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HEALTH FACILITIES &
SERVICES REVIEW BOARD

October 5, 2012

Illinois Health Facilities and Services Board
525 West Jefferson St., 2nd Floor
Springfield, IL 62761

Dear Members of the Illinois Health Facilities & Services Board:

As the owner/operator of two 16-bed ICF-DD facilities, I urge the board to keep Jacksonville Developmental Center open. Further, I ask that all state operated facilities currently slated for closing be kept open as well.

I am a strong supporter of community living whenever possible, and appropriate. Despite what advocacy organizations such as ARC promote, the fact is one size does not fit all. State operated developmental centers continue to provide a necessary and cost-effective option for numerous individuals with developmental challenges. Simply put, CILA is not the only option, nor is it always appropriate or desired by individual residents. Advocacy groups too often present a heavy-handed approach to residents and families when presenting community living as always the best option. This is not only intimidating to residents and families, but may not be in the best interest of the individuals to be served.

Keep all residential options available. A person-centered approach does not mean that everyone has to transition to community living arrangements, like it or not. There is no reason to fix a problem that does not exist.

Thank you for your consideration.

Respectfully,

R. Stephen Gomes

October 6, 2012

TO: IL Health Facilities and Services Board

RE: Planned Closure of the Jacksonville SODC

AGAINST CLOSURE OF JACKSONVILLE SODC

Governor Quinn's planned closure of state operated homes for the disabled creates an unfunded community mandate for police, paramedics, firefighters and hospitals. Just the populations of Jacksonville and Centralia Illinois centers will require many new community homes- equipped with special services and advanced levels of care. The State of Georgia has found it necessary to establish and fund 12 crisis teams and 11 emergency respite homes under similar circumstances. The flawed Illinois plan continues to focus on moving people out while giving communities no time to prepare. A local attorney experienced with cases of community failures estimates a need for three years of preparation, not a small number of weeks or months.

The very real scenario of under-staffed community residences calling first responders (*911) for behavior problems, seizures, etc, creates additional demands on local services:

- First Responders deserve training, preparation and communication support for dealing with an increased population of special needs
- Front Line Residential Staff deserve training, reasonable pay and a better crisis plan than peers on-call
- Disabled Citizens deserve individualized effective communication, compassion and their civil rights

One city's chief of police called the scenario "compelling in its' implications." It certainly impacts dispatchers, officers, EMT/paramedics, firefighters and emergency rooms. Preparation for this added responsibility starts with training and awareness for all. Training and awareness that will require time and funding:

- Education; Descriptions, recognition, traits and limitations of specific disabilities
- Training; Specialized communication skills and effective techniques
- Planning; Specific procedures for deaf, blind, mute, behavioral, physically impaired, mentally impaired and compound disabilities
- Strengthen community-based supports for people with extraordinary behavioral challenges

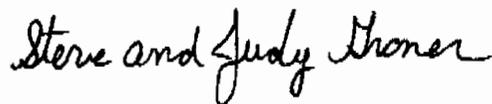
The Quinn Administration is skipping key safety and transitional steps of their own plan (Blueprint For System Redesign Update, May 2012). The blueprint reminds the Illinois Department of Human Services (DHS) that many corrective steps must occur before facilities are closed and residents displaced.

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The community-based structure needs more time to prepare before significant changes like closures are made to the State's service delivery system. Time and time again, DHS has been told about lack of confidence and lack of accountability. DHS has been told to get statewide systems in order for quality assurance, consistency, efficiency and safety. The structural changes either have not occurred, or occur at a snail's pace. Often, through trial and error methods which are not acceptable for the fragile and disabled. The Administration has again placed less emphasis on repairing critical flaws in the delivery of services.

Projected cost savings from closures are overstated due to the intensive care needs of many SODC residents. To provide necessary care in less populated settings will be very expensive- way above planned reimbursement rates. Both the architect of the "Blueprint" (Human Research Services Institute, HSRI) and also the rehabilitation facilities themselves (Illinois Association of Rehabilitation Facilities, IARF) have pointed out that investment into community providers must come first- not from after-the-fact and from questionable savings projections. The Illinois Nurse's Association (INA) agrees. DHS must focus on quality of service delivery via dramatically improved consistency, documentation and accountability. Also to assure that fundamental changes like facility closures occur only after the community infrastructure is in place, funded and actually demonstrating the ability to take on the additional responsibilities and clients asked of them.

Sincerely,



Judy & Steve Groner
531 East Gorman Street
Nashville, Illinois 62263



**Murray Center
Parents & Friends**

October 7, 2012

To: Illinois Health Facilities & Services Board

Re: Closure of Jacksonville SODC

Position: We are AGAINST Closure

Governor Quinn's plan to close DHS/SODC facilities that care for the most medically fragile and mentally impaired citizens will leave central Illinois without the appropriate spectrum of services.

For example, Murray Center is a highly regarded care facility for the developmentally disabled in Centralia. Family members of Murray Center residents make one or more visits each week-year after year because "you just don't ignore family". Drivers and care givers age, yet still rush to attend or support a loved one in need. Distance makes everything in an already difficult life worse and the Governor's proposed plan creates a 288 mile service gap if mid-state facilities like Centralia and Jacksonville are closed.

Federal law mandates that Illinois provide a full range of services to meet the needs of medically fragile and mentally impaired citizens. For developmental center residents, community alternatives have been tried and often found to be not appropriate or safe. Many square miles and many counties of this state will be deprived of necessary services.

The Murray Parent's Association (MPA) is a non-profit organization founded over 40 years ago with the purpose of assisting and caring for those with complex and profound disabilities. MPA is also known as "Murray Parent's and Friends" - a trusted voice for loved ones who call central Illinois home.

Submitted on behalf of our membership,

Rita Winkeler, President *RW/S*
618-210-9678
ritawreads@gmail.com
1535 West McCord
Centralia, IL 62801

www.murrayparentsassociation.com

FAX

TO:

NAME Illinois Health Facilities and Services Review Board
ORGANIZATION Illinois Department of Public Health
PHONE NUMBER 217-782-3516
FAX NUMBER 217-785-4111
DATE October 8, 2012

FROM:

NAME MARK M. ABEND
PHONE NUMBER 618-624-3468
MOBILE NUMBER 618-910-8222
FAX NUMBER 618-624-3468 (home)
ADDRESS 1034 Nottinghill Drive, O'Fallon, IL
62269-6874

EMAIL mmabend@aol.com

SUBJECT: Opposing Closure of State Operated Development Centers

Total # of pages 3 (including this page)

October 8, 2012

**Illinois Health Facilities and Services Review Board
2nd Floor
525 West Jefferson Street
Springfield, Illinois 62761**

Dear Members of the Review Board:

I write in opposition to closure of the state operated developmental centers at Centralia and Jacksonville. I am the stepfather of a young man named Eric who lives at Murray Center in Centralia.

The closure of Murray Center is illogical and dangerous health policy and will deny needed services to a population that must depend on others for advocacy. Determining that Murray Center will be closed and then assessing the needs of individual residents is the equivalent of "fire, ready, aim." It is a backwards and dangerous approach to treatment planning. Governor Quinn has stated publicly that this is a budget issue, but then states that this plan is motivated by providing the developmentally disabled residents of Murray Center, along with Jacksonville, with a better quality of care. The mass closure of mental health facilities that began in the late 1960s was also dangerous health policy: those closures have resulted in the establishment of a permanent underclass of the homeless chronically mentally ill in America. While community group homes meet the needs of some developmentally disabled adults, but not all. Many need a more intensive level of care.

Let me introduce my stepson to you: Eric is severely impaired by autism and has lived at Murray Center since June 1999. He lived in a community-based residence for four years but it was not able to provide him with the programming he needs because of the severity of his disability. The state of Illinois sent him to Murray Center because there was not sufficient day programming for Eric in the Metro East. There are still not appropriate residential opportunities for him in the Metro-East.

Not long after he came to Murray Center, Eric had a bowel obstruction. He could not tell anyone he was in pain, but Eric took the hand of the nurse who gave him his morning medicines and put it on his abdomen. She assessed Eric, notified his physician, and sent him to the local hospital where he had surgery a few hour later once he was stable. If a nurse had not been present, he could have suffered a rupture of the bowel with massive infection (sepsis) that could have been fatal.

Eric can be loving to family and friends, but has the potential to become easily frustrated with outbursts of aggression; this is characteristic of autism. Because of his size, he could easily injure another person, especially with inadequate numbers of staff to supervise him. What will a community home do if he becomes aggressive? Call the police? In January 2012 a teen with autism was shot and

killed by police in Calumet City IL in his parents' home when police, who had been trained to work with him, shot him. National stories have reported the use of Tasers on autistic persons in the community. In my professional opinion as an experienced mental health nurse, moving a low functioning autistic person into a minimally staffed group home is tantamount to placing toddlers in a understaffed day care center. Safety of both the residents and the staff are threatened when low functioning autistic persons are placed in programs that are inadequate to meet their unique needs.

Eric's mom and I visit with Eric in Centralia about every 2 weeks, taking him out for lunch or dinner, shopping, and other social experiences. Every 4 to 6 weeks, we bring him home to O'Fallon for a weekend visit where we try to engage him in family activities in the St. Louis community. We will not allow the state to move Eric away from his family in the Metro-East; for him, Murray Center is an appropriate and least-restrictive environment. He has matured and become more social at Murray.

Eric regressed with each transfer to a new living setting. He became more aggressive when he first moved to Hope School just before his 18th birthday. He was aggressive and tried to elope from Clinton Manor in New Baden when he first went to live there. He had many episodes of aggression that resulted in Eric being placed in restraints during his first couple of years at Murray Center. His aggressive behaviors have become almost nonexistent over the last 9-10 years. If he regresses and becomes aggressive when living in the community-based residence, what will happen? Will a single staff person be able to handle his outbursts? Will that staff person call the police for help? Will the police treat him like a "normal" adult or will they treat him like a toddler trapped in a large man's body?

What will happen to Eric if he is placed in a community-based facility that cannot meet his needs and there is no Murray Center for him? Would the state place in a facility far from his home, making it impossible for his mother and I to see him every two weeks as we now do? What will happen if the state of Illinois fails to pay a community-based organization and the home discharges him? What if the lack of a 24/7 presence of nurses results in another life-threatening health problem?

Stop the closures of Murray Center in Centralia and Jacksonville Developmental Center. Ensure that these essential health care services are made available to those who need them.

Sincerely,



Mark M. Abend
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618-910-8222/mmabend@aol.com

FAX

TO:

NAME Illinois Health Facilities and Services Review Board
ORGANIZATION Illinois Department of Public Health
PHONE NUMBER 217-782-3516
FAX NUMBER 217-785-4111
DATE October 8, 2012

FROM:

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SUBJECT: Opposing Closure of State Operated Development Centers

Total # of pages ⁴ ~~5~~ (including this page)

October 8, 2012

**Illinois Health Facilities and Services Review Board
2nd Floor
525 West Jefferson Street
Springfield, Illinois 62761**

Dear Members of the Review Board:

I write in opposition to closure of the state operated developmental centers at Centralia and Jacksonville. I am a registered nurse and president of ANA-Illinois, the Illinois affiliate of the American Nurses Association. But, more importantly, I am the mother of Eric who lives at Murray Center in Centralia.

As an expert psychiatric nurse with a background in health policy, I oppose the closure of Murray Center because the proposed closure is both bad public policy and bad health policy. By extension, I also oppose the closure of Jacksonville Developmental Center.

Closing Murray Center is bad public policy because it will devastate the community of Centralia. A study by the U of I Institute of Government and Public Affairs, commissioned by the Department of Human Services, estimates a loss of 826 jobs in the Centralia community, a loss of \$52 million in income, \$63 million in production, and about a \$1million in state and local taxes. This would devastate a community that is already suffering from severe economic stress.

The closure of Murray Center is illogical and dangerous health policy and will deny needed services to a population that must depend on others for advocacy. Determining that Murray Center will be closed and then assessing the needs of individual residents is the equivalent of "fire, ready, aim." It is a backwards and dangerous approach to treatment planning. Governor Quinn has stated publicly that this is a budget issue, but then states that this plan is motivated by providing the developmentally disabled residents of Murray Center, along with Jacksonville, with a better quality of care. As an expert psychiatric nurse, with decades of experience, I am appalled that the state is attempting to balance the budget on the backs of disabled persons who cannot speak for themselves. While politically expedient, this is morally appalling and is dangerous health policy. The mass closure of mental health facilities that began in the late 1960s was also dangerous health policy: those closures have resulted in the establishment of a permanent underclass of the homeless chronically mentally ill in America. While community group homes meet the needs of some developmentally disabled adults, but not all. Many need a more intensive level of care.

Let me introduce my son to you: Eric is severely impaired by autism and has lived at Murray Center since June 1999. He lived in a community-based residence for four years but it was not able to provide him with the programming he needs because of the severity of his disability. The state of Illinois sent him to Murray

Center because there was not sufficient day programming for my son in the Metro East. There are still not appropriate residential opportunities for him in the Metro-East.

Eric stopped talking around 30 months of age. Eric can feed and clothe himself, but needs help with basic hygiene: bathing, tooth-brushing, and toileting. He cannot use a knife or tie his shoes. He is 6'5" and weighs 250 pounds, a toddler in a linebacker's body. Eric is able to communicate with a limited vocabulary in signed speech and gestures. His IQ measures around 38-40. He needs around the clock care to ensure his well-being, including nursing care, which community group homes do not provide.

Eric went into residential care a few months before his eighteenth birthday in 1991. The search for residential care began shortly after he turned 16. Applications went out to 80 agencies. Two responded: one in Texas that was caught up in an abuse scandal and the Hope School in Springfield IL. Eric spent four years at Hope School; before he "aged out" of Hope School about 30 applications were sent out. Only one agency indicated interest in him. Southern Illinois Living Center, the parent company of Clinton Manor Living Center, offered possible placement. This was his community-based residence for four years, until his placement failed and he moved to Murray Center because no other agency in or near the Metro-East would consider my 6'5" son.

Not long after he came to Murray Center, Eric had a bowel obstruction. He could not tell anyone he was in pain, but Eric took the hand of the nurse who gave him his morning medicines and put it on his abdomen. She assessed Eric, notified his physician, and sent him to the local hospital where he had surgery a few hour later once he was stable. If a nurse had not been present, he could have suffered a rupture of the bowel with massive infection (sepsis) that could have been fatal.

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I worked with a case manager from DHS a couple of years ago to determine if there was appropriate community-based care for Eric that met his unique needs. After more than a year, the case manager indicated that appropriate services did not exist in the Metro-East. Like the other 274 residents of Murray Center, Eric needs close supervision and nursing care. He currently is checked at night every

15 minutes. No CILA can offer that kind of supervision with one employee for 8 residents at night. Eric's stepdad and I recently met with the director of the only agency in the Metro-East that provides community-based services for adults with autism. The agency cannot provide the structured environment and nursing assessment that Eric requires.

Eric's stepdad and I visit with Eric in Centralia about every 2 weeks, taking him out for lunch or dinner, shopping, and other social experiences. Every 4 to 6 weeks, we bring him home to O'Fallon for a weekend visit where we try to engage him in family activities in the St. Louis community. I will not allow the state to move my son away from his family in the Metro-East; for him, Murray Center is an appropriate and least-restrictive environment. He has matured and become more social at Murray.

Eric regressed with each transfer to a new living setting. He became more aggressive when he first moved to Hope School just before his 18th birthday. He was aggressive and tried to elope from Clinton Manor in New Baden when he first went to live there. He had many episodes of aggression that resulted in Eric being placed in restraints during his first couple of years at Murray Center. His aggressive behaviors have become almost nonexistent over the last 9-10 years. If he regresses and becomes aggressive when living in the community-based residence, what will happen? Will a single staff person be able to handle his outbursts? Will that staff person call the police for help? Will the police treat him like a "normal" adult or will they treat him like a toddler trapped in a large man's body?

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As president of the state nurses association and the mother of a Murray Center resident, I am eager to speak to any member or members of the Review Board who would like to learn more about the need for state operated development centers. Please stop the closures of the state developmental centers at Centralia and Jacksonville now!

Sincerely,



(Dr.) Karen Kelly
1034 Nottingham Drive, O'Fallon IL 62269
618-910-8223/kkellys@aol.com