

HEALTHCARE ACCESS FOR PEOPLE WITH DISABILITIES IN RURAL PENNSYLVANIA



CONTENTS

1	Introduction
2	PHAN's Work
3	The Impact of COVID-19
4	Methodology
6	Findings
6	Transportation
8	Provider Relationship
17	Availability of Services
17	Dental
18	ABA Therapy
20	Needed Services Not Covered by Insurance
22	Medical Equipment
23	Understanding / Navigating Healthcare System
25	Technology
26	Recommendations
28	Moving Forward
29	Acknowledgments

CONSUMER STORIES

- 6 Tammie Snyder - *Using MATP While Vision Impaired*
- 7 Jamielynn Fisher - *Lack of Transportation Options*
- 8 Donna Frye - *Long Trips to Appointments*
- 9 Linda Heffelfinger - *Interview with Dr. Bernard Adukaitis*
- 10 Anonymous - *Hospital Staff Did Not Value the Life of a Patient With Disabilities*
- 11 William Bressi - *Doctor Did Not Communicate Well*
- 12 Marie and Ray Prince - *Lack of Communication Devices and Interpreters*
- 12 Mary Bachman - *Nurses Refuse to Turn Down Lights for Son*
- 13 Tammi Raabe - *Psychiatric Department Refuses to See Son*
- 13 Deanna Hartnett - *Providers Unwilling to Treat Person With Disabilities*
- 14 Tammie Snyder - *Bad Experiences in the ER*
- 15 Cara Spatz - *Problems With Early Intervention Staff*
- 18 Larisa Geissler - *Availability of ABA Therapy*
- 19 Brittany Malone - *ABA Therapy and Insurance Coverage*
- 21 Joanne Henry - *Communication, Race, and Provider Choice*
- 22 Brian Habermehl - *Waiting for a Standing Wheelchair*
- 23 Abbie Morrison - *Challenges Transitioning to Adult Care*
- 23 Tammie Snyder - *Access to Medical Records in Braille*
- 24 Jerry L. Webb - *Taking Understanding for Granted*
- 25 Janell Weaver - *Accessibility Needs Flagged in Medical Records*
- 25 LeeAnn Thomas - *Challenges Accessing Communication Devices*

INTRODUCTION

Navigating the Pennsylvania healthcare system is frequently challenging. Long wait lists, unexpected costs, and lack of coverage for needed services affect many healthcare consumers in Pennsylvania.¹ These issues are especially acute in the rural parts of the state where many live in poverty, distances are longer, transportation infrastructure is limited, and there may be fewer options for treatment.



People with disabilities living in rural areas encounter all of these problems as well as prejudice, ignorance, and various barriers that impact their ability to access healthcare services, facilities, and equipment.



This report features stories from people with disabilities, their family members and caregivers about barriers to healthcare access. We collected these stories through surveys, face-to-face meetings, phone conversations, and public listening sessions during 2019 and 2020. The goal of this report is to document barriers, better understand the perspectives and needs of those facing them, and raise awareness of the need for improved accessibility.



¹“Consumer” refers to anyone who uses healthcare services--which includes essentially everyone. The healthcare field has adopted this term to highlight the fact that people are constantly affected by the healthcare system even when they are not a ‘patient’ receiving treatment.

PHAN'S WORK

The Pennsylvania Health Access Network (PHAN) is Pennsylvania's only statewide consumer-driven organization working to expand and protect access to high-quality, equitable, affordable healthcare for all Pennsylvanians. Since 2007, PHAN has brought together health care consumers and community organizations across the state to advocate for expanded access to health care in Pennsylvania. To achieve this, PHAN blends coalition-building and policy advocacy with our unique model of community health organizing that focuses on supporting and empowering consumers to get the treatment they need and become advocates for better healthcare in their local communities and statewide. PHAN has successfully organized consumers to push back against health plan rate hikes, helped seniors in Western Pennsylvania maintain access to critical doctors, led the consumer-driven campaign for Medicaid² Expansion, defended and elevated the core consumer protections and coverage options in the Affordable Care Act, and brought together housing and healthcare providers to better address the social determinants of health through Medicaid. In addition to this project, PHAN is currently

working on addressing healthcare affordability burdens for all Pennsylvanians, lowering the cost of prescription drugs, ensuring the seniors and people with disabilities are supported in the transition to Community HealthChoices, and increasing access to transportation for medical appointments.

THE RURAL HEALTHCARE ACCESS PROJECT

This report is released as part of the *Rural Healthcare Access Project*, an initiative by PHAN, funded by a grant from the Pennsylvania Developmental Disabilities Council. This project is intended to ensure healthcare locations, equipment and services in rural Pennsylvania are accessible to all.

Information gathering is only a preliminary step--our goal is to address problems, not merely document them. Many of those who contributed their stories to this report have joined regional teams and are pushing for the changes they themselves have identified.

² The most common type of insurance held by people with disabilities is Medicaid (called Medical Assistance in Pennsylvania), which provides essential medical care, equipment, and supportive services that help many consumers remain in their homes and communities. This care is typically unavailable through private insurance and is too costly for all but the wealthiest people to fund out of pocket.



THE IMPACT OF COVID-19

Just prior to the release of this report, the world was hit by the COVID-19 pandemic. This will have far reaching consequences for all of us and the disability community in particular. This crisis also creates new opportunities to monitor and improve practices, ideally forcing medical professionals and government agencies to consider accessibility in new ways and examine the integrity of the social safety net.

PHAN has responded by following up with the organizations and community members we have connected with through this project in order to monitor how COVID-19 is affecting the rural disability community.

The issues outlined in this report are all the more relevant, and new ones have appeared. People with disabilities and their family members in rural areas have lost loved ones to COVID-19, have had surgeries postponed, have lost their jobs or had to quit in order to care for their children. Many are at high risk of infection and are afraid to leave their houses. Some have no one to drive them to the grocery store, and others are facing housing instability--all of which are social determinants of health. People are forced to make tough decisions about whether resuming therapy is worth the risk of infection. Isolation and boredom adversely impacts mental and emotional health. Care workers are limiting home visits and prioritizing the most vulnerable. Family

members caring for loved ones at home are extremely isolated and may get little support. There are many isolated community members that we haven't connected with who may be experiencing more dire problems. Meanwhile the death toll in nursing homes, prisons, and other institutions rises. People with intellectual and developmental disabilities are at higher risk.³

The Pennsylvania Department of Health recently released a set of guidelines for healthcare providers on how to use limited resources to save the greatest number of lives during crisis situations in which not everyone can be treated. On March 27, 2020, PHAN signed onto a letter from Disability Rights Pennsylvania to the PA Department of Health, citing the shortcomings of these guidelines in failing to safeguard against stereotypes and biases on the part of healthcare providers which may cause them to see people with disabilities as less deserving of life-saving care--as well as failing to require adequate review and oversight when making life or death decisions concerning who gets priority in receiving care. The Department of Health has since released a revised set of guidelines which addressed these issues. However, continued monitoring is needed to ensure these guidelines are being followed correctly.

³<https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili>

METHODOLOGY

Our approach to data collection was qualitative in nature. Through surveys, face-to-face meetings, phone conversations, and public listening sessions throughout 2019 and 2020, we were able to hear a wide variety of perspectives on the healthcare system in each of the counties. We talked to people in group homes, sat in at events organized by The Arc chapters and Centers for Independent Living, engaged local nonprofits, and connected with family support groups. We asked people about their experience with their local healthcare system and the biggest barriers to receiving quality healthcare. We have connected with over 200 community members with disabilities, their family members, and caregivers and formed partnerships with over 100 local community organizations.

The area covered by this project includes Schuylkill, Columbia, Montour, Northumberland, Union, Snyder, Juniata, Mifflin, and Perry counties. We have also heard from people in Luzerne and Lycoming Counties.



GUIDING PRINCIPLES AND VALUES

Generic Healthcare

Although some issues are specific to certain types of disability, the majority of this report is about *generic healthcare* by which we mean healthcare that everyone uses, such as family doctors, behavioral health, dental, vision, or specialists that are not specific to particular disabilities. Although accessibility issues related to disability-specific healthcare are included in this report, we have found that basic issues that affect everyone are the biggest barriers for people with disabilities. Furthermore, a provider's competency in treating people with disabilities is an extension of a patient-centered approach in general.

Additionally, we recognize that the availability of child care, access to healthy food, employment, and other social determinants of health⁴ are relevant to this discussion. In addition to sharing their experiences with the healthcare system, many we interviewed expressed the need for independence and inclusion in the community.

⁴ Social determinants of health are conditions such as where a person lives and what resources are available to them that affect their health.

Systemic Change

Disability is a normal part of the human condition and those asking for accommodations are not asking for an “exception”. The onus is on healthcare systems and other social institutions to provide these accommodations. This type of change is not achieved through temporary fixes or one-time adjustments. Too often we have seen agencies solve problems by making exceptions for the most vocal individuals rather than fixing the underlying cause and benefiting everyone. We seek systemic change; and change that impacts policies and practices. Because the proposed recommendations for improvement are focused primarily on systemic issues, they will improve the delivery of healthcare for everyone, including non-disabled people.

Empowerment

Through every stage, we strive to ensure that the work is both led by and accountable to people with disabilities. People with disabilities are most impacted by these issues and were our primary source of information on the problems and solutions, and our game plan on how to implement these solutions is created through group process. Furthermore, work on these issues is not undertaken purely for the sake of fixing the problem but most importantly to encourage impacted community members to lead the way in shaping our healthcare system.

Working With Providers

It is our intent to work collaboratively with providers throughout this project and support them in improving their practice. Healthcare providers in rural areas face challenges as well, including lower reimbursement rates and a smaller pool from which to recruit qualified staff. Although there are many opportunities for improvement, we also learned about many promising practices. Many consumers said that they were happy with the healthcare they are receiving and praised their providers for being compassionate, informative, respectful, and accommodating. As we move forward, we will further document the practices of healthcare providers who are serving consumers with disabilities well in order to lift up positive examples and outline best practices.

Disability competency refers not only to a healthcare provider’s ability to understand and accommodate consumers with various disabilities but also to a provider’s ability to establish a relationship of reciprocity and trust with consumers, regardless of their ability status.

FINDINGS

Transportation

Transportation is an extremely important resource in rural areas where destinations are spread out, public transportation is minimal or non-existent, and needed healthcare services may not be available locally.

Medical Assistance Transportation Program (MATP)

MATP provides non-emergency transportation to medical appointments for Medical Assistance recipients who do not have transportation available. The service typically employs vans that do not follow a fixed route but pick people up and drop them off depending on the needs of the consumers using the service on that day. Thus, those using MATP will have to allow for the time it

takes for the van to pick up and drop off other riders. MATP rides can often consume most of a day for a commute which would ordinarily take an hour or less. An MATP provider we interviewed stated that the spread out nature of rural geography and limited funding for services in rural areas places limitations on the quality of service they can provide.

Those reporting problems with MATP usually stated that the system works acceptably, but long wait times are hugely inconvenient. Drivers may not ask about accessibility needs. Others report being stranded by MATP or not being dropped off at the right place. Sometimes drivers show up ahead of schedule and miss the consumer. It was also reported that cancelling rides can be difficult.



Tammie Snyder is a member of the Pennsylvania Council of the Blind and an MATP user. She reported a lack of disability competency on the part of MATP drivers. Although Tammie has repeatedly told the MATP provider that she needs the driver to enter the building and let her know they have arrived, they rarely do this.

Tammie fears being left stranded, “I let them know that if I ever get stuck they’ll hear from me!” She says the county has minimized her concerns. “They tell me I’m asking for an exception. The only exception I want is some understanding.”

Community members also had difficulty bringing their aids along on an MATP trip. Although policy states that aids must be allowed, MATP providers and consumers may not be aware of this. The authorization process can also be challenging. An additional problem is that healthcare consumers may require transportation for trips not covered by MATP, such as trips to the benefits office.

Medical Assistance recipients may not know about the benefits available under MATP, particularly mileage reimbursement. Even if consumers know about its availability, the process for getting reimbursed can be so time consuming as to make it not worth it for

the modest amounts of money consumers receive. Prior to COVID-19, a Medical Assistance recipient could be reimbursed at 12 cents per mile for using their own vehicle to drive to appointments, which is less than the current IRS rate for medical transportation, 17 cents. This is barely enough to cover the cost of gas and does not compensate for wear and tear on the vehicle. This has been temporarily raised to 25 during the pandemic. Those who have a vehicle encounter more barriers to using MATP. However, they may not be able to drive due to health issues, mechanical problems, or other circumstances.



Jamielynn Fisher has a driver's license and vehicle so is not eligible for van trips through MATP. Because they only have one vehicle, she must drop her husband off at work before going to her appointments, a tough and stressful schedule. She says that the local transportation system is far worse than other places she has lived, "I don't see how people get around here." At one point she needed an overnight sleep test but could not drive herself due to the effects of the testing and could not arrange transportation for that time of night.

Jamielynn is concerned not just for herself but for others in the community, "A lot of people who can't drive for medical reasons or can't afford a car can't get to other parts of the county. Taking a taxi or an Uber is not an option, it costs \$20 to go to Wal Mart (10 minutes each way)."

Long Commutes

Many consumers reported regular commutes of up to 90 minutes to access services. Some must travel one to three hours each way to access healthcare providers in other counties. Consumers regularly travel from Bloomsburg, Lewistown and other areas to Hershey or Philadelphia to access sedation dentistry, neurology, and other services. These trips often require a full day and in some cases must begin before dawn, all of which places an extreme burden on consumers and caregivers.

Donna Frye of Mifflin County needs someone to take her to appointments.

“I have a brain tumor so driving is not an option. Finding someone who will wait for you and pick you up isn’t an option either.”

Donna has Medicare and Medical Assistance and had to go to State College to find a dentist that would take her insurance, a 40 minute drive. Dentists in Lewistown had a four to six month waiting period.

Provider Relationship

The importance of the rapport between providers and consumers, both in general and in reference to healthcare accessibility, cannot be overstated. Having various facets, it was by far the most frequently discussed topic during our listening session. Providers with good disability competency are sought after by consumers as they play a pivotal role in the healthcare experience and outcomes.

Before we describe instances that were not satisfactory for the consumers, we would like to emphasize that many of those we interviewed reported being satisfied with the care they were receiving and praised their providers for being compassionate, informative, respectful, and accommodating. Recording these positive examples not only helps portray a balanced picture of the

healthcare landscape in rural Pennsylvania, but also serves as a guide for future advocacy by helping articulate what we would like to see more of.

The number one form of praise that project participants gave to their providers was that they took time and listened to them. It should come as no surprise that communication is the foundation of a positive consumer/provider relationship, especially when the consumer is a person with a disability. Participants also valued providers who were willing to go the extra mile to make sure they got the treatments they needed, as well as providing information on community resources. This information sharing was particularly effective at locations with on-site social workers.



Linda Heffelfinger interviewed her pediatrician **Dr. Bernard Adukaitis** as a provider with a high degree of disability competency. In particular, Linda appreciated the amount of information he provided on autism services for her son Justin, something that some pediatricians don't do.

Dr. Adukaitis is a general pediatrician but studies developmental pediatrics because he sees a lot of kids with developmental disabilities. He believes that more training in developmental pediatrics should be given to general pediatricians.

"Every child is different so it's important to listen to the parent," Dr. Adukaitis said, when asked about his methods for treating patients with disabilities. Children with disabilities like the same things their peers like, such as music, shaking hands, or slapping five, and these can be great ways to engage them.

He would love to have more time with his patients, but that isn't always possible. He stated that low reimbursements through Medical Assistance can discourage some providers from treating consumers with Medical Assistance. "I try not to know what insurance they have to make sure I treat them the same."

Bias

A dismissive and/or disrespectful attitude on the part of doctors, nurses, schedulers, and other healthcare staff when dealing with people with disabilities was frequently reported. Some healthcare staff have been intolerant toward consumers with intellectual disabilities or behavioral health needs. Healthcare staff may ask those they

view as unacceptably noisy and disruptive to leave. Some services and supports staff even reported that doctors do not value the lives of people with disabilities. They reported hearing comments like “He’s already lived a long time for someone with this condition,” or even stating that the consumer would be “better off dead.”

“I hope you learn that these individuals are human beings and deserve to live an everyday life.”

Liz DeVett, CEO of Shared Support, a service and supports agency for people with intellectual disabilities, reported that a doctor intended to take a consumer in their care off life support even though the consumer did not have a terminal condition and eventually recovered. The consumer was admitted for seizure activity where she was given a breathing tube. After a week in the Intensive Care Unit, hospital staff attempted unsuccessfully to wean her off the breathing machine. It was discovered that swelling in her throat prevented her from breathing on her own. The doctor told Shared Support staff and

family members that they wanted to remove the breathing tube and presented the options of either giving the consumer a tracheotomy or giving her medications to make her comfortable and letting her die. It was eventually discovered that the consumer had pneumonia. She was treated with antibiotics and was eventually able to breath on her own. In a letter to the CEO of the health organization the hospital was affiliated with, Shared Support Program Specialist Heather Good stated that hospital staff ignored signs and symptoms of the infection for five days, treating the consumer with psychiatric medication to “help with her agitation”. She writes “I can only hope you learn from this experience and learn that doctors need to be better prepared when caring for individuals like [name redacted]. I hope you learn that everyone deserves the outstanding care you pride your hospital on.”

Communication

Consumers frequently reported that doctors do not take the time to sufficiently explain conditions and treatments to consumers with disabilities, family members, and caregivers.

Consumers on the autism spectrum, with intellectual disabilities, hearing impairment, or other conditions that affect communication or processing of information

may need specialized accommodations to effectively participate in the patient/doctor decision-making process. For example, one consumer on the autistic spectrum finds face-to-face verbal communication extremely difficult and would rather communicate to his doctor through typing or text while in the exam room.



William Bressi was at an appointment with his community support staff **Victoria Chapman**. Victoria Says that the doctor was using jargon which neither she nor William could understand. Victoria later overheard the doctor talking to one of the hospital staff, stating that he doubted they would be able to get consent for the treatment because he believed William was incapable of understanding. Victoria had to explain to the doctor that William would be able to understand if he used more accessible language.



Marie and Ray Prince reported repeatedly requesting Video Remote Interpreting (VRI) during hospital visits. When Marie had surgery, she asked for VRI to be set up in the waiting room in case the doctor needed to talk to Ray. The hospital never provided the VRI and Ray had to rely on other family member present to communicate with the doctor about Marie's condition. "You constantly have to remind these guys!" Marie says. In another instance, the nurses brought them an iPad, thinking

it was a VRI. Marie is concerned about the lack of certified interpreters in the area as well as the lack of interpretation in ambulances and other emergency situations.

Willingness to Make Accommodations

"When my four year-old son first walks into an exam room he turns out the fluorescent lights because they are just too bright for him. Several times it's been a struggle with the nurse or the provider to leave the light out and just use the natural light from the window."

- Mary Bachman, Union County



Providers are often unaware of how important accommodations like turning down the lights can be for consumers with disabilities. Consumers must seek out providers willing to accommodate them, further limiting their choice of provider.

Consumers reported issues with the physical accessibility of buildings, staff not knowing

how to safely lift or move a consumer, not having an x-ray that would accommodate a wheelchair, and not having side rails on the hospital bed for a consumer with sleep apnea. One service and supports agency reported that because residents refuse to drink the prescription laxative while in their group home, they need to do colon prep in hospital, and the hospitals will not accommodate this.

Providers may be unwilling to treat people with disabilities due to a perceived risk of complications. Participants reported that some doctors and dentists refuse to treat people with disabilities, stating that it's "outside of their scope of practice."

A local health system refused to provide a psychiatric appointment for Tammi Raabe's son Kieran who is an adult on the autism spectrum who has a comorbid bipolar diagnosis. "They stated that they couldn't

treat him because of his autism diagnosis. That's discrimination." Tammi and her son must travel an hour and a half to see a pediatric psychologist who has seen him since childhood and continues to see him because he can't get treatment anywhere else. Interviewed after the COVID-19 outbreak, Tammi said, "I don't know how a system like this would handle my son during a crisis. How would they value him? That's a concern for me as a parent."

“Instead of giving her a few moments and trying again, he proceeds to say she is finished and he’ll see her back in six months.”

Excerpts from a conversation with **Deanna Hartnett** - Program Supervisor, Community Services Group, Schuylkill County

“The individual that goes to the dentist, gags every time the dentist attempts to clean her teeth. Instead of giving her a few moments and trying again, he proceeds to say she is finished and he’ll see her back in six months. Meanwhile she is leaving the office without a proper cleaning and tartar build up.”

“Several times we have had an individual seen in the ER [...] and the hospital does not have the proper equipment to make sure individuals are transferred safely. They usually don't even realize they are immobile and have already come in the room to discharge us without offering any kind of help to get

the individual back in their chair safely. [...] We have recently tried in the past few months to have a bone density scan done on an individual on two different occasions. On both occasions the test was unable to be completed due to not having the proper equipment to take her out of her chair to put her in on the table/machine.”

Supported Decision Making

Services and supports agencies also frequently reported that consumers in their care often refuse vital treatments because they are scared or uncomfortable. Although they do have the right to refuse treatment, services and supports staff suggested that doctors often choose not to treat the consumer without first exploring how to address their concerns and make them more comfortable. Again, this could be due to bias, constraints on doctors' time, or a fear of treating patients that might have complications.

Diagnostic Overshadowing

Diagnostic overshadowing refers to cases where physical health issues are mistakenly attributed to behavioral issues or vice versa.

In one example, an agency had to fight to get a urinalysis for a client who was exhibiting aggressive behavior. The hospital staff were dismissive toward the caregivers, who correctly suspected that the cause was the consumer's bladder infection.

Doctors may misdiagnose due to a lack of familiarity with the consumer and their behavior. Services and supports staff reported that adjusting medication is often the default way hospitals and psychiatrists deal with problems which, for non-verbal consumers, may have underlying physical causes.

Emergency Room Visits

All of these considerations are more acute in an emergency room setting. Services and supports staff reported that consumers in their care frequently did not have their health issues addressed by preventative or primary care due to inattention on the part of providers, which often resulted in multiple emergency room visits.

Virtually all services and supports agencies reported difficulty communicating with hospital staff about a consumer's needs. This can cause life threatening circumstances if, for example, a consumer has specific needs around eating or drinking and may refuse to eat or choke if those needs are not met. Services and supports staff must often remain in hospital in order to make sure instructions are followed, which places a financial and staffing burden on the agency. Likewise, there is frequently a breakdown in communication when the consumer is discharged, leaving caregivers unaware of the consumer's medical needs.

Tammie Snyder's mother had gone to the local emergency room with a heart condition. She was admitted to the hospital but then discharged before she was fully recovered because the staff needed her bed and was told to "go home and deal with it." Tammie herself reported horrible experiences at the ER, saying that they ignored her request to go to the bathroom and didn't make sure she had a way home after discharge.

Training

Consumers reported that therapeutic support staff, home health aids, and therapists lack not only disability competency but a basic ability to perform their jobs. Families reported that teachers and therapists in Early Intervention (a program for young children who exhibit developmental delays) can be negative, punitive, neglectful, or abusive. Families also reported caregivers showing up late or not at all. This lack of reliability made it impossible to plan.

Other families reported having an autism diagnosis withheld or taken away because their child made eye contact. Eye contact is one among many indications of autism and should not be used as the sole basis for a

diagnosis. Not getting the correct diagnosis can be a serious obstacle to getting needed services.

Family members and caregivers of consumers with intellectual disabilities reported situations when they felt they knew more about their loved one's condition than the medical staff. It was often challenging to get the medical staff to take them seriously. They were sometimes asked "Are you a doctor?" or questioned in other disparaging ways. One caregiver reported catching a potentially lethal interaction with medications that were about to be given to her daughter. This situation could have been avoided if the staff had taken more time to review her medical history.



diagnosis was taken away by an autism institute because he made eye contact during an assessment. Cara said the clinician who reversed the diagnosis spent less than an hour with Jackson when assessments typically take three to four hours. She believes that the clinician was not properly trained. Cara had purchased private insurance specifically to enroll Jackson in a behavioral therapy clinic, which he was ineligible for once the diagnosis was removed.

Cara Spatz had problems with a behavior specialist provided through early intervention for her son Jackson. "She hit Jackson with a folder, and now he's afraid of folders." In another incident, a behavior specialist held Jackson by the wrist. "She was holding him too hard. He was in pain and crying, but she wouldn't let go. He had a mark afterward." Jackson was only two when this occurred. Jackson's autism

Scheduling and Wait Times

Overbooking, resulting in long periods in the waiting area, was frequently reported. These long waits are especially taxing on family members with jobs and other commitments. Consumers with intellectual disability or mental health issues who may not be able to tolerate the waiting room environment for long periods. In many cases a consumer with intellectual disability or mental health issues may need to make multiple visits to a provider site in order to feel comfortable enough to receive treatment. This is rarely allowed. In fact, one agency reported that some doctors and dentists only allowed a certain number of cancellations. Many people in their care had disabilities or mental health issues which forced them to exceed the limit of cancellations, and they were denied care.

Behavioral Support

Services and supports staff have said that some hospitals force them to either remain with a consumer while in hospital to manage the consumer's behavior, and may also prematurely discharge them. Healthcare staff are sometimes intolerant toward consumers with intellectual disabilities or behavioral challenges. One services and support staff said that a hospital threatened to put a consumer into a mental institution if the agency failed to provide staff to manage their behavior during hospitalization.

As a result, services and supports agencies are finding themselves more and more medically involved with the consumers in their care. During the time a person on medical assistance is hospitalized, the services and supports agency can not bill the state for staff remaining in hospital because the state is already being billed for the hospital visit during that time. The services and supports agencies must therefore absorb the cost.

Availability of Services

Although the state establishes network adequacy standards, many consumers reported an inability to find local providers, especially dentists, ABA therapists, as well as psychiatrists and even general practitioners. Network adequacy refers to a health plan's ability to provide access to enough in-network healthcare services such as primary care and specialists. Other needed services not available locally include gynecology, developmental pediatrics, specialists for multiple diagnoses, and Down syndrome specialists. Numerous families stated that they were considering moving to access treatment.

Choice is further limited since not all providers are qualified and willing to treat people with disabilities. Medical Assistance recipients frequently reported wait lists of one to two years. Providers limit the number of patients on Medical Assistance they accept, if they accept any.

Multiple families reported problems with Certified Nursing Assistants (CNAs)--that they frequently call off and can be unreliable. This forces family members to change their plans or look for last minute alternatives. In cases where nursing is provided in schools, children are unable to attend school when nurses call off. Families suggested that there is such a high demand for CNAs in rural areas that nursing agencies do not demand enough of their employees.

Families of school-aged children also frequently reported school districts being unwilling to provide behavioral supports to allow their children to remain in the classroom. Families must often advocate extensively to procure needed services and many families are not aware of their legal rights or may lack information necessary to determine the best options for their children.

Dental

Access to oral healthcare came up in virtually every conversation. A shortage of dentists that take Medical Assistance, whether for disabled or non-disabled people, was frequently reported. Wait lists are frequently one year or more. Consumers with intellectual disability or behavioral issues that require sedation during dental exams and procedures can face wait lists of two to three years.

We have documented multiple cases when consumers were forced to go to the ER for dentistry either because of wait lists, because other dentists had refused to see them or because a dental clinic wanted to pull their teeth. Medical Assistance only pays for tooth extraction, and does not authorize procedures that may save the teeth. One consumer reported that he has known people who have pulled their own teeth due

to fear of the dentist and/or lack of coverage. Those who can afford to pay out of pocket for dentists with availability and good disability competency. The provider relationship issues discussed above especially apply to dentistry because dental exams and cleanings are procedures that require both the person receiving care and the provider to be comfortable. Dental patients may worry that the procedure will hurt and trust is required

to allow the dentist to access their teeth. Consumers may require multiple visits to become comfortable, and dentists are rarely accommodating of this. Dentists may not know how to put the consumer at ease or may not attempt to. Dentists may worry about being bitten or the patient gagging or choking, and may be unwilling to treat a consumer with disabilities for these reasons.

ABA Therapy

“ABA is not available in most places. It’s difficult to find it and almost impossible to find a program with ABA for 40 hours a week. [...] Wraparound is not ABA.”

- Larisa Geissler, Schuylkill County

Applied Behavioral Analysis (ABA) was one of the most frequently cited services lacking in the region. ABA therapy is a form of intensive therapy that improves communication, social skills, and other constructive behaviors. It is most prescribed to autistic children as a form of early intervention, but is relevant to a variety of other therapeutic contexts. Family members report multiple challenges to accessing the prescribed weekly hours of quality ABA therapy. Due to the lack of adequate reimbursement, many ABA providers decline to accept Medical Assistance. Families are often stuck paying for treatment out of pocket. This leads to an unacceptable financial burden and less effective treatment since families cannot afford the prescribed number of hours. As

with other provider shortages, the wait lists may be one to two years. Families find this unacceptable due to the brief window ABA is most effective. The situation is so dire in Central PA that families frequently relocate.

In the case of ABA therapy, the Department of Human Services recently passed regulations that define further who can provide ABA. Previously, ABA was provided as part of Behavioral Health Rehabilitation Services (BHRS) but there were concerns, such as those raised by Larisa Geissler in the quote above, about the quality of services. The new regulations should, in theory, lead to better quality services. However, some providers suggest that they place the bar too high, while organizations of ABA

practitioners say they don't go far enough. One small autism services provider expressed concern that this would lead to a two-tiered system in which, given the higher cost of certified ABA practitioners, behavioral health providers would have to choose between providing autism services

and accepting Medical Assistance. Continued advocacy will be required to bring agencies into compliance and support providers in accessing the funds needed to hire qualified ABA therapists so that the net result is greater access for consumers.



Brittany Malone of Schuylkill County reported that her husband Ryan's insurance plan has a \$7000 deductible which must be met before they will cover services for her daughter Maddy at an ABA therapy center. "Maddy has an individual deductible of \$3000 and a family deductible of \$7000," says Brittany. "The insurance wrote in a specific exclusion where they will not cover ABA services until the family deductible is met." The cost of therapy is \$2000 per week. "We have a running tab with the therapy center and we never seem to catch up. \$7000 out of pocket each year is a lot of money!"

Needed Services Not Covered by Insurance

Several consumers reported insurance companies denying claims, questioning medical necessity, refusing to cover required benefits such as overnight stays in hospital, prescriptions, surgeries, medical equipment such as wheelchairs, and forcing consumers to apply for prior authorizations. Prior authorization is a practice in which doctors are required to get approval from an insurer before prescribing a certain medication or treatment. It was suggested that insurance companies draw out the pre-authorization process as long as possible by asking for more and more detailed information.

One non-verbal consumer with an intellectual disability stopped using her right arm and is unable to communicate the reason to her caregivers. They have been waiting for two years to get authorization for tests to determine the cause.

Consumers reported that insurance companies will often only cover treatments that are less effective. Step therapy, also known as “fail first”, is a method health insurance companies use to control cost by

requiring a patient to try a generic, usually less effective medication before authorizing the more effective medication.

People with rare conditions often must go outside of their Managed Care Organization (MCO) or across state lines to find qualified practitioners. This causes transportation challenges as well as issues with authorization, as they must get authorization both from the MCO and the out-of-network provider.

One parent reported hitting roadblocks with the insurance companies due to a vague diagnosis of her son’s condition. Her son was eventually diagnosed with autism, possibly because the provider thought he would receive better access to services. Although services for children with autism are by no means robust, children with less common diagnoses may have additional difficulties getting services.

Finally, children on the autism spectrum are prescribed medical marijuana, which is costly and not covered by insurance.



Joanne Henry reported on her difficulties finding local therapists and doctors that meet her needs. In 2015, Joanne was hit by a truck, suffering physical and psychological trauma. She continues to struggle to find a therapist that practices the type of therapy modality she needed. Her choice was further limited by the fact that many therapists would not take Medicare or Medicaid.

She also struggles to find mental health professionals with literacy around racism, as her experience as a person of color in a racist society impacts her mental health. She reported that when describing her experience of being the target of racialized aggression, her therapist would focus on

her behavior without taking the systemic context of white supremacy into consideration.

Joanne had similar experiences with physical health. "The best doctor I ever had, who unfortunately left the area, understood the connection between my physical health and mental health." She reported that other healthcare professionals have talked down to her. "If you explain things to me, I can understand them. The problem is that some doctors don't bother to explain anything. That might also be related to race." Joanne noted that it has been documented that perceptions of intelligence are influenced by race. She sees that in her interactions with her healthcare providers.

She added, "It seems that the idea of 'bedside manner' is apparently no longer considered important in the delivery of medical support. Maybe it is the manner in which doctors are trained, but many don't feel the need to really explain a diagnosis or a remedy terribly well in layperson's terms. I know that there has been research done on how race and gender intersect with the history of medicine. Perhaps this is one of the major issues in obtaining the best healthcare available here in rural Central Pennsylvania."

Medical Equipment

Consumers consistently reported problems accessing medical equipment. Consumers are bounced between multiple agencies while attempting to get this equipment, drawing out the process for years in some cases.

One caregiver reported a two year wait for a shower chair. Another reported a wait period of several months for an immobilizer for a man who had sustained multiple leg fractures. Another consumer needed a new wheelchair because the old one no longer fit and was wearing out. A medical goods supplier offered to “tune it up”, but the consumer couldn’t drop it off because she wouldn’t have been able to leave without it. In another case, a consumer’s mother sold her wheelchair and she was unable to get a new one for six years. When she finally received it, it was not measured correctly

and she kept sliding off of it. It has been months and she is still waiting for a correctly adjusted replacement. Another caregiver reported that Medical Assistance was unwilling to fund multiple varieties of equipment of the same type. For example, a consumer with incontinence may require thicker underwear for sleeping, but lighter underwear while awake. Medical Assistance would only pay for the thicker underwear, which they argued could be used for all circumstances, but which is uncomfortable when worn during the day. Multiple types of wheelchairs for different circumstances are also desirable. It was reported that requests for multiple types of motility devices (which includes wheelchairs, walkers, and other devices) are frequently denied through Medical Assistance on the assumption that a person should only need one such device.



Brian Habermehl is the Director of Self Advocates at The Arc Susquehanna. Medical Assistance wouldn’t pay for a power standing wheelchair. Brian was able to get the wheelchair through the Office of Vocational Rehabilitation because he uses the power standing feature for work, but the process took two years. “It’s a problem that these chairs aren’t more available,” he says. “They allow people to move and stretch out and they prevent sores.” Brian was disappointed in the state agencies he dealt with, “They made the process harder than it needed to be. Something that should have taken months at the most ended up taking years.”

Understanding / Navigating Healthcare System

Community members reported that needed information is often poorly advertised or not advertised, not consolidated, unclear, incomplete, or simply not available. They requested a single source of information such as a website that would be easy to access and understand.

There appears to be a general lack of information reaching consumers. Families reported that doctors gave them no information on available resources after receiving a diagnosis for their child. MCOs typically have Special Needs Units to help consumers with disabilities, but many consumers are not aware of this. Meetings for public input are often poorly advertised and consumers reported being passed back and forth between providers, insurance companies, and the state looking for answers. Waiting for months to receive test results

was also reported. In some cases the provider staff was unwilling or unable to help the consumer understand and interpret the results.

Tammie Snyder has had difficulty getting information from her doctor, such as medical records and list of covered over the counter medicine, printed in braille. Additionally, lack of information available in Spanish and lack of translation services limits access for Spanish-speakers.

Finally, several consumers expressed doubts and concerns about changes in coverage when turning 21. When a consumer turns 21 they are no longer eligible for pediatric services and must move into adult care. This requires starting from scratch in developing relationships with providers and building one's medical team.



Abbie Morrison reports that transitioning to adult care was challenging. “As a minor, I had a multi-disciplinary team working for me. That vanished when I turned 21 and moved on from a pediatric hospital.” Abbie has written an auto-ethnography about her experience with illness as part of her academic studies. She was permanently discharged from her physician's care immediately following major surgery because her 21st birthday was approaching and her plan of care was changing due to her age. Until recently, she found it extremely difficult to access preventative care or get periodic appointments. “I’m still deeply affected by the lack of care, it’s often only when there’s a crisis that they respond.”



Jerry L. Webb is an advocate and father. In an interview, Jerry observed that healthcare providers as well as insurance companies and state agencies often assume that people have all the information they need, know what options are available to them, and know that they can ask questions.

His son Sam has an intellectual disability and Jerry explained that doctors as well as staff at the county assistance office are often pressed for time and don't always take the time needed to fully explain things to Sam.

"It's not just people with intellectual disabilities," he noted, going on to say that anyone can be lacking in the information they need to navigate their healthcare effectively. He recounted his own experience of not being

aware that he was eligible for Veterans Benefits for several years.

Jerry works with his local Center for Independent Living where he and other staff and volunteers provide community members with disabilities with information about the healthcare system and support them in advocating for themselves. "I see a lot of people who are getting better services because they're asking more questions."

Technology

Technologies such as communication devices, telehealth, and online interfaces play an important role at every level of accessibility.

Telehealth is the use of telecommunication technologies such as videoconferencing for a variety of applications. A major benefit of telehealth for rural consumers and consumers with disabilities is that it allows consultations with specialists to take place without going out of area. However, telehealth is not ideal for all circumstances and billing for telehealth is not currently standardized by state regulations except in the case of telepsychiatry.

Janell Weaver, nurse and parent of a child on the autism spectrum, is spearheading a pilot project that would allow a patient's accessibility needs to appear as flags in medical records. Janell writes, "So you present to the ER because you broke your leg- anyone who logs into your chart can know that you have a tremendous issue with oral thermometers, but temporal thermometers are okay. Or you have an appointment with a specialist at a clinic you've never been to, they can know your communication methods in advance." The system automatically alerts the Child Life Specialist who ensures the plan is followed.



LeeAnn's Thomas' son Camden was recommended for a communication device during his autism diagnosis. When she contacted the local IU there were only a handful of devices available. There was only one person at the IU trained to perform assessments for the device, who LeeAnn was never able to reach. His speech therapist had a device Camden was able to try, but the therapist was only familiar with one software type and LeeAnn was told he would need to try three different communication programs before insurance would cover the cost. Camden's father Patrick, who suffered from a stroke, also uses a communication device. For Patrick, getting the device was easy but the staff were not trained to use and program the device,

or even turn it on. Patrick remarked that it just sits there "collecting dust." Dynavox offers free training on how to use the devices but LeeAnn stated that these trainings had been cancelled for the past three years because not enough people registered.

RECOMMENDATIONS

The community members we interviewed also discussed what they thought were the underlying causes of these issues and the right course of action to improve access to care. These initial recommendations are based on those conversations.

Training and Education

Consumers as well as providers recognized the need for increased education on disability competency in medical schools and as ongoing education for healthcare providers. This training should go beyond medical information and techniques to accommodate consumers with various disabilities but also address internalized bias and effective communication with consumers and caregivers. Because no two individuals are alike, developing this type of competency is an extension of a patient-centered approach in general.

This could potentially alleviate some of the situations reported above such as Cara Spatz's issues with her son's therapists, Tammie Snyder's negative experiences with MATP, William Bressi's challenges communicating with his doctor, and the situation described by Shared Support staff in which a patient was nearly removed from life support for a non-terminal condition.

Enforcement and Advocacy

It is important that providers and insurance companies adhere to existing rules, such as network adequacy standards and medical necessity standards for authorizing insurance claims through Medical Assistance. This will help to ensure that access to needed treatments and equipment within a reasonable amount of time--as in the case of Brian Habermehl and other consumers mentioned in this report.

This can be accomplished by educating consumers about their rights, connecting them with legal assistance organizations, and employing other entities that provide community-level support, education, navigation, and troubleshooting. Consumers should be aware of other options for care and actions they can take when providers display poor disability competency or are otherwise unable to meet their needs. The availability of patient advocates, Special Needs Units, and social workers should be better advertised.

Many consumers reported feeling overwhelmed or lost when engaging with the healthcare system. To address issues with understanding/navigating the healthcare system, advocates should push state agencies to consolidate and generally better publicize the availability of resources. A user-friendly online interface could make it easier to make appointments and manage them. Some healthcare networks have smartphone apps to collect feedback on patient experience and resolve issues. One person interviewed for the project reported successfully using such an app to promptly resolve issues.

Creating and expanding feedback channels between consumers, providers, MCOs and state agencies is another important strategy. Several counties have coalition groups composed of healthcare providers and human services organizations. These can be a valuable forum for collaboration and information sharing, especially when consumers are included directly.

One service and supports agency reported that they were able to bring family members, hospital staff, insurance companies, and other stakeholders together to build a shared understanding of the needs of the consumers in their care. This effectively preempted many of the issues with hospitalization described in the *Provider Relationship* section. In many cases, advocating for better implementation of existing policy is not enough. Those we interviewed cited several shortcomings with existing policy.

Policies and practices should be improved to better connect consumers with community

resources such as MATP and autism services, and case management systems should provide information and navigation automatically to overwhelmed and newly diagnosed consumers. Additional staff should be available to address accessibility issues at appointments, in hospitals or other facilities, and on MATP.

Policy Change

Improving transparency, efficiency, and standardization of the prior authorization process for insurance claims could reduce delays in coverage and prevent drawn out disagreements about what is medically necessary. Legislation should be passed allowing exceptions to “step therapy”.

Improved network adequacy standards could remedy long wait lists and long commutes. Currently, network adequacy standards for rural areas in state contracts with MCOs are based on the number of providers within 60 minutes travel distance of the consumer’s home. These standards do not ensure that consumers will be able to find a provider locally or get an appointment within a reasonable time.

Healthcare providers we surveyed have expressed the need for improved regulations, increased funding, greater efficiency in credentialing and other MCO functions, and technical assistance and support in maintaining compliance with state regulations. There is additional space for managed care organizations to better engage their provider networks and support

providers in the field. The need is especially acute for smaller providers, who are often the most integral in meeting the unique needs of a rural community.

Finally, Pennsylvanians are still waiting for a telemedicine parity law that would require insurers to reimburse telemedicine services in the same way as in-person services. Supporting telemedicine could potentially reduce travel for consumers living in rural areas and benefit consumers with mobility issues.

Funding

Increased funding to rural health systems has the potential to remediate problems such as poorly qualified staff and high staff turnover, limited number of providers who accept Medical Assistance, and limited transportation infrastructure. Both providers and consumers suggested during the listening sessions that lower reimbursement rates in

rural areas is an underlying cause for long wait times and inattention on the part of providers, particularly when treating patients with Medical Assistance. While we believe that many problems can be addressed through better use of existing resources, funding limitations also impact the quality of services. An effective approach to improving accessibility involves supporting rural healthcare providers while at the same time holding them accountable.

Consideration should also be given to value-based payment, which ties provider payments to improved health outcomes for consumers, in contrast to the traditional fee-for-service model which pays based on the amount of service performed. These models give providers a financial incentive to improve health care for everyone, but especially consumers with disabilities because it shifts the focus from quantity to quality of care and incentivizes specific and appropriate outcomes.

Moving Forward

Through this report, we have attempted to document some of the greatest barriers to healthcare access affecting people with disabilities in rural PA, verified by the lived experience of those who face these barriers on a daily basis. We invite providers,

insurers, local organizations, and state agencies to join PHAN and impacted consumers in using these stories as a foundation for a more inclusive healthcare system in the commonwealth of Pennsylvania.

Acknowledgements

PHAN would like to thank the following people whose support, guidance, and enthusiasm made this project possible:

Dr. Bernard Adukaitis
 Nicole Adams
 Pam Auer
 Mary Bachman
 Judy Banks
 Jennifer Ray Beckman
 Kathleen Bentley
 Jennifer Billig
 Susan Blue
 Susan Bolig
 Lisa Bollinger
 William Bressie
 Jackie Brehm
 Patty Brofee
 Cheryl Callahan
 Emily Camerer
 Victoria Chapman
 Tima Cummings
 Mark Davis
 Cliff Deardorff
 Oksana Dearment
 Erin Demcher
 Helen Denker
 Bob Derr
 Elizabeth Devett
 Melinda Diggan
 Misty Dion
 Lacrisha Diven
 Wendy Dombrowsky
 Chelsea Drob
 Danielle Duke
 Jessica Duperee
 Megan Epler
 Kelly Feiler
 Carol Ferez
 Jamielynn Fisher

John Fisher
 Donna Frye
 Glenda Fultz
 David Gates
 Larisa Geissler
 Bette Grey
 Brian Habermehl
 Brenda Harding-Albert
 Jay Harner
 Brendan Harris
 Patty Harris
 Sadie Hart
 Deanna Hartnett
 Melissa Hawkins
 Linda Heffelfinger
 Joanne Henry
 Anthony House
 Christine Hunsinger
 Jeff Iseman
 Leeshla Jimenez
 Ann Kalinoski
 Peter Keitsock
 Linda Kinne
 Mike Kinne
 Karen Koch
 Crystal L.
 Sherri Landis
 Jim Laughman
 Kaye Lenker
 Sue Lichtenfels
 Tim Longwell
 Denise Lorson
 Steve MacAnaney
 Brittany Malone
 Dawn Marron
 Matthew Martin

Laval MillerWilson
 Tessa Moore
 Abbie Morrison
 Eileen Musgrave
 Anna Murray
 Marie Prince
 Ray Prince
 Tammi Raabe
 Geysa Rodriguez
 Robert Roush
 Nadine Rubright
 Jessica Rusnak
 Terri Salata
 John Shosh
 Lisa Shosh
 Chris Smith
 Ryan Smith
 Tammy Snyder
 Cara Spatz
 Mary Strausser
 LeeAnn Thomas
 Dana Thompson
 Carol Thornton
 Eric Troup
 Leslie Updegraff
 Peg Van Schaick
 Arvind Venkat
 Dale Verchick
 Janelle Weaver
 Jerry Webb
 Koert Wehberg
 Sheri Welsh
 Michele Whitenight
 June Young
 Jim Yoxtheimer
 Beth Zong

We would also like to recognize the following organizations who contributed to this project by sharing information, providing feedback, connecting with consumers, and/or offering event spaces:

ABA in PA Initiative	PA College of Cardiology
AmeriHealth Caritas	PA College of Emergency Physicians
Anthracite Region Center for Independent Living	PA Council of the Blind
The Arc of PA	PA Cystic Fibrosis Society
The Arc Susquehanna	PA Department of Human Services
Autism and Behavior Resources	PA Department of Labor & Industry
Autism and Developmental Medicine Institute	Office for the Deaf and Hard of Hearing
Autism Diagnostic Resources and Services Avenues	PA Developmental Disabilities Council
Central PA Center for Independent Living	PA Disability Rights Network
Central PA Clinic	PA Family Network
Central Susquehanna Opportunities	PA Office of Developmental Programs
Central Susquehanna Sight Services	Bureau of Autism Services
Columbia County Volunteers in Medicine	Parent to Parent Connections
Community Care Behavioral Health	Parent to Parent PA
Community Services Group	PA Special Olympics
Community Strategies Group	PA Statewide Independent Living Council
Compass Community Connections	Performcare
Down Syndrome Society of the Susquehanna Valley	Perry County Coalition for Better Health
EOS Therapeutic Riding Center	Perry County State Health Center
Geisinger	Perry Family Partnership
Greater Susquehanna United Way	Pottsville Free Public Library
Grey Medical Advocates	Quality Insights
Hand in Hand	Rabbit Transit
Hope Enterprises	Rehabilitation and Community Providers Association
Juniata County Library	Redco Group
Juniata Food Pantry	Regional Healthcare Quality Unit
Juniata Valley Behavioral and Developmental Services	River Valley Health and Dental
Lehigh Valley CIL	Salvation Army
Merakey	Self Advocates United as 1
Mifflin County State Health Center	Schuylkill Autism and Special Needs Families
Mifflin-Juniata Area Agency on Aging	Schuylkill Transportation Authority
Mifflin-Juniata United Way	Self-Determination Project
North Central Center for Independent Living	Selinsgrove Regional Engagement Center
Northumberland County Administrative Entity	Service Access Management
PA Assistive Technology Foundation	Shared Support
PA Advocacy and Resources	Skills of Central PA
	Special Needs Parent Support Group
	Supportive Concepts for Families
	Union County Library
	UPMC

This publication is supported by a grant from the Pennsylvania Developmental Disabilities Council; in part by grant number 1901PASCDD-02, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

Copyright © 2020 Pennsylvania Health Access Network and Pennsylvania Developmental Disabilities Council. Permission to reprint, copy and distribute this work is granted provided that it is reproduced as a whole, distributed at no more than actual cost, and displays this copyright notice. Any other reproduction is strictly prohibited.