

# **Living with Independence Fairness & Equality**

**FUND CRITICAL SERVICES FOR PEOPLE WITH DISABILITIES**

## **Activity Summary and Media Report** **Success through Communication, Execution and Publication**

**Presented by Morreale Public Affairs Group (MPAG)**





## The Arc of Illinois

**LIFE – Living with Independence, Fairness and Equality / Fund Critical Services for People with Disabilities**

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The objective of the LIFE campaign is to alert Illinois legislators and other policy makers about the critical need to fund services geared towards keeping people with disabilities in their homes and communities. A combination of media, legislative and community outreach, in addition to engaging a strong coalition of stakeholders, contributed to the overall success of our mission.

To start, MPAG created a graphic and theme to be used consistently throughout the campaign. The logo is simple yet a highly identifiable way to get our message across to "Fund Critical Services for People with Disabilities." The LIFE logo incorporates key messaging while intentionally depicting a diverse group of people to humanize the issue.

MPAG executed a strategic legislative campaign with a primary focus on the staff in the governor's office and legislative leadership in the House and Senate. The secondary focus was members in the House and Senate Human Services and Appropriations Committees. The toughest challenge for the campaign was making the case in a very short time-frame to restore proposed budget cuts while the state struggled to plug an estimated \$13 billion budget shortfall, the largest in state history. We were prompt and consistent while we prepared legislative packets that went to every member of the General Assembly. This was followed-up with a visit from a member of the lobbying team to answer questions from lawmakers. The lobbying kit contained a fact sheet, frequently asked question sheet and invitation to a legislative coffee. In order to truly humanize our issue for lawmakers, MPAG internally produced a compelling DVD that told the story of how families would struggle on a daily basis if funding was eliminated. This DVD was shown at our well attended legislative breakfast in Springfield and The Arc's annual convention in Lisle and was also posted on YouTube (almost 900 viewers) and shared on Facebook.

MPAG also executed a strategic media campaign to inform and educate local and state media about the crisis facing people with disabilities. Through media relations, MPAG created and distributed press releases and executed three press events announcing the LIFE campaign and explained that the people of Illinois with disabilities and their families are united in preserving funding to keeping people with disabilities in their homes and communities. MPAG also executed a statewide editorial board swing, created and pitched an informative Op-Ed and in-turn encouraged coalition members to voice their support through on-line posts and/or letters. Additionally, MPAG arranged media tours in Springfield and Rockford. Throughout, the campaign MPAG reached-out to key media partners to encourage coverage which resulted in state-wide placement as well as monitored media coverage to share with supporters to maintain and build momentum.

MPAG partnered with The Family Support Network and managed a strong grass roots and community outreach effort. We determined that we needed a credible, strong, unified voice to expose the crisis facing Illinois and outlined a realistic solution. The LIFE Coalition was created and proved to be a valuable asset for people with disabilities and their families in Illinois because we were able to provide necessary counsel, key messaging and a variety of tools to help increase advocacy efforts. These tools



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included a script for calling or visiting with legislators, a legislative report card, sample letters to the editor and legislators, budget fact sheets, a sheet outlining frequently asked questions and other action items. Outreach efforts included educating advocates by participating at the Arc of Illinois annual conference and the Autism Walk. We offered supporters to share their concerns through Facebook, an electronic petition drive as well as the Chicago rally. We currently have over 500 friends on Facebook, over 8,000 signatures of support and over 300 people attend the Chicago rally. During the rally in Chicago, MPAG organized a very visible petition delivery to the Governor and also arranged for delivery to the leaders in Springfield. The coalition partners, key communicators, families and advocates appreciated this concentrated effort although they had limited resources and time to make advocating a top priority.

Additionally, MPAG engaged in social media to create the LIFE Facebook page where families and advocates were asked to share personal stories through video, photos or comments on what cuts to critical services mean to them and their family as well as posted campaign news and action alerts. Facebook posts from people with disabilities and their families humanized funding needs and we are confident that this outlet was used to educate hometown legislators, reporters and editors about the dire impact that cuts will have on communities where they work and live.

The LIFE campaign realized a fantastic outcome given current economic conditions and lawmakers plight to cut state funded programs in order to plug a \$13 billion deficit. Medicaid rate cuts seemed imminent but during the final hours of negotiations cuts to proposed Medicaid rates were restored. Perhaps our biggest accomplishment was that funding for community disability programs was reinstated and grants that were slated to be completely eliminated or significantly reduced were reinstated. This includes funding for Respite, Dental and UIC Grants.

Following you will find a collection of materials created for the LIFE campaign and an extensive media report from March 15 – June 15, 2011.



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## Legislative Coffee

The legislative coffee was well attended. The following people joined us to learn more about the LIFE campaign; Representatives Arthur Turner, John D'Amico, Robyn Gabel, Joseph Lyons, Michael McAuliffe, Monique Davis, Chris Nybo, Patti Bellock, Mark Beaubien, Jr., Michael Tryon, Richard Morthland, Patrick Verschoore, Donald Moffitt, Camille Lilly, Emily McAsey, Daniel Brady, Jerry Mitchell, Wayne Rosenthal, John Cavaletto, David Reis, Dwight Kay, Mike Bost, and Brandon Phelps. In addition, Senators Don Harmon, Sam McCann, John Mulroe, and Suzi Schmidt.

Charlotte Cronin, Parent and Executive Director, Family Support Services and Tony Paulauski, Executive Director of The Arc of Illinois, with one of our champions, Rep. Patti Bellock



Tony Paulauski and Dorelia Rivera, Parent, Director of Strategic Alliances, Community Support Services and Arc of Illinois Board Member with Senator John Mulroe





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Rep. Camille Lilly, Shirley A. Perez, Parent and Family Advocate, Illinois Life Span, Rep. Robyn Gabel, Deb LeCrone, and Michele Westmaas, Parent and Advocacy Consultant for Family Support Network



Rep. Cavaletto with Misty White, Parent, Advocate and Member of Family Support Services, Lt. Gov. Sheila Simon, Tony Paulauski and Sue Brown, Parent and Board Member of The Arc of Illinois



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## Petition Delivery

Tony delivers 8,000 petitions to Governor's office in Chicago.



Carlissa Puckett, Executive Director of SPARC, and Charlotte Cronin smile for the camera as John Porter hands our petitions to a staffer for House Speaker Mike Madigan.





## Editorial Board Meetings

Daily Herald: Tony Paulauski, Julie Cicarelli, David Cicarelli, and Bob Okasaki



The Pantagraph: Tom Bennett, Tony Paulauski, Yvonne Hall, and Deb Sheppard



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Peoria Journal Star: Charlotte Cronin, Tony Paulauski, and Doris Hayes



## Rockford Press Conference

Arc President Jacki Neil Boss, Arles Hendershott from Milestone, and Tony Paulauski





## Springfield Press Conference, May 18, 2011

Representative Esther Golar speaking at LIFE's press conference.



Misty White, Parent, Advocate and Member of Family Support Network, Charlotte Cronin, Tony Paulauski and Representative David Leitch at LIFE's press conference.



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## Chicago Press Conference and Rally, May 25, 2011

Tony Paulauski leading the crowd by chanting, "This budget is upside down!"



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Jose Ovalle, Executive Director, Grupo SALTO, featured speaker at the rally.



Regina Thurston and Jason Thurston, featured speakers at the rally.



Donald Dew, President, Habilitative Systems, featured speaker at the rally.





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## Chicago Press Conference / Rally

Over 300 advocates attended the rally!



## Chicago Press Conference / Rally

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More photos can be found on LIFE's Facebook page.

<https://www.facebook.com/pages/LIFE-Fund-Critical-Services-for-People-with-Disabilities/137495486323077>



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## Leaders in The Arc:

We are excited to launch the LIFE public affairs campaign!

Above is our new graphic and theme that we will be using throughout the campaign. It is simple A yet highly identifiable way to get our message across to "Fund Critical Services for People with Disabilities."

The goal is to alert our legislators and other policy makers about the critical need to fund services geared towards keeping people with disabilities in their homes and communities. A combination of media, legislative and community outreach, in addition to engaging a strong coalition of stakeholders, will contribute to the overall success of our mission.

You will have many opportunities to volunteer, and your participation will be a critical link to the LIFE campaign's media and legislative strategy. In the coming weeks, we will ask you to share your personal stories on what cuts to critical services mean to you and your family. This will humanize funding needs and be used to educate your hometown legislators and reporters about the dire impact that cuts will have on your daily life.

Here is a timeline of some of the action items:

### Week of April 4th

Like LIFE on Facebook

Record 'A Day in My Life' video

Display LIFE signs throughout your community

Participate in the electronic petition drive

### Week of April 11th

Attend the Springfield press conference and breakfast with legislators

Write a letter to your editor

### Week of April 18th

Participate in district lobby week and visit your legislators

Attend a local editorial board meeting happening throughout the state



## Week of April 25th – Week of May 30th

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Take part in various calls to action and follow-up outreach to legislators

Please look for volunteer opportunities and campaign updates in the coming weeks. A comprehensive campaign kit will be available to enable you to easily volunteer and be a key part of the campaign. The kit will include talking points, fact sheets, sample letters to the editor, LIFE press releases and scripted messaging for when you meet with legislators and reporters.

Our true strength will be our constant outreach so the media, legislators and advocates easily recognize us. Thank you in advance for your continued support and participation!

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## FAQ ON PROPOSED FY 2012 BUDGET

*It is time to rebalance the Developmental Disability System in Illinois to provide quality of life for people with disabilities and for the State of Illinois to spend taxpayer money in the most economical and responsible way. We need to end the waiting list for the 21,000 adults and children in the PUNS database, restore funding for critical community developmental disability services and adopt a four-year plan to phase out the funding of state institutions!*

### What are community based disability services?

Community based disability services support people with significant disabilities in the communities of their choice with family, on their own, or in residential settings in traditional neighborhoods, offering the opportunity to live full and vibrant lives that maximize independence and full inclusion.

### What types of programs are considered community based services?

Community based disability services are any of the multitude of supports needed by people with disabilities to be successful in their daily lives. Those supports may include help with the everyday needs of life such as eating, bathing, grooming, and dressing. They may help with medications and therapies. They may help with developing skills for overcoming communication or behavioral challenges. They may help with learning social skills or offering support for work opportunities. They also provide support and respite to caregivers of children and adults with disabilities so that they can be the resource their loved ones need them to be.

### How does community based services compare to institutions?

Community based disability services help children and adults live with independence, dignity and equality close to family and friends able to participate in all the opportunities community offers. Community living provides safer, more effective and healthier environments for people with disabilities to live.

### What is the cost of community based services compared to institutional costs?

The state pays \$192,000 per person in an institution versus approximately \$50,000 per person for community based disability services. Nearly four people can be served with community based services for every one person in an institution.

### Is there evidence documenting the advantages of community programs vs. institutions?

Yes. The Illinois Developmental Disability System has been studied many times and the overwhelming opinion is to downsize state institutions and to invest more in a community system. Persons with disabilities thrive in community based settings, which are much more cost effective.

### How great is the need for community based services?

The "Prioritization of Urgency of Need for Services" (PUNS) database maintained by the Illinois Division of Developmental Disabilities shows almost 21,000 people actively in need of services. That's 21,000 children and adults and their families living lives of frustration, isolation, and exhaustion because these programs are grossly underfunded. There are currently 40,000 children and adults receiving state funded community based disability services.



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### What impact will the Governor's proposed \$76.3 million cuts actually have?

Last year \$16 million was cut from the budget of the Division of Developmental Disabilities. Those cuts were vital grant funded direct services in the community for about 15,000 individuals with intellectual and developmental disabilities. Additional cuts will mean 3,052 direct care community staff layoffs, 6% cuts in services, and the elimination of critical programs. It will mean cutting the lifeline impacting 220,000 people with disabilities and their families living in the State of Illinois.

### The state is in a fiscal crisis, how can we afford to fund these programs?

We can't afford not to. While persons with disabilities will be the most impacted, many others will feel the pain. According to the Governor's proposed budget, it is estimated that 3,052 direct care staff will be laid off and vital programs will be eliminated. The current budget invests \$30 million in state institutions while it cuts community services by \$76.3 million, even though funding community living is proven to be more cost effective. Illinois ranks last in funding community programs. The budget includes the hiring of 950 state employees and grants employees an 8.25% wage increase. The budget has the wrong priorities and needs to be rebalanced to address the more critical needs of Illinois citizens.

### How does Illinois compare to other states in funding community programs?

Illinois ranks 51<sup>st</sup> in the nation for supporting citizens with developmental disabilities in their home communities. There are 11 states that have already phased out state institutions that have proven to be an antiquated way of caring for people with disabilities. Illinois' neighboring state of Indiana closed its one remaining institution last year.

### What are some of the programs that will be cut/eliminated?

All community services funded by Medicaid are cut across the board by 3 - 6%. Those services include but are not limited to: Community Integrated Living Arrangements (CILA), Day Services, Therapies, Intermediate Care Facilities for the Developmentally Disabled (ICF/DD), Pre-Admission Screening (PAS) Services, Individual Service and Support Advocacy and all Community Services. The Governor's proposed budget disqualifies Illinois for more than \$31 million in federal match money. So, Illinois is only realizing 3% of the anticipated 6% in cuts, services and funding Illinois can not afford to lose.

The Children and Adult Home-Based Services Programs will be cut by 10% and directly assist families supporting their children and adult children in their homes.

Additionally, the proposed budgets either eliminates or drastically cuts the Family Assistance Program, The UIC Family Clinic and Assistive Technology Unit, all Epilepsy Grants, all Dental Grants, SIU Telemed Grant and all Respite Grants.

### What is the best course of action?

End the waiting list for the 21,000 adults and children in the PUNS database, restore funding in community developmental disability services and adopt a four-year plan to phase out the funding of state institutions. Funding state institutions is proven to be an antiquated way of caring for people with disabilities. It is time to rebalance the Developmental Disability System in Illinois.

**The Arc of Illinois** represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families. The Arc is a member of the Responsible Budget Coalition and support reasonable revenue estimates to help minimize harmful budget cuts. For more information contact: Tony Paulauski at 815- 464-1832 or [tony@thearcofil.org](mailto:tony@thearcofil.org).

SOURCE: The Arc of Illinois



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All community services funded by Medicaid are cut across the board by 3 - 6%. Those services include but are not limited to: Community Integrated Living Arrangements (CILA), Day Services, Therapies, Intermediate Care Facilities for the Developmentally Disabled (ICF/DD), Pre-Admission Screening (PAS) Services, Individual Service and Support Advocacy and all Community Services. The Governor's proposed budget disqualifies Illinois for more than \$31 million in federal match money. So, Illinois is only realizing 3% of the anticipated 6% in cuts, services and funding Illinois can not afford to lose.

The Children and Adult Home-Based Services Programs will be cut by 10% and directly assist families supporting their children and adult children in their homes.

Additionally, the proposed budgets either eliminates or drastically cuts the Family Assistance Program, The UIC Family Clinic and Assistive Technology Unit, all Epilepsy Grants, all Dental Grants, SIU Telemed Grant and all Respite Grants.

### What is the best course of action?

End the waiting list for the 21,000 adults and children in the PUNS database, restore funding in community developmental disability services and adopt a four-year plan to phase out the funding of state institutions. Funding state institutions is proven to be an antiquated way of caring for people with disabilities. It is time to rebalance the Developmental Disability System in Illinois.

**The Arc of Illinois** represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families. The Arc is a member of the Responsible Budget Coalition and supports reasonable revenue estimates to help minimize harmful budget cuts. For more information contact: Tony Paulauski at 815- 464-1832 or [tony@thearcofil.org](mailto:tony@thearcofil.org).



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## FY2012 BUDGET FACT SHEET

### **RESTORE THE \$76.3 MILLION THAT FUNDS CRITICAL SERVICES FOR ILLINOIS' MOST VULNERABLE CITIZENS! END THE WAITING LIST FOR THE 21,000 ADULTS AND CHILDREN IN THE PUNS DATABASE!**

*The LIFE Campaign supports the funding of individualized, comprehensive and integrated community based services for persons with disabilities. The proposed budget will cut the lifeline of critical community-based services that support children and adults with significant disabilities in their homes and communities and their ability to live Life with Independence Fairness & Equality. Illinois ranks 51st in the nation for supporting citizens with developmental disabilities to live in their home communities.*

### **THE 2012 PROPOSED BUDGET HAS ALL THE WRONG PRIORITIES**

- \$76.3 million in cuts from community developmentally disability services will
  - Reduce rates for community services by 6% (while saving the state only 3%)
  - Reduce the Children's and Adults Home-Based Support Services available monthly allotment by 10% (while saving the state only 5%)
  - Eliminate these critical programs: Family Assistance Program, UIC Family Clinic, UIC Assistive Technology Unit, all Epilepsy grants, all Dental grants, SIU Telemed grants, and all Respite grants
- The cost to institutionalize people with disabilities far from family and friends will rise to \$192,000 per person and not one of the 21,000 children and adults will move off the state's waiting list
- Illinois institutionalizes more people than any other state
- The average cost to support one person living in the community is \$50,000 compared to \$192,000 per person in one of the eight state institutions
- An estimated 3,052 local community employees will be laid off while this budget proposes a 8.25 % wage increase for state employees AND the hiring of 950 NEW state employees
- An additional \$30 million will be invested in state institutions while cutting community services by \$76.3 million
- No provision is made to pay community providers promptly - currently a six month backlog
- Illinois will be turning away \$31.15 million dollars in 50 % federal match



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- This budget will de-construct the current DD system, forcing many agencies to simply close and many people with very significant disabilities out "on the curb."

An estimated 220,000 persons with developmental disabilities live in Illinois. People with disabilities have the right to enjoy the same freedoms and responsibilities as all Illinoisans in the community of their choice.

For more information, contact Tony Paulauski at (815) 464-5292, [tony@thearcofil.org](mailto:tony@thearcofil.org) or visit [www.thearcofil.org](http://www.thearcofil.org).

***The Arc of Illinois** represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families.*



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## FY2012 BUDGET FACT SHEET

### **RESTORE FUNDING FOR CRITICAL SERVICES FOR ILLINOIS' MOST VULNERABLE CITIZENS!**

### **END THE WAITING LIST FOR THE 21,000 ADULTS AND CHILDREN IN THE PUNS DATABASE!**

*The LIFE Campaign supports the funding of individualized, comprehensive and integrated community based services for persons with disabilities. The proposed budget will cut the lifeline of critical community-based services that support children and adults with significant disabilities in their homes and communities and their ability to live Life with Independence Fairness & Equality. Illinois ranks 51st in the nation for supporting citizens with developmental disabilities to live in their home communities. None of the budget proposals address the 21,000 people on the state's waiting list for disability services.*

### **THE 2012 PROPOSED BUDGET HAS ALL THE WRONG PRIORITIES**

#### **Governor's Proposed Budget**

- \$76.3 million in cuts from community developmental disability services.
- Reduces rates for community services by 6% (while saving the state only 3%).
- Reduces the Children's and Adults Home-Based Support Services available monthly allotment by 10% (while saving the state only 5%).
- Eliminates these critical programs: Family Assistance Program, UIC Family Clinic, UIC Assistive Technology Unit, all Epilepsy grants, all Dental grants, SIU Telemed grants, and all Respite grants.
- An estimated 3,052 local community employees could be laid off while this budget proposes a 8.25 % wage increase for state employees AND the hiring of 950 NEW state employees.
- An additional \$30 million will be invested in state institutions while cutting community services by \$76.3 million.
- No provision is made to pay community providers promptly—currently a six-month backlog.
- Illinois will be turning away \$31.15 million dollars in 50 % federal match.

#### **Senate's Proposed Budget**

- The Senate's revenue estimate is \$1.2 billion lower than the Governor's revenue estimate.
- All Medicaid services are cut across the board by 3%. Those include CILA, Day Services, Therapies, ICFDD's, PAS Services, Individual Service and Support Advocacy and all Community Services.



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- Children and Adult home-based services are cut by 10%. These programs offer critical support to families to keep their children and adult children in their homes.
- Cuts the following by 50%: Respite and Dental Grants, Family Assistance Program, UIC Family Clinic and Assistive Technology Unit, Epilepsy Grants and the SIU Telemed Grant.
- Cuts Best Buddies, Illinois Life Span and The Autism Program by 25%.

### House's Proposed Budget

- The House's estimate of revenues is about \$1.1 billion lower than the Senate's estimate.
- Cuts an additional \$1.4 billion from the Governor's budget.
- Reduces the Children's and Adults Home-Based Support Services available monthly allotment by 10% (while saving the state only 5%).
- Cuts The Autism Program by 1%, Best Buddies by 26% and Illinois Life Span by 15%.
- Eliminates All Respite, Epilepsy and Dental Grants, Family Assistance Program, UIC Family Clinic and Assistive Technology Unit and SUI Telemed Grant.

### OTHER FACTS

- The cost to institutionalize people with disabilities far from family and friends will rise to \$192,000 per person and not one of the 21,000 children and adults will move off the state's waiting list.
- Illinois institutionalizes more people than 47 other states.
- The average cost to support one person living in the community is \$50,000 compared to \$192,000 per person in one of the eight state institutions.
- This budget will de-construct the current DD system, forcing many agencies to simply close and many people with very significant disabilities out "on the curb".
- An estimated 220,000 persons with developmental disabilities live in Illinois. People with disabilities have the right to enjoy the same freedoms and responsibilities as all Illinoisans in the community of their choice.

**The Arc of Illinois** represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families. The Arc is a member of the Responsible Budget Coalition and supports reasonable revenue estimates to help minimize harmful budget cuts. For more information, contact Tony Paulauski at (815) 464-5292, [tony@thearcofil.org](mailto:tony@thearcofil.org) or visit [www.thearcofil.org](http://www.thearcofil.org).

*Source: The Arc of Illinois*



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## TAKE ACTION AGAINST STATE BUDGET CUTS

**The State of Illinois is considering record budget cuts that will translate into devastating reductions in disability services that allow us to keep**

**Living with Independence Fairness & Equality.**

Follow these four simple steps to stay informed and to make sure your voice is heard!

1. **Rally at the Thompson Center in Chicago!** Join us at 10:00 a.m., Tuesday, May 24, 2011 at The Thompson Center in the Plaza at 100 west Randolph. We need hundreds of people with signs. This is the moment for your family to make itself seen. This is the moment for your agency to load up its vans and get downtown. We need to put faces on our issues. Media will be there. Families will be speaking about the cuts to disability services and our LIFE Petitions will be delivered to the Governor.
2. **Join our petition drive.** Our goal is to get 10,000 signatures delivered to Governor Quinn and members of the General Assembly.
3. **Contact your State Representative and Senator.**
4. **Write a letter to your local newspaper editor.**

Visit [www.thearcofil.org](http://www.thearcofil.org) to find your legislators and get campaign materials, write a letter to the editor and to join our petition drive.



FIND US ON FACEBOOK



**Living with Independence Fairness & Equality**

FUND CRITICAL SERVICES FOR PEOPLE WITH DISABILITIES

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## TAKE ACTION AGAINST STATE BUDGET CUTS

**The State of Illinois is considering record budget cuts that will translate into devastating reductions in disability services that allow us to keep**  
**Living with Independence Fairness & Equality.**

Here are six simple steps to stay informed and to make sure our voices are heard...

1. **Call your State Representative and Senator.** Identify them at <http://www.elections.il.gov/DistrictLocator/DistrictOfficialSearchByAddress.aspx>.
2. **Join our online petition drive.** Our goal is to get 10,000 signatures delivered to Governor Quinn and members of the General Assembly. <http://www.thearcofil.org/LIFE/LifeCampaignPetition.aspx>
3. **Share the word with other advocates** in your communities and organizations.
  - Forward our e-mails
  - Like us on Facebook: [LIFE-Fund-Critical-Services-for-People-with-Disabilities](http://www.facebook.com/LIFE-Fund-Critical-Services-for-People-with-Disabilities).
4. **Become a "Key Communicator"** (phone tree captain). We'll provide you with contact info for others (usually about a dozen) in your community, asking you to encourage them to make those critical phone calls to your legislators. Contact Michelle Westmaas at [michelewestmaas@gmail.com](mailto:michelewestmaas@gmail.com).
5. **Record your story for our Facebook page:** [LIFE-Fund-Critical-Services-for-People-with-Disabilities](http://www.facebook.com/LIFE-Fund-Critical-Services-for-People-with-Disabilities). Let us know how state funded disability services impact your life. Each video should show what "A Day in My Life" is like and how disability services are your lifeline to work, friends, family and other activities. Each video should explain:
  - The programs you or your family member participate in
  - How these programs allow you to continue Living with Independence Fairness & Equality
  - What your life would be like if these programs were not funded or...
  - Or what your life is without services.





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Contact the Family Support Network at [fsn@familysupportnetwork.org](mailto:fsn@familysupportnetwork.org) to share it with us. Count on us to edit your video down to about a minute before we post it. THANKS!!

**6. Write a letter to your local newspaper editor.** Need someone to help you jump start the letter? We can provide templates...



Visit [www.thearcofil.org](http://www.thearcofil.org) or [www.familysupportnetwork.org](http://www.familysupportnetwork.org) for campaign materials and more information.



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# Please Join the LIFE Campaign for a Legislative Breakfast

**May 4, 2011  
8:30 a.m. – 10:30 a.m.  
Rathskeller Cafeteria**

*The LIFE campaign supports the funding of individualized, comprehensive and integrated community based services for persons with disabilities. The LIFE campaign is part of the The Arc of Illinois that represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families.*

**For more information contact:  
Kim Morreale at 847-401-8564 or  
Liz Brown at 217-502-7703**



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## LEGISLATIVE VISIT SCRIPT

### INTRODUCTION

- Tell them who you are – an advocate on behalf of the LIFE campaign to help Fund Critical Services for People with Disabilities; A parent of, or person with, a developmental disability; and an advocate for community-based services.
- Give details about your "personal story" – how has your/ your family members disability impacted your life; why do you care about community services, and how did you get involved in advocacy? Leave them with a picture in their minds.
- Let them know who LIFE is. The LIFE campaign supports the funding of individualized, comprehensive and integrated community based services for persons with disabilities. The LIFE campaign is part of the The Arc of Illinois that represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families.

### PURPOSE OF VISIT

- You are here in response to Governor Quinn's proposed budget. There are \$76.3 million in cuts slated for community developmentally disability services. **No 6 percent cut restore all grants the Dental and respite, ect grants for and no cuts to home base services.**
- The cuts will eliminate critical programs, such as: Family Assistance Program, UIC Family Clinic, UIC Assistive Technology Unit, all Epilepsy grants, all Dental grants, SIU Telemed grants, and all Respite grants. Explain how these cuts will impact you.
- There are over 21,000 adults and children waiting for services in the PUNS database
- Illinois will be turning away \$31.5 million dollars in the 50% federal match (please share fact sheet w/ Legislator)



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## ASK

**"Are you willing to be our advocate in Springfield and reject a budget that cuts community based disability services? Will you work on our behalf to restore our funding? Our community needs your leadership on this issue."**

*(take good notes on Lobby Report Card)*

## THANK YOU

- Leave your contact information for the Representative/ Senator, along with the LIFE Budget Fact Sheet
- Return your legislative report card to [life@morrealepag.com](mailto:life@morrealepag.com), fax to 312-277-7477 or mail to Morreale Public Affairs Group 8770 West Bryn Mawr Ave., Suite 1300 Chicago, IL 60631.



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### Legislator Meeting Report Card

Your Name \_\_\_\_\_

Your Organization \_\_\_\_\_

Legislator Name \_\_\_\_\_

Did you get to meet in person?	YES	NO	
If NO, did you leave behind information?	YES	NO	
If YES, were they supportive of your issue?	YES	NO	UNDECIDED
If YES, did they agree to vote against a budget that cuts community based disability services?	YES	NO	UNDECIDED

COMMENTS:

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Please return all report cards to Michelle Arnold:

Email – [life@morrealepag.com](mailto:life@morrealepag.com) / Fax – 312.277-7477 / Mail- Morreale Public Affairs Group 8770 W. Bryn Mawr Avenue, Suite 1300 Chicago, IL 60631.



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Honorable

State (Rep or Senator)

(Address)

Dear Representative/Senator (Name):

I am writing to you as a *(parent of a person, or person) with a developmental disability* and an advocate for community-based services in response to Governor Quinn's proposed FY 2012 budget. I strongly urge you to consider restoring the \$76.3 million that the Governor cut to fund critical services for individualized, comprehensive and integrated community based services for persons with disabilities. The proposed budget has all the wrong priorities. The slated cuts will have devastating consequences to the more than 220,000 people with disabilities and their families who are frustrated, angry and scared because of the uncertainty that comes with not knowing how we will continue to care for people who have nowhere else to turn.

Illinois will be turning away \$31.5 million dollars in the 50% federal funding match because of the 6% cut to all community-based Medicaid funded services. This will be the last straw for many of our providers of service who already struggle to provide quality services with inadequate reimbursement. The Children and Adult Home-Based Services Programs' 10% cut directly affects families supporting their adolescent and adult children in their homes. The cuts will also eliminate critical programs such as: all Respite services, all Dental grants, the Family Assistance Program, UIC Family Clinic, UIC Assistive Technology Unit, all Epilepsy grants and SIU Telemed grants. All while there are over 21,000 adults and children waiting for services in the PUNS database.

Our community needs your leadership on this issue. We need your assistance in restoring the Governor's proposed budget cuts to community developmental disability services. People with disabilities have the right to enjoy the same freedoms and responsibilities as all Illinoisans in the community of their choice.

I am part of the LIFE Coalition working to Fund Critical Services for People with Disabilities. The LIFE Campaign is part of the The Arc of Illinois that represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families.

I appreciate your support and ask that you call me if you have any questions.

Sincerely,



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Dear Governor Quinn:

We are writing to you as leaders and advocates representing citizens that utilize *community-based disability services* in response to your proposed 2012 budget. We are asking that you reconsider the proposed \$76.3 million in cuts for community-based disability services. These services are a lifeline for our community and they offer individualized, comprehensive and integrated services that allow people with disabilities to remain active, proud and productive members of our community. Governor, our community needs your leadership on this issue. We urge you to consider moving the priorities of the state budget away from state institutions to community based services for our people with disabilities. People with disabilities have the right to enjoy the same freedoms and responsibilities as all Illinoisans in the community of their choice.

The 2012 proposed budget has all the wrong priorities. The slated cuts will have devastating consequences to the more than 220,000 people with disabilities and their families who are frustrated, angry and scared because of the uncertainty that comes with not knowing how we will continue to care for people who have nowhere else to turn. Reductions of 6% in rates for services will be the last straw for many of our providers of service who already struggle to provide quality services with inadequate reimbursement. The Children and Adult Home-Based Services Programs' 10% cut directly affects families supporting their adolescent and adult children in their homes. The cuts will also eliminate critical programs such as: all Respite services, all Dental grants, the Family Assistance Program, UIC Family Clinic, UIC Assistive Technology Unit, all Epilepsy grants and SIU Telemed grants. All while there are over 21,000 adults and children waiting for services in the PUNS database.

Illinois will be turning away \$31.5 million dollars in the 50% federal funding match because of the 6% cut to all community-based Medicaid funded services.

The numbers don't add up. The average cost for a person in a state institution is \$192,000 a year, while the cost of supporting an individual in a community-based program is \$50,000 per person. It doesn't make sense that the state is investing \$30 million in new state monies for state institutions even though numerous studies show that community-based programs provide a safer, healthier and more cost effective way of caring for people with disabilities. Although Illinois ranks 4<sup>th</sup> in the country for the number of citizens with disabilities, we are 51<sup>st</sup> in funding for small group homes and 47<sup>th</sup> on community spending for adults and children with disabilities.

We are members of the LIFE Coalition, which is spearheaded by The Arc of Illinois and the Family Support Network of Illinois. The LIFE Coalition is working to raise awareness about the serious impact these budget cuts will have on people with disabilities. You can learn more about the LIFE campaign by visiting [www.TheArcofIL.org](http://www.TheArcofIL.org). Finally, we encourage you to find us on Facebook so you can gain a better sense of how important it is to fund community-based disability services and follow the Coalition's progress.

We appreciate your support and look forward to your response. Please feel free to contact Tony Paulauski and Charlotte Cronin if we can be of further assistance to you or your office.

Sincerely,



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## RESTORE FUNDING FOR CRITICAL SERVICES FOR ILLINOIS' MOST VULNERABLE CITIZENS!

The LIFE Campaign supports the funding of individualized, comprehensive and integrated community based services for persons with disabilities. The proposed budget will cut the lifeline of critical community-based services that support children and adults with significant disabilities in their homes and communities and their ability to live Life with Independence, Fairness & Equality.

These services need to be fully restored at these levels in the FY 2012 budget. We urgently need your assistance to save critical programs that will be eliminated under the current budget proposal.

Restore the \$15.456 million in cuts to critical disability services! Programs include:

In Home Respite Services	\$7.166 million
Voucher Respite	\$2.292 million
Group Respite	\$973 thousand
Dental Clinic Grants	\$1,103 million
UIC Family Clinic and Assistive Technology Unit	\$1.790 million
Epilepsy Grants	\$1.087 million
Family Assistance Program	\$890 thousand
SIU Telemed Grant	\$155 thousand

**Total: \$15.456 million**

People with disabilities have the right to enjoy the same freedoms and responsibilities as all Illinoisans in the community of their choice.

The Arc of Illinois represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families that live in Illinois. The Arc is a member of the Responsible Budget Coalition and supports reasonable revenue estimates to help minimize harmful budget cuts. For more information, contact Tony Paulauski at (815) 464-5292, [tony@thearcofil.org](mailto:tony@thearcofil.org) or visit [www.thearcofil.org](http://www.thearcofil.org).



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### Leaders in The Arc:



The LIFE Campaign is now active on Facebook!

**Please support the campaign by liking the LIFE – Fund Critical Services for People with Disabilities page. We will consistently share “real time” campaign and legislative news and post urgent action alerts. You in turn will have the opportunity to share your story, feedback and comments as well as build campaign momentum by recruiting supporters simply by recommending the LIFE profile page to friends and family. This tool allows all of us to share useful content, opinions, insights, experiences, perspectives and news as well as build an online community of advocates.**

**We have also learned that Facebook is an effective tool for communicating with reporters and editors. Facebook’s membership has topped 500 million people and U.S. users spent 41.1 million minutes on Facebook in August 2010. Friend us on Facebook today!**

**<https://www.facebook.com/pages/LIFE-Fund-Critical-Services-for-People-with-Disabilities/137495486323077>**



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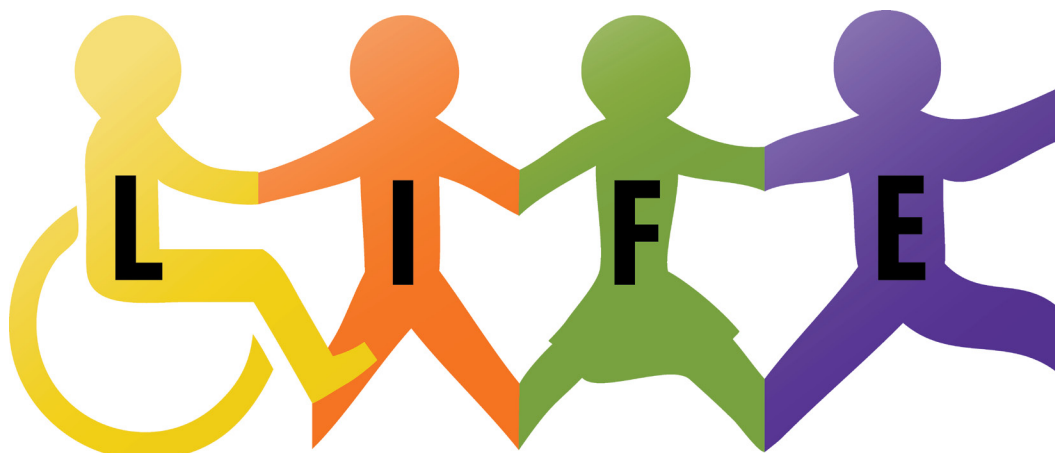
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# Living with Independence Fairness & Equality

FUND CRITICAL SERVICES FOR PEOPLE WITH DISABILITIES



<http://www.youtube.com/watch?v=yD8nKaeHEcl>

The State of Illinois is looking at \$76.3 million in cuts to community based disability programs. Several services will be eliminated and all other programs will be cut 6-10%. It is critical that you call Governor Quinn and your State Senator and Representative and let them know that cuts to community based disability programs are not an option. Help us to live Life with Integrity, Fairness and Equality. For more information visit [www. thearcofil.org](http://www.thearcofil.org) or find us on Facebook.



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It is time to balance the Developmental Disability System in Illinois to provide quality of life for people with disabilities and for the State of Illinois to spend taxpayer money in the most economical and responsible way. We need to end the waiting list for the 21,000 adults and children in the PUNS database and restore \$76.3 million that funds critical community developmental disability services and adopt a four-year plan to phase out the funding of state institutions!

[illegible]



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## Our Challenges

### **\$76.3 Million Cut to DD Services**

- 6% cuts in rates for services
- 10% cut to Home-Based Support Services
- Elimination of critical grant programs
- 6 month delay in services

### **21,000 on the PUNS Waiting List**



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## Our Challenges

### Moments of Great Passion

- Illinois is a big state
- Hard to coordinate
- Wonderful advocates
- Wonderful local organizations
- Wonderful statewide organizations



## Our Challenges

**Then we fall back to doing what we do best...**

Supporting each other in our everyday lives...



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## Our Answer

### A Statewide Advocacy Campaign

With professional help...  
Coordinating our efforts at every level



## Our Team

**The Arc of Illinois**  
**The Family Support Network**  
**Morreale Public Affairs Group**  
**You! Your friends! Your Organizations!**



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## Our Tools

### COORDINATION!!

- Intense Media Campaign
- Strategies at the Capitol
- Facebook
- Petition 10,000!
- Key Communicators
- Your Letters
- Your Phone Calls
- Your Visits



## Our Successes

- Facebook – 245 yesterday!
- Media Launch – Rockford
- Materials developed and online
- Petition link created- 10,000!
- Key Communicators engaged
- Legislative Breakfast scheduled



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## How You Can Help **SHARE YOUR STORY!**

- Record your story!
- Contact your state legislator
- Join our online petition
- Write a letter to your local newspaper
- Like us on Facebook 
- Forward our e-mails



## For More Help...



- [www.thearcofil.org](http://www.thearcofil.org)



- [www.thefamilysupportnetwork.org](http://www.thefamilysupportnetwork.org)



- [LIFE-Fund-Critical-Services-for-People-with-Disabilities](#)



## LIFE – Living with Independence, Fairness and Equality / Fund Critical Services for People with Disabilities

Media Relations Report: April – June 2011

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Through media relations, MPAG crafted key messaging, developed and distributed media advisories and press releases and executed three press conferences. The first press conference was held at The Arc of Winnebago, Boone & Ogle Counties to announce the LIFE campaign and to expose the severity of the proposed budget cuts to community disability services and showed the economic impact specific to the Rockford area. The LIFE campaign showed that people with disabilities, their families and other stakeholders are united in preserving funding and programs to keep people with disabilities in their homes and home communities. The second press conference was held at the Illinois State Capitol to formally launch the statewide campaign and emphasized the critical need to fund disability services from a mother's perspective. The goal was to humanize the issue. We provided talking points and conducted media training to advocates and spokespeople to ensure that everyone stayed on message. We continuously leveraged MPAG's media relationships by informing and educating reporters and diligently pitching the LIFE campaign's story throughout the state. These efforts led to placements in the Chicago Tribune, Rockford Register Star, Peoria Journal Star, State Journal Register, Daily Herald and numerous interviews on TV and radio public affairs programs throughout Illinois. Reporters also learned of the "A Day in My Life" campaign which asked people to tell their story and how state funded disability services help them and how their life would change if those services were cut. People were asked to post a video, three minutes or less, on the LIFE Face- book home page. We received overwhelming response and many reporters liked the concept.

The third press event was in Chicago strategically timed to take place before the General Assembly was scheduled to adjourn and while final budget negotiations were taking place. This event was designed to engage stakeholders so in addition to targeting the press we asked people with disabilities, their families and disability advocates to attend the press conference/rally. We had more than 300-people attend the rally which was held at the James R. Thompson Center. Many families brought homemade signs that sent a strong message to lawmakers that cutting home based disability services was not an option. Tony Paulauski, The Arc of Illinois Executive Director, kicked off the press conference and was joined by service providers and a mother of a disabled son who has been on the waiting list for state services for more than a decade. At the conclusion of the event we delivered petitions with more than 8,000 to a senior staff member of Governor Quinn's Office.

MPAG organized a statewide editorial board tour including all major media markets while keeping a local perspective to engage interest by including a hometown advocate and providing impactful data specific to each community. This effort resulted in positive editorial reviews and a strong show of support for the LIFE campaign's mission and overall backing for people with disabilities and their families. In addition, we wrote and distributed a compelling op-ed on behalf of Tony Paulauski. As the op-ed was published we proactively encouraged advocates to respond by writing a letter to the editor supporting our position. We drafted a sample letter to the editor in an effort to boost participation. Successful placement from a wide variety of stakeholders in



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newspapers across the state helped raise awareness and really demonstrated a broad range of support and perspective. With the success of our media relations campaign, which focused on raising public awareness of the LIFE coalition and its mission, educating the general public on the unbalanced budget crisis in Illinois and reinforcing the need to support the coalition's budget plan, LIFE was able to effectively communicate with its target audiences through print, radio, television and online media. Additionally, MPAG monitored media coverage and coordinated a news-clip stream to The Arc of Illinois' website as well as posted articles to LIFE Facebook in order to keep participants informed of campaign news and progress.

As a result, we secured coverage in the following media outlets:

### Paper and Online

Chicago Tribune

Chicago Sun-times

Bloomington Pantograph

Champaign News-Gazette

Daily Herald

Peoria Journal Star

The Southtown Star

State Journal-Register

Dixon Telegraph

ABC Chicago Online

Sauk Valley

Rockford Register Star

The Times Weekly – Joliet

Trib Local – Deerfield

Sauk Valley – Dixon

Quincy Herald Whig

Lawndale Bilingual News

### Broadcast (Radio & Television)

WBBM News Radio 780 (Chicago), WNTA AM (Rockford), WREX-TV Channel 13 (Rockford) WQRF-FOX 39 (Rockford), WIFR-Channel 23 (Rockford), WTVO-Channel 17 (Rockford), Illinois Channel, ABC Channel 7 (Chicago), WEFT Champaign, WSIL TV (Southern Illinois)

We have it covered!



## Press Release – For Immediate Distribution

Contact: Jacki Neil Boss      The Arc of Winnebago, Boone & Ogle Counties  
 Ph: (815) 965-3455      1222 East State St.  
 Fax: (815) 965-3673      Rockford, IL 61104      [jackinb@arcwbo.org](mailto:jackinb@arcwbo.org)

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**Press Conference -Thursday, April 14<sup>th</sup> 10 am at The Arc, 1222 East State St,  
 The Arc of Illinois launches campaign for LIFE:**



Tony Paulauski, Executive Director of The Arc, Illinois will be in Rockford on Thursday to launch – **LIFE, Fund critical services for people with disabilities.** "Illinois budget cuts are devastating the community based service system counties like Winnebago, Boone and Ogle depend on, and forcing many agencies to close, leaving people with very significant disabilities out "on the curb", says Paulauski.

Illinois spends less than any other state to support citizens with intellectual and developmental disabilities to live in their home communities. The average cost to support one person living in the community is \$50,000 compared to \$192,000 per person in state institutions, and yet the proposed 2012 budget adds \$30 million to state institutions while cutting community services by \$76.3 million. An estimated 3,052 local community employees across the state will be laid off while this budget proposes an 8.25 % wage increase for state employees AND the hiring of 950 NEW state employees.

"People with intellectual/developmental disabilities and their families in our 3 Counties want to live in their own communities. Community agencies can provide the support they need and also provide employment for local people while costing tax payers much less than institutions. This proposed budget cut isn't good for anyone." Jacki Neil Boss, The Arc, Winnebago, Boone and Ogle Counties.

For more information contact Jacki Neil Boss, 815 965-3455 or visit [thearcofil.org](http://thearcofil.org) or stop by: **Open House from 5 to 6:30pm at The Arc office; 1222 East State Street in Rockford.**



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## FOR IMMEDIATE RELEASE

May 17, 2011

## CONTACT:

Kim Morreale

847-401-8564

[kim@morrealepag.com](mailto:kim@morrealepag.com)

Liz Brown

217-502-3703

[liz.brown@gmail.com](mailto:liz.brown@gmail.com)

## LIFE CAMPAIGN PRESS CONFERENCE

**What:** The LIFE campaign will hold a press conference in response to the proposed budget cuts affecting community based disability programs. Campaign leaders will discuss the impact proposed budget cuts will have on persons with disabilities and their families in addition to identify cost saving measures that can help to restore slated cuts to services. The group will also launch and discuss the "A Day in My Life" Facebook campaign and call on the public to join its petition drive.

**Who:** Tony Paulauski, Executive Director, The Arc of Illinois  
Springfield mother of a disabled child  
Chicago mother of a disabled child  
Advocates for maintaining funding for community based disability programs

**When:** Wednesday, May 16, 2011  
11:00am

**Where:** Blue Room (Illinois State Capitol)

**About LIFE:** The LIFE campaign supports the funding of individualized, comprehensive and integrated community based services for persons with disabilities. The LIFE campaign is part of the The Arc of Illinois that represents 220,000 infants, children and adults with intellectual and developmental disabilities and their families. For more information visit [www.thearcofil.org](http://www.thearcofil.org) and friend us on Facebook.



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### FOR IMMEDIATE RELEASE

May 24, 2011

### CONTACT:

Kim Morreale

847-401-8564

[kim@morrealepag.com](mailto:kim@morrealepag.com)

Michelle Arnold

312-623-6024

[Michelle@morrealepaga.com](mailto:Michelle@morrealepaga.com)

### **DISABLED COMMUNITY RALLIES OUTSIDE GOVERNOR'S OFFICE AGAINST PROPOSED BUDGET CUTS**

*Community Based Disability Service Reductions Are Disproportionate and  
Cut the Lifeline for Services for Thousands of Disabled Residents*

(Chicago, IL)- Hundreds of people with disabilities and their families are striking back at policy makers today at the proposed cuts to community based disability programs. Reductions in services that help the disabled population remain in their home communities could be cut by more than \$77 million and several critical programs are slated to be eliminated. Advocates for equitable funding for disability services that keep people in their home communities delivered petitions with more than 6,200 signatures to Governor Quinn, Senate President John Cullerton, Senate Minority Leader Christine Rodogno, House Speaker Michael Madigan and House Minority Leader Tom Cross today.

Advocates are worried that once the three budget proposals are reconciled the cuts will deepen. Governor Quinn along with the Illinois House and Senate have presented their own budgets with little coordination on how these reductions to community disability programs will truly impact the more than 220,000 children and adults living with disabilities and their families. The Governor's budget and the House budget will have the most severe impact by eliminating critical programs like the Family Assistance Program, UIC Family Clinic, UIC Assistive Technology Unit along with SIU Telemed, Dental, Epilepsy and Respite Grants. They reduce the Children's and Adults Home-Based Support Services allotment by 10% and cut rates for community services by six percent, making the state ineligible for the 50% federal match totaling \$31.15 million. The House budget cuts \$77.7 million from community disability programs.



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The Governor's budget appropriates \$30 million to state institutions and reduces community based services by \$76.3 million even though numerous studies prove community services are safer, more effective and efficient. It cost taxpayers \$192,000 for each person in an institutional setting compared to just \$50,000 for each person in home based care. Four people can be served in a community setting for every one person in an institution.

The Senate's proposed budget cuts all Medicaid services by three percent, reduces programs that help to keep children and adult's in their homes by 10% and cuts funding for vital grant programs by 50%.

Advocates warn that these cuts will deconstruct the already fragile disability system, leaving people with nowhere to turn, in some cases homeless, and forcing many service providers to close.

"Illinois ranks last in the nation in supporting people with disabilities in their home communities despite the fact that we have among the largest population," says Tony Paulauski, executive director of The Arc of Illinois. "Our programs are hanging by a thread and we have already absorbed more reductions to services than we can handle. It's time to bring balance to the system so people with disabilities aren't constantly living in fear- wondering how they are going to survive each time our policy makers threaten to take away their lifeline."

The Arc estimates that an estimated 3,052 direct care staff will have to be laid off because of the slated cuts. At the same time the budget calls for the hiring of 950 state employees and grants union employees an 8.25% wage increase.

"The budget has the wrong priorities and the process is flawed", says Regina Thurston of Chicago, the mother of a son with disabilities. "My son Jason has been on the state waiting list for disability services since 1998. My biggest fears are wondering what will happen to Jason when I am gone and losing our home because our policy makers chose to leave us behind."

The Thurston's along with 21,000 other people are stuck in the Prioritization of Urgency of Need for Services (PUNS) database, all waiting for state disability services.

The Arc of Illinois has identified ways for the state to better prioritize its spending, avoid cuts to critical disability services and bring desperately needed programs to the 21,000 people on the state's waiting list.

- Act on more than five studies, including the Blueprint for Illinois that call for the closing of state institutions. Immediately close four institutions and reinvest the savings into community programs.
- Use reasonable estimates for revenue projections- The House is using revenue projections \$1.1 billion below the Commission on Government Forecasting and Accountability (CGFA), a bipartisan agency with a proven track record of making accurate revenue projections. Using a reasonable average of CGFA's estimate of revenues will save critical disability programs.



- \$600 million can be made available if the State opts out of a new federal accelerate depreciation tax deduction for corporations. Passing such legislation does not place additional tax burdens on businesses. It simply maintains the status quo.
- Pay community providers on time. If necessary, restructure indebtedness in order to fulfill commitments to service providers.

For more information visit [thearcofil.org](http://thearcofil.org), friend us on Facebook or watch a video that tells the story of two families that have children with disabilities <http://www.youtube.com/watch?v=yD8nKaeHEcl>.

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## Rockford Register Star Editorial Board Meeting Agenda

**Thursday April 14, 2011**

**1:00pm**

**99 E. State Street**

**Rockford, IL 61104**

**815-987-1200**

### AGENDA

1. About The Arc
2. Governor's budget overview as it relates to disability services
3. 21,000 people in the waiting list
4. Types of services that will be cut
5. The impact these cuts will have on persons with disabilities and their families
6. Cost for institutions vs. community based services
7. State budget increases in new employees/raises



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## PRESS CONFERENCE

**WEDNESDAY MAY 18, 2011**

**10:00AM**

**ILLINOIS STATE CAPITOL BLUE ROOM**

## AGENDA

- I. **TONY PAULAUSKI, THE ARC OF ILLINOIS, EXECUTIVE DIRECTOR**
- II. **CHARLOTTE CRONIN, FAMILY SUPPORT NETWORK AND MOTHER OF A SON WITH DISABILITIES**
- III. **MISTY WHITE, PLEasant PLAINES, IL AND MOTHER OF A CHILD WITH DISABILITIES**



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## THE ARC OF ILLINOIS PRESS CONFERENCE / RALLY

**TUESDAY MAY 4, 2011**

**1:00AM**

**THOMPSON CENTER**

### Speakers

- I. Tony Paulauski, Executive Director, The Arc of Illinois**
- II. Donald Dew, President, Habilitative Systems, Inc.**
- III. Regina Thurston, 22-year old son Jason Thurston has been on the state's waiting list for disability services since 1998**
- IV. Jose Ovalle, Executive Director, Grupo SALTO**



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Dear Editor,

I am writing to you as *an advocate for community-based disability services* in response to Governor Quinn's proposed FY 2012 budget. The Governor's proposed budget has \$76.3 million in cuts for community-based disability services. These services are a lifeline for people with disabilities and their families. Community-based services allow people with disabilities to remain active, proud and productive members of our community.

The slated cuts will have devastating consequences to the more than 220,000 people with disabilities and their families who are frustrated, angry and scared because of the uncertainty that comes with not knowing how we will continue to care for people who have nowhere else to turn.

The numbers don't add up. The average cost for a person in a state institution is \$192,000 a year, while the cost of supporting an individual in a community-based home is \$50,000 per person. It doesn't make sense that the state is investing \$30 million in new state monies for state institutions even though numerous studies show that community-based programs provide a safer, healthier and more cost effective way of caring for people with disabilities.

The proposed budget has all the wrong priorities. Illinois will be turning away \$31.5 million dollars in the 50% federal funding match because of the 6% cut to all community-based Medicaid funded services. This will be the last straw for many providers who already struggle to provide quality services with inadequate reimbursement. The Children and Adult Home-Based Services Programs 10% cut directly affects families supporting their adolescent and adult children in their homes. Not to mention grant cuts that will eliminate critical programs such as Respite and Dental services among others. All while there are over 21,000 adults and children waiting for services in the PUNS database.

Illinois needs to do what makes sense. People with disabilities have the right to enjoy the same freedoms and responsibilities as all Illinoisans in the community of their choice.



## LIFE OP-ED May 2011

Published in The Chicago Tribune, Rockford Register Star, The Times Weekly – Joliet, Trib Local – Deerfield, Sauk Valley – Dixon, The News Gazette – Champaign, Quincy Herald Whig

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Illinois is planning devastating cuts to services for individuals with physical, developmental and intellectual disabilities. These cuts target our most vulnerable citizens and are being sold as a way to balance Illinois' estimated \$13 billion deficit. The truth is, these cuts are short sighted and will send us on a path of destruction.

Illinois ranks last in the nation for supporting citizens with disabilities in their home communities. Disability services that are the life line to more than 220,000 people with disabilities and their families have already experienced deep cuts and are hanging by a thread. In addition to funding reductions several critical programs are being eliminated and it's estimated that 3,052 direct care staff will be laid off as a result. At the same time the budget calls for the hiring of 950 state employees and grants union employees an 8.25% wage increase. The budget has the wrong priorities and the process is flawed.

### **There are currently three budget proposals on the table, The Governor's, House and Senate.**

The House's estimate of revenues is about \$2 billion lower than the Commission on Government Forecasting and Accountability (CGFA), a bipartisan agency with a proven track record of making accurate revenue projections. Using CGFA's reasonable estimate of revenues could save critical disability programs.

The Senate's proposed budget disproportionately impacts individuals with disabilities by prioritizing programs that do not maximize taxpayer dollars. The Autism Program is reduced by 25% and the Centers for Independent Living is cut by 36%.

The Governor's budget appropriates \$30 million to state institutions and cuts community based services by \$76.3 million even though numerous studies prove community services are safer, more effective and efficient. Four people can be served in a community setting for every one person in an institution. This is unconscionable.

Furthermore, the proposed budgets do nothing to address the backlog in payments owed to disability service providers. Some have been forced to shut their doors and others are on the brink of collapse because the state is six months behind in payments.

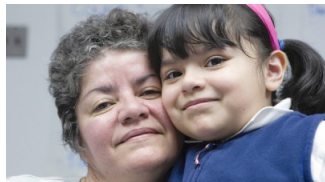
The disabled community can not withstand additional cuts. The budgets deepen the gap to accessible disability services and does nothing to address the 21,000 people in the Prioritization of Urgency of Need for Services (PUNS) database who are desperately waiting for state services.

Most people would agree that services to help people with disabilities live life with independence, equality and dignity are the kind of programs that are worthy of taxpayer funds. That is what our society was built on. It is what our founding fathers had in mind when developing the system of government. We must provide assistance to help those who truly and desperately need it. It's not a hand out it's common decency. Now it's up to our lawmakers to make the right choices.



# Chicago Tribune

Quinn's spending plan threatens lifeline for many struggling families - Clinics for people with disabilities could fall victim to cost cutting



Maria Limon's daughter Eileen, 9, has gotten help for her autism from a UIC clinic threatened by state budget cuts. (Alex Garcia/Tribune)

By Rex W. Huppke, Tribune reporter  
WQAD.Com 6:26 p.m. CDT, April 18, 2011

Chicago Tribune – April 19, 2011

About five years ago, Maria Limon brought her daughter to a clinic at the University of Illinois at **Chicago**. Eileen Limon has **autism** and, at the time, was nonverbal. Her mother couldn't afford the kind of therapy Eileen needed, but doctors at the publicly funded West Side clinic said they could help.

Now, at 9, Eileen speaks beautifully, is getting straight A's in third grade and has made progress her mother never dreamed possible.

"Without the clinic, she probably wouldn't even be talking," Maria Limon said. "She wouldn't have had much opportunity in life."

For two decades, the Developmental Disabilities Family Clinics at UIC have been serving low-income families in the Chicago area, but the future of this service is now in doubt. Nearly 90 percent of the clinics' funding comes from a \$1.2 million state grant, one that has been written out of **Gov. Pat Quinn's** current budget.

"This program came into being because the state said there was a need for it," said Linda Sandman, clinical director of the UIC clinics. "But it's small and, unfortunately, it becomes easy to eliminate these types of services."

As politicians at the state and federal levels wrestle with rising debt and a push for greater fiscal austerity, many social service programs like the UIC clinics find themselves in danger of being wiped out.

"They're on the governor's proposed budget to be eliminated — it gets no more serious than that," said Tony Paulauski, executive director of The Arc of Illinois, an advocacy group for people with developmental disabilities. "What's unique about the UIC clinic is it's one of the few resources available for a large number of minority children and adults in that area to get their specialized services."

But the role of social service operations like the family clinics must now be weighed against the sizable fiscal crisis Illinois is facing. It remains to be seen what value lawmakers will put on programs like this, but already in the federal budget deal reached by Democrats and **Republicans**, many services for the poor are being eliminated.

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In total, the proposed 2012 Illinois budget cuts \$76.3 million from community services for people with developmental disabilities, according to The Arc of Illinois. That includes defunding the UIC clinics and a program that provides respite care for parents of children with developmental disabilities, and slashing \$56 million from group homes, day centers and employment programs.

Advocates for people with intellectual or developmental disabilities have long asserted that early intervention — which requires a large front-end investment — saves taxpayers money in the long term, as it cuts down on the need for institutionalization. According to The Arc of Illinois, the average cost to support one person living in the community is \$50,000 per year compared with \$192,000 per year in one of the state's eight institutions.

"The data all show that early intervention has an impact, not just in terms of economy, but in terms of the person's quality of life," Sandman said. "People tend to think so short-term. It doesn't always make sense."

During the last fiscal year, the family clinics at UIC helped conduct initial evaluations on 855 clients and provided clinical and therapeutic services to 1,260 clients. Almost 90 percent of the families that use the clinics are either uninsured or on Medicaid or Medicare, and 70 percent come from minority populations.

"Where do these families go?" Paulauski said. "When there is no place to go, you get in the crisis mode. They show up at the emergency room and families start to look at institutionalization, and even that's limited. The families really have very few options."

The clinics offer bilingual services for Spanish-speaking families of children with disabilities, a rare service in the region. They also have the state's largest Hispanic autism support group, Grupo SALTO.

Limon, who lives in **Little Village** and speaks primarily Spanish, said the support group helped her immediate family better understand and help Eileen.

"Many people in my community don't really understand autism," she said. "But when they came to these sessions, then they understood what was happening with the child. You can find services in English, but for those who struggle with the language, this is the best place that can be found."

Also at UIC is a group called the Assistive Technology Unit, which travels across 12 northern Illinois counties helping people with motorized wheelchairs, communication devices for people who are unable to speak and an array of other services. About 70 percent of the unit's annual funding — \$567,405 — is set to be cut as well.

A mobile team from the technology unit was at a facility in Oak Park on a recent morning helping several clients, including Lakeshia Knight, a 24-year-old with **cerebral palsy** who relies on a computer attached to her wheelchair to communicate. With the help of physical and speech therapists, Knight has learned to manipulate her computer using head movements.

Through the device, she talked about her favorite television show — "Smallville" — and her love of horror movies. The team has worked with her for eight years and has been able to tailor the devices she relies on to her specific needs and environment.



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Jim Graham, a fabrication specialist who repairs and modifies many of the assistive-technology devices, said loss of funding would put many of the hundreds of clients the team works with in a difficult position.

"The most immediate impact would be a delay in getting services," he said. "But in addition, all the people we work with would have to find other ways of accessing or even transporting themselves to other services, which for our clients can be a tremendous obstacle."

That would be the case for Lorraine Phifer, 81, of Chicago, who cares for her 54-year-old son, William. He was born with cerebral palsy and has been helped by people from the technology unit since 1996. Just recently, members installed a lift in his room so his family can get him in and out of bed.

"I have a wheelchair van, but I can't get him in all by myself anymore, so the fact that they come out to the house is a lifesaver," Lorraine Phifer said. "I'm not sure what we'd do without them."



Bloomington Pantagraph, May 19, 2011

## Groups call for closing state facilities

By Kurt Erickson | [kurt.erickson@lee.net](mailto:kurt.erickson@lee.net) | Posted: Wednesday, May 18, 2011 11:45 am

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*The state has been successful in closing large institutions in the past. Lincoln Developmental Center (above), for example, was shuttered by former Gov. George Ryan in 2001. (Pantagraph file photo/Steve Smedley)*

SPRINGFIELD -- Disability advocates are again calling on lawmakers and Gov. Pat Quinn to shutter some of the state's institutions for the developmentally disabled as a way to help smaller group home operators survive possible budget cuts.

Faced with lengthy payment delays and threatened funding reductions, a coalition of community-based providers said Illinois could save \$170 million if it closed four of the state's eight institutions.

The group didn't identify any specific institutions to close, but they could include state-run facilities in Anna, Dwight, Dixon, Centralia and Kankakee.

In an appeal to lawmakers at a press conference in the Capitol, Tony Paulauski, executive director of the Arc of Illinois, said community-based group homes are more than three times cheaper to operate than the state facilities. Yet, institutions are getting additional money while private providers could see funding reductions in the budget year beginning July 1.

"We're concerned you're cutting too deep," Paulauski said.

The state has been successful in closing large institutions in the past. Lincoln Developmental Center, for example, was shuttered by former Gov. George Ryan in 2001. Howe Developmental Center was closed last year.

However, Quinn has signed an agreement with the state's largest employee union pledging to not close any state facilities. That agreement expires in July 2012.

The pact with the American Federation of State, County and Municipal Employees



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Council 31 also bars Quinn from laying off any union workers in exchange for the rank-and-file employees deferring their scheduled raises and taking voluntary furlough days.

Paulauski said the general outlines of a state budget plan could result in not-for-profit group home operators to close, hurting workers and the people they care for.

"We are not a line item," Paulauski said.

Some lawmakers agree that the state institutions should be closed.

State Rep. David Leitch, R-Peoria, called the facilities "dinosaurs."

"These should be closed as soon as possible," Leitch said.



## Lawndale Bilingual News, Thursday May 26, 2011

### Disabled Community Protests Budget Cuts



Hundreds of people with disabilities and their families protested policy makers at the proposed cuts to community based disability programs on Tuesday, May 24 at the James R. Thompson Center. Reductions in services that help the disabled population remain in their home communities could be cut by more than \$77 million and several critical programs are slated to be eliminated. Advocates delivered petitions with more than 6,200 signatures to Governor Quinn, Senate President John Cullerton, Senate Minority Leader Christine Rodogno, House Speaker Michael Madigan and House Minority Leader Tom Cross. Advocates are worried that once the three budget proposals are reconciled the cuts will deepen. Governor Quinn along with the Illinois House and Senate have presented their own budgets with little coordination on how these reductions to community disability programs will truly impact the more than 220,000 children and adults living with disabilities and their families. The Governor's budget and the House budget will have the most severe impact by eliminating critical programs like the Family Assistance Program, UIC Family Clinic, and UIC Assistive Technology Unit along with SIU Telemed, Dental, Epilepsy and Respite Grants. They reduce the Children's and Adults Home-Based Support Services allotment by 10 percent and cut rates for community services by six percent, making the state ineligible for the 50 percent federal match totaling \$31.15 million. The House budget cuts \$77.7 million from community disability programs. Advocates warn that these cuts will deconstruct the already fragile disability system, leaving people with nowhere to turn, in some cases homeless, and forcing many service providers to close. To read how advocates identified ways for the state to better prioritize its spending, visit [www.thearcofil.org](http://www.thearcofil.org).

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## Our View: People with disabilities deserve better from Illinois



### **RRSTAR.COM EDITORIAL**

Posted Apr 27, 2011 @ 05:53 PM

In the state's proposed budget, the cost to keep one person with disabilities in an institution will rise to \$192,000. And not one of the 21,000 children and adults will move off a waiting list for community services. The cost of care to support one person living in the community is just \$50,000 — or about one-quarter of the cost of institutional care. If it were a dollars-and-cents issue only, it would be bad enough. But view it in human terms: A person with disabilities should not live in an institution if he or she can function well in a community setting. **Illinois has its priorities** exactly backward, and the silence on the issue from the governor's office is deafening. Tony Paulauski spoke to the Editorial Board this month as executive director of The ARC of Illinois, an organization that represents 220,000 infants, children and adults with intellectual or developmental disabilities and their families. Paulauski explained that community-based services allow people with disabilities to be employed, perhaps bagging groceries, greeting shoppers, assembling products or working at a bakery. Community-based services provide the coaching and training for these individuals to get and keep jobs. They offer the hygiene, socialization and behavioral help for a person with disabilities to live well with others. In addition, people with disabilities can live among their family and friends — who wouldn't want that? Even so, the proposed state budget invests \$30 million in state institutions while cutting community services by \$76.3 million. **Is it any wonder** why Illinois is ranked 51st in the nation for supporting citizens in their communities? The ARC's Paulauski testified at a Senate Human Services appropriation hearing April 12 that Illinois has 840 caregivers 80 years of age and older whose adult children with disabilities remain on the waiting list for community-based services. It has 1,542 caregivers, 70 to 79 years old, waiting for the same. We fear they may die waiting, leaving their loved ones to be placed in institutions. It's a terrible legacy for our state — one that we don't have to tolerate

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## The Southtown Star

### Home care for disabled targeted for state cut

Phil Kadner pkadner@southtownstar.com | (708) 633-6787 May 2, 2011 11:06PM

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Let's cut government spending.

Get rid of all those lazy patronage workers.

Eliminate big wasteful contracts for campaign contributors.

Make government more efficient.

For years, I've been warning people that when the deep cuts finally come, the folks feeling the pinch are not going to be the ones with political clout.

Gov. Pat Quinn is using a red pen to trim millions from the state budget, which is in sorry shape. No doubt about that.

And among the programs on the chopping block is one that provides respite care for the families of the developmentally disabled. It's a program that pays for a caregiver to come into the home of someone with a mental disability so a parent can spend a few hours leading a normal life.

For a single mother, that could be enough time to allow her to hold down a job instead of staying home full-time or institutionalizing a child.

Or it could just mean a few hours each week so that parents with an autistic son can spend a little time with a daughter who otherwise would never get much attention.

It could just mean giving a parent enough time to do the dishes, do the grocery shopping or tend to any number of daily chores they wouldn't have time for because their developmentally disabled child requires constant attention, said Shirley Perez, a family advocate for The Arc of Illinois.

The Arc of Illinois represents the families of more than 200,000 infants, children and adults with developmental disabilities in Illinois.

Tony Paulauski, the agency's executive director, stopped by the SouthtownStar newspaper office with Perez and parent Regina Thurston to say that Illinois has its budget priorities "upside down."

The Illinois Department of Human Services is planning \$76 million in cuts to programs for the developmentally disabled. These cuts would impact agencies such as Blue Cap in Blue Island, St. Coletta's in Tinley Park and Park Lawn in Oak Lawn, just to mention a few.

"The employees at these places have had only three cost-of-living raises in the last 11 years," Paulauski said. "There's a six-month delay in state payments in money owed to them."

"In other words, these agencies have been taking budget cuts each year, and now the state wants to cut another 6 percent. If that happens, some of these places are going to be forced to close or cut their programs."

Paulauski said that means more developmentally disabled people will end up in institutions instead of living at home, which will cost the state more money. It also means that



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the 330 employees at St. Coletta's might be out of work and looking for jobs.

"About 8.5 percent of the state's entire work force is employed in non-profits, and if you keep cutting them that impacts the state's entire economy," he said. "It means fewer jobs. Less revenue for the state. It makes no sense."

Paulauski said the state's unionized labor force, in the meantime, is due for salary increases of 8.25 percent.

"Eliminate that wage increase, and you don't have to cut programs for the developmentally disabled," he said.

He also called for fewer state institutions for the developmentally disabled and relocating those clients to group homes.

"That would save the state millions of dollars as well and serve the client base better," Paulauski said.

If the state would just pay its bills on time, he said, some of these agencies that help the developmentally disabled could be saved because they wouldn't have to take out loans to keep operating.

Thurston said her son Jason, 22, has been on a state waiting list for disability services since 1998. There are about 21,000 people on the PUNS waiting list. PUNS stands for Prioritization of Urgency of Need for Service, and it is kind of a joke.

If you are developmentally disabled and need any sort of government service, you first have to get on the PUNS list.

There are people 60 years old on the PUNS list and still waiting. Their parents, who know their lifetime is nearing an end, wonder if their children are ever going to get the help they need.

Every not-for-profit organization and special interest group is trying to get the attention of the public these days as they face cuts due to the budget crisis in Illinois.

Most do good work. That's why the state, in its wisdom, decided to fund many of these programs in the first place.

But even with an income tax hike, Illinois is going to have to cut something.

If you thought waste, mismanagement and pay-for-play would be eliminated, you are wrong.

The mentally disabled, who can't fight back, are among those being targeted.

I am not surprised.



## Disabled would be hit hard by proposed cuts

By The Pantagraph Editorial Board | Posted: Sunday, May 15, 2011 7:00 am

Agencies that provide services for people with developmental disabilities have as good an argument as any — and better than some — for pushing back against proposed state budget cuts.

They have been dealing with spending reductions and delayed payments for years.

We have seen the impact of these budget decisions with the closing in 2009 of the Occupational Developmental Center in Bloomington-Normal that provided much-needed training and jobs for people with disabilities.

But many others are in that same situation in the state.

What makes this group different, noted Tony Paulauski, is it is offering a solution.

Paulauski, executive director of The Arc of Illinois, said his organization, which represents 60 agencies throughout Illinois that care for people with intellectual and development disabilities, is calling on the state to close four of the eight state-run institutions that serve the developmentally disabled.

The idea is to switch money from the closed state institutions to community-based facilities, which are less expensive to operate and which advocates have long said provide better, more personalized care than large institutions.

Most of the residents from the closed institutions would go to community facilities, although some could go to remaining state institutions, if that was deemed more appropriate.

In addition to the Fox Developmental Center in Dwight, the state operates developmental centers in Anna, Centralia, Dixon, Jacksonville, Kankakee, Park Forest and Waukegan.

We don't doubt that there are many dedicated, caring people working in those state facilities. However, the trend in recent years has been moving toward community-based settings — and Illinois lags far behind other states that have scaled back or eliminated state-run institutions for those with developmental disabilities.

It is important that any closing of facilities be done with adequate planning and consultation with the families involved, unlike what happened when the Lincoln Developmental Center was closed in 2002.

Paulauski said the average annual costs to care for a person in one of the state institutions is \$192,000 compared to \$50,000 in a community-based facility.

However, moving to close any state institutions would run into the ill-advised agreement Gov. Pat Quinn made last fall with the state's largest public employees' union not to lay off state employees or close any state facilities.

The question becomes whether that agreement is binding on the General Assembly.

This isn't something that is likely to be settled quickly. That means it might not provide the reallocation of money that Paulauski is seeking in this budget. But it is still a matter worthy of consideration — for financial as well as humanitarian reasons.

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# SJ-R.COM

The State Journal-Register • Springfield, IL • The Oldest Newspaper in Illinois

May 23, 2011

Our Opinion: State plan to help disabled is backward

Last fall, Gov. Pat Quinn negotiated a deal with the state's largest public employee union: In exchange for AFSCME members accepting \$70 million in health insurance concessions and working with the state to find up to \$50 million in additional savings, Quinn pledged no layoffs and no closures of state institutions through July 1, 2012. We were critical of this deal at the time for strictly financial and political reasons. "Quinn is asking us to trust him as he puts the state's most effective tool in bargaining for union concessions into storage for the next 22 months," we wrote. Today we're lamenting that pledge once again, though this time on purely human terms. Among those institutions that Quinn rendered closure-proof are eight state facilities — in Dwight, Anna, Centralia, Dixon, Jacksonville, Kankakee, Park Forest and Waukegan — that house people with developmental disabilities. For years, advocates for the developmentally disabled have tried, with very limited success, to persuade the state to move away from reliance on institutions and toward greater use of residential group homes and community programs for those with developmental disabilities. At the same time, programs that serve the developmentally disabled and their families have suffered through years of steady cuts to their budgets and long delays in payment from the state. These are organizations like Sparc in Springfield, which operates small group homes, runs programs that provide employment for the developmentally disabled and provides important services to families of children with disabilities. Quinn's budget proposal for fiscal 2012 proposes to cut \$76.3 million from these types of programs while increasing the budgets for state institutions by \$30 million. It's time for the state to realize that both financially and therapeutically, that formula is backward. Housing an individual in an institution costs about \$190,000 a year, or roughly four times the cost of living in a community setting, says Tony Paulauski, executive director of The Arc of Illinois, a consortium of roughly 60 agencies that serve the developmentally disabled and their families. Paulauski points to studies that show Illinois ranks fourth in the nation in the number of people housed in institutions and is 47th in the amount it spends on community services that keep people out of institutions and allow them to lead more productive lives. Paulauski is pushing a plan in which the state would close at least four of its institutions and move their funding into community programs. Residents from those institutions would be moved into group home settings, like those operated locally by Sparc. "We have a number of individuals in our programs who came from state institutions," says Carlissa Puckett, director of Sparc. "If they will just transfer the resources to where people really want to live, we can do it." Lawmakers need to listen to people like Paulauski and Puckett. Illinois must move out of the dark ages in treating its most vulnerable citizens. More importantly, they should listen to people like Charlotte Cronin of Peoria, whose adult son moved into a group home at age 18. "When you take people with disabilities and you cluster them in this huge setting where all they know is other people with disabilities and people who treat them like they're disabled," Cronin said, "they become far more disabled than they are or need to be."

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# Chicago Tribune

## Editorials, Unkindest cuts

May 23, 2011

Even with a tax increase, [Illinois](#) is broke, owes billions of dollars and needs to make deep budget cuts. Practically everyone who depends on the state will take a hit. There will be pain. By making smart cuts, however, the state can avoid unnecessary pain.

Unfortunately, [Gov. Pat Quinn](#) has targeted some of Illinois' most vulnerable citizens for his least sensible cuts.

Experts in the field calculate that in his proposed budget for 2012, Quinn whacks \$76.3 million from community services for the developmentally disabled: That includes people with [Down syndrome](#), [cerebral palsy](#), autism and other challenges. At the same time, Quinn directs \$30 million in additional spending to state institutions that serve far fewer residents at much higher costs. His budget similarly favors institutional care for mental health over a community-based approach. Along the way, he would forgo tens of millions in federal matching dollars.

How wrongheaded can you get? For decades now, other states have moved away from institutionalizing the developmentally disabled and mentally ill in government-run facilities — with great success. Care is better, and costs far lower. Indiana recently went in that direction, and the results have been positive.

Illinois institutionalizes far more people than most states. While the estimates vary, government-run facilities for the developmentally disabled cost as much as \$500 a day per resident. A community group home typically runs \$135 a day, with superior outcomes.

State legislators have pushed back on this issue. Sen. Heather Steans, D-Chicago, is among those who aim to reverse the direction of Quinn's budget by cutting funding for state-run centers and boosting it for community providers. "For many, many years, we've been behind on this," she noted. Budget cuts present an opportunity to bring Illinois up to 21st century standards.

Last fall, Quinn signed an astonishing agreement with the state's public labor union that promised no layoffs and no facility shutdowns through mid-2012. Quinn's reward: an immediate endorsement from the union for his re-election bid.

Governor, you made a bad promise you can't in good conscience keep. If you keep it, it will be at the expense of Illinois' most vulnerable citizens.

It's appalling to think of the political calculus that went into slashing dental care and home-based supports for the developmentally disabled while hiring hundreds of new state employees and handing pay hikes to the rest. Talk about skewed priorities.

Disability advocates say the state could save roughly \$170 million by closing four of its eight institutions. This needs to happen in a way that's least disruptive for the patients at these institutions. But it needs to happen.

That agreement by the governor — he signed it alone. The House and Senate members didn't sign it. They should agree on a budget that requires Illinois to live within its means and that funds the most *cost-effective* services in the state.

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And governor, if you're tempted to twirl a veto pen to preserve your labor deal — remember which citizens you'll harm.

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## Chicago Tribune - Voice of the People

*May 26, 2011*

The Tribune correctly argues that **Illinois** should move away from funding institutionalized **mental health** care and invest rather in more efficient and effective community-based services ("Unkindest Cuts," Tribune Editorial, May 23) and the budget plan offered by the Illinois House seeks more boldly to accomplish that goal.

While both the **Illinois Senate** and House budgets reduce the governor's proposed \$221 million budget for the state's five mental health institutions—which is \$18 million above last year's budget for those facilities --the House's proposal cuts institutional operations far deeper.

The Senate slices \$11 million from the governor's budget while the House cuts \$50 million, a difference of \$29.3 million. As a result, the House budget plan, which won bipartisan approval in the lower chamber, 83-25, plows more money into community care programs where the state can get more bang for its buck.

By providing community-based care instead of funding costly institutions, we can serve more people for far less money.

While both the House and Senate must reconcile their competing versions of the budget for mental health services, we are philosophically--and fortunately-- pursuing the same fiscal strategy to provide better care at lower costs. However, we should be as bold as possible in the pursuit of that goal and the governor should follow our lead.

-- *Rep. Sara Feigenholtz (D-Chicago) Chair, House Human Services Appropriations Committee*

## Chicago Tribune - Voice of the People

*June 2, 2011*

### Less humane

Thank you for your fantastic May 23 editorial "Unkindest cuts," which clearly highlighted the shameful fact that Illinois is still an "institutional" state when it comes to serving people with developmental and mental disabilities. This outmoded and even dangerous system of isolating people with disabilities in large congregate settings (out of sight/ out of mind) should go the way of orphanages. The whole nation is leaving Illinois in its dust in moving these residents into small, integrated community settings. Not only is that more humane but during these tough economic times makes much more sense, since the average cost to the state would be a third of what it is in the large facilities. We must stop pandering to the state employees' union by maintaining a system which just doesn't work.

— *Don Moss, executive director, United Cerebral Palsy of Illinois, [Springfield](#)*



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## Disabling the Disabled

*Commentary/Politics - Editorials*

WRITTEN BY KATHLEEN MCCARTHY

THURSDAY, 26 MAY 2011 05:35

From the beginning of the Social Security system in America, there was a clear mandate from taxpayers: Take care of our disabled, whether because of birth defect, illness, accident, or warfare. Americans have insisted, and been more than willing to fund, the care of our developmentally and intellectually disabled people.

Once again, however, Illinois' developmentally disabled community is taking an undeserved hit with \$76 million in cuts in the governor's proposed Fiscal Year 2012 budget that translates into \$540,000 in cuts for Rock Island County, alone. The \$76 million represents approximately 6 percent of a \$1.2-billion budget for services for 40,000 developmentally disabled individuals in Illinois, leaving a waiting list of 21,000 that includes adults, children, and infants.

Other sources of funding, such as grants from United Way and other not-for-profit organizations, work to fill some of the funding gaps, but these organizations are also struggling, resulting in less available resources each year.

Kyle Rick, executive director of the Arc of Rock Island County, explains: "This community of individuals, including the severely developmentally and intellectually disabled, through no fault of their own, needs the most support, but is least able to ask for it, or defend itself against any decrease in resources."

Across the state, calls are being made and letters and petitions are being sent to lobby Illinois legislators to recalculate the cuts to the developmentally disabled community, because cuts will mean job reductions and the loss of critical services that are often the only lifeline these individuals possess.

As Rick wrote in a letter to State Representative Patrick Verschoore: "From Fiscal Year 2002 through the proposed Fiscal Year 2012 [budget], an 11-year period, we will have had only three increases to keep up with inflation, four years with nothing, and four years of cuts. ... The cuts in Fiscal Year 2012 will be the most severe yet."

### Community Alternatives to State Institutions

The hopeful news is that the developmentally disabled services budget actually has viable alternatives to the proposed cuts if legislators would have the courage to act. Of the \$1.2-billion budget, \$300 million goes to eight state institutions that serve only 1,900 developmentally disabled individuals. The remaining \$900 million is allocated for the other 38,100 individuals cared for by community-based services. This is a highly disproportionate distribution of resources.

According to Living with Independence Fairness & Equality Coalition's "FAQ on Proposed Fiscal Year 2012 Budget," "community-based disability services support people with significant disabilities in the communities of their choice with family, on their



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own, or in residential settings in traditional neighborhoods, offering the opportunity to live full and vibrant lives that maximize independence and full inclusion." (TheArcOfIL.org/LegislativeToolkit)

The FAQ reminds us that community-based services help with everyday living tasks, such as bathing, dressing, and grooming; with medications and therapies; with developing skills for overcoming communication or behavioral challenges; with improving social skills; and with creating work opportunities. Another vital service is offering support and respite to caregivers of children and adults with disabilities, both in-home and in the community. Finally, long-term residential care is provided for the more severely disabled individuals, for whom around-the-clock care is required.

The Arc of Rock Island County has approximately 250 employees caring for disabled individuals through programs administered by Arc Industries, Heritage Fifty-Three, Respite Center, Opportunity Center, Arc Business Supply, and Moments Remembered, to name a few of the vital organizations that serve developmentally disabled individuals in the Quad Cities.

Evaluations of the Illinois developmental-disability system have consistently revealed that individuals being served through community-based services (including long-term residential care) have demonstrably better outcomes in safety and health. State institutions tend to be archaic, less accountable, inefficient, in need of repair, and technologically deficient. Eleven states have closed such facilities in favor of the more cost-effective community-based-services model.

"There is nothing magic about the state institutions," says Tony Paulauski, executive director of the Arc of Illinois. "More and more counties, including Rock Island County, have already closed their state institutions and transferred the severely disabled individuals traditionally cared for in state institutions to community-based residential-care facilities, where they are more than equipped to cope with the level of care required."

In Illinois, seven out of eight institutions were cited with violations – most of which dealt with a lack of proper record-keeping and documentation – during the Auditor General's last report digest (covering 2007 through 2009), which is a limited-scope review of their operations and books. (Auditor.Illinois.gov/Audit-Reports/ABC-List.asp)

In the case of Illinois' 2012 proposed budget, state institutions will require an additional \$30-million funding infusion, the lion's share of which is allocated to wages and pensions for employees of these facilities. Meanwhile, cutting the budget by \$76 million for community-based services will result in the loss of federal matching funds of \$31 million.

To better illustrate, the average annual cost of caring for an individual in state institutions is \$192,000. The average annual cost of caring for an individual via community services, including residential care, is \$50,000. Nearly four individuals can be served with community-based services for every one person in an institution.

With the cost/benefit analysis so clearly weighted in favor of community-based services, what is keeping legislators from making the conversion away from state institutions? The answer lies in jobs, and the reluctance of the American Federation of State, County, & Municipal Employees (AFSCME) to allow those jobs to migrate away. State institutions pay significantly higher wages than community-based services for the same jobs – on average \$53,000 to \$28,000.



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Community-based-service organizations are mostly private-sector groups that contract with the state to provide care for the developmentally and intellectually disabled; therefore only half of their employees are AFSCME members.

AFSCME is in a difficult situation in this particular case because, while it's fighting to keep public-sector wage and benefit packages at current levels that include annual raises, some of its members' jobs in the community-based-services sector will be sacrificed for AFSCME's greater good.

### Disposable Disabled

Illinois' proposed budget is calling for 950 new jobs throughout state government – averaging \$50,000 in salary and benefits and costing approximately \$47.5 million overall – as well as an 8.25-percent raise for the current state workforce staggered over 18 months, according to Paulauski.

Meanwhile, 3,052 jobs in the community-services sector are in jeopardy, as are critical services for our disabled community that those jobs provide. "Last year's cut of \$16 million negatively impacted services for approximately 15,000 individuals because of loss of services due to program shut-downs," Paulauski says.

Clearly, the Illinois legislature needs to better sort out its priorities. It is one thing to have to make necessary cuts because there are no alternatives. It is entirely another thing when those cuts greatly benefit one segment of society at the hugely disproportionate expense of another segment, especially a segment that has zero other options for care and survival. Legislators are sending the message that our disabled are disposable – a message that should be met with statewide resistance, including by AFSCME members, who are 90 percent of Illinois' public-sector workforce.

Because of a deal Governor Pat Quinn made with AFSCME last year – which does not allow for any layoffs of state employees – hands are tied within many agencies because they have no control over their labor costs. With contractual raises to account for, operational cuts loom large. A major concern is that the proposed budget cuts will cause community-based-services programs to shut down, creating a network of employees with nothing to do because the programs they were hired for will be gone.

By closing or downsizing the number of state institutions, their funding – including for labor and facilities – could be absorbed into community services, creating enormous savings. The savings could then be reallocated to far more efficient, successful programming that would keep services for the current 40,000 individuals, cover the 21,000 on waiting lists (Rock Island County has an active waiting list of 155 individuals), and perhaps begin to address the 180,000 additional developmentally disabled individuals in Illinois who receive no services whatsoever.

"The State of the States' Developmentally Disabled," a 2008 report by the University of Colorado that was released to providers in 2010, rated Illinois 51st among states and the District of Columbia relative to its care. More cuts will only aggravate this dismal rating. Implementing a planned reduction of half of the state institutions would be a start. Freezing any new hires for the facilities beginning in 2012, and other cost-saving measures that focus on this goal of transferring services, could alleviate some of the pressure on the community-services budgets.



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Frustrating the 2012 budget process this time around is the sizable discrepancy between House and Senate revenue projections – \$33.2 billion and \$34.3 billion, respectively. They are more than \$1 billion apart, causing cuts to be deeper for the House's budget because its revenue projection is lower.

The Commission on Government Forecasting & Accountability, a bipartisan body established specifically for the purpose of revenue projection, estimates revenues for Illinois in 2012 at \$34.9 billion, which includes a portion of the new income-tax increase (from 3 to 5 percent), as well as \$720 million from two plans not yet approved by legislators – one that would cut state corporate-income-tax refunds and another that splits state tax practices from a federal tax plan. As such, only the governor's budget is using that figure. Because the House and the Senate have derived their own projections, negotiations are more convoluted.

Regardless, the community-based-services budget cuts have a remedy – one that requires moral as well as fiscal determination to accommodate the most vulnerable segment of our society. There is no worthy argument for greatly diminishing the quality of life for our disabled individuals.

Paulauski has been working tirelessly for months to convince legislators to reconsider the community-based-services budget before the May 31 deadline to pass a state budget with a mere majority of both chambers. "This is an upside-down budget," he admonishes. "It kicks families in the shins; it's devastating to the children and adults who are intellectually and developmentally disabled. We are supposed to take care of these people first. Everything else is secondary."

Visit [TheArcOfIL.org](http://TheArcOfIL.org) for more information, including examples of letters and fact sheets for distribution to family, friends, and neighbors, to support and help Arc convince legislators to reverse the proposed cuts and restore the vital funding to Illinois' 2012 community-based-services budget. Let's enable – not disable – the disabled, who are counting on us to protect them.



## Peoria Journal Star

### Our View: Illinois budget needs balance in how it treats most vulnerable

Posted May 26, 2011 @ 11:29 PM

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Of all the budget cutting going on in Springfield, perhaps the most lamentable has been to programs serving the developmentally disabled and their families. These are among the most fragile people in Illinois, often with almost nowhere else to turn. Anybody who flippantly endorses cuts in those areas simply has not walked in those shoes.

Nonetheless, these are financially desperate times in state government, so programs that provide even very critical, life-saving services have been forced to accept austerity measures. We have long endorsed shared pain on the budget-cutting front on the premise that tough decisions now are necessary to avoid a meltdown later. What makes no sense, however, is why in the worst budget situation in memory, state government would actually hike funding for programs that research has shown provide less bang for the buck and may do their clients less good over the long haul.

That seems to be what's happening in the fight for limited funds between community-based social service programs such as those offered by Peoria's PARC and state-run institutions for the disabled, of which there are eight spread across Illinois. If the governor's proposed budget would cut millions from the former - already hit harder than most over the last couple of decades, while having to wait forever for payment for services they've already provided - it would throw more dollars at the latter.

There are reasons for this, few of them justifiable. Politically, the voice of these community-based programs and those they serve isn't as loud as others. To those not directly impacted by a disabled family member, these are invisible people. They don't have a powerful union like AFSCME to go to bat for them.

We appreciate that Gov. Quinn made a promise to AFSCME that he wouldn't support any layoffs or closure of any institutions where its members work through July 1, 2012 - in return for budget concessions, to be sure, but also for arguably his own political benefit during a hotly contested election campaign last year. We condemned that at the time. We don't blame AFSCME for looking out for AFSCME members; we do fault any political leader who would sell out another, very vulnerable constituency in making that deal.

We're accustomed to Illinois not being on the cutting edge of anything, but at some point state government has to get smarter about how it delivers services. If the trend nationwide has been toward community-based residential programs for the disabled that arguably do a better job of providing the same services at a fraction of the cost, Illinois ranks near the top nationally in the number of people institutionalized - at a reported \$190,000 per individual annually - while sitting near the bottom in its spending on community services that keep folks out of those institutions. There may always be a need for some larger facilities to house those few who cannot be accommodated elsewhere, but Illinois is way out of balance here.

And when that institutional care comes at the expense of some really important local programs - like respite care for stressed, exhausted families who just need a break every now and again and a clear conscience in knowing their kids are in a safe



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environment, like group homes that have waiting lists to get in - it's regrettable and then some. Families in these situations need resources close to home, not half a state away for their loved ones, for whom it's especially unhealthy to be uprooted: "Everything they know has changed," said Charlotte Cronin, director of The Family Support Network based here in Peoria and herself the mother of a severely disabled young adult son. "Can you think of a hell bigger than that?"

From where we sit, the priorities here are upside down. This fails the fairness test. In the few days left in this legislative session, we hope the Legislature can correct this imbalance, and begin bringing social service delivery in Illinois into the 21st century.



## Chicago Sun-Times

### Editorial: Finally, disabled can choose where to live

Editorials June 14, 2011 7:36PM

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Most states recognized a long time ago that people with developmental disabilities are just like the rest of us.

They want to work. They want to choose where they live and with whom. And they don't want to be cut off from the rest of society.

States that have seen the light have moved away from warehousing people with disabilities in large, residential facilities in favor of placing them in smaller, community-based settings.

Illinois, though, continues to rely heavily on institutional care for the disabled and the mentally ill, spending less per capita on community-based services than just about any other state.

We're pleased, then, by the terms of a proposed settlement to a federal lawsuit that will force the state to do right by thousands of its disabled residents.

The settlement, expected to be approved today by a federal judge, would change the way the state pays for the care of adults with developmental disabilities.

Instead of allocating funds to large private facilities, the state would adopt a "money follows the person" model that will make it easier for people to choose where they live.

The agreement was reached in response to a class-action lawsuit filed in 2005 by people with disabilities who were denied requests to live in community settings.

What we like about this settlement is that it doesn't force people who want to remain in institutions to move out. It simply makes it easier for the vast majority of people who would rather live in a smaller setting to do so.

Not only is providing community-based housing the right thing to do, it's also cheaper. The Arc of Illinois estimates that it costs \$192,000 a year to house someone in an institution, compared to \$55,000 in a smaller setting.

For a state looking to cut costs wherever it can, spending less on expensive institutional care is imperative.

Of course, that's easier said than done. Over the past decade, state funding for community-based services for the disabled has not kept pace with demand.

Already, there are about 21,000 people statewide who have been waiting, sometimes as long as a decade, to receive services.

Having to resolve these complicated issues within the six-year time frame set by the court won't be easy. But it's absolutely necessary.

**WSIL-TV 3 ABC****TOP STORIES**

Site Last updated 10:18 pm CT May 19, 2011.

**Mental Health Budget Debate***Posted: Wednesday, May 18th*

WSIL-- Illinois lawmakers are trying to trim billions of dollars in spending. Some fear state budget cuts could lead to the closing of mental health centers like the one in Anna.

A bill that passed last week would slash funding for state-run centers like Choate Mental Health in Anna by 25%. Funding for community-run agencies would be cut by up to 6%.

Now it seems the threat of cuts has turned service providers against one another.

Today Arc, a group that represents those with developmental disabilities, tried to convince legislators to close at least four state-run mental health facilities. They say the \$180 million in savings should go to group homes instead.

"We're your neighbors, we're your friends, we need some support...We have a solution for our situation. The state needs to close four of those state institutions," says Illinois ARC Director Tony Paulauski

Suggesting funding for people with mental disabilities be shifted from large state

[http://www.wsiltv.com/p/news\\_details.php?newsID=13171&type=top](http://www.wsiltv.com/p/news_details.php?newsID=13171&type=top) **Page 1 of 2**

Suggesting funding for people with mental disabilities be shifted from large state run facilities, like Choate Mental Health in Anna, to smaller, privately run group homes.

Rita Burke President of Friends of Choate is horrified.

"You could call it soul-less. Where are these people to go? Almost every person who is in a state operated center has been somewhere else first," says Burke.

Burke is not only an advocate for state-run disability centers, she's a mother of a patient.

"His brain is injured. He doesn't have an off button," she says.

Burke says her family moved from Georgia to southern Illinois just so her son could access Choate.

While it's not certain Choate would be one of the centers to close, she says any sort of budget cuts there are cruel.

"I don't think most people would say, lets target the most severely disabled people, people who cannot be served anywhere else but in the state operated disability center," she says.

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Burke says community based centers don't have to serve everyone-- especially if it's too costly to provide one-on-one attention.

"My son has been expelled from several community or private settings," she says.

But some lawmakers are siding with Arc-- saying state run centers are inefficient and outdated.

"For a long time the states systems for helping the developmentally disabled and the mentally ill have been at the mercy of large dinosaurs," says State Rep. David Leitch, R-Peoria.

Burke is headed to Springfield to try to influence legislators. While the General Assembly approved the cuts, it's part of an ongoing budget process, so details could still change. No action has been taken on the Arc group's suggestion to close state-run mental health facilities.

By: Christen Craig [ccraig@wsiltv.com](mailto:ccraig@wsiltv.com)

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