

*Jacksonville*  
*Developmental Center*

Public Comments  
as of 02/02/2012



February 2, 2012

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Representative Patti Bellock  
 Senator Jeff Schoenberg  
 Commission on Government Forecasting and Accountability  
 703 Stratton Building  
 Springfield, IL 62706

Dear Co-Chairs Bellock and Schoenberg:

On January 19 of this year the Illinois Department of Human Services notified COGFA of two facility closures – the Jacksonville Developmental Center and the Tinley Park Mental Health Center.

We note that COGFA has already acted to require IDHS to file new recommendations for closure under the State Facilities Closure Act. Unfortunately, however, it does not appear that you are taking the subsequent steps prescribed by the Act. We have just learned that it is the Commission's intent to hold a combined—and relatively brief—hearing on the closures at the State Capitol in Springfield next Tuesday.

We are very disturbed to learn that COGFA has no apparent plan to hold public hearings on these closures in the impacted communities as required by the Act (30 ILCS 608/5-10b) and I write to urge you to reconsider that course of action.

Not only does the current hearing plan violate the law, in our opinion, but it also appears to be intended to make it as difficult as possible for some of the parties most directly impacted to be able to participate. Holding such a brief hearing on such short notice and at considerable distance for many stakeholders is certain to depress turnout and limit the opportunity for a full range of views to be heard.

The Quinn Administration asserts that the closure plans now proposed are newly-developed as part of a broader system “rebalancing” plan that was not unveiled until after the COGFA hearings that were held last fall. If these plans truly are new and different, then citizens in the affected communities should have the opportunity to evaluate them and to present public testimony based on those evaluations.

As you know, families of those who rely on these centers, local law enforcement, state's attorneys, human service providers, local government officials and community hospitals all have a strong interest in the matter of these proposed closures. It is very likely that the current hearing plan will significantly hamper their ability to participate. Moreover, if past experience is any guide, the presentation by and questioning of the Department of Human Services could easily take up the entire two hours that are scheduled, leaving

02/11



**American Federation of State, County and Municipal Employees, Council 31**

TEL (312) 641-6060 FAX (312) 861-0979 WEB www.afscme31.org 205 North Michigan Avenue, Suite 2100, Chicago, Illinois 60601

open the possibility that even those who are able to travel to Springfield on such short notice will not have the opportunity to have their voices heard.

When Senior Advisor Michael Gelder presented the Quinn plan at a COGFA hearing on November 11, Commissioner Poe asked whether families and loved ones were being consulted. Mr. Gelder assured him that they were. In fact, they had not then been consulted—and still have not been. For example, both the Jacksonville family association and the state center family organization have been rebuffed repeatedly in their attempts to have any input into the Administration's so-called "rebalancing" plan. Relying solely on a Springfield hearing will further disenfranchise these individuals and families from meaningful input into a plan that impacts their very lives.

If COGFA has already determined that the JDC and TPMHC plans are not new and different, then obviously the only appropriate course would be to re-issue the advisory recommendations it had made based on the previous plans—and to recommend against the closures. By scheduling this hearing it is apparent you believe there may be new information. The many individual, family, provider and community stakeholders deserve to have a full opportunity to give you their views on that information.

In our view, the "new" plans actually differ very little from the fundamental flaws of the original plans--there are still no specifics on where the individuals currently served at JDC and TPMHC will be served in the future.

For these reasons, COGFA public hearings in the impacted communities will be very important to ensure all voices are heard on these important services and we would urge you to schedule them as expeditiously as possible. Further, we urge that you direct DHS to comply with the Act by not taking steps to implement either closure until this process is complete.

Sincerely,



Henry Bayer  
Executive Director

Midwestern Consortium  
Division of Survey and Certification

**CMS**

CENTERS for MEDICARE & MEDICAID SERVICES

July 1, 2010  
By Overnight Mail



Peggy Davidsmeyer  
Administrator  
Jacksonville Developmental Center  
1201 South Main Street  
Jacksonville, IL 62650-3396

Dear Ms. Davidsmeyer:

**SUBJECT: COMPLIANCE WITH THE 2000 EDITION OF THE LIFE SAFETY CODE**

The Illinois Department of Public Health (IDPH) completed Life Safety Code (LSC) surveys of Jacksonville Developmental Center on April 28, 2008 and May 6, 2009. Both of these surveys have revealed that your facility did not comply with the various provisions of the National Fire Protection Association (NFPA) 101, the 2000 Edition of the Life Safety Code. We at the Centers for Medicare & Medicaid Services (CMS) have determined that the extent of these LSC deficiencies were such that your facility is not in compliance with the Standard, Life Safety from Fire, as well as not in compliance with the Physical Environment Condition of Participation (42 CFR § 483.470 Physical Environment).

In response to both the 2008 and 2009 surveys, you submitted plans of correction that included requests for numerous waivers. Both plans of correction/requests for waiver were reviewed by Daniel Kristola, Program Representative here in the CMS Regional Office. In both instances, CMS determined that the plans of correction/requests for waiver were not acceptable. They were not acceptable since they did not include specific dates of correction for each deficiency, and did not contain provisions that were designed to provide additional safeguards to ensure the safety of clients, staff and visitors pending correction of the deficiencies. The IDPH was advised by this office that your requests for waiver were denied.

When CMS denied your request for waiver following the April 28, 2008 survey, we expected that you would submit an acceptable plan of correction/waiver request, and proceed to take corrective action to achieve compliance with the Medicaid Conditions of Participation for Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR). It now appears after our review of the May 6, 2009 survey, that you did not do so.

In ongoing discussions with IDPH, we are aware that on June 3, 2010 another LSC survey was conducted at your facility. This survey identified 67 deficiencies in LSC across seven building types (an increase from the 63 LSC deficiencies identified on the previous year).

In order to participate in the Medicaid Program as an ICF/MR, providers must achieve and maintain compliance with the Conditions of Participation and must submit an acceptable plan of correction to any standard level deficiency. Failure to submit an acceptable plan of correction is grounds for termination from the Medicaid program as an ICF/MR.

233 North Michigan Avenue  
Suite 600  
Chicago, Illinois 60601-5519

Richard Bolling Federal Building  
601 East 12<sup>th</sup> Street, Room 235  
Kansas City, Missouri 64106-2808

Enclosed with this notice is a copy of the CMS-2567 from the IDPH's May 6, 2009 LSC survey and the June 3, 2010 LSC survey. The specific waivers you requested following the May 6, 2009 survey were: K67 for Bushnell #23, K67 for Jones #33, K38 Parts A, E, F and K67 for Dix #24, K20 Parts A, B, K25, K33 Parts A, B, C, and K38 for Gillespie # 43, K12 Part A, K20 for Drake and K38 Part A, B, E, F for Bowen.

The failure to correct these long-standing LSC deficiencies is a serious matter. If you do not take action to correct these deficiencies and achieve compliance with the Medicaid Conditions of Participation, we will initiate the process to terminate your participation in the Medicaid program as an ICF/MR. Under Section 1910(b) of the Social Security Act, as amended by Public Law 101-239, the Secretary of Health and Human Services may cancel approval of an ICF/MR's eligibility to participate in the Medicaid program when the Secretary determines that the provider fails to meet the basic requirements.

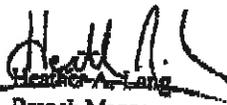
You must submit a plan of correction (POC) for all deficiencies with denied LSC waivers cited on the May 6, 2009 and the June 3, 2010 Statement of Deficiencies (CMS-2567) within thirty (30) calendar days of receipt of this notice to both IDPH and CMS. To be considered acceptable, your POC must include your planned action to correct the deficiencies and the expected completion date. Please note that the last two years of waiver requests have been denied based on a lack of a specific plan to safeguard client, staff and visitors safety and clearly benchmark plans to correct significant LSC deficiencies. Your POC must be specific and realistic, stating exactly how the deficiency was or will be corrected, not just what needs to be corrected and the expected cost. The POC must be placed directly on the CMS-2567 and signed and dated by the administrator or your authorized official. Additional documentation may be attached to Form CMS-2567L, if necessary.

Please submit your LSC allegation of compliance and POC to the attention of: Daniel Kristola, Division of Survey and Certification, 233 North Michigan Avenue, Suite 600, Chicago, Illinois 60601-6519. If we do not receive an acceptable plan of correction to these deficiencies within thirty (30) calendar days of your receipt of this notice, we will assume that the non-compliance has not been corrected, and will initiate termination procedures.

If we accept your allegation of compliance and plan of correction, representatives of CMS or IDPH will revisit your facility to verify necessary corrections. If CMS or IDPH determines that the reasons for termination remain, you will be informed in writing of the termination of your provider agreement. If corrections have been made and compliance with the conditions of participation has been achieved, the termination procedures will not be pursued.

If you have any questions, please contact Daniel Kristola, LSC Principal Program Representative in the Chicago Regional Office at (312) 886-5210. Information may also be faxed to (312) 777-0276.

Sincerely,

  
Heather A. Long  
Branch Manager  
Long Term Care Certification  
& Enforcement Branch

Enclosure

cc: Illinois Department of Public Health  
Department of Healthcare and Family Services  
Gregory Fanton, Illinois Department of Human Services

Midwestern Corporation  
Division of Survey and Certification



CENTERS for MEDICARE & MEDICAID SERVICES

Provider  
Number 14G038

September 3, 2010  
(By Fax and Regular Mail)

Peggy Davidsmeyer  
Administrator  
Jacksonville Developmental Center  
1201 South Main Street  
Jacksonville, IL 62650-3396

Post-IP Fax Note	7671	Date	9/2/10
To:	Peggy Davidsmeyer	From:	CMS
Call Ref:		Ch:	
Pages:		Phone:	
Fax:	217-287-1165	Fax:	

Dear Ms. Davidsmeyer:

**SUBJECT: Notice of Acceptance of the Plan of Correction**

On July 1, 2010, we notified you that we were initiating termination of the Jacksonville Developmental Center from the Medicaid Program, for continued non-compliance with the Medicaid Conditions of Participation for Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR). This action was to be taken if we did not receive an acceptable Plan of Correction within thirty (30) days of our July 1, 2010 notice. A Plan of Correction (POC) was submitted on July 30, 2010, but the POC was not found acceptable. On August 10, 2010, a conference call was held to review the POC. A revised POC was submitted for one of the seven buildings on August 24, 2010. The fax cover letter stated, "...if what is written in this document meets the expectations that were conveyed to us during our conference call [sic], we will have the completed POC to you by COB on Friday, August 27, 2010." On August 25, 2010, the revised POC for one of seven buildings was determined to be unacceptable and the cause for the denial was forwarded to the facility representative with a deadline for an acceptable POC by close of business on Monday August 30, 2010. On Monday August 30, 2010 a POC was submitted. The POC was considered acceptable as of September 2, 2010.

We have accepted your allegation of compliance and plan of correction and representatives of CMS or Illinois Department of Public Health (IDPH) will revisit your facility to verify necessary corrections. CMS will be in contact with the IDPH regarding recertification of your provider agreement to participate in Medicaid as outlined by the times set forth in your POC.

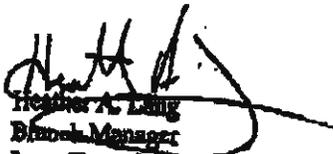
233 North Michigan Avenue  
Suite 600  
Chicago, Illinois 60601-3519

Richard Bolling Federal Building  
601 East 12th Street, Room 233  
Kansas City, Missouri 64106-2808

Page 2

If you have any questions, please contact Daniel Kristola, LSC Principal Program Representative in the Chicago Regional Office at (312) 826-5210. Information may also be faxed to (312) 777-0276.

Sincerely,

  
Heather A. Long  
Branch Manager  
Long Term Care Certification  
& Enforcement Branch

cc: Illinois Department of Public Health  
Illinois Department of Health Care and Family Services



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## Legislative Consultant

**Terry Steczo**  
Government Strategy Associates  
Phone: 847/712-1134  
t.steczko@comcast.net

**Maureen Mulhall**  
Government Strategy Associates  
Phone: 847/638-8175  
mozhouse@springnet1.com

## Association Office

**ACMHAI**  
P.O. Box 17187  
Urbana, Illinois 61803  
Phone: 217/369-5168  
Fax: 217/367-5741  
Email: acmhai@shout.net

# ACMHAI

Association of Community Mental Health Authorities of Illinois

**To:** Governor Patrick Quinn, Senate President Cullerton, Speaker Madigan and Members of the Commission on Government Forecasting and Accountability

**From:** Association of Community Mental Health Authorities of Illinois (ACMHAI)

**Re:** Planned closures of state operated facilities housing people with severe mental illness and developmental disabilities

**Date:** October 7, 2011

It is the policy of this association to collaborate with the State of Illinois, Department of Human Services and other relevant stakeholders to planfully reduce the State's investment in State Operated Facilities (SOF) for people with mental illness or developmental disabilities. Decisions to close SOFs should be predicated on a well thought out plan which assures there are adequate beds for people who require the highest level of care in terms of restrictiveness and supervision. In addition, all dollars saved as the result of closure or reduction in beds should be fully allocated to support community-based care for people who are affected by the SOF reduction. Redirection of resources to community alternatives should include:

- Reinstatement of CHIPS funding to private hospitals to cover the cost of inpatient psychiatric services to the indigent population.
- Recruitment of additional medical staff to increase the number of private hospital beds.
- Development of community-based crisis beds as an adjunct and step down to inpatient services.
- Resources to expand psychiatric, nursing, case management, residential treatment and linkage case management to stabilize community treatment for the non-Medicaid population.
- Closure of Developmental Disabilities facilities accommodated with appropriate resources to address one-on-one care and medical issues.

It is ACMHAI's understanding that the State of Illinois DHS has not promulgated a long term plan for SOF closure or reduction of beds for people with mental illness or developmental disabilities. Input from ACMHAI and other community-based stakeholders has not been sought to determine the extent to which closures or bed reductions of SOFs should be implemented. Also, the State of Illinois DHS has a poor track record for transferring the savings which result from closures to community-based providers. Most recently, the Zeller Mental Health Center in Peoria, Illinois was closed and this resulted in a savings of about \$19,000,000 per year. Only \$4,000,000 of the savings was transferred to community-based providers.

ACMHAI is adamantly opposed to the current closures proposed by Governor Quinn, and views these decisions as arbitrary and capricious; furthermore, they were made, not in the best interest of clients served by these facilities, but as positioning for reappropriation of funding. Our opposition is based on the absence of a plan which is linked to an assessment of need and appropriately transitions people in these facilities to the community. Lastly, there is no evidence the State of Illinois DHS intends to transfer the savings from closures to community-based providers. Because of these deficiencies, ACMHAI believes the current round of closures is irresponsible and places people at risk.

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# The Civic Federation

177 North State Street, Suite 400, Chicago, IL 60601 • 312.201.9066 fax 312.201.9041 • civicfed.org

October 17, 2011

Senator Jeffrey Schoenberg  
Co-Chair  
Commission on Government Forecasting and Accountability

Representative Patricia Bellock  
Co-Chair  
Commission on Government Forecasting and Accountability

Dear Senator Schoenberg and Representative Bellock:

The Civic Federation supports Governor Quinn's plan to close state-operated centers for the developmentally disabled in Jacksonville and Dixon. The closings are consistent with the July 2010 strategic plan of the Department of Human Services' Division of Developmental Disabilities. That plan calls for bringing Illinois in line with federal law and national standards of care by 2017 by reducing reliance on state-run institutions and moving residents into settings that are not isolated from the broader community.

However, the Federation remains concerned that the compressed timetable proposed for the closings might not be adequate to relocate residents to the most integrated settings appropriate to their needs. The Federation is also concerned about the lack of detailed information available about the financial impact of the closings—net of additional costs—on the State's FY2012 budget.

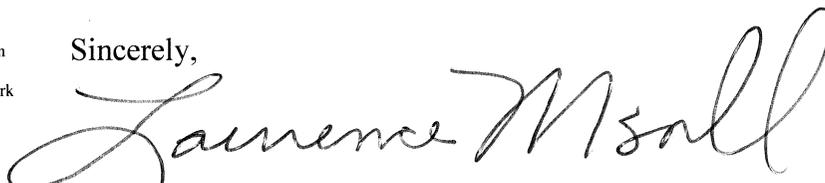
The Civic Federation is an independent, non-partisan government research organization founded in 1894. The Federation's membership includes business and professional leaders from a wide range of Chicago area corporations, professional service firms, and institutions. Our mission is to promote rational tax policies that will improve the quality of our local governments and eliminate unnecessary burdens on taxpayers.

The Federation urges the State of Illinois to provide more details about access to community-based services for relocated residents and about projected financial savings.

The Federation is not taking a position on the Governor's proposed closings of mental health, correctional and youth detention facilities due to insufficient information on the logistical and financial planning related to the closing of these facilities and the proposed alternatives.

Thank you for this opportunity to submit commentary.

Sincerely,



Laurence Msall  
President



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\*Executive Committee  
☼ Past Chairmen's Council

**RESOLUTION NO. 2011-R-156**

**A RESOLUTION IN SUPPORT OF  
CONTINUING OPERATIONS AT  
THE JACKSONVILLE DEVELOPMENTAL CENTER**

WHEREAS, in September, 2011 the Governor of Illinois announced his intention to start the process to close the Jacksonville Developmental Center and the state Department of Human Services submitted its recommendation to close the Jacksonville Developmental Center;

WHEREAS, the Jacksonville Developmental Center is the home for 196 residents with developmental disabilities and they are a part of our community;

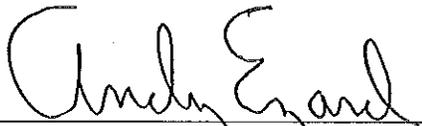
WHEREAS, claiming intent to move 170 individuals to the community, without any assessment that such a move is in their interest or even possible is unconscionable and moving residents from JDC can be an especially traumatic experience for the developmentally disabled;

WHEREAS, closing the Jacksonville Developmental Center will take 420 staff from Jacksonville, with many likely to lose their jobs;

WHEREAS, the impact of this closing on Jacksonville and Morgan County has been estimated to be over \$47 million at a time when we need more jobs and more economic development, not less;

NOW, THEREFORE, BE IT RESOLVED that the Jacksonville City Council do adamantly compel Governor Pat Quinn and the Illinois Legislature to continue the operation of the Jacksonville Developmental Center.

PASSED AND APPROVED at a regular meeting of the City Council of the City of Jacksonville, Illinois this 10<sup>th</sup> day of October, 2011.

  
Andy Ezard, Mayor

ATTEST:

  
Skip Bradshaw, City Clerk

10/19/2011

Commission on Government Forecasting and Accountability  
ATTN: Facility Closure  
703 Stratton Building  
Springfield, IL 62706

I am the Director of the Mental Health Centers of Central Illinois in the Jacksonville office. I am against closing the Jacksonville Developmental Center.

Points related to Jacksonville Developmental Center:

- Maintains a solid certification record
- Remains in good standing with the federal government
- Had \$2 million in Life Safety Code construction this summer
- Cut 22% for this fiscal year and lived within their means through cuts the previous years
- Has a Health Care Center with a setup similar to a doctor's office which trains residents to go to a doctor's appointment in the community
- Provides a Short Term Assistance Program which works with statewide crisis teams and admits people who have psychological or behavioral needs
- Coordinates work programs within the facility and two in the Jacksonville community
- The closure of JDC will not save the state money. These people with disabilities will still need skilled staff to care for them. JDC provides that excellent care now.
- We need to prevent disrupting the lives of the 195 residents.
- JDC's Central Illinois location would be an outstanding site if the state would create a long range plan that includes having three Illinois developmental centers with one in the northern, central, and southern regions.

It does not seem reasonable that every person with a severe Developmental Disability can be housed in a group home setting in the community in a safe way or that it would be less cost effective to do so. Also, there are not sufficient CILA/group homes in the State or a reasonable expectation that enough homes would be established for these needs. Those with DD issues and in crisis would not have anywhere to go and it is not reasonable to put this burden on general hospitals.

Robert L. Heape, MS, LCPC, Director



**FIRST NATIONAL BANK**  
SINCE 1882

October 19, 2011

Commission on Government Forecasting and Accountability  
ATTN: Facility Closure  
703 Stratton Building  
Springfield, IL 62706

Re: Jacksonville Developmental Center

Dears COGFA members:

I am writing as a concerned citizen in support of the Jacksonville Developmental Center. It is my understanding that your role as a commission is to make a recommendation to the Governor regarding the proposed closure of JDC.

**I am NOT in favor of the proposed closure of JDC.**

JDC provides an extremely valuable human service to the developmentally disabled population in our community. The cost to provide housing, health care and education for this population will not decrease as a result of closing JDC. In fact, I believe it would actually increase the tax burden for Illinois taxpayers.

I would encourage you to carefully consider all the consequence (direct and indirect) that will result from the proposed closure and make your recommendation to NOT close JDC.

Thank you for your consideration.

Sincerely,

Kai D. Schnitker  
President & CEO

**[www.fnbarenaville.com](http://www.fnbarenaville.com)**

110 S. Charles Street, P.O. Box 19, Azenzville, Illinois 62611, 217-997-5585 • 217-997-7593 (fax)  
1904 S. Main Street, South Jacksonville, Illinois 62650, 217-245-8559 • 217-245-8779 (fax)  
1839 W. Morton Ave., Jacksonville, Illinois 62650, 217-245-5585 • 217-245-6540 (fax)



# Ray Graham Association

Empowering people with disabilities

October 14, 2011

Senator Jeffrey M. Schoenberg, Co-Chair  
Representative Patti Bellock, Co-Chair  
Commission on Government Forecasting and Accountability  
703 Stratton Building  
Springfield, IL 62706

RE: Support of SODC Closures – Jacksonville and Mabley

Dear Senator Schoenberg, Representative Bellock, and members CGFA,

My name is Kim Zoeller and I am the President and CEO of Ray Graham Association (RGA). I am writing to you on behalf of the nearly 2,000 children and adults with intellectual and developmental disabilities and their families served by Ray Graham Association. Further I represent a team of 400 employees.

I fully support the closure of both Mabley and Jacksonville Development Centers. I have prepared some materials that highlight some important issues.

- A brief summary of several former institution residents who have moved to RGA community residential programs. Among the people highlighted is a gentleman who spent 25 years in state institutions before moving to RGA last year. Hopefully information such as this helps to dispel the myth that some people will always need institutional care.
- A narrative summary of “Fact vs. Fiction” concerning the community vs. institution debate.
- Key pieces of data that outline rates comparisons, Illinois spending relative to other Great Lakes states, and current unmet needs in Illinois.

As a provider of community based services for people with intellectual and developmental disabilities in Illinois, we stand ready and eager to partner in an effort to advance our system to one that is focused toward the rebalancing of resources and that values our citizens who often times do not have a voice. Please feel free to contact me at (630) 620-2222 or at [kimz@raygraham.org](mailto:kimz@raygraham.org).

Best regards,

Kim Zoeller  
President and CEO  
Ray Graham Association  
901 Warrenville Road, Suite 500  
Lisle, IL 60532

**Kimberly R. Zoeller**, President and CEO  
901 Warrenville Road, Suite 500 • Lisle, IL 60532  
Phone: 630.620.2222 • Fax: 630.628.2350

[www.raygraham.org](http://www.raygraham.org)



## Ray Graham Association Partners for a Solution

### Real Life Stories

#### Profiles of Former Residents of Illinois State Institutions Who Now Live, Grow and Thrive in the Community

Despite the suggestion that people leaving state institutions cannot be supported in the community, Ray Graham Association (RGA) has supported a number of people to move from isolated and costly state institutions, into neighborhood homes where they're able to explore and become a part of their community and begin to experience a productive and meaningful life. Families are overwhelmingly positive about receiving Community Integrated Living Arrangement (CILA) services through RGA, and thankful that they and their loved one have become a part of the Ray Graham family.



Laura moved from the Howe state institution in 2007, where she had lived for nearly 25 years. Because she had resided in an institution for most of her adult life, it was not an easy transition for Laura to move into a home. However, Laura had a full team of professionals and direct support staff working with her to make sure that she would be successful. Today Laura is cheerful, fun-loving and adventuresome. She loves living in Naperville and exploring the community around her, including regularly volunteering for Meals on Wheels and taking advantage of the many parks and resources her community has to offer. Laura's connection and involvement with her family has strengthened during the past few years, and she now attends and actively participates in family celebrations and important events.



Michael is another former state institution resident who is thriving in his new home. Michael moved to RGA after having lived for nearly 20 years at the oldest state institution in the country (opened in 1879). Michael's family wanted him to move closer to them and to be able to experience a better quality of life than what the institution offered. Michael and his family visited several homes where Michael could live, so that they could choose they thought would be the best fit for him. Through the individualized planning process, Michael and his family were able to let staff know what he liked, disliked and things he wanted to do now that he lived in a community. Michael and his roommates lead an active life, including attending sporting events, concerts and shopping. Michael's family is regular visitors and he's able to spend as more time with them now that he's not a 2 hour drive

away. Michael's father couldn't be happier with his progress: "I think he's doing well at Ray Graham. He didn't have the liberty or the social involvement when he was living at Shapiro that he has now. The staff is also teaching him to be more independent!"



Angel lived in state institutions from the time he was 5 until finally moving into his own "home" 3 years ago. One of the excuses for Angel living in an institution was that his uncontrolled seizure activity required continuous nursing presence. With support and determination from RGA, Angel's medications have been adjusted with great success. While he requires continuous close monitoring, Angel's condition doesn't require him to live in a segregated institution. Now Angel fully participates in the life of the community, including attending a Community Learning Center during the week, volunteering, participating in activities at his home and going out with friends on the weekend. Staff became aware of Angel's interest in animals, and have created numerous, ongoing opportunities for him to interact with a variety of different animals, including pet therapy, visiting the horses and barn area at an RGA program site, and visiting pet stores near his home.



Billy had lived in state institutions since 1959, until finally moving to an RGA CILA home less than a year ago. Billy and his family visited his home several times before moving, to make it a smooth and comfortable transition. Billy was able to get to know his housemates and staff and was excited when he got to join them permanently. Being close to his family was a priority for Billy and his family. Billy's family expressed surprise that they could visit with him so freely and that he could join them at important family events; his mother reported that staff at the institution had discouraged them from visiting with Billy and establishing a meaningful relationship with him. The family experienced their first RGA Holiday Party this year, and was thrilled to see so many other families present and see how happy their son was with his new friends. A treasured memory of this event for both Billy and his family is the picture staff took of them in front of the Christmas tree – the first family photo they had with their son.



Harlan was a resident of the Howe institution for nearly 25 years before moving to an RGA CILA home. Harlan immediately began to blossom and expressed his happiness with his new home, staff, friends and opportunities. Harlan enjoys going to concerts, playing sports, going out to dinner, bowling and visiting the zoo. Harlan is happy to have the responsibilities of living in home, and enjoys helping with cooking, chores and deciding how he spends his free time. Most importantly Harlan feels safe in his new home and is enjoying life day by day!



Rick also moved to an RGA CILA home from the oldest state institution in the country, where he had lived for many years. Rick's father was seeking alternative placements for Rick because he felt that there were better options for Rick to live in other than a state institution. Rick and his father are both very happy with the decision to have Rick move into a CILA home. Rick's dad has stated on several occasions that Rick is so much happier living in his new home than when he lived at the institution. Rick has been able to pursue more of his personal interests since moving, including playing and listening to music and attending concerts. Rick plays the keyboard and has performed at the Annual RGA Holiday Party.

Ray Graham Association is able to provide services to former residents of state institutions at a much lower cost -- we could support nearly 4 people in a CILA home for what the state pays to house 1 person in an institution. Of course, far more important than the savings in a community program, is the quality of life that people such as Rick, Harlan, Billy, Angel, Michael and Laura experience as a result of moving from an institution into a home in the community. The commitment, flexibility and our person-centered and mission-driven focus supports people to grow, thrive and live a meaningful life.

People with disabilities and support needs deserve the same opportunity as everyone else to chart their destiny and follow their dreams; moving from an institution into a home in the community is the first step on this journey.



**Ray Graham Association  
Partners for a Solution**

## **Setting the Record Straight**

### **Why Illinois Cannot and Should Not Continue to Support Costly Institutionalization for Citizens with Disabilities**

The lives of tens of thousands of people with disabilities and their families across the state of Illinois depend upon how our lawmakers allocate the precious little amount of money available for disability services. It's an emotional issue for everyone:

- Those currently in Illinois institutions;
- Those receiving limited and under-funded services in the community;
- Those living at home receiving no services; and
- The families of every Illinois citizen with a disability who is either now confronting the reality of living in a state which only surpasses 3 others in per-capita community-based service funding, or those whose children are still in the school system and don't yet even realize their well-educated children will leave school only to discover that they are entering an adult service system that cannot support them, because Illinois won't fund the services they need.

There is no quick or easy solution to the challenge of equitably and responsibly allocating limited resources, but there is a right solution – Illinois' support of archaic, costly and outdated institutional settings must end, and our limited resources be used to support as many people as possible in a community-based service delivery system.

The issue of how to best support people with disabilities in Illinois is gaining increasing prominence:

- Taxpayers are demanding accountability for the use of public revenues;
- At least 21,000 citizens of Illinois are registered with the state as needing community-based services, with no plan on the state's part for meeting this demand;
- The stability of the existing community service delivery system is subject to a growing threat caused by delayed and insufficient payments from the state; and
- The continued reliance on a system which throughout the world, is recognized by professionals, advocates and people with disabilities themselves as archaic and outdated, has become completely indefensible.

The debate over how scarce resources will be spent becomes more critical with each passing day, and as such, sometimes facts become clouded or overshadowed. A few facts about institutional and community-based services in Illinois warrant repeating:

#### **Costs**

- In FY12, it will cost an average of \$192,000/person to keep an Illinois citizen with disabilities in an institution, versus an average of \$50,000/person to support that same person to live in a community residence.

- This year, Illinois is projected spend more than \$307,500,000 (Three-Hundred Million, Five-Hundred Thousand dollars) on institutional services for 2,101 residents of state institutions. Nearly 3 times that number of people could be served for the same amount of money in community residential settings.

### **Support Needs**

- Thousands of former residents of institutions are leading productive and fulfilling lives living in community residences. There is no clinical or diagnostic standard that distinguishes residents of institutions, from people supported in community residences. Indeed, for the former residents of state institutions who have moved into the community during the past several years, the most relevant criteria is whether the person's guardian will permit the move.
- State institutions hold the same licensure category as hundreds of facilities throughout Illinois. These facilities are held to the same standard of care and service as state institutions, though are reimbursed at one-third the cost of state institutions.
- A common argument made by advocates of institutions is that many residents of such settings have "failed" or been "discharged" by the community. In fact, there is no quantitative research on the population of Illinois institutions to support this claim. Many responsible community providers feel that if the state would fund services for people with more intense needs at a reasonable level, those actual instances where a community agency petitions for discharge would decline precipitously.

### **Personnel**

- The majority of contact residents of institutions or community settings have is with Direct Support staff. There is no discernable difference between the training, competency or commitment of people functioning in this capacity, based on where they work.
- Many providers of community based services are mission-based, local, not for profit organizations with a history and connection with their local community. Staff in institutions are part of a bureaucracy, overwhelmed by rules and subject to a myriad of requirements that are completely unrelated to the provision of care and support to people with disabilities.

### **Numbers**

- In the current fiscal year there were 2,100 residents of state institutions and 21,000 residents of Illinois who qualify for, but don't receive any disability services. Policymakers, politicians and professionals in the field all know that as long as those 2,100 people continue to be housed in institutions, the remaining (and growing) group of our citizens who are equally deserving of services, will be left with nothing.

# Comparison of Rates for Institutional and Community Services



Ray Graham Association for People with Disabilities

Average FY11 Cost in an Illinois Institution

**\$168,656**

Average Payment to RGA for all 24/7 CIA Residents (N=108)

**\$ 52,797**

Average Payment for RGA ICFDD (same licensure and regulations category as State Institutions) N=98

**\$ 58,828**

Average Payment to RGA for People Leaving State Institutions 2007 – 2010 (N = 8)

**\$ 54,654**

Annual Savings Generated by 8 Former Institution Residents Living in Community Residences:

**\$912,016**

# Unmet Need for I/DD Services in Illinois as of 9/1/11

## Unduplicated Count of PUNNS Records with Current Needs

- ▶ Emergency: 3,398
- ▶ Critical: 11,602
- ▶ Planning: 6,490

A total of 21,490 Illinois residents are identified as needing services and supports today!



# Comparison of Illinois and Great Lakes Region States Spending for Intellectual/Developmental Disability Services



Ray Graham  
Association of Illinois  
1000 North Dearborn Street, Suite 100, Chicago, IL 60610

Source: State of the States in Developmental Disabilities 2011 Braddock et. al.

Prepared by Ray Graham Association for People with Disabilities

Iisle, Illinois

Indicator	Illinois	Great Lakes Region	% Difference	Comments
Total Fiscal Effort for I/DD Services per \$1,000 Personal Income	\$3.13	\$4.90	64%	Total community and institutional spending for I/DD services, per \$1,000 of personal income
Community Fiscal Effort for I/DD Services per \$1,000 Personal Income	\$2.02	\$4.18	48%	Spending for residential settings for 15 or fewer persons and non-residential community services and supports, per \$1,000 of statewide, aggregate personal income.
Institutional (16+ Persons) Fiscal Effort for I/DD Services	\$1.10	\$0.71	155%	Note - this is <u>not</u> an indicator on which Illinois wants to be ahead of our neighboring states
Home and Community-Based Services Waiver Federal-State Spending Per Capita (note - per citizen of the general population)	\$38.00	\$95.00	45%	The Home and Community Based Services (HCBS) Waiver is the principal Medicaid program funding I/DD long-term care services. The HCBS Waiver funds a wide variety of residential and non-residential community services and supports
Average Annual Cost of Care in SODC	\$181,717.00	\$181,230.00	100%	The average "Topline CIA Rate" for "High-Need" individuals in Illinois is \$56,105 (Source DHS Website CIA Rates Update June 2011)
Average Daily Cost of Care in SODC	\$498.00	\$497.00	100%	The cost of institutional care does not vary across the region; however Illinois is substantially more reliant on this expensive archaic model of service delivery than any of our Great Lakes neighbors
Community Spending as a % of Total I/DD Spending	65%	85%	76%	Community spending is lower in Illinois than in neighboring states, as is overall I/DD spending
% of Total Out-of-Home Placements in Settings of 6 or Fewer	38%	71%	54%	Illinois residents with I/DD are substantially less likely to be served in a small integrated home in the community than residents of neighboring states
% of Total Caregiving Families Receiving Public Funding	8%	15%	53%	The vast majority of families who care for a member with I/DD do not receive any public support
Individual and Family Support Spending Per Capita (Per capita: Per citizen of the general population.)	\$13.00	\$49.00	27%	Individual and Family Support spending consists of spending for individuals with I/DD (supported living/personal assistance and supported employment) and for family support.



## Comparison of Illinois and Great Lakes Region State Census and I/DD Funding

Source: State of the States in Developmental Disabilities 2011 Braddock et. al.; United States Census Bureau

Prepared by Ray Graham Association for People with Disabilities

Lisle, Illinois

State	I/DD Total Spending 2009	2010 Total State Census	Total I/DD Spending Per Capita	Total Number of People Served in Out-of-Home Settings	Total Number of People Receiving Family Support and Supported Employment Services	Total Number of People with I/DD Served	Total # of People with I/DD Served as a % of Total State Census
Wisconsin	\$1.16 billion	5,303,925	\$218	16,176	19,105	35,281	0.67
Minnesota	\$1.68 billion	5,686,986	\$295	18,258	9,119	27,377	0.48
Michigan (1)	\$1.31 billion	9,883,640	\$132	28,233	19,891	48,124	0.49
Ohio (2)	\$2.82 billion	11,536,504	\$244	30,417	25,830	56,247	0.49
Indiana	\$909.2 million	6,483,802	\$140	12,642	7,005	19,647	0.30
Illinois	1.71 billion	12,830,632	\$133	23,730	8,694	32,424	0.25

**Notes:**

1. Even though Total I/DD spending per capita is roughly the same in Illinois and Michigan, Michigan serves far more people due to Illinois' reliance on costly institutional care
2. Ohio is the closest Great Lakes Region state in size to Illinois and serves almost twice as many residents as a % of state census



**October 25, 2011**

**IARF Recommendations to the Commission on Government Forecasting and Accountability:  
Proposed Closure of Jacksonville and Mabley Developmental Centers**

The Illinois Association of Rehabilitation Facilities (IARF) represents over 90 community-based providers serving children and adults with intellectual/developmental disabilities, mental illness, and/or substance use dependencies in over 900 locations throughout the state. For over 35 years, IARF has been a leading voice in support of public policy that promotes high quality community-based services in healthy communities throughout Illinois. Approximately 600 licensed and/or certified community-based providers provide services and supports to over 200,000 children and adults in the community system.

Based on our analysis of the state fiscal year 2012 budget for the state-operated developmental centers, the Association anticipated the Department of Human Services (DHS) would be forced to announce implementation plans to manage the reduced appropriations. However, the announcement to close the Jacksonville and Jack Mabley Developmental Centers along an aggressive timeframe with an estimated 250 individuals recommended for transfer to community-based settings was alarming. A major policy decision such as the closure of a state facility should not be completely driven by budget restrictions, as is the case with these two announcements, but should be driven by a commitment to making Illinois a leader in providing high quality community living for all individuals with intellectual/developmental disabilities.

Community-based providers want to provide services to individuals currently residing in state facilities, and many have a successful track record of serving former residents. IARF has identified recommendations that we believe must be implemented to ensure a successful downsizing/closure of a state facility and transition of individuals residing in those facilities to more integrated community-based settings. The recommendations below are more fully developed in the attached document.

- Establish a closure timeframe driven by process, which requires adequate preparation of community capacity prior to initial transitions of individuals from state facilities to the community.
- Provide an accurate assessment by an independent contractor of the facility residents with medical and/or behavioral issues that require careful planning.
- Establish a formal process for ensuring family members' and/or guardians' understanding of the closure process and the options available.
- Develop community-based capacity to appropriately address the needs and wishes of individuals transitioning to the community. This requires funding to supplement – not supplant - existing resources for individuals currently being served in the community.
- Revise existing Community Integrated Living Arrangement (CILA) rates to cover the cost of providing care and clearly identify specialized rates where appropriate. Timely payment must be secured as well.

***In order to implement these recommendations, we do not believe the aggressive closure timeline of the developmental centers as recommended by the Department is conceivable. IARF has full faith and confidence in our members to serve individuals transitioning from state facilities if a commitment to implement these recommendations is made by the state.***



Illinois Association of Rehabilitation Facilities  
206 South Sixth Street  
Springfield, Illinois 62701

P: (217) 753-1190  
F: (217) 525-1271  
www.iarf.org

## **Attachment: Description of IARF Recommendations to the Commission on Government Forecasting and Accountability: Proposed Closure of Jacksonville and Mabley Developmental Centers**

### ***Comments on the Announcements***

IARF believes a strong network of community-based providers are integral to healthy communities in Illinois and reflective of the intent of the landmark *Olmstead* court case, which determined that services and supports for individuals with intellectual/developmental disabilities should be provided “in the most integrated settings appropriate to the needs of qualified individuals.”

As indicated in the summary cover page, IARF has full faith and confidence in our members to serve individuals transitioning from state facilities. That confidence is based on the assumptions of sound planning and reasonable timelines, the state meeting its obligations of adequate resources for the safe transition of individuals, and assurance that those resources will supplement – not supplant – resources currently supporting individuals in the community. We believe these assumptions are reflected in our recommendations, which are more fully described below.

These recommendations were developed by a workgroup specifically designated by the IARF Board of Directors, and include revisions from previous recommendations IARF developed in 2007. This workgroup includes representation from members that:

- have successfully served individuals who have previously transitioned from state facilities;
- currently provide services to residents from Jacksonville and Mabley Developmental Centers;
- are involved in the pre-admission screening process (PAS); and
- have administered state-operated developmental center programs in the past.

As evidenced by the composition of this workgroup, we believe our recommendations are supported by best practice and lessons learned from previous state facility closures in Illinois and other states.

### ***Closure Process Recommendations:***

*Recommendation 1: Establish a closure timeframe driven by process, which requires adequate preparation of community capacity prior to initial transitions of individuals from state facilities to the community.*

Data from past closures of state facilities in Illinois and data from other states indicate the closure process occurred from one and a half to as long as five years.<sup>i</sup> While five years may be an extended period of time – as we believe there are individuals currently residing in these state facilities that could transition soon to existing community capacity – IARF supports a time frame of twelve to eighteen months for other existing residents to ensure DHS’ Division of Developmental Disabilities is working collaboratively with individuals being served, their family members/guardians, and community-based providers to ensure the other recommendations we have provided are meaningfully implemented.

*Recommendation 2: Provide an accurate assessment by an independent contractor of the facility residents with medical and/or behavioral issues that require careful planning.*

Currently, community-based providers intending to serve an individual transitioning from a state facility must rely on a compilation of reports developed by state facility staff provided to PAS agencies. These reports are intended to provide a clear understanding to the provider of the behavioral, medical, and rehabilitation needs of the individual, as well as the individual's goals so that provider can ensure its capability of addressing those specific needs and empowering the individual to achieve desired goals. This information is critical to a successful transition.

While not citing any individual or system, there has often been a less than objective assessment that has preceded individuals from state facilities to the community. This is dangerous for the person and is unacceptable. Therefore, we recommend the Department establish a process for contracting with a third-party contractor to provide independent assessments of the residents of these facilities with medical and/or behavioral issues that require careful planning by an independent contractor to ensure no bias in the determination of the individual's service plan.<sup>ii</sup> This recommendation is in line with legislation sponsored by Senator Heather Steans (SB 1622 as introduced) and Representative Sara Feigenholtz (HB 1687) this year.

The Association also recommends the arbitrary geographic limitations on the operations of PAS agencies be lifted to allow for free choice in the system and to preclude the 'overloading' of any one PAS office geographically closest to the state facility recommended for closure.

*Recommendation 3: Establish a formal process for ensuring family members' and/or guardians' understanding of the closure process and the options available.*

Most likely due to the budget driven nature of the closure announcements, family and guardian notification came as an unexpected surprise, and so the very public resistance and vehemence for the facilities to remain open is understandable. Based on our review of previous closure processes, we believe this anxiety is due to the Department:

- not previously providing families/guardians with the reasons the closures are occurring;
- presenting families/guardians with an unimaginable timeline for their family member to be moved; and
- providing inadequate information about the services and/or supports that are available to them in the community.

The combination of these factors, as well as the experience at Howe provided insight into how high staff ratios<sup>iii</sup> at state facilities (not based on individual need and inordinately high) compared to community settings instill fear in families that their family member will receive less care in the community than at a state facility.

Family/guardian involvement in the transition/closure process is essential. A collaboration of community stakeholders developed an excellent guide for family involvement called the "Community for All Toolkit."<sup>iv</sup> The basic tenets of the toolkit are:

1. Information Sessions are critical for the families to feel engaged;
2. Open Houses in the community should be planned so families can learn what is available;
3. Families of individuals currently living in the community – especially those whose family member has moved from a state operated facility to the community – are essential in helping educate other families and allay concerns;
4. Set up a Family Buddy System between state facility families and community families; and

5. Families must be invited and involved in the actual relocation, so scheduling around their time is critical and they should be encouraged to stay involved with their family member's activities and with their parent buddy family as well.

*Recommendation 4: Develop community-based capacity to appropriately address the needs and wishes of individuals transitioning to the community. This requires funding to supplement – not supplant existing resources for individuals currently being served in the community.*

The development of community-based capacity targeted to address the needs and wishes of individuals transitioning from state facilities to community-based settings is a requirement for successful transitions. There are several important components to capacity building, which are outlined below.

- *Workforce Training* – Adequate community-based staff training is a pre-requisite to a transition. Individuals who have been institutionalized require more supports during and after a transition as opposed to an individual who has never been institutionalized. That support is essential and staff in the community agencies must be aware and have the support to be fully prepared to engage with new individuals in the same way they have engaged in the lives of others living and working in the community. Experience gained from transitions from Fox Developmental Center and the closure of Howe Developmental Center, wherein state facility staff familiar with the individual worked collaboratively with staff in the community-based agency to create a “bridge” of experience, lead to increase transition success. For a period of time after transition the state facility staff most familiar with the individual in transition should continue to provide technical assistance and support until the individual is fully adjusted to his or her new home.
- *Direct Support Wages & Benefits* – Direct Support Professionals (DSPs) are the frontline workers that are integral to assisting individuals with intellectual/developmental disabilities realize their goals of living, working, and recreating in the community. Wages and benefits paid to direct support professionals account for 90 cents of every dollar invested in community-based agencies.<sup>v</sup> However, the disparity between the wages paid to DSPs working in community-based agencies compared to those working in state facilities is growing, with an average entry wage of \$8.85/hr for a community employed DSP as compared to the average entry wage of \$14.77/hr for counterparts working in a state facility.<sup>vi</sup> This disparity represents nearly a \$6.00/hr differential. Unfortunately, state fiscal year 2008 was the last time an increase for these wages and benefits was approved, but only at 2.0% - compared to significant wage and benefit increases gained by counterparts working in state facilities. Adequate funding for DSP wages and benefits must be prioritized in state budgets to address the disparities and encourage growth in the field to address the dramatic need for these workers over the coming years as the baby boomer generation approaches retirement and primary care givers are unable to tend to the needs of individuals with intellectual/developmental disabilities living in-home.
- *Nursing Supports* – Since the approval of SR 514 by the Illinois Senate during the 94<sup>th</sup> General Assembly, IARF has advocated for the need to increase nursing support in community-based residential settings, specifically Community-Integrated Living Arrangements (CILA). Despite our advocacy efforts, the state has shown little interest in investing the revenues necessary to implement the recommendations of the CILA Nursing Services Report – despite evidence that the needs have reached the critical, if not crisis, stage.<sup>vii</sup> The current CILA Rule (Rule 115) and the Medication Administration Rule (Rule 116) must be updated to reflect the level of need of individuals currently living in the community as well as individuals who may transition from state facilities.

- *Behavioral Supports* – Adequate behavioral supports are also essential to the transition planning process. The community-based provider must be fully able to provide such supports for the time necessary to integrate an individual transitioning to their new residence and possibly their new work environment. Individuals will have to meet new staff and build trust while developing new relationships. The community-based provider staff will need to be perceptive to changes in behaviors that if left unaddressed, could escalate, causing serious adjustment issues and possible harm to the individual. Whether those behavioral supports are provided by the community-based provider or through linkages with other community resources, they must be planned and they must be funded. That funding must recognize that adjustment times will vary from individual to individual and community-based providers must be assured that an “add-on” will not arbitrarily disappear without strong clinical evidence that the transitioning individual is stable in his or her new setting.
- *Crisis Supports* - It is strongly indicated that behaviors can change throughout a person’s life for a number of reasons unique only to that person. When that happens, funding must be available to assess what additional supports are necessary and for the duration of the stabilization of the individual. Resources must be quickly available when the situation warrants.
- *Residential Capacity* – There is limited existing CILA capacity in the community-based system, however, the majority of individuals currently residing in CILA group homes are under the six to eight bed CILA model. The shift this CILA size is primarily driven by individual CILA rates that don’t cover the costs of smaller group home settings. We believe it is the intent of DHS’ Division of Developmental Disabilities to transition individuals from state facilities to the four bed CILA model, as this model will provide enhanced federal matching assistance percentage (FMAP) according to the Money Follows the Person (MFP) Demonstration Program. However, as evidenced by the current landscape, the four bed model is not predominant due to inadequate rates and reimbursements.

We encourage the Division to explore utilizing existing capacity where and when appropriate to serve individuals that may transition from a facility, however, we acknowledge that the existing capacity is insufficient to serve the estimated 250 individuals the Division has recommended to transition. This will then require community-based providers to either purchase, renovate, or build new group homes – a process that requires capital and time to meet permit and building code requirements. We note that the state’s existing process of cutting community funding and delaying payments to community-based residential providers has all but wiped out any resources providers might’ve had in the past to develop this infrastructure. IARF therefore recommends that as a component of building residential capacity, the state must prioritize an improved payment cycle for providers and capital support to not only build capacity, but cover the cost damage or destruction to property that often occurs during an institutional-to-community transition.

*Recommendation 5: Revise existing Community Integrated Living Arrangement (CILA) rates to cover the cost of providing care and clearly identify specialized rates where appropriate. Timely payment must be secured as well.*

If the state truly wants to drive the future of services and supports to community-based settings – as articulated by Governor Quinn during his September 8, 2011 announcement, then the Department must be willing to shift previous decisions relative to rate and reimbursement methodologies.

Recent rate studies<sup>viii</sup> conducted by DHS’ Division of Developmental Disabilities have looked at the real cost of serving individuals in group home settings of four persons defy the current discussions of using the “average” CILA reimbursement to support individuals transitioning from state facilities. Similar studies have determined that that

‘average’ does not support individuals living in six and eight-person settings and are disquieting when compared with other state ‘averages’ for similar supports in those settings. For example, Acting DHS Division of Developmental Disabilities Director Kevin Casey is openly concerned about the transition discussions considering Illinois pays – on average - \$55,000 per person and his previous state experience in Pennsylvania paid – on average - \$90,000 for essentially the same service packages. The ‘average’ CILA rate will not support individuals who transition during the early months/years of their transition in the best of circumstances. Furthermore, the ‘average’ CILA rate will not come close to supporting individuals who transition to a four-bed group home setting, which as noted above has been the policy determination by the Division in these discussions.

Specialized rates and rate add-ons<sup>ix</sup> that actually pay for the identified supports an individual transitioning from a state facility to a community-based setting are essential. A multi-year commitment must be made by the state to these specialized rates and add-ons as long as they are deemed appropriate. Unfortunately, the most current experiences of several community-based providers that have responded to the state’s requests to serve individuals transitioning from state facilities is they are promised initial rate packages that are subsequently reduced against the clinical determination of the individual’s needs.

Illinois has reduced community resources through successive years of budget cuts, specifically 19.3% over four years – or \$174.58 million in cuts. Furthermore, the state has used specifically community-based providers as creditors of the state through years of long payment delays dating back to 2008. This situation has not improved, despite the expectation that once the payment cycle requirements of the American Recovery and Reinvestment Act (ARRA) expired, that more parity would exist in payment cycles for all health care providers. The state cannot expect the reality of the existing funding situation and payment delays to be ignored in the planning of potential transitions from Jacksonville and Mabley Developmental Centers.

### ***IARF Members are Focused on Solutions***

There is great anticipation among community-based providers about supporting individuals transitioning from state facilities to the community. Evidence shows that persons who have been institutionalized for much of their life can successfully live in the community<sup>x xi</sup> and organizations have honed their skills in areas needed to open that opportunity to individuals and families who exercise their choice to transition.

However, there is great apprehension in the community as well. That apprehension is not based on their confidence to successfully support the individual – it is based on their confidence in the state to hold up its end of the bargain. That responsibility – to transition resources – has historically been spotty at best. Of even greater concern is the fact that these recent closures have been precipitated by inadequate resources, not policy decisions driven by sound planning. Furthermore, the community is expected to serve as many as 9,000 additional individuals with intellectual/developmental disabilities over the next six years per the *Ligas* court ordered consent decree.

As clearly stated in our cover summary page, IARF has full faith and confidence in our members to serve individuals transitioning from state facilities if a commitment to implement these recommendations is made by the state. If the state can bring these assurances to the table, then the discussions of closing Jacksonville and Jack Mabley Developmental Centers will produce quality outcomes for individuals that transition and as importantly, their families.

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<sup>i</sup> ARC of New Jersey. “The Future of Individuals with Developmental Disabilities and New Jersey’s Developmental Centers.” May, 2009. Accessible at: <http://njddc.org/ResourcesforPolicyMakers/copy/The%20Future%20of%20NJ's%20DCs.pdf>

<sup>ii</sup> Shannon, Anne. “Howe Developmental Center – Final Report” June 2009. Accessible at: [http://www.realchoiceinillinois.org/documents/Howe%20report\\_Shannon.pdf](http://www.realchoiceinillinois.org/documents/Howe%20report_Shannon.pdf)

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<sup>iii</sup> *Ibid*

<sup>iv</sup> American Association on Mental Retardation (AAMR), ARC of the United States, Center on Human Policy, Council on Quality and Leadership, National Association of Councils on Developmental Disabilities (NACDD), University of Minnesota's Research and Training Center on Community Living, and Tash. "Community for All Toolkit – Resources for Supporting Community Living." August, 2004. Accessible at: <http://thechp.syr.edu/toolkit/>

<sup>v</sup> 2011 IARF Salary Survey. Accessible for purchase at: <http://www.iarf.org/Public/SalarySurvey.aspx>

<sup>vi</sup> Mosaic Collaborative for Disabilities Public Policy and Practice. "ANCOR 2009 Direct Support Professionals Wage Study: A Report on National Wage, Turnover, and Retention Comparisons. August, 2010. Accessible at: [http://www.youneedtoknowme.org/downloads/research/ancor\\_wage\\_data\\_summary\\_2009.pdf](http://www.youneedtoknowme.org/downloads/research/ancor_wage_data_summary_2009.pdf)

<sup>vii</sup> Navigant Consulting. "Report of the Community Integrated Living Arrangement Nursing Services Reimbursement Work Group to the Secretary of the Department of Human Services, the Illinois General Assembly, and the Honorable Rod R. Blagojevich, Governor, in Response to Senate Resolution 514." October 2006. Accessible at: <http://www.iarf.org/uploads/docuploads/forums/cburnett@iarf.org/CILA%20Nursing%20Services%20Report%20Final%20October%202006.pdf>

<sup>viii</sup> CILA Rate Workgroup. "Interim Report of the CILA Rate Workgroup of the Statewide Advisory Council Rates Committee – CILA Model and Reimbursement Issues." March 2009. Accessible at: <http://www.iarf.org/uploads/docuploads/forums/cburnett@iarf.org/CILA%20Rates%20Interim%20Report%203-9-09.pdf>

<sup>ix</sup> IARF Concept Papers on Specialized Rates and Reimbursements. Accessible at: <http://www.iarf.org/Members/PolicyInformation.aspx>

<sup>x</sup> University of Minnesota Research and Training Center on Community Living. "Status of Institutional Closure Efforts in 2005." September, 2005. Accessible at: <http://www.iarf.org/uploads/Univ%20of%20MN%20Policy%20Brief.pdf>

<sup>xi</sup> Braddock, David and Richard Hemp. "Establishing a Tradition of Commitment: Intellectual and Developmental Disabilities Services in Indiana: Executive Summary." October, 2008. Accessible at: <http://www.iarf.org/uploads/Braddock%20Summary%20Report%20Final%202008.pdf>



**SPRINGFIELD CENTER FOR  
Independent Living**

330 South Grand Avenue West | Springfield, Illinois 62704  
Phone 217-523-2587 (v/tty) | Fax 217-523-0427 | [www.scil.org](http://www.scil.org)

October 17, 2011

Commission on Governmental Forecasting & Accountability (COGFA)  
Facility Closure  
703 Stratton Building  
Springfield, Illinois 62706

**Senator Jeffrey Schoenberg, Co-Chair COGFA**

**Representative Patti Bellock, Co-Chair COGFA:**

The Springfield Center for Independent Living (SCIL) supports the closing of Jacksonville and Mabley Developmental Centers. We at SCIL see this as an opportunity to rebalance the archaic system that serves people with Developmental Disabilities in Illinois.

Community residential settings have been the national standard for years, Illinois has continued to operate institutional settings and has fallen further and further behind on how it serves some of our most vulnerable citizens.

Illinois is clearly not following a national trend to move people with disabilities into community settings. We rank 49<sup>th</sup> in the provision of community integrated settings by housing more people with developmental disabilities in state institutions than 48 other states.

As the Commission on Governmental Forecasting & Accountability examines relevant facts to make a decision about the closing of the Jacksonville and Mabley Developmental Centers, please consider the following:



- The transition from an institution to a community setting must include a transition period that will not just “dump” people somewhere else. “One size does not fit all”.
- Each resident should be treated on an individual basis with family members included in the decision making process.
- The safety and welfare of every resident should be the highest priority.
- Funding should be available to move residents into appropriate community based settings.
- The Olmstead decision of 1999 should be the standard as you decide how to move forward in your considering the futures of the Jacksonville and Mabley residents. This Supreme Court decision on Olmstead “is a prohibition, mandated by federal law, against avoidable and unnecessary institutionalization of individuals with developmental disabilities, and as a requirement that states make reasonable efforts to place institutionalized individuals with developmental disabilities in the community”.
- Fourteen states have closed all of their institutions. Perhaps a visit to some of these states that have successfully created community settings would be worth considering: District of Columbia, New Hampshire, Vermont, Rhode Island, Alaska, New Mexico, West Virginia, Hawaii, Maine, Michigan, Oregon, Alabama, Minnesota, and Indiana.

Sincerely,



Pete Roberts

Executive Director

[scil@scil.org](mailto:scil@scil.org)



*Serving Morgan & Scott communities since 1965*

221 East State Street  
Jacksonville, Illinois 62650  
217.479.4627  
FAX: 217.479.4629  
[www.jredec.org](http://www.jredec.org)

October 20, 2011

Mr. Dan R. Long, Executive Director  
Commission on Government Forecasting and Accountability  
ATTN: Facility Closure  
703 Stratton Building  
Springfield, IL, 62706

Dear Director Long and Members of COGFA:

The Jacksonville REGIONAL Economic Development Corporation, the Jacksonville Area Chamber of Commerce, the Jacksonville Main Street Organization, and the Jacksonville Area Convention and Visitors Bureau are all **adamantly** opposed to the closure of the Jacksonville Developmental Center (JDC) in Jacksonville, Illinois. Our organizations are made up of nearly 900 members (industries, businesses, professionals, non-profits, and civic-minded individuals). When issues of the magnitude of this proposed closure of the Jacksonville Developmental Center arise, we are not ones to sit idly by. Therefore, **all** of us want you, the members of COGFA, Governor Quinn, the Illinois Department of Human Services, and the General Assembly to **clearly** understand that we **do not** want to see the closure of this valuable facility as a means to solve any of the State of Illinois financial woes!

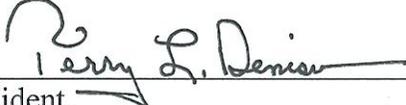
Our Region has suffered through the loss of more than **1,700** jobs since the year 2000. The consequence has been higher unemployment, lost population, retail and service businesses closing, a higher poverty rate, a lowering of the quality of life, and lost tax revenue for our communities and county because of these job losses. In addition, business and industry recruitment is almost nonexistent in downstate Illinois, which adds to the struggle of economic development. It makes keeping what we have even more important!

Now, with the proposed closure of the Jacksonville Developmental Center, the loss of **another** 413 jobs, and its \$21 million payroll, the result will be **catastrophic** for our Region. The **IDHS Economic Impact Study** cites total **employment loss** numbers related to the closure of JDC at 591 which includes Direct, Indirect, and Induced jobs.

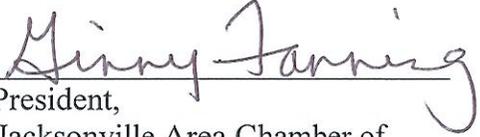
And, **total labor income** lost from these same types of jobs at almost **\$36 million**. The closure of this facility will have a **severely negative** impact on our Region.

In closing, we want to thank you for the opportunity to present the economic facts about how important the Jacksonville Developmental Center is to all of us. And, again, on behalf of all of us, our 900 members-**and most importantly**, the residents and families of the Jacksonville Developmental Center-**Do Not Close this Facility!**

Sincerely,

  
\_\_\_\_\_  
President,  
Jacksonville Regional Economic  
Development Corporation

  
\_\_\_\_\_  
Executive Director,  
Jacksonville Main Street

  
\_\_\_\_\_  
President,  
Jacksonville Area Chamber of  
Commerce

  
\_\_\_\_\_  
Executive Director,  
Jacksonville Area Convention and  
Visitors Bureau

## JACKSONVILLE

### EMPLOYMENT

Description	Direct	Indirect	Induced	Total
11 Ag, Forestry, Fish & Hunting	0	0	0	1
21 Mining	0	0	0	0
22 Utilities	0	0	0	1
23 Construction	0	1	0	1
31-33 Manufacturing	0	2	1	3
42 Wholesale Trade	0	2	2	4
44-45 Retail trade	0	2	20	21
48-49 Transportation & Warehousing	0	2	1	3
51 Information	0	2	1	3
52 Finance & insurance	0	9	8	17
53 Real estate & rental	0	2	1	3
54 Professional- scientific & tech svcs	0	5	2	7
55 Management of companies	0	0	0	0
56 Administrative & waste services	0	4	1	5
61 Educational svcs	0	0	4	4
62 Health & social services	441	6	29	476
71 Arts- entertainment & recreation	0	1	2	3
72 Accommodation & food services	0	7	14	21
81 Other services	0	3	7	10
92 Government & non NAICs	0	5	3	8
<b>Total</b>	<b>441</b>	<b>53</b>	<b>97</b>	<b>591</b>
<b>Multiplier</b>	<b>1.34</b>			

### LABOR INCOME

Description	Direct	Indirect	Induced	Total
11 Ag, Forestry, Fish & Hunting	\$0	\$17,461	\$36,178	\$53,639
21 Mining	\$0	\$109	\$82	\$191
22 Utilities	\$0	\$91,749	\$90,418	\$182,167
23 Construction	\$0	\$49,762	\$22,602	\$72,364
31-33 Manufacturing	\$0	\$162,406	\$123,620	\$286,026
42 Wholesale Trade	\$0	\$169,989	\$135,334	\$305,323
44-45 Retail trade	\$0	\$64,715	\$800,197	\$864,913
48-49 Transportation & Warehousing	\$0	\$116,917	\$96,465	\$213,381
51 Information	\$0	\$98,309	\$61,948	\$160,257
52 Finance & insurance	\$0	\$642,752	\$562,958	\$1,205,710
53 Real estate & rental	\$0	\$113,353	\$84,549	\$197,902
54 Professional- scientific & tech svcs	\$0	\$491,102	\$153,516	\$644,618
55 Management of companies	\$0	\$1,757	\$337	\$2,094
56 Administrative & waste services	\$0	\$276,685	\$56,095	\$332,780
61 Educational svcs	\$0	\$5,731	\$231,140	\$236,871
62 Health & social services	\$27,186,872	\$374,275	\$1,772,348	\$29,333,496
71 Arts- entertainment & recreation	\$0	\$13,961	\$57,516	\$71,476
72 Accommodation & food services	\$0	\$200,218	\$386,345	\$586,563
81 Other services	\$0	\$118,232	\$234,661	\$352,893
92 Government & non NAICs	\$0	\$373,173	\$233,392	\$606,565
<b>Total</b>	<b>\$27,186,872</b>	<b>\$3,382,656</b>	<b>\$5,139,700</b>	<b>\$35,709,229</b>
<b>Multiplier</b>	<b>1.31</b>			

**TOTAL OUTPUT**

<b>Description</b>	<b>Direct</b>	<b>Indirect</b>	<b>Induced</b>	<b>Total</b>
11 Ag, Forestry, Fish & Hunting	\$0	\$31,235	\$64,716	\$95,951
21 Mining	\$0	\$254	\$192	\$445
22 Utilities	\$0	\$234,118	\$230,720	\$464,838
23 Construction	\$0	\$74,762	\$33,957	\$108,719
31-33 Manufacturing	\$0	\$1,293,988	\$984,959	\$2,278,948
42 Wholesale Trade	\$0	\$231,895	\$184,620	\$416,515
44-45 Retail trade	\$0	\$64,251	\$794,459	\$858,710
48-49 Transportation & Warehousing	\$0	\$175,340	\$144,668	\$320,009
51 Information	\$0	\$254,896	\$160,621	\$415,517
52 Finance & insurance	\$0	\$1,431,751	\$1,254,008	\$2,685,759
53 Real estate & rental	\$0	\$1,494,286	\$1,114,566	\$2,608,852
54 Professional- scientific & tech svcs	\$0	\$495,074	\$154,758	\$649,832
55 Management of companies	\$0	\$2,140	\$410	\$2,550
56 Administrative & waste services	\$0	\$383,735	\$77,798	\$461,533
61 Educational svcs	\$0	\$6,465	\$260,741	\$267,206
62 Health & social services	\$31,054,572	\$427,521	\$2,024,489	\$33,506,582
71 Arts- entertainment & recreation	\$0	\$21,372	\$88,049	\$109,421
72 Accommodation & food services	\$0	\$322,606	\$622,507	\$945,113
81 Other services	\$0	\$138,822	\$275,528	\$414,349
92 Government & non NAICs	\$0	\$262,135	\$163,945	\$426,080
<b>Total</b>	<b>\$31,054,572</b>	<b>\$7,346,646</b>	<b>\$8,635,710</b>	<b>\$47,036,929</b>
<b>Multiplier</b>	1.51			

10/18/11

Commission of Government Forecasting & Accountability

Jacksonville Developmental Center has been the home for my 69 year old brother since he was very young.

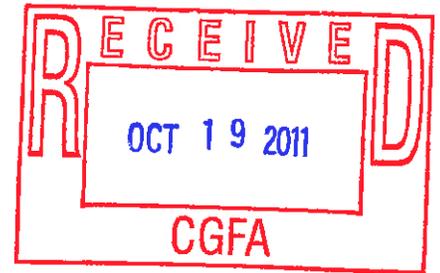
Can you imagine what closing this facility would do to him & all the others?

Please don't take their home and loving care away from them.

Keep JDC open.

Barbara Clary  
1039 Decatur  
Barr, IL 62312

Mr. Dan R. Long, Executive Director  
Commission on Government Forecasting and Accountability  
703 Stratton Office Building  
Springfield, IL 62706



Dear Mr. Long,

I am writing to ask for your support in closing the developmental institution at Jacksonville.

It is a fact that many states have already closed their institutions in favor of community services. National studies indicate that Illinois needs to move away from spending money on institutions for people with disabilities and instead reallocate funds for more community services.

Many parents want their family member who has a developmental disability in a protected and safe environment and they believe institutionalization provides that. But national studies have shown that parents change their attitudes after their family member has moved into a community. Parents saw an increase in their family member's quality of life and began to view the institution less positively. Community services can provide a healthy and safe environment by improving quality of life and relationships.

The average cost of an Illinois state institution is \$181,700/ person per year while the average Community Integrated Living Arrangement (CILA) cost is \$52,454.

This is clearly an opportunity to do what is right -- honoring the rights of people with disabilities and saving the state needed funds.

Please support the closing of this state institution and a safe transition of these individuals into the community by providing for the necessary community services.

Thank you for your time and efforts in this matter.

Sincerely,

A handwritten signature in black ink that reads "Mary Jansen Parrent". The signature is written in a cursive, flowing style.

Mary Jansen Parrent  
2nd Vice President, Board of Directors  
Coalition of Citizens with Disabilities in Illinois

# LONNIE J. JOHNS

P.O. Box 340

JACKSONVILLE, Illinois 62651

Members of COGFA:

October 14, 2011

Closure of Jacksonville Developmental Center

On June 22, 1999, the U.S. Supreme Court issued its OLMSTEAD decision. Advocates have claimed that Olmstead requires the closure of the Jacksonville Developmental Center.

Olmstead was NOT about closing anything, but instead about choices for patients and their parents/guardians and their doctors, about alternatives for treatment and care. Olmstead anticipates a continuum of options, including in intensive larger settings.

U.S. Supreme Court Justices Kennedy and Breyer warned against false interpretations.

Justice Kennedy (usually the swing vote on the Court) and Justice Breyer (one of the more liberal members) as part of the majority in a concurring opinion in Olmstead said:

"It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive for fear of litigation, to deprive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision."

Kennedy and Breyer pointed to mistakes in the past:

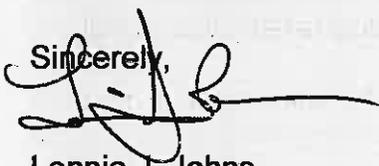
"The depopulation of state mental hospitals has its dark side. According to one expert, 'For a substantial minority...deinstitutionalization has been a psychiatric Titanic. Their lives are virtually devoid of dignity or integrity of body, mind, and spirit. Self-determination often means merely that the person has a choice of soup kitchens. The least restrictive setting frequently turns out to be a cardboard box, a jail cell, or a terror-filled existence plagued by both real and imaginary enemies.' "

As part of the majority in Olmstead, Kennedy and Breyer stated:

"The opinion of a responsible treating physician in determining the appropriate conditions for treatment ought to be given the greatest of deference."

"In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition."

Sincerely,



Lonnie J. Johns

# Lonnie J. Johns

P.O. Box 340

JACKSONVILLE, Illinois 62651

Representative Patricia Bellock

October 27, 2011

In the proposed closing of the Jacksonville Developmental Center (JDC) the following appear to be true.

(1) DHS is *not* in compliance with the State Facilities Closure Act, Sec. 5-10, which mandates that the recommendation for closure "must include" the "location or locations to which the functions" of the facility would be moved. In fact DHS specifically states on page 2 of its letter to you of Sept. 23, 2011, "Until we can meet with each individual and his or her guardian, if applicable, to discuss transition plans, we cannot provide specific locations of the new services." In its own words, DHS's proposed closure is premature.

(2) In contrast to what DHS and some others claim about legal jeopardy because of the U.S. Supreme Court decision in *Olmstead*, this 1999 decision of the Court does *not* require closing anything, but instead that individual decisions be made for individuals.

(3) JDC has an exemplary record of care, of making individual decisions for individuals as to community care, and has a staff that can provide the full range of medical and psychological services so needed by those at JDC.

(4) Closing JDC would be life-threatening. In DHS's own 2010 study, from 2001 to 2008 133 of the over 2,500 residing at the 10 developmental centers died, while of the 1,480 that left the developmental centers, 164 died. So 11% of those that left died, but only 5% of those in residence died.

(5) As to the physical condition of JDC, over \$1.8 million has just been spent to assure that JDC fully complies with all life-safety codes, \$100,000 to assure that one boiler in the power plant will be in service for years to come, and JDC was built to last in that its standards of construction and craftsmanship are of a much higher quality than is currently required.

If you should need further information on any of the above, please call 217-473-4485.

Sincerely,

Lonnie J. Johns

To Whom This May Concern,

I am writing to express my opposition to the closing of the Jacksonville Developmental Center in Jacksonville IL. My name is Wayne Cravens and I am the legal guardian of my brother, Robert Cravens.

My brother, Robert Cravens, is 60 years old and is severely mentally retarded with a brain function of a four year old. He has several health problems including problems swallowing, trouble walking, bladder problems, vision in only one eye, and has had pneumonia several times recently.

Robert Cravens has been a resident in State of Illinois facilities for over 45 years. He has been a resident at the Warren Murray Center at Centralia, IL, the Lincoln Developmental Center at Lincoln IL, the Adolph Meyer Center at Decatur IL, and the Jacksonville Developmental Center at Jacksonville IL. He has also been a resident in two group homes at Decatur IL, and a group home at Champaign IL. All three times were unsuccessful because he didn't get along with the staff and other residents.

In conclusion I think it is better for my brother, Robert Cravens, to continue to be a resident of the Jacksonville Developmental Center where he receives very good care and he receives fine care for his health problems.

Sincerely,

Wayne Cravens

*Wayne Cravens*

Jean C. Collins  
P.O. Box 512  
Western Springs, IL 60558

October 17, 2011



Mr. Dan R. Long  
Executive Director  
COGFA  
703 Stratton Office Bldg.  
Springfield, IL 62706

Dear Mr. Long:

Please know that I support Governor Quinn's proposal to close the Jacksonville & Mabley Developmental Centers.

We urge the state to develop a plan to help the people who live at these two institutions Transition in an organized & safe manner & to insure that there are the necessary services and supports in the communities (not institutions) where they live.

Thank you for your respect, and that of all the \*members of CGFA.

Yours truly,

  
Jean C. Collins

\*Jeffrey Schoenberg, Michael Frerichs, Matt Murphy, Suzi Schmidt, Dave Syverson, Donne Trotter, Patricia Bellock, Kevin McCarthy, Elaine Nekritz, Raymond Poe, Al Riley, & Michael Tryon.

Ladies & Gentlemen,

We are writing this letter as our written testimony that will be made a part of the records for the October 24, 2011 hearing.

Let me introduce ourselves. We are Roger and June DeWerff, legal guardians of our nephew, Todd Lin Grimes, for the past 14 years. Todd's mother was Roger's sister. She asked us to be Todd's guardians before her death because of her failing health. Todd's father, John Grimes, had already passed away. So, because we love Todd very much and had been a part of his life, watched him go through all his stages of growing up, we agreed and have been actively involved since 1997 in taking responsibility for him.

Part of that responsibility is to be his "voice" to represent him to the best of our ability, to help him have a life with dignity within his limitations of being developmentally disabled.

We live at 18345 E. 22<sup>nd</sup> Rd. in Nokomis II, 62075. We've been married and active in the farming business for 45 years. We have 3 grown daughters and 7 grandchildren. We are also active in our church. So we know about meeting budgets, managing money and we do have an understanding of what's happening in our state's economy.

We are very distressed to hear about the possibility of the closure of Jacksonville Developmental Center and would like to share Todd's story of his journey to J.D.C.

Todd is a white male, 37 years old and weighs about 110 lbs. He was born microcephalic with a pronounced nose and a small chin. He also has severe mental retardation, impulse central disorder and bipolar disorder. He walks with a forward lean and looks very young for his actual age. He is usually smiling and likes interacting with others. He's highly curious and doesn't understand the meaning of danger. He has a very short attention span, and when bored he can resort to aggressive behavior. He is unable to speak but does know some sign language.

Todd requires a watchful eye because he can move with speed and can also escape from the premises if not observed at all times. He does well when kept constantly occupied or kept on task with some activity. He likes to assist staff with chores and can be redirected from aggressive behavior. He does have sudden outbursts of aggression at times and this has caused him problems in the past with the small group home setting.

When Todd became a resident of J.D.C., we felt he had truly found his home, his own special place that welcomed him and accepted him for who he is. We felt J.D.C. was a perfect fit for him.

Let's go back to 1997 when we became more involved with finding help to meet his many unique needs. We started the process of looking for a facility that would meet these needs. We were directed to Country View Living Center in Latham, IL. (this is closed now). It was an all male facility and he only lasted there about 6 months before they recommended he be moved elsewhere for his own well being so they helped us find a different facility.

They directed us to a smaller group home (16 residents) in Taylorville, IL. called Taylorville Terrace. He resided there for 5 years. It was during his stay there that his mother Patricia, passed away in 2002. During his last year there a new administrator took over and she immediately showed a dislike and a lack of respect for Todd and his behaviors and it progressively got worse. Todd was very unhappy during this time and we saw something was terribly wrong. She didn't seem to have a good understanding of Todd's mental health and the behaviors he exhibited. Within a few months we were given notice through the mail Todd was being involuntarily discharged from there, and we had 30 days to find him alternative living arrangements. This was a very stressful, emotionally charged time in both Todd's and our lives. We didn't know what the future held for him and felt poorly equipped to deal with this matter. This was in 2002, shortly after his mother passed away.

We spent weeks floundering with this until we ran across the help of an advocate, Barb Becker, who helped us tremendously in trying to find placement for Todd. He was turned down by several group homes. The write up that his past administrator had put in his files went very negatively against Todd finding any small group home accepting him. We went through hours and hours of research, and interviewing places. We went as far as Chicago, Galesburg and Alton and were turned down over and over again. We were desperate to find some place that would accept Todd. Because of our experiences with this we don't feel the small group home setting is appropriate to meet Todd's needs.

That's when Barb Becker started looking elsewhere and came to us with the recommendation, which also was the past administrators written recommendation that Todd would better benefit from a bigger facility with more structure and more trained staff such as psychiatrists, psychologists, nurses and behavioral specialists to monitor his behavioral changes and issues. We have that letter in our records. This is when Barb Becker recommended Jacksonville Developmental Center to us.

We were very skeptical at this point, but when we met with its staff and toured the facility we were very much encouraged that it might work well for Todd and us. J.D.C. was an answered prayer for us as it turned out. We were very happy with the individual care and guidance Todd received there. We've never been disappointed or changed our opinion since.

J.D.C. has been his home now for 9 years, but besides that Jacksonville is his home town. When we take him out for a day trip there he is recognized as a member of that community. People will see him, recognize him, stop and say "hi" and shake his hand. They know him for who he is! This is a long term relationship that Todd has with his staff members and friends at J.D.C. and friends in the community.

We've been through involuntary discharge with the small group home; we've been rejected by other group homes not accepting him. They are unable to meet the requirements that it takes to properly care for Todd.

So we feel that the option of moving to a small group home facility is unsatisfactory for Todd with his challenging developmental disabilities. Todd is entitled to ICF/MR level of care which includes State Operated Developmental Centers or private Intermediate Care Facilities for the Developmentally Disabled. The state is required to provide that level of care to those who qualify and JDC residents do

qualify. If Jacksonville closes we will be asserting our rights to have Todd receive services in another SODC or ICF/DD.

We recommend that the people who will make this decision to close JDC actually take the time to investigate further, to tour and observe this place. We have high respect and admiration for the dedicated, giving employees who show Todd dignity as a disabled adult and make his daily life, more worthwhile. Todd has his rights too, and he deserves a place where he can excel, one that shows him unconditional love to him even with his disabilities. This is a great place for people who deserve a place to live that meets their needs. It deserves to stay open.

These families of employees that serve JDC give a large portion of their lives to make people like Todd's life better. Being in business ourselves, we realize these are difficult decisions, but we hope you will see individuals who are not able to speak up for themselves, whose way of life will be taken away from them because of the decision to close JDC.

Their quality of life is in your hands. We will pray that God will guide you to make the right decision and keep JDC open to serve a group of developmentally disabled individuals who deserve this place.

I'm sure you have children and families yourselves and if you were in this position you too would want the very best you could get for them. Make this decision as if it was in your child's best interest to live at JDC.

Thank you for this opportunity to speak for Todd and voice our concerns for him. We love him and are deeply distressed about what Todd's quality of life will be in the future.

Thank you again for listening to us.

Respectfully,

Roger & June DeWerff

October 17, 2011

TO: Commission on Forecasting and Accountability  
Attention: Facility Closure

FROM: Halima M. Jabulani, Board Member, The Arc of Illinois

RE: Closing of the Jacksonville Developmental Center

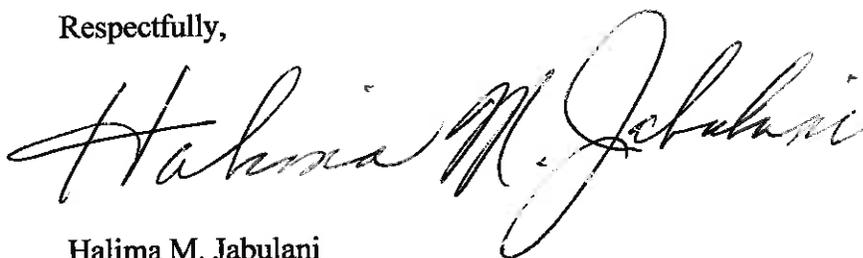
I am a concerned citizen, parent of an adult with a disability and advocate who believes Everyone should be supported in the community. I am in support of the closing of the Jacksonville Developmental Center and for the transitioning of the people there with All the needed resources and support in a safe and appropriate manner.

I have a daughter with a disability who has been waiting two years for placement in a group home. Additionally, I have MS and this delay has caused great stress for both of us.

Illinois is 50<sup>th</sup> in small community settings and 47<sup>th</sup> in community spending.

I fully support your decision to close the Jacksonville Developmental Center.

Respectfully,

A handwritten signature in cursive script that reads "Halima M. Jabulani". The signature is written in black ink and is positioned to the right of the typed name.

Halima M. Jabulani  
305 W. Swann Street  
Chicago, Illinois 60609

Name: Alan L. Thomas  
Title: Deaf Services Coordinator  
Organization: PACE, Inc. Center for Independent Living  
Please indicate your relationship to Facility: Employee  
Address: 1317 E. Florida Avenue, Urbana, IL 61801  
Email: [alan@pacecil.org](mailto:alan@pacecil.org)  
Your position: No Position  
Type of Testimony: Written Statement

To Editorial Board,

My name is Alan L. Thomas. I work as Deaf Services Coordinator for PACE, Inc. Center for Independent Living in Urbana, IL. I am representing in behalf of deaf and deaf-blind residents with developmental disabilities.

People with disabilities can and should be supported in their communities. I am concerned about deaf and deaf-blind people in Jacksonville Developmental Center. They have been living there successfully for years with community supports. They have gained independent living skills that many residents would not have predicated.

The community system mentioned can better serve the nearly 30 deaf and 7 deaf-blind residents with developmental disabilities of this institution to be closed. For a responsible transition, the governor and legislators MUST see that the money saved follows those individuals into the community for group homes and other supportive services. Planning for the transitions must be based on the need of the individuals.

Research surveys of parents of formerly institutionalized individuals report that in the community their loved ones changed for the better in a number of ways: being more communicative independent, responsible and happier; showing positive behavior change and gaining daily living skills especially with Deaf community and Deaf culture.

Both chambers of the Illinois legislature have adopted a resolution calling for a plan to enhance and expand access to quality community services and supports for people with developmental disabilities. Those community services are woefully underfunded in Illinois. Closing the institutions presents both an opportunity AND a responsibility. Our elected officials have the responsibility to provide appropriate funding for Illinois citizens with developmental disabilities.

Sincerely yours,

Alan L. Thomas

Dick Rawlings  
35 Briarwyck Dr  
Jacksonville, IL 62650

October 26, 2011

Representative Jim Watson (R-97)  
325 West State Street  
Suite 102  
Jacksonville, IL 62650

RE: JDC Public Hearing

Dear Representative Watson,

The Illinois "Commission on Government Forecasting and Accountability" (CGFA) conducted a public hearing regarding the closing of JDC at the Bruner Building on Illinois College campus on Monday, October 24, 2011.

DHS staff gave a budgetary break down of monetary savings for placing JDC residents in area group homes.

As I recall, the savings would amount to approximately \$10 million/year if all JDC consumers were placed in group homes.

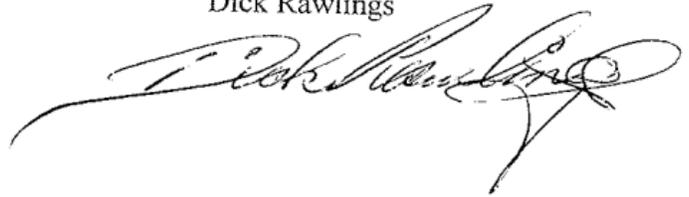
I question the savings amount and do not feel a full analysis of costs to close the JDC facility have been considered. For example:

- 1) Cost of acquiring and staffing and maintaining group homes.
- 2) Cost of closing and maintaining the closed facilities at the JDC campus.
- 3) Relocating, retraining, unemployment costs of present employees of JDC.
- 4) Maintaining the JDC campus grounds after closing.
- 5) Costs of security of the building and disconnecting utilities.
- 6) Cost of breaking contracts for utilities, commissary goods, etc.
- 7) Cost to demolish abandoned buildings and environmental clean-up.
- 8) Cost to demolish existing power plant and the environmental clean-up.  
(Versus retrofit to natural gas)

- 9) Cost to remove the elevated water storage tank.
- 10) Numerous other unaccountal costs to abandon the existing JDC facilities.

In closing, I want to express my concern that closing JDC will be detrimental to the JDC residents, and will ultimately cost the State of Illinois millions in tax money to abandon and lay waste the JDC campus. I will appreciate knowing if C.G.F.A. has accounted for these costs.

Sincerely Yours,  
Dick Rawlings

A handwritten signature in cursive script, appearing to read "Dick Rawlings". The signature is written in black ink and is positioned below the typed name.

November 4, 2011



Commission on Government Forecasting and Accountability  
ATTN: Facility Closure  
703 Stratton Bldg.  
Springfield, IL. 62706

I am writing regarding the closure of the Jacksonville facility for the disabled. This should be done. It is a great waste of money and an outdated building requiring renovations. The people who now live at this facility would be much better served in a community setting. And., at the same time, the state would be saving a lot of money. My daughter is in a community living facility living in a bungalow with five other ladies. This is a perfect setting for them and it is not costing the state nearly so much money.

A handwritten signature in cursive script that reads "Charlene Sebert".

Charlene Sebert  
353 Nottingham  
Carol Stream, IL 60188  
e-mail : Gramseb@aol.com

## Public Comments on the Facility Closure of the Jacksonville Developmental Center



The Institute on Public Policy for People with Disabilities  
683 South Prospect Avenue  
Elmhurst, Illinois 60126  
[cathyfickerterrill@yahoo.com](mailto:cathyfickerterrill@yahoo.com)

To: The Members of the Commission on Government Forecasting and Accountability

From: Cathy Ficker Terrill, Institute on Public Policy for People with Disabilities

Re: Closure of the Mabley and Jacksonville Centers

Date: October 10, 2011

The State Facilities Closure Act charges you with providing an Advisory Opinion in regard to the closure of state developmental centers to the executive and legislative branches. As you are aware, Governor Quinn has proposed the closure of Mabley and Jacksonville Developmental Centers. The Institute fully supports the closure of all state operated residential facilities in a way that allows for the safe transfer of individuals as well as the provision of quality supports for a meaningful life.

**Government Operations.** Illinois should not be in the business of operating residential facilities for people with disabilities. It can be done more effectively and efficiently in the private sector. The privatization of this line of service should be the preferred model.

**Success.** Fourteen states have closed all of their state operated institutions. Illinois institutionalizes more people with intellectual and other developmental disabilities than 48 other states with Illinois's eight state institutions. Many studies of Illinois' developmental disability system by national experts clearly state the need to move away from institutional spending and invest in community services.

**Rebalance.** The federal government is offering states enhanced Medicaid match funds for moving in a direction away from large institutional settings toward smaller homes for 4 or fewer individuals. This is an opportunity to rebalance by re-allocating funds during the veto session to ensure the smooth transition of individuals to the community. A supplemental appropriation may also be needed next year since the savings from the closure of an institution lag 1-2 years behind the closure. I urge you to support sufficient funding to rebalance Illinois' system of service provision towards community services.

**Community Capacity.** As Illinois moves toward a rebalancing of the Medicaid long term care system in Illinois, it is essential that Illinois also focus on building community capacity so that individuals with complex medical and or behavioral challenges have innovative supports available to them.

**Quality.** As people transition from state operated residential facilities to new options in the community, their service plans need to be person centered and include outcomes for success.

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My parents were in their 50's when they finally placed my brother into the loving hands of Jacksonville Developmental Center. City and State agencies had encouraged them for years, pointing out that Billy would outlive them, and then what would happen? They claimed that the earlier they placed him, the better the transition. But it felt like a failure on their part, even though they knew it truly was best. It was the hardest day of my mother's life, God rest her soul.

How did the State benefit? Billy's family lives a life of service to their communities. There are three Veterans of Foreign Wars, two active members of service (one currently in Afghanistan). Two members of the family worked at a Veteran's hospital; another still does. Four members are actively involved in church and civic groups. We work hard, live within our means, pay our taxes. We donate blood and money. Our children are educated to be altruistic; from Eagle Scouts to Job's Daughters; foster parents and advocates for animal rights.

We work and live next to you and the only difference between us is that we feel a greater debt because we have to ask you to help us care for a member of our family.

So, as you consider the impact of what these closures mean to you, we ask you to be mindful of the blessings you have that you are not in a position to have to beg for compassion. It's just a vote, a phone call, a postcard to the Governor. The families of these residents will continue to serve the Heartland, always with you in mind.

Lorna Dempster, My Brothers' Guardian

Lorna Dempster  
4452 State Line Road  
Kansas City, KS 66103  
913-562-4197 [hear.andnow@yahoo.com](mailto:hear.andnow@yahoo.com)

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As county Coroner, I am very acquainted with long term care facilities in Jacksonville. Most everyone is aware of the detrimental effect on the economy here by this closing. However, I have a different insight. I have been in JDC and local group homes as well as nursing homes since 1974 as I was also involved in emergency medical services. I can tell you that there is a very marked difference in the care of the mentally challenged residents of these facilities. JDC personnel are highly trained in the care of these individuals. There are doctors with specific training managing their care as well as registered nurses 24 hours a day, and the trained mental health technicians. If closed, these JDC residents will be assigned to group homes and nursing homes. Their care at these facilities is inferior as the physicians that will manage their care will be family practice physicians and there will not be 24 hour nurses on site. The other workers will not have the training and experience that JDC staff have.

I have seen the detrimental affect on these individuals that has happened in the past when JDC was downsized.

I am available to answer any questions by calling my cellphone 217-473-5708.

Sincerely,

Jeff Lair  
Morgan County Coroner

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I am pleading to you to please keep JDC open. I do understand that over the decades there have been people wrongfully placed in many of these institutions.

Years of evaluations have proven many of them could function in group homes. We are now down to the Profoundly developmental residents.

The form of care many would require could not be met at a group home setting. It would also not be in the interest of these residents to be placed in other institutions where family members would not be able to travel to to visit.

These residents are people, not cattle that get shifted from one farm to another.

Please care enough for the ones who are the most helpless.

God be with you in your decisions.

I will be praying for you.

Jill Winkeljohn  
jwinkel@adams.net

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I am writing to tell the State of Illinois that I support the closure of Jacksonville SODC. It is the oldest state long term care institution for people with developmental disabilities in Illinois, and we want and need Illinois to be free of large long term care institutions that warehouse people with disabilities! Community integration is our civil right.

Theresa Pacione, M.S.

Coordinator

Bodies of Work

a Network for Disability Art and Culture University of Illinois at Chicago Dept. of Disability and Human Development

773 772-6092 [www.bodiesofworkchicago.org](http://www.bodiesofworkchicago.org)

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Proponent of closing Jacksonville.

As an advocate for individuals with intellectual and other developmental disabilities for over 30 years, I support the closure of the Jacksonville Developmental Center. It is time to re-balance the disability system in Illinois. This is long overdue.

The time to close state institutions is now. There are now fourteen states without state institutions.

With 2,027 individuals in institutions, Illinois now institutionalizes more people with intellectual and other developmental disabilities than 48 other states.

Illinois ranks 50th in small community settings.

Illinois ranks 47th in community spending.

For the above reasons and more, I fully support your decision to close the Jacksonville Developmental Center.

The money saved by closing state institutions needs to be reinvested in the community and to support the 21,000 children and adults on the waiting list.

In addition, the transition needs to be safe, smooth and based upon the individual needs of the people leaving Mabley and Jacksonville.

We are in a time of scarce resources, so we must invest our state resources in community settings where people grow and prosper. It is the right thing to do!

Tony Paulauski  
Executive Director  
The Arc of Illinois

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As an advocate and parent, I support the closure of the Jacksonville Developmental Center. It is time to re-balance the disability system in Illinois.

I have a daughter that is in need of community based services and closing of costly and ineffective institutions offers a real opportunity to focus scarce funding on community based solutions.

The time to close state institutions is now. There are now fourteen states without state institutions.

With 2,027 individuals in institutions, Illinois now institutionalizes more people with intellectual and other developmental disabilities than 48 other states.

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For the above reasons and more, I fully support your decision to close the Jacksonville Developmental Center.

The money saved by closing state institutions needs to be reinvested in the community to support the 21,000 children and adults on the waiting list.

In addition, the transition needs to be safe, smooth and based upon the individual needs of the people leaving Mabley and Jacksonville.

We are in a time of scarce resources, so we must invest our state resources in community settings where people grow and prosper. It is the right thing to do!

Sincerely,

Charles Miles  
1015 Westfield Course  
Geneva, IL 60134

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I am the parent of a young man with autism and I am STRONGLY IN FAVOR of CLOSURE of all SODC's, including Jacksonville and Mabley. I am a proponent of closure because it is the right thing to do both for individuals with intellectual and developmental disabilities and it is the best use of taxpayer dollars to provide community living arrangements. With appropriate supports, everyone can and should live in his or her own community, close to family and friends. We need to rebalance the system and reallocate resources. It is imperative that in moving individuals to community, we take into account their specific needs. Some individuals will need additional resources in order to maintain health and safety. Many of the individuals who are funded at over \$150,000/ per year will need far less to live safely and productively in the community. We need to build in incentives for providers who have been underfunded and unpaid. We have an opportunity to do the right thing and to save the state money in the long run. SODC employees can and should be trained to work in the community. Let's bring DHS/DDD into the 21st Century and join Alabama, the most recent state to close it's institutions for people with I/DD.

Thank you.

Ellen Garber Bronfeld, mother of Noah Bronfeld

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My son David Cicarelli is finally in the process of moving from a large facility Riverside Foundation to a CILA Clearbrook Home close to us. I hope Illinois will close the large state facilities, catch up to the rest of the country, and give the intellectually disabled residents of our state the services they need in homes.

Thank you,

JULi Cicarelli,  
1220 Vargo Lane  
Arlington Heights, 60004.

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I appeal to all those gathered here today to please live up to the edicts of the Olmstead act by closing this facility. Illinois needs to stop this archaic and outdated service model. Why can't Illinois follow the lead of 14 other states in the union that have successfully closed their institutions? Supporting these closures are longitudinal studies that followed deinstitutionalized people in Minnesota, showing that this population exceeded prior status or stayed the same in almost every domain after being integrated into the community and at a savings to the state. Furthermore, no other state in the union has as many institutions as we do in Illinois giving us an embarrassing ranking of 51st in way of services for those with developmental disabilities. Because these facilities exist and are a financial drain on the state, hundreds of adults with DD have been on a waiting list for placement into community based living arrangements. They are waiting because our legislators believe it is better to keep funding a broken and ancient model, more concerned about the employees than the clients of said facilities and no concern at all for the hundreds across the state on waiting lists. I say shame on you! Shame on Illinois, and shame on the bullies employed at this facility that use fear tactics to gain support for warehousing and isolating people from their community.

In closing, my daughter has been waiting over four years and we see no other choice but to leave this state and take our earnings and taxes with us and pay into a better state system that is out of the dark ages in way of services. I am not alone in this choice and many stakeholder organizations in Illinois will support the fact that families are fleeing this state in search for better services. I guarantee that if any of the legislators assembled here today given the choice of living in a community setting or an institution would pick the community. I beg that all of those with the power to change the lives of the powerless look to your hearts and do what is right for all. The clients may not understand it initially, but their lives can be changed for the better, but only if done in the correct manner with the right supports in place and fair funding. It has been done! It can be done! It must be done! And must be done soon!

The committee gathered here today should also consider the silence of those afraid to speak up in support of closing this facility. Those silenced may include our local legislators, clients in JDC, and family members of clients in JDC. We are up against a very strong opponent: the AFSCME union. Members of which may be our neighbor, congregant member, caring for a loved one housed at JDC or a friend. These people may be in fear or retaliation towards themselves or their loved one at JDC. Please remember those silenced by fear or unable to speak for themselves.

Tired of waiting on a broken system,  
Amy and Kesley Grau

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As the mother of two adult sons with developmental disabilities I believe that the time to close state institutions is now! There are now fourteen states without state institutions. With 2,027 individuals in institutions, Illinois now institutionalizes more people with intellectual and other developmental disabilities than 48 other states. Illinois ranks 50th in small community settings. Illinois ranks 47th in community spending. For the above reasons and more, I fully support your decision to close the Jacksonville Developmental Center. The money saved by closing state institutions needs to be reinvested in the community to support the 21,000 children and adults on the waiting list. We are in a time of scarce resources, so we must invest our state resources in community settings where people grow and prosper. It is the right thing to do!

Respectfully Submitted,  
Betty Korey  
1416 Hackberry Rd.  
Deerfield, IL 60015

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I am the parent of two young men with autism and I am a proponent of closure because it is the right thing to do both for individuals with intellectual and developmental disabilities. And especially because it is the best use of taxpayer dollars to provide community living arrangements. With appropriate supports, everyone can and should live in his or her own community, close to family and friends. We need to rebalance the system and reallocate resources. It is imperative that in moving individuals to community, we take into account their specific needs. Some individuals will need additional resources in order to maintain health and safety. Many of the individuals who are funded at over \$150,000/ per year will need far less to live safely and productively in the community. The money saved by closing state institutions needs to be reinvested in the community to support the 21,000 children and adults on the waiting list. For those 2027 in state institutions, the transition needs to be safe, smooth and based upon the individual needs of those being served. We need to build in incentives for providers who have been under funded and unpaid. We have an opportunity to do the right thing and to save the state money in the long run.

The opportunities for our sons as they reach adulthood are so few and inappropriate in Illinois that it just makes a hard situation even harder than it needs to be. We are in a time of scarce resources, so we must invest our state resources in community settings where people grow and prosper. It is the right thing to do!

Elisabeth K Grzywa  
5805 Washington St.  
Downers Grove IL 60516

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The Governor has made a good decision to better utilize public funds because community services is a better investment and result is positive outcomes for people.

Dianne Kariotis

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I am extremely pleased that Governor Quinn and his administration are moving forward to close Mabley and Jacksonville Developmental Centers. This action will enable the State of Illinois to better utilize public funds. Illinois State Institutions have a proven record of providing negligent services that have placed people at great harm and often times resulting at death. These sub-standard services currently provided to 2,156 people come at a very high cost. The average annual cost per resident in a State Institution is \$168,656. The average annual cost per person served in a 24-hour supervised community based setting is near \$50,000. [Data source: Don Moss and Associates, 2/2011] If today the State of Illinois made a commitment to serve its 2,156 citizens residing in state-run institutions in community settings, there would be an estimated \$200 million savings. There are more than 20,862 people waiting for community services. 14,757 people have an emergency or critical need today. [Data Source: March 7, 2011 DHS PUNS Summary] I am saddened and angered that so many people are unable to receive the supports they need. The State needs to be more responsible in their spending so that more people with disabilities can be supported. I propose that State institutions be closed and residents of those institutions be supported in community-based settings at less than 1/3 of the cost of supporting them in State institutions, and that the money that is saved be used to support people with disabilities who currently do not receive services. The Ray Graham Association supports people who previously lived in a State institution, and since coming to Ray Graham's community integrated living arrangement (CILA or group home in the community) and attending a community learning center, these individuals have made tremendous growth. State institutions are also inefficient with their use of funds and staff. When one individual who lives in a State institution visited a Ray Graham CILA, he came with a driver and a direct support staff. While the individual was visiting the CILA for a few hours, the driver just sat in the vehicle. This occurred because the driver could only drive and the direct support staff could only support individuals. I urge you to ensure the closure of these State facilities and use the money saved to support individuals with disabilities in community settings.

Rosalie Der  
QHSP  
Ray Graham Association for People with Disabilities  
748 Whalom Ln.  
Schaumburg, IL 60173

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Dear Commission Members:

As an advocate for people with disabilities, I support the closure of the Jacksonville Developmental Center. It is time to re-balance the disability system in Illinois.

I am a retired professional who worked with people with disabilities over 40 years, I have seen first-hand the benefits of living with family or in one's home in the community.

The time to close state institutions is now. There are now fourteen states without state institutions.

With 2,027 individuals in institutions, Illinois now institutionalizes more people with intellectual and other developmental disabilities than 48 other states.

Illinois ranks 50th in small community settings.

Illinois ranks 47th in community spending.

For the above reasons and more, I fully support your decision to close the Jacksonville Developmental Center.

The money saved by closing state institutions needs to be reinvested in the community to support the 21,000 children and adults on the waiting list.

In addition, the transition needs to be safe, smooth and based upon the individual needs of the people leaving Jacksonville.

We are in a time of scarce resources, so we must invest our state resources in community settings where people grow and prosper. It is the right thing to do!

Sincerely,

Elizabeth Lacey  
Member, Board of the Arc of Illinois  
5421 S Cornell  
Chicago, IL 60615

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Concerning the closure of Developmental Centers, I support the Governor's actions. However, as usual, such action is being taken for the wrong reasons. While closing large state facilities will surely save money, we should be concerning ourselves with the quality of services afforded to people who need our help. People with developmental disabilities and/or mental illness who cannot speak for themselves, if they are to have a better life in the community, are going to need some system changes. I believe that the closure needs to take place along with the following actions if it is to be regarded as successful:

- The community system requires a significant upgrade in order to support people with more serious needs. In fact, the community system is now supporting some people with very challenging behavior, or severe medical needs, but the data suggests that placing such persons in the community in large numbers is likely to fail. There are not enough medical supports available in the community Medicaid system, and there are virtually no behavioral supports except the mobile crisis teams.
- The community funding model (CILA) is not structured in a way that allows success. The physical plant expenses being borne by community agencies are enough to collapse the system, let alone the ever-increasing cost of food, energy, transportation, and employee benefits. The Home-based waiver system is even worse, but that is an issue for another day.
- If anyone is to take seriously the contention that jobs in the community are a replacement for state jobs lost through closures, then someone had best examine the ability of community agencies to pay employees a living wage. Minimum wage and minimal benefits are not a replacement for a state job that pays over \$25,000 per year with outstanding benefits. This is purely a funding issue, and only if some of the funds realized through closure are re-directed into the community will any change occur.

Thank you for the opportunity to comment.

Sally Ritchey  
400 Maple lane  
Shorewood, IL 60404

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I support the closure of Jacksonville facility

Yvonne Rogala

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My wife and I are the parents and guardians of Olivia Voit who is 23 years old and has a moderate cognitive disability. Olivia currently receives services that are funded by the home and community waiver. She receives in home respite support and developmental day services from a local community organization. Olivia is on the PUNS list currently waiting for residential CILA funding. My wife and I are in our sixties and must plan for Olivia's future needs. The only acceptable residential alternative for Olivia is a small community integrated CILA home. The only way we have any hope for funding is if the State of Illinois closes high cost institutions and transfers current residents in these facilities to less costly and better quality CILAs. This will free up the funding to address those families waiting for high quality community CILAs. We fully support the Governor's effort to close state institutions that care for adults with disabilities.

Thank you

John and Kathy Voit  
3119 Thorne Hill Ct  
Lisle Illinois 60532

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Good Afternoon. I am emailing to support the closure of Jacksonville and Mabley Developmental Centers. Closing these state facilities is the right thing to do for people with disabilities and a good decision to better utilize public funds. Community Services for people with disabilities is a much better investment.

Thank you.

Sharon Anderson  
A Concerned Citizen  
215 S. Grant St  
Westmont, IL 60559

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To Whom It May Concern:

We support closure and an institution free Illinois!

Much Thanks

Sam Knight

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On behalf of families in Illinois who are successfully supporting people with disabilities in their home communities, I ask you and other legislators to move forward with the closure of both the Mabley and Jacksonville Developmental Centers. In addition, we ask that you ensure that funding follows these residents into the community, where it is so desperately needed for their success. Third, there will be a temporary need for additional funds during the closure transition so that communities, agencies and families can begin to prepare. We ask that you support additional appropriations to assure a successful transition.



One of the greatest fears that we, as parents, have, is that our loved one with disabilities will end up in places like Jacksonville and Mabley if Illinois doesn't take this opportunity to begin the process of building community supports. The State-operated developmental centers are sucking the life out of good community supports in Illinois, with an average cost per resident exceeding \$180,000. Granted, some residents may need that level of support once living in the community, but most won't.

AFSCME members and some legislators look at SODCs as a source of good jobs, but in fact, people with disabilities who live in SODCs will still need the support of staff when living in community settings. The jobs won't go away, they will change into a form that better meets the needs of people who are served by them. Please do not consider maintaining institutions that are outdated vestiges of the 1960s. We can do better. The disability community has never come together so strongly. We CAN work together to make closure work for people with disabilities, the staff who serve them, and for the many in Illinois who still have no services.

Our project recently made a short video which describes the process and benefits of individuals with disabilities being supported well in their communities. The video is available at <http://vimeo.com/25665805>. I encourage you to take a few minutes and view the video to listen to people who just want to live near friends and family, make a contribution to their communities, with the freedom to make choices in their life at whatever level they are able.

If Jacksonville, Mabley, and, down the road, other institutions are shuttered, those who assisted in making it happen will be heroes of the disability community in Illinois. Please don't let us down.

Vicki Niswander  
Executive Director  
Illinois Association of Microboards and Cooperatives  
<http://iambc.org>  
104 Woodcreek Ct.

Mahomet, IL 61853

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To Whom It May Concern:

My name is Barbara Pritchard and I am the co-founder of the Community for All Coalition and the Campaign for Real Choice in Illinois with my late husband, Lester Pritchard. I am also a board member of the Illinois Council on Developmental Disabilities and the State-wide Independent Living Council.

I am in support of the closure of the Jacksonville Developmental Center. I am a disability rights advocate. It is my belief that every person with a disability can be served in the community of their choice with individualized supports and services tailored to their needs. There are 14 other states which have closed all of their state-run developmental centers. Michigan, for example, serves more people in the community with less funding than Illinois does at this point. Michigan just closed it's last Center about 1 year ago. The reason I cite Michigan is because it is similar in its economic status and a very unionized state, much like Illinois. I believe if Michigan and 13 other states have moved people to the community, Illinois can do this as well.

It is the right of Illinois citizens to live where they choose and be surrounded by family and friends with the supports they need. We are in the Land of Lincoln, which should provide freedom and choice for all, regardless of a disability.

I will be giving an oral testimony at the Hearing on Monday, October 24th with copies given to COGFA and its members.

Barbara Pritchard  
Barb Pritchard  
bmpritchard@comcast.net  
1907 Autumn Ridge Drive  
Urbana, Illinois 61802

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SODCs are obsolete. Other states have shown that there's no need for them.

The governor is right to close them.

Mike Ervin  
Chicago

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1740 W. McDonough Street, Joliet, Illinois 60436  
815-741-0800

E-mail us at [ADVOCATESUNITED@AOL.COM](mailto:ADVOCATESUNITED@AOL.COM)

October 14, 2011

Commission on Government Forecasting and Accountability  
ATTN: Facility Closure  
703 Stratton Building  
Springfield, IL 62706

Dear Mr. Schoenberg and Ms. Bellock,

The Mission of the Advocates United organization is to work together for quality life choices for all people with disabilities. The closure announcement of a facility or service for the Intellectually Disabled (ID) community impacts all of us in many ways and therefore limits the choices available for the ID community.

The announcement on September 8<sup>th</sup> to close the Mabley and Jacksonville Developmental Centers causes great concern for the ID community. The reason for closure of these facilities is to reduce the State of Illinois budget deficit. This is not a justifiable reason to displace fragile people from their caregivers and services. The State of Illinois is still financially obligated to provide the needed services to the ID community, even in community settings.

The Mabley and Jacksonville Developmental Centers provide intensive, highly specialized services to their residents that are not readily available nor provided in the current community settings. Around the clock nursing care, access to medical and dental clinics are not easily accessible in community group homes. It is not just choice that is compromised. It is the needed services that will also be compromised. The need for services does not go away with the closure of a facility. The person's need for intensive, highly specialized services does not go away and neither does the cost. Moving ID people from their home and requiring families to travel long distances to visit their loved ones will cause great harm and suffering.

Community Service Providers are on the brink of closing because state funds are not forthcoming for services that have already been provided. They are underfunded and understaffed to handle individuals with complex needs. These individuals need a strong, secure safety net. How is the budget going to support these specialized needs in a different setting?

The State of Illinois must be held accountable for the decision to close facilities. Until the State of Illinois makes public a detailed, comprehensive plan for closure that includes the same intensive, highly specialized services that are provided at state facilities, closure of the Mabley and Jacksonville Developmental Centers is the wrong choice.

Sincerely,

*Sarah Ross*

Sarah Ross  
Secretary  
Advocates United Organization  
<http://www.advocatesunited.org>

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Hello,

I want to voice my agreement with these closings. I have a brother who spent 21 years at Dixon State School. In 1980 Mike moved to Iona Glos Specialized Living Center in Addison, IL. We have come a long way in the humane treatment of the profoundly retarded. Institutionalization was my parent's only option in the 1950s when my brother went into the system. Now we have wonderful care, at a much lower cost, in group homes and cilas.

The closings of Jacksonville and Mabley are good for everyone concerned. Change is hard for those who know of nothing else for their loved ones. But those of us who have come out of that archaic system recognize the blessing of our loved ones living right in our communities, being part of something positive and healthy on a daily basis.

Thank you.  
Sincerely,

Mary E Spreitzer

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Hello,

My name is Curtis Harris from disability rights activist organization ADAPT. I am in support of the closure of Mabley state-run institution in Dixon and Jacksonville state-run institutuion. I want to see people with developmental disabilities live in the community with supports such as Community Integrated Living Arrangement (CILA).

Curtis Harris

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Hello, my name is J. Michael Herron

I am the secretary of the Chicago chapter of the national disability rights group ADAPT.

I am calling to let you know that the disability community here in Illinois and across the country supports the closure of Jacksonville Developmental Center.

People with all types of disabilities are better served in the community, and it is time for Illinois to close large long term care institutions that waste taxpayer dollars and violate civil rights. We need to change to a system of community based supports that both integrate people with disability in the community, and provide jobs for workers.

J. Michael Herron

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Hello,

I am the mother of a son who resides in Shapiro. While it is in vogue to say close the state op, not all special people are successful in the community. We cannot close state ops unless there are extra supports available to the institutionalized people who have all too long been institutionalized. Unless, we are simply moving these folks to the prisons, which I fear is where my son would end up. So PLEASE do NOT close ANY STATE OPS until there are solid, extra, long standing community supports available. My son would require a 1:1 for an extended period of time, and this is something the state of illinois does not provide.

Thank you,  
Cynthia Bogue  
18437 Glen Oak Avenue  
Lansing, IL. 60438  
Mother of a son at Shapiro

---

I a concerned citizen for the rights of the disabled. Isupport the closure of Jacksonville and Mabley because it is the right thing to do for people with disabilities because it better utilizes public funds in that community services are a better investment and result in more positive outcomes for people.

Kathleen Luttrell  
340 N. Lombard Avenue  
Lombard, IL 60148-2013

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I support the closure of Jacksonville and Mabley because it is the right thing to do for people with disabilities. It is also a better use of taxpayer money. Staff from those sites should be ashamed of themselves for griping about losing their jobs when community agencies do a better job for less. Not to mention if they were smart they would see that community agencies will need staff to accommodate the people leaving the institutions. However, how many staff can be hired & at what rate depends on where the money previously spent on maintaining the outdated facilities ends up. Now there's something to think about. Let's see if the government can continue to do the right thing and allocate that money to the actual people with disabilities receiving Medicaid and/or the agencies supporting them. I'd rather see my money go to them than people who choose to stay home, have 6 kids they don't take care of, receive welfare, (my money!), use my money at the grocery store then leave in their ESCALADES while I spend the last of our checking account every month and leave in my old dented Honda!!!!!!!!!! Go to any Food For Less or Aldi in a lower middle class neighborhood and that is what you will see. At least I know firsthand that people with disabilities not only appreciate what they get; they want to & do work and those that aren't able volunteer. How many Medicaid recipients can honestly say that? LINK and Medicaid was meant to be transitional not a way of life for people who know or at least should know better. It would be nice to see the American/Illinois people finally do something right for people who truly need support but yet give back all they can rather than continue to reward greedy, lazy people who take pride in robbing the government and me.

Amy

Amy Castro  
Systems Administrator  
Ray Graham Association

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We support the closing of these facilities in order to provide a better quality of life for the disabled persons currently living there, at a lower cost per individual, thus also freeing up more funds to help additional disabled individuals in need of services.

Mary Ellen & Paul Johnson,  
Concerned Citizens and parents of a disabled child, now 30 years old  
107 N. Maple  
Bloomington, IL 60108

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Hello.

I'm Robert Sandidge an advocate for persons with disabilities through our web site [www.FundOurFriends.com](http://www.FundOurFriends.com).

I can be reached at 847.658.9273 or [Robert@FundOurFriends.com](mailto:Robert@FundOurFriends.com).

FundOurFriends advocates strongly for community residential living vs. institutional living for persons with disabilities. We know from our work in the field that the quality of life is richer and the cost is less than institutional living.

Certainly there are challenges in making the shift from institution to community but we are confident that with careful planning and appropriate funding the outcome for all concerned is a higher quality of life at a more manageable cost.

We encourage the closing of these facilities and the orderly movement of clients into community supported living.

Thank you for your consideration.

Robert L. Sandidge  
1421 Lowe Drive  
Algonquin, Illinois

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I think this is a wonderful idea. I do want to caution, however, that as each client is moved, AID, our local community non-profit based in Aurora and Elgin, must be given on DAY ONE the same amount as is presently costing that client for an extended period of time, perhaps as long as a year. AID has been cut for several years by the state. Last year they had to severely cut staff and find other ways to manage. Each new client will require more intense care and assistance in coming from a more hospital type setting. So there should be no "quick fix" The long term should be a good change.

Mary Lou Conover, an interested person  
no relative has ever been a client of AID. though the children of several neighbors have been  
age range -- over 80  
Oswego, IL

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The Autistic Self-Advocacy Network fully supports the closure of two institutions for developmentally disabled people in Illinois as proposed by Governor Quinn. Illinois is one of three states that institutionalizes cognitively and developmentally disabled people at dramatically higher rates than the rest of the nation. Institutions for cognitively and developmentally disabled people serve as significant barriers to meaningful inclusion in the community. Over the last few decades, most states have taken steps to reduce the number of people living in institutions, and ultimately, to close institutions for the cognitively and developmentally disabled. Research has repeatedly shown better outcomes for people who live in the community than for those who live in institutions. Not only will closing institutions save the state of Illinois millions of dollars in revenue, but it will also serve to improve the quality of life for those who would otherwise have been placed in those institutions.

Closing institutions is an excellent step towards promoting meaningful community inclusion for cognitively and developmentally disabled people. By encouraging cognitively and developmentally disabled people, their family members, and their caregivers to explore living and housing options based in the community rather than in a closed-campus institution, closing institutions promotes the idea that cognitively and developmentally disabled people not only have a right to live in the community but hold a particular place of value in their communities as peers of the non-disabled members of those communities. We urge you to support institutional closure.

Autistic Self-Advocacy Network

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I am a concerned citizen who supports the closure of Jacksonville and Mabley because it is the right thing to do for people with disabilities. Public funding can be better used to support people with disabilities than to support people in State Operated Facilities.

I will not be able to be present at the hearing but would like my statement filed.

Thank you very much.

Sarah Pape  
Lead Qualified Human Services Professional  
Ray Graham Association  
837 South Westmore Meyers Road, Suite A22  
Lombard, IL 60148

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Ladies & Gentlemen:

It has come to my Attention that Gov. Pat Quin is proposing the Closure of Mabley and Jacksonville Dev. Institutions - I am in support of this decision. These Individuals should be placed into CILA's instead.

Peggy Fetting  
Waiting on AID's Group Home Waiting List for Son - Brian Fetting (Age 31)  
Concerned Citizen and Guardian and Mother of Disabled Adult  
630 E. Main Street  
South Elgin, IL 60177

---

I am a concerned citizen, and am writing regarding the closure of the following institutions: Mabley and Jacksonville. I am a proponent of the institutions being closed. They drain our state and communities of much needed resources for community services for adults with mental disabilities. People should be served in more normal community environments at a fraction of the cost.

Thank you.  
Sincerely,  
Anu Khetarpal  
309 West New Indian Trail Court  
Aurora, IL 60506.

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Hello,

My name is Cynthia Bogue and I want these facilities open until such time the State of Illinois commits to approving and delivering services to individuals who have become institutionalized and require extended services, i.e., an extended 1:1. Failure to do so, would more likely result in increase State expenditures in the manner of increase inpatient psychiatric admissions, and/or increase prison admissions when the individual acts out and possibly hurts someone.

Thank you,  
Cynthia Bogue

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October 17, 2011

Dear Hearing Committee,

On behalf of families in Illinois who are successfully supporting people with disabilities in their home communities, I ask you and other legislators to move forward with the closure of both Mabley and Jacksonville Developmental Centers. Additionally, I ask that same funding follows these residents into the community where it is desperately needed for their success. Third, there will be a temporary need for additional funds during the closure transition so that communities, agencies and families can begin to prepare. Please support additional appropriations to assure a successful transition.

Every day of my life is centered around thinking, planning, supporting, developing, creating and pushing so my 17 year old son with autism will never have to live in a place like Jacksonville or Mabley. My son has been in situations where expectations were low, and medication, isolation and restraint were high. As a result of such an environment he responded horribly. Hitting, kicking, falling to the floor, biting others, running away and screaming, were all daily occurrences. At 6 ft 4 and nearly 300 pounds – each day I was stretched beyond my limits. Then, I decided that expecting him to behave in an “unhealthy” environment was analogous to telling a battered woman she could not leave until she learned to cope with her current situation. So, we did everything humanly possible to change and demand others around him change too. We had no funding and essentially were in a war against time and energy.

Specifically, I decided we needed to expand his communication support, raise expectations for reading, chores, and interaction with others. This didn't happen quickly or easily. Unspeakable sacrifices were made by my husband and younger son. But, I knew we were doing the right thing. Many loving people responded to my plea with “treatment” that really mattered such as communication supports, higher expectations (not lower!) exercise, better nutrition, massage and music therapy. We also formed a microboard, a small, formalized, circle of support that connects him to people he cares about in ordinary ways.

Our son was on the fast track to an SODC. But, because of our changes, he has changed. Our son still has classic autism, he is still nonspeaking and has difficulty finding the right words. His anxiety and frustration still swing out of control throughout the week. But now, in part because of community funding at the rate of about \$20,000 (and saving taxpayers 160,000) he swims, bikes, goes to movies, texts friends, homecoming, sporting events, is in a youth group, volunteers at various opportunities, cares for his dog, puts dishes away, and uses the internet with ease. What changed? We did. Our supports, expectations and environment changed and then he in turn, began to develop, grow and mature. Asking someone with a disability to thrive in an environment where there are no opportunities to make your own meals, move throughout some or most of the day at your own pace, have relationships with people that aren't constantly

coming and going and take medication that is designed to dull will never result in freedom and dignity out in the community.

I felt it was my obligation to share our story today so that others may think a little differently about “residents” and their value as human beings. We are grateful for community funding. I know where we would be without it.

I refuse to be ashamed of my son. Even when hateful people say or do things, I remind myself that he is worth more than the inconveniences and misfortunes we sometimes endure.

Some day we will look back and be horrified at how we treated our brothers and sisters with disabilities. Let us take correct action now, and pride in knowing we rolled up our sleeves to do what was right and good.

Wendy Partridge, MS, QSP  
Rockford, Illinois

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Please keep the Jacksonville Developmental Center open. It is important to ensure the care of the current residents, as well as the future of the Jacksonville community.

Kristin Jamison  
1545 Mound Avenue  
Jacksonville, Illinois 62650

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As a concerned citizen, I request you reconsider the efforts to close JDC. I am a retired educator, and I know not all of the residents of JDC could not appropriately live in other living situations. It is important to recognize the rights of all citizens regardless of their ability to speak for themselves. These individuals need to live in the least restrictive environment with appropriate support .

Also, important , of course are the jobs which are affected. However, my main concern is for the individuals whose way of life would change, and they would not have had the opportunity to be heard.

Please do not close JDC.

Phyllis Lape

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Dear Commission:

I would like to submit written statement opposing the closure of the Jacksonville Developmental Center. As a physical therapist in the Jacksonville area, I would like to tell you it is extremely important to keep the Jacksonville Developmental Center open. I know there is opposition to this by others in the state who do not like the idea of having people institutionalized. If the people that oppose this facility had first hand experience of the patients served by the Jacksonville Developmental Center, I strongly believe their opinion would change. It is the safest, most economical and compassionate way to treat these patients and maintain our community. Your support would be greatly appreciated.

Trevor Huffman P.T., M.S., S.C.S., A.T.,C.  
Board Certified Sports Physical Therapist  
Director of Rehabilitation Services  
Passavant Area Hospital  
Jacksonville, IL 62650

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To Whom It May Concern"

We are a small city dedicated to the welfare of our handicapped citizens including those of the Jacksonville Developmental Center.  
Keep the Jacksonville Developmental Center open. It is important to ensure the care of the residents and the future of our community.

Sincerely,

Michele T.Doyle

Doyle Family Chiropractic  
1521D West Walnut Street  
Jacksonville, IL 62650  
217.243.4333

---

Regarding the closure of the Mabley and Jacksonville facilities--

Given the state of the Illinois financial status these closings and the moving of clients to CILA facilities is the correct move. The appreciation of the folks involved goes beyond the money aspect. While unable to voice their thanks please believe that your actions are embraced by all.

Sincerely,

Don Cote  
Geneva, IL 60134

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I support JDC!!!!

Pam Bickhaus

---

Leave this facility OPEN, cut the pork on someone else's pet project not on the weakest in our community.

William Ryan

---

I support JDC

Brandy Lagergren

---

I would oppose the closure of this facility for two reasons - the detrimental effect on the residents of the facility, and the great likelihood that no state monies will actually be saved once replacement housing and care is factored in.

Respectfully,  
Steve Turner

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October 21, 2011

Commission on Government Forecasting and Accountability

ATTN: Facility Closure  
703 Stratton Building  
Springfield, IL 62706

My name is Skip Bradshaw and I am the City Clerk for the City of Jacksonville. I am also a concerned citizen! My address is 7 Manassas Ave. Jacksonville, IL 62650 and I am very much opposed to the closure of the Jacksonville Developmental Center.

I am a lifelong resident of the City of Jacksonville and know many people, through my 56 years, who have worked, or still work, at this facility. There are the 196 residents housed at this facility (JDC) to think of! For many of them, this has been their home for many years! Their families have security knowing that their loved one is being cared for by people who care and have worked with them for years. To disrupt their lives, and the lives of the 400 plus employees, is not rational! All of these people are dependant on each other and the City of Jacksonville is dependent on the tax paying employees who live here and spend their earnings here and pay taxes so the City can survive! Yes, survive! In many cities across Illinois, the local government is only surviving with the losses of the many jobs in their individual communities. Jacksonville is one of them! Please do not increase our unemployment rate and upset the lives of many, residents and employees of the Jacksonville facility! Jacksonville needs more jobs, not less!

Thank you

Skip Bradshaw  
City Clerk  
City of Jacksonville

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# AMVETS POST 100

210 East Court Street  
Jacksonville, IL 62650  
217-243-9990

20 Oct 11

Subject Jacksonville Developmental Center Closing

Commission on Government Forecasting and Accountability  
Attn: Facility closure  
703 Stratton Building  
Springfield, IL 62706

Ladies and Gentlemen:

AMVETS Post has been a member of the Jacksonville community for 65 years. We have 270 some members, 60+ members of our Sons Squadron and almost 150 members in our Ladies Auxiliary.

Each and every one of us is **against** the proposed closing of the Jacksonville Developmental Center (JDC).

The JDC cares for more than 200 of our least fortunate individuals. These are people who in most cases have nowhere else to go. They cannot live independently; their families are unable to care for them and the JDC is their home.

The JDC employs around 400 people. The Jacksonville area is their home. They work here, raise families here, their children go to school here, they pay taxes here, they shop here and they support the community.

The JDC is an important part of the local community. Its closing would create a hole that cannot be filled. Our region has already lost too many jobs (over 900 I understand) in the last few years. Our economy is in shambles and we cannot afford a devastating blow like this.

If you need any further information or have any questions please feel free to contact me on my cell phone 217-473-5988 or at [jimmy@jimmyduncan.net](mailto:jimmy@jimmyduncan.net).

Thank you for your time and consideration.

Respectfully,

Jim Duncan, Commanding  
AMVETS Post 100



## AMERICAN LEGION POST 279

903 West Superior, Jacksonville, IL 62650

20 Oct 11

Subject Jacksonville Developmental Center Closing

Commission on Government Forecasting and Accountability

Attn: Facility closure

703 Stratton Building

Springfield, IL 62706

Ladies and Gentlemen:

American Legion Post 279 has been a member of the Jacksonville community since the early 1900's. We have 230 some members, a dozen members of our Sons Squadron and over 100 members in our Ladies Auxiliary.

Each and every one of us is **against** the proposed closing of the Jacksonville Developmental Center (JDC).

The JDC cares for more than 200 of our least fortunate individuals. These are people who in most cases have nowhere else to go. They cannot live independently; their families are unable to care for them and the JDC is their home.

The JDC employs around 400 people. The Jacksonville area is their home. They work here, raise families here, their children go to school here, they pay taxes here, they shop here and they support the community.

The JDC is an important part of the local community. Its closing would create a hole that cannot be filled. Our region has already lost too many jobs (over 900 I understand) in the last few years. Our economy is in shambles and we cannot afford a devastating blow like this.

If you need any further information or have any questions please feel free to contact me on my cell phone 217-473-5988 or at [jimmy@jimmyduncan.net](mailto:jimmy@jimmyduncan.net).

Thank you for your time and consideration.

Respectfully,

Jim Duncan, Service Officer  
American Legion Post 279

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# VET-2-VET

79 Alice Drive  
Jacksonville, IL 62650

20 Oct 11

Subject Jacksonville Developmental Center Closing

Commission on Government Forecasting and Accountability  
Attn: Facility closure  
703 Stratton Building  
Springfield, IL 62706

Ladies and Gentlemen:

VET-2-VET is a nationwide organization for Veterans helping Veterans. The Jacksonville area group was the second to open in Illinois. We currently have about two dozen members. Our members have served in WW II, the Koran War, Viet Nam, Iraq, Afghanistan and everywhere else we have been called to defend our great country.

Each and every one of us is **against** the proposed closing of the Jacksonville Developmental Center (JDC).

The JDC cares for more than 200 of our least fortunate individuals. These are people who in most cases have nowhere else to go. They cannot live independently; their families are unable to care for them and the JDC is their home.

The JDC employs around 400 people. The Jacksonville area is their home. They work here, raise families here, their children go to school here, they pay taxes here, they shop here and they support the community.

The JDC is an important part of the local community. Its closing would create a hole that cannot be filled. Our region has already lost too many jobs (over 900 I understand) in the last few years. Our economy is in shambles and we cannot afford a devastating blow like this.

If you need any further information or have any questions please feel free to contact me on my cell phone 217-473-5988 or at [jimmy@jimmyduncan.net](mailto:jimmy@jimmyduncan.net).

Thank you for your time and consideration.

Respectfully,

Jim Duncan, Facilitator  
VET-2-VET

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People with disabilities should live in public communities and have access and the resources available to them as any other person in our community. Not only is it the moral thing to do, it is also financially responsible. Illinois is in a horrible budget situation and many more people with disabilities can be supported with funding given to community services than in an SODC setting. There are many people on the waiting list for services who are currently receiving nothing. It is in the public's interest that these dollars are put towards the most efficient and effective way possible. Once again, I strongly express my desire for Illinois to proceed with the closure of Jacksonville and Mabley SODC and continue to close the other SODCs in the state of Illinois as well.

Thank you.

Kathleen Gerhold

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October 19, 2011

Dear Mr. Quinn and COGFA Members:

I am writing in regard to the moving of my son Ronald and any other residents in the Jacksonville Developmental Center at Jacksonville, IL.

Like so many others I feel this is a very unnecessary move, Ron has been moved several times in his life and change is something he has difficulty with.

I have always believed that there are certain places where state funding should not be cut but increased, facilities like JDC and group homes that benefit those who are unfortunate enough to not be able to live the same productive lives afforded to us so called NORMAL individuals. My son like so many others needs to know that his future is a secure one.

Mr. Quinn, instead of closing JDC and other places like it, I feel funding should be given to improve their lives and security for the future. I recently was made aware of a Prison facility in Cook County that is built like a palatial mansion. It is a new and nicer facility, (see SNOPEs, palatial prison) than criminals deserve. Prisoners are to be punished not rewarded.

Why don't you build an equally magnificent facility for those who are disabled?

Spend time Governor Quinn, touring these facilities and meeting those in need. The disabled are often a joy to be around. Remember most people have a home to live in until THEY want to move.

Those at JDC may not all be voters but they have rights and you are about to VIOLATE theirs, which includes stability, security and a safe harbor.

It is my understanding that some that live at JDC have no real families to visit on special occasions or anytime. And a few people in facilities have spent their entire lives there and know no other home.

At those times like birthdays and holidays when you really need to have someone they need to have a birthday with or a holiday especially those like Thanksgiving and Christmas should be celebrated with loved ones. The staff at JDC are the family for them.

If any of these residents were your family, and you weren't the Governor and needed JDC you would be equally HOT UNDER THE COLLAR TOO.

Don't look at these facilities as only numbers but as a place to live and work.

Any further questions or statements you wish to have from me on this matter free free to call me.

Thank you for your time,

Doris A. Ross

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October 21, 2011

Commission on Government Forecasting and Accountability

ATTN: Facility Closure

703 Stratton Building

Springfield, IL 62706

RE: October 26, 2011 Hearing for the Jacksonville Developmental Center

To COGFA Members:

I am a concerned citizen and business owner in Jacksonville, IL and write you in opposition of the closure of JDC.

Our community has suffered through closings of two (2) manufacturing plants (EMI and AC Humko) in recent years, and a third is in the process (AGI). With the current economic conditions, the closing of this facility will be devastating to the Jacksonville area. The jobs lost and the transcending dollars not spent in our community will increase mortgage default rates, unemployment rates, taxes, and the need for more services for which the funding will not be available.

Please understand; closing JDC will not just affect Jacksonville, but surrounding communities and counties from which these employees reside.

Frankly, the issue is not about jobs as much as it is about labor. The negotiated contracts with the labor unions are one of the driving forces to our burgeoning debt. Address the heart of the problem; don't allow a quick and temporary fix which will raise the unemployment of our city, have a negative impact on home values, and create a tougher climate for buyers to find their American Dream.

Respectfully,

Michael D. Oldenettel, CRS, GRI

Managing Broker/Owner

RE/MAX Results Plus, Inc.

1046 W. Morton Ave

Jacksonville, IL 62650

mikeo@remax.net

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Commission on Government Forecasting and Accountability  
ATTN: Facility Closure  
703 Stratton Building  
Springfield, IL 62706

Letter sent via e-Mail

Dear Commission Members:

I am an employee of Passavant Area Hospital, the largest employer in Jacksonville, Illinois. I am greatly disappointed to learn of your continued efforts to close the Jacksonville Developmental Center (JDC).

I personally know 4 of the residents and directly see how this facility and its employees positively impact their lives. JDC has a record of success with all of their clients, as well as compliance with State and Federal regulations. The closure of JDC will not save the State money. These people with disabilities will still require skilled care and continuity of services to ensure their continued physical and emotional care. These citizens cannot survive on their own, outside their care setting.

Jacksonville cannot afford another loss to its economy. We have had several large plant closings over the past few years that have affected the entire community. With over 400 employees involved in this closure, and an estimated \$47 million impact on Morgan County, this closure would have a devastating impact on the lives of Jacksonville citizens and those from surrounding communities.

I support keeping the Jacksonville Developmental Center open! Without a definitive plan on where to place displaced workers and clients no one will win. Working together we all win!

Sincerely,

Diane M. Lietz, RN, BSN, MSN/FNP student

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**Testimony of Mary Rizzolo, Ph.D.**  
**Illinois Commission on Government Forecasting and Accountability**  
**October 20, 2011**

Senate Co-Chair Schoenberg, House Co-Chair Patricia Bellock, and members of the Commission, I am pleased to have this opportunity to provide written testimony on services for people with developmental disabilities in Illinois. My name is Mary Rizzolo. I am the Associate Director of the Institute on Disability and Human Development, the University Center for Excellence in Developmental Disabilities for the State of Illinois. For the past fourteen years I have worked on a project called the State of the States in Developmental Disabilities. I am here on behalf of myself and two of the co-authors of the latest monograph, David Braddock and Richard Hemp.

The study was established by Dr. Braddock in 1982 to investigate the determinants of public spending for developmental disabilities (DD) services in the U.S. The project maintains a 33-year longitudinal record of revenue, spending, and programmatic trends in the 50 states and DC. Analysis of the rich detail of the data base reveals the impact over time of federal and state fiscal policy, and illustrates important service delivery trends in the states in community living, public and private residential institutions, family support, supported employment, supported living, Medicaid Waivers, demographics, and related areas.

The following are some highlights from the 2011 State of the States report and from a report by David Braddock and Richard Hemp funded by the Illinois Council on Developmental Disabilities comparing services in Illinois to five comparison states in the Midwest.

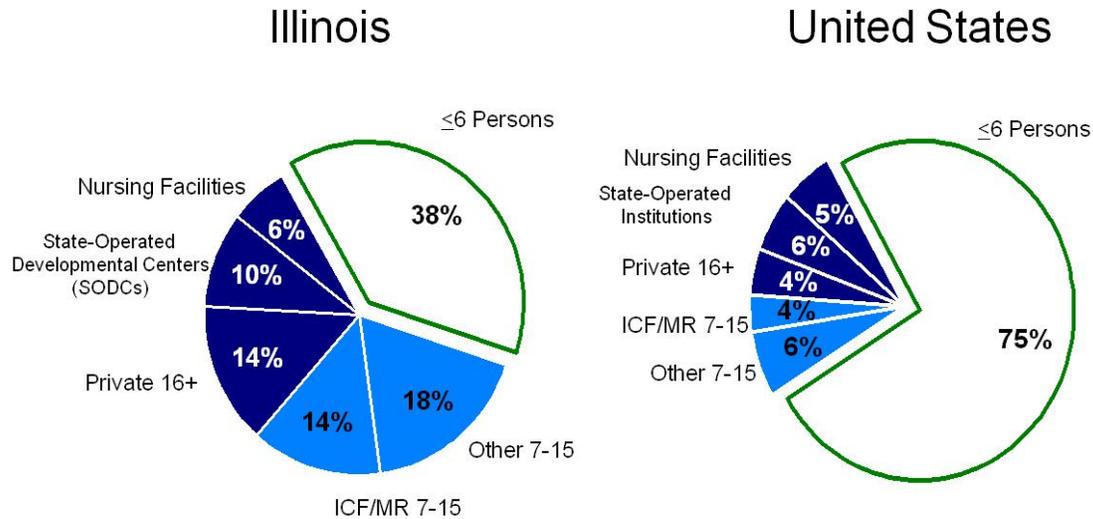
**1- Illinois Over-Relies on Developmental Centers and Private Institutions for 16+ Persons**

- Illinois has made some progress in the past few years in downsizing congregate care settings (settings for 16 or more). However, our utilization rate for state-operated institutions in 2009 is still over 60% above the U.S. rate, 113% above Wisconsin's rate, over seven times higher than Indiana's rate, and twenty five times higher than Michigan's rate.
- In 2006, use of all public and private DD institutions in Illinois was 85% above the U.S. average, and 75% above that of the five comparison states combined<sup>1</sup>.

**2- Illinois Allocates Comparatively Limited Resources for Community Services**

- In 2009, Illinois ranked **next to last** among all 50 states and DC in use of settings for six or fewer. Only thirty-eight percent of Illinois' DD residential placements were in settings for six persons or less versus 75% in the U.S. and from 64-89% in Indiana, Michigan and Wisconsin.
-

- A comparatively large component of Illinois’ “community residential facilities” are large group homes for 7-15 persons. They made up 32% of all out-of-home placements in the State in 2008, compared to only 10% in the U.S.



Source: Braddock, et al., State of the States in Developmental Disabilities, 2011.

- Illinois ICF/DD spending in 2009 was 49% greater than HCBS Waiver spending. This is in dramatic contrast with the U.S. and all our Great Lakes neighbors, in which the large majority of funding is associated with the Waiver.
  - Only 29% of total I/DD spending in Illinois in 2009 was devoted to the HCBS Waiver, compared to 47% nationally, 51% in Indiana and Wisconsin, 61% in Michigan, and 66% in Minnesota.
- Illinois ranked 47<sup>th</sup> in federal-state HCBS Waiver spending per capita. Only Georgia, Texas, Nevada, and Mississippi were below Illinois.

The following are a list of selected recommendations from the Braddock and Hemp report.

**1 - Continue to reduce reliance on the remaining eight state-operated institutional facilities and the large private ICFs/DD.** Medicaid ICF/DD resources should be reallocated to the HCBS Waiver.

**2- Expand Community Services and Related Supports to Address the State’s Waiting List and Aging Caregivers**

- There are currently over 9,000 persons with DD on the Illinois waiting list for residential services (over 1,900 of these are designated as “emergency” needs). The need for additional Waiver services will continue to increase rapidly due to growing numbers of aging caregivers in the State.

**3- Develop a Plan to Significantly Strengthen Community Services Infrastructure**

- A multi-year plan should be developed to increase funding for community-based services and supports. The plan would incrementally increase Illinois spending to match the average state’s expenditure for DD community spending by 2020.

These recommendations are consistent with recommendations from the Illinois Council on Developmental Disabilities' Blueprint for System Redesign. The Blueprint provides 16 action steps including steps to reduce reliance on large congregate settings in favor of more integrated settings and steps to build capacity in the community to support people with all levels of need.

With your help, we can make Illinois a better place to live for people with disabilities. We don't have to be 50th!

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October 22, 2011  
Senator Jeffrey Schoenberg  
Co-Chair  
Committee on Governmental Forecasting and Accountability

Representative Patricia Bellock  
Co-Chair  
Committee on Governmental Forecasting and Accountability

Dear Senator Schoenberg and Representative Bellock:

As members of the Commission on Government Forecasting and Accountability (COGFA), per the State Facilities Closure Act, you are charged with providing an Advisory Opinion concerning the closure of state developmental centers to the executive and legislative branches. As you are aware, Governor Quinn has proposed the closure of Mabley and Jacksonville Developmental Centers. There are times when a fiscal crisis can provide an opportunity to do the right thing and save the state money at the same time. This is one of them.

On behalf of the Springfield Area Disability Activists, I urge you to support the closure of Mabley and Jacksonville. The facts to support closure are overwhelming. Fourteen states have already closed all of their state institutions. Illinois institutionalizes more people with intellectual and other developmental disabilities than 48 other states with our eight (8) state developmental centers. All of the national studies conducted regarding Illinois' developmental disability system clearly state the need to move away from institutional spending and invest in community services. The current system is unsustainable both financially and morally.

Numerous national studies indicate differing views among the vast majority of parents. The great number changed their attitudes about community living after their family member had moved to the community. After experiencing community living, parents viewed the institution less positively than they did when their family member lived there. Moreover, parents observed improved quality of life and relationships for their family member after the move out of the institution. Overall, individuals served in the community are safer, healthier, and have a higher quality of life than individuals living in institutions have.

It is true that with some previous closures of institutions, a small number of individuals have returned to a state institution. However, this was not a failure of the individual but a failure of the system to develop sufficient supports for the individual. We believe that Illinois' low rank (47th in the nation) in community spending on community services can explain these infrequent occurrences.

We now have the opportunity to rectify this situation by re-allocating funds during the veto session to ensure the smooth transition of individuals to the community. The General Assembly may need to fund

an additional supplemental allocation next year since the savings from the closure of an institution lag one to two years behind the closure. We, thus, urge you, the legislative members of COGFA, to support sufficient funding to rebalance Illinois' system of service provision towards community services.

There is a reason that 14 states have closed all of their state institutions, and this is not based on programmatic or quality of life considerations alone. It also happens to be true that community services, in general, are also more cost effective than institutional services. The average cost of an Illinois state institution is \$181,700 per person per year while the average Community Integrated Living Arrangement (CILA) cost is \$52,454. In this time of fiscal austerity, how can we justify the continuing existence of these two developmental centers? Let us take the savings from the closure of Mabley and Jacksonville to expand community supports and services in the community.

In the short term, closing these institutions will cost the state more money. However, the long-term savings will far outweigh the initial outlay of funds and, eventually, save the state tens of millions of dollars every year. Yet, it is imperative that the legislature apportion the appropriate frontloaded monies to ensure a safe and smooth transition of residents from state institutions into the community. It is easily convenient to assign blame to state agencies that have not prepared and promoted adequately for the transition of people with disabilities in institutions to life in the community. However, the state government, at its highest levels, is responsible for the well-being of all people in Illinois, and that sense of responsibility for inadequate preparation must be shared throughout all layers of Illinois government, the disability advocacy community, union members, and even the families of those living in the institutions. Nonetheless, that is not a conversation in which we, collectively, have time to engage. Too much is at stake, and far too much time has already been wasted.

To avoid discussion of whether or not appropriate community services are already in place, it is important to note that Illinois is 12 years behind the Olmstead decision of the US Supreme Court that mandates people with disabilities living in state operated facilities and nursing homes have the right to live in the "least restrictive environment" of their choosing. We could end much of the debate between advocates, union members, and families if the state had put the infrastructure in place to ensure quality community services were now available for people with disabilities transitioning into the community. Moreover, COGFA and the General Assembly could allay the fears of family members, if they saw the proof, which does exist, that residents currently in institutions receive the same high quality care in the community. Workers in the institutions can transition as well to jobs in the community providing that same type of care, and knowing that fact alleviates anxiety over unemployment or retraining. If done correctly and smartly, the proposed closures will provide victories for all the most interested and important parties.

The disability advocacy community urges you, based on both fiscal and programmatic reasons, to support the Department of Human Services' recommendation to close Mabley and Jacksonville Developmental Centers. Further, we ask that you provide sufficient funding to ensure the smooth transition to the community for individuals in need of long-term supports. Thank you for your time and attention.

Tyler D McHaley  
Co-Leader, Springfield Area Disability Activists  
334 Norwalk Rd.  
Springfield, IL 62704

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To the Members:

I am the parent of a young adult with autism who is still in high school. My daughter lives at home with us, so I know how challenging it is to parent an individual with disabilities. As a parent and an attorney, I would like to raise several questions about the transition plan at the early stage of planning. These questions and others must be considered before the proposed transition is implemented.

We hear that decentralizing the placement of these individuals will mean that they will be closer to family in the community. In truth, how easy will it be to place them in homes in communities near parents? Will local zoning rules be eased so that a transition will allow these individuals to live in different communities or will they be relegated to the least desirable communities that may lack any opposition to group homes? What is Illinois planning to do to help make a transition to local communities possible?

We all watched in horror the recent story of disabled adults locked in a furnace room in Philadelphia. Who will be monitoring the individuals that are moved out of centralized facilities? We are hearing how much money will be saved when individuals are moved out of large institutions. Do the expected savings include calculations as to monitoring costs for many more small facilities? Will Illinois be trying to educate members of the community that they will have to help in monitoring these facilities for safety and to prevent abuse? These are our most vulnerable citizens and most CANNOT advocate for themselves. Even their families may not be around to do real monitoring. What is the plan to protect these most vulnerable adults when this transition happens?

Finally, some very medically complex or fragile individuals may not be able to transition to the community. Or, the cost of providing these services in many small facilities could be very expensive. What plan exists for appropriate placements for individuals that are not going to be transitioned into the community?

I would like to hear answers to these questions from the government officials making these proposals for individuals with disabilities. Any transition to a decentralized system must ensure the safety of these most vulnerable citizens.

Pauline Shoback

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October 24, 2011

Greetings,

My name is Charlotte Cronin and I am from Peoria. I am the mom of Daniel Cronin, a handsome young man with very severe disabilities.

I share with all the families in this room the incredible passion that comes with loving a child and the ferociousness of parenthood that grows as we discover that our children will grow into adulthood with huge challenges and vulnerability.

Nothing on God's green earth can prepare a parent for the discovery that their child has a disability.

All of Daniel's life, his dad and I have fought to keep him close to home. All of Daniel's life I have known that he has the right to live, laugh, learn, and love in the community that he would have grown up in if he didn't have a disability.

Daniel's disabilities are huge. He has no speech. He has horrible fine and gross motor skills. At 26, he is completely incontinent. As he has aged, mobility has become more and more difficult. But, his most challenging disability is his behavioral challenges. In 2005, they were beyond belief. An attempt was made to try to force us to move Daniel to Fox Developmental Center in Dwight an hour and a half away. We fought to keep him close to home... and we succeeded.

Today Daniel is an extraordinarily happy young man. His behavioral challenges have almost disappeared. He lives in a group home 10 minutes from the home he grew up in. He goes swimming twice a week and participates in Therapeutic Horseback Riding. He is home at least once a week after attending church with his family. He shops and recreates in the community where he is greeted by the friends and family that he has known all his life.

I tell you all of this because many believe that their family members cannot be successful in the community. They believe their family members' challenges and needs are too huge. I want you to know that if Daniel can be successful in the community, anyone can be successful in the community... with appropriate supports. If you were to meet Daniel, you might say, "His needs aren't that big." But, that is because that life outside the institution is so successful. I want you to know that I believe that Daniel would be a shadow of himself if he had been forced to move to Fox six years ago. I believe that he would be miserable. I know that I would be heartbroken.

I want you to know about "Chuck". He moved to Peoria from a state institution. He joined his new friends for a hot dog roast at our house where he spent the whole evening on his hands and knees chasing our family dog, trying to pet her. Totally inappropriate. The next year, Chuck was a new person, so many of his "odd behaviors" had disappeared... because he was around people who didn't have disabilities... he no longer chased our dog.

I want you to know about “Robert” and “Stanley”; both had lived in state institutions. They became full members and ushers at our church. Of course, like most of us their favorite moment was Coffee Hour. Who doesn’t like cookies? “Stanley” recently passed away. His memorial service was well attended and led by our Pastor who had a very real and meaningful friendship with him.

The civil rights movement taught us that separate cannot be equal. State Operated Developmental Centers are an antiquated way of providing services to people with severe disabilities. People who have disabilities can and should be served in the community with appropriate supports. Today we know better. It's time for a real change.

Thank you,

Charlotte Cronin  
5739 W. Martindale Lane  
Peoria, IL 61615

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Keep the Jacksonville Developmental Center open. It is important to ensure the care of the residents and the future of our community.

Gary Goodwin

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Preeteka Dhamrait  
2008 Hidden Mill  
Springfield, Illinois 62711

To whom it may concern,

I implore the decision makers concerning the closing of Jacksonville Developmental Center or ANY of the Developmental Centers in Illinois keep in mind that many of the residents at these centers are severely mentally disabled with little to no cognitive abilities combined with speech, vision and other developmental complications. They are human beings with individual and varying needs.

Many of the residents including my brother(Jagdeep) have lived in JDC /Lincoln Developmental Center for most of their lives and consider those centers HOME. These centers provide around-the-clock safety, personnel, and medical care that they would not get elsewhere. "One-size-fits-all" Group Homes in the community are NOT the answer and would pose personal, physical, emotional and developmental trauma to my brother . To uproot my brother as well as other residents from their home is cruel, deplorable and heartless. I do hope some rethinking will be done on this matter and in turn ensure that individuals who are severely mentally disabled can keep there home at developmental centers where they can obtain the individual and humane care they require.

My brother has profound retardation who can not speak let alone feed himself. He already had to deal with a transition when they closed Lincoln Developmental center 10 years ago. JDC has a wonderful staff that can take care of my brothers needs. He was 17 years old when he placed at SODC and now he is 50 years. He use to be physically aggressive and would hit himself but not anymore thanks to SODC. The SODC are better equipped to deal with him. He is no longer aggressive and he is well adjusted to his home. However if he was to be forced to a group home or other SODC this will traumatize him. He is a creature of habit like the rest of us. Last year when he had a bout of pneumonia the doctors and nurses took immediate action, they are better equipped to deal with my brothers tendency to aspirate food into his lungs, a condition that cause pneumonia and other infections. Also my family and I live near JDC so we are able to visit Jagdeep regularly there and bring him home on the weekends. If he is forced to be moved to Chicago or down state it would be much harder if not impossible to bring him home for visits. My father is 80 years old my mother is 75 years old their health is declining and the drive would be difficult.

Please reconsider the Governors decision this is my brothers home. Please keep JDC open otherwise where will my brother go??????

Sincerely,

Preeteka Dhamrait Rph  
Sister of a resident of JDC  
Member of Friends of JDC

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## Testimony of Tamar Heller, Ph.D.

### Illinois Commission on Government Forecasting and Accountability

October 23, 2011

Senate Co-Chair Schoenberg, House Co-Chair Patricia Bellock, and members of the Commission, I am pleased to have this opportunity to provide written testimony on services for people with developmental disabilities in Illinois. My name is Tamar Heller. I am the Director of the Institute on Disability and Human Development, the University Center for Excellence in Developmental Disabilities for the State of Illinois. For the past thirty years I have researched the impact of residential settings and services and supports for people with developmental disabilities. I also have a sister with developmental disabilities who once resided in an institutional setting (a nursing home) and is now happily living in a community residence.

As a researcher I would like to provide some up to date testimony on what the research tells us about the impact of institutional closures and transfers to the community for people with developmental disabilities. As a family member I would like to provide a personal account of my sister's experience moving out of the nursing home into a home in the community.

#### **Outcomes of Closures and Deinstitutionalization**

Numerous studies and reviews of the outcomes of closures and deinstitutionalization in several countries 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.<sup>i</sup>
- 2) Improved adaptive behaviors, including social skills, self-care, and domestic skills and inconsistent results regarding challenging behaviors.<sup>ii</sup>
- 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.<sup>iii i</sup>
- 4) Greater satisfaction of families with community placement versus the previous institutions, despite the fact that many families initially opposed deinstitutionalization<sup>1,iv</sup>

#### **Cost Savings of Closures**

Generally community living is less costly to state government than community placements. Several recent reports from other states have indicated significant cost savings, including estimated savings of about 40% in Massachusetts<sup>iv</sup> and 50% in Kansas<sup>vi</sup>. Other studies have reported savings closer to 25%.<sup>vii</sup>

While over time there are considerable cost savings of closing institutions, these savings do not usually occur until the institution is entirely closed. During the transition the costs can remain high as there is still a need to maintain the facility and most of the staff. Cost savings from deinstitutionalization are achieved primarily through the elimination/reduction of the high costs of operating a large state operated developmental center, leveraging less costly community services (social, educational, recreational), and avoiding the high costs of remodeling older institutions to meet federal standards.

**In Illinois the new “State of the States in Developmental Disabilities 2011,”<sup>viii</sup> the average daily spending per person in state institutions was \$498 or \$181,770 per year for 2009, The average CILA cost is \$52,454 according to the Division of Developmental Disabilities, March/2011.**

### **Personal Comments**

Often opponents of closure of institutional settings note that their relative is too severely disabled to live in a community setting. My sister is an example of someone with high support needs who is thriving in her home where she lives with a few other residents. Prior to moving into the home, she was obese, had diabetes necessitating four shots per day, had frequent angry outbursts, was non-ambulatory, and had to be transferred from her bed to the toilet using a hoist. Within one year after leaving the nursing home she lost 60 pounds, no longer had diabetes, and no longer had to take insulin. She is involved in day activities in a local program, is generally cheerful, and reports being “very happy.” My parents, who are in their 80’s say that the good news from my sister has given them a new lease on life.

### **References**

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<sup>1</sup> 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.

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<sup>lv</sup> Larson, A. and Lakin, C. (1991), Parental Attitudes about Residential Placement before and after Deinstitutionalization: A Research Synthesis. *JASH*, 25-38.

<sup>v</sup>Massachusetts Executive Office of Administration and Finance (2010). Report to the Legislature on DDS's Community Expansion and Facility Consolidation Plan.

<sup>vi</sup>Kansas Facilities Closure and Realignment Commission (2009). Facilities Closure and Realignment Commission Meeting Discussion on Rehabilitation Center for the Blind and Visually Impaired, Kansas Neurological Institute and Parsons State Hospital October 26, 2009 Topeka, Kansas

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To Members of the Commission on Government  
Forecasting and Accountability (CGFA)  
October 17th and 24th, 2011  
Submitted as written and oral testimony for 10.24.11

My name is Ms. J. Hadley Ravencroft and I am the Director of Programs and Advocacy at PACE, Inc. Center for Independent Living in Urbana, Illinois.

I address the commission with a variety of relevant experience: as a service provider to people with disabilities; (including those who are Deaf, Blind and have a developmental disability); as a woman with Cerebral Palsy; as a community member who is successfully living in my own home and working full-time in the community, with the assistance of the State of Illinois Home Services Program. I am a proponent of the closures of Mabley Developmental Center in Dixon IL and Jacksonville Developmental Center in Jacksonville IL.

I am asking you to support closing these State Operated Developmental Centers. Stop the institutional bias that exists for people with developmental disabilities. Illinois institutionalizes more people with intellectual and other developmental disabilities than 48 other states with our eight (8) state developmental centers. All of the national studies conducted regarding Illinois' developmental disability system clearly state the need to move away from institutional spending and invest in community services. Appropriations for comprehensive transition plans that are written with appropriate supports based on the unique and perhaps challenging needs of the individuals moving into community settings of their choice are paramount.

YOU do not move from one home to another without saving money, looking for a safe neighborhood in which to live, surveying the area for schools, proximity to work, leisure activities, doctors, hospitals, etc., so why would you expect less from people with developmental disabilities, or is that the problem? People with disabilities can and should be supported in the communities of their choice with the proper supports they need to maintain their independence. Overall, individuals served in the community are safer, healthier, and have a higher quality of life than do individuals living in institutions have.

Now legislators are remembering the Howe closure. You want to protect vulnerable populations from another "disaster." Advocates for closure like me urge the Commission to push for re-allocation of funds from institutions to the community. Rebalance the service delivery system for individuals with developmental disabilities towards community services.

14 states have closed all of their state institutions. Community-based services MAKE COMMON SENSE, enhance quality of life, and in general, are more cost effective than institutional services. The average cost of an Illinois state institution is \$181,700 per person per year while the average Community Integrated Living Arrangement (CILA) cost is \$52,454.

Both chambers of the Illinois legislature have adopted a resolution calling for a plan to enhance and expand access to quality community services and supports for people with developmental disabilities. Those community services are woefully underfunded in Illinois. Closing the institutions presents both an opportunity AND a responsibility. Our elected officials have the responsibility to provide appropriate funding for Illinois citizens with developmental disabilities.

Sincerely,

J Hadley Ravencroft

Director of Programs and Advocacy

Persons Assuming Control of their Environment, (PACE) Inc.

1317 E Florida Avenue Urbana IL 61801-6007

E-mail: [hadley@pacecil.org](mailto:hadley@pacecil.org); [info@pacecil.org](mailto:info@pacecil.org); [www.pacecil.org](http://www.pacecil.org)

217-344-5433 Voice 217-689-0289 VP 217-344-5024 TTY 217-344-2414 Fax

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I'm Phyllis Weyand, of Bureau County, Illinois, 150 miles due north of here. My brother has been living at JDC since 1993. He is incapable of speaking for himself, and that is why I'm here.

JDC is my brother's home. (Here you see us sharing a DQ burger in JDC's beautiful



park.)

Initially as a child, my brother developed and learned to speak complete sentences, just as any normal little boy. My parents had hopes, I'm sure, that he would be the fourth generation to take over the family farm.

This was not to be.

Today at age 54 he cannot read, write, or carry on true conversation. He has been diagnosed as severely retarded with obsessive compulsive disorder. His OCD has him carrying out bizarre "non functional routines or rituals" that people find frightening and repulsive. He will lash out physically at people when he finds himself in frustrating circumstances.

JDC staff are caring professionals who give my brother the respect and dignity due one human to another. They work with medical professionals to provide the high level of care that he needs, with an individualized program of active treatment.

In a group home, unless it has a very solid ICF/DD level of service, he would be a danger to himself, other residents, staff, and the community. But if any high-level care homes exist, they apparently have no room for my brother, as social workers have been looking for a place for him for years with no success. Be that as it may, my brother, along with his peers at JDC, has the legally enforceable right to an SODC, or at the very least, an ICF/DD.

On the street, totally on his own, my brother wouldn't have a chance.



Please do not take his home from him.

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October 24, 2011

The Commission on Government Forecasting Accountability  
Attention: Facility Closure  
703 Stratton Building  
Springfield, IL 62706

I am writing as a concerned citizen of the Jacksonville community regarding the proposed closing of the Jacksonville Developmental Center. I am adamantly opposed to its closure. Please accept this as a written statement of my position as a concerned citizen.

I am a lifelong resident of the Jacksonville area and I know what an impact it makes on our community, both from unemployment standpoint but more importantly from a service to the needy. If the facility is closed, what is to happen to these people? Where are they to go? I have seen these patients in the community and know that they are not ready to interact with society without care or sponsorship. Many of the families are not financially nor physically equipped to care for these individuals.

I urge you to reconsider the proposed closing of the Jacksonville Developmental Center.

Respectfully,

Allan Worrell AFM, ALC  
Managing Broker  
AW: jaj

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My name is Peggy Bradshaw and I am an Office Coordinator at the Illinois School for the Deaf under the Department of Human Services in Jacksonville, Illinois. As a concerned citizen and taxpayer, I am opposed to closing the JDC in Jacksonville, Illinois. Please reconsider this decision and do not disrupt the lives of the most vulnerable JCD residents.

Peggy Bradshaw  
7 Manassas  
Jacksonville, IL 62650

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I am writing in response to the proposal to close the Jacksonville Developmental Center. I feel I can address this issue as I have worked in both the community setting and at the Center.

While I agree that the "least restrictive setting" should be the basis for all individuals who live at JDC, I also know that there are some who cannot live in a community setting without becoming a danger to themselves and/or others. There are instances in community settings where supervision of something so simple as mealtime safety cannot be attained. It sounds easy to place someone in a community home BUT....Someone who needs pureed food and thickened drink is in danger of choking when seated at a table with others who have food of another consistency if staff cannot be directly beside the individual to see that food is not taken from a tablemate's plate. Seating at another table is not an option as this individual can get up at will and go to another table. The staff ratio that community setting can provide (also due to state budget cuts to their funding) won't allow for this level of supervision.

The JDC has been seeking community placement for individuals. But there are some individuals who cannot handle the relative freedom of a community setting. They, by law, can choose not to take the medication that gives them the ability to behave in a manner appropriate for community living. The Center has a support system in place to address this circumstance.

The situation in Jacksonville is unique in that the Center and the community programs are inseparable. Both Elm City and Pathway Services provide day training for many residents of the Center. The closure of the Center will affect the community as a whole in a far greater measure than the individuals and staff from the Center. Pathway Services has set in motion an expansion to provide sheltered workshop training to prepare individuals to get employment in community businesses. Taking the individuals from this venture will in essence sabotage the project.

I feel the Jacksonville Developmental Center should remain open while communities are given time and funding to expand the living and work opportunities for persons who reside at the Center. The timeline of February closure is unrealistic if one truly has the best interests of the individuals from the Center at heart.

Respectfully submitted,

Linda L.Mueller

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I have family that are employed there and are truly dedicated to their job. They solely depend on that for their livelihood.

Jan Smith

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My family has worked for years behind the scenes for the rights of people with mental challenges,  
My grand parents were founding members of a local agency to provide day training for people with those challenges.

But at no time, did we ever believe in tearing people out of the the only home they know and violate there rights , because some government agency said they could.

Who is protecting the rights, of the people of this facility? Sure isn't the governor!  
Sure isn't dhs,

Why is it every time the budget needs a trim they go after the worse off populations??

Why not look at the raises that legislater has given themselves hidden inside other laws they have passed,

Then do we need to discuss the additional economic empact that the lose of more jobs is gonna do to this area?

People stop and look around at whats happening, we are the people of illinios and your killing us .  
We are loosing our homes , jobs and pride and the future of this state, just so a polotition, can earn more money,

Michael T. Austin

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Dear Commission Members:

As the largest employer in Jacksonville, Illinois, Passavant Area Hospital's management and employees are disappointed to learn of your continued efforts to close the Jacksonville Developmental Center (JDC).

JDC has a record of success with their clients, as well as compliance with State and Federal regulations. The closure of JDC will not save the State money. These people with disabilities will still require skilled care and continuity of services to ensure their continued physical and emotional care. These citizens cannot survive on their own, outside their care setting.

Jacksonville cannot afford another loss to its economy. We have had several large plant closings over the past few years that have affected the entire community. With over 400 employees involved in this closure, and an estimated \$47 million impact on Morgan County, this closure would have a devastating impact on the lives of Jacksonville citizens and those from surrounding communities.

I support keeping the Jacksonville Developmental Center open! Without a definitive plan on where to place displaced workers and clients no one will win. Working together we all win!

David A. Bolen

Chet Wynn

Teresa Jackson-DeGroot

Ben Story

Gerald Prevett

Diana Olinger

Robin Kruzan

Jeanne Curry, RN

Melinda Byal

Robin Talkemeyer

Janie Cook

Rosemary Hopkins

Monica Eoff

Pam Bickhaus

William Ryan

Brandy Lagergren

Lanette Goldsborough

Carla Scroggins

Wendy Easton

Sandy Milton

Patricia G Brown

Sylvia Woolfolk

Peggy Sparks

Tammy Middleton

Jenna Curry

Leslie Winkelman

Jay Diers,

Sherry Clayton

Julie Tennill

Vicki West

Kathy Turner

Debora Wooley

Jamie Ledger

Kathy Six

Kathy Hartley

Sharon Burger

Mila Reichert

Jennifer Wilson

Thomas J Templin

Martha A Templin

Patty Bryant

Jamie Lewis

Marge Coats

Susan Wikert

Bonnie Brown

Donna Sorrill

Paula Stucker

Jody Claussen

Kris Schwirderski

Reverend Patsy Kelly

Rebecca Goodman

Flo Bryant

Allan Worrell

Rick Mogler

Emily Barfield

10/20/11

To whom it concerns:

Please allow Jacksonville Developmental Center to remain open. I have worked at JDC for 25 years. My career started as a Mental Health Technician, then I worked as an Activity Therapist until that position was eliminated due to budget issues. Now I work as a QSP (Qualified Support Professional). I care about the people we serve at JDC and want them to remain in their home until they are ready for community placement. They should not be rushed into various homes away from their family. If they are not successful in the home they will be sent back to another SODC and the process will start over. From my experience those that return from a community placement have many issues to overcome before being placed back in a community setting. Many have been placed on several types of medication in an attempt to manage the behavioral issues. Medical issues have not been ruled out due to physicians not accepting the clients due to behavior issues or lack of funds for payment. When a person returns to JDC the medical issues are resolved and the person's medication is reduced to the lowest effective dose. We rely on behavioral programming rather than over medicating the person.

The people who live at JDC are there for training. That does not mean they are all ready to move now. This means they are working on training programs to prepare them for the next step in their life, which is successful placement in a community home. When the team (the person served, guardian, various professionals from JDC and the day program QSP) feels that the person is ready for community placement, the process begins. Finding a home to meet the person's needs is very important.

The people at JDC have barriers that keep them from moving to the community. It may be a behavioral issue, medical issue or a guardian that has had bad experiences with community placement in the past. The process of moving forward takes time. Each day I see success with the people I serve. It may be a small in comparison to some but to that person it is a major accomplishment.

JDC has had success with short term admissions. When people at community homes are in crisis they have been referred to JDC. The team works with the person and assists in resolving the issues. When we work with the short term admissions we also work with the SST (Support Service Team) to ensure they are placed back into the community as soon as possible.

We were told that the power plant at JDC is a major reason we were targeted for closure. Maybe a local power provider would better serve JDC. Also, if the only reason for closure would be the power plant or that some of the buildings are old, consider moving JDC to another location. Consider consolidating ISD and ISVI and moving the people who live and work at JDC to the vacant school.

The closure would have a great impact of Jacksonville's economy. There has already been a study completed to prove this. What about the surrounding communities? Many people who work at JDC do not live in Jacksonville. Some commute from Springfield to Jacksonville each day. Others live in the rural areas such as Lincoln, Mt. Sterling, Pittsfield, White Hall, and Roodhouse. There are very few jobs in

the rural areas. Those who could not find jobs would have to rely on unemployment and other government programs they qualify for.

I am so sorry that the people we serve, the guardians and the people who work at JDC had to go through this. The people that work at JDC have compassion and concern for the people who live at JDC. It is not "just a job" to many but it is an extended family. The guardians are worried and concerned about the fate of their loved one. Please do not close JDC. This is a service that is needed and should not be cut from the budget.

Thank you very much for your consideration,

Linda DeJaynes. QSP  
219 S. Walnut St.  
Pittsfield, IL 62363

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At the Oct. 27 COGFA meeting, the Department of Human Services (DHS) passed out a misleading hand-out on deferred maintenance and made a misleading comment on action by CMS against the Jacksonville Developmental Center (JDC).

DHS has now provided details of JDC's supposed deferred maintenance which is on the COGFA website, but DHS DELETED the words "This does not necessarily mean they need to be replaced."

The Capital Development Board (CDB) divided these into REN (Renewals) and REQ (Requirements). Less than \$1.8 million was REQ, Requirements, and over \$100 million was REN, Renewals. I filed a FOIA with CDB and received the original document.

In its description DHS deleted two critical sentences that are included in the original CDB description of REN (Renewals): "It is important to note that items are not projects, but systems that are aged beyond their useful life. This does not necessarily mean they need to be replaced."

In other words, CDB looked at how old something was after assigning an arbitrary useful life factor, and then without any evaluation of whether it was properly functioning or not, or any evaluation of whether replacement was actually needed, said it should be put under needed REN (Renewals).

And then DHS eliminated the CDB cautions (not projects, not necessarily mean they need to be replaced) in the language it sent to COGFA.

We now know that DHS Secretary Saddler's comment about the "Official Notice of the imminent de-certification of JDC" was completely misleading. The subject of the CMS letter of July 1, 2010, was "COMPLIANCE WITH THE 2000 EDITION OF THE LIFE SAFETY CODE" and that the recent expenditure of \$1.8 million at JDC has 100% COMPLETELY CORRECTED those life safety problems.

This CMS letter had absolutely NOTHING to do with the care provided patients by the staff at JDC.

At the beginning of the Oct. 27th COGFA meeting Sen. Schoenberg asked why recommend closing the Jacksonville Developmental Center, JDC, but not Choate?

DHS Secretary Saddler said there was one reason: Within 2 years DHS received Official Notice of the imminent de-certification of JDC from the federal agency, CMS.

Lonnie Johns

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As the mother of an autistic adult, I am in favor of closing Jacksonville facility because I feel more of the disabled can be served in community-based programs.

Sincerely,  
Lourdes Diamond  
Wheaton, IL

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Please don't close JDC

John David Bum

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Please consider the impact that the closing of this facility will have on everyone involved, not only the people who call JDC home, but the people employed, the community and the families of everyone involved. Jacksonville is a teaching facility, ultimately with the goal for every person served is to be able to live in a group home. Some times that is obtainable, and in the cases that it is successful we have all been proud of the milestones achieved, but as each person being an individual, not every case is the same. Therefore in many cases it has become not a institution, nor a facility, but a home to many people. So, please take this is to consideration as you weigh in on a vote.

Thank you,  
Bobbi Kindred

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PLEASE DON'T CLOSE JDC IN JACKSONVILLE.....I HAVE 3 FAMILY MEMBERS THAT WORK AT JDC.....WHAT WILL THEY DO?? YOU ARE TAKING AWAY JOBS THAT PAY TAXES ~~ THEY TAKE CARE OF PEOPLE THAT CAN'T TAKE CARE OF THEMSELVES ~~~ WHAT WILL THEY DO??? I AGREE THAT THE BUDGET NEEDS TO BE TRIMMED ..... BUT THINK ABOUT THE PEOPLE'S LIVES THAT YOU ARE HURTING WITH THE CLOSING OF THE JDC FACILITY...

Donita Luber

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Do not close JDC in Jacksonville. To many familyies as well as the community will suffer with a closure.

Janet Zachary

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Do not close Jacksonville JDC.

Sharon McGillicuddy

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Please do not close JDC, the people we serve do not want to lose the only home some of them have ever known.

Evelyn McCormick

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Dear Commission on Government Forecasting and Accountability,

I am so glad that my sister lives in a group home with 5 other adult disabled women, in a nice house, in a fine residential community 20 minutes from my house. My sister has been under the care of the Ray Graham Association for over thirty years.

I thank God often for the wonderful Ray Graham Association and all that it does for my sister. The thought of my sister living in a large, state institution, isolated from a residential community, far from me and the rest of her family Makes me sad.

I wish that the people living in those large, nonhomes could have what my sister has. I wish that Illinois tax payers could pay less and get more care for their disabled brethren.

Please consider taking a positive step in the care of the disabled and choose community based care provided by organizations such as Ray Graham Association.

Sincerely,  
Paul Sebert  
Roselle, IL

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Please vote to keep Jacksonville Developmental Center OPEN.

Thank you,  
Betty Lefler

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Please don't close the Jacksonville Developmental Center. It serves a great need to the developmentally delayed population and there currently is not another place for them to be besides the streets. As the mother of a child with developmental delays it is comforting to know there is a place for him to go should I be unable to care for him.

Linda Smith

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To whom it may concern: I am writing you this letter in regards and on the behalf of the residents in the Jacksonville Developmental Center. I do not know these residents personally however I used to work at a group home in Beardstown Illinois I know that alot of these residents do not have family members who are able to care for them and this hits me personally because this happened to my great grandmother years ago when she suffered from mental illness and was in JDC and was decided that either JDC was going to be closed at that point in time or something and she was thrown out onto the

streets luckily for her she had a daughter who loved her very much and brought her home. I just feel that by closing this place that they have known as their home is going to be a trauma on them because they are obviously going to have to be moved and for some of them this may mean multiple times that they have moved which could cause them a sense of insecurity. Please keep JDC open for the residents and for the workers who care for these residents and the families that they have at home to support.

God Bless You,  
Sincerely  
Melissa Luna

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No one told Joan Taylor, after her son James died in August 2005, that there had been a similar bathtub drowning four months earlier.

Or that the other drowning, like her son's, took place at a group home operated by a local chapter of the New York State ARC, the nation's largest nonprofit organization serving the developmentally disabled.

In both cases, there had been concerns that ARC had too few staff members to supervise the developmentally disabled residents.

Dalton Lacombe died at the ARC home in Malone, N.Y., in April 2005, after being left alone in a bath for up to 20 minutes. The house had 11 residents and one overnight staff member on duty. The state recommended hiring more employees, but backed off after discussions with ARC management.

The death "wasn't related to staffing levels," Lester G. Parker, executive director of the Adirondack ARC, which oversees the Malone house, said in an interview. "It was related to a staff person clearly and significantly neglecting their duties."

Mrs. Taylor had pushed for an increase in staffing at her son's group home near Schenectady, where three workers looked after eight severely developmentally disabled residents.

ARC officials in Schenectady declined to comment. After Mr. Taylor drowned, the organization's only significant response was to fire his caregiver.

"The guy who left James unattended is the scapegoat, and the agency really took no responsibility from the top," Mr. Taylor's sister, Patricia Taylor, said.

Marc Brandt, ARC's statewide leader, acknowledged that no broad changes were enacted after the drownings, but said it was up to the state, not his organization, to take action.

"If they see anything that is wrong, they've always let us know," he said.

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New York Times, November 6, 2011

In State Care, 1,200 Deaths and Few Answers

By Danny Hakim and Russ Buettner

For James Michael Taylor, an evening bath became a death sentence.

Mr. Taylor, who was 41 and a quadriplegic, had little more ability than a newborn baby to lift his head. Bathing him required the constant attention of a staff member at the group home for the developmentally disabled where he lived, near Schenectady, N.Y.

One summer night in 2005, a worker lowered Mr. Taylor into the tub, turned on the water and left the room. Over the next 15 minutes, the water slowly rose over his head. He drowned before anyone returned.

Joan Taylor, his mother, remembers the words her husband said as dirt was shoveled onto their son's grave.

"This is the last time they're going to dump on you," he told his dead son.

James Taylor's death was no aberration.

In New York, it is unusually common for developmentally disabled people in state care to die for reasons other than natural causes.

One in six of all deaths in state and privately run homes, or more than 1,200 in the past decade, have been attributed to either unnatural or unknown causes, according to data obtained by The New York Times that has never been released.

The figure is more like one in 25 in Connecticut and Massachusetts, which are among the few states that release such data.

What's more, New York has made little effort to track or thoroughly investigate the deaths to look for troubling trends, resulting in the same kinds of errors and preventable deaths, over and over.

The state does not even collect statistics on specific causes of death, leaving many designated as "unknown," sometimes even after a medical examiner has made a ruling.

The Times undertook its own analysis of death records and found disturbing patterns: some residents who were not supposed to be left alone with food choked in bathrooms and kitchens. Others who needed help on stairs tumbled alone to their deaths. Still others ran away again and again until they were found dead.

Mr. Taylor was hardly the only resident to drown in a bathtub. Another developmentally disabled man at a house run by the same nonprofit organization drowned in a tub four months earlier.

Through a Freedom of Information request to the State Commission on Quality of Care and Advocacy for Persons With Disabilities, The Times obtained data for all 7,118 cases of developmentally disabled people — those with conditions like cerebral palsy, autism and Down syndrome — who died while in state care over the past decade.

The data from the agency, which is responsible for overseeing treatment for the developmentally disabled, included only the broad “manner” in which people died — by homicide or suicide, accidents or natural causes.

By far the biggest category, other than natural causes, was “unknown,” accounting for 10 percent of all deaths in the system.

The records suggested problems in care may be contributing to those unexplained deaths. The average age of those who died of unknown causes was 40, while the average age of residents dying of natural causes was 54.

The Times reviewed the case files of all the deaths not resulting from natural causes that the commission investigated over the past decade and found there had been concerns about the quality of care in nearly half of the 222 cases.

The records also showed that problems leading to deaths rarely resulted in systemwide steps, like alerts to all operators of homes, to prevent mistakes from recurring. Responses were typically limited to the group home where a resident died.

At homes operated by nonprofit organizations, low-level employees were often fired or disciplined, but repercussions for executives were rare. At state-run homes, it is also difficult to take action against caregivers, who are represented by unions that contest disciplinary measures.

New York relies heavily on the operators of the homes to investigate and determine how a person in their care died and, in a vast majority of cases, accepts that determination. And the state has no uniform training for the nearly 100,000 workers at thousands of state and privately run homes and institutions.

The value of analyzing death records for problems in care that could be prevented through alerts or training has been well established, and is encouraged by the federal Government Accountability Office. Officials in Connecticut, for example, noticed four choking deaths in 2006, the first year the state published such data. They developed a statewide program — two days of initial training and a refresher course every two years thereafter. The state has had just one choking death since 2007. New York has had at least 21 during that same period.

“It’s incredibly important,” said Terrence W. Macy, commissioner of the Department of Developmental Services in Connecticut. “If everybody knows you study it this hard and you have this level of detail, it’s going to have an impact.”

There is no question that it can be extremely challenging to care for the developmentally disabled, a population that includes some people who are fragile and immobile and others who are unruly and inclined toward violence. But the problems in the New York system appear especially troubling given that the state spends \$10 billion a year caring for the developmentally disabled — more than California, Texas, Florida and Illinois combined — while providing services to fewer than half as many people as those states do.

Lawsuits are relatively rare after the deaths of developmentally disabled people in New York, in part because economic damages are difficult to prove, given that the victims are seldom employed. And sometimes families are simply grateful to the group home for years of care for their relative.

This year, Gov. Andrew M. Cuomo forced the commissioners of the two agencies that oversee the developmentally disabled to resign amid a Times investigation of group home workers who were beating and abusing residents.

In interviews, the officials who replaced them acknowledged problems with how the state tracks and seeks to prevent untimely deaths.

Courtney Burke, the commissioner of the Office for People With Developmental Disabilities, which operates and oversees thousands of group homes, acknowledged that her agency suffered from a lack of transparency and what she called “a culture of nonreporting.”

“One of the things I’m seeking to do,” she said last month, “is have better data on those deaths.”

#### A Recurring Problem

One evening last year, a large piece of London broil was left marinating in the refrigerator of a state-run group home in the hamlet of Golden’s Bridge, in Westchester County.

The kitchen was supposed to be locked overnight. As in many homes for the developmentally disabled, residents known to be at risk for choking were not allowed to be left alone with food. But the kitchen was open during the early morning of June 5, 2010. No one noticed as Cynthia Dupas left her bedroom, opened the refrigerator and bit off a chunk of raw beef. She collapsed outside her bedroom and died. She was 51.

Hers was hardly an isolated case. A quarter of the 222 death files reviewed by The Times involved a person choking to death. And given the state’s poor recordkeeping, the actual number of choking deaths

is likely larger. The deaths often occur when residents try to eat food too quickly; physical limitations also play a role. Some of the fatalities came in quick succession:

At a home near the Finger Lakes in 2001, a resident died after stuffing down a steak that was left on the kitchen counter after dinner, in violation of safety guidelines for several residents.

Four months later, Maxwell Channels died at a Schenectady-area group home after being left alone to eat a steak. A nonprofit group that cared for Mr. Channels during the day had determined he was a choking risk who required mealtime supervision, but a second nonprofit agency that ran the group home where he lived had no such protections in place. He was 66.

Less than two weeks later, Virgil Macro was served a breakfast that had not been prepared according to a meal plan devised to keep him from choking. Staff members at his Dutchess County group home also failed to supervise him while he ate. He was 39.

In each case, the response suggested by the Commission on Quality of Care was mostly limited to the place where the death occurred. Workers who made mistakes were disciplined. Some employees in the home, or the local area, were retrained.

But other states take broader action.

In 2006, Ohio officials recognized an increase in choking deaths and issued a statewide alert.

A year later, California officials noticed a similar rise in one part of the state and began an educational program that reduced deaths.

A lack of standards and accepted definitions of basic terms also leads to deadly confusion.

Terms like “bite-size” and “chopped,” which are key to defining what is safe for a person to eat, can be left open to interpretation by the staff at a given institution or group home.

The Commission on Quality of Care regularly asks individual homes to revisit those definitions, but the state has not resolved varying interpretations.

In contrast, Connecticut’s training materials, which the state credits with sharply reducing choking deaths, precisely define such terms with photographs and dimensions.

State officials in New York cannot even agree on how many people are dying. The Office for People With Developmental Disabilities says 933 people in state care died in 2009. The Commission on Quality of Care says 757 did. Neither agency could explain the discrepancy.

Outside experts said they were particularly puzzled that records maintained by the state would list the cause as “unknown” in more than 700 deaths over the past decade, and wondered how hard state officials had tried to determine what happened.

Bruce Simmons was one of the many people the state had listed as dead of unknown causes. But a review of the records from the state’s own investigation reveals what occurred. He lived in a group home in Cortland, N.Y., which kept him under tight supervision around food because of his history of stealing food and choking. But the nonprofit group that took care of him during the day decided that was not necessary, and he choked to death in November 2008. He was 52.

### Lapses in Fire Safety

All that is left of the house at 1534 State Route 30 in the Adirondack town of Wells is a grassy field and an empty driveway.

More than two and a half years ago, the house, home to nine developmentally disabled residents, burned to the ground, killing four of them.

The fire revealed shortcomings in staff training and safety standards. And the home’s evacuation plans were based on unrealistic expectations that developmentally disabled residents would be able to flee in an emergency.

Large institutions for the developmentally disabled are built much like hospitals, with extensive fire safety measures. The group home had some safety features, like sprinklers in parts of the house, but was permitted to meet building codes akin to those of homes with able-bodied residents who know they should flee from a fire.

Yet though the Wells fire took place in March 2009, the state has not undertaken a broad review of whether group homes, which now care for a vast majority of the state’s developmentally disabled, have appropriate safety modifications to protect residents who often do not understand that they are in danger.

The fire at the house, known as Riverview, occurred in the early morning, starting in a trash can on a screen porch and spreading rapidly up vinyl siding into the attic of the L-shaped, one-story residence.

An automatic alarm call was made at 5:25 a.m. to a monitoring company. The protocol established by the Office for People With Developmental Disabilities required that the company call the group home before notifying the Fire Department, which wasted minutes and violated state fire standards. By 5:30, the local fire company was dispatched, alerting Ken Hoffman, a firefighter who lived across the street and rushed over to help.

When Mr. Hoffman arrived, all nine residents were still inside, but he and two staff members helped most of them evacuate. Then one resident fell, distracting the two staff members as three residents wandered back into the burning house, according to state records.

There were further complications. The state had not informed local fire officials about the presence of the group home, leaving them ill prepared.

“There was no contact,” said Peter Byrne, a Rockland County fire safety official who was on the panel of experts convened by the state after the fire. “If I roll into a single-family dwelling at 2 or 3 in the morning, I’m expecting mom, dad and 2.3 kids, whatever the average is, not 11 challenged individuals.”

Credible investigations were performed — one by a local grand jury, one by the State Office of Fire Prevention and Control, and another by the panel that included Mr. Byrne.

But a follow-up review undertaken by the two agencies most responsible for the developmentally disabled — the Office for People With Developmental Disabilities and the Commission on Quality of Care — included questions like whether residents’ day-to-day medical care needs were being met.

The questions “were not germane to the fundamental questions posed by the Wells fire — what was the cause of the fire and what can we do in the future to prevent such fires from occurring in such a tragic manner,” Roger Bearden, the new head of the commission, said in an interview.

Like most group homes in New York, the Riverview house was required to meet residential building codes, which are less than stringent.

There were no sprinklers in the attic at the house, or on the screen porch where the fire started. Records showed that the building’s original plans required fire retardant materials on the porch ceiling and that a planned barrier wall in the attic was abandoned during construction.

While the house was required to meet standards from the National Fire Protection Association, an interview with a top association official suggests that while the standards are open to interpretation, the house could have been more robustly protected.

“There’s been an unresolved question about why a sprinkler wasn’t provided on that porch area,” said Robert E. Solomon, a fire safety expert at the association who served on the state panel.

“Our standards would have probably put a sprinkler on that porch area where that fire occurred,” he said, which could have prevented the fire from spreading.

The Riverview case also underscores widespread problems in how fire drills at group homes have been conducted. The Times reported in March that a whistle-blower warned a senior state official in 2008

that drill records were being routinely faked or implausibly speedy evacuation times were being claimed. State investigators found that was the case at the Riverview house.

The staff also seemed unprepared; time was spent battling the fire with an extinguisher instead of evacuating residents. The grand jury convened by the district attorney of Hamilton County noted that fires were common in group homes, adding, "It would be a grave mistake to view Riverview's tragedy as an isolated incident."

Some steps have been taken since the fire: tighter rules guiding new construction, bringing in outside supervisors for fire drills and outside experts for inspections. But Ms. Burke's agency did not say when it would review whether other homes in the system might also be lacking fire safety features sufficient enough for developmentally disabled residents.

After several weeks of inquiries from The Times, Ms. Burke said she would reconvene the state panel that investigated the fire. Mr. Hoffman said he could not shake the memory of the fire.

"It's still something that comes back to my mind on a weekly basis," he said. "We lost four neighbors that night."

#### A System's Failure

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Or that the other drowning, like her son's, took place at a group home operated by a local chapter of the New York State ARC, the nation's largest nonprofit organization serving the developmentally disabled.

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Marc Brandt, ARC's statewide leader, acknowledged that no broad changes were enacted after the drownings, but said it was up to the state, not his organization, to take action.

"If they see anything that is wrong, they've always let us know," he said.

Mr. Taylor's mother has been a fierce advocate for people with developmental disabilities for decades.

Mrs. Taylor, 86, started a parent group, lobbied in Albany and was appointed to the capital-area Board of Visitors of the Office for People With Developmental Disabilities. She is most proud of helping get legislation passed in 2002 that gave parents control over end-of-life decisions for the developmentally disabled. "I was insulted I couldn't make that decision for my son, who I wanted to die with dignity," she said.

On a recent day, as Mrs. Taylor sat on the back porch of her apartment at a retirement home in Saratoga Springs, wearing tennis shoes and shorts, she leafed through the guestbook from her son's funeral, filled with 300 signatures, including those of local elected officials.

"I don't know if my kid died with dignity or not," she said.

She grew up on Long Island and trained as a nurse; her late husband, Robert, was an engineer with General Electric. She knew something was wrong with James, their youngest child, when he was still a baby. Suspecting he could not hear, she slammed cupboard doors near their infant son, and he did not flinch.

She got a much greater shock after a doctor told her, "Your son is mentally retarded."

Doctors recommended that he be institutionalized. Mrs. Taylor resisted, but she had five other children. Dealing with James, her sixth child — quadriplegic, sleepless and with the intellectual capacity of a 3-month-old — filled her days and nights.

Eventually, she felt she had no choice.

"I will never forget that day," Mrs. Taylor once wrote in an essay. "My husband and I woke up that morning both fighting back the tears. I dressed James in his very best suit and we drove the 30 miles back to the institution and left him there."

“We both cried all the way home,” she said. “I thought it was the worst day of my life.”

She has done advocacy work with ARC and Mr. Brandt over the years, and calls him “a saint,” but she is angry about what happened to her son.

Her daughter said it was because of her mother’s advocacy work that Mr. Taylor’s death received attention.

She worries about the developmentally disabled who die and have no family around to push for answers for them.

“These deaths are marginalized because these sort of people are not valued by society,” Patricia Taylor said.

When she was in the fourth grade, she dreamed of taking her brother and running away with him, protecting him. She finds it hard to accept that no one was able to protect him after he grew up.

“I believe that God put these people here for a purpose, because if we didn’t have them to look after, we would lose our humanity,” she said. “How would we know compassion? It says in the Bible, do ye so unto the least of my brothers. I think that’s what it’s all about.”

Lonnie Johns

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Please don't close JDC! It's the wrong thing to do for the people!

Jason Carey

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Please dont close JDC.  
thank you

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JDC is home to so many people. People who have grown up there. People who wouldn't know how to live without this place. Why take that away from them? You also hurting the people who have worked there. For example, my dad has worked there for 20 years. He has worked so hard for the position he is at right now and he doesn't deserve it being taken away from him. By closing JDC, you are doing more harm than help. More people are going to be without home, without jobs, and without their life they

have always known. Make the easier decision and choose to not close Jacksonville Developmental Center.

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