Arc Testimony on the Closing of Murray Developmental Center

The Commission on Governmental Forecasting and Accountability

April 20, 2012

The Arc represents infants, children and adults with intellectual and other developmental disabilities.

The Arc and other advocates have been calling for the rebalancing of the disability system for many years. We are committed to working with families at the Murray Developmental Center and other state institutions to ensure a safe and meaningful transition into community living. There is no question that this is an emotional time for families. We want those living in Murray and their families to know that they are not alone. The Arc is committed to being their partner and offering resources to make this transition comfortable and productive. We have helped people with the most severe disabilities successfully transition into a community setting, and they are eager to share their experiences and offer support. Yes, a safe transition for individuals who require 24-hour care has already been done in Illinois, and The Arc and its partners are committed to helping more people with disabilities live life in their communities with independence, equality and opportunity. See the success stories of four individuals who now have the freedom of community living at the end of this testimony on page 4.

The Governor has developed a Rebalancing Initiative bringing in national experts to assist individuals and their guardians to make a safe and secure move to community living. The approach is very different from past state institutional closings because it requires the full participation of the individual and their guardians every step of the way utilizing a person-centered approach. This could well be a national model for institutional closures.

Members of the Commission should vote to support the closing of Murray now that the administration has developed a comprehensive and progressive plan for closing Murray.

The Arc believes it is imperative that state institutions be closed in Illinois. In Illinois, thousands of individuals have successfully transitioned from institutions to community living. We believe that many of the current individuals now living in CILA have successfully transitioned from state institutions and nursing homes. We know how to do this.

Community living offers people with disabilities a safer way of living with quality, independence and equality.

Let's do a review of what state and national experts on intellectual disability systems have to say about Illinois. All of their reports state that Illinois needs to be re-balanced by closing state institutions and supporting community living.

1. A Quest for Equality: Breaking The Barriers For People With Disabilities, A Call for Action For Illinois Leaders, The Chicago Community Trust, 2011.
2. The Blueprint for System Redesign in Illinois, Human Services Research Institute, 2008.
3. State Funding of Community Agencies for Services Provided to Illinois Residents with Mental Illness and/or Developmental Disabilities: Final Report to the Illinois General Assembly, Elizabeth T. Powers, Ph.D., University of Illinois, 2006.
4. Financing Service to Individuals with Developmental Disabilities in the State of Illinois, Robert Gettings, National Association of State Directors of Developmental Disabilities Services, 2003.

There are also two recent Legislative Resolutions calling for re-balancing the Developmental Disability System in Illinois.

1. Senate & House Joint Resolution 15 – 2011
2. House Joint Resolution 28 – 2009

There is also tremendous editorial support for re-balancing the disability system by closing state institutions, including most recently the Chicago Tribune's, Sept 30, 2011 editorial, *Moving to Community Care – State-Run Centers for Developmentally Disabled Finally on the Way Out!* and the Chicago Tribune again, Jan. 27, 2012 editorial, *A Change for Better Treatment: No Reason to Fear Community Care;* State Journal Register, Feb 29, 2012, *Address JDC Fears, Make Care Transition.*

Editorial boards supporting re-balancing:
1. State Journal Register – Feb 27, 2012
2. Chicago Tribune – Jan 27, 2012 (See page 10)
3. Chicago Tribune – Sept 30, 2011
4. Chicago Sun Times – June 15, 2011
5. Chicago Tribune - May 23, 2011
6. State Journal Register – May 22, 2011
7. Pantagraph – May 22, 2011
8. Rockford Register Star – April 27, 2011

There are now 14 states without state institutions including our neighbors (Page 9 for the full list):
1. Minnesota – 2000
2. Indiana – 2007
3. Michigan – 2009

Nationally, the trend is very dramatic in states closing their state institutions from 1968, a high of 194,650 individuals in state institutions to 33,732 in 2009. See the chart in this testimony. (Page 8)

Ask yourself, "Is this where we as public servants should be investing scarce resources for our state?"

The national research of outcomes of closures and deinstitutionalization is extensive dating back to 1982 through 2011. The findings are quite conclusive on outcomes regarding quality of life, adaptive behaviors, and health of individuals and satisfaction of families:

1) Improved quality of life, including more choice-making opportunities, more friends, greater community participation, and greater residential satisfaction.[i]
2) Improved adaptive behaviors, including social skills, self-care, and domestic skills and inconsistent results regarding challenging behaviors.[ii]
3) Similar or improved health status and health care access, with some difficulty in accessing some types of health care such as dental services, and less polypharmacy.[iii],[i]
4) Greater satisfaction of families with community placement versus the previous institutions, despite the fact that many families initially opposed deinstitutionalization.[1,iv]

Everyone can live in the community with the proper supports.

It is imperative that the individuals at Murray be properly supported for a successful transition to community living.

We already know how to do this.

What we need now is the political will to do the right thing and move this antiquated institutional system into a community system that supports everyone based upon their individual needs.

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[i] Kozma, A., Mansell, J., and Beadle-Brown, J. (2009) Outcomes in Different Residential Settings for People With Intellectual Disability: A Systematic Review. American Journal of Intellectual and Developmental Disabilities 114(3) 193–222.

[ii] Lakin, K.C., Larson Kim, S.A., and Kim, S., (2011). Behavioral Outcomes of Deinstitutionalization for People with Intellectual and Developmental Disabilities: A Review of Studies Conducted Between 1977- and 2010. Policy Research Brief, April 2011, Vol.2, No. 2, pp. 1-12.

[iii] Hayden, M., Kim, S.H., and DePaepe, P. (*2005*) Health Status, Utilization Patterns, and Outcomes of Persons with Intellectual Disabilities: Review of the Literature. Mental Retardation: June 2005, Vol. 43, No. 3, pp. 175-195.

[iv] Larson, A. and Lakin, C. (1991), Parental Attitudes about Residential Placement before and after Deinstituitionalization: A Research Synthesis. JASH, 25-38.

Billy Ray

Billy Ray has severe developmental disabilities and has a behavioral health condition. He has now lived in a CILA home for two years. He has health issues that require close monitoring, but in general he is calmer and happier. He has his own room. He likes to help around the house. He enjoys listening to music, walking in the neighborhood, going to workshop, shopping for groceries, dining out, and attending the occasional baseball game. He is living a life that no one thought was possible except his mother. His first community agency closed, so he went to Howe Developmental Center at the age of sixteen. After over twenty years at Howe, he moved to another community provider but it didn’t work out. He came back to Howe, where he lived for several more years. His mother was concerned about his health and safety at Howe. She felt that his autistic characteristics were overlooked and that noise and stress caused him to act out. With the proper supports, Ray is doing well in the community.

Helen

Helen lived at home until she was an adult. She has autism and had become aggressive and self-abusive. She moved to Howe Developmental Center, where she lived until she was 48. She has now lived in a CILA home for several years. She has her own bedroom and has a kind of peace and independence she’s never experienced in her adult life. She makes her own snacks and takes care of her own things. Her speech and ability to relate to other people has dramatically improved. She has a best friend and friends at her workshop. Helen enjoys parties and activities, but most of all enjoys sleeping in on a Saturday morning if she wants to and doing things at her own pace.

John

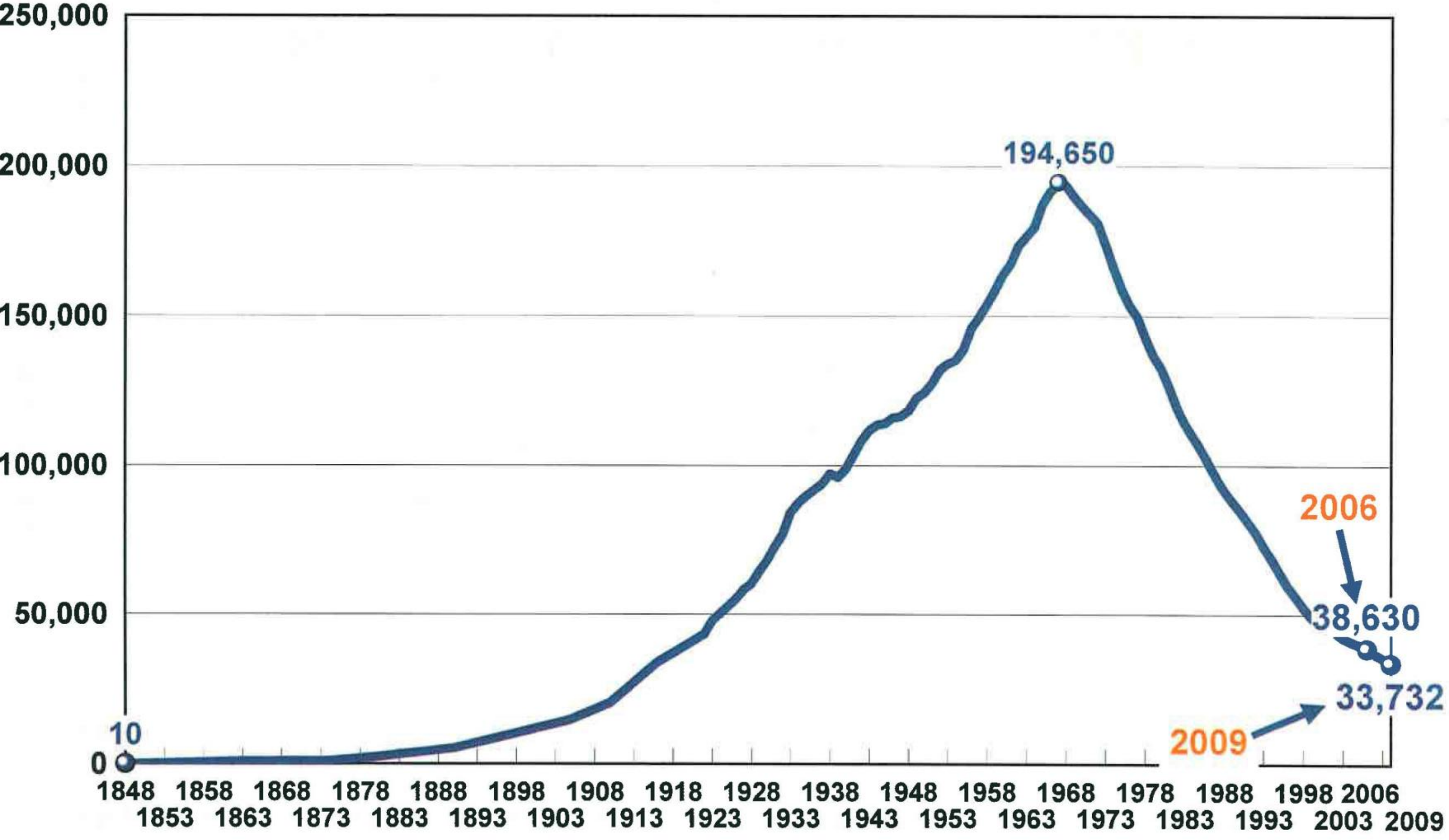
John has lived in a number of homes in the community over the years. Some worked out better than others. He moved to Howe Developmental Center after one such failure and lived there for a number of years before moving to another CILA home, where he has lived successfully for several years now. He is now able to see his parents more frequently. John has his own room and doesn’t have to put up with others moving his possessions around. He has a cell phone and likes to keep in touch with his many friends. He enjoys sports and listening to the radio. John is very proud that he’s achieving his goal of having a real job, working at McDonald’s several days a week. He loves to advocate for himself and others. He belongs to advocacy groups, his agency’s human rights committee, and has testified on the need for rebalancing and has met with legislators and members of the media.

Willa

Willa lived most of her adult life at Howe Developmental Center. She now lives in a CILA home and attends the same workshop she did when she lived at Howe, so she's kept in touch with her friends there. Her new home (for over two years now) is on a quiet street in an attractive neighborhood. She is responding well to the calm environment and has learned new words and phrases. She uses a wheelchair and the home is fully accessible. Her meals are pureed for her. She likes parties, movies, and dining out, but she also has personal shopping days for her own errands.

STITUTIONAL RESIDENTS WITH I/DD THE U.S.: 1848-2009

coleman institute
for Cognitive Disabilities
University of Colorado System



ource: Braddock, D., State of the States in Developmental Disabilities, 2011.

Excludes nursing facilities [32,469 persons in 2009].

There are Now14 States Without State-Operated Institutions*

1. District of Columbia (1991)
2. New Hampshire (1991)
3. Vermont (1993)
4. Rhode Island (1994)
5. Alaska (1997)
6. New Mexico (1997)
7. West Virginia (1998)
8. Hawaii (1999)
9. Maine (1999)
10. Minnesota (2000)
11. Indiana (2007)
12. Michigan (2009)
13. Oregon (2009)
14. Alabama (2012)

*Challenges in Developmental Disabilities: State of the States, State of the Nation, 2011, D. Braddock, Ph.D., Arc US Convention.

Chicago Tribune

Breaking News, Since 1847

A change for better treatment

No reason to fear community care

January 27, 2012Gov. Pat Quinn announced plans last week to close two state mental health institutions and move their patients into community-based care. The governor is getting a ton of heat over this decision, from politicians, from parents of patients and from community leaders. Rep. Jesse Jackson Jr. said the state is "balancing its budget on the backs of our most vulnerable citizens."

Quinn is making the right decision. He's making a sound decision in terms of public health and the state's financial health.

The facilities that Quinn has targeted should have closed decades ago.

At the Tinley Park Mental Health Center in south suburban Chicago, just five of eight buildings on campus are operational. The federal government decertified it in 2009 amid quality concerns.

The downstate Jacksonville Developmental Center dates in part from the pre-Civil War 1850s. The state pays $1.2 million a year to buy coal for its antique heating system. The governor plans to close Tinley Park in July and Jacksonville in October.

This will result in a huge fiscal payoff for the state. Illinois spends on average between $150,000 and $210,000 every year to support a person in a state facility for developmental disabilities, according to the governor's office. The annual average cost in community care is $45,000 to $84,000.

If this were purely dollars and cents, if it put residents at risk, it wouldn't deserve support. But this is the right health care decision, too.

The evidence shows that community settings will give better care for the residents of the state facilities. It has worked in most states across the country that have undergone the shift. Illinois has the luxury of learning from the experience of Michigan, for instance. Quinn's staff has incorporated some important lessons into his plan — such as a person-centered approach and a commitment to follow-up monitoring.

The transfer creates some uncertainty for the residents and their parents and guardians. Citizens who have serious mental-health conditions are a vulnerable population.

The governor, though, has established a clear, workable framework for managing the transition to community care. His plan for closing these inefficient facilities takes every reasonable precaution. It puts the interests of residents first — as it should.

Each individual will receive a personal evaluation to determine the best possible placement. Families and guardians will play an active role in the determinations. Funding will follow each person to his new home. If a state-run institution is the best option, that will be available through other facilities that remain open.

After the transition, many people now locked into restrictive environments will live with greater freedom and comfort in smaller-scale homes located closer to their loved ones.