



Routes 413 & 213 • P.O. Box 36
Langhorne, PA 19047
215.750.4000 • www.woods.org

March 13, 2017

Written Testimony for the Record

Submitted electronically to Gene DiGirolamo at gdigirol@pahousegop.com.

Re: Department of Human Services' proposed renewals of the Consolidated and Person/Family Directed Support waivers

Good Morning Chairman DiGirolamo, Chairman Cruz and Honorable Members of the House Human Services Committee. My name is Dr. Scott Spreat, and I am President of Woods Programs and Chief Research Officer at Woods Services. Joining me today is Tine Hansen-Turton, President and CEO of Woods.

Woods Services is a non-profit organization that provides a continuum of highly individualized supports and services for approximately 4000 individuals with intellectual disability, autism, brain injury, challenging behavior, intensive medical needs, and various forms of emotional disturbance. We are a unique and one-of-a-kind provider in that the majority of individuals served by Woods are medically frail and behaviorally challenged. Our mission is to help people experience the joys of achievement while maximizing their personal potential.

Woods Services is headquartered in Langhorne, Bucks County, Pennsylvania, with five affiliate programs in both Pennsylvania and New Jersey. Our Langhorne based program provides educational, residential, health care, clinical and vocational supports and services to more than 630 people of all ages and levels of care with a unique model that drives greater achievement for individuals – and best practices for the industry. As part of these services,

Woods operates two sheltered workshops in Langhorne, and one sheltered workshop in Exton.

As we are all aware and are here to discuss today, in December, the Department of Human Services' (DHS) Office of Developmental Programs (ODP) issued proposed changes to its Medicaid waivers and program regulations that would have essentially eliminated day habilitation and prevocational services in favor of forced community placement. Pennsylvania has long embraced a commitment to supporting individuals with intellectual disabilities to exercise choice in how, where and with whom they live, a mentality that is consistent with the rights promised to these individuals both constitutionally and by the federal Americans with Disabilities Act (ADA). However, ODP's proposal represented a dangerous deviation from that commitment and would have narrowed the day program options available to individuals with intellectual disabilities running counter to the principle of choice embedded in "Everyday Lives," a framework for service planning promoted by ODP that is intended to provide opportunity outcomes that help people live the life they want and counter to recognizing that these individuals have the right to choose how to spend their time just like you and I.

This proposal was cause for great concern across the Intellectual Disability community and especially at Woods where the individuals served often have extreme medical and behavioral challenges. In addition to reducing choice, this proposal did not recognize that some individuals either by virtue of the magnitude of their disability or the seriousness of their behavioral health challenges, may not be employable within integrated settings or that these individuals find value and satisfaction from the work they are able to accomplish in a sheltered workshop setting.

However, since the initial proposal, ODP has circulated documents indicating their intention to revise their initial proposal in a way that would now require 25% community

integration for these individuals by September 2018 instead of 75% and allow for certain exemptions and increased consumer choice. Woods strongly believes that mandates on how individuals with intellectual disabilities must spend their time without consideration of individual circumstances is unnecessary and a threat to personal freedom, the proposed revisions from ODP represent an attempt at compromise and a thoughtful reflection on the comments received.

On behalf of Woods Services, we are here today to offer qualified support for this revised proposal regarding the renewals of the Consolidated and Person/Family Directed Support waivers. We believe that ODP, with the assistance of Chairman DiGirolamo's office, has modified their initial proposal in a manner that better respects the welfare and individuality of consumers and complies with the federal CMS Home and Community Based Waiver rule. I use the term "qualified support" because the details of the plan need to be solidified and shared in a formal manner, and I have every reason to believe that this will occur. Our support is for the conceptual approach most recently put forth by ODP on March 3, 2017. However, we still have some specific concerns that we would like to bring to the Committee's attention:

1. **Exception process** – We applaud the inclusion of an exceptions process that recognizes that some individuals, by virtue of the medical needs or behavioral challenges, are not going to be employable in a community setting. Some even may be endangered in the community. The authority for exceptions to derive from the treatment team as detailed in ODP's most recent notice, is supported by Woods. The team is closest to the consumer and has the best understanding of risks for each consumer.

We would not support an exception process that relies on a blanket "one-size-fits-all" bureaucratic decision.

2. **Choice** – A consumer can choose to not seek community employment if it can be demonstrated that his/her decision was at least supported by some relevant information and experience. This makes perfect sense. A decision without knowledge of all factors is not really a decision. For example, historically we saw how many families were satisfied with Pennhurst without knowledge of an alternative community system. Consumers should be given exposure to options so that community employment decisions are as informed as possible. That said, the critical role of consumer choice must continue to always be recognized in these regulations and any going forward. Disability does not eliminate the fundamental right for an individual to make choices and decisions or to choose how and when to participate in the community.
3. **Size limits** – The proposed size limit of 150 individuals for existing programs and facilities is acceptable. The 25 individual limit for new programs seems to be consistent with regulatory requirements for program specialists. I suspect that the low number will discourage entrepreneurs from opening such venues, which is likely the intent
4. **25% Community participation** – The revised 25% number is a reasonable target. There is wisdom in recognizing the shortcomings of an approach that entirely closes sheltered forms of employment, and we thank ODP for recognizing this after further thought. When Maine attempted to shift from sheltered work to more integrated forms

of employment, they witnessed a decrease in hours worked and number of employees working. In Vermont, the closing of workshops was associated with a decrease in the amount of supportive employment. In Oklahoma, there was no collateral increase in integrated forms of employment as the use of sheltered workshops declined. It does not appear that closing one alternative automatically opens another. An incremental approach will enable PA citizens with intellectual disability to maintain levels of employment.

While offering support for the ODP revised plan for increased community participation through day activities, I want to raise a cautionary note. We all recognize that there are not enough jobs out there. December 2016 U-6 employment was 9.2% nationally, and PA has been lagging behind the rest of the nation. We will not be able to find or create enough community based jobs to provide meaningful integrated vocational engagement, even for the proposed 25% of the time. So what activities will fill the vacuum? In Oklahoma, employment, albeit segregated employment, appeared to have been replaced by unemployment. Oklahoma providers refer to the filling of this vacant time as "Option Quest." Option Quest is a pejorative term used to describe made up day programs. Our concern is that Option Quest ultimately robs people of the joys of achievement and the personal sense of dignity that comes from actual work. We must take care that the 25% day programming, not devolve into trips to the gym, visits to the mall, and walks in the park. Wherever possible, the focus should be on work. We should not deny individuals the dignity that is derived from employment.

When Pennsylvania closed Pennhurst State School and Hospital in 1987 under Judge Raymond Broderick's order, substantial planning, preparation, and funding went into the process to ensure the welfare of those individuals leaving Pennhurst. And frankly, PA did a pretty good job in developing the community system to support those (and other) individuals who were transitioning from Pennhurst to community placement. A similar planning, preparing, and funding effort will be necessary if we wish to ensure meaningful integrated vocational engagement for individuals with intellectual disability.

Finally, Woods would like to offer a couple of suggestions that might increase the likelihood of success for this venture.

Suggestion #1 – Encourage providers to open for-profit businesses to employ individuals with and without handicaps. Woods Services has a demonstrated ability to create integrated forms of employment and believes these integrated models should be promoted across the Commonwealth. At Woods, we have opened a gift kiosk at a local mall and a small flower shop in a shopping center in Langhorne, PA. We rotate a relatively large number of individuals with intellectual disability through positions at these sites and we pay minimum wage, but most only are scheduled to work a few hours a week. We have elected to involve more people in the work, and refrained from hiring people without handicaps because they would take employment opportunities away from individuals with intellectual or developmental disabilities. Integration comes from the interaction with the general public at the point of sale. This program works very well, but has limitations. If the typical employee works only 5 hours per week, then what are we to do with the remaining 35 hours? "Option Quest" activities do nothing to enhance the personal dignity that derives from a job. As such, we rely on

sheltered workshops and enclaves as an acceptable alternative. Note that we aren't really making money in these projects, nor is that our primary intent. And it must be recognized that programs less healthy than Woods may need subsidies or incentives in order to open such businesses.

Suggestion #2 – Incentivize Employers to hire individuals with disabilities by giving consideration to tax incentives and/or subsidies. With high unemployment comes increased employer selectivity. Action must be taken to increase the probability of an employer hiring an individual with a disability. Such tax incentives would cover any financial loss sustained by a company thereby subsequently creating more integrated job opportunities for individuals with intellectual disabilities.

The core of the vocational engagement vs. "Option Quest" issue is a matter of values. Should people work, or is idleness acceptable? Woods sides with the value of work, noting that it affords dignity to the employees, it provides income that is necessary for real community integration, and the structure of work typically minimizes the exhibition of dangerous assaultive or self-injurious behaviors.

Woods supports and proposes that there be 100 percent meaningful day program that incorporates all levels and forms of vocational engagement as dictated by individual service plans and treatment teams. This should include competitive employment, supported employment, sheltered employment, and day activities for those who are not yet prepared to work.

I appreciate the opportunity to testify. If Woods can answer any questions or be of any assistance, please feel free to contact me at (215) 750-4015 or sspread@woods.org or our Director of Policy and Government Relations Kristen Erway at (215) 750-2985 or kerway@woods.org.

Very truly yours,

Scott Spread, Ed.D.
Senior Vice President/President Woods Programs/Chief Research Officer
Woods Services, Inc.