



**Written Comments of Richard Edley, President and CEO,
Rehabilitation and Community Providers Association (RCPA)**

**Before the Pennsylvania Senate Health and Human Service and
House Human Service Committees
Harrisburg, PA
June 5, 2019**

My name is Richard Edley and I am the President and CEO of the Rehabilitation and Community Providers Association (RCPA), a statewide association representing over 350 providers of health and human services across the Commonwealth, and our member organizations serve well over 1 million Pennsylvanians annually. RCPA is among the largest and most diverse state health and human services trade associations in the nation. RCPA members offer mental health, drug and alcohol, intellectual and developmental disabilities (IDD), brain injury, medical rehabilitation, criminal and juvenile justice and child welfare, and physical disabilities and aging services through all settings and levels of care for individuals of all ages.

I want to express my appreciation to the Chairs of the Senate Health and Human Service and House Human Service Committees for holding this hearing. My written comments deal with the Office of Developmental Programs' (ODP) Community Participation Supports (CPS) proposal.

I also want to thank the Office of Developmental Disabilities (ODD) and Deputy Secretary Kristin Ahrens. If this hearing were 1 year ago or even 2 months ago my position would have even more of an edge to it. But the department has listened and made some changes which certainly are in the right direction.

Often in politics and policy we look for compromise. So, you might ask- "as long as the department has made some movement, isn't that reasonable enough?"

The problem is that we are talking about people's lives. If policy potentially negative impacts tens of thousands of individuals and now only thousands- should we be satisfied? Should we be satisfied if even one disabled individual is negatively impacted?

In fact, that is my overarching concern about the topic today- community participation supports (CPS)- and many which come from ODP. Even well-intentioned policies can leave individuals behind, especially those with serious and complex conditions which require significant services and assistance. We can't leave those individuals behind.

At the highest level, the goal of the department is twofold:

1. Assist disabled individuals to participate in inclusive community activities to the highest extent possible, and
2. To assist disabled individuals in obtaining meaningful, competitive, employment in the community.

Who would be against these goals? It's what we should be doing.

The problem lies in the detail- the method to get to those goals.,

Consider the following:

1. The target is for individuals to be in the community 25% of the time. The deputy secretary and I visited one facility last week- Cambria Association for the Blind and Handicapped (CAB). CAB has created a tremendous industry in Cambria County supporting hundreds of disabled individuals to competitively work. This target of 25% literally means taking people away from their paid facility jobs to go into the community- To go to a coffee shop? The mall? To volunteer at a local library?

And 25% means just over a day a week, making scheduling very difficult- even 20% (i.e., one day per week) would have made more sense in planning.

2. Individuals are required to go into the community in groups no larger than 3. With staffing shortages everywhere, this is a significant burden to recruit, hire, and retain staff to meet this artificial target. And if you take the three individuals out into the community and run into 3 other disabled individuals being served by a different agency you have to find a new location- because now you have 6 disabled individuals together which does not meet the artificial target. We have lost the forest for the trees.
3. Individuals with significant medical and/or behavioral needs can get a "variance" and remain in the facilities- but there the rates are low enough such that providers must consider potentially closing the facilities or programs for those who are not going out into the community 25% of the time or more.

These individuals are those most in need of services and would now be forced to simply sit at home with no services. If this is their family home and not a community residence, then family members who work would need to shift their schedule to be at home to care for their loved ones.

4. Community activities are limited. Especially free ones. Imagine every week trying to find 1 ½ days in the community? Could you do it in a meaningful way? And think of the challenges in rural areas. And this is in lieu of the individual being in a facility working and getting paid.

And there are additional practical concerns- the need for public bathrooms, for example. The need for medical assistance when in public; helping one individual while other disabled individuals are now without supervision. The staffing challenges, and the liability/risk is high.

5. And the rates. The base assumptions behind them are in many cases not accurate or complete. Not only what I have referred to thus far in terms of staffing, but add training requirements, vacation, sick time, increased need for transportation and vehicles, insurance, paying for activities and meals- it is not as easy as "get everyone out 1 ½ days per week in groups of 3 or less".
6. Finally, the entire policy does not take into account the person's whole life. They might be in the facility working a full day and not going out- but then they go out at night or on the

weekends with family or their peers at their community home or through some other activity/ group. Like we all do. But this policy only looks at the slice of time that the individual is with the facility as if that is the totality of their life. What if the person just simply does not want to go into the community that day? What if it's raining or snowing? This is the real world that we live in.

In sum, the policy might work for very high functioning individuals who can pretty independently work and navigate through the community. That's not who I am talking about. I am/ we are worried about those most in need, those with serious and complex needs who require 24/7 assistance and supervision. Getting variances for these individuals does not address the fact that if costs are not supported, programs may close, and these individuals will not have services.

I ask that ODP continue to look carefully at the impact of these policies and rates and consider mid-year, continuous, changes and exceptions. I know that is harder and more complex to implement. So more typically we see problems and then focus on proposing changes in the upcoming fiscal year. That would mean watching the impact of CPS over the next year for potential changes in July 2020. If even one individual is negatively impacted through these policies, that is too long to wait.

Again, thank you and I would be glad to take any questions.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Edley', with a stylized, flowing script.

Richard S. Edley, PhD

President/CEO

Rehabilitation and Community Providers Association (RCPA)