

# Community Integration Makes Sense

March 24, 2015

The Arc of Illinois and the Going Home Campaign are calling on the state to close 6 of the 7 state-operated institutions by 2020.

The research and data prove that Illinois can no longer afford to operate a dual-system.

The Arc has developed this white paper, "Community Integration Makes Sense" to supply advocates with data on developmental disabilities services, housing and community integration.

Additionally, we have been working on a proposal based on economics and social justice to invest in community programs so people with all disabilities have the opportunity to live in the community just like you and me.

The Arc has compiled several reports and sources for you to better understand how Illinois ranks nationally with disability programs and to share this message with policy makers. I am confident that policy makers will clearly see the benefit of downsizing state institutions and investing in Community Integrated Living Arrangements (CILAs).

Generally speaking, a developmental disability is a diverse group of chronic conditions that are due to mental and/or physical impairments. Developmental disabilities cause individuals living with them many difficulties in certain areas of life, especially in "language, mobility, learning, self-help, and independent living". Developmental disabilities can be detected early on, and do persist throughout an individual's lifespan.

Some basic data on individuals with intellectual and other developmental disabilities, IDD:

1. One in 63 births are infants with intellectual and/or developmental disabilities (IDD).
2. There are 220,000 infants, children and adults with IDD in Illinois.
3. There are 32,732 caregivers aged 60 years or more in Illinois.\*
4. There are 22,811 children and adults on the Illinois PUNS Waiting List. (Those waiting for critical disability services.)

Illinois is extremely institutional in the supports/services available to individuals with IDD. As a result, Illinois is ranked among the lowest in the nation for funding and support for people with disabilities to live full lives in the community and there are only two states that have more people with disabilities institutionalized. Here are some quick facts about how Illinois ranks compared to other states:

- Illinois spends \$428,754,550 annually on State Institutions\*\*
- There are 1,730 individuals in seven fully operational state institutions, 3<sup>rd</sup> highest in the nation.
- Community Fiscal Effort Ranking is 47<sup>th</sup>\*
- Size of Residential Setting Ranking is 50<sup>th</sup>\*

- 14 states/jurisdictions have closed ALL state institutions.
- 49 of 51 states (including the District of Columbia) downsized institutions between 2011 - 2013. The two states that did not downsize increased the institutional population by four people with a total of just 195 people in institutions.

Facts about funding community programs:

- The state can fund 4.5 people in the community for every one person in an institution.
- Illinois is spending an average of \$248,000 per person for institutional care vs. the average cost of \$54,000 for offering improved supports and services in the community.
- The average Community Integrated Living Arrangement (CILA) has 6-8 people. The ideal living situation is no more than four individuals.

Nationally, because of the Olmstead Supreme Court Decision, the Americans with Disability Act and other federal statutes, the Centers for Medicare & Medicaid, Dept. of Health and Human Services and the Dept. of Justice are calling for more person-centered services that are integrated into the community such as housing, employment and meaningful day supports. The recently released Centers for Medicare & Medicaid rules on community residential and day services are the outcomes states are expected to transition to in the next four years. In my opinion, this is going to be very problematic for the underfunded Illinois Disability System which is heavily reliant on institutional service delivery.

Illinois now has three Olmstead consent decrees. The one that directly relates to the Developmental Disability System is the Ligas Consent Decree. The Court Monitor's Reports have expressed concern about low rates for community services, the need for small accessible housing and meaningful day services, including employment for Class Members.

See Arc Fact Sheet, "Court Monitor Ligas Implementation Concerns".

Because of an antiquated and inflexible Medicaid Adult Home & Community-Based Waiver, residential options are for the most part available in large CILA Group Homes (6 to 8 people) Intermediate Care Facilities for IDD for 16 People or State Operated Institutions. There are some smaller CILA Group Homes and Intermittent CILA, but they are by far and away the exception to available housing options for people with IDD here in Illinois. Illinois is now ranked nationally 50<sup>th</sup> in the nation in small residential settings only behind Mississippi. Nationally the average number of persons living with IDD in a residential setting was 2.3 people in 2011. Here in Illinois, we are talking about four people living together as the goal, which is out of line with the rest of the national trends at 2.3 people in community living settings.

See Arc Fact Sheet, "Average Number of Persons with IDD per Residential Setting".

Recently disability advocates have been insistent upon developing smaller, more person-centered housing options including but not limited to supported living, duplexes, apartments, condominiums and host homes. These living arrangements can be held by

the consumer, provider, family/guardian, or host family. The idea is to expand residential options beyond traditional models and open more, less expensive options, some of which can be consumer or family directed.

See Fact Sheets, "Basic Housing Options for IDD," and "Developmental Disability Housing Recommendations".

At the center of building an inclusive community system of services and supports is the need to move away from and to continue closing costly and antiquated state operated institutions. Closing expensive state institutions and reinvesting those resources in community services/supports is what other states have done to build contemporary community services for individuals with IDD. Illinois has seven fully operational state institutions at a cost to taxpayers of \$428,754,550.\*\*

There are now 14 states without any state institutions in the nation. There are also 10 states with 129 individuals in state institutions (2013 numbers so could be less) so in the not too distant future half of the states will no longer have state institutions.

See Arc Fact Sheet, "14 States Without State Institutions".

In Illinois we have seen the slow reduction of individuals living in state institutions. According to the "State of the States" in 1977, Illinois had 6,394 individuals with IDD living in state institutions. In 2015 according to the Illinois Dept. of Human Services, Division of Developmental Disabilities, there are currently 1,730 individuals residing in seven fully operational state institutions at a cost to taxpayers of \$428,754,550. The average per person cost of state institutions in Illinois is \$247,835 and rising. This amounts to a daily cost of \$679.00 per person. Compare that to the average cost of CILA in the community of \$53,627 per person, but I would point out that this figure is too low and needs to be adjusted upward to support settings of four individuals or less.

See Fact Sheet, "Daily Census of ID State Institutions: 1848-2013".

We know how to move people from state institutions into the community. Illinois has been doing this a very long time. The closure of the Jacksonville Developmental Center, JDC, was a remarkable effort that in the end resulted in 89.2% of the guardians interviewed by UIC reporting they were very/somewhat satisfied with the new community setting. In addition, 14 individuals with IDD were interviewed who moved out of JDC were "very happy in their new homes."

See "An Evaluation of the Jacksonville Developmental Center Closure: Preliminary Results".

Nationally as states began to close state institutions it became common practice to do research on the outcomes of the closures. In research dating back to 1980 and including the most recent research here in Illinois of the closure of the Jacksonville Developmental Center, the outcomes have been consistent. The research has found:

1. Improved quality of life
2. Improved adaptive behaviors
3. Similar, improved health status and health care access
4. Greater satisfaction of families

See Arc Fact Sheet: "Research of Outcomes of Closures and Deinstitutionalization".

In Illinois there have been numerous studies and expert reports all coming to the same conclusion: that Illinois is a very institutional state. All of these reports called for the inclusion of people with IDD in the community by closing state institutions.

See Arc Fact Sheet, "What The Experts Say About The Illinois Developmental Disability System".

In addition, there has been strong editorial support for community inclusion of individuals with IDD. Over the years, The Arc has met with editorial boards on this very topic. The following editorial boards support investing in community services by closing antiquated and costly state institutions: Chicago Tribune, State Journal-Register, Pantagraph, Rockford Register Star and the Chicago Sun-Times.

See Arc Fact Sheet, "Editorial Support for Community Inclusion".

The Going Home Campaign applauds Governor Rauner for his commitment to continue to transition people out of state institutions. We would like to see this commitment escalated by continuing to close state institutions to offer people with disabilities equal opportunity to live in the community. Yes, it is controversial but economically and socially speaking, it is the right thing to do.

Illinois now has a system of early intervention, early childhood education, special education and a growing adult community service system. We certainly cannot defend any longer the need for seven fully operational state institutions in Illinois costing taxpayers \$428,754,550.

The Arc of Illinois and the Going Home Campaign are calling on the state to close 6 of the 7 state-operated institutions by 2020.

It is time to reinvest into our community system to keep infants, children and adults with intellectual and developmental disabilities, supporting them to keep their families intact and, as they age, supporting them to remain close to family and friends.

Everyone can live a rich and fulfilling life in the community with the proper supports.

Tony Paulauski  
Executive Director  
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\*State of the States in Developmental Disabilities, D. Braddock, Ph.D., UC, 2015.

\*\*DHS, Division of Developmental Disabilities, 2015.



## **Court Monitor Ligas Implementation Concerns**

### **DOES SIZE MATTER?**

Tony Records, Ligas Court Monitor, Presentation at The Arc Convention, April, 2014

1. Of all Class Members who moved to CILA, 66% moved to 7-8 person group homes.
2. 73% of class members who moved from an ICF/DD moved to 7-8 person group homes.
3. Only 14% moved to settings of 1-4.

This is inconsistent with current practice.

For many class members, this was not their choice!

The Arc Leadership Conference, Feb. 2015

### **Ligas Third Year Report and Recommendations**

Clear Need to Expand Options!!!!

1. Employment and Meaningful Day Options
2. Smaller Residential Settings
3. Accessible Settings
4. Services for People with Intensive Behavior Support Needs

Tony Paulauski

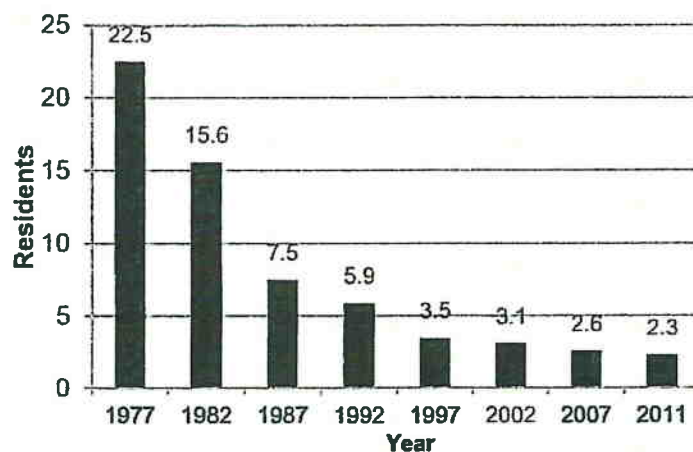
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Institute on Community Integration, University of Minnesota, 2013

**Figure 2.1 Average Number of Persons with IDD per Residential Setting on June 30, 1977 to June 30, 2011**



U.S. Average of Persons with IDD was 2.3 People in 2011.

States with Largest Average Residential Settings Were: Iowa (4.4), Illinois (4.7), New Jersey (5.1), South Carolina (5.2) and Mississippi (8.5)

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**Basic Housing Options for People with Intellectual or Developmental Disabilities**

Features	Housing Type	Lease Arrangement	Property Owner	Level of Support	Type of Support	Earned/Unearned Income
Options	Single Family Home	Provider Held	Provider	24-Hour	Shift Staff	Provider Controlled -\$50
Options	Duplex	Consumer Held	Family or Trust	Intermittent	Companion	Consumer Controlled w/Payee (not provider)
Options	Apartment	Host Family Held	Consumer	Home Based	Parent	Consumer Controlled w/Payee (provider)
Options	Condominium	Companion Held	Non Provider	Family	Host Family	Consumer Controlled w/o Payee
Options	Host Home	Family/Guardian Held	Host Family		Drop In	
Options		Non Applicable	IFF - Home First Illinois			

Features	Utilities	Property Maintenance	Property Upkeep	Code Compliance	Property Licensure	Number of Residents
Options	Provider	Provider	Provider	Local Building Codes	Not Required	1-2 Persons
Options	Non Provider Owner	Non Provider Owner	Non Provider Owner	National Fire Protection Agency (NFPA) 101 enforced by State Fire Marshal	State License	1-3 Persons
Options	Consumer		Consumer			1-4 Persons
Options	Host Family		Host Family			1-5 Persons
Options	Companion		Companion			1-6 Persons
Options	Family or Trust		Family or Trust			1-7 Persons
Options						1-8 Persons

5/15/2014

Housing Features look very different from place to place. There are a multitude of options to consider based on the individual needs of the consumer.

## **Developmental Disability Housing Recommendations\***

1. Continue the roll out of the Supportive Housing Options (SHO) pilot project.
2. Downsize the CILA system into four-person or fewer settings for those who really need 24-hour care and transition those who don't need 24-hour care into individual housing options. This will also assist in complying with the Federal HCBS new regulation.
3. Create a state rental subsidy targeted to persons with I/DD who don't need 24-hour care to assist in the re-sizing of the CILA system.
4. Upgrade the DDD technology for rate methodology so that the yearly HUD Fair Market Rent (FMR) can be used as the basis for room and board rates within four-person or fewer CILA.
5. Create an Assistive Technology Bureau in the Division of Developmental Disabilities that is responsible for approving assistive technology purchase and use, trains ISSA/PAS agencies and service provider agencies, and facilitates the use of assistive technology in order to support people with I/DD in the community.

\*Lore Baker

Statewide Housing Coordinator for Long Term Care Reform





### **14 States Without State 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)

\*State of the States in Developmental Disabilities, D. Braddock, Ph.D., UC, 2015.

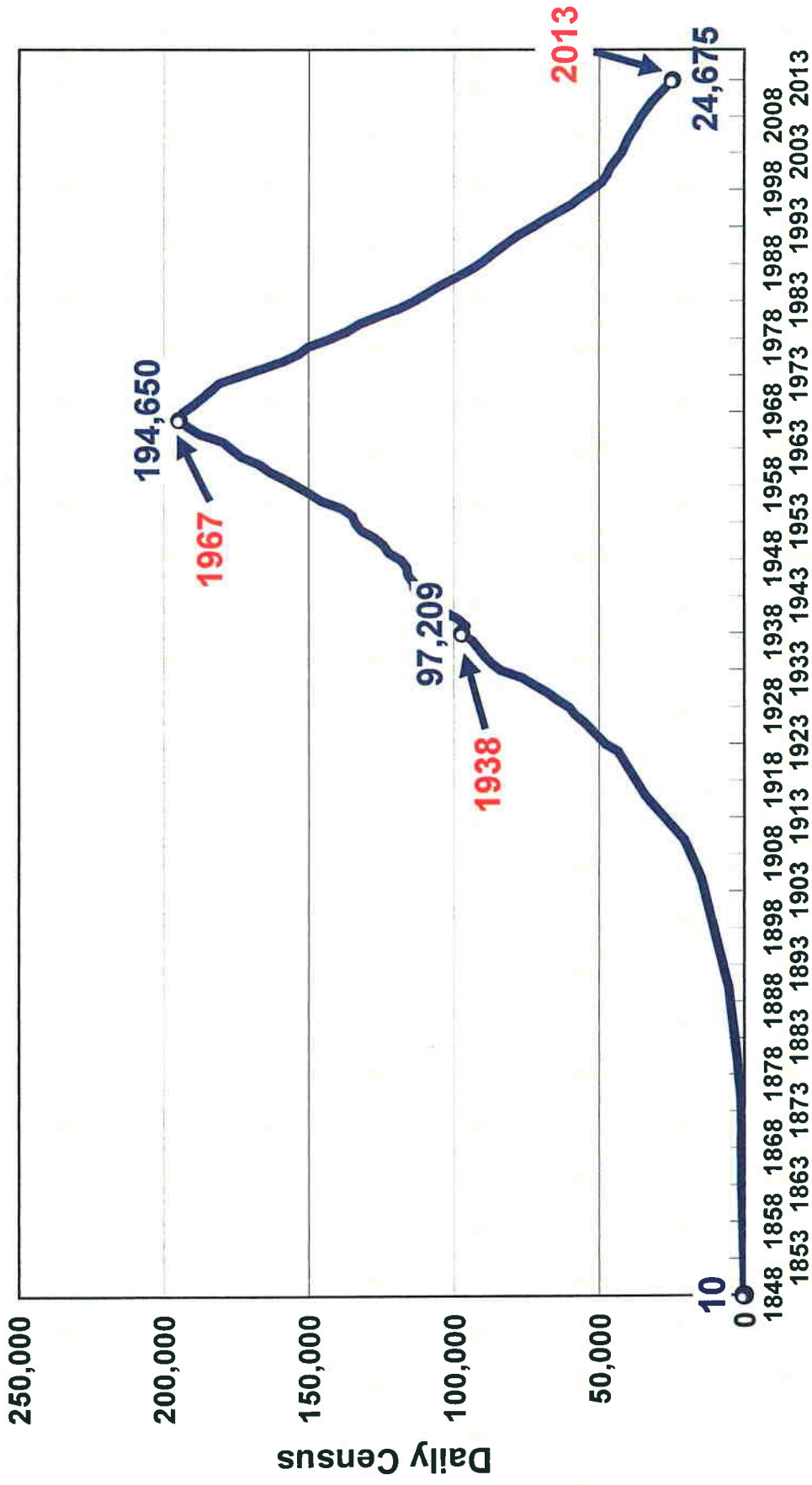
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# UNITED STATES

## Daily Census of ID State Institutions: 1848-2013



**Source:** Braddock, et al. (2014) State of the States, Coleman Institute and Department of Psychiatry, University of Colorado.

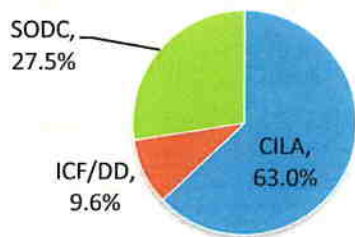
# An Evaluation of the Jacksonville Developmental Center Closure: Preliminary Results

**Research Brief**  
**Institute on Disability and Human Development,**  
**University of Illinois at Chicago**  
 Revised May 2014

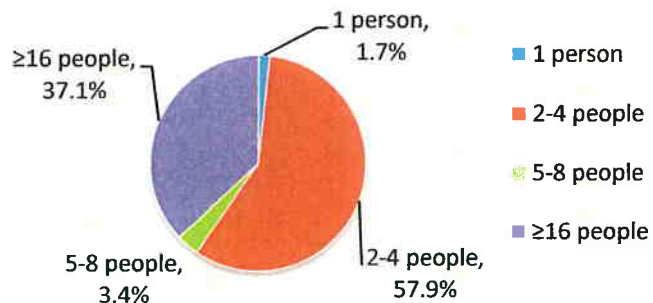
**UIC** Department of Disability and  
 UNIVERSITY OF ILLINOIS AT CHICAGO Human Development  
 COLLEGE OF APPLIED HEALTH SCIENCES

The Institute on Disability and Human Development (IDHD), through a contract with the Illinois Department of Public Health (IDPH) is conducting an evaluation of the Jacksonville Developmental Center (JDC) closure. This brief contains information obtained from: 1) family/guardian surveys; 2) stakeholder interviews; and 3) individual interviews.

**Figure 1. Where did people move?\*** (n = 178)



**Figure 2. How large were settings people moved into?\*** (n = 178)



\*As of 12/31/2012

## Family/Guardian Survey – Key Findings

- 65 guardians completed the survey.
- The majority of survey respondents (87%) indicated that they believe that their relative is **better off or the same** as they were when they lived at JDC. No one reported their relative was significantly worse off.

**Figure 3: Is the individual better or worse off as compared to when they lived at JDC?** (n = 65)

