
 - Lack of resources available to support family caregivers
- Interventions
 - Many interventions, including mental health & school-based, were not implemented due to reduced in-person work

Adverse Social Impacts of Efforts to Mitigate the Pandemic

- Unemployment:
 - By August 2020, one million U.S. workers with disabilities had lost their jobs
 - **1 in 5** workers with a disability compared to **1 in 7** workers in the general population affected
- Unmet Needs:
 - For some, the pandemic impacted transportation options and reduced access to medications, food and other basic necessities
 - Home and community-based service providers did not receive the level of federal pandemic assistance made available to other health care providers, and at least half of states saw permanent closure of HCBS providers

Disparities in the COVID-19 Response

- Lack of data
- Estimates of COVID-19 cases and deaths from nursing home data reflect just a fraction of the population with disabilities
- Data collection is a fundamental pillar of public health and lack of information perpetuates social injustice
- Inaccurate data on COVID-19 and vaccine rates can misguide public health approaches

Disparities in the COVID-19 Response

- Inaccessible testing and vaccination
- For some people who cannot drive due to a disability, drive-through testing created accessibility challenges
- Vaccine registration websites violated disability rights laws, creating inequity for people with disabilities
- States and territories varied in vaccine prioritization for the disability community
- Vaccination sites lacked accessibility and accommodations

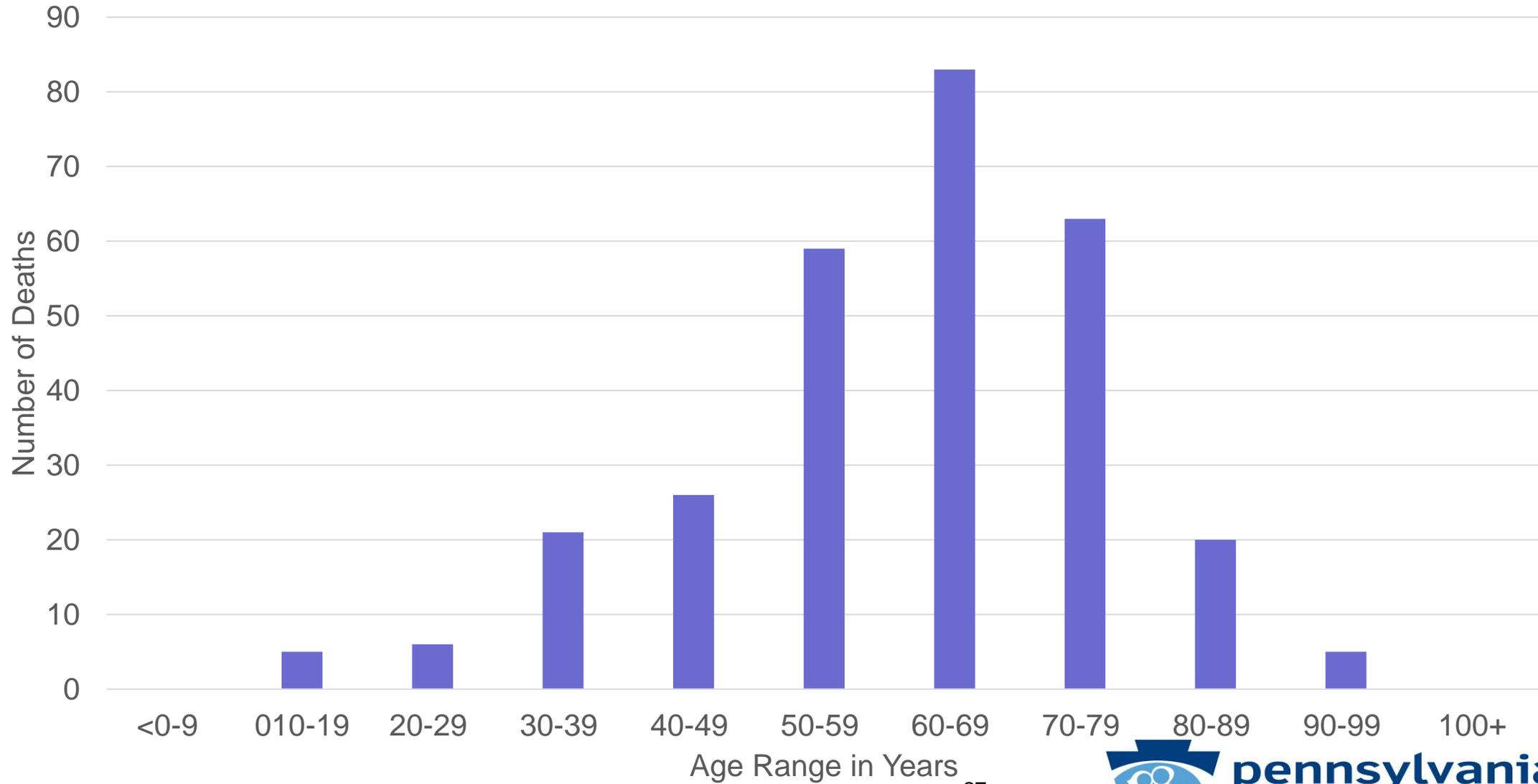
Disparities in the COVID-19 Response

- Obstacles to accessing information on pandemic
- Lack of captions or alternative text
- Difficult to find information relevant to variety of conditions
- Overwhelming and confusing information

ODP Covid-19 Data

- The total population of individuals registered with ODP during SFY 20-21 is 55,503 (based on a 6/30/2021 extraction date)
- As of 10/29/2021, 6,161 individuals have tested positive for COVID-19
- Since March 2020, 285 individuals registered with ODP have died as a confirmed result of COVID-19. In addition, there are 44 individual deaths where a final cause of death has not been determined but is suspected to be COVID-19 related.

Confirmed Deaths by Age Range



ODP Licensed Facilities

- COVID-19 Cases Since March 2020
- This data provide the total number of COVID-19 cases that have occurred in community-based residential settings licensed by DHS's Office of Developmental Programs.
- These include Community Homes for Individuals with an Intellectual Disability and Life Sharing Homes

	COVID-19 Positive Persons Receiving Services	COVID-19 Death Persons Receiving Services	COVID-19 Positive Staff
STATE TOTAL	3,840	170	7,612

ICF for Persons with Intellectual Disabilities

- COVID-19 Cases Since March 2020
- This data provide the total number of COVID-19 cases that have occurred in Intermediate Care Facilities where residents are funded by DHS's Office of Developmental Programs.
- Data does not include information from DHS' state centers

	COVID-19 Positive Persons Receiving Services	COVID-19 Death Persons Receiving Services	COVID-19 Positive Staff
STATE TOTAL	703	40	1,320

State Operated Intermediate Care Facilities

State Center	Current Census of Persons Receiving Services	Current Positive Cases Among Persons Receiving Services	Cumulative Positive Cases Among Persons Receiving Services	Deaths of Persons Receiving Services due to COVID-19	Current Census of Staff	Current Positive Cases Among Staff	Cumulative Positive Cases Among Staff
Ebensburg	180	8	127	Less than 5	681	40	470
Polk	147	Less than 5	160	Less than 5	503	6	365
Selinsgrove	182	9	137	Less than 5	665	76	474
White Haven	75	0	44	7	272	10	182

Analysis of Medicaid Data

- The University of Pittsburgh on behalf of DHS analyzed Medicaid data to examine the burden of covid-19 among PA Medicaid enrollees, including those with with intellectual and developmental disabilities and autism spectrum disorder.
- Explored associations between intellectual and developmental disabilities (IDD), and autism spectrum disorder (ASD) with COVID-19 diagnoses, hospitalizations, and death.
- Enrollees were further stratified based on whether they were receiving long-term care or were living in the community.
- In the cohort of 1,172,454 enrollees over age 20, **2.4%** (N = 33,128) received long-term care with the rest living in the community (N = 1,139,326)

Analysis of Medicaid Data

- About 12% of enrollees in the long-term care group were diagnosed with IDD, compared to 3.2% in the community.
- IDD enrollees in the long-term care group had significantly lower unadjusted rates of COVID-19 diagnoses (13.5% vs. 17.8%), hospitalizations (3.9% vs. 4.0%) and deaths (2.8% vs. 4.5%) compared to enrollees without IDD.
- In contrast, IDD enrollees in the community had significantly higher unadjusted rates for all 3 measures compared to other enrollees in the community

Analysis of Medicaid Data

- After controlling for demographic and health status variables, enrollees with IDD in the community (36,994) were significantly more likely to be diagnosed, hospitalized, and die with COVID-19 relative to other community enrollees (1,102,332).
- In long-term care, IDD enrollees were less likely to be diagnosed with COVID-19, but more likely to be hospitalized relative to other long-term care enrollees.

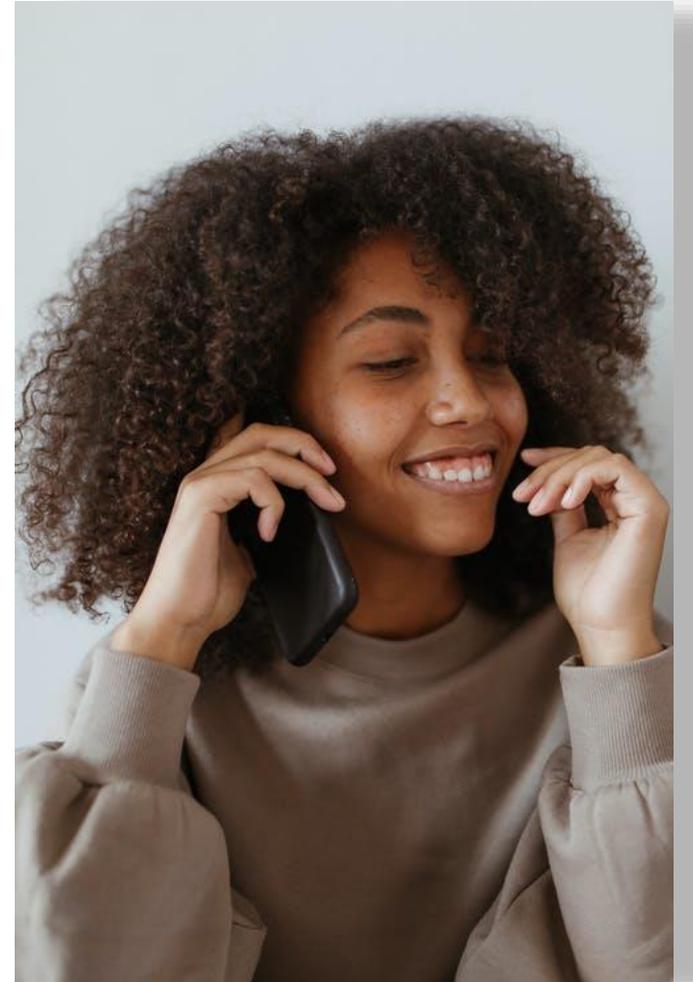
Analysis of Medicaid Data

- Between 1 and 2% of enrollees in the long-term care and community groups were diagnosed with ASD.
- Unadjusted rates of COVID-19 diagnoses, hospitalizations and deaths are relatively low among enrollees with ASD.
- Using multivariable models, the analysis did not detect any statistically significant positive association between ASD and the 3 COVID-19 measures of diagnosis, hospitalization and death.

Some mitigation efforts to address disparities

ODP Vaccination Call Center

- Established a call center for individuals with intellectual disabilities or autism and their families/caregivers to access the COVID-19 vaccine.
- Operated from April to June 30, 2021
- Supported through a partnership with Rite-Aid





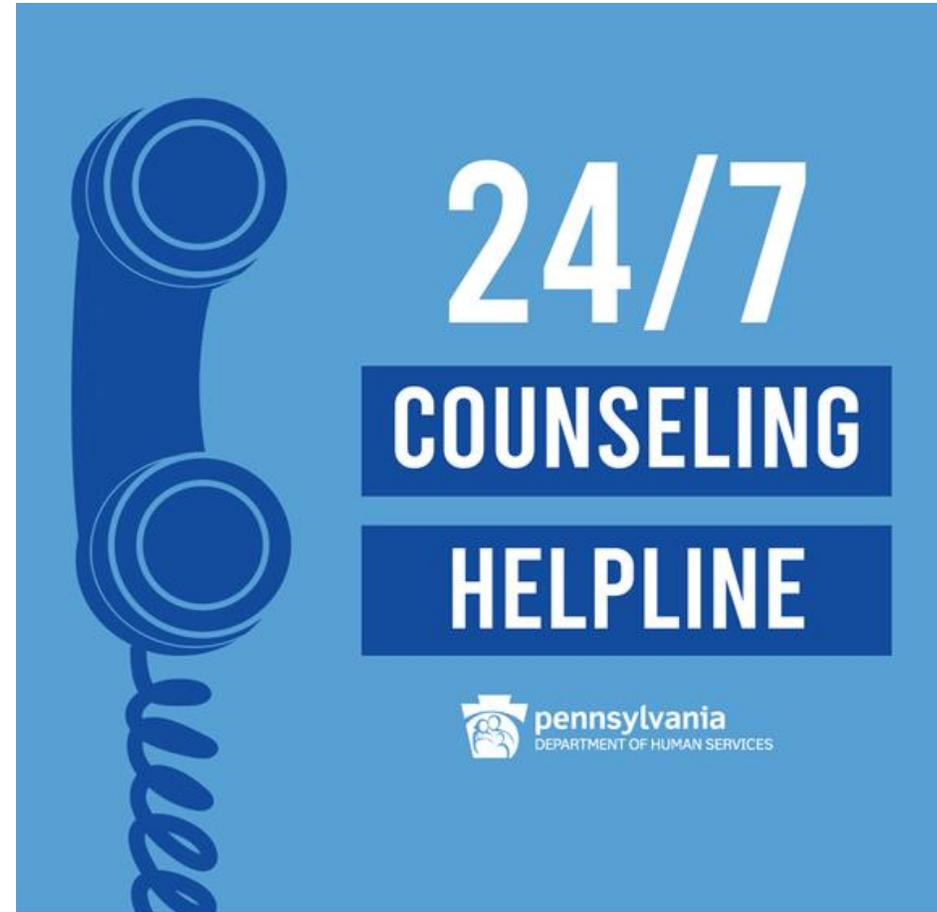
Autism and Intellectual Disabilities in Pennsylvania

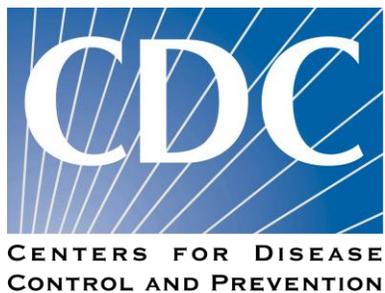
Health Care Quality Units
Autism Services, Education, Resources, and Training

- Health Care Quality Units (HCQUs)
 - <https://www.myodp.org/mod/page/view.php?id=7699>
- Autism Services, Education, Resources, and Training (ASERT)
 - <https://paautism.org/resource/coronavirus-resources/>

The Statewide Support & Referral Helpline

- The toll-free, round-the-clock support line is officially operational.
- Dial 1-855-284-2494.
- For TTY, dial 724-631-5600.





<https://www.cdc.gov/coronavirus/2019-ncov/index.html>



www.health.pa.gov



<https://www.myodp.org/mod/page/view.php?id=26808>



Additional References

- [Physicians' Perceptions Of People With Disability And Their Health Care \(healthaffairs.org\)](#)
- [Disability, Health Equity & COVID-19 \(nihcm.org\)](#)
- [Telehealth and Disability: Challenges and Opportunities for Care - National Health Law Program](#)
- [New obstacles and widening gaps: A qualitative study of the effects of the COVID-19 pandemic on U.S. adults with disabilities – ScienceDirect](#)
- [COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State - PubMed \(nih.gov\)](#)