

Family Support Network

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June, 2018

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

Hello Family Support Network Family and Friends,

Thank you for your faithful commitment to us! As you know the Family Support Network is one of the many programs of the Arc of Illinois, whose Executive Director is Meg Cooch. Together we have experienced yet another year with its unique opportunities and challenges. The Arc continues to lead the way in advocacy for people with Intellectual /Developmental Disabilities (I/DD) and their families. This year we have worked urgently with legislators, Medicaid experts, and policy makers in both the Department of Human Services as well as in Health and Family Services to correct Medicaid errors that resulted from the roll-out of a new computer system, which caused the sudden loss of services for many families.

We are also working with the Department of Human Services to address issues and concerns around the discontinuation of Service Facilitation (as we have known it) in the Home Based Service Program; and the addition of an optional service that is new to many of us. 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 Direction Assistance (SDA).

Please keep in mind that we are in the forefront of these issues in great part thanks to you. Your calls, letters, and emails enable us to offer you resources and advocacy support, but also give us early warning of large systemic issues that affect many other individuals and families.

Happily, in spite of these and other challenges, I am excited to say that as of the writing of this newsletter, Republican Gov. Bruce Rauner has signed into law a \$38.5 billion spending plan for state government, approving a full budget for the first time since he took office in 2015. The spending plan for the fiscal year that begins July 1st breezed through the state legislature with strong bipartisan support - in marked contrast to previous years. You may want to call or email your legislators and thank them for helping to make this happen.



Shirley Perez
Executive Director,
Family Support
Network of Illinois

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Revenue from the tax increase is incorporated in the new budget. The budget adds \$350 million to a new K-12 school funding formula enacted last year, increases higher education spending by 2 percent, reduces cuts in state aid to local governments, and appropriates \$1.3 billion to pay previously incurred expenses. About \$270 million from the sale of the state's main office building in Chicago is once again counted on in the budget, even though that transaction remains unrealized.

Several personnel changes this year are worthy of note. Director Greg Fenton retired as Director of the Division of Developmental Disabilities (DDD) after 3 years in this position and many years in service to the Department. We want to thank him for his dedication to people with disabilities throughout his 36 year career. Individuals with I/DD and their families can testify to his commitment, accessibility, and kindness. Melissa Wright has temporarily come out of retirement to become the Interim Director of the Department. She is a former Director of DDD, who worked her way up through the ranks over a 20 year

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“The Arc continues to lead the way in advocacy for people with Intellectual – Developmental Disabilities and their families.”



Deb Fornoff
Director
Illinois Life Span
Program

Illinois Life Span provides information related to advocacy, services, and supports for individuals of any age with intellectual and developmental disabilities and their families, and the professionals who serve them. Information is provided via their website at www.illinoislifespan.org, through their toll-free line at 1-800-588-7002, via e-mail, and at events statewide. Before Illinois Life Span, there was truly nowhere for families to turn for help with the broad array of questions that arise about systems, services, and supports.

The Illinois Life Span Program continues to grow and evolve. Our website was reconfigured a few years ago to better reflect the wealth of information available online and we made it simple to find the most commonly requested local resources. Many families still need and want to connect with a person who can help them find the information and resources they need, so access to a knowledgeable individual to help answer your questions and find resources continues to be a most important service of our program.

Our Monthly Lunchtime Webinars are a popular new offering from Illinois Life Span. Designed with

***“Before Illinois Life Span,
there was truly nowhere for
families to turn for help”***

families in mind to cover a variety of topics over the course of the year, these hour-long webinars have provided information on topics from the ABLE Act and Supportive Housing to Special Recreation and Special Olympics in Illinois! There is also a page with links to the webinar registration information for upcoming webinars and the recordings and presentations from past webinars.

Illinois Life Span is proud to welcome Missy Kichline as an Outreach Coordinator for Southern Illinois! Missy worked for the Ligas Family Advocate Program of The Arc for the last four years so many of you are already familiar with Missy. Missy lives in Godfrey and her middle daughter is a Ligas Class Member. She has knowledge and experience in working with issues concerning the Rehabilitation Act, ADA, IDEA, transportation and the Illinois Developmental Disability Service System. Missy holds a BS in MIS from SIUE and a Master of Arts in Teaching. She is committed to expanding opportunities and supports for people with intellectual and/or developmental disabilities in community.

Cindi Swanson is a veteran of the Illinois Life Span Program, serving as a Resource Specialist and helping with Outreach in the Chicago suburban area as well. Cindi and her family are active advocates in the Naperville area and Cindi has her

Let's Do Together What We Can't Do Alone! | Shirley Perez

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period, serving as Chief of many of the DD Division's bureaus during that time, ultimately serving as Director from 1999 – 2002. After leaving the Division, she held several upper level administrative positions at the Illinois Department of Healthcare and Family Services (IDHS), including the Director of Operations for the Division of Community Health and Prevention and the Director of the Office of Business Services. She also served as Governor Rauner's first Chief of Staff prior to her retirement in December 2015.

Illinois Department of Healthcare and Family Services Director Felicia Norwood has accepted a position in the private sector. Per Secretary Dimas, "Director Norwood has been steadfast in her efforts to ensure the state's most vulnerable citizens have access to quality healthcare. She led Illinois' Medicaid reboot that will deliver better services at a better price. Her leadership was critical to restructuring our managed care network into a more effective and efficient delivery model while integrating mental health into the delivery of services. Her dedication and

commitment led to one of the most significant developments in the history of our health programs, securing a \$2 billion federal 1115 waiver — "Better Care Illinois" — a multi-agency effort to create a nation-leading approach to behavioral health." The search for her replacement is currently underway. Director Norwood's last day with the Administration is June 15, 2018, and we wish her well in her new endeavor.

The FSN/Ligas 6th Annual Informational Seminar was a huge success. We are so grateful to Ryan Croke, Executive

MSW in Social Work. Cindi has been an advocate for people with disabilities since the birth of her son, Adam. Adam, who has Down syndrome, is now a young adult leading a busy and fulfilling work and social life. Cindi has a particular interest in employment issues and building social capital and has presented on these and other issues for many years.

Deb Fornoff is the Director of the Illinois Life Span Program and has been with the program since shortly after it was founded. Deb's background includes an MS in Counselor Education, working as a Parent Liaison in Early Intervention, and for the Family Support Network with Charlotte Cronin. Deb and her family live in central Illinois and her son Brad, who has Down syndrome, has been the motivation for her advocacy efforts over the years.

Although a place to call for information and resources may sound like a simple service, if you don't know where to turn, it can be critical. Known as the "411" for disability information, this program helps find resources and assistance for the broad range of issues that families experience in their journey through the multiple, complex systems encountered over the lifetime of their loved ones with disabilities. Illinois Life Span has been there for more than 17 years to share information and direct Illinois families to available resources. Please let your legislators know that Illinois families continue to need this important service and that you support the Illinois Life Span Program of The Arc of Illinois!

Director, Illinois Network of Centers for Independent Living, Barry Lowy, Director, Office of the State Guardian, and Ronnie Cohn, Ligas Court Monitor, for their outstanding presentations and willingness to answer questions and talk one on one with families. We will continue to empower our families through quality education and firsthand information.

The number of vendors was impressive. It is so gratifying to meet both new vendors and see those faithful friends who come back year after year. But this event simply wouldn't happen without our inspiring FSN members and self-advocates and families who seek to

educate themselves about important issues and mentor other families who are at the beginning of their struggle. We are all better informed and ready to continue the fight!

It has been my continued privilege to meet families who are exploring new options thanks to the Ligas Consent Decree – and demonstrating their own unique interpretations of the 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. Our diversity, enthusiasm, and dedication when shared make all of our lives better. Thank you, FSN community. You make our advocacy family strong.

Sincerely,

Shirley A. Perez
Executive Director



Meet The Arc's Executive Director

Meg Cooch has now served as Executive Director of The Arc of Illinois for over a year. We appreciate her deep commitment to the organization and to all it represents, to the disability community, and to the individuals and families we serve. She is engaged with our mission and vision on every level and she encourages



Meg Cooch
Executive Director
The Arc of Illinois

members of both the Arc Staff and the Arc Board to examine our roles and look for ways to improve our performance. Her energy and enthusiasm are felt by all who come in contact with her. We look forward to her continuing inspiration in the years ahead.



We're on the Web!
See us at:
www.familysupportnetwork.org



The 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 Need (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 Independent Service Coordination Agency (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.

This has been a year of changes for our program. Two of our original Ligas Family advocates have moved on to other positions, we are so grateful for their years

of services and wish them well. The Ligas Family Advocate position for the northern part of the state has been filled and you will learn more about her in this newsletter. We are finalizing the hiring of the

Ligas Family Advocate for the southern part of the state. We have been able to meet the deliverables for this program and have been granted a contract for 2019. We continue to work with Ligas class members from previous PUNS selections and a total of 848 Ligas class members selected during the April 2017 PUNS selection have been contacted

and information shared with the following breakdown: 633 in the Northern part of the state and 215 in the Southern part of the state.

We continue to 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.

"This has been a year of changes for our program."

Contact information for this program:

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www.LigasFamilyAdvocateProgram.org
www.facebook.com/Ligasfamilyadvocateprogram

Disability Policy Seminar • Washington D.C.



Ligas Family Advocate for Northern Illinois

It's our pleasure to introduce Mary Dixon, The Arc's Ligas Family Advocate for Northern Illinois. She will be working with Ligas class members served by the following ISCs: Suburban Access, CAU and DayOnePact.

We asked Mary to tell us a little bit about herself, so the following are her words:

My husband and I live in the southwestern suburb of New Lenox. We have two boys, Andrew, age 20, and Steven, age 18, both of whom are home for the summer from their studies at college. We also have three cats -Luigi, Johnny Toews and Patrick Kane. Yes, we are Blackhawks fans!

My interest in being a Ligas Family advocate comes in large part from my desire to see my nephew Robbie, a person with autism, living a meaningful life in his community, with employment. Robbie is 21, lives at home with his parents and needs daily help with many aspects of life. One of his current goals is to find a job. When we get together with extended family we regularly enjoy a Jeopardy game that we all play with Robbie. Subjects such "unusual fish", "dinosaurs" or "Disney songs" give Robbie a chance to share how much he knows about some of his favorite topics. He also loves to sing, and at 6'3" with a booming voice, can belt out his favorite song (You're a Mean One, Mr. Grinch) in perfect syncopation.

Being a Ligas Family Advocate for The Arc of Illinois allows me to channel my hopes for adults with developmental disabilities into advocacy on their behalf. Thanks to the Ligas case, the fight for adequate state resources of sufficient quality, scope and variety for meaningful lives in the community continues. I look forward to my work with individuals and families in this effort!



Mary Dixon
Family Advocate
Northern Illinois

My prior work as an advocate includes fighting in state court as an Assistant Public Defender for those accused of crime, in Springfield for the ACLU-IL for equality in governmental policies and finally, for the past almost two years, working as the ACLU-IL's Health Justice Director to protect gains made by the Affordable Care Act from repeal efforts of Congress and watering down by the Trump Administration.

We look forward to working with Mary and we are so happy that she understands our issues and shares our concerns.

Spring Fling

Family Support Network Family Training on Navigating the State System and Natural Supports
April 14, 2018 - Bogan Technical High School, Chicago.



Family Transition Project

2017-2018 Year in Review



Katherine
Hamann
Director
Family Transition
Program

This year The Family Transition Project has exciting developments in our program to report. One basic never changes though. We are here to serve Illinois citizens with intellectual and developmental disabilities (I/DD) and their families. We offer hope, support, and advocacy to individuals with I/DD who wish to transition from institutional living to community living and to their families. So our new pilot program, FTP Transition Mentors, is closely aligned with our purpose. The program involves four self-advocates who have lived in state operated developmental centers and now live and work in the community. They are from different areas of Illinois. Getting everyone together for their first training session in Bloomington/Normal this June took some planning, but succeeded brilliantly. Transition mentors will provide their unique firsthand perspective when the FTP talks to individuals, families, family groups, advocacy groups, professionals in the I/DD field, legislators, members of the general public, and even members of the Media. Since it's a pilot program, the mentors themselves are helping determine the direction. It's already clear that they have a lot to offer in the way of insight. Transition can be more challenging for the family than for the person who is making the change. Families tend to worry about safety and quality of services in their

loved one's new life. Mentors talked more about quality of life issues that had initially made them anxious about going somewhere new – will I have my own room? Will I be able to keep in touch with friends? Do I have to go to a workshop every day? They are completely cognizant of the word "mentor" in their job description. They understand that their experiences with both institutional and community living and their ability to talk about the differences between the two qualifies them to teach the rest of us. They are eager to talk to people currently living in SODCs (state operated developmental centers) and their families. They are positive examples and bringers of hope.

Every year the FTP talks to individuals and families who dream of a better life in the community.

Every year our goal is to support them during the transition. And every year we learn along with them what is needed to make their transition successful. Funding is an obvious issue. People who are living in SODC's have funding for community living already available. They don't need to fight that battle. Often, though, they will need some additional funding for extra supports or home modifications in order to move. This is not necessarily a deal breaker and has been accomplished for many. What can be more perplexing is finding a situation that is the right fit for someone. Our state continues to lag behind others in the variety and flexibility of services available and everyone knows there is a shortage of direct support professionals. On the individual level, though, where most of us live, sustainability can boil down to small details. Eating our favorite foods, wearing clothes we find comfortable, surrounded by congenial companions, feeling

unhurried by others' schedules, working at meaningful jobs, enjoying space and privacy – none of these small details is really small because it adds up to being treated with respect and feeling at home in our world. We continue to wish this for everyone we talk to and we stay with individuals and families through the ups and downs of their transitions. We have seen great and small successes over the years. Sometimes

all we can do is listen. Several times I have been moved to hear families say, "I don't know anyone else who understands what I'm going through." Then I will get a call from someone who has been struggling with his work situation for years and just got a big promotion! As a family member I know these ups and downs personally. That's why the FTP is always available to listen and we seek outside help if we can't help.

This is also where teamwork comes in. The Family Transition Project continues to be grateful to the other programs of the Arc – particularly the Family Support Network, Life Span, and Family to Family – who always extend their expertise to families with questions outside of our scope. We all know how a single voice can cut through a jumble of

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Family Transition Project

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information and misinformation and set us on the right track. For me and the families I talk to that voice often belongs to the FSN Director, Ms. Shirley Perez! We are thankful for her wise and kind support.

In spite of a short lay-off last year, the Family Transition Project kept up an action packed schedule. We still play a large role in the life of the Going Home Coalition (more about that in a separate article) and work with other advocacy groups, such as Supporting Illinois Brothers and Sisters, and various committees, agencies, and organizations around the state. Many meetings and events were highly informative, such as the Disability Policy Seminar in Washington, D.C. Still, it was the contacts made with families, self-advocates, legislators, professionals, and advocates that created so many memorable moments. Self-advocate Brian Dixon was invited to speak at Congressman Brad Schneider's Disability and Inclusion Round Table in February. Brian and I had met at past advocacy events and he asked for help finding his way around the Capitol in Springfield. It was a joy to meet Brian Donovan last fall, the film maker of Kelly's Hollywood, a brother who did the exact opposite, helping his sister achieve her dream of celebrity, and keeping her dream alive. The Speak Up and Speak Out Summit is an amazing repository of stories. Every year I hear something new about someone I thought I knew. This year a woman told me with great pride that she is leaving her ICF for real community living, as she has dreamed of for years. Participating in "Policy, Advocacy, and You/Why Personal Stories Matter" was a crash course in using our stories to effect change. I met someone later at the 6th Annual FSN Informational Event who said she had seen me there and thanked me for sharing my sister's story. The Family Transition Project is all about sharing stories. We also share hope.

**Please feel free to contact me.
708/465-2827**

Thoughts from one of our newest staff members at the Arc Family Support Network: **Shakari**

Becoming a staff member of The Arc of Illinois has been a great opportunity for me. I am amazed by how many lives this organization touches. So many different organizations are partners in our efforts to support people with disabilities. My best friend works for Cornerstone, an agency that I only realized after I started working at The Arc is an active chapter member. Once we re-connected and learned more about each other's jobs we were able to start sharing helpful information to the benefit of the individuals and families we serve. It's refreshing to work for an organization that is known and respected by people I respect and to be part of a major movement that is strictly nonprofit - providing training and assistance to individuals and families in the disability field. Above all, I am proud to be part of an organization that is committed to empowering people to advocate for themselves.



Shakari

SPECS

Advocacy Coordinator Vivienne Harvey, providing training in the 10th Ward Alderman Susan SPECS Parents Family Support Group in March of 2018





Self-Direction Assistance (SDA)

Based on the concerns and additional questions the Division received after the SDA webinar on May 8, 2018 we decided it was necessary to provide further guidance and clarification.



According to the Illinois Department of Human Services Medicaid Waiver approved by Centers for Medicare and Medicaid Services (CMS), Self-Direction Assistance provides information, assistance and skills training to individuals/families so that they can self-direct their services. SDA is not a new name for Service Facilitation, as previously (and mistakenly) stated on the DHS/DDD Website; rather it is a new service. All duties provided under SDA must fall within the description in our approved Waivers. In addition, these services should not overlap those provided by the ISC; these roles must remain separate. In order to streamline the services provided and to bring clarity to the guidelines, the following information is being provided:

- Effective immediately, SDAs are no longer required to develop an Implementation Strategy for the services they will provide as a SDA. If an individual/family purchases SDA services, the details of what will be provided should be included in the Employer of Record Implementation Strategy. The SDA Frequently Asked Question (FAQ) document from May has been updated to reflect this change.
- The Employer of Record Implementation Strategy has been updated to reflect "The SDA should not complete the form for the Employer of Record". The SDA can assist, train and provide information on completing the form/process.
- Monthly notes, often referred to as Q or QIDP Notes, are not required when providing SDA. SDA provider agencies must maintain a detailed chronological log of all activities performed for audit purposes and in order to verify their billing.
- SDA services must not include visits to monitor services. Monitoring of Waiver services is the role of ISCs and therefore is a conflict for SDAs to also monitor services. SDAs provide information, assistance and skills training. The location in which these services (provide information, assistance and skills training) occur should be mutually agreed upon between the individual/family and SDA provider.

The DHS/DDD website and previous FAQ documents will be updated to reflect this clarification.
(Source: DDD Scoop dated June 12, 2018)



Family to Family Health Information Center

The Arc of Illinois Family to Family Health Information Center is a free service for families of children and youth with special need up to age 22, funded by the U.S. Health Resources and Services Administration (HRSA) and The Arc of Illinois.

Since 2006, we have been a program of The Arc of Illinois. This May, we were told by HRSA that our program was awarded funding for three more years (until May 2021), so we have just started our 13th project year.

A collaborative project with Family Voices of Illinois, we are part of a national network speaking on behalf of children and youth with special health care needs.

There is now a Family to Family Health Information Center in each of the 50 states. All of us are parents or family members of people with disabilities and/or special health needs.

We have a toll-free information line for families to call, are active on social media, and hold an Annual Healthcare Conference for families and providers. This year, our conference will be on September 13, 2018 in Alsip.

We answer questions related to health care of children with any type of disability, special needs and/or chronic illness up to age 22, and serve the whole state of Illinois.



Going Home Coalition

The Going Home Coalition is a group of “self-advocates, family members, educators, legislators, activists, and community leaders” who believe that “everyone, no matter what challenges they may face in life, deserves the opportunity and means to live a full life in the community.” This is quoted from the GHC website: goinghomeillinois.org. Going Home also has a Facebook page – Going Home/A Full Life In the Community. In both locations you will find short videos about individuals with intellectual/developmental disabilities (I/DD) who lived in state institutions and are now doing well living in the community. Their stories and their struggles explain why Going Home Coalition members are so passionate in their desire to see Illinois put more focus on providing the kinds of services and supports families want for their loved ones with I/DD in their own home communities.

For a number of years the GHC has sponsored a large rally in the Capitol Rotunda in Springfield, followed by visits to legislators. Often the legislators aren’t available and instead of a visit

happening, packets of information are left. This year, the group decided to try hosting a series of Advocacy Days in late March/early April to encourage GHC members to visit their state legislators in their district offices and discuss the need for rebalancing funding from state operated developmental centers

“..everyone, no matter what challenges they may face in life, deserves the opportunity and means to live a full life in the community.”

(SODCs) to the community. The hope was for self-advocates particularly to begin to develop a relationship with their legislators and to share their enthusiasm for community living. Some visits were made, but the GHC continues to think of ways to make this happen on a larger scale.

In the past, GHC’s emphasis has been

on community living as a rights issue and the key to a higher quality of life. Although these points have not changed, this year the statistics were so compelling that the “leave-behind” for legislators emphasized that “Community Living Is An Investment In Our Future!” Three salient points: more than 19,000 people with I/DD are actively waiting for services, 1,685 people with I/DD are living in 7 state institutions, and an average of \$288,837.00 per person per year is the cost of living in an SODC.

Although GHC is a coalition, it has been closely linked to The Arc of Illinois since its inception. This August, GHC member organization ICDD (Illinois Council on Developmental Disabilities) is sponsoring a leadership conference to help GHC members brainstorm new goals and a new framing of our message. This is part of an initiative to revitalize our organization and expand our membership.

If you are interested in the Going Home Coalition, check out our website or Facebook page. Or contact me, Katherine Hamann, at 708/465.2827 or katherine@thearcofil.org.

Our work focuses on these six outcomes:

1. Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive;
2. Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;
3. Families of CSHCN have adequate private and/or public insurance to pay for the services they need;
4. Children are screened early and continuously for special health care needs;
5. Community-based services for children and youth with special health care needs are organized so families can use them easily;
6. Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

www.familyvoicesillinois.org | familytofamily@thearcofil.org
708-560-6703 (voice) | 866-931-1110 (toll free for Illinois families)
email us at familytofamily@thearcofil.org.



Providing Education, Information, Training, and a Network of Support

The mission of the Family Support Network (FSN) 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. As our society continues to depend on the active engagement of family caregivers for the support of individuals with I/DD, it is essential to meet the needs of those caregivers, so they can continue providing care in the community. The alternative for individuals with I/DD should not be more costly and unwanted institutions. Resources and information are all too often unavailable to those who need it the most.

The Family Support Network will help meet this needs by: Providing education, information, training, and a network of support to individuals with disabilities, their family members, and the community of service providers, professionals, and policymakers who serve them.

The FSN/Ligas 6th informational seminar was a great success – thanks to all that attended .FSN has reached and shared information to over 8,000 people which included families, self-advocates, providers, and other organizations state-wide. These activities were conducted through telephone conferences, emails, presentations, website, Facebook page and webinars including in person meetings.

July 1, 2017 – June 25, 2018, 3,030 users visited our website with over 7,613 page views, and 3,597 sessions. We conducted 75 one on one advocacy sessions, which involved helping individuals navigate DHS's website, address issues with ISCs, providers and attended staffing with families. FSN participated in 13 legislative outreach events, including presentations in the 6th, 10th, 19th, 21st. and 27th ward. FSN, advocacy coordinator and other Arc staff and families attended the 2018 Disability Seminar in Washington DC and was able to connect with over 900 advocates as we strategized about ways to fight any cuts to disability services. Many great sessions were held and as always the event culminated with a visit to the hill with legislators.

Please find a few pictures from some of our 6th FSN/Ligas Informational Seminar, state-wide Know Your Options and training events as well as pictures from Washington DC Disability seminar:

March 22, 2018 • 6th Annual FSN/Ligas Informational Seminar



Together we can make a difference!

State-wide Know Your Options • May 3, 2018



FSN/Ligas Guest Presenters • March 22, 2018



Washington DC • Disability Seminar





Phil Milsch

Legislative Update with Phil Milsch

ARC OF ILLINOIS LEGISLATIVE REPORT JUNE 8, 2018

Unless otherwise indicated, the following bills have passed both houses of the Illinois General Assembly and will be sent to the Governor within 30 days of passage. He will then have 60 days to either sign or veto the bill. The budget and budget implementation bills have already been signed into law. Chief sponsors are indicated in parentheses. Note that this is probably not a complete list of bills pertaining to disabilities, but is intended to highlight the key bills.

BUDGET

HB 109

(G. Harris & J. Cullerton)
This is the Fiscal Year 2019 budget bill. It also includes FY 2018 supplemental appropriations.

Status:

Public Act 100-0586,
effective June 4, 2018.

HB 3342

(G. Harris & Steans)
Fiscal Year 2019 budget implementation ("BIMP") bill. The bill includes a .50/hour wage increase for frontline personnel who work with individuals with intellectual or developmental disabilities in community-based agencies. It also includes adult dental coverage for adults under the Medicaid program.

Status:

Public Act 100-0587,
effective June 4, 2018.

DIVERSION HOMES

SB 2424

(Steans & Gabel)
An Arc of Illinois and Trinity Services initiative that creates a 3-year pilot program of up to 6 community residences for individuals who have significant behavioral challenges or dual diagnoses who cannot be appropriately served in CILA or short-term stabilization homes and who would otherwise be at risk of entering facility-based care. The pilot is subject to appropriation or the availability of other

funds at the discretion of the Department of Human Services.

Status:

Passed both houses.

DHS OFFICE OF INSPECTOR GENERAL

SB 3237

(Harmon & Guzzardi)
An Arc of Illinois and IARF initiative to enhance the due process rights of community provider agencies and facilities, alleged victims and guardians of alleged victims with respect to OIG investigations of abuse and neglect. The bill provides that requests for reconsideration may be filed without submitting additional evidence and must be reviewed using a multi-layered process that includes at least one person who was not involved in the original investigation. The bill also requires that the final determination on a reconsideration appeal be made by the Inspector General.

Status: Passed both houses.

SB 3179

(Murphy & Mussman)
IARF bill that amends the Department of Human Services Act to ensure that DHS OIG investigators receive ongoing training in investigations of abuse and neglect in SODCs and community agencies, and also receive ongoing training in standards and

licensure requirements for CILA and in minimum certification requirements for developmental training programs.

Status:

Passed both houses.

HB 5000

(Frese & McConchie)
Amends the Department of Human Services Act to provide that upon the completion of an investigation by the DHS OIG, the victim and the victim's guardian shall be provided with a redacted copy of the investigation report if the allegations of abuse or neglect are substantiated. The bill further provides that an unredacted copy of the investigation report, as well as the raw data, may be shared with local law enforcement, a State's Attorney's office, or a county coroner's office upon request.

Status: Passed both houses.

PROTECTION OF INDIVIDUALS WITH DISABILITIES IN THE CRIMINAL JUSTICE SYSTEM TASK FORCE

HB 4420

(Davis & N. Harris)
This Arc of Illinois bill extends the life of the Task Force created in 2017 by extending the sunset date for two years and extending the due date of the first report to the Governor and General Assembly for one year. The member appointments

were recently made by the Governor and the Task Force has not held its initial meeting.

Status:

Passed both houses.

HEALTHCARE

HB 4383

(Feigenholtz & Steans)
Requires that disenrollment of a Medicaid enrollee from a managed care organization under contract with the Department of Healthcare and Family Services must be in accordance with federal regulations whenever a contract is terminated between a Medicaid managed care plan and a primary care provider that results in a disruption to the Medicaid enrollee's provider-beneficiary relationship.

Status: Passed both houses.

HB 4165

(G. Harris & Koehler)
Provides that the State is prohibited from applying for any federal waiver that would reduce or eliminate any protection or coverage required under the ACA that was in effect on January 1, 2017. Provides that the State may only apply for such a waiver only if granted authority by the General Assembly by a joint resolution. Contains similar limitations and conditions with regard to a State application for any federal waiver under the Medicaid

Legislative Update

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program or Children's Health Insurance Program that would result in more restrictive standards, methodologies, procedures or other requirements than those that were in effect on January 1, 2017.

Status:

Passed both houses.

HB 4736

(Crespo & Koehler)
Amends the Public Aid Code. Prohibits the Department of Healthcare and Family Services from requiring children who are authorized to receive in-home shift nursing services required by EPSDT or who are eligible for Medicaid under the home and community-based waiver program for medically fragile and technology dependent children to enroll in or transition to the State's Medicaid managed care program. Provides that those children who are enrolled in the managed care program on or before the effective date this legislation shall be given the option to disenroll and receive medical assistance coverage under the traditional fee-for-service program.

Status:

Passed both houses.

EMPLOYMENT

SB 1453

(McCann & Mussman)
The bill would expand the Employment and Economic Opportunities for Persons with Disabilities Task Force by adding the Board of Higher Education, Community College

Board, Department of Central Management Services and Department of Juvenile Justice to the Task Force. It would also repeal the Interagency Coordinating Council and fold its responsibilities into the Task Force.

Status:

Passed both houses.

SB 3222

(Murphy & Hurley)
Amends the Workforce Innovation Board Act to provide for the appointment of 2 representatives of community-based organizations that provide or support competitive integrated employment for individuals with disabilities to the Board. The 2 representatives must be individuals who self-identify as persons with intellectual or developmental disabilities and who are engaged in advocacy for the rights of individuals with disabilities. The bill further requires that these individuals shall be provide reasonable accommodations to participate, if required.

Status:

Passed both houses.

ASSISTIVE TECHNOLOGY

SB 3048

(Manar & Cassidy)
IATP bill that allows the Department of Healthcare and Family Services to enter into an arrangement with the State's AT program to provide reutilized durable medical equipment to consumers under certain specified conditions. Excludes

prosthetics, orthotics and complex rehabilitation technology. Gives the consumer the option of whether to obtain a reused device.

Status:

Passed both houses.

SB 454

(Koehler & Crespo)
Amends the School Code to require written notification to parents at the initial IEP meeting and all annual review IEP meetings of the IEP team's responsibility to discuss whether the child requires assistive technology in order to receive a free, appropriate public education, and requires the notification to include the toll-free number and web address of the State's AT program.

This bill also includes provisions regarding the Chicago Public Schools following the public inquiry conducted by the State Board of Education and recommendations made by advocacy groups. For example, the bill would require CPS to provide a draft copy of the IEP to the parent no later than 5 school days prior to the IEP meeting including all relevant information collected regarding the child and copies of all evaluations conducted.

Status:

Passed both houses.

LOCAL DEVELOPMENTAL DISABILITIES BOARDS

SB 3041

(McConnaughay & Moeller)

Amends the Community Care for Persons with Developmental Disabilities Act by enabling municipalities and townships, by referendum, to appeal for regional and local funding of services for developmental disabilities. Currently the law only allows counties to levy for DD services, whereas counties, townships and municipalities can levy for mental health services.

Status:

Passed both houses.

ABLE ACCOUNTS

SB 2660

(Bennett & Breen)
Amends the Trusts and Trustees Act. Provides that, unless prohibited by federal law, upon the death of a designated beneficiary, proceeds from an ABLE Account may be transferred to the estate of a designated beneficiary or to an account for another eligible individual specified by the designated beneficiary or the estate of the designated beneficiary. Further provides that a State agency or instrumentality of the State may not seek payments from an account or its proceeds under section 529A(f) of the Internal Revenue Code for benefits paid to a designated beneficiary. Note that we are advised that this legislation conflicts with federal law regarding the claw back of certain benefits paid to beneficiaries.

Status:

Passed both houses.



We're on the Web!

See us at: www.familysupportnetwork.org

The Arc of Illinois Convention • April 2018



Beloved Health Care • May 2018



Someone You Should Know!



Janet Donahue
Director of Development
The Arc of Illinois

Janet Donahue, Director of Development for The Arc of Illinois, celebrated 25 years of commitment to The Arc and to our mission of advocacy for people with disabilities on May 24, 2018. Many of you have participated in one or more of the Arc's trainings over the past 25 years. Janet is the person quietly working in the background to make all of our events run smoothly. Because she makes it look easy, attendees often miss how much is involved. Every detail receives Janet's attention and her personal touch. In the process, she has provided networking and education opportunities for thousands of individuals, families and disability professionals, creating unique experiences that inspire, energize, and inform. One of the many highlights of her career was the creation of The Arc's Assistive Technology Program in 2015. She was instrumental in raising funds to ensure that almost 500 children and adults with disabilities

were able to access iPads that they would otherwise have been unable to obtain.

Janet is patient and helpful to co-workers and colleagues, even under pressure. But it's her passion for this work and for the families we serve that makes a real difference in families' lives. Please join the Arc staff and board members in celebrating and thanking Janet for coming to the Arc of Illinois 25 years ago and for continuing to share her many gifts with us!



Save the Dates!

Lunchtime Webinar on Supportive Housing with CSH

Jul 10, 2018 12:00 PM CDT

August 21, 2018
Full Day on Benefits
Doubletree Hotel, Alsip, IL

September 13, 2018
Health Care Coverage Options for People with Disabilities
Doubletree Hotel, Alsip, IL

October 2, 2018
Living with Autism Conference
Hilton Hotel, Lisle, IL

October 29-31, 2018 Speak Up and Speak Out Summit

(Funded by the Illinois Council on Developmental Disabilities),
Wyndham Hotel, Springfield, IL

January 29, 2019
17th Annual QIDP Conference
Doubletree Hotel, Alsip, IL

February 6-7, 2019
Leadership Conference
Hilton Hotel, Lisle, IL

March 21, 2019
FSN/Ligas 7th Annual Event
Heritage Plaza, Chicago, IL

April 24-25, 2019
The Arc of Illinois 69th Annual Convention
Hilton Hotel, Lisle, IL

May 3, 2019
Planning for the Future for Children & Adults with Special Needs

Brian Rubin, J.D., Sherri Schneider and Benjamin Rubin, J.D.,
Evanston, IL Location TBD

Please visit the Arc of Illinois' website for more information about these upcoming events: www.thearcofil.org



FAMILY SUPPORT
NETWORK

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

Shirley A. Perez, Executive Director
Shakari Asbury, Administrative Assistant



The Arc Family Support Network would like to say thank you to Rev. Dr. Alan V. Ragland and the Third Baptist Church of Chicago for their continued collaboration with the Arc in our efforts to bring resources to an underserved community. Over the past 6 years utilizing the Heritage Plaza Facility we have shared information and resources with hundreds of families, individuals and self-advocates! Thank you!

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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.