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

# **Hello Family Support Network and Friends!**

What an amazing year for the Family Support Network (FSN) at The Arc of Illinois! Thank you to each family member and self-advocate who stood together and shared their personal stories to explain the need for the "live-in caregiver exemption" in the Homebased program. Four listening sessions were held by the Illinois Division of Developmental Disabilities to gather feedback from families/stakeholders. I am proud to announce that due to your feedback from these listening sessions and ongoing discussions with stakeholders and other interested parties, the Illinois Department of Healthcare and Family Services (HFS) has reversed the initial decision and will allow live-in caregivers to be exempt from Electronic Visit Verification (EVV) requirements in the DHS-DDD HCBS waiver programs.

FSN remains grateful for our incredible, ongoing partnership with families across the state. We have worked together to advocate, explore, and connect around the needs and interests of families in the developmental disability system in Illinois. In collaboration with our community partners, programs of The Arc of Illinois, and FSN staff, we have kept focused on our core goals of keeping families together, empowering caregivers, improving support options, encouraging family participation, and making a positive difference within the disability community.

The advocacy opportunities we pursue are based on the concerns and interests of the families we serve. That includes advocating for accessibility in living options and transportation, providing continued outreach about Electronic Visit Verification, and ensuring families have access to accurate and timely information about the developmental disability system.

Families contacted us this year seeking therapeutic resources, requesting assistance in improving the quality of supports their loved ones receive, asking for guidance in improving family-provider communication, and offering their support and advocacy for many disability issues that concern all of us. Our 1:1 advocacy work is at the heart of our program, and we are encouraged by the number of families who reach out for support and guidance during particularly challenging moments in their lives. Families have trusted us to walk with them through some of the most difficult situations they encounter in supporting a loved one with a disability.

FSN enjoys our continued partnership with Rubin Law and Brian and Benji Rubin. In 2023, we welcomed back The Future Planning Webinar Series. These presentations allow participants to explore core needs in future planning. We shared information about waiver options, DD system navigation and Home-Based Supports, while encouraging families to build a flexible, creative, and individualized plan in collaboration with loved ones.

Our 11th Informational Seminar in March was a great success. We were deeply gratified by the turnout and the lively participation of attendees. Experts in the disability field shared their knowledge of the Ligas Consent Decree, Future Planning, the Role of the Independent Service Coordination Agency, the Power of Storytelling, and Key Updates from the Division of Developmental Disabilities. We are grateful for the many professional partners who allow us to provide vital information year after year. Mark your calendars, as we anticipate another fantastic event in the Spring of 2024.

We look ahead to a new year, undoubtedly full of changes and challenges in the DD system. We welcome you to join us in our advocacy efforts. Connect with us online at <a href="#">Family Support Network | Arc of Illinois Disability Assistance & Support (thearcofil.org)</a>.

All the Best,

#### **Shirley Perez**

Family Support Network/Ligas Family Program
Director

June 2023



**Shirley Perez** 

Family Support Network Program Director

Ligas Family Advocate Program Director The Arc of Illinois

"The advocacy opportunities we pursue are always based on the concerns and interests of the families that we serve."

#### **Reflections from the Executive Director**



Amie Lulinski, PhD
Executive Director
The Arc of Illinois

#### FY23 was another year of growth and success at The Arc of Illinois!

We welcomed back Envision Unlimited and Avenues to Independence as organizational affiliates and added McManus Consulting and Don Moss and Associates as two new organizational affiliates! We rely on individual, chapter, and organizational affiliates to fund our advocacy efforts.

With regard to advocacy, we were relieved that the Department of Healthcare and Family Services decided to exempt live-in caregivers from the Electronic Visit Verification (EVV) implementation. Thank you to all of you who shared your concerns at the listening sessions and via emails.

In November 2022, we held our first ever IDD and Mental Health Conference which was geared towards professionals and family members who support individuals with intellectual and developmental disabilities who have an additional psychiatric diagnosis.

We welcomed over 300 attendees to this virtual event and are looking forward to repeating it in November of 2023.

In April 2023, we were over the moon to be back in person at our 73rd Annual Convention this year for the first time since 2019. For the first time, The Arc of Illinois Convention was hybrid, enabling participation virtually or in-person.

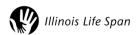
Another new addition to this event was a Spanish language track, allowing greater participation of Spanish speaking advocates. We were thrilled to have so many attendees and sponsors.

We have been partnering with Dr. Theodote Pontikes at the Department of Psychiatry at Loyola University Medical Center in Maywood, IL on educating psychiatric residents on mental health needs of people with IDD. Susan Kahan, MA, LCPC, from the DD Family Clinics at University of Illinois Chicago, and I provided an introduction to IDD in October 2022. In January of 2023, program Directors from The Arc provided a presentation on our offerings at a Grand Rounds, which have resulted in several referrals to our programs. This led to an invitation to facilitate a 6-week seminar for psychiatric residents to educate them about issues related to mental health and IDD. It is our intent that by providing education, this cohort of psychiatrists will be more competent in treatment of patients who have IDD in addition to a mental health diagnosis. The availability of psychiatrists who work well with people with IDD will increase community capacity.



# Illinois Life Span







MSW, LCW

Director of
Illinois Life Span
The Arc of Illinois

The Illinois Life Span team is made up of Rocio Perez, Director of Illinois Life Span, and three (3) regional Information and Resource Specialists: Suzanne Aaron in Northern Illinois, Erica Stearns in Southern Illinois, and in September 2022 we welcomed our newest team member, Tiffany Steinhauser from Central Illinois. Our regional coverage allows each team member to become familiar with local and regional resources in their area. On a limited basis, Faye Manaster provides research and helpline support.

The Illinois Life Span Program (ILS) is the Information and Referral division of The Arc of Illinois. Think of us as your generalists under The Arc of Illinois umbrella. Families, self-advocates, caregivers, and professionals can connect to The Life Span Program with questions they have about services and supports (federal, state and local) for people living with Intellectual and Developmental Disabilities (IDD). We cover a wide range of topics and find our passion in helping families navigate these services.

Some of the topics we cover include how to sign up for PUNS, finding respite, helping families who are planning a move to and/or out of IL navigate the process, and how to connect with a special education advocate in their area. If we are not able to answer your question, we will refer you to the program within The Arc of Illinois or the outside agency/office that can help.

We help Illinois families and professionals stay up to date on important and timely topics through our monthly Webinar series, which are held on the second Tuesday of each month at noon. Within The Arc of IL, we recently partnered with the IL Family to Family Health Information Center (F2FHIC) to expand the list of topics. We collaborate with the Family Support Network (FSN) to assist those families who may have questions that require a deeper dive with complex support needs.

Rocio joined the ILS team in December 2018 and feels fortunate to work with such a great team. Each one of having their own expertise and passion. This position allows Rocio the satisfaction of empowering families and professionals with information that can lead them to a service, a device, or a connection to a provider agency. Rocio states, "I am also proud that I am bilingual (English/Spanish) and able to assist Spanish speaking families throughout the State of IL who may be hesitant to request assistance because of a language barrier. Speaking their language builds their trust in me and in The Arc of Illinois".

As of April 30, 2023, Illinois Life Span has responded to 1,227 inquiries and hosted 17 webinars. There were 31,493 users on the Illinois Life Span website. Our team completed a total of 89 community outreach events. This figure includes both in person and virtual events. Of these 89 events, 37 were specifically for audiences outside the metro Chicago area and 14 events were specifically for the Spanish speaking population.



# The Arc Fact Sheet Book

SCAN THE QR CODE TO RECEIVE THE FACT SHEET BOOK ON YOUR PHONE



# Folleto de Hojas Informativas de The Arc

ESCANEAR EL CODIGO QR PARA RECIBIR EL FOLLETO EN SU TELEFONO





# Illinois Life Span







**Tiffany** Steinhauser. M. Ed ILS Info & Outreach **Specialist** 

Tiffany ioined the ILS team in September of 2022 as Information Outreach & Specialist for Central Illinois. Tiffany enjoys her work at Arc of Illinois different reasons than most. She isa special education teacher who left the classroom last May. Tiffany said, "I knew I needed to parents help our and families, who at times can feel desperate in a different way than teaching in a classroom would allow.

The connections I make with families during outreach events and when covering the helpline, fulfills a deep need I have to support our IDD population. am constantly learning new and helpful information regarding another side of special education that I've not been a part of before. The stories I hear about as an information specialist have taught me so much about what our families experiencing while they struggle navigate a very challenging system. I am happy and privileged to be here to help support a population of individuals that have given me so much joy in my career."



**Erica Stearns** ILS Info & Outreach **Specialist** 

Erica joined the ILS team in July 2021 as Information & Outreach Specialist for Southern Illinois.

Erica states, "One of the most satisfying parts of my job is building relationships with the people we serve and represent in the IDD Faye Manaster, community. Through every interaction, where it's with a coworker or someone reaching out to us, I gain new and useful insights.

The stories and experiences shared by our community have taught me valuable lessons, which I am grateful to pass on to others. Having access to a wealth of information and resources that I can use for my own family and eagerly share with others in Southern Illinois is a privilege that I deeply appreciate".



ILS Info & Outreach Specialist

Suzanne joined the ILS team in July 2021 as the Information and Outreach Specialist for Northern Illinois. Suzanne has worked in the disability advocacy and family support field since 2008 and is a 2018 graduate of Illinois's Partners in Policymaking. She Suzanne Aaron navigated disability services in Indiana, Ohio, and Illinois, so she has а special understanding of moving services across state lines.

Suzanne states, "It is my calling and my life's passion to help people navigate the world of disability services. I understand firsthand how overwhelming, confusing, and complicated it can be. Being able to speak directly with a caller and answer a question, provide a resource (or several), and simply listen is one of the most satisfying parts of my job. I am truly humbled to have the opportunity to assist families, caregivers, selfadvocates, and professionals by directing them to the services that are available to support them. The depth of knowledge that is within this team and the entire staff of The Arc of Illinois means that help is just a phone call away".

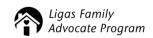


M. Ed

ILS Info & Outreach **Specialist** 

Fave is the Information Specialist for The Arc of Illinois. Favs states" I am now semi-retired and work part-time, after 16 years as Director of our Family to Family Health Information Center. Most of my work now is behind the scenes supporting colleagues at The Arc of Illinois by researching resources and information for the individuals and families who contact us I really enjoy collaborating to develop staff training materials as well as fact sheets for the public. Health care financing is my area of expertise."





# The Ligas Family Advocate Program (LFAP)

The purpose of the Ligas Family Advocate Program is to provide family-to-family support for individuals and their families selected through the Illinois Department of Human Services, Division of Developmental Disabilities (IDHS/DDD), from the PUNS database resulting from the Ligas Consent Decree. A program director and two Ligas Family Advocates staff the program. The program benefits from the resources of the multiple programs of The Arc of Illinois. Funding provided by the Illinois Department of Human Services Division of Developmental Disabilities.

The Ligas Family Advocate Program (LFAP) started as a small pilot program in 2014, serving 275 individuals and facilitating three Know Your Options educational events. The program has grown into a robust, adaptable, and diverse education and advocacy service. In 2022, the LFAP staff conducted twelve English, and twelve Spanish Know Your Options trainings. The program kicked off January 2023 by connecting with 1,338 individuals who received Early Notification letters from DDD pending budget approval would be eligible to apply for wavier services later in the summer of 2023. We remain on track to provide 28 Know Your Options hybrid programs, including twelve in Spanish. The Know Your Options program serves individuals in the Children's Waiver (18 -21). those in the Adult Waiver, and those speaking Spanish.

For the last nine years, The Arc of Illinois has developed and managed the Ligas Family Advocate Program, meeting all program goals while growing the program into a support system that educates and supports families and self-advocates who have received Early Notification for an anticipated PUNS selection. those who received an invitation to apply for the Medicaid Home and Community Based Waiver, and those who have experienced difficulty/barriers in accessing reauired supports and services. The LFA Program will continue to provide accessible programs focused on assisting Ligas Class Members and their families in understanding the state requirements and benefits before, during, and after a PUNS selection.

As a bilingual program, the LFAP connects with self-advocates and families in several ways, including written invitations be a part of our community, one-to-one consultations, closed-captioned online trainings, monthly Know Your Options webinars, follow-up communications, distribution of our newsletter (News You Need to Know), bulletins, and updates from DHS/DDD.

Furthermore, we will continue to tailor educational resources to the individual needs of each family we serve. Marketing materials will be available in both English and Spanish. Families for whom technology is a barrier we offered phone consultations, correspondence via US Postal Service, and in-person meetings as appropriate.

The Ligas Family Advocate Program remains engaged, growing, and active state-wide in Illinois. We have expanded our educational offerings and continue to develop relationships with community partners. Education is at the heart of the LFA program. Our individual consults focus on exploring the unique needs of each family, creative funding uses, basics of utilizing waiver funding, and connection to community resources.

As we move into the summer of 2023, we look forward to partnering with over 1,300 families who will receive invitations to apply for Adult Wavier Services; and individuals 18-21 selected to apply for the Children Support Wavier. We will continue to find creative ways to connect with families, conduct training online and inperson, share updated information, and manage concerns raised.

# **Ligas Reach**

- Facebook: 18,200
- Website users: 1,831
- Sessions: 1,449
- Page views: 2,875
- Letters to Individuals who receive Early PUNS Notification Recipients: 1,338
- Number of Consults, Webinars/trainings/Online events: 80
- Telephone calls: 1,500

# **Central/Southern Senior Ligas Family Advocate**



MA, QIDP
Senior Ligas Family
Advocate

What a difference a year makes! We have been deeply encouraged by the increased engagement of family members and self-advocates seeking supports following an Early Notification or PUNS selection. Our increasing numbers tell the story – families want and need accurate information about developmental disability supports in Illinois. Families have sought out information on system navigation, community connection, barriers in service, and current advocacy efforts.

We have partnered with families as they work tirelessly to implement supports that are meaningful and individualized, and we are endlessly inspired by their creativity and tenacity in navigating a challenging system. We have watched families implement their own CILAs, build communities of home-based supports, explore creative housing, and challenge the options available to them.

Our monthly Know Your Options program has allowed connections to families across the state, and we have seen families engage repeatedly in the monthly discussions. LFAP families demonstrate what we already know to be true, that family-to-family support is effective and meaningful. Families have shared concerns about community capacity, lack of day program and CILA access to individuals with high support needs, Electronic Visit Verification, staff turnover, difficulty finding and keeping Personal Support Workers, and challenges in communication within the system. The LFAP team has worked with families to advocate, educate, and explore options in every area of the state.

We have partnered with community provider groups, and Independent Service Coordination Agencies to provide education about options for support, managing shared challenges, and advocating for the needs and hopes of individuals with I/DD. Our team has presented issues impacting families, including families engaging in quality improvement work, storytelling as advocacy, and system navigation.

We close out the year with a thank you to our most important partners – families seeking high quality and creative supports and services. We are so appreciative of your advocacy, willingness to share your experiences, and engagement in seeking the most effective and meaningful supports for your loved ones.

# **Northern Ligas Family Advocate**



Ruth Aguilar, QIDP Ligas Family Advocate

As a bilingual professional, Ruth has an opportunity to serve the Hispanic population in the Developmental Disabilities community. The Arc of Illinois is taking a step forward in recognizing this need and offered Spanish track sessions for the first time at the Annual Convention. Ruth states, "I am proud to be part of this initiative and I am committed to doing my part in strengthening outreach and support for those who may not have had access before." During the past year, Ruth conducted a great number of bilingual events and virtual trainings and she continues to deliver monthly webinars in 100% Spanish called Conoce Tus Opciones! for those who received the Early Notification from The Department of Human Services. Additionally, Ruth helped almost 100 Hispanic families with their applications for the Consumer Stipend Program and the Technology fund.

One family at a time, we are constantly moving forward removing language barriers. Moreover, Ruth is proud to share with you that part of her job is to help Ligas Class members in navigating the process of getting services under the Developmental Disabilities Medicaid waiver. Recently, she received a thank you note from a family she helped with an appeal process, and they are now receiving services. Making a difference in the lives of individuals is what matters most!

# **Northern Ligas Family Advocate**

Ruth Aguilar, QIDP Ligas Family Advocate

Como profesional bilingüe. Ruth tiene la oportunidad de servir a la población hispana en la comunidad de discapacidades del desarrollo. The Arc of Illinois está dando un paso adelante al reconocer esta necesidad y ofreció sesiones de seguimiento en español por primera vez en la Convención Anual. Ruth afirma: "Estoy orgullosa de ser parte de esta iniciativa y estoy comprometida a hacer mi parte para fortalecer el alcance y el apoyo para aquellos que tal vez no hayan tenido acceso antes". Durante el año pasado, Ruth realizó una gran cantidad de eventos bilingües y capacitaciones virtuales y continúa impartiendo seminarios web mensuales en 100 % en español llamados ¡Conoce Tus Opciones!

Para aquellos que recibieron la Notificación Temprana del Departamento de Servicios Humanos. Además, Ruth ayudó a casi 100 familias hispanas con sus solicitudes para el Programa de Estipendios para el Consumidor y el Fondo de Tecnología. Una familia a la vez, avanzamos constantemente eliminando las barreras del idioma. Además, Ruth se enorqullece de compartir con usted que parte de su trabajo es ayudar a los miembros de Ligas Class a navegar el proceso de obtener servicios bajo la exención de Medicaid para Discapacidades del Desarrollo. Recientemente, recibió una nota de agradecimiento de una familia a la que ayudó con un proceso de apelación y ahora están recibiendo servicios. ¡Marcar la diferencia en la vida de las personas es lo que más importa!

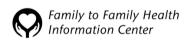
# **Contact info for the Ligas Family Advocate Program:**

**Shirley Perez Program Director** Shirley@thearcofil.org

**Megan Mutti Senior Ligas Family Advocate** Megan@thearcofil.org

**Ruth Aguilar Ligas Family Advocate** Ruth@thearcofil.org





# Family to Family Heath Information Center



to Family Health Information Center

The Arc of Illinois Family-to-Family Health Information Center (F2FHIC) has been a program of The Arc of Illinois since 2006. Our project is funded by the federal Health Resources Services Administration (HRSA), Maternal Mary Dixon, JD and Child Health Bureau, Division of Services for Children with Director of Family Special Health Care Needs. We are both a program of The Arc of Illinois and the Illinois affiliate of a The Arc of Illinois Family Voices, a national

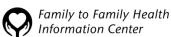
grassroots network organization of families and friends of children and youth with special health care needs and disabilities. Our F2F is part of a network of F2Fs, one in each State and each U.S. Territory, all run by experienced parents of children of all ages with disabilities. Currently, the F2F Health Information Center is staffed by its Director, Mary Dixon.

The primary work is one-to-one assistance with information/resources that auides decision-making of parents of children/teens up to age 21 with any disability/chronic health condition

and the professionals who serve them. We also present in person and virtually upon invitation on topics of interest relating to federal and state benefits programs, health insurance -private and public, and Medicaid waivers and create useful navigation guides/fact sheets that are family friendly on a variety of topics.

December of 2022 closed out with a F2F Monthly webinar on the Educational Parent Surrogate Training for children with disabilities who do not have a parent to attend their IEP meetings. This offered Consuelo was bv Puente. Multicultural Trainer, Family Matters Parent and Information Center. PowerPoints for our Monthly webinars and Annual Healthcare Conference F2F available the on webpage: www.familyvoicesillinois.org





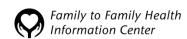
# **Family to Family Heath Information Center**

Here are some of the highlights of the major accomplishments over the past year:

- We continue to maintain strong relationships with staff at the Illinois Department of Human Services, and the Department of Health Care and Family Services (HFS), which enables us to help families navigate barriers related to eligibility, and enrollment in public health benefits programs. Recently we co-hosted with the Illinois Life Span program a webinar featuring HFS staff on the topic of the postpandemic return to annual Medicaid income redetermination.
- We offered Monthly Health Care Webinars from July to December 2022 on a variety of topics.
  - In July we heard from Amanda Walsh, Director of the Illinois Children's Mental Health Partnership. This was an opportunity for families to learn about the Partnership's plans for the future and discuss the Governor's Children's Behavioral Health Transformation Initiative as well as discuss the barriers to mental health care for children that families face.
  - In August we hosted a panel discussion with four Illinois families sharing their experiences in advocating for children with disabilities to obtain needed services and healthcare, including Jackie, the parent of then six year old (Owen) who cerebral palsv and has vision impairment; Linda the parent of then 18 year old (Preston) who is legally blind, has a developmental disability and several other complex diagnoses; Debi and Jim, the parents of then 19 year old Kelsey, who DeafBlind, has developmental а disability and was born with CHD; and Erin and Josh, parents of then 2 year old Alison who was born with a complex genetic disorder. This allowed those who joined us to hear what these families needed; how they advocated for it, what support was received/how it was obtained, and their advice to other families.
  - In September we hosted a virtual Health Benefits Conference: <a href="https://www.thearcofil.org/health-care-conference-2022/">https://www.thearcofil.org/health-care-conference-2022/</a>

- In October, we hosted a webinar about STARnet, a statewide system that assists the IL State Board of Education Early Childhood Division in meeting regional and local needs by providing professional development services throughout Illinois for families and professionals, presented by Rose Ann Slaght, Family Resource Specialist for STARnet Regions 1 & 3.
- November's webinar was about Illinois' Early Intervention program, presented by Cindy Luzeniecki, Local Interagency Transition Coordinator, the office of Early Intervention/Child & Family Connections 15.
- In 2023 we began hosting webinars jointly with the Illinois Life Span program of The Arc of Illinois, including a January webinar new statewide program children/teens up to age 21, enrolled in Medicaid in need of intensive, tiered, inhome supports for complex behavioral health needs. Presenting was Kristine Herman, HFS Bureau Chief, Behavioral Healthcare. We focused on Special Recreation and Summer camps February with presentations from three Special Recreation Association Directors and the Director of a Park District Special Recreation program and in March, we hosted a webinar/training offered by Georgia Gerdes, Avisery Senior Training Specialist, Age Options on the addition of Medicaid for adults with disabilities who have Medicaid and/or parental employer health insurance.
- Our annual Health Care Conference will take place virtually on 9/14/23 and will include speakers on Medicaid programs, IL Health Insurance for Immigrant Children and Families (with a webinar on 9/19 to be offered in Spanish): SSI and SSDI eligibility and benefits; Aetna Better Health - Medicaid Managed Care on care coordination and help with homemodifications, durable medical etc..; equipment, diapers, Health Insurance savings through the ACA Marketplace; and а parent panel discussing the benefits and limits of different Medicaid waivers their children.





# **Family to Family Heath Information Center**

- The F2F Health Information Center Director attended school transition and health resource fairs throughout the year to offer information about our program, about other programs of The Arc of Illinois and to answer questions from families attending.
- We presented at the 2022 National United Leukodystrophy Family Conference in Itasca, Illinois about national resources -such as our network of F2F Health Information Centers across the country as well as other resources for those attending from Illinois.
- Together with our colleagues at the Illinois Chapter, American Academy of Pediatrics (ICAAP), Committee on Children with Chronic Illinois and Disabilities, we provide input regarding Illinois' programs and policies related to health and community living for children with disability and chronic health conditions and their families across state agencies.

With a combination of our own professional training and expertise, our personal experiences and our strong linkages with project partners and colleagues at The Arc of Illinois, we always do our utmost to assist families in helping their children.

We look forward to connecting with you soon.

The Family to Family Health Information Center (F2FHIC):

1-866-931-1100; Espanol: **800-588-7002**;

office: 815-464-1832 x1017



# **Going Home Coalition**



Carole Rosen, M.A.I.D. C.A.P.S. Going Home Coalition Manager

As its mission states, the Going Home Coalition continues to, "advocate to create systems change, transition away from institutional living through increasing community capacity, and empower fair and equal choices and opportunities for people with intellectual and developmental disabilities." Comprised of self-advocates, family members, non-profit members, service provider agencies, consultants, universities, allies, and other advocacy organizations, the Coalition continues to grow its diverse membership base of 50 statewide participants and is welcoming new members. The outreach of these organizations totals over 30,000 people.

This past year included Going Home Coalition (GHC) presentations during The Arc of Illinois Annual Convention, Speak Up and Speak Out Summit, Operation Welcome Home webinar, television, and radio programs. Going Home Coalition's advocacy continued meeting with legislators, state organizations, and leaders with government oversight.

In early March, 34 organizations as well as almost 1,000 individual sign-ons were included in letters to Governor Pritzker and state legislators, reiterating the ongoing human rights abuses which occur in State Operated Developmental Centers (SODC) and specifically requested the closure of Clyde L. Choate Developmental Center in Anna, IL (Choate).

On March 8th, Governor Pritzker announced Illinois's transformation plan for Choate which includes transitioning over 100 Choate residents to other settings of their choosing. GHC will continue to advocate for the remaining 1,642 residents remaining in other SODCs to be transitioned into community residential settings.

# **Going Home Coalition**



GHC also advocated for raising direct support professional (DSP) wages which has now been written into the budget as a \$2.50 per hour increase. We continue to advocate for developing innovative, supportive, diverse, and inclusive housing alternatives to group homes, shortening the amount of time spent on wait lists to receive critical services, redirecting and/or increasing investments from the state to IDD community supports from funds earmarked for SODCs, and mitigating the risks of re-institutionalization for those with IDD living in the community.

Going Home Coalition acknowledges with gratitude member organizations, participants, and additional contributors who graciously and generously donated to GHC this past year. We are also tremendously pleased to announce Going Home Coalition has been awarded funding through The Coleman Foundation to continue our much-needed advocacy work.

Your Advocacy Matters! Contact us at <a href="https://www.goinghomeillinois.org">https://www.goinghomeillinois.org</a>.









# The Family Transition project annual update 2023



Director of Family Transition Project The Arc of Illinois

Despite COVID-19 and the retirement of the longtime Director of the Family Transition Project or FTP, 2023 was a good year for us. The Family Transition Project (FTP) supports individuals with intellectual and developmental disabilities (IDD) and their families undergoing transitions from state operated developmental centers (SODCs) into the community. We believe these individuals deserve to be listened to with respect and compassion, offered helpful information and meaningful connections to navigate the system, and supported by other individuals and families who have had similar experiences. It's a simple vision, but one that we have Greg Walkington found highly successful. Newer self-advocates and their families have valued the opportunity to talk with other seasoned self-advocates and family members who have already transitioned from an SODC to the community. Individuals that transitioned from an SODC before them can help self-advocates and their families identify barriers to community and help provide solutions.





# The Family Transition project annual update 2023

#### **Greg Walkington** Director of Family Transition Project, The Arc of Illinois

The Family Transition Project will provide support to them along their journey. We stay with them providing support even after their move if they wish. Thanks to a generous grant from the Aigner Foundation, we have been able to provide the individuals transitioning from an SODC to the community with up to \$500.00 stipend to help purchase items they might need to make the transition more comfortable for them. This program, Operation Welcome Home, has really taken off this year.

In addition to the stipend, Operation Welcome Home also provides monthly webinars to all families interested in what a transition to the community might look like for them. Some of the subjects we have presented on are transition from a sibling/guardian perspective, transition from a provider's perspective, Support Services Team (SST), Equip for Equality and their role during the transition and the transition process from the Department of Developmental Disabilities as well as many others. We have a list of frequently asked questions for families to ask during their transition. These questions help families know what possible information they will need to inquire about.

The Arc of Illinois has a resourceful team and we can provide wrap around supports for individuals with intellectual and developmental disabilities. Here at The Arc of Illinois colleagues from Family to Family, Life Span, Family Support Network are all incredibly helpful in bringing information and solutions to assist people during this process. When I am asked a question, I don't know the answer to, someone from the other departments at The Arc of Illinois always has the answer. If they don't have the answer immediately, they will find it.

I want to take a moment to thank FTP's six mentors James Elliott, Susan O'Connor, Robert Peterson, John Porter, Hector Renta, and Robert Rowley have all lived in SODCs and made successful transitions to the community. All six of them are active advocates for community living. They talk openly about the benefits and challenges of the transition and this authenticity is what makes their words so powerful. The Family Transition Project would not be able to do its work without their help. Their words and experiences are invaluable to the Program and they do a wonderful job telling their stories. With the assistance of interns from the University of Chicago, the mentors have developed a power point presentation and an elevator speech to share their story and experiences. They have also worked on proper Zoom meeting etiquette for a more polished presentation. They practiced starting the meeting on time, professional presentation, muting themselves when they are not talking, etc.

One of the things we will be working on in the upcoming year is to assist with the transformation of Choate Developmental Center. In January Governor Pritzker announced that they will be transforming the Choate campus in Anna, Illinois and over 120 people will be moving to other locations. The Family Transition Project stands ready to assist any of the individuals and their families wanting to explore a transition to the community. The transformation of the Choate campus is slated to take place over the next three years.

In closing, please check out at <a href="https://www.thearcofil.org">https://www.thearcofil.org</a> and take a look at the Family Transition Project and the Operation Welcome Home webpage. You can also feel free to email with any questions you may have at <a href="mailto:greeg@thearcofil.org">gree@thearcofil.org</a>.

# Family Transition Project (FTP)

https://www.thearcofil.org/ab out-us/programs/familytransition-project/



**FTP Mentor Brochure** 



# Operation Welcome Home

https://www.thearcofil. org/operationwelcome-home/





# The Training Department



Becca Schroeder Director of Development The Arc of Illinois

The Training Department has seen some changes this year. We provided a new event in the fall, "IDD and Mental Health Conference", which focused on the mental health of individuals with intellectual and/or developmental disabilities and the resources and programs available to those with a dual diagnosis. This full-day, virtual conference was a great success. Stay tuned for more information on the next IDD and Mental Health Conference this fall.

We continue to provide virtual, hybrid, and in-person events throughout the year, including the first hybrid Speak Up and Speak Out Summit (SUSO) in October 2022. SUSO is a one-of-a-kind event that brings together individuals with intellectual and developmental disabilities from across the state to learn how to become stronger advocates.

Last year's theme was "My Voice, Our Choice." Important topics discussed included using your passion for advocacy, supportive housing, important lessons in advocacy, and support decision making. We are thankful to the Illinois Council on Developmental Disabilities (ICDD) for funding this event every year.

We recently held the first hybrid Annual Convention in April 2023. It was great to be back in person, but still provide an opportunity to attend virtually. This year's theme of "Reimagining" Expectations" focused on navigating the "new normal" in a near post-COVID world. With resilience and connection, people with intellectual and developmental disabilities, their families, and the people who support them have adapted and found new ways to learn, work, and engage. We were excited to offer a track of breakout sessions presented in Spanish.

We look forward to continuing to provide learning opportunities on the latest topics and trends.

#### Save the Dates!

Stay tuned for more information in our Event Update emails.



#### **Virtual Events**

- Home-Based Services: Making it Work for You - August 23, 2023
- Healthcare Conference September 14,
- Personal Support Workers: Understanding the Role - September 28, 2023
- IDD and Mental Health Conference, Virtual -November 15, 2023
- 22nd Annual QIDP Conference January 23,
- 12th FSN/Ligas Informational Seminar Late Operation Welcome Home Quarterly March 2024

# **Ongoing Virtual Events**

- Know Your Options with the Home and Community Based Waiver for Adults with **Disabilities (English version)**, First Thursday of every month, 12:00 - 1:00 p.m. on Zoom
- Comenzando Julio 2023, Los **Entrenamientos Conoce Tus Opciones!**
- Cada Primer Viernes del mes a las 12 del medio dia.
- ILS & F2FHIC Lunchtime Webinar Series
- **Webinar Series**

#### **Hybrid Event**

Speak Up and Speak Out Summit, HybrId - October 5 - 6, 2023



# **The Training Department**



#### Someone You Should Know

We are pleased to introduce you to our new Event & Outreach Coordinator as someone you should know.



Kim Swanson Events & Outreach Coordinator

Kim Swanson joined The Arc of Illinois as the **Events** ጺ Outreach Coordinator. Kim has previously worked at the American Cancer Society as a Senior Coordinator, supporting many events raising money for the fiaht against cancer. including athletic events and galas. She recently moved to Illinois to help take care of her mom.

She loves volunteering wherever needs to help make a difference. She has four grown children who live all over the country and loves to travel and spend time with them. Kim holds a Bachelor's Degree of Science in Advertising from Northern Illinois University.



Office Manager

Karin is at the core of The Illinois of team. providing support and guidance as the Office Manager. Karen assists families and professionals to link up to appropriate Illinois Arc of provides programming, Karin Mentzer technical assistance with projects, and assists in coordinating events and managing the webpage.





Heidi Booth. **MBA** Marketing & Communications Manager

Heidi creates marketing materials through print, online and social media channels. She carries a Marketing undergraduate degree and MBA from Northern Illinois University. A mom of a daughter with a disability, she is passionate about advocating individuals with intellectual and developmental disabilities. She enjoys her involvement in national parent and caregiver online social groups and blogs. Heidi has also published articles in magazines.



Diane Sotiros. **CPA** 

Director of Finance

Diane, a CPA, brings over 20 years of experience serving as the lead finance and accounting professional for small nonprofit organizations in the Chicagoland area. She has worked on the foundation side as well as the program delivery side philanthropy, and in leadership positions overseeing finance and operations. Diane obtained her BS from Illinois State University with a major in Accounting. She also has an MA in History, Latin America, and the Caribbean from the University of Illinois Chicago. She is a member of the Illinois CPA Society and the CFO Roundtable of Chicago.





# The Family Support Network (FSN) Program

The Family Support Network works to uncover the resources, funding, and services needed to help people with developmental disabilities live fulfilling lives in their own homes. By focusing on the needs of both family members and individuals, we help break down barriers to clear the way for long-term success. We are staffed statewide by a Program Director, Family Liaison and Family Advocate Specialist. We are funded by the Illinois Department of Human Services. Division of Developmental Disabilities. FSN has reached and shared information to over 38,000 people, using various formats. Our reach includes families, self-advocates, providers, professionals, stakeholders and organizations state-wide. We look forward to continuing to strongly advocate for families and self-advocates in Illinois.



Trov is our dedicated, well respected Family Advocate Specialist with over 25 years of experience in troubleshooting issues that families face. He continues to fill a significant family advocacv: increasing our ability to assist unique

**Troy Markert** families with Family Advocate difficult situations, particularly Specialist in downstate Illinois.

Within his role, relationships with Independent Service Coordinators Agency (ISC'S), families, developmental and other disability organizations continue to expand, increasing the resources that can be offered to families. He continues to be a critical resource working with the ISCs, Division of Developmental Disabilities, and families to address and come up with solutions to very complex issues. Troy has strengthened our ability to effectively advocate on behalf of families and self-advocates. Please reach Troy at Troy@thearcofil.org.

# **Family Support Network aims to:**

**Keep Families Together** 

until the person with a disability chooses to live independently

**Empower Caregivers** 

to meet the many needs of their family member with a disability **Improve Support** 

to families while minimizing the need and the cost of out-of-home placement **Allow family Participation** 

in integrated leisure, recreational, and social activities

Make a Positive Difference in the lives of people with disabilities as well as the lives of family members



Family Liason

Shakari is coming into her 5th year as the Family Liaison for FSN under Director Shirley Perez. FSN going strong providing support referring our families to resources that provide the Shakari Asbury help that they need to live independently in their community. FSN staff

connect with families daily through email inquiries, phone calls, and in-person outreach events. Inquiries range from IEP meetings, questions related to Medicaid, home and vehicle modifications, guardianship in Illinois, and the newly introduced EVV system. FSN is always happy to investigate and advocate for individual/families in situations that may be deemed complex. You may have seen FSN the staff presenting 11th at Annual Informational Seminar, which was a huge success! A plethora of resources was provided to families that are not always readily located when it comes to navigating the IDD system in Illinois. Outside of the annual event FSN also participated in The Arc of Illinois 73rd Annual Convention. monitorina breakout sessions on Financial Literacy for individuals with IDD. If you haven't done so, please be sure to sign up for our online webinars or in person conferences by visiting The Arc of Illinois website, www.thearcofil.org. Contact Shakari at Sharaki@thearcofil.org.

#### **Our Main Goals**

We focus on family first, respecting all cultural, social, economic, and spiritual differences to help improve home-life dynamics and foster even stronger family bonds.



# The Family Support Network (FSN) Program

#### **FSN Engagements by the Numbers**

FSN has reached and shared information to over 38,000 individuals, including families, self-advocates, providers, and organizations state-wide.

• Facebook page: 8,195

Number of electronic newsletters: 12

• Electronic newsletters reach: 20,257

• Training (one-on-one): 129

• Organizational partners: 8

• Telephone calls (approximate): 938

• Other outreach events/Conference: 14

Website engagement:

Users: 3,329

Website page views: 4,638

Website sessions: 2,617

Webinars/training: 30

## Two State-wide Virtual events were hosted by FSN:

The first event was held on July 27, 2022, with 437 registered participants.

Home Based Services Conference entitled HBS Back-Up Plan and Wavier updates featuring:

**Derek Hedges** Medicaid Waiver Unit Manager

Mike Vespa Department of Human Services, Division of Developmental Disabilities, PUNS Tasha Whiteside Illinois Program Director, Aces\$

Shirley Perez Director Family Support Network, The Arc of Illinois

The second event was held on March 23, 2023, with 310 registered participants.

11th FSN/Ligas Informational Seminar featuring:

Keynote:

Meg Cooch, Deputy Director Ligas Consent Decree/Sarah Myerscough-Muller, Interim Director, DDD

Brian Rubin, JD Rubin Law

Ruth Aguilar, QIDP, Ligas Family Advocate and Family member The Arc of Illinois

Barry Taylor, Equip for Equality Ronnie Cohn, Ligas Court Monitor

Patty O'Brien, Developmental Disability Manager, Suburban Access, ISC

Amie Lulinski, PhD, FAAIDD, Executive Director, The Arc of Illinois

Megan Mutti, Senior Ligas Family Advocate The Arc of Illinois

## Thank you Sponsors, Exhibitors of the Arc FSN/Ligas 11th Informational Seminar



Aces\$ - Avenue to Consumer Employment Services and Supports. ACES\$ Illinois, 7820 Graphics Drive Suite 200, Tinley Park, IL 60477. Central/Southern Illinois office: 830 South Spring Street, Springfield, IL 62704. Toll Free Number: 877-223-7781 www.mvcil.org



The Department of Human Services is one of Illinois' largest agencies, with more than 13.000 employees. Illinois created IDHS in 1997, to provide our state's residents with streamlined access to integrated services, especially those who are striving to move from welfare to work and economic independence, and others who face multiple challenges to self-sufficiency. IDHS is proud of its diversity, efficiency, and the services that the agency and its community partners provide to Illinois citizens.

https://www.dhs.state.il.us/?item=27897



Rubin Law, a professional corporation, LIMITS its law practice to Special Needs Legal & Future Planning for Brian & Benjamin Rubin's fellow Illinois families of children & adults with special needs, including all required "traditional" Estate Planning & Estate Administration (Wills, Trusts, Estate Tax Planning, Trust Administration, Probate – including Guardianships & related matters). For more information, email us at: email@rubinlaw.com visit us at <u>www.rubinlaw.com</u> Buffalo Grove · Chicago · Old Orchard-**847-**279-7999 · Toll Free 866.To.Rubin



Equip for Equality's mission is to advance the human and civil rights of children and adults with disabilities in Illinois.

Main/Chicago Office (other locations 10 North Michigan Avenue, Suite 300 Chicago, IL 60602 Phone: 312-341-0022 | 800-537-2632 (Voice) | 800-610-**2779** (TTY) https://www.equipforequality.org/about/contact-us/

# Congratulations to all of the 11th FSN/Ligas Informational Seminar Winners:



First Family Member to Register

Trish Schultz (\$25 Gift Card)

First Self-Advocate to Register Curtis Harris (\$25 Gift Card)

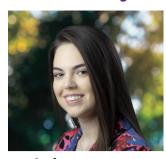
### **Trivia Winners**

Linda Hall Christina Hodge Rebecca Williams Anita Barraza

Organization with the most registered professionals: **Envision Unlimited** (\$25 Gift Card)

First Professional to Register Paula Humke (\$25 Gift Card)

## **Public Policy and Advocacy**



Sabrina Wyman Advocacy Legislative Coordinator

Sabrina states, "It is a dream come true that I was able to step into the new Legislative Advocacy Coordinator position last Fall. The Arc of Illinois has always been committed to empowering and supporting the disability community and I am excited that I was able to begin expanding our advocacy efforts. This has enabled us to raise awareness about the needs and rights of individuals with intellectual and developmental disabilities. At the heart of my role, my goal is making advocacy accessible to all. I understand that the intricacies of the legislative process, both state and federal, can be overwhelming so I am dedicated to simplifying the information". Every fall, we survey our membership to inform our public policy priorities which are developed by the Public Policy Committee (PPC).

The PPC meets monthly during the Spring Legislative Session, and we provide up-to-date information on legislation and how our priorities are developing. The PPC were extremely active in their efforts this Spring, writing and calling their legislators, as well as filling out witness slips.

Additionally, over the past six months we have been active in conversations with The They Deserve More Coalition regarding an increase in pay for Direct Support Professionals and we met with Governor Pritzker and Senator Duckworth's offices regarding system capacity building. We were able to send almost 1,000 messages from our supporters to elected officials regarding the status of Choate Developmental Center. We strive to be at the forefront of positive change for individuals with IDD through collaboration and staying informed.

Naturally, as we continue to navigate this new chapter, we remain committed to continuous growth. Through collaboration, public forum, and targeted campaigns, we have amplified our voice, influencing lawmakers and key decision-makers.

# 2023 Spring Session Legislative Update with Phil Milsk



Phil Milsk, JD Legislative Consultant

Spring 2023 Disability Legislation Summary

The following bills passed both houses of the General Assembly and will be sent to the Governor for consideration. Chief sponsors are indicated for each bill.

Senate Bill 99

Requires public universities and community colleges to adopt certain policies and procedures governing the documentation required to verify that a student seeking Section 504 supports has a disability. This bill has been sent to the Governor. House: Johnson Senate: Fine

Senate Bill 216

The training of court-appointed guardians on the duties and responsibilities of guardians mandated by the Probate Act must include content regarding Alzheimer's disease and dementia. Senate: Edly-Allen House: Moeller

Senate Bill 250

The budget bill for State Fiscal Year 2024, beginning July 1, 2023. Senate: Sims House:Gordon-Booth

Senate Bill 724

Omnibus bill regarding children's behavioral health services that includes provisions about the PUNS selection of children eligible for the Children and Young Adults Services Waiver if funds are appropriated. Senate: Feigenholtz House: LaPointe

Senate Bill 855

A bill concerning investigative reports issued by the Office of Inspector General (OIG) of the Department of Human Services pertaining to allegations of abuse or neglect of residents at State-operated facilities. Authorizes the OIG to report substantiated instances of material obstruction of an investigation. Senate: Fine House: LaPointe

Senate Bill 1298

Omnibus Medicaid reform bill. Includes a rate increase for nursing services under the Medically Fragile Technology Dependent Waiver Program, rate increases for various therapies, provisions regarding coverage for ABA therapy services for children with a diagnosis of autism spectrum disorder, and many other provisions.

House: Gabel Senate: Gillespie

Senate Bill 1558

Amends the Public Community College Act to require the Illinois Community College Board, after consultation with various stakeholders, to submit recommendations for a model program of study for credit that incorporates the training and experience necessary to serve as a Direct Support Professional. Senate: Murphy House: Moeller

Senate Bill 1674

Initiative of the Department of Human Services-Division of DD to revamp the long and short-term stabilization homes pilot programs designed to address the need's of individuals needing significant behavioral supports in the community instead of in institutions and to extend the programs to January 1, 2028.

Senate: Fine House: LaPointe

Senate Bill 2039

Amends the School Code to revise and update provisions governing public schools sharing of information about the PUNS with students with IEPs and their parents or guardians. Senate: Pačione-Zayas

House: Syed

Senate Bill 2123

Omnibus elections bill that, among other things, creates the Access to Voting for Persons with Disabilities Task Force to review and make recommendations to improve access to voting for persons with disabilities.

Senate: Morrison House: Stuart

Senate Bill 2247
The bill makes a few technical changes with regard to the ABLE account program, including ensuring the privacy of records obtained or compiled by the State Treasurer containing information about the designated beneficiary or designated representative. In addition, allows the ABLE Account Program to be named after the late Senator Scott Bennett.

Senate: Faraci House: Burke

**House Bill 2248** 

Creates a new State civil cause of action that would allow the recovery of damages for emotional distress for violations of certain federal civil rights statutes due to a 2022 SCOTUS decision holding that emotional distress damages are not allowed in federal courts for such violations.

House: Cassidy Senate: Peters

House Bill 2380

Makes various changes to the Human Services Professional Loan Repayment Program Act.

House: LaPointe Senate: Fine

House Bill 2443

Effective January 1, 2025, makes mandatory health insurance coverage for hearing aids applicable regardless of age (now limited to individuals under age 18). House: Chung Senate: Koehler

House Bill 2878

Omnibus procurement bill that includes changes to the section of the Procurement Code governing the State Use Program that eliminate the subminimum wage consistent with Executive Order 2021-26, remove the Section 14c certification requirement for vendors, and makes other changes regarding vendor qualifications.

House: Hoffman Senate: Castro

House Bill 3224

Students with disabilities and their parents must be provided with information about the availability of dual credit courses that may be relevant to the student's transition planning goals.

House Bill 3817

State Fiscal Year 2024 Budget Implementation bill (BIMP). Includes some cleanup language regarding Money Follows the Person (pp. 49-58, pp. 400-403), and the \$2.50/hour DSP wage increase effective January 1, 2024, subject to federal approval (pp. 473-474), among many other things.

Houše: Gordon-Booth Senate: Sims

House Bill 3680

Extra accommodations during emergencies at school may be taken into account when developing a student's IEP or 504 plan. In addition, the bill changes the School Safety Drill Act to provide that when deciding whether the exempt a student from participating in a walk-through lockdown drill, the student's IEP team or 504 plan team shall be included in the decision-making process (rather than having the decision made by an administrator or school support personnel).

House: Benton Senate: Faraci

The Family Support Network works to uncover the resources, funding, and services needed to help people with developmental disabilities live fulfilling lives in their own homes. By focusing on the needs of both family members and individuals, we help break down barriers to clear the way for long-term success. We benefit from the other programs of The Arc of Illinois.



We are so happy to share with you a letter from one of our families that was sent to our Executive Director, Dr. Amie Lulinski. We are sharing with permission. The end results are possible because of the collaboration of the Family Support Network and The Ligas Family Advocate Program.

# Thank You

December 2022

Dear Ms. Lulinski,

I am writing to let you know of the excellent service and support my family received from Ruth Aguilar and Shirley Perez of the staff at The Arc of Illinois. My family has been working with both Ruth and Shirley for almost two years since our son was initially preselected from the PUNS list for the Medicaid Waiver program. As the first year progressed our son was initially deemed ineligible for services first by our ISC and then ultimately by the State. Both Ruth and Shirley worked tirelessly with our family at each critical step both encouraging and supporting us with expert advice and guidance. After being denied by the State our family made the difficult decision to appeal our case before an Administrative Judge.

This was a daunting endeavor on two levels; first was the intimidating task of presenting an appeal before a judge appealing a decision by the State of Illinois, and secondly, we knew nothing about the mechanics of presenting a case. We were novices to it all. Ruth and Shirley were especially important to us during this stage of the process as we had no one else to guide or advise us. This was probably one of the most challenging times our family has ever faced. While both Ruth and Shirley left it to us to make the decision to go forward, they both offered us encouragement and support along the way. We are aware that there is a fine line that The Arc staff must follow when working with families to ensure not to overstep boundaries. Ruth and Shirley were always professional, yet they provided us with caring and encouraging support.

Approximately two weeks ago, (early December 2022) we received word from the Court that our family had won our appeal. My husband and I both believe that Shirley and Ruth's advice, support and encouragement were instrumental in our winning the appeal. These two ladies consistently went above and beyond over the course of the last two years to assist our family. We will always be grateful to The Arc of Illinois but especially Ruth and Shirley. Please share our gratitude and appreciation with them both.

Sincerely,

Terry and Jim



#### **Arc Family Support Network**

9980 190th Street | Suite C | Mokena, IL 60448

Office: 815.464.1832 ex 1032 Phone: 708-331-7370 Email: shirley@thearcofil.org

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

Shirley Perez, Director Troy Markert, Family Advocate Specialist Shakari Asbury, Administrative Assistant

# AMPLIFY YOUR IMPACT.

Together we are more **powerful**.
Together we have more **resources**.
Together our individual actions create **momentum** for change.





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.