

# Family Support Network

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June, 2017

## 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. The Family Support Network (FSN), one of the many programs of The Arc of Illinois, has experienced a changing of the guards. Tony Paulauski retired after 25 years as Executive Director of the Arc of Illinois. **For many of us he served as the face of advocacy for people with intellectual/developmental disabilities in Illinois** - we wish him well! Our new Executive Director, Meg Cooch, brings many gifts and credentials to the table. Welcome, Meg.

FSN's 5th Annual Informational Seminar was a huge success. We will continue to empower our families through **quality education and firsthand information**. A special thank you to our presenters this year: Barry Taylor, Keynote presenter, Sherri Schneider and Benji and Brian Rubin; all were outstanding. Thank you to our special guests DD Director Greg Fenton, Lore Baker and Ronnie Cohn, Ligas Court Monitor. The number of vendors was impressive and it is so gratifying to have both new vendors and those who

come back year after year. But this event simply wouldn't happen without faithful FSN members and self-advocates and families who seek to educate themselves about important issues. We are all better informed and ready to continue the fight!

We are struggling into the 3rd year without a state budget. The

budget situation is unlikely to be resolved before you receive this issue. We strongly encourage you to continue to cultivate a good relationship with your state legislators. Let them know what is important to **you!**

Congress is on the fast track to repeal major portions of the Affordable Care Act (ACA) and to partially fund it by capping the federal payout and making drastic cuts to the Medicaid program. These cuts, over time, would decimate the Medicaid program. FSN continues to advocate against any cuts to Medicaid.

On the positive side, it has been my continued privilege to meet families who are exploring new options thanks to the Ligas Consent Decree - freedom to do exactly what we advocate for - to live a full life in the community in a new home or to use the Home Based Services to enrich their lives and hold on to everything that's precious to them about their current home. We rejoice that the system is working for them, but we never forget how many families are still struggling with no services or inadequate services.

As always, FSN will continue to advocate for services and supports that allow children and adults with disabilities to remain in their own homes or to choose just the right home in their 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.

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



Shirley Perez

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# Tony Paulauski Retires after 25 years as Executive Director of the Arc of Illinois



Tony Paulauski

## Reflection of the past 25 years in his own words!

When I first started, The Arc and families were not at the table, any table in Illinois public policy. The thought of including individuals with

intellectual and other developmental disabilities in that arena was unheard of. The charge of the board of directors to me was to change the current state of affairs and provide leadership by bringing individuals, families and The Arc to the table.

Also on my agenda was the Bogard Consent Decree. At the time, it was the largest consent decree in the nation and still may be. I had the opportunity to work with some of the greatest public policy legal attorneys in the states. The decree was about the inappropriate placement of individuals with IDD in nursing home. The implementation of this consent decree was a phenomenal success. Among other supports/services the consent decree created CILA and freestanding

Individual Service Coordination Agencies around the state.

Today lawsuits continue to be the way we change the disability system here in Illinois. The good work of legal advocates and court monitors in Ligas are now protecting community services and fighting for rebalancing the system. With the uncertainty in our nation's Capital, that may be the way for our future.

In those early days staff recruitment and retention were also an issue. So I became actively involved in working in coalition fighting for higher wages and benefits and that fight continues today.

The Arc has authored and was instrumental in creating numerous disability policy legislation. We worked with many talented and honorable legislators. We worked with good and decent people in the various administrations with a common mission of supporting individuals with IDD. We also worked hard with families and people with IDD to testify before legislators, committees and commissions on the importance of community inclusion and building a network of

advocates for community.

Some of the legislation we worked on that I am most proud of included:

- Prohibition of Capital Punishment for Individuals with IDD
- Many Special Education Transition Bills
- The Early Intervention Act
- The Disability Services Act of 2003
- Protection of Individuals with IDD who had been sexually abused
- Delegation of Special Education Students Rights
- Brittany's Law
- PUNS Waiting List
- Special Education 22 Law
- Prohibition of Aversive Behavioral Therapies
- Employment First

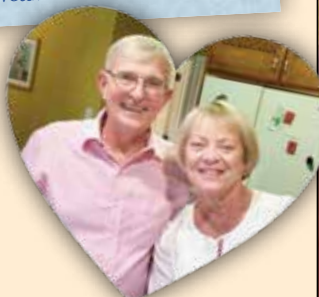
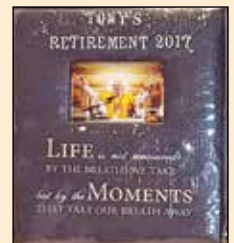
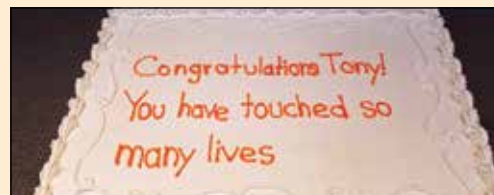
Working with our partner the Illinois Council on Developmental Disabilities, we became very active in advancing the self-advocacy movement here in Illinois. Creating a very real place at the policy table for individuals with IDD. We created the Going Home Campaign

## Photos from Tony's Retirement Celebration and 25 Years of Leadership

Dear Tony,

All that one can ask for is an OPPORTUNITY - You, my FRIEND, have given many an OPPORTUNITY!

Best wishes to you and Barbara!  
- The Arc Team



hosting rallies in the Capitol, talking to the media, meeting with editorial boards and filming success stories. The creation of the Speak UP & Speak OUT Summit with ICDD continues to be a contemporary leadership training summit for individuals with IDD. Last year the Summit had over 525 individuals attending!

The Arc has become the voice of rebalancing the disability system as a civil right. We are fighting for full inclusion for infants, children & adults in their home communities close to family and friends. Regrettably, Illinois continues to be a very institutional state with seven fully operational state institutions.

The Arc has become a major player in the media by taking our message for inclusion and rebalancing to the public and policy makers. I have had the opportunity to work with many brilliant communications experts over the years to our great advantage. The Arc is the place to go for reporters and the media. We are respected by newspaper editorial boards around the state.

Some of the highpoints of my career in The Arc include:

- Rallies in the State Capitol and The Arc Media Work
- Developing a Statewide Network of Advocates including Self-Advocates, Families and Providers

- Working with Tremendous Legal Advocates and Even Court Monitors!
- The Arc of Illinois Award and The Arc of the United States Award presented to Governor Quinn for his championship of progressive Disability Policy

- The Signing of Employment First

I am extremely proud to have been your Executive Director at The Arc of Illinois. I am only one of 38 state executive directors in the nation, a close fraternity of outstanding advocates that I have learned so much from.

In addition, we have created excellent resource and advocacy programs for individuals and families including:

- The Illinois Life Span Program, the 411 of disability services
- The Ligas Family Advocate Program, providing resources and advocacy for class members moving off of the waiting list and more.
- The Family Transition Project, a network of people with IDD and families who have transitioned out of state institutions.
- The Arc's Family to Family Health Education Center, providing resources to families who have children with special health care needs.
- The State Chapter of Family Voices

- The Consumer Stipend Program, a grant from ICDD where we distribute \$100,000 per year so individuals with IDD and families can attend important educational events.
- Bringing and Sustaining the Family Support Network under The Arc's Umbrella

The Arc's Board of Directors, their courage and commitment to advocacy and inclusion led by Board President Terri Devine and the continued support of so many Past Presidents. What an opportunity to serve they have given me.

But I am most proud of The Arc Team, our staff. They are an incredible team of advocates always helping me through the minefields of Illinois politics, always standing with me against those who would deny freedom and the dignity of risk for the individuals we are here to serve.

I leave The Arc in great hands and commitment to our leadership for full inclusion for everyone. That will not change.

Meg Cooch, the New Executive Director of The Arc of Illinois is a person we can all be proud of. She is a leader who will write the next chapter in the organization we all cherish - The Arc.

Until we meet again good friends.

Lead on!





Deb Fornoff

The Illinois Life Span Program is a “one stop shop” for information on disability advocacy, services, and supports, focused on individuals with intellectual and developmental disabilities. Illinois Life Span provides assistance through its website at [www.illinoislifespan.org](http://www.illinoislifespan.org), via toll-free help line at 1-800-588-7002, by email, and in person at outreach events.

The Illinois Life Span Program (ILS) was originally a project of The Illinois Council on Developmental Disabilities (ICDD). This grant was awarded in 2001 to The Arc of Illinois. At that time, the ICDD identified a central resource for information related to intellectual and developmental disability advocacy, supports and services as a gap in service in Illinois. The Illinois Life Span Program fills that gap.

Much of the original “Scope and Intent” of the program still guides our efforts today.

*People with disabilities and their family members must have access to accurate and up-to-date general information and linkage to advocacy resources to meet their needs throughout their lives.*

*Illinois needs a strong, central location for people with disabilities and their families to get information and to locate the advocacy resources they need. The Illinois Life Span Project assures that people are directed to advocacy resources that are successful in helping them meet their needs.*

Illinois DHS Division of Developmental Disabilities recognized the importance of this service to families and professionals and has been the primary funding source for the last several years. Illinois Life Span funding and services were abruptly ended along with a number of other grant programs in April 2015. Funding was reinstated for two additional months and then cancelled again for a 15-month period from July 2015 through September 2016. We resumed services on October 1, 2016 and are funded through June 2017. Making sure that families and professionals are aware that we are “back in business” has been a challenge. The Arc of Illinois continues to advocate for an Illinois budget that includes the Illinois Life Span program and other important grant programs that serve people with disabilities and their families.

Illinois Life Span Program staff members include Cindi Swanson, a Naperville resident, parent of a young adult with disabilities, and an experienced

advocate with 15+ years with ILS. Cindi’s experience includes a Master’s degree in School Social Work, consulting on inclusive education and employment issues, and participation in many advocacy efforts in her community. Cindi assists callers and does outreach in the Chicago suburban area.

Olivia Sanchez is new to ILS, starting in January 2017. Olivia has extensive non-profit social service experience and speaks Spanish. Olivia provides outreach in the Chicago and suburban area, focusing on the underserved Spanish speaking population. Olivia has been very busy over the last several months doing outreach, working on translating documents that are shared frequently by Programs of The Arc of Illinois, and learning about the services and supports that are available to assist those who contact ILS for help.

Deb Fornoff is the Director of the ILS Program and has been with The Arc of Illinois for more than 13 years. Deb lives in central Illinois and is also the parent of a young adult with Down syndrome. Deb answers inquiries for ILS, maintains the ILS website, and provides outreach downstate. Deb’s experience includes a Master’s degree in Education, Counselor Education; past participation on her local Down syndrome group board; and served on the Illinois State Advisory Council on the Education of Children with Disabilities, chairing the Transition Committee.

Although there have been many changes in the scope of the work of the Illinois Life Span Program and the structure of the Illinois disability system over the last 16+ years, there are several issues that remain the same.

- The systems for services throughout the lifetime for people with disabilities in Illinois remain complex and difficult to navigate.
- Parents/caregivers must learn about and navigate multiple complex systems throughout the lifetime of their loved one with disabilities.
- Every individual, family, and situation is different.
- Families and caregivers, individuals with disabilities, and professionals all need help, at times, to access assistance and information.
- The Illinois Life Span website and staff are available to help you find the information/resources you need.

We look forward to communicating with you by phone, email, and in person at outreach events near you!



# Ligas Family Advocate Program

The purpose of the Ligas Family Advocate Program is to provide family-to-family support for individuals (and their families) who are selected through the Illinois Department of Human Services, Division of Developmental Disabilities (DDD) Prioritization of Urgency of Needs (PUNS) process as a result of the Ligas Consent Decree. Family advocates address the needs of individuals with intellectual/developmental disabilities (I/DD) and their families by providing information about available community options, including Home-Based Support Services (HBSS) and Community Integrated Living Arrangement (CILA) services, to build full and integrated lives in their homes and communities. Ligas Family Advocates conduct Know Your Options events around the state.

The program director is a parent of an individual with disabilities and has over thirty years' experience working in the DD field including eight and a half years at an ISC. Every Ligas Family Advocate has a combination of professional experience and a

critical family component. They are all experienced stakeholders in the DD system, who know that family advocacy is necessary and tough choices have to be made every day to juggle responsibilities as family members and professionals and to empower their loved ones to live a full life. This unique family component makes LFA's particularly accessible to families and gives LFAP staff an ability to empower Ligas class members and their families in a way that can only strengthen family advocacy in Illinois, an area that has long needed this support.

We conduct Know Your Options events state-wide. These events create a unique and instant personal connection for Ligas class members and their families to other Ligas class members and families who are just beginning their Ligas journey, as well as to more experienced families who have navigated the DDD

system and can offer their first-hand experience. Class members and their families hear experts in the areas of housing, employment, person centered planning; and many other topics.

Know Your Options events are held in family-friendly settings which allow class members and their families to interact directly with the speakers, as well as with providers, ISC staff, the Ligas Court monitor and Executive staff from DDD. This is a great resource that provides class members and families the options to talk one on one with Ligas Family Advocates in person by phone and email.

### Contact information for this program:

The Arc Ligas Family Advocate Program  
Shirley Perez, Program Director  
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Shirley@thearcofil.org  
www.LigasFamilyAdvocateProgram.org  
www.facebook.com/  
Ligasfamilyadvocateprogram

## 5th Informational Seminar

March 23, 2017 – Heritage Plaza

*Congratulations to our raffle winners!*



FAMILY SUPPORT NETWORK



# Know Your Options and FSN Outreach events across the State:

March 24, 2017 – Collinsville



Ronnie Cohn, Ligas Court Monitor, answers questions from participants.

## Know Your Options and ISC Training

September 20, 2016  
Suburban Access in Homewood



October 27, 2016 ISC,  
Training Service Inc. Joliet



## Know Your Options Training at CSO in Chicago

with Ligas Court Monitor, Professionals,  
DHS Representative and Class members,  
September 27, 2016



# Other legislative events in the community

January - May 2017

Vivienne Harvey, Advocacy Coordinator, partnered with CAC to provide legislative advocacy training at monthly meetings



## Town Hall Meeting with Black Caucus

## State-wide - Transition

This year's conference held in Effingham. What a fabulous turnout! Vending area became very crowded as you can see.



# Family Transition Project



Katherine Hamann

The Family Transition Project (FTP) serves families. Our focus is on citizens with intellectual/developmental disabilities (I/DD) who live in State Operated Developmental Centers (SODC's) and their families. We are there to encourage and support their transitions into homes and communities of their choice. Along the way, we connect them with other individuals with I/DD and their families who have already experienced a successful transition to community living and can offer hope that a positive transition is possible, in spite of many kinds of barriers. FTP Family Advocates don't approach this from a purely professional or academic standpoint – we have family members with I/DD and we know what kinds of barriers pop up.

This past year (third year without a state budget) has created a lot of frustration for Illinois citizens with I/DD and their families. If you are of the philosophy that for every door that closes another opens, this was a good year for you. This was a year that needed an extra dose of hope. As a guardian whose sister has thrived in a CILA home for 9 years (after 63 years in state institutions), I get that dose of hope every time I visit her and see the good care she gets and the real affection she has for the staff who work with her; affection that is reciprocated.

There are signs of hope even in these challenging times and we always rejoice to see them. Revisiting people who have left SODC's over a period of years has been very encouraging and I heard some great stories this year. Just like those of us who have never lived in large institutions, their lives have ups and downs. In some cases they have experimented with different living arrangements before finding one that works. In some cases people have discovered new interests or had time to pursue interests that were difficult to pursue in a large institutional setting. I think of a man who learned to play the guitar from his neighbor and several people who enjoy their pet companions. Very simple things we take for granted that were not possible before are now possible. One gentleman has a cell phone, something that was never allowed where he lived before. Several people have better jobs or their own room. Big ticket purchases like furniture of their choice and computers are now attainable for some people because they are making more money. I know three men who have stopped smoking and have stuck to it. In one case it's been three years.

The Family Transition Project has always had a close relationship with the Going Home/A Full Life in the Community Coalition. In the last year, Going Home has been extremely active. A year ago in April a remake of the Going Home video began, with funding from the Illinois Council on Developmental Disabilities and the actual filming and editing done by Launch Digital Marketing. The self-advocates who told their stories on film had lived in the Shapiro, Jacksonville, Howe, Dixon, and Lincoln SODC's. All of them live in homes in the community now and lead more robust lives. In several cases, their loved ones had strong doubts that this would ever work and are amazed and pleased by how well they are doing. The stories we collected are all available to view on [www.goinghomeillinois.org](http://www.goinghomeillinois.org), the Going Home website, which has had a complete makeover. There is also ongoing information/discussion on community living on the Going Home/A Full Life in the Community Facebook page. Going Home video participants were celebrated in a luncheon presentation at The Arc of Illinois Annual convention on April 27th. This May 24th, several hundred Going Home supporters, coalition members, disability professionals, and family members gathered in Springfield in the Capitol Rotunda to rally for the closure of large expensive institutions and the re-allocation of Illinois funding for disabilities from SODC's to community based supports and services. Rally participants visited Illinois legislators afterwards to pass on their message. We were proud to have Stanley Ligas as a rally guest and speaker, the man who sparked the lawsuit and settlement that bear his name and have provided community services to thousands of Illinoisians. With Ronnie Cohn, the Ligas Court Monitor at his side it felt full circle. Two other very special guests were The Arc's new Executive Director, Meg Cooch, and the new Executive Director of the Illinois Council on Developmental Disabilities, Kim Mercer-Schleider. Both women bring experience and energizing ideas to their new roles.

Recently FTP made a presentation to Lana Waselewski, Chair of the SODC Transition Committee for the Department of Human Services and the transition coordinators at every SODC in Illinois. We hope this will be the beginning of a collaboration that will allow us to reach out more effectively to families involved in transitions and especially to those SODC families who have concerns about community transition for their loved ones.



## Thank you, Sherri Schneider!

The Family Support Network would like to say thank you to a very Special Lady, not only was she an awesome presenter at FSN's 5th informational seminar, she donated many of our raffle items!

For more than 25 years, Sherri Schneider as founder of Family Benefit Solutions, Inc. has been tirelessly dedicated to helping individuals with special needs and their families. Her career began as a Case Manager in a Community Integrated Living Arrangement (CILA) where she helped those with developmental disabilities and mental illnesses acquire the government benefits they so desperately needed,



including SSI, Medicaid and food stamps. She was instrumental in creating one of the first Community Living Facility (CLF) facilities funded under a Medicaid waiver. Sherri now meets privately with families to thoroughly assess their individual situation and pursue the appropriate benefit assistance program(s), personally guiding them through the application process. Based on her vast experience, she has skillfully established and maintained open, productive

relationships with government agencies involved in the decision-making process. Professionals find her in-service expertise to be invaluable as they navigate the government benefit process.



**We're on the Web!**

See us at: [www.familysupportnetwork.org](http://www.familysupportnetwork.org)

### Family Transition Project

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Once again, we were asked to present to visiting disability professionals from Japan. It's always a treat to converse with Professor Kiyoshi Yamaki of UIC and his graduate students. They are especially interested in increasing community supports and family involvement for people with I/DD. They have a heart for their profession and deep interest in the history of disability issues.

FTP staff attend many trainings and relevant conferences to keep up to date with issues related to community living. I also serve on the board of SIBS (Supporting Illinois Brothers and Sisters). This year two events that stood out were a Pathways to Justice workshop held by The Arc of Winnebago, Boone, and Ogle Counties in Rockford, Illinois and the 2017 Disability Policy Seminar in Washington, DC. It was great to see self-advocate involvement in action on both a local (Rockford) level (advocating for a more workable justice system for people with disabilities) and on the national stage (advocating for policies that support people with disabilities everywhere). The Disability Policy Seminar included

a national level sibling breakfast and it was interesting to meet and learn that we have the same concerns across the US.

As always, the Family Transition Project enjoys working with all of our Arc of Illinois colleagues, especially if we are making a team effort to help families. We are proud to work with the Family Support Network and to attend their annual informational seminar. It's a great opportunity to meet families and hear their stories, as well as always learning something new.

A series of articles in the Chicago Tribune called "Suffering in Secret" (by Michael J. Berens and Patricia Callahan) explored the negative side of a community system that is being stretched to its limits and beyond. Horrible and painful as it was to read these stories and tragic as it was for the people who lived the stories, it was good to clear the air and see these troubling issues in the light of day where it is possible to address them.

What is equally concerning to families, advocates, and self-advocates all over Illinois is the thought that fear will

force us back to an era where large institutions will seem a more viable option for our loved ones with I/DD. The community system came about because people with I/DD and their families wanted more. They wanted the same life and opportunities that all citizens are entitled to by law. The Family Transition Project was the creation of our recently retired Executive Director of The Arc of Illinois, Tony Paulauski. He firmly believed that life in the community was not an option but a right for everyone and that with individualized supports everyone could achieve it. This absolutely does not mean that we accept or condone inadequate services. We are always advocating for services that allow people to thrive and participate fully in their own lives and communities. The Family Transition Project links families together in this endeavor.

Katherine Hamann  
Director, Family Transition Project  
[katherine@thearcofillinois.org](mailto:katherine@thearcofillinois.org)  
708/465-2827

Please feel free to contact me with questions/concerns.



# Home Based Services Program Overview

Helping Families. Supporting Communities. Empowering Individuals.

The Home-Based Services (HBS) program is designed to enable participants to remain living in their family home or in the case of adults, a home of their own if feasible, while receiving services that support them to achieve their personal goals. The HBS program provides a monthly allocation that can be used to purchase services from authorized community agencies, or to pay for Personal Support Workers (PSW) who are directed by the individual or his/her designee.

HBS resources can be used to purchase direct services such as Developmental Training (DT) and employment services from community agencies enrolled in the Medicaid Waiver program. An organization must have an authorized Medicaid contract with the state in order to have HBS resources pay for program services. Programs offered by park districts, health clubs and community colleges do not meet this criteria and cannot be paid for directly through the HBS program. Both the Children's and Adult HBS programs permit hiring family members to perform PSW duties, though the Children's HBS program does not permit parents or other legally responsible adults to provide such services, while the Adult HBS program does permit this option. The Adult HBS program prohibits spouses or children from providing PSW services. Community agencies may also offer PSW services on an hourly fee basis.

The 2014 CMS Rule governing Medicaid Waiver programs applies to the HBS program, as well as other

waiver programs such as Community Integrated Living Arrangements (CILA) and Developmental Training. This Rule outlines the expectations that all recipients of Waiver funded services participate to the fullest extent possible in planning their services and experience the community to the same degree as all others in their community, regardless of disability. The Rule also promotes competitive integrated employment as a key outcome for adults with disabilities.

HBS services are expected to promote maximum growth, independence and self-direction on the part of the individual. Services purchased through the HBS program should support the goals and priorities outlined in the Personal Plan which is developed in conjunction with the Independent Service Coordinator (ISC), the person receiving services and others invited by him/her to participate in the planning process. A pending change to the program that will take effect on July 1, 2017 is removing the requirement that all HBS participants purchase a minimum of 2 hours of Service Facilitation per month. Service Facilitation assists program participants and their families in developing the support plan that details how the HBS resources will achieve the goals outlined in the Personal Plan. Service Facilitation also interfaces on behalf of participants on issues such as maintaining Medicaid eligibility, processing PSW payroll with fiscal intermediary agencies and navigating both public and private sector disability system organizations. Individuals who choose to opt out of Service Facilitation after July 1, 2017 will be responsible

for performing these duties independently.

<http://www.dhs.state.il.us/page.aspx?item=93849>



## The Division is changing the name of Service Facilitation.

It is officially known in the Waiver(s) as Information and Assistance in Support of Participant Direction. In Illinois, we will be referring to it as Self Directed Assistance (SDA).

## Remembering... Sheila Romano



Illinois lost a devoted leader for community inclusion this year! Sheila T. Romano, Ed.D., age 53, a longtime resident of Naperville, IL, passed away peacefully on March 12, 2017 at her home, surrounded by family and friends. She was born on May 31, 1963 in Chicago, IL and grew up in Addison, IL. Sheila had a passion for working with people with intellectual and developmental disabilities. She started her career working with the Ray Graham Association, later became a Special Education teacher at Lisle High School and then served as the Director of the Illinois Council on Developmental Disabilities for 17 years. Her love for people and especially self-advocates will truly be missed. RIP!

# Home-Based Services Program:

## FREQUENTLY ASKED QUESTIONS

### 1. What is the Home-Based Service Program?

The Home-Based Service (HBS) program is one option available to children and adults with intellectual and developmental disabilities through the Medicaid Waiver program. The HBS program provides individuals with a monthly allotment they can use to purchase needed services and supports that allow a person to continue to live in the family residence or a live in their own home in the community.

### 2. How many people are in the HBS program in Illinois?

6,784 adults and 1,368 children participated in the HBS program as of 12/31/16.

### 3. How much money is available to people in the HBS program?

Adults participating in the HBS program receive a monthly allotment of \$2,205 which is used to purchase services; children in special education receive a monthly allotment of \$1,470 to purchase services.

### 4. How can my family member participate in the HBS program?

If your family member is selected through the Prioritization of Urgency of Need for Services (PUNS) to receive Medicaid Waiver services, you can select this program from among the Medicaid Waiver options that your Independent Service Coordinator shares with you. If you feel that your family is in a crisis situation, you can ask your Independent Service Coordination (ISC) agency about applying for crisis funding.

### 5. What change is occurring in the Home-Based Services (HBS) program?

Effective 7/1/17, HBS participants will now have the choice whether to purchase Service Facilitation (SF) from a community agency.

### 6. Why is this change occurring?

The federal agency that oversees the Medicaid program, has informed Illinois that the current practice of requiring HBS participants to

purchase Service Facilitation is no longer permissible, and that HBS participants must be free to choose whether or not they want to purchase this service.

### 7. What does a Service Facilitator do?

Service Facilitators provide skills training to enable families and participants to independently direct and manage self-directed services. They provide information and assistance in recruiting, hiring, communicating with, and managing Personal Support Workers. They provide assistance with budgeting and funding allocation management. They provide training and assistance with completion of timekeeping and other employer-related tasks required to interface with the Fiscal Management Agency.

### 8. Who will be responsible for completing Service Facilitator duties if I choose not to purchase it?

If you choose not to purchase Service Facilitation, you will be responsible for completing the tasks which are presently completed by a Service Facilitator.

### 9. What happens to the current money being spent for Service Facilitation if I choose not to continue purchasing it?

Your total monthly allocation does not change; if you choose not to continue purchasing Service Facilitation, you can use the money you are currently spending on Service Facilitation to purchase other waiver authorized services.

### 10. I'm not sure what I should do, is there someone I can talk to in person about this decision?

Yes, your current Service Facilitator and Individual Service Coordinator (ISC) can assist you in understanding the options available to you and assist you to decide what's best for you and your family.

### 11. If I choose not to purchase Service Facilitation, can I change my mind?

Yes, choice is an important quality within all Medicaid Waiver programs. However, agencies are not required

to provide Service Facilitation and some agencies are considering whether this is a service option they will continue offering in the future. Your ISC can help you find out which agencies in your community will be offering this service in the future and share information with you on how to contact them if you are interested in resuming Service Facilitation.

### 12. What is the difference between a Service Facilitator and an Individual Service Coordinator?

Individual Service Coordinators fulfill the conflict-free case management duties that the federal government requires each state to include in their Medicaid Waiver program. "Conflict-free" means that ISC agencies only provide that service and do not also offer program services. The specific requirements that ISC's fulfill include:

- Determine eligibility for Waiver services;
- Advocacy;
- Development of a Person-Centered Plan to guide service delivery;
- Referral and linkage to services and resources;
- Service monitoring;
- Conflict resolution; and
- Monitoring of a person in the DD Waiver to ensure the health, welfare, and safety.

Service Facilitators provide skills training to families so that they can more independently direct and manage self-directed services. They will assist the participants and families with issues related to hiring and managing personal support workers. See Question #7.

### 13. Has the state received input about the changes to the HBS program?

Yes, the state has established a workgroup, consisting of a wide range of stakeholders including self-advocates, families, service providers, ISC agencies, statewide membership associations and state agency personnel to assist in creating resources and materials to help individuals and families

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# Frequently Asked Questions Regarding Service Facilitation and the Home-Based Services Program

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understand the pending changes and what options they have. The workgroup continues to meet and share ideas and input with the state regarding Service Facilitation and other aspects of the HBS program to assure that everyone understands the purpose of the HBS program and requirements for participants.

## 14. I've heard about Person Centered Planning; how does this affect the HBS program?

Person Centered Planning is another requirement that Illinois must comply with to continue to receive Federal Medicaid Waiver funding. Person Centered Planning must be completed by a "conflict-free" entity that does not also provide direct services. Illinois is presently training ISC agencies on new tools

that will be used for all participants in Medicaid Waiver programs, including the HBS program. The ISC will meet with the person and others the person invites to develop a plan that will guide service delivery. The plan address the areas listed below, recognizing that not all areas will be priorities or equally important for all people:

- Relationships and Social Status
- Life at Home and in the Community
- Career
- Health and Wellbeing
- Choice and Decision-Making

The ISC will review ongoing service delivery to assure that services the person is receiving address the priorities outlined in the person-centered plan and are supporting

the achievement of outcomes included in the plan.

## 15. If I choose not to continue to purchase Service Facilitator services, who can I call if I have a problem?

Your first contact should be with your Individual Service Coordinator to see if they can assist you or direct you to a resource that may be helpful.

## 16. If I choose to continue purchasing Service Facilitation, do I have to make a commitment to purchase it for a designated period?

Individual agencies may establish their own policies and practices for Service Facilitation requirements so that they can make hiring and other decisions necessary to assure the availability of sufficient personnel to provide the service.

## Resources for Home-Based Services Program Participants

The below topics include areas where individuals/families will need to address issues that may arise if they choose not continue purchasing Service Facilitation as a component of the Home-Based Services program. This list is not intended to be exhaustive, but rather serve as a starting point for exploring and accessing resources that may be helpful in completing duties currently performed by Service Facilitators.

TOPIC	AGENCY	WEBSITES
Medicaid eligibility and maintaining Medicaid	Illinois Department of Healthcare and Family Services	<a href="https://abe.illinois.gov/abe/access/">https://abe.illinois.gov/abe/access/</a>
Social Security, Supplemental Security Income	SS Administration	<a href="https://www.ssa.gov/">https://www.ssa.gov/</a>
Supplemental Nutrition Assistance Program (SNAP) and other benefits I may be eligible to receive	Illinois Department of Healthcare and Family Services	<a href="http://www.dhs.state.il.us/page.aspx?item=30357">http://www.dhs.state.il.us/page.aspx?item=30357</a>
Opening a case with the Division of Rehabilitation Services	Illinois Division of Rehabilitation Services	<a href="http://www.dhs.state.il.us/page.aspx?item=29736">http://www.dhs.state.il.us/page.aspx?item=29736</a>
Personal Support Workers - hiring, requirements, terminating	Illinois Department of Human Services, Division of Developmental Disabilities Waiver Manual	<a href="http://www.dhs.state.il.us/page.aspx?item=45227">http://www.dhs.state.il.us/page.aspx?item=45227</a>
Payment/timesheets for Personal Support Workers	Fiscal Employer Agents-Aces\$ Public Partnerships, PPL	<a href="http://www.dhs.state.il.us/page.aspx?item=48374">http://www.dhs.state.il.us/page.aspx?item=48374</a>
Tax requirements for Personal Support Workers	Fiscal Employer Agents-Aces\$ Public Partnerships, PPL	<a href="http://www.dhs.state.il.us/page.aspx?item=48374">http://www.dhs.state.il.us/page.aspx?item=48374</a>
Learning about services I can purchase through HBS	Independent Service Coordination Agency	<a href="http://www.dhs.state.il.us/page.spx?module=12&amp;officetype=3&amp;county=">http://www.dhs.state.il.us/page.spx?module=12&amp;officetype=3&amp;county=</a>
What to do if I'm unhappy with my ISC	Independent Service Coordination/Individualized Service and Support Advocacy Transfer Request	<a href="http://www.dhs.state.il.us/page.aspx?item=83824">http://www.dhs.state.il.us/page.aspx?item=83824</a>
How to apply for an accessibility modification award	Illinois Department of Human Services, Division of Developmental Disabilities Waiver Manual	<a href="http://www.dhs.state.il.us/page.aspx?item=53193">http://www.dhs.state.il.us/page.aspx?item=53193</a>
What to do if I or my family member is in crisis	Independent Service Coordination Agency	<a href="http://www.dhs.state.il.us/page.spx?module=12&amp;officetype=3&amp;county=">http://www.dhs.state.il.us/page.spx?module=12&amp;officetype=3&amp;county=</a>
Who can I contact if I have further questions	Division of Developmental Disabilities	Staff Members: Dave Adden 217-524-0848 <a href="mailto:Dave.Adden@illinois.gov">Dave.Adden@illinois.gov</a> David Donner 217-524-2521 <a href="mailto:David.Donner@illinois.gov">David.Donner@illinois.gov</a> Jennifer Elders 217-558-1426 <a href="mailto:Jennifer.Elders@illinois.gov">Jennifer.Elders@illinois.gov</a> Andrea Medley 217-524-2520 <a href="mailto:Andrea.Medley@illinois.gov">Andrea.Medley@illinois.gov</a>

<http://www.dhs.state.il.us/page.aspx?item=93376>

# 5th Informational Seminar

March 23, 2017 – Heritage Plaza

We would like to take this opportunity to say thank you to all of the families, self-advocates, professionals, vendors and friends who help make our 5th Annual Informational Seminar a success!

A special thank you to our presenters: Barry Taylor, Sherri Schneider and Benji and Brian Rubin; they



FAMILY SUPPORT NETWORK

were outstanding. Thank you to our special guests: Director Fenton, Lore Baker and Ronnie Cohn, Ligas Court Monitor. We are all better informed and ready to continue the fight!

A special thank you to Pastor Ragland and TBCOC for continuing to partner with the Arc of Illinois.



Together we can make a difference!

# Legislative Update with Phil Milsk



Phil Milsk

## **HB 109**

**G.Harris/J. Cullerton**

**Summary:** FY 2017 Stop Gap Budget-Includes Life Span \$\$  
Passed House-Senate 3rd Reading Support

## **HB 737**

**Meier/Righter**

**Summary:** CILA/Revoked Licensee/Access to Resident and Information and Link with P & A Agency  
Passed House-Senate 3rd Reading Support

## **HB 739**

**Meier/Righter**

**Summary:** CILA/Revoked Licensee Barred from new license  
Passed House-Senate 3rd Reading

## **HB 740**

**Bellock/Righter**

**Summary:** CILA-Securely Store Resident ID Information  
Passed House-Senate 3rd Reading

## **HB 741**

**Bellock/Righter**

**Summary:** CILA-Extend Temporary Permit from 6 mos. to 2 yrs.  
Passed House-Senate 3rd Reading

## **HB 742**

**Bellock/Righter**

**Summary:** CILA-Revocation of License/Extend DHS-OIG Jurisdiction for 1 year  
Passed House-Senate Assignments Support

## **HB 2383**

**Frese/Syverson**

**Summary:** MH/DD Facility Medication Errors Must be Reported by IDPH to DHS-DDD  
Passed both Houses

## **HB 2452**

**Bellock/Nybo**

**Summary:** CILA- DHS Must Inspect Facility Records at least once every 2 years  
Passed both Houses

## **HB 2482**

**Hammond/Weaver**

**Summary:** Changes various references in statute from Workforce "investment" to Workforce "Innovation"  
House/Motion to Concur w/ SA 1 Recommended for Adoption

## **HB 2641**

**W.Davis/Bennett**

**Summary:** Creates Task Force on Disabilities and Criminal Justice House/Senate Amendment 1 Recommended for Adoption-Extension of Deadline to June 30, 2017  
ARC Bill-Support

## **HB 2665**

**W.Davis/Silverstein**

**Summary:** Training for Guardians appointed for adults with disabilities w/in 1 year. Exempts Cook Co.  
House/Senate Amendment 3 on Concurrence Calendar Extension to June 30

## **HB 2959**

**Fine**

**Summary:** Incorporates Pre-existing Condition Exclusion Prohibition into IL Law  
Passed both Houses Support

## **HB 3110**

**Currie/Jones**

**Summary:** Social Services Agency Contract with State-Termination Notice Required  
Passed both Houses Support (Passed in 2016 and Vetoed)

## **HB 3163**

**Manley/Bennett**

**Summary:** ABLE Accounts Contribution up to \$10,000/year deductible from State adjusted gross income  
Senate-3rd Reading Support

## **HB 3899**

**Jimenez**

**Summary:** Changes State Use Program re qualifications of providers and strategic plan  
Passed both Houses Same as SB 1274

## **HR 61**

**Meier**

**Summary:** Urges Congress to investigate IL DD advocacy groups receiving federal funding  
Assigned to House Special Needs Committee Oppose

## **HR 272**

**Bellock**

**Summary:** Urges US Dept. of Labor to designate DSP as its own occupational classification  
House-Calendar Order of Resolutions Support

## **SB 84**

**Stears/Gabel**

**Summary:** DHS Task Force to review potential Fed. funding to expand home and community based options.  
Passed both Houses Support

## **SB 955**

**Stears**

**Summary:** DSP Wage Increase to \$15/hr and rate adjustment  
House-2nd Reading/Deadline Extension to 6/30 Support

## **SB 1274**

**Connelly/Costello**

**Summary:** Changes State Use Program re-qualifications of providers and strategic plan  
House Rules-Dead Bill Same as HB 3899

## **SB 1353**

**Stears**

**Summary:** Personal needs allowance increase to \$60/mo. for CILA, SMHRF, ICF-DD, MH/DD Act Facility  
Passed both Houses Support

## **SB 1405**

**Stears**

**Summary:** Raises Personal Needs Allowance to \$100/mo. in CILA and SMHRF  
Senate 2nd Reading

## **SB 1453**

**McCann**

**Summary:** Creates a Supported Employment program for State employment  
Passed Senate-In House Support

## **SB 1522**

**Stears**

**Summary:** DHFS-Medicaid Managed Care LTCSS Compliance with Fed. Rules  
Senate 3rd Reading-Deadline Extended to 5/31/17

## **SB 1747**

**Righter**

**Summary:** CILA/Revocation: Denial of New License  
Senate 3rd Reading-Deadline Extended to 5/31/17, See HB 739

## Someone You Should Know!



Meg Cooch,  
Executive Director  
Arc of Illinois

With almost 20 years of nonprofit experience, **Meg Cooch** brings a passion for disability, aging and health policy, advocacy and organizing with her to the Arc of Illinois.

Most recently, Meg served as the first Executive Director of the Illinois State Alliance of YMCAs, overseeing the formal development of the organization and leading the state public policy efforts and programmatic initiatives.

Prior to moving to Chicago, Meg worked on federal level disability policy in

Washington, DC as the Director of Policy and Advocacy for Lutheran Services in America Disability Network and as the Deputy Field Director for the Alliance for Retired Americans.

Meg also has local experience working directly with individuals with disabilities, seniors, families and service providers at Planning for Elders, a grassroots San Francisco-based advocacy organization, where she worked in many capacities including as Executive Director.

For the past three years, Meg has served on the Board of Directors of the Arc of Illinois and currently is the public policy chair. Meg has a bachelor's degree from the University of Virginia and master's degree in public policy from Harvard's Kennedy School of Government.

She lives in Chicago with her husband, Justin, and two children, Persephone and Ezekiel.

## Save the Dates!

**October 3, 2017**  
**Living With Autism**  
*conference at the Hilton in Lisle*

This year one of our Keynote Presenters is Ron Suskind, a parent and the award winning author of "Life Animated." Ron will share his family's two-decade struggle with regressive autism and their transformation from a quiet solitude to animated communication!



**September 14, 2017**  
**Update on Health Care Reform for Children and Adults with Special Needs**  
*at the Doubletree Hotel in Alsip*

**January 23, 2018**  
**14th Annual QIDP Leadership Conference**  
*at the Doubletree Hotel in Alsip*

## Legislative Update

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**SB 1748**  
**Righter**  
**Summary:** Comprehensive CILA Reform bill including language from HBs 737, 740, 741, 742  
Passed both Houses

**SB 1749**  
**Righter**  
**Summary:** CILA: Extend Temporary Permit to 2 years  
Senate 3rd Reading-Deadline Extended to 5/31/17, See HB 741

**SB 1750**  
**Righter**  
**Summary:** CILA/Extend

OIG Jurisdiction 1 year  
Senate 3rd Reading-Deadline Extended to 5/31/17  
See HB 742

**SB 1751**  
**Righter**  
**Summary:** CILA/Revoked License: Inform Residents of Rights  
Senate 3rd Reading-Deadline Extended to 5/31/17, See HB 737

**SB 1851**  
**Hunter/Gabel**  
**Summary:** Changes Medicaid provisions to rename LTC for under age

22 to "Medically Complex for DD Facility"  
House-Re-referred to Rules-Dead Bill

**SB 6**  
**Steans/G.Harris**  
**Summary:** SFY 2017 Supplemental Budget and SFY 2018 Budget  
House-Second Reading

**SB 9**  
**Hutchinson/W.Davis**  
**Summary:** Comprehensive Senate Revenue Bill  
House-Second Reading-Deadline Extension to 6/30

**SB 42**  
**Manar/G.Harris**  
**Summary:** SFY 2018 Budget Implementation Bill  
House-Second Reading-Deadline Extension to 6/30

**SB 1719**  
**Biss/Welch**  
**Summary:** Raises Tax on Investment Management Transactions  
House Second Reading-Deadline Extension to 6/30



FAMILY SUPPORT  
NETWORK

## Family Support Network

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E-mail:

Shirley@thearcoifll.org

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

Shirley A. Perez, Executive Director

Rhonda Dobbs, Administrative Assistant

Vivienne Harvey, Advocacy Coordinator



Family to Family Director:

Faye Manaster

866-931-1110 English

800-588-7002 Spanish

### **The Arc Of Illinois Family To Family Health Information Center**

The Arc of Illinois Family to Family Health Information Center is the Family Voices State Affiliate Organization.

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through this national network, Family Voices provides families tools to make informed decisions, advocates for improved public and private policies, builds partnerships among professionals and families, and serves as a trusted resource on health care.

#### **We offer:**

- Information and referral
- Health-related training opportunities for families, youth, and professional helpers (providers)
- Specialized training for parent leaders and organizations
- Linkages to local, regional, statewide and national partners

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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.