

TESTIMONY OF MARK J. MURPHY
CHIEF EXECUTIVE OFFICER
DISABILITY RIGHTS NETWORK OF PENNSYLVANIA

My name is Mark Murphy, and I appreciate the opportunity to testify today. I am the Chief Executive Officer of the Disability Rights Network of Pennsylvania. DRN is a state-wide, non-profit organization that advocates on behalf of people with disabilities and their families. DRN employs 60 staff, most of whom are full-time advocates and lawyers. DRN also operates a telephone intake system where people with disabilities and their families can call for help. DRN receives thousands of calls each year, which gives us a good understanding of the problems that people with disabilities in Pennsylvania are facing.

DRN does not provide direct services to people with disabilities, and none of the ODP payment policy issues which are being discussed here today will affect us as an organization. However, those ODP policies will have a profound – and negative – impact on people with intellectual disabilities and their families. My purpose today is to make the Committee

Protecting and advancing the rights of people with disabilities

aware of some of the significant negative implications these payment policies will have on the people for whom DRN advocates.

People with intellectual disabilities need life-long supports and services. Even a designation of mild intellectual disability (what used to be called mild mental retardation) is a very significant disability. Many people have profound intellectual disability along with other disabilities, such as blindness, inability to walk, or epilepsy. In many cases, individuals live with their families through much of their lives. But often families cannot provide all of the support their sons and daughters with intellectual disabilities need without help. For example:

- A single parent who works cannot keep her son or daughter at home without supports during the day.
- A family with several children may need assistance given the needs of both the person with intellectual disabilities and the parenting responsibilities for the other children.
- A family may need help managing their son or daughter's complex medical needs.
- Sometimes, given all that they must do, a family may just need a break to keep going.

Additionally, families often reach a point where they are simply no longer able to provide supports at home for the individual with intellectual disabilities. For example:

- A couple in their 80s may have their own medical conditions to address, which prevent them from being caretakers for their son or daughter with intellectual disabilities.
- The behavioral needs of the person with intellectual disabilities may be beyond the ability of a family to manage.
- A mother in her 50s who is undergoing treatment for cancer may be unable to care for her son or daughter.
- It also is important to note that often the years of going without any help take their toll, and the family just cannot keep doing it anymore.

There is only one place that these families can go for help. The only support available is under the Commonwealth's Medical Assistance program through one of two federally supported waivers. Private insurance does not cover the type of services that a person with an intellectual disability requires.

Intellectual disability services are generally provided by a network of providers, almost all of which are community-based, nonprofit organizations. The services can be provided in the home or in other home-like settings. These services are paid for by funding from the Office of Developmental Programs. Unlike other Medical Assistance funded programs such as hospitals or nursing homes, however, there is no private insurance or private payment going to these providers. If, as a result of changes in ODP's payment policies, there is a decrease in the amount funds available, costs cannot be shifted elsewhere. The providers themselves must absorb the effects of decreased funding, which in turn directly affects the people who rely on these crucial services.

We recently have seen two major trends that are directly related to changes in provider funding. First, it is increasingly difficult to find services for people with medical and behavioral complexities. Second, we see more and more critical situations where people are without services. As I will explain in more detail, these failures to ensure access to necessary waiver services not only hurt people with intellectual disabilities and their families, they also increase state and federal taxpayer costs.

Many people today will testify about ODP payment policies and why they not only are causing a decrease in the amount paid for some services

but also increasing uncertainty and distrust within the provider community. I wish instead to focus now on how these policies negatively affect the people who rely on these ODP-funded services.

People with complex behavioral and medical needs

As I mentioned previously, people with intellectual disabilities sometimes have other conditions as well. The two conditions that most often create service access problems are complex behavioral problems and medical needs.

DRN is frequently contacted concerning individuals who can no longer live at home, but for whom no provider is willing to develop services. There is no question that these people can live successfully in community programs. They are in the waiver, and thus ODP has a duty to provide services to them. Yet, DRN is repeatedly being told that changes in payment policies have resulted in no provider being willing to serve these individuals. As a result, they end up in much more costly emergency rooms, psychiatric hospitals, or state-operated institutions.

One DRN client spent more than a year after she was ready for discharge at a psychiatric hospital at a cost of over \$1,000 per day while ODP struggled to find a provider to serve her. This was not only a terrible

experience for the individual, but a terrible use of scarce resources. In addition, DRN has worked on behalf of numerous clients who are entitled to waiver services but due to a lack of a provider end up institutionalized at a state center at a cost to taxpayers in excess of \$250,000. Again, there is not only harm and injustice to the person with intellectual disabilities who is forced to leave his or her community, taxpayers also pay far more than is necessary when people are institutionalized.

Additionally, there are people with intellectual disabilities living in state psychiatric hospitals and state centers who do not need to be there and who want to leave. They cannot leave, however, because providers are not willing to develop programs for them given the current ODP policies. As a result, these people continue to receive services they neither need nor want, all at significantly increased taxpayer expense.

DRN has frequently been told that many providers facing decreased funding have reduced their clinical staff (such as nurses and psychologists). Not surprisingly, these cuts are having a profound impact on the quality of services and also help explain why people with complex needs are having trouble finding providers to serve them.

In addition, as fewer providers are willing to develop new services because of ODP's payment policies, people with intellectual disabilities also have less choice regarding which provider will serve them. Although Medicaid law requires that people have a choice of qualified providers, in practice this is often not the case. People with intellectual disabilities who should not be living together because of differences in age or gender or the existence of behavioral problems have been forced to share a home due to a lack of appropriate alternatives. DRN receives many requests to assist people who are having terrible experiences in their group homes because they have been placed with the wrong roommates. For example:

- DRN had a case involving a passive women living in a group home with a sexually aggressive male.
- DRN currently is working on a case involving two men living together who assault one another regularly.
- DRN also currently has a case involving two men who do not get along and strongly do not want to live together, but despite their wishes plans are being made to put them together in a group home.

Finally, and perhaps most alarmingly, DRN is now regularly seeing something that I have never seen before in my 25 years of working in the

intellectual disability system: People are being terminated from their services, including residential services, because providers claim that they do not have the resources to meet their needs. As I noted earlier, people with intellectual disabilities have nowhere else to go – there is no other service system where their needs can be met. If ODP's payment policies drive providers away from all but the easiest-to-serve people with intellectual disabilities, institutions will re-fill, costs will skyrocket, and Pennsylvania's proud history of leadership on the inclusion of people with disabilities in their communities will have been for naught.

People waiting for services

While not a payment policy issue, I would be remiss if I did not mention the thousands of people with intellectual disabilities who are desperately in need of services but for whom nothing is being offered because there is no money in the budget now under consideration to remove people from the waiting list.

- 431 individuals on the emergency waiting list are living at home with parents over 60 years old.
- 155 of the individuals on emergency waiting list are over 60 years old themselves.

- 700 students with intellectual disabilities will graduate from high school this year and then receive no services at all.

Please do not forget these people and the thousands of others who are waiting for service.

Thank you for the opportunity you have given DRN to address this committee on these critically important issues. I will be happy to answer any of your questions.

