



**The Arc**<sup>™</sup>

*Pennsylvania* ————— Summer 2022 - Volume XXIII, Issue 1

# Pennsylvania Message

## THE ARC OF PENNSYLVANIA: COVID-19 HEALTH DISPARITIES AMONG PEOPLE WITH DISABILITIES INITIATIVE

COVID-19 and the pandemic have had an unimaginable, tragic impact on our world. That impact was felt to a very serious degree by people with disabilities. Overall, people with disabilities became more ill; were hospitalized more; and had many deaths. There are many reasons for these sad facts. One reason is that public health and healthcare systems' response to COVID-19 was often not inclusive or accessible to people with disabilities. The system was not fully prepared to help people with disabilities during these extreme emergency conditions. The Arc of Pennsylvania is working on these critical issues. Our project, "COVID-19 Health Disparities Among People with Disabilities" is funded through the Pennsylvania Department of Health.

There were and are many disparities faced by people with disabilities during the pandemic. When we use the word "disparities" we mean that, overall, people with disabilities had more severe hardships from the pandemic than did most other groups, communities, and populations. This was especially true for people with disabilities from minority groups and communities or rural areas of the state.

Our project has three main, connected parts. First, is to learn about health barriers directly from people with disabilities and those that support them in the communities where they live. Our way to learn about peoples' pandemic experiences focused on "Listening Tours." The Listening Tours were created to make space for people with disabilities and allies to share their experiences, both bad and good.

During Listening sessions, we asked people about strengths, problems, and disparities that they saw or experienced. People in the groups were able to listen

**“ People who had the most resources were able to do that [get vaccinated], but the ones that didn't, the have-nots ... we just had to just wait, we'd wait and wait.”**

*— Participant with lived experience*

**COVID-19 Barriers to Health Care**

- Location** (Building icon): Vaccines are mostly available at chain pharmacies and large hospitals that may not be present in minority communities.
- Language** (Language icon): Government websites used to find vaccines often lack translation options. Vaccination clinics have limited translation help available.
- Accessibility** (Wheelchair icon): People with disabilities reported not knowing how and where to get a vaccine. Information is often not provided in an accessible and easily understood format.
- Availability** (Medical clipboard icon): There are 54% fewer physicians in rural Pennsylvania compared to urban Pennsylvania.



# President's Message Jessica Capitani



As the mother of a teenager with IDD and multiple medical diagnoses, this issue of the PA Message is truly important to me. We know that healthcare disparities for people with disabilities have always existed. But after the impact of COVID-19, these inequalities should not be ignored any longer.

During the pandemic, the systemic ableism of the healthcare system was undeniable. It intensified existing challenges while creating new ones. Unfortunately, I have experienced this disability bias in healthcare with my 16-year-old son who has Down syndrome and chronic health conditions. His most recent diagnosis began with symptoms that started several years ago. Over time, his endurance for physical activity dropped a great deal.

I took him from specialist to specialist: neurology, orthopedics, physical therapy, and others. In each instance, I felt my concerns were not taken seriously and we left without answers. One physician never even got my son off the examining table to observe my son walking, though that was one of my primary reasons for being there. It seemed most couldn't get beyond his primary diagnosis of Trisomy 21. One doctor told me, "You know, mom, your son has Down syndrome,

SO..." Another told me, "This is just the way he is", which begged the question, "Would that still be your answer if he had 46 chromosomes instead of 47?" Throughout our frustrating search for answers, my sports-loving son continued to lose his physical abilities. He had difficulty running and using stairs and ultimately, he needed a wheelchair.

By chance, we had decided to get orthodontics to straighten my son's teeth. When the orthodontist did the initial comprehensive x-ray, she observed possible arthritis in his jaw and referred us to yet another specialist – a rheumatologist. Finally, we had found a physician who truly listened and even spoke directly to my son about his symptoms. After examining his movements and performing diagnostic tests, she confirmed that his deterioration was due to juvenile idiopathic arthritis.

When my son finally received appropriate medical care, he quickly improved. He regained many of the physical skills that he had lost, and he hasn't used the wheelchair in a year and a half. But I can't stop wondering about those other specialists we visited. My son has permanent damage in some joints from years of suffering with this undiagnosed autoimmune disorder. That damage could have been and should have been prevented.

I would like to think that I am a person who knows how to advocate. I am certainly familiar with the healthcare system from raising a child receiving medical care for multiple conditions since birth. If I was unable to get my son beyond disability bias, what about those that have not yet found their advocacy voice? How acute must their symptoms become before being too obvious to continually dismiss? How will that delay in care worsen their health?

From communication barriers to disproportionate outcomes to lack of access, the pandemic highlighted the deep need for training in providing equitable healthcare for those with disabilities. Systemic ableism must be confronted to end these inequities in healthcare. A review of the COVID 19 response is the perfect opportunity to restructure healthcare to ensure disability inclusion.

I am very excited about The Arc of Pennsylvania's initiative in healthcare disparities for people with disabilities. I hope you will enjoy learning about these efforts and join us in this critically important advocacy work.



## Visit The Arc of PA online [thearcpa.org](http://thearcpa.org)





# Executive Director's Message Sherri Landis



This issue of the PA Message focuses on a very important topic and an Arc of Pennsylvania initiative—The Arc of PA Initiative to Address COVID-19 Health Disparities Among People with Disabilities. Of course, we all realized that before the pandemic there were inequities faced by people with disabilities in this area. But the Covid-19 pandemic has served to “pull back the curtain” on these issues. The crisis magnified and shone a light on deep disparities that exist for people with disabilities in many areas of healthcare.

The disability community is disproportionately affected by the pandemic. It has had higher risk for isolation, hospitalization, and death. These issues are even greater for those with disabilities living in rural, minority, and ethnic communities.

I am excited about the initiative, funded by the Pennsylvania Department of Health. There are several goals:

- Create regional groups and bring people together to learn about real experiences in local communities.
- Ask the people who have struggled, what would help them.
- Report data-driven findings to

the PA Department of Health.

- Create inclusive and accessible media campaigns to educate on mitigation efforts for COVID-19
- Share recommendations for reform to prevent disparities in future health emergencies.

Frankly, our work to date has been humbling. We have learned about so many real-life obstacles that people with disabilities faced throughout Pennsylvania. We have heard about specific and distinct Covid-19 challenges for minority and rural communities. And our work has also been energizing and inspiring. There are many identified strengths in our communities on which healthcare equity and justice can build on. The disability community has many innovative ideas for building healthcare equity. The Arc of Pennsylvania is dedicated to helping the state create plans to eliminate inequities, while building inclusive, accessible future healthcare emergency plans.

While this issue of the PA Message shares our work here at The Arc of Pennsylvania, we also feature several articles about work happening throughout Pennsylvania and at several chapters. You'll learn about The Arc of Philadelphia's interrelated health initiatives to support improved health, lifespan, and quality of life for those with IDD. The Arc of Pittsburgh/Achieva has a long history of healthcare advocacy. We'll feature its current, unique advocacy effort underway to address inequities. Finally, ideas from the field, such as a healthcare equity curriculum from doctoral student Cheryl Richardson, can conceivably be replicated throughout Pennsylvania. We hope you'll join us in advocacy to create healthier futures for people with IDD in Pennsylvania, now and into the future.

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*Achieve with us.*

and talk to each other about the disability experience in their community during the pandemic. We also used interviews and surveys for people to share their lived experiences of the pandemic. These strategies helped us gain a deeper understanding of the many issues faced by the disability community during these pandemic years. We also learned about community strengths and opportunities that helped people stay healthy and survive.

**“ How does a blind person do a take-home test? Tests are not at all accessible. I felt like walking into the drug store and asking the guy behind the counter if he would administer the test and tell me the results.”**

— *Participant with lived experience*

Another part of our project is to create and share a media campaign to specifically target COVID-19 education for people with disabilities, with extra attention to those from minority and rural communities. While the most severe stage of the pandemic may be passing, all of us will need to continue to be safe and live with the virus. Our goal is to provide education that is accessible and specifically made for the diverse disability community. Our work will reduce misinformation; help lessen the unequal impact of Covid-19 on the disability community and assure access to prevention and support services. We will create materials that have accessible and plain language; translate to multiple languages and cultures; and include American Sign Language and Braille. Our media materials will include both online and print media.

Finally, we will create a report for the Pennsylvania Department of Health. Our report, “Findings and Recommendations: COVID-19 Health Disparities Among the Disability Community” will share all that we have learned. The real importance of the report will be recommendations in our Health Equity Plan. Our greatest goal for this plan is to assure that the Pennsylvania Department of Health has the information it needs so that in any future health emergency, the needs of people with disabilities are fully understood, considered, and included and that all plans are accessible to the diverse disability community.

These efforts are possible because of many partners across the state. To hold Listening Tours and for all other parts of our project, we work with those who know their part of Pennsylvania the best. Our partners include people with disabilities, families, Arc chapters, healthcare providers, public health officials, other service providers, and disability advocacy organizations. Local, regional, and state partners all have a very important role to play. Their contributions and time are invaluable.

## Health Outcome Disparities for Minority Populations



**Black and Latinx populations experience the greatest disparities.**



More likely to have poor physical and mental health



More likely to have obesity and diabetes



More likely to get cancer



Less likely to survive prostate, breast and lung cancer

## People with Disabilities

### Magnified Healthcare Disparities



Experience higher mortality rates



Visit health care providers more often

**Minorities with disabilities face even greater disparities**

**“ The pandemic made it a crisis for my son to remain in his group home. Parents have had to act as teacher, nurse, paraprofessional, and more.”**

— *Participant with lived experience*

We have completed the first phase of the project. Currently, project staff are compiling all information we collected and are analyzing and organizing it.

We welcome you to join us to assure Pennsylvania has accessible and equitable health emergency planning for people with disabilities. Contact Project Coordinator Nancy Shirley at [nshirley@thearcpa.org](mailto:nshirley@thearcpa.org) or 717-234-2621, ext. 106 for more information.

# THE ARC OF GREATER PITTSBURGH/ACHIEVA LEADS ADVOCACY FOR UNDERSERVED POPULATION DESIGNATION

The Arc of Greater Pittsburgh/Achieva has a long history of demonstrating and advocating for ways to promote healthcare equity for people with disabilities. Recently, its attention has turned to specific changes in policy that would help release funding to Pennsylvania to reduce or eliminate disparities.

In the United States when populations face health inequities and disparities, like people with disabilities do, the federal government has some tools to help. Mainly, the Health Resources and Services Administration (HRSA) can provide a designation to a group so that more federal funds are available to address disparities. One designation is called “Medically Underserved Area/Population.” But to get this designation, 30% of the population must live in the same geographic area. Because of that, the population of people with disabilities can never qualify for the designation. People with disabilities are diverse. They do not all live in one area; but are everywhere and in every community.

The Arc of Greater Pittsburgh, recognizing the need for more funds to address healthcare disparities for people with disabilities, is working on an alternative to the HRSA designation. Its advocacy is focused on a different option called “Governor’s Exceptional Medically Underserved Population” (EMUP). With this option, the Governor of a state can request the EMUP

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status from the U.S. Secretary of Health and Human Services. Requests are often granted. When requests are granted, federal funding can be released to fund:

- Grants to support primary care services
- Grants for research
- Funding to train medical, behavioral, and dental professionals
- Payment incentives for federally qualified health centers to serve the population

Pennsylvanians with disabilities still face hardships when trying to access adequate healthcare, especially for routine screenings. An EMUP designation would increase access to federal funding for care, research, training, recruitment, loan repayment, and provider incentive payments. All these options are needed to encourage more providers to accept public insurance and provide care to people with disabilities.

To learn more about these advocacy efforts, contact Vanessa Rastović, Policy Manager for the Disability Healthcare Initiative for The Arc of Greater Pittsburgh/Achieva at 412-995-5000 Ext. 569 or email [vrastovic@achieva.info](mailto:vrastovic@achieva.info).



# THE ARC OF PHILADELPHIA HEALTH INITIATIVES

The goal of The Arc of Philadelphia's HealthMeet Initiative is to decrease disparities and increase life span and quality of life for people with IDD. The organization partners with local universities and colleges that offer medical and health-related degrees. Executive Director Shane Janick says, "We are working to build a healthcare workforce that is comfortable and confident when working with people with IDD, while eliminating disability-bias in clinical spaces."

The Arc of Philadelphia's healthcare initiatives are interwoven and interrelated. They include:

## Health Promotion Classes

Students from various health disciplines teach virtual classes covering a variety of topics. They include topics such as diet and nutrition, sun safety, sleep health, and physical activity. In the prior two years, 80 students taught 49 classes.

## Inclusive Healthcare Discussion Panels

Over the past year, approximately 800 medical and allied health students attended discussion panels facilitated by The Arc of Philadelphia. The panels provide students with a vision of what inclusive practices look like in healthcare, and include the organization's staff, self-advocates, family members, and practicing physicians or therapists. In each session, the panel shares both the positive and negative actual experiences of people with IDD in the healthcare system. Sharing and discussing these stories helps students understand how bias contributes to building barriers. Panelists also offer strategies and recommendations to remove bias and create inclusive practices.

## Fieldwork Placements

Students in healthcare fields can also complete fieldwork

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through The Arc of Philadelphia in partnership with SpArc Services. The organization recently hosted over a dozen advanced degree-seeking students in disciplines such as occupational therapy and public health. The fieldwork is individualized to each student's interests and course needs. All placements involve interacting with individuals who have IDD.

## Health Screenings

In the year before the Covid-19 pandemic, 50 volunteer medical students provided one-to-one observational health screenings through The Arc of Philadelphia's unique clinic. Assessments focused on general health, vision and hearing, oral health, mental health, diet and nutrition, physical activity, and other areas. The screenings are free, and students also help people access other healthcare services they may need. Ninety percent of the medical students reported that this contact with people with IDD was their first and they had not had any previous courses or training that helped

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them learn to provide care to people with IDD. One such student reported, "The most important thing I learned is that caring for an individual with a disability is no different than any other patient. It just takes adaptability." The organization hopes this part of the initiative can begin again soon.

These efforts have been difficult to facilitate during the pandemic, but The Arc of Philadelphia is committed to continuing to provide resources and in-person

experiences that help inform healthcare practices for medical and nursing students. "Our goal is to have every student who graduates into the healthcare workforce feel confident to provide care for the population with IDD, already having experience working with the people with IDD while earning their degrees, and to enhance social interactions, communications skills, and knowledge of health conditions associated with disabilities," said Janick.

## EDUCATING PROFESSIONALS IN-TRAINING TO ADDRESS HEALTH DISPARITIES

When people with intellectual and developmental disabilities (IDD) are in the healthcare system, they interact with highly trained professionals. Whether that professional is a physician, physician's assistant, or nurse, they have years of training in the medical field. That training usually includes no formal training in providing care to people with IDD. The lack of training serves to reinforce different and more undesirable patterns and outcomes for people with IDD than for other populations.

Cheryl Richardson, a doctoral student at Penn State College of Medicine, wants to see that change. She created a course to formalize training for students and others in the healthcare field. Richardson says, "Healthcare staff and individuals with intellectual disabilities report communication barriers and less than ideal interactions with one another. This discomfort during exchanges may lead to medical harm events. Individuals with ID are more than twice as likely to experience a harmful situation while undergoing medical care."

Past life experiences with people with IDD led to Cheryl's interest in this topic. For a period, she worked in community living settings, case-management, and other roles. During that time, she saw that, "advocacy involved more than going to meetings, and leadership for people with intellectual disabilities meant incorporating a lot of choice, patience, and situational adjustments." Further along in her life, sharing her home with a man with IDD who developed a terminal illness and becoming a nurse alerted Richardson to the ways healthcare providers were at a loss to communicate, interact, or offer meaningful health choices to those with IDD.

"Providing Care for Individuals with Intellectual Disabilities: Addressing Health Disparities" is the name of Richardson's course. A combination of lecture, simulation, and independent study, the course explores:

- The role of society and history to understand health disparities for people with IDD
- Patient safety and error prevention behaviors
- Strategies for effective, respectful social support
- Behavior as communication, and,
- Issues of informed consent and supportive decision-making

The involvement of individuals with IDD is central to the developing course. They will take part in simulation activities and as guest speakers. Their involvement will help participants understand the far-reaching impact of assumptions and interactions.

To begin offering the course in 2023, Cheryl Richardson needs grant funding. She says, "From a research perspective, my greatest hope is that we will see a decrease in medical harm events for people with intellectual and developmental disabilities. My greatest hope from a personal level is simply to meet the needs of individuals with intellectual and developmental disabilities while also helping healthcare staff feel competent and prepared to provide care to this amazing population of individuals. I believe that improving communication skills in safe settings will help improve patient outcomes and make the entire healthcare experience more equitable."



# Your Voice Matters

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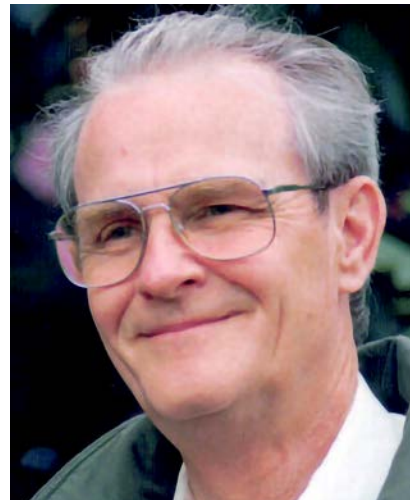
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The Arc of Pennsylvania is affiliated with The Arc of the United States. We have 30 local chapters serving 50 counties and over 12,000 members.

## PHIL ROSENBAUER

The Arc of Pennsylvania is sad to report that the Treasurer of our Board of Directors, Phil Rosenbauer, passed away in February. He was an energetic, generous, and compassionate volunteer and advocate for many years. Phil served for over 30 years as the Executive Director of The Arc of Butler County as well as a multitude of other leadership roles. He is greatly missed by the local (Butler area), state, and national Arc network and community. Our continued thoughts and prayers are with his family.



### MISSION STATEMENT

*The Arc Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.*