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Deinstitutionalization is possible.

There are myths, assumptions and misconceptions about deinstitutionalization. As a community, we need an open discussion of how to plan for a future. People with disabilities and their families want to live, work and play in their community like anyone else. Individuals should never have to give up their civil rights in exchange for services. We need to discuss how to move forward and begin a coordinated effort to close all large congregate segregated facilities. It is the right thing to do.

The National Council on Disability published a report in 2012 titled: Deinstitutionalization: Unfinished Business. We have provided you a copy of part of that report.

This report is helpful as a starting point to begin a discussion of how best to move forward. We need to dispel some of the myths around the issue.

Myth: PA needs institutions to serve the “most difficult to serve”... those who are medically fragile, have dual diagnosis, and those involved in criminal justice.

Reality: Eleven other states closed public institutions and developed the capacity to serve everyone in the community. They used approaches such as Person Centered Planning, integrated supports with medical or psychiatric care, crisis teams, stabilization services and specialized housing.

Myth: People in institutions are more severely disabled those who live in community, and no evidence shows that they can be served effectively in the community.

Reality: There are MORE people with extensive support needs in the community. Many people in institutions require a high level of services...but many people like them are already living in the community and being supported – often with their families.

To illustrate this, data from California (page 40) 18% of people in institutions and 5% of people in community are dependent on medical technology. More than 80,000 people are in community compared to just over 2,000 in state institution, thus more than 4,000 technology dependent people live the community and only 405 are in state institutions.

Myth: Closing the State Centers will not save money.

Reality: The average cost serving people in the community shows us that it is cost effective. While some people leaving State Centers will cost more than the average; closing an institution will yield overall savings to the system over time. The report shows on pages 40-43 how cost savings are

demonstrated and will vary by state. I have provided a bar graph with the cost per setting for people in Pennsylvania for your reference.

Also, when you look at our state budget, you will see that the cost to maintain our state centers increases every year, even as the population decreases.

	2012/2013	2013/2014	2014/2015
State Centers costs	4% increase	12% increase	9% increase
Population	1,112	1,060	970

There are discussions in the Office of Developmental Programs about how our community system needs reforms to make it sustainable over time, and the ODP Futures Plan is intended to address some of those changes...clearly the State Centers are not financially viable over time --- but changes to that system were not included in Futures Plan.

But really this is not about money...it's about civil rights and quality of life.

Myth: Lives of people with ID don't change significantly when they leave the institution.

Reality: Life in the community provides for freedom, dignity and a sense of belonging that is not possible in an institution. There have been a number of studies that all show that quality of life improves when people leave institutions and there are positive outcomes on health, competence in daily living skills, and people will have more opportunities to acquire new skills.

People in community have more relationships and friends and also report to like where they live at a much higher rate. See comparison on page 50 of quality of life indicators from the National Core Indicators project.

I have highlighted some of the research and data that supports deinstitutionalization; you can read the entire report to gather more information. Pennsylvania can learn from the 11 other states that have closed their state institutions.

Our Recommendations:

1. Develop a plan to close the State Centers and commit to fully funding a robust and responsive community system capable of supporting all people with intellectual disabilities and autism. Each person in community must be fully and appropriately served.
 - Improve or enhance the current service definitions to allow for real person centered supports based on assessed need. Remove restrictive language and allow providers and families the flexibility to design and organize services.
 - Adequately fund the enhanced community based services to meet the needs of individuals with complex situations. Support providers to meet needs, especially individuals with medical and behavioral challenges.

2. Create Mobile Crisis Teams and short-term stabilization services. Individuals who are medically fragile and those with a dual diagnosis (mental illness and intellectual disability) are more likely to experience a crisis that threatens their ability to successfully live in the community. Georgia established mobile crisis units that could respond quickly anytime of the day or night. They have been highly effective in providing immediate and short term services to avoid placements. See details on page 39.
3. Convene a review panel comprised of experts from the Department of Public Welfare, the Office of Developmental Programs, the governor's office and the legislative branch to provide oversight regarding each and every admission to Private Licensed Facilities, Intermediate Care Facilities, State Centers and Nursing Homes. Each branch of government has a responsibility to the people of this state to assure civil rights are being honored and that all people receive highest quality care in their community.
4. There needs to be accountability and transparency in what is happening in the community system. We need regular reports from the Department of Public Welfare describing what is happening that caused individuals to get placed in institutional settings. We request a quarterly report of placements in State Centers, Nursing Homes, ICFs and PLFs. When there is understanding as to why the community system is failing in these cases, the stakeholders can make changes and recommendations to improve the system.

Pennsylvania ranks 9th highest in the nation in state center population; we can do better. While we have moved from housing nearly 10,000 people in state centers in 1977 to just around 1,000 now...it is time to take the next bold step and close the remaining 5 State Centers.

"Deinstitutionalization is a human and civil rights issue. People should not be required to give up their rights to receive the services they need." (page 13, NCD report)

Thank you for your time and consideration.