

Sunday Forum: Life on the outside

Everyone deserves a chance to live in the community, says Robert Stack

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Bernard Krakosky works as a receptionist for New Jersey's Department of Human Services. He owns his own condominium and, at one time in his life, he resided in a state institution.

Bernard is an example of what a person with a disability can accomplish when given the opportunity. He can make his own decisions. He has become independent and able to live life to the fullest and realize his potential.

This is not a right afforded to the 50,000 people living in the nation's state developmental centers, institutions for people with developmental disabilities. Pennsylvania operates five centers with a total of 1,200 residents, including the Ebensburg Center in Cambria County and Polk Center in Venango County. Western Center in Canonsburg closed in 2000.

Many of these individuals can live in the community and flourish in the community yet are segregated to institutions while millions of dollars are wasted on keeping them there. This is a matter of basic civil rights. Individuals living with developmental disabilities have a right to choose where they want to live. They have a right to freedom, opportunity and life in the community.

Since the implementation of federal regulations in 1988, there has been a major shift in thinking in the field of developmental disabilities. Emphasis is now on people living in their own homes, controlling their own lives and being an integral part of their home community. Under the regulations, states must undertake all reasonable steps necessary to allow people with developmental or mental disabilities to live in the community to the fullest extent possible.

State developmental centers have received unfavorable ratings by federal regulators and subsequent investigations by the Department of Justice, citing violations of the Civil Rights of Institutionalized Persons Act. Despite a settlement agreement, the threat of decertification and attendant loss of federal funding is real, and would be financially catastrophic for many states. The average cost for a person living in the developmental center is roughly \$233,000 as opposed to \$86,000 for a person to live in a home in the community. Closing down the developmental centers would appear to be a no-brainer. For each person transitioned from a developmental center to a community-based program, states may save on average up to \$147,000 per person. These savings are more than enough to fund additional community resources and still yield a profit.

The rest of the country seemed to have it figured out. Across the country, 140 institutions for people with developmental disabilities have closed and reallocated funding to community-based services. The District of Columbia and 10 states have no state-operated institutions for people with disabilities (Alaska, Hawaii, Indiana, Maine, Minnesota, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia). Michigan is scheduled to be next, as its last 61 institutional residents will move to the community by September, and there are six other states with fewer than 100 institutional residents. The national trend is closing costly institutions and investing in community services.

People argue that those who require intensive care will not be safe living in the community. Yet many other states have successfully closed all or some of their institutions, placing those with significant medical needs in the community with successful strategies to support them. Studies have shown that people with challenging behavior and/or psychiatric disabilities have found improvements in their behavior after moving into the community from an institution. Those with complex medical needs can have specialized medical services created in their community residence. We know from research that with careful planning and implementation of needs, people with complex medical concerns can live successfully in the community.

Research shows that moving people out of segregated living situations into the community has a positive effect on those who get this opportunity. Their quality of life is significantly improved. They have the opportunity to make choices in areas of their lives that they did not have a say in previously, such as their meals, outings, housemates and employment. These are decisions that you and I would take for granted but that 50,000 of our fellow citizens today are not able to make.

We are doing a huge disservice to our citizens living in the states' developmental centers. They are people who should be afforded the same rights as any citizen, yet they are segregated to living in institutions with limited freedom of choice and

other rights.

I have witnessed firsthand people who have thrived after leaving an institution. They become active members of their community who are gainfully employed. We have seen people who have been tax burdens become taxpayers. We hope to see many more.

Robert Stack is president and CEO of Community Options Inc., based in Princeton, N.J., which provides homes and employment to more than 1,100 physically and mentally challenged individuals in 10 states, including Pennsylvania. He is a native of West Elizabeth.

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