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## Study results

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To: Robert Roush <executive@thearcsusquehanna.org>

Absolutely. I think that opening a health clinic would be a needed and very impactful project, let me know if you decide to go forward with that.

We will be releasing a summary report after all the listening sessions are completed sometime in August. However, I already started compiling a list of the key issues, since there is a remarkable level of consistency in the problems people describe across the counties. Here's what I have so far, would love to hear your thoughts. I would add that another problem I've been seeing is that not every county has active social groups for people with disabilities, which increases isolation and prevents the sharing of relevant information.

## Key Issues

What follows is a discussion of issues which were fairly consistent across conversations so far in order of most to least frequently mentioned. I did a rough content analysis of notes from one on ones and surveys to determine the top issues.

I did not include a breakdown by county. This is due to the fact that stories so far are overwhelmingly consistent across the region.

In and around Lewisburg and Pottsville, two groups of parents emerged around the issue of access to ABA therapy. These groups have needs and concerns that were consistent with one another but distinct from the rest of the people surveyed. Their specific relationship to each of the key issues outlined below will be discussed in its own section.

### Transportation

This category includes both problems with NEMT and long commutes to provider sites. Long commutes are connected to a variety of other issues including insurance coverage, provider shortages and provider relationship. That is, people often need to travel long distances (1-3 hours each way) to access providers that are able to accept new patients, will take their insurance, and will treat them competently and with respect.

Those reporting problems with NEMT usually stated that the system works acceptably, but long wait times are hugely inconvenient and drivers may not have good disability competency. An additional problem is that consumers may require transportation for trips not covered by NEMT such as trips to the benefits office.

### Provider Relationship

Many people reported a dismissive and/or disrespectful attitude on the part of healthcare staff when dealing with people with disabilities. It was frequently reported that doctors (especially psychiatrists) do not take sufficient time with the consumer. They also may misdiagnose due to a lack of familiarity with the individual and their behavior. Medical issues may be mistakenly seen as behavioral and vice versa.

Some even reported that doctors do not value the lives of people with disabilities making comments like "He's already lived a long time for someone with this condition." It was reported that one doctor intended to

take a consumer off life support even though she did not have a terminal condition and eventually recovered.

Many residential care organizations reported difficulty communicating with hospital staff about an individual's needs. This frequently causes life threatening circumstances. Often an individual may have specific needs around eating or drinking and may refuse to eat or choke if those needs are not met. Residential care staff must often remain in hospital in order to make sure instructions are followed. The residential care organizations may have to eat the cost of this additional care.

Providers are often intolerant toward individuals which exhibit behaviors that are seen as noisy or disruptive and are unwilling to make accommodations for specific needs such as dim lighting for people with sensory-related disorders. Thus these individuals must seek out providers willing to accommodate them, further limiting their choice.

One organization reported that 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.

### **Provider Shortages**

Many reported an inability to find local providers, especially dentists, as well as GPs and psychiatrists. Choice is further limited by type of insurance (usually MA and Medicare), whether the provider is accepting new patients, and whether the provider is well qualified and willing to make needed accommodations. Wait lists are typically 1-2 years. Providers also overbook, which can lead to long wait times at the appointment, which may be particularly stressful for people with disabilities.

### **Understanding / Navigating Healthcare System**

Community members reported that needed information is often poorly advertised or not advertised, not consolidated, unclear, fragmented, or not articulated. They requested a more consolidated repository of information such as a website that would be easy to access and understand. Providers should provide this information when giving diagnosis.

### **Needed Services Not Covered by Insurance**

This issue was most frequently reported regarding ABA therapy. However, several other individuals reported insurance companies arguing about and/or refusing to pay for needed treatment such as overnight stays in hospital, prescriptions, surgeries, durable medical equipment, and others.

### **Dental**

A shortage of dentists that take Medical Assistance, whether for disabled or non-disabled people, was frequently reported. Wait lists are frequently 1-2 years. Consumers that require sedation due to intellectual disability/behavioral issues find it even more difficult to find a dentist. Individuals may require multiple visits to become comfortable, and many dentists will not accommodate this. For people on MA, dentists may favor tooth extraction as a less complex and costly "alternative" to procedures that may save the teeth.

### **Access to ABA**

See below.

### **Medical Equipment**

Although only reported by 2 disabled individuals, problems accessing medical equipment were consistently reported by staff at caring facilities. One staff member reported a 2 year wait period 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 reported that MA 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. MA would only pay for the thicker underwear for all circumstances, which is uncomfortable when worn during the day. Multiple types of wheelchairs for different circumstances are also desirable.

## Access to ABA

ABA (Applied Behavioral Analysis) is a form of intensive therapy which can improve communication, social skills, and other constructive behaviors. It is most often used with autistic children as a form of early intervention, but is relevant to other types of developmental disabilities and a variety of other contexts. ABA is considered a medically necessary treatment by the state for children with autism but not other types of disabilities. It has been shown to dramatically improve outcomes for children with autism if pursued intensively (25-40 hours per week for a period of 1-3 years). A child diagnosed with autism is typically prescribed a certain number of hours of ABA. It is best to start as early as possible and most children complete their course of ABA before age 6.

However, parents report multiple challenges to accessing the prescribed amount of quality ABA therapy.

Due to the lack of adequate reimbursement, many providers of ABA decline to accept MA. Families often require *center based* ABA (as opposed to a home, school, or community setting) due to the intensive nature of the therapy. However, center based ABA is not covered by MA and is often a specific exclusion on private insurance plans. In one case, an employer wrote in a specific exclusion after a family had tried to access ABA through their insurance plan. Families are often stuck paying for treatment out of pocket. This leads to an unacceptable financial burden (one family reported having to sell a car to pay for their son's ABA) and results in less effective treatment since families can not afford the prescribed number of hours.

Parents reported a shortage of qualified therapeutic staff. This is primarily due to the fact that providers in rural areas are not reimbursed adequately. This is a barrier to recruitment and retention of qualified staff.

As a result, wait lists may be 1-2 years. This is unacceptable due to the brief window in which ABA is most effective. The situation is so dire in Central PA that families frequently relocate.

Many parents of children needing ABA therapy reported an appalling lack of training on the part of therapeutic staff. Lack of streamlining and standardization of who can practice ABA leads to two problems. In the first case, MA requirements may force organizations to hire overqualified staff at an unsustainable cost, when less qualified staff working under supervision would be acceptable. In the second more common case, organizations may claim to offer ABA therapy but employ staff with only one day of training - in contrast to the graduate-level certification normally required of a Board Certified ABA therapist.

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