

# Family Support Network

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## Let's Do Together What We Can't Do Alone!

Hello Family Support Network Family and Friends,

Thank you for your faithful support! Together we've experienced another year with its unique opportunities and challenges. This year we have been fighting hard for the extension of the state income tax! Unfortunately, both the House and the Senate passed a budget plan that doesn't include the necessary income to balance the state's budget. For example, \$101 million was borrowed from state funds to meet community services expenses for the Division of Developmental Disabilities (DDD). This represents 18% of the DDD budget.

So, fellow advocates, this means our work is far from done. Over the summer and into the fall, we need you to meet with your legislators in their home offices and encourage them to:

- Support the income tax extension
- Continue rebalancing the disability system
- Support the Care Campaign efforts to increase Direct Support Professional wages by \$1.00 per hour



FSN, Arc, Family to Family, Illinois Life Span and Ligas Family Advocate staff

Your Family Support Network (FSN) will continue to educate policymakers, legislators, congregations, and families about the issues that are relevant to the disability community. We are grateful for our partnership with The Third Baptist Church of Chicago. They allow us to utilize their Heritage Plaza Banquet facility as a meeting place for our annual Informational seminar. This partnership allows us to bring training and information to an under-served community. We are also grateful for the championship of our very own Representative Thaddeus Jones, who represents FSN's home district. Above all, we are grateful for your ongoing active involvement. As always, FSN will continue to advocate for those much needed services and supports that allow children and adults with disabilities to remain in their own homes with their own families and friends or to choose just the right home in the



Rep. Thaddeus Jones with Arc, FSN, LFAs and Sam, self-advocate in the Capitol

community. But we need your help. Please make that appointment today to meet with your legislator!

If you are not a member of the Family Support Network, please join today. For information on how to become a member visit our website at [www.familysupportnetwork.org](http://www.familysupportnetwork.org). You make our advocacy family strong.

Sincerely,

Shirley A. Perez  
Executive Director, Family Support Network of Illinois

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# Ligas Consent Decree Reaches Three Years of Implementation



Tony Records

The *Ligas* Consent Decree was ordered by the Court on June 15, 2011. The Decree calls for the infusion of significant new resources for community-based services and provides for

thousands of class members and their families to have choices of how and where services will be provided. The Decree also calls for people with developmental disabilities (class members) who live in privately-operated ICF/DD facilities to receive funding to transition to community-based services if they choose to do so.

Since the signing of the Decree, more than 1,600 people with developmental disabilities who were on the PUNS waiting list are now receiving community services and supports funded through the Illinois Medicaid Home and Community-based waiver. Families have often rejoiced when they received the "Ligas Letter" which indicates that their loved one was chosen to receive funding for services. Some people who

were chosen for services have been waiting for over ten years. A large majority of the people who were selected to receive funding have chosen the home-based option, thus electing to stay living with their families and receiving ongoing supports. In addition to the class members coming off of the waiting list, more than 600 people who once lived in an ICF/DD facility have since transitioned to community-based services and are now living their lives in a new home they chose.

All class members who move are entitled to a written *Ligas Service Transition Plan*. This person-centered document is now used for any *Ligas* class member who is selected for funding for community-based services and who moves from one location to another. To learn more about this planning process see the Illinois DDD website.

The Council on Quality and Leadership (CQL) is fully implementing activities for people in ICFs/DD to help families and potential class members who have not yet made a choice learn about their options about how and where services can be provided.

More than two hundred guardians of potential class members have been initially contacted to determine their interest in community options.

Some families of individuals who have been chosen for funding under *Ligas* have continued to express frustration with the limitations and lack of flexibility in the home and community-based waiver, particularly as it applies to smaller residential options as well as options for employment related day supports. DDD, in conjunction with the *Ligas* Monitor has formed a Class Member and family Advisory Council to learn more about the experiences for families in the *Ligas* process and respond to their concerns. Two members of the *Ligas* council are *Ligas* Family advocates.

The FSN/Arc *Ligas* Family Advocate program is up and running – sharing information with families about options and creative ways to use their funding. Comments or complaints about your experience with the *Ligas* process and services or to find out if you are a *Ligas* class member should be directed to Troy Markert at DDD. He can be reached at 217-785-6171 and [troy.markert@illinois.gov](mailto:troy.markert@illinois.gov).

## Ligas Family Advocate



Missy Kichline

My name is Missy Kichline. My family lives in Godfrey along the Mississippi River. My husband, Brian, and I have raised three delightful, young women; Leigh-Ellen who is 25 and living in China, Samantha (Sam) who is 23 and living at home with an active life and Grace who is 21 and attending school in Carbondale.

What drives my passion for being a *Ligas* Family Advocate at the heart is my daughter Sam. Sam is a Red Cross blood donor and proud of it! She volunteers at two local agencies, attends a program at a local community college, enjoys going to movies, plays, swimming, restaurants and being with her boyfriend and friends. She uses public transportation and para-transit services.

Sam has Down Syndrome. Down Syndrome is different for everyone who has it. For Sam, it

means she needs daily living assistance in many aspects of life; from finding employment opportunities to personal grooming activities such as cutting finger nails.

We completed the paperwork for the Home-Based Support Services the first year the program became a Medicaid Waiver Program for adults with developmental disabilities. We then waited for roughly eight years along with 20,000 some odd other individuals for services.

The *Ligas* settlement provides the opportunity for individuals to secure and create meaningful lives in community. My excitement is driven by the opportunities this landmark settlement provides. I look forward to sharing and working with other individuals and families on this same journey.

# Ligas Family Advocate Program



FSN/Arc Ligas Family Advocates are working with the State of Illinois to ensure that information about all available options for services reaches consumers and their families, according to the requirements of the Consent Decree. This program will initially focus on Ligas class members within the areas served by three Independent Service Coordination agencies: Community Service Options Inc., Developmental Disabilities Services Metro East and Suburban Access. Our advocates will work closely with a designated representative from within each of these agencies, sharing information with families. Two of these agencies serve the greater Chicago area and the third serves the St. Louis metropolitan area. This targeted area will provide broad experience for the program and the opportunity to develop and employ necessary materials and protocols. We anticipate expanding this program statewide as soon as possible!

The Ligas Family Advocate Program has one purpose – to connect recipients of Ligas award letters seeking Home Based or CILA services and their families with family advocates who are knowledgeable about creative ways to utilize their Ligas funding to build successful lives in the community. Ligas family advocates will work to provide information to award letter recipients and their families about options. A primary goal of the program is to connect families with other families so they can share their unique perspective as stakeholders in the system. It is equally important to provide consistent information across the state early enough in the planning stage that award letter recipients and their families have a chance to consider choices that may be outside what is already familiar to them.

During outreach activities with class members, guardians and supporters, FSN/Arc staff will provide information about the Ligas Consent Decree, the rights of class members, and information about choices for living and receiving services. Staff will share the history of and current parameters for the Home-Based Support Services Program and Community Integrated Living Arrangement (CILA); information on Illinois' Employment First legislation and resources for employment assistance; effective advocacy strategies and resources; potential questions for use in choosing a service provider; and person-centered planning and self-determination information/resources. Information will be shared through presentations, brochures and documentation.

In addition, advocates will collect data that identifies: services needed but unavailable, observed trends, barriers to employment, barriers to successful development and implementation of an individual's service plan, level of consumer/family satisfaction with the Home-Based Support Services Program or CILA as implemented, descriptions of successful strategies used to reach individuals/families, barriers encountered in attempting to connect with the selected Ligas class members. The end result of this data collection will be the ability to provide program data summaries and recommendations to both the Ligas Court Monitor and the Illinois Department of Human Services that will ultimately result in positive systemic change.

If you are interested in learning more about the Ligas Family Advocate Program you can contact FSN at 708-331-7370 or email [Shirley@familysupportnetwork.org](mailto:Shirley@familysupportnetwork.org). You will be connected with a Ligas Family Advocate in your area.

## Ligas Family Advocate



Toni Howard

My son Kevin currently resides in an ICF-DD. His father and I would like for him to live in a smaller setting, preferably a CILA. Kevin was diagnosed as having Autism when he was approximately two years old. This was over twenty-five years ago when Autism was relatively unheard of. I was familiar with Autism because I had studied it briefly during my Graduate studies in Special Education. My son's diagnosis and lack of support changed me from being a quiet and rather passive mother into someone who had to become aggressive

about securing my son's future. My goal then is the same as it is now to make sure that Kevin lives a life that encourages him and others to reach their full potential.

I am currently serving on the LIGAS Class Member/Family Advisory Council. I hope that in my position of Family Advocate that I can share information about options with other class members and their families that will ultimately lead to a better quality of life for our love ones!

## Ligas Family Advocate



Kimberly Johnson-Evans

Hello Everyone,

My beautiful family which includes my two sons and my husband reside in the South Suburbs of Chicago. My son, William (age 20) was diagnosed with Persuasive Development Disorder (PDD), Speech Delay, and Autism Spectrum Disorder (ASD) at the age of six. In the early 90's, resources and services for children with Autism were extremely limited, especially in my area. I was determined that our son would live up to his full potential and that is when the seed was planted for me to become my child's voice and advocate. William currently attends Lincoln College in Lincoln, Illinois where he lives on campus with a school sponsored support program called "ACCESS."

During my journey I realized that many other families in my area were impacted by ASD with no information and no idea where to get help. I continued my advocacy as a volunteer parent advocate with Chicagoland Autism Connection

(formerly Chicago Southside) Support Group providing families with information and resources to help support their family members. Several years ago, I implemented the "A Team" Social and Recreation Club for teens and young adults with ASD to encourage social interaction with peers through planned outings and life skills workshops.

I am excited and look forward to working as a LIGAS Family Support Advocate to continue to bring families together and provide them with information. Working with LIGAS Class members will allow me to continue my outreach as a professional advocate for a program that I am truly passionate about. It is important

*"We are each other's harvest; we are each other's business; we are each other's magnitude and bond."*

— Gwendolyn Brooks

to me that every person who has an intellectual or developmental disability is able to build a successful life within their own community and reach their full potential.

Sincerely,  
Kimberly L. Johnson-Evans

## Photo Highlights

Family Support Network Informational Seminar March 27, 2014  
Held at the Heritage Plaza Banquet Facility, Chicago, IL



Shirley Perez and Michael Hurt



Shirley Perez and David Ogunbode



Kimberly J. Evans and the Butler family



Brian, President of the Arc Board, Kimberly Johnson Evans, LFA and Shirley Perez, Executive Director FSN

**SAVE THE DATE:**  
**March 26, 2015**  
**for FSN's Third Informational Seminar**

# Someone You Should Know

Illinois Life Span Director, Deb Fornoff



Deb Fornoff

Illinois Life Span (ILS) is often referred to as the “411” for disability information. When individuals with intellectual /developmental disabilities, their family members, or professionals are in need of information or resources to assist someone with a disability, they think first of the Illinois Life Span website at [www.illinoislifespan.org](http://www.illinoislifespan.org) or call an ILS Resource Specialist at 1-800-588-7002.

The Illinois Life Span website provides information on advocacy, services, and supports through an extensive database of providers. This database, searchable by Service Type, Provider Type, Agency Name, and county (or counties) helps website users locate resources for specific service and support needs.

The ILS website provides much more than the provider database, however. An Event Calendar provides information on upcoming trainings, conferences, workshops and other activities that may be of interest to individuals with disabilities and their families statewide. Organizations that would like to share information about upcoming events can contact ILS or share that information through the “Suggest an Event” feature on the website. An extensive Website Links section and an Advocacy Toolbox are also available to assist

ILS website visitors. ILS staff members provide outreach at events and resource fairs statewide to share information and assist families. ILS also offers support in Spanish to individuals/families in need of that assistance.

The Illinois Life Span program is staffed by Lydia Galan, Latino Outreach Coordinator; Cindi Swanson, Resource Specialist; and Deb Fornoff, Program Director. Deb has worked for the Illinois Life Span Program for over ten years as a Resource Specialist and as Program Director since November, 2013.

Deb and her husband have two children and live in Washington. Their younger son, Brad, has Down syndrome and has been the inspiration and motivation for Deb’s involvement in advocacy, information, and support for other families. Deb has an MS in Education, Counselor Education, and her experience includes working for The Arc of Illinois Family to Family Health Information Center, Family Support Network, and as a Parent Liaison in Early Intervention.

You can reach Deb by e-mail at [deb@illinoislifespan.org](mailto:deb@illinoislifespan.org). Please mark the Illinois Life Span website at [www.illinoislifespan.org](http://www.illinoislifespan.org) as a favorite!

## The Arc of Illinois President Award

**Congratulations, Dr. Sheila Romano!**

The President’s Award is not given every year- only when the Arc Board President feels someone should be recognized for outstanding contributions on behalf of individuals with intellectual/developmental disabilities. Dr. Romano was chosen to honor the leadership she demonstrates in including individuals ID/DD in their communities and advocating for supports that give them richer and fuller lives.



Arc President Brian Rubin, Sheila, Michael Gelder, Governor’s Office and Tony Paulauski

Here is what Brian Rubin, President of the Board of The Arc of Illinois said about Sheila. “Over the past fifteen years of her Directorship, she has been an outstanding advocate within the administration, throughout all of Illinois and nationally. She is very passionate about self-advocacy, community living and employment for people with intellectual and developmental disabilities.”



**REMINDER: The date for Speak Up Speak Out is November 4-5, 2014. Registration will begin on the evening of November 3, 2014. Stay tuned for more information.**

## Family Transition Project Update



Katherine Hamann

In the whirl of meetings, events, presentations, conferences, and legislative outreach, my sister Margaret remains my true compass for the work the Family Transition Project is charged to do. All of these other things are important, but Margaret reminds me that there is always hope that a person with intellectual and developmental disabilities can lead a fulfilling life in the community. After 63 years in state operated developmental centers, Margaret moved to a CILA home and she is embarking on her 7th year there. All families will understand this – I still pinch myself every time I visit and wonder if this is really my sister’s life now.

The other day Margaret heard me at the front door, greeted me with a big smile on her face and leaned in for a hug. She is a person who used to be in a constant angry turmoil, pacing and humming loudly, unable to relax, unable to communicate what was troubling her. She is still profoundly disabled. She doesn’t talk or sign. She still has physical and emotional scars from her difficult life. But she is understood, known and valued by her staff and housemates. She seems comfortable in her home and in herself. The FTP’s main goal is unchanging - to share success stories like these with other families and help them negotiate the transition from institutional to community living with the best possible results for everyone involved.

This can mean listening supportively, advocating, sharing information, or simply putting a family in touch with someone who can help. One new way to learn about the Family Transition Project is via the State of Illinois website. Under the

Department of Human Services there is a section about ACCT (Active Community Care Transition) and this includes a page about the FTP. The direct link is [www.dhs.state.il.us/page.aspx?item=65826](http://www.dhs.state.il.us/page.aspx?item=65826).

The Family Transition Project is still closely involved with The Going Home/A Full Life in the Community Coalition. Success stories and lots of information about rebalancing, community transitions, and the FTP specifically is available on [www.goinghomeillinois.org](http://www.goinghomeillinois.org) and the Going Home Illinois Facebook page.

In the last year, the Going Home Coalition and FTP have increased involvement with state legislators. This includes a campaign to encourage legislators to visit CILA homes and learn about community living for everyone. Senator Dan Kotowski and Representative Marty Moylan made a highly successful visit to an Avenues to Independence home in Des Plaines and met the men who live there. We hope this will be the first of many visits. A number of others are in the works.

Communicating with families whose loved ones live at the Warren G. Murray Developmental Center in Centralia has been a priority for the last couple of years, since it is scheduled to close. Lawsuits and politics have complicated our outreach, but we still have heard from Murray families and have learned of some outstandingly successful transitions. We are also reaching out to families at the other state operated developmental centers. Over 150 people at these other SODCs are looking at moving to homes in the community in the near future. The FTP is working with the Department of Human Services to host provider expositions at all of the SODCs in the next year – a great way to connect with families!

Teamwork is vital to what we do and this has been another year of wonderful engagement with the Family Support Network. We are always grateful to them for their friendship and cooperation.

Please email me - Katherine Hamann - at [katherine@thearcofil.org](mailto:katherine@thearcofil.org) or call me at 708.465.2827 if you wish to learn more about the Family Transition Project. We welcome your stories of successful transitions and we want to be of service if you are contemplating or are in the midst of transition from an SODC to community life. We are always here to listen and encourage – like family!



left to right, top to bottom :Katherine Hamann, Senator Dan Kotowski, Rep. Marty Moylan, and Bob Okazaki, CEO of Avenues To Independence

## Resources: Programs of the Arc of Illinois

### **The Arc of Illinois**

Tony Paulauski, Executive Director  
[www.thearcofil.org](http://www.thearcofil.org)  
815-464-1832

The Arc of Illinois is Illinois' largest statewide advocacy organization for individuals with intellectual and developmental disabilities. The Arc of Illinois provides legislative advocacy and training for self-advocates, family members, and professionals. Individuals interested in learning about issues important to their loved ones with ID/DD can stay informed and active in shaping the system through membership in The Arc of Illinois.

### **Illinois Life Span (ILS)**

Deb Fornoff, Program Director  
[www.illinoislifespanspan.org](http://www.illinoislifespanspan.org)  
309-444-2496  
1-800-588-7002

Illinois Life Span provides resources and information to individuals with ID/DD, their families, and professionals on advocacy, services, and supports statewide. Individuals who are seeking information related to disability supports or services can use our website or toll-free line to gather information by Service Type, Provider Type, and County.

### **The Arc of Illinois Training Department**

Janet Donahue,  
Director of Development  
[www.thearcofil.org/events](http://www.thearcofil.org/events)  
815-464-1832

The Arc of Illinois provides ongoing trainings and conferences throughout the state for self-advocates, family members, and professionals. We provide an Annual "Living with Autism" Conference, Annual Convention, Annual QIDP Conference, Annual Leadership Conference and many one-day seminars. Also, outside agencies interested in event planning services can contact Janet and ask for Just For You Design and Planning services.

### **Ligas Family Advocate Program**

Shirley Perez, Program Director  
[www.familysupportnetwork.org](http://www.familysupportnetwork.org)  
708-331-7370

The Ligas Family Advocate Program has one purpose – to connect recipients of Ligas award letters seeking Home Based or CILA services and their families with family advocates who are knowledgeable about creative ways to utilize their Ligas funding to build successful lives in the community. Ligas family advocates will work to provide information to award letter recipients and their families about options. A primary goal of the program is to connect families with other families so they can share their unique perspective as stakeholders in the system. This program will initially focus on Ligas class members within the areas served by three Independent Service Coordination agencies: Community Service Options Inc., Developmental Disabilities Services Metro East and Suburban Access. The overall goal is to roll out this program state-wide. Data collected from Ligas class members and their families will be shared with the Ligas Court Monitor and the Division of Developmental Disabilities to promote positive systemic change.

### **Consumer Stipend Program**

Mary Lynne Paris, Program Director  
[www.thearcofil.org/events](http://www.thearcofil.org/events)  
815-464-1832

The Arc of Illinois administers the Consumer Stipend Program, funded by the Illinois Council on Developmental Disabilities. Consumer stipends are distributed to qualified applicants, enabling individuals with developmental disabilities and their family members to attend conferences/trainings directly related to disability issues.

### **Family Transition Project**

Katherine Hamann, Project Director  
[www.goinghomeillinois.org](http://www.goinghomeillinois.org)  
708-465-2827

Home and family is at the heart of the Family Transition Project. FTP families have experienced the successful transitions of their loved ones from state operated developmental centers to homes in their communities of choice. We share these successes with families who are contemplating or just beginning the process. We provide compassionate support to families, helpful information, and a lifelong experience in coping with the challenges our loved ones face and the barriers we and they may encounter. But most of all we offer hope that a successful transition is possible and is well worth it.

### **Family Support Network of Illinois (FSN)**

Shirley Perez, Executive Director  
[www.familysupportnetwork.org](http://www.familysupportnetwork.org)  
708-331-7370

The mission of the Family Support Network is to unify individuals with disabilities and their families to advocate for funding, services, and community resources that strengthen and support the individual and the family directly by responding to their individual needs and empowering them to live in their own homes. The Family Support Network further seeks to ensure the continuation of all individual supports through the life span of the individual. The FSN has expertise in the adult service system and works with families who have questions/concerns and need assistance.

# Do you or a love one have a disability and NEED services?

The first and most important step you and your family can take to get assistance is to register with the Waiting List/Prioritization of Urgency of Need for Services (PUNS) database.

To register, you must meet with a Pre-Admission Screening/Independent Service Coordination Agency (PAS/ISC) to see if you are eligible for services. You can visit DHS' website at <http://www.dhs.state.il.us/page.aspx?item=29733> to find your location.

Please find below a list of DHS Pre-Admission Screening/Independent Service Coordination Agency (PAS/ISC) Service Providers:

## **Access Services of Northern Illinois**

*Developmental Disability Services*  
7399 Forest Hills Road  
Loves Park, IL 61111  
Phone: (815) 282-8824  
TTY: (815) 282-8824  
Website: <http://www.accessni.com>

## **Central Illinois Service Access (CISA)**

*Developmental Disability Services*  
101 Madigan Drive  
Lincoln, IL 62656  
Phone: (217) 732-4731  
TTY: (217) 732-4731  
Fax: (217) 732-4870  
Toll Free: (877) 437-9588  
Crisis after hours: (217) 732-4731

## **Champaign Co Regional Planning Commission (CCRPC)**

*Developmental Disability Services*  
1776 East Washington Street  
Urbana, IL 61802  
Phone: (217) 328-3313  
TTY: (217) 328-3313  
Fax: (217) 328-2426  
Crisis after hours: (217) 531-3188

## **Community Alternatives Unlimited (CAU)**

*Developmental Disability Services*  
8765 West Higgins Road, 3rd Floor  
Chicago, IL 60631  
Phone: (773) 867-4000  
TTY: (773) 867-4168  
Website: <http://www.cau.org>  
Crisis after hours: (773) 867-4000

## **Community Service Options (CSO)**

*Developmental Disability Services*  
6845 South Western Avenue  
Chicago, IL 60636  
Phone: (773) 471-4700  
TTY: (773) 471-4772  
Fax: (773) 471-4770  
Toll Free: (888) 276-4467  
Website: <http://www.cso1.org>  
Crisis after hours: (773) 471-4700

## **CSO/RIM**

*Developmental Disability Services*  
3601 Morton Drive, Suite 1  
East Moline, IL 61244  
Phone: (309) 278-0020  
TTY: (309) 278-0020  
Crisis after hours: (309) 236-5204.

## **DayOne Network**

*Developmental Disability Services*  
1551 East Fabyan Parkway  
Geneva, IL 60134  
Phone: (630) 879-2277  
TTY: (708) 879-2795  
Fax: (630) 879-9098  
Toll Free: (888) 282-0997  
Website: [www.dayonenetwork.org](http://www.dayonenetwork.org)  
Crisis after hours: (630) 879-2277

## **Developmental Disabilities Services Metro East (DDSME)**

*Developmental Disability Services*  
2900 Frank Scott Parkway West,  
Suite 928  
Belleville, IL 62223  
Phone: (618) 236-7957  
TTY: None  
Fax: (618) 236-7925  
Website: <http://www.ddsme.org>  
St. Clair Phone No: (618) 236-7957;  
Madison Phone No: (618) 656-9663;  
Crisis after hours: (618) 830-0520;

## **Great Rivers Service Coordination (GRSC)**

*Developmental Disability Services*  
901 West Morton Avenue, PO Box  
369  
Jacksonville, IL 62650  
Phone: (217) 243-2330  
TTY: None  
Fax: (217) 243-3971  
Crisis after hours: (888) 807-8564

## **Livingston County Mental Health Board**

*Developmental Disability Services*  
310 East Torrance Avenue, PO Box  
504  
Pontiac, IL 61764  
Phone: (815) 844-7708  
TTY: None  
Crisis after hours: (815) 844-7708

## **Options & Advocacy McHenry County**

*Developmental Disability Services*  
365 Millennium Drive  
Crystal Lake, IL 60012  
Phone: (815) 477-4720  
TTY: None  
Toll Free: (888) 376-8828  
Website:  
<http://www.optionandadvocacy.org>  
Crisis after hours: (800) 892-8900

## **PACT, Inc**

*Developmental Disability Services*  
750 Warrenville Road, Suite 300  
Lisle, IL 60532  
Phone: (630) 960-9700  
TTY: (331) 481-4347  
Fax: (630) 960-9823  
Toll Free: (800) 637-7181  
Website: [www.pactinc.org](http://www.pactinc.org)  
Crisis after hours: (630) 960-9700

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## Service Providers Listings

### **PrairieLand Service Coordination**

*Developmental Disability Services*  
100 South Water Street, Suite 220M  
Decatur, IL 62521  
Phone: (217) 362-6128  
TTY: None  
Fax: (217) 362-6129  
Toll Free: (800) 866-8779  
Crisis after hours: (217) 362-6128

### **Southern Illinois Case Coordination Services (SICCS)**

*Developmental Disability Services*  
140 South Locust Street, PO Box 588  
Centralia, IL 62801  
Phone: (618) 532-4300  
TTY: (618) 532-4300  
Toll Free: (800) 828-7422  
Crisis after hours: (800) 828-7422

### **West Central Service Coordination**

*Developmental Disability Services*  
957 West Washington Street  
Pittsfield, IL 62363  
Phone: (217) 285-5227  
TTY: None  
Toll Free: (888) 279-4812  
Crisis after hours: (217) 285-5227

### **Service, Inc**

*Developmental Disability Services*  
1740 McDonough Street  
Joliet, IL 60436  
Phone: (815) 741-0800  
TTY: None Fax: (815) 741-1678  
Toll Free: (800) 244-8008  
Crisis after hours: (815) 741-0800

### **Suburban Access, Inc.**

*Developmental Disability Services*  
900 Maple Avenue  
Homewood, IL 60430  
Phone: (708) 799-9190  
TTY: (708) 799-9190  
Toll Free: (800) 507-5057  
Website: [www.suburban-access.org](http://www.suburban-access.org)  
Crisis after hours: (708) 799-9190

### **Western Illinois Service Coordination (WISC)**

*Developmental Disability Services*  
509 North Lafayette Street, Suite 203  
Macomb, IL 61455  
Phone: (309) 833-1621  
TTY: (800) 699-3672  
Toll Free: (800) 699-3672  
Website:  
<http://www.wiscmacomb.org>  
Crisis after hours: (309) 333-0406

## Photos from The Arc Convention

April 23-24th, 2014 in Lisle, IL

Members of the Arc's staff



Rep. Robyn Gabel  
the Arc's Legislator of the Year



Pictured: Faye, Rep. Gabel, Tony, Shirley, Ann, and Katherine

# Family Support Network Highlights

Autism Walk, May 17, 2014 at Soldier's Field

Cynthia, Katherine, Kimberly and Toni sharing information at Soldier's Field



**SAVE THE DATE: The Arc of Illinois • Living With Autism Conference 2014**  
Thursday, October 9, 2014 • Hilton Hotel 3003 Corporate West Drive, Lisle, IL

# Legislative Coffee Going Home Campaign

March 26, 2014 • Springfield, IL

Family Support Network is so proud to be a part of the Coalition



Rep. Camille Lilly and Tony Paulauski



Self-Advocate, John Porter, Katherine Hamann, and Rep. David McSweeney



Rep. Thaddeus Jones with staff members and self-advocates from SouthStar Services



Dr. Romano, Rep. Feigenholtz, Barb Pritchard, Tony Paulauski, Cheryl Jansen and Director Kevin Casey



Rep. Will Davis and Tony Paulauski



Phil Milsk

## Legislative Scoop with Phil Milsk

The following bills of interest passed both houses of the General Assembly this year:

### **SB 220 (Kotowski) (Madigan)**

Passed both houses 5/30/14

FY 2015 Budget Implementation

Bill includes:

- Interfund Borrowing and Transfers
- PACE/ADA Paratransit grant of \$3.825 million

- Extending until July 1, 2015, indefinite grants suspension
- Adds "other eligible primary care providers" to address health care disparities in underserved areas under the Family Practice Residency Act
- Raises the grant level for refugees and asylees who are elderly or disabled who do not qualify for SSI under Federal Law from \$500/month to 90% of the maximum SSI payment amount per month (applies to about 150 persons)

Raises the personal needs allowance for persons residing in a CILA or ICF-DD to \$60/month for FY 2015 only.

### **SB 229 (Delgado) (Golar)**

Passed both houses 5/30/14

Requires the uniform application to serve on a board or commission to include a data field where the applicant shall disclose his or her ethnicity, gender, and disability status for reporting purposes. Requires the Governor to file an annual report with the General Assembly detailing the demographic information.

### **SB 741 (Trotter) (G. Harris)**

Passed both houses 5/29/14

Omnibus Medicaid Bill includes:

- New hospital rate methodology
- Extends hospital assessment programs to July 1, 2018
- HFS to request federal approval for new federal dollars for hospitals serving newly eligible Medicaid recipients who are reimbursed at 100% match and will raise roughly \$400 million annually. This will be distributed to hospitals across the state.
- Clarifies the responsibilities of MCOs and ACEs and hospitals regarding enrollment of Medicaid clients into managed careRep. Will Davis and Tony Paulauski
- Clarifies the responsibilities of MCOs and nursing homes for Medicaid clients enrolled in the Medicare-Medicaid Alignment Initiative (dual eligible)
- Expedited Long Term Care eligibility processing by simplifying eligibility verification policies, redeploying caseworkers trained in LTC eligibility, foregoing resource review for some cases and transmitting certain information and Medicaid applications electronically.
- Changes for SMHRFs: Allows Health Facilities and

Services Review Board to relocate SMHRF to an underserved area of the State. State will develop and implement a service authorization system available 24 hours/day 7 days/week for approval of services in the 3 levels of care in SMHRFs. SMHRFs may locate a triage unit, or short-term crisis stabilization center, in a separate facility within 1,000 feet of the SMHRF.

- Benefits changes include: (1) Restoration of adult dental services; (2) Restoration of adult podiatry services; (3) Elimination of prior authorization under the 4 prescription drug policy for anti-psychotic drugs; (4) Elimination of 4 prescription drug policy for children with complex medical needs who are enrolled in a care coordination entity (CCE) solely to coordinate care for the children, if the CCE has a comprehensive drug reconciliation program; (5) Eliminates the maximum 20 visits for speech, hearing, language, OT, PT, and replaces with a prior approval process; (6) Coverage for one or more vendors procured by CPS to manufacture eyeglasses for CPS students; (7) Coverage for kidney transplants for non-citizens with end-stage renal disease who are otherwise not eligible for Medicaid coverage, with some restrictions.
- Rate increases for nursing homes, supported living facilities, residential facilities and transitional facilities serving children with clinically complex needs, home health services and SMHRFs (one-time payment for FY 2014)
- Brings State into compliance with federal law by providing coverage for children without private insurance for 3 months (instead of 12 months)
- Brings State into compliance with federal law regarding reinstatement of client who is cancelled during redetermination if documentation is produced within 3 months (instead of 1 month).
- Gives HFS and contracted MCEs access to IDPH's immunization data, essential for care coordination.

### **SB 822 (Hastings) (K. Burke)**

Passed both houses 5/14/14

Changes provisions in the Mental Health and Developmental Disabilities Administrative Act regarding the net proceeds of the sale of real estate when a state facility is closed. Provides that a portion of the proceeds may be set aside by the Department for deposit into the Human Services Priority Capital Program Fund. The portion set aside may be used to make grants to the Illinois Facilities Fund to make long term below market rate loans to nonprofit human services providers working under contract with the State to assist providers in meeting their capital needs.

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### **SB 2586 (Steans) (Gabel)**

**Passed both house 5/16/14**

CBHA bill that requires the Governor's Office of Health Innovation and Transformation (GOHIT) to oversee a process for identifying needed mental health services in different geographic regions of the State and identifying financing strategies for developing needed services. Report of findings and recommendations due July 1, 2016.

### **HB 0008 (Flowers) (Hutchinson)**

**Passed both houses 5/28/14**

Amends the IL Human Rights Act. Makes it a violation to discriminate in employment based on pregnancy. "Pregnancy" is defined as pregnancy and medical or common conditions related to pregnancy or childbirth. Provides that it is a human rights violation if an employer (1) fails to make reasonable accommodations as requested unless undue hardship on the ordinary operation of the business can be shown; (2) denies employment opportunities or benefits or takes adverse action against an otherwise qualified employee or applicant based on pregnancy; (3) requires a job applicant or employee to accept an accommodation that the applicant or employee chooses not to accept; (4) requires the employee to take leave if another reasonable accommodation can be provided. Prohibits retaliation against a person for requesting an accommodation or attempting to use a reasonable accommodation. Requires the employee seeking accommodation to submit documentation to the employer that is properly requested. Effective January 1, 2015.

### **HB 2747 (Crespo) (Kotowski)**

**Passed both houses 5/30/14**

*Creates the Grant Accountability and Transparency Act.*

Purpose is to establish uniform administrative requirements, cost principles, and audit requirements for State and federal pass-through awards to non-federal entities. Provides that on or before July 1, 2015, GOMB, with the advice and technical assistance of the Single Audit Commission, shall adopt rules which adopt the Uniform Guidance at 2 CFR 200. Addresses:

- Adoption of federal rules applicable to grants
- Conflicts of Interest provisions
- Mandatory Disclosures
- Supplemental Rules
- Applicability of Act
- State grant-making agency responsibilities
- State program exceptions
- Annual report that demonstrates the efficiencies, cost

savings, and reduction in waste, fraud and abuse as a result of the implementation of the Act.

- Recreates the Single Audit Commission with some changes
  - Sunsets 5 years from effective date
- Immediate effective date

### **HB 3638 (Fine) (Kotowski)**

**Passed both houses 5/28/14**

Creates the Health Insurance Consumer Protection Act of 2014. Requires certain information to be provided to health insurance consumers with respect to qualified health insurance plans offered on the State's health insurance marketplace:

- For each plan offered, a recently published prescription drug formulary, information on tiering and cost-sharing structure for each tier and where consumers can obtain additional information about co-payments
- Most recently published provider directory and other information about providers, medical groups, institutional affiliations, etc.
- Make information available on the Internet and through other means for persons who do not have Internet access.
- Requires Department of Insurance to ensure that State-operated websites provide links to Internet-based materials and tools to help consumers be informed purchasers of health insurance.
- Requirements apply to all plans made available on and after January 1, 2015.
- Same requirements apply to Managed Care Plans
- Includes a "medical exceptions" requirement and process that would allow consumers to obtain prescription drugs not on the formulary
- Establishes a prior authorization form and process and 72 hour timeline for approval or denial, and a 24 hour timeline in the case of an expedited coverage determination (does not apply to Medicaid or Medicare recipients)

Immediate effective date.

### **HB 3700 (Osmond) (Bush)**

**Passed both houses 5/20/14**

Amends the School Code to require the State Board of Education to amend its administrative rules on special education to incorporate an international definition of dyslexia. Further provides that, subject to specific appropriation or the availability of private donations, the State Board of Education shall establish an advisory group to develop a training module or modules to provide

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## Legislative Scoop with Phil Milsk

education and professional development to teachers, school administrators and other education professionals regarding multi-sensory, systematic, and sequential instruction in reading. The advisory group is abolished on July 31, 2015. Effective immediately.

### **HB 3793 (Currie)(Kotowski)**

Passed both houses 5/30/14

This is the 1,100+ page capital projects bill.

### **HB 3830 (Golar) (Hunter)**

Passed both houses 5/20/14

Amends the Department of Human Services Act regarding the Inspector General by requiring the IG to report a finding of financial exploitation of an individual to the Department of Public Health. Effective immediately.

### **HB 4033 (Golar) (Hunter)**

Passed both Houses 5/20/14

Removes the requirement of ID badges for staff of ICF-DDs and CILA.

### **HB 4327 (G. Harris) (Haine)**

Passed both houses 5/28/14

Clean up bill to Adult Protective Services Act passed in 2013. Effective immediately.

### **HB 4407 (Gabel) (Morrison)**

Passed both houses 5/29/14

Provides that the "stay-put" placement rule applicable to children in the Early Intervention program applies to cases in which the parent has requested a due process hearing, filed a State Complaint with DHS, or asked for Mediation. (NOTE: Other matters raised in the introduced bill such as service implementation timelines and notification of rights to parents were negotiated with DHS and amended out of the bill.) Effective immediately.

### **HB 4527 (Chapa Lavia) (Lightford)**

Passed both houses 5/29/14

State Board of Education bill that requires charter schools to comply with all State and federal special education and English Language Learner requirements. Effective immediately.

### **HB 5307 (G. Harris) (Steans)**

Passed both houses 5/29/14

*CILA recipient's fund protection bill.* Provides as follows:

- Service provider may accept recipient's funds for safekeeping and management upon written authorization from recipient or recipient's guardian
- Provider must maintain a written record of all financial arrangements and transactions involving each recipient and shall allow recipient or recipient's guardian to have access to the written record;
- Provider shall provide each recipient, recipient's guardian or the recipient's immediate family member (in order of priority) with a written itemized statement of all financial transactions involving the recipient's funds or a copy of the recipient's checking or savings account register at least quarterly or for a requested period of time;
- Provider shall purchase a surety bond or other commercial policy with crime coverage in an amount equal to or greater than all of the recipient's personal funds deposited with the service provider to which employees of the provider have access;
- The insurance company shall notify DHS-DDD of any policy cancellation or reduction of coverage;
- Shall keep recipients' funds in an account or accounts separate from the service provider's funds
- Provider shall not withdraw all of recipient's funds unless the service provider is (1) returning the funds to the recipient upon the request of the recipient or another person authorized to make the request, (2) paying the recipient his or her allowance or (3) making any other



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payment authorized by the recipient or another person entitled to make the authorization.

- All funds in excess of \$100 must be deposited in an interest-bearing account insured by agencies of or corporations chartered by the State or federal government, and clearly indicate that provider has only a fiduciary interest in the account
  - Up to \$100 may be kept in a non-interest bearing account or petty cash fund for ready availability for recipient's current expenditures
  - Provider shall return all funds upon request
  - Makes other changes
- Effective immediately

### **HB 5598 (Feigenholtz) (Morrison)**

Passed both houses 5/22/14

Creates the Custody Relinquishment Prevention Act. Requires an interagency agreement of DHS, DCFS, ISBE, HFS, DJJ and IDPH to address the problem of parents seeking to relinquish custody of children with serious mental illness to DCFS in order to protect the family and obtain services for the child. There is \$7 million in the FY 2015 budget for services for these children that was taken out of the budget line for Individual Care Grants. (The ICG program lapsed \$7 million in FY 2013). Effective January 1, 2015.

### **HB 5707 (Cassidy) (Steans)**

Passed both houses 5/29/14

Makes changes to the School Code with respect to school district bullying prevention policies. Requires each policy to have a reporting and investigation process, and notification to parents and to the school principal. Requires schools to make all reasonable efforts to investigate and address reported incidents within 10 school days. Emphasizes the need for restorative measures and interventions for both the victim and the student who engages in bullying behaviors. Requires a policy evaluation process every two years. Effective Immediately.

### **HB 6060 (G. Harris) (Steans)**

Passed both houses 5/30/14

FY 2014 supplemental appropriations bill. Includes \$60 million for DHS Child Care, \$10 million for community-based addiction treatment and \$8 million for Early Intervention.

### **HB 6096 (Madigan)(Cullerton)**

Passed both houses 5/30/14

*FY 2015 human services budget bill.* DD services are essentially flat funded. GRF cuts to community based services made up with special fund appropriation.



## Best Wishes to Amie Lulinski

Amie Lulinski, PhD, currently serves as Senior Research Specialist in Developmental Disabilities at the Institute on Disability and Human Development at the University of Illinois at Chicago which is the

University Center for Excellence in Developmental Disabilities for the State of Illinois.

Amie received her MS in Disability and Human Development in 2008 from the University of Illinois at Chicago and defended her dissertation titled "Community Capacity to Provide Mental/Behavioral Health Services to People with Developmental Disabilities" in April of 2014, thus earning her PhD in Disability Studies. Amie's interests are in Medicaid funded long term services and supports as well as the mental/behavioral health needs of people with

intellectual and developmental disabilities.

Amie has served in various capacities for many years supporting people with disabilities, including as a Direct Support Professional, a Service Coordinator, and a Director of Quality Assurance and Training at agencies serving individuals with developmental disabilities. Additionally, Amie is a long-time member of The Arc family, including serving as Secretary of the Board of The Arc of Illinois and Chair of its Managed Care Task Force.

In 2011, Amie served as the Disability Policy Leadership Fellow at the Association of University Centers on Disabilities where she worked alongside coalition members (including The Arc staff) on national disability policy efforts in Washington, D.C., including the passage of the Combating Autism Reauthorization Act and opposing the block granting of Medicaid.

We will miss you! Amie joins the Arc' Public Policy team in Washington DC on July 1, 2014



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*Let's do together  
what we can't do alone!*

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Alan Bell, FSN Chairman

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The mission of the Family Support Network is to unify individuals with disabilities and their families to advocate for funding, services and community resources that strengthen and support the individual and the family directly by responding to their individual needs and empowering them to live in their own homes. The Family Support Network further seeks to ensure the continuation of all individual supports throughout the life span of the individual.