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, 3rd highest in the nation.
- Community Fiscal Effort Ranking is 47th*
- Size of Residential Setting Ranking is 50th*
• 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 50th 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.


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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**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

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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

<table>
<thead>
<tr>
<th>Features</th>
<th>Housing Type</th>
<th>Lease Arrangement</th>
<th>Property Owner</th>
<th>Level of Support</th>
<th>Type of Support</th>
<th>Earned/Unearned Income</th>
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<td>Intermittent</td>
<td>Companion</td>
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<td>Options</td>
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<th>Property Maintenance</th>
<th>Property Upkeep</th>
<th>Code Compliance</th>
<th>Property Licensure</th>
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<td></td>
<td>1-8 Persons</td>
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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.

5/15/2014
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)
4. Rhode Island (1994)
5. Alaska (1997)
6. New Mexico (1997)


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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

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)

- SODC, 27.5%
- ICF/DD, 9.6%
- CILA, 63.0%

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

- ≥16 people, 37.1%
- 5-8 people, 3.4%
- 2-4 people, 57.9%
- 1 person, 1.7%

*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)

- Significantly better, 33%
- Somewhat better, 27%
- Same, 27%
- Somewhat worse, 13%
- Significantly worse

This evaluation was made possible through funding from the Illinois Department of Public Health. Special thanks to the Illinois Department of Human Services, Division of Developmental Disabilities for significant assistance with data collection.
Initially, the majority of guardians (83%) were very/somewhat dissatisfied with JDC's closure; however, the majority (89.2%) reported being somewhat/very satisfied with their ward's current living situation.

Figure 4. Guardian Satisfaction with JDC Closure and Current Setting (n = 65)

- The majority of survey respondents felt that the closure process moved too quickly.
  - 52% said it was too fast;
  - 43% said it moved at a good pace; and
  - 5% said it moved too slowly.

Stakeholder Interviews – Key Insights
- 53 stakeholders involved in the closure were interviewed.
- Overall, stakeholders expressed satisfaction with:
  - Active Community Care Transition (ACCT) Process:
    - Person-centered approach;
    - Use of 3rd party to assist with evaluation and transition planning;
    - 4-person CILA homes;
    - Individualized budgets; and
    - Weekly phone calls among system partners.
  - Provider involvement; providers “stepped up to the plate”
- Stakeholders expressed dissatisfaction with the following:
  - Timeline: it was too rushed;
  - Too many cooks in the kitchen: there was confusion about who was in charge;
  - Role confusion: at times parallel transition processes were occurring at JDC;
  - Lack of resources: JDC staff did not have needed personnel as staff vacated positions; and
  - Provider meetings: could have been more organized to make better use of time.

Individual Interviews – Key Insights
- 14 individuals who moved out of JDC were interviewed and indicated:
  - They felt sad when they heard JDC was closing but are very happy in their new homes;
  - They have more freedom and are taking on new responsibilities such as budgeting, banking and laundry;
  - They are making new friends;
  - They are taking classes; and
  - Some would like to explore new job opportunities.
Research of Outcomes of Closures and Deinstitutionalization

From 1980 to 2011, numerous studies and reviews of the outcomes of closures and deinstitutionalization in several states report the following outcomes regarding quality of life, adaptive behaviors, and health of residents and satisfaction of families:

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


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What The Experts Say About The Illinois Developmental Disability System

All of the following expert reports have called for including people with disabilities in the community by closing state institutions.

- Services and Funding For People with Developmental Disabilities: How Does Illinois Compare to Other States? D. Braddock, Ph.D., UC, 2011

Legislative Resolutions Calling for Rebalancing the DD System

- House Joint Resolution 28 – 2009
- Senate & House Joint Resolution 15 - 2011

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EDITORIAL SUPPORT FOR COMMUNITY INCLUSION

Now is the time to reform the Developmental Disability System in Illinois. The following editorial boards support closing state institutions and investing in community integration.

**Chicago Tribune, May 1, 2014** – “Most other states have closed these facilities and moved residents whenever it’s appropriate to community-based homes. It is the compassionate and cost effective thing to do.”

**Chicago Tribune, May 23, 2011** – “Disability advocates say the state could save roughly $170 million by closing four of its eight institutions. This needs to happen in a way that’s least disruptive for the people at these institutions. But it needs to happen.”

**Chicago Tribune, Sept. 30, 2011** – “Illinois’ treatment of the developmentally disabled lags way behind the times. Other states have proved convincingly that in most cases, institutionalizing people in big government-run facilities hurts everyone concerned and wastes money.”

**State Journal-Register, May 22, 2011** – “For years, advocates for the developmentally disabled have tried, with very limited success, to persuade the state to move away from reliance on institutions and toward greater use of residential group homes and community programs for those with developmental disabilities...Illinois must move out of the dark ages in treating its most vulnerable citizens.”

**Pantagraph, May 22, 2011** – “…the trend in recent years has been moving toward community-based settings – and Illinois lags far behind other states that have scaled back or eliminated state-run institutions for those with developmental disabilities.”

**Rockford Register Star, April, 2011** – “Illinois has its priorities exactly backward.”

**Chicago Sun-Times, June 15, 2011** – “For a state looking to cut costs wherever it can, moving away from expensive institutional care is imperative...States have seen the light, and have moved away from warehousing people with disabilities in large, residential facilities in favor of placing them in smaller, community-based settings.”

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