

Testimony on Renewal of Medicaid Waivers for Individuals with Intellectual Disabilities

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Good morning Chairman DiGirolamo, Chairman Cruz, committee members, and staff. Thank you for the opportunity to testify before you today. The Department of Human Services (DHS) is aware this hearing was called in response to concerns about one aspect of the Department's proposed applications to renew two home- and community-based waivers for individuals with intellectual disabilities -- the impact on sheltered workshops. That topic will be addressed specifically, but first a broader context will be provided by describing the full range of advances DHS is making with the renewal of these two waivers.

There are two waivers to be renewed. The Person/Family Directed Support (PFDS) Waiver is a waiver that provides services that support 13,900 people living in the community with their families. The waiver has a per person cap which in the renewed waiver will be \$33,000. The Consolidated Waiver provides services to over 18,000 people with a broad range of services, including group homes, and without an individual cap.

The renewal of these waivers is based on a set of values and 13 recommendations published as *Everyday Lives, Values into Action* which was developed by the Office of Developmental Programs' Information Sharing and Advisory Committee (ISAC), a group made up predominantly of people with disabilities and their families. The 13 recommendations and accompanying strategies include increasing employment, expanding options for community living, increasing community participation, and supporting families throughout the lifespan.

These recommendations reflect what DHS hears from individuals and families – individuals who sometimes refer to themselves as “self-advocates,” want to fully participate in the life of their community. They want to work in real jobs and to make other contributions to the community through volunteer work and being part of civic groups; they want to spend time with friends and family; they want to have fun in the ways available to us all and they want respect. Families want

to make it possible for their family member with a disability to have all of those experiences. Families are the primary support for the majority of the people we serve. But families need support themselves - to shore up their efforts and to assure their ongoing capacity throughout their life time.

It is in our interest to support and invest in the dreams and hopes of self-advocates. The life that they want to live, an Everyday Life, will lead to better health by staying active and by having meaningful relationships and feeling connected to others. Self-advocates' desire to fully engage in the community and to work will lead to more independence and reliance on natural supports.

It is also in the commonwealth's interest to support and invest in families. By making it possible for family members to support their family member with a disability, people with disabilities will have a high quality of life and the request for out-of-home, 24-hour residential services, the most expensive and labor-intensive services in our system, will be delayed or avoided entirely.

DHS is committed to providing 24-hour residential services to everyone who needs them, but there is no question that as more people are successfully supported by families, DHS will be able to serve more people with the resources available.

So, let me tell you what is in these two waivers that advances the recommendations of *Everyday Lives* and honors the wishes and dreams of self-advocates and families.

To assure that everyone served by the Office of Developmental Programs has equal access to all services and opportunities, we will broaden eligibility to include individuals with autism. This is particularly important when we recognize that approximately 35% of individuals with the diagnosis of intellectual disability also have autism and that up to 50% of individuals diagnosed

as autistic also have an intellectual disability. The types of services and supports people need are the same regardless of their diagnosis.

To increase employment, we have added employment services to help people find and train for a job that is integrated in the community and at competitive wages. People served through the P/FDS waiver who are working toward employment will be permitted to exceed the financial cap. DHS-enhanced transportation for people who need to get to their job and partnered with the Office of Vocational Rehabilitation in the Department of Labor and Industry to expand their role in preparing young adults ready to transition from school to adult life.

To expand community living options, we are adding a supported living service to allow self-advocates, who do not need 24-hour support but who would like to live in their own apartments, to live on their own or with a friend under the umbrella of a provider agency who will provide support as needed and watch out for the person's overall quality of life. Without this service these individuals are likely to move into a group home which provides more than they need and can also be unnecessarily restrictive. This will make it possible for people to live on their own or with a friend and will assure families that someone will be present as needed and available all the time. We are adding tenancy service to help people find their own place and to accept the responsibilities of being a good tenant.

Life sharing is another cost-effective alternative to 24 hour staffed residential services. Life sharing has always matched up people in need of support with others in the community to share their lives together. The life sharing provider receives a payment, as well as training and oversight from an agency. In the waiver renewal, DHS is enhancing the reimbursement rate to encourage the development of life sharing and is opening the option for family members

including brothers, sisters, aunts, and uncles so they assure the continuity of family life with the needed support.

To support families throughout the lifespan DHS added family training, nutritional counseling, and therapies. We are making it easier for people to direct their own services including hiring and firing caregivers and are adding a “goods and services” option to the P/FDS waiver to allow people to spend up to \$2,000 of their allotted funds for things that would help but are not available through other waiver services. As an example, an individual could purchase a microwave that would allow more independence in preparing meals and reduce the need for on-going paid staff support. We have launched the supporting families collaboration across our intellectual disabilities system to focus on providing families with knowledge, skills, and support to plan for their family member and how services might support that future.

Lastly is the service that has created the controversy – Community Participation. It is important to understand that it is not only the recommendation in *Everyday Lives*, but it is the federal government that is prompting DHS to improve efforts in this area. The Americans with Disabilities Act, the Workforce Innovation and Opportunity Act, and the federal Home and Community-Based Services Rule emphasize maximum community integration.

Why? Interaction with a wide range of people in the community who are like us and with those different from us, those who work where we work and those who have other jobs, people who have talents and interests we share and those who have different talents and interests is what makes life wonderful. These planned and unplanned interactions stimulate our growth and life-long learning; they expand the circle of people we know and increase the possibility of making new friends, all of which decreases our loneliness and makes us feel like we matter. These exchanges inspire and motivate us to learn and grow.

With this understanding, DHS wanted to find a way to assure that every single person we serve will be guaranteed the opportunity to engage in activity in the community – not just physically in the community but through involvement in their community.

DHS has over 20,500 people in sheltered workshops and adult day training facilities every day and for the most part these individuals do not engage in community activity. Recognizing this and in order to hold on to over \$140M in federal funds to maintain these services, DHS proposed a required amount of participation be offered to every person in every facility. The original proposal, developed by a group of stakeholders, stirred a great deal of opposition. DHS went out and listened to families and providers to hear their concerns. The outcome is a revised proposal that achieves the guarantee to make it possible for each person to participate in the community, while leaving the decision of whether to not to participate in the community, and what type of and amount of activity they will engage in, with the person. Attached to this testimony, please find the stakeholder message DHS issued on March 3, 2017 explaining the initial and revised proposals.

In the end, what DHS wants is for everyone to be able to live an Everyday Life, with the same rights and opportunities for growth and learning we all have. Each person is unique and their hopes and dreams are unique. DHS wants to make sure that our services do not place unnecessary limits on their hopes and dreams and how they choose to live their lives, but instead make them possible. Thank you for the opportunity to testify today.