Hello Family Support Network Family and Friends,

The Family Support Network closes this year on a note of deep gratitude to our families, self-advocates, and supporters, all of whom have generously shared their experiences, frustrations, needs, and successes throughout this very challenging year. While the pandemic presented deep difficulties, it also exposed opportunities for connection and advocacy that would have otherwise gone unexplored.

We are excited that this legislative session the Illinois General Assembly passed, and Governor Pritzker signed, a budget for Fiscal Year (FY) 2023 that provides $209M in new funding towards I/DD services! This comes after an investment of $170M in FY 2022. These are historic increases, bringing the Division of Developmental Disabilities an FY 2023 budget just shy of $2.4 billion. We are especially excited that this budget includes funding for 700 new adult PUNS selections and 100 children’s Home-Based Support PUNS selections. This is the first time in 12 years that a children’s PUNS selection will occur! We are hopeful that with this funding, the Division of Developmental Disabilities will be able to invest additional resources into the service system, including implementing all promised deliverables for FY 2023 as outlined in the Guidehouse Study Implementation Plan. If you feel so inclined, please send a note of thanks to the Governor and your state legislators. They are listening and you might be surprised how much your appreciation means to them. (Source for budget data is the FY 23 DDD Budget Message, [https://www.dhs.state.il.us/page.aspx?item=143957](https://www.dhs.state.il.us/page.aspx?item=143957).)

As we start a new year, we pledge to continue our one-to-one advocacy work, connecting daily with individuals with intellectual and developmental disabilities and their families across the state to ensure they receive appropriate supports, opportunities for community living, inclusion and access to all the services to which they are entitled. With the support of our many community partners and all of the additional programs of The Arc of Illinois, and funding from the Illinois Department of Human Services/Division of Developmental Disabilities, we will continue to provide online and in-person education. Our focus remains, as always, on ensuring that families can navigate the system and fully participate in all developmental disability supports and programs in Illinois. Join us as we work to ensure that every family is heard, all systems are inclusive, and every self-advocate has the choice to participate fully in their community.

The Arc Family Support Network is here for you. Our job is to keep abreast of changes and to stay ahead of the curve whenever possible so that we can keep you accurately informed and look for solutions to systemic issues that affect you. We cannot do this without your support, your information, your thoughtful questions and concerns. Please keep them coming! One thing we have all learned in these last two years is how critical good communication is. We are here to share information and we will always share hope! Thank you for your trust in us. You make our jobs fulfilling every single day.

Sincerely,
Shirley Perez,
Executive Director,
The Arc Family Support Network

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“Let’s Do Together What We Can’t Do Alone!”

-- Shirley Perez
Executive Director, Family Support Network of Illinois

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"We pledge to continue our one-to-one advocacy work, connecting daily with individuals with intellectual and developmental disabilities and their families."
Reflections from Arc of Illinois’ Executive Director

As I reflect back on the whirlwind of the past year, I am reminded of the amazing team here at The Arc of Illinois. I started my role as Executive Director at The Arc of Illinois on June 1, 2022 and am proud of all our team has accomplished since and even more excited about what lies ahead. Over the course of the COVID-19 pandemic, The Arc of Illinois has not only survived, but we have thrived!

We saw the retirement of long-term team members, we welcomed new ones, and congratulated others on promotions. We supported self-advocates to Speak Up and Speak Out, attend the Disability Policy Seminar virtually, and meet with their members of Congress to discuss issues important to them including: community living, voting, SSI reform, and the Direct Support Professional (DSP) workforce crisis.

We supported families in navigating the IDD system in Illinois and learning about changes in the IDD system impacting them and their loved ones.

We supported professionals by providing high quality training affording them continuing education units needed to maintain licenses and certifications.

We served on boards and committees, bringing self-advocate, family, and professional perspectives from our nearly 450 years of combined experience to the table.

We began to do community outreach again with a focus on our chapter and partner members, downstate events, Spanish-speakers, and transition-aged youth.

Among many other policies, we advocated for a rate study of the Home Based Services (HBS) Waiver program (SB 3859) to determine shifts in the buying power of over 11,000 individual and families who participate in the HBS and were not included in the 2020 Guidehouse study. We advocated alongside our colleagues in the They Deserve More Coalition to increase DSP wages and fund the recommendations from the Guidehouse Study.

We shared hundreds of resources and opportunities through multiple modes including a weekly newsletter, monthly webinars, social media, and community events.

We could not do any of this without you! We are striving to remain (or become) your go-to source of IDD information and resources. We hope that you will consider joining us to support not only the robust programming we have provided for decades, but to expand to meet the ever-changing needs of individuals and families with IDD in Illinois. Please consider achieving with us by becoming a member today.

Most sincerely,
Carole

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Going Home Coalition

It has been a great honor and pleasure to step into the role of Going Home Coalition Manager as of October, 2021 alongside Tia Nelis as Going Home Coalition Leader. GHC has revised and reimagined its mission and vision statements, but our purpose remains 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.”

The Coalition is currently comprised of approximately 50 statewide participants, including family members, self-advocates, non-profit partners, service provider agencies, consultants, universities, and other advocacy organizations. The outreach of all these organizations totals over 30,000 people. In the past year we have met with legislators and decision makers and presented to a number of self-advocacy groups, as well as to large audiences at The Arc of Illinois Annual Convention and the Speak Up and Speak Out Summit. We advocated for important legislation. In meetings with Governor Pritzker’s staff and Deputy Governor Sol Flores, and in a letter to Governor Pritzker’s office we asked for the closure of the Clyde L. Choate Developmental Center, the focus of a number of serious charges and allegations. Although our generous grant from the Illinois Council on Developmental Disabilities ends June 30, 2022, Coalition members will continue to advocate. We are a much-needed voice in the disability community and there’s still important work to be done!

Most sincerely,
Carole

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Grantee Products
In partnership with the Illinois Council on Developmental Disabilities. This project was supported, in part by grant number CFDA 93.630, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not necessarily represent official ACL policy.

CDD Products
This project was supported, in part by grant number CFDA 93.630, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not necessarily represent official ACL policy.
Rocio Perez stepped into the role of Director of Illinois Life Span in 2021, having joined The Arc of Illinois in December 2018. The Illinois Life Span Program is The Arc of Illinois’ information and referral resource for families, self-advocates, caregivers and professionals across the state. We answer questions about anything related to services for people with Intellectual and Developmental Disabilities across the entire lifespan. Among all the programs of The Arc of Illinois, we are the generalists or your information hub. We provide this guidance through our statewide toll-free helpline, questions submitted through our website, and our monthly Lunchtime Webinar series, which covers broad topics of interest to help educate people about important services, resources and topics of interest. The Life Span staff have extensive training about a wide range of disability-related topics including healthcare, federal and state programs, special education, respite, guardianship options as well as many other disability-related topics, and receive continuing education through in-services several times per year.

We collaborate with our Family Support Network partners when a family needs a deep dive for assistance or needs multiple agencies to assist, and consult regularly with the Family To Family Health Information Center. We work with all the other programs of The Arc of Illinois in order to best serve the families that reach out to us and are proud of the spirit of collaboration between all programs of The Arc of Illinois.

As of April 30 2022, Illinois Life Span has responded to 1042 calls and hosted 15 webinars. 23,552 web customers have used the Illinois Life Span website. We have participated in 76 community outreach events, 28 of which were outside metro Chicago, and 9 events specifically targeted the underserved Latinx population. We can be reached Monday – Friday via Telephone: 1-800-588-7002

Suzanne Aaron joined the ILS team in July 2021 as Information & Outreach Specialist for Northern Illinois. Navigating disability programs & policies can be overwhelming and at times can almost seem deliberately confusing! I remember how lost I felt when I started navigating this world on behalf of our son, and I am driven to help other parents, caregivers and self-advocates not feel as lost as I did. I love being able to help people understand these programs and direct them to the help that is out there.

I have learned about the determination and dignity of self-advocates, and it motivates me to try to make the world a more accessible, understandable and open place for them and for everyone. I have also learned that despite the challenges, there are wonderful and dedicated professionals out there who are working tirelessly to make things better for people with disabilities. So to paraphrase Mr. Rogers, when things are difficult or scary, I look for the helpers to feel better about the world.

Erica joined the ILS team in July 2021 as Information & Outreach Specialist for Southern Illinois. The connections that I make with the community of people we serve and represent is one of the most enjoyable aspects of my job. In every conversation that I have, be it with a colleague or a caller, I am constantly learning something both new and helpful. The stories from our community have taught me valuable lessons that I am honored to share with others. I feel privileged to have access to a wide variety of information and resources that I can utilize for my own family and excitedly share with folks in Southern Illinois.

Sabrina Wyman joined ILS in December 2021 as Information & Outreach Specialist and covers the Central Illinois region. I enjoy every aspect of my job for different reasons, but I love being able to make a difference in a community that is important to me. It’s an honor getting to be a resource for families who need information and someone to listen to them. I learn something new every day and truly appreciate spreading the word about respite care to families that could benefit from it.
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 who are selected through the Illinois Department of Human Services, Division of Developmental Disabilities (IDHS/DDD), PUNS as a result of the Ligas Consent Decree. The program is staffed by a program director and two Ligas Family Advocates. The program benefits from the resources of the multiple programs of the Arc of Illinois. We are funded by the Illinois Department of Human Services Division of Developmental Disabilities. The Ligas Family Advocate Program continues to expand in our outreach to families and self-advocates in Illinois.

The Ligas Family Advocate Program remains engaged, growing, and active state-wide in Illinois. We have expanded our educational offerings, grown online programming, and maintained relationships with community partners. Education is at the heart of the LFA program. In 2021/2022, we were able to offer webinars on system navigation, respite supports, transitioning to adult supports, and waiver options. Our individual consultations focused on exploring the unique needs of each family, creative funding uses, basics of utilizing waiver funding, and connection to community resources.

We are able to reach Hispanic families with consistency. The Northern LFA, Ruth Aguilar, contributes to the team with her personal and extensive professional experience, as she previously worked as both an Individual Service Coordinator and Self-directed Assistant. We are thrilled to see the expansion in outreach that has allowed us to serve many Spanish speaking families and self-advocates. The LFAP strives for diversity and inclusion, we are proud to say that we are moving in the right direction. Many documents, presentations, meetings and one-on-one advocacy calls are now being conducted in English and Spanish. We respect and embrace all cultural backgrounds and promote acceptance and inclusion towards a better and brighter future. The LFAP program provides support and advocacy to individuals seeking adult developmental supports and services throughout Illinois. Our educational offerings, whether one-to-one or in a group format, focus on understanding adult I/DD service and support options under the Medicaid Home and Community Based Waiver, system navigation, and residential and in-home supports.

January, 2022 The LFAP program mailed out 1,216 letters of introductions to families and individuals seeking support and education as they begin the process of preparing for services after they received an Early PUNS Notification letter in December 2021. We continued to work with individuals selected July, 2021. As we move into the summer of 2022, we look forward to partnering with these families as they begin planning their course for community supports and inclusion. We will continue to find creative ways to connect with families, conduct trainings online and in-person (when safe to do so), share information, and manage concerns raised.

LIGAS REACH
- Facebook: 17,200
- Website users: 1,731
- Sessions: 1,349
- Page views: 2,575
- Letters to Individuals who receive Early PUNS Notification Recipients: 1,216
- Number of Webinars/trainings/Online events: 75
- Telephone calls: 2,500

Contact information for Ligas Family Advocate program:

Shirley Perez
Program Director
Shirley@thearcofil.org

Megan Mutti
Senior Ligas
Family Advocate
Megan@thearcofil.org

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

While this past year has been challenging, it has been satisfying as well. One of the biggest challenges has been the lack of interpersonal connections and socialization with colleagues and people I serve. The technology has opened many doors to expand outreach and provide accessibility. I love the fact that The Arc of Illinois uses technology to its maximum potential. As a Northern Ligas Family Advocate, I work with families in Cook, DuPage, Lake, Will, Kane, Kendall and McHenry Counties. If I were to travel to these places on a regular basis, I would only be able to meet with a small number of families. However, using technology, enables me to expand the outreach by saving time from the commute. Our program offers an array of services and platforms to make it easier and enjoyable for the families to access reliable information while navigating the Medicaid Waiver system. I am available to these families with just one click! During past year, I have worked with approximately five-hundred families by providing information, resources and guidance to obtain benefits such as CILA, Home Based, Community Day Service programs and other community connections. It feels rewarding to receive calls from families expressing their gratitude for being there for them in such daunting process. Additionally, as the primary Spanish contact in our program, I conduct monthly “Know Your Options” webinars for the Hispanic population. Moreover, I constantly participate in professional development to better serve our community. I recently attended the Latino National Social Workers Conference that allowed me to connect with organizations nationwide. I can confidently say that working at The Arc of Illinois is a wonderful experience!

Si bien este último año ha sido desafiante, también ha sido satisfactorio. Uno de los mayores desafíos ha sido la falta de conexiones interpersonales y socialización con colegas y personas a las que sirvo. La tecnología ha abierto muchas puertas para expandir el alcance y brindar accesibilidad. Me encanta el hecho de que The Arc of Illinois utiliza la tecnología en su máximo potencial. Como defensora de familias de Northern Ligas, trabajo con familias en los condados de Cook, DuPage, Lake, Will, Kane, Kendall y McHenry. Si tuviera que viajar a estos lugares con regularidad, solo podría reunirme con un pequeño número de familias. Sin embargo, el uso de la tecnología me permite ampliar el alcance al ahorrar tiempo en el viaje. ¡No te equivoques! Nuestro programa ofrece una variedad de servicios y plataformas para que a las familias les resulte más fácil y agradable acceder a información confiable mientras navegan por el sistema de exención de Medicaid. Estoy disponible para estas familias con solo un clic de distancia. Durante el año pasado, trabajé con cerca de quinientas familias al brindarles información, recursos y orientación para obtener beneficios tales como CILA, Home Base, programas de Servicio Comunitario D umo y otras conexiones comunitarias. Se siente gratificante recibir llamadas de familias que expresan su gratitud por estar ahí para ellos en un proceso tan desalentador. Además, como contacto principal en español de nuestro programa, realizo seminarios web mensuales “Conozca sus opciones” para la población hispana. Además, participo constantemente en el desarrollo profesional para servir mejor a nuestra comunidad. Recientemente asistí a la Conferencia Nacional Latina de Trabajadores Sociales que me permitió conectarme con organizaciones a nivel nacional. ¡Puedo decir con confianza que trabajar en The Arc of Illinois es una experiencia maravillosa!

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**Central/Southern Senior Ligas Family Advocate**

Downstate families in Illinois have shared their needs and concerns, and we have worked closely with them to ensure that they are connected to programs and professionals who can effectively partner with them in the selection of services. Our monthly online “Know Your Options” programs have been designed to introduce families to the Adult Developmental Disability Support System in Illinois. We work closely with families to assist them in understanding system navigation and advocacy basics.

Our downstate families, like families in the Chicago region, have been offered education and guidance regarding the state DD system, the options that will be available to them after a PUNS selection, and the evaluation process required to qualify for the Medicaid Home and Community Based Waiver. We continue to work with families at two key times - during the Early Notification process and following an invitation to apply for the Medicaid Home and Community Based Waiver following a PUNS selection.

Early Notification consultations allow a unique opportunity for the families to make important decisions regarding residential supports, and flexible, family centered supports in Home-Based funding. Families are offered guidance regarding key preparatory steps, including accessing Medicaid coverage, becoming familiar with local developmental disability providers, and importantly, connecting with their Independent Service Coordination Agency.

The needs of self-advocates and families in the downstate area vary widely, but certain trends and barriers are common. Families are seeking individualized, small settings for residential supports, and flexible, family centered supports in Home-Based funding. Families have repeatedly shared their desire to participate in program planning and selection, often with a focus on individualized programming at the community level, with the ability to maintain community connections and relationships. Families report great relief at the reduction in wait times on the PUNS list. Additionally, self-advocates and families seem to be increasingly open to exploring the support available in Host Home programs.

In many areas of downstate, CILA access continues to be a concern, as does the wait time from PUNS selection to service implementation. Families also frequently experience difficulties recruiting and keeping PSW’s in Home-Based supports, and would benefit from additional support in maintaining consistency in their support staff. More families than ever have shared their interest in connecting with other families to start their own CILA homes, and the interest in thinking “outside of the box” continues to grow.

We look forward to continuing to expand the supports and education we offer to families within the LFA program over the next year. Please reach out with questions, suggestions, and needs.

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Ruth Aguilar
Ligas Family Advocate

Megan Mutti
Ligas Family Advocate

Central/Southern Senior Ligas Family Advocate

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Megan Mutti
Central/Southern Senior Ligas Family Advocate
The Family Transition Project has stood strong through the turmoil of the last two years and continues to stand for all of the same values and beliefs we defined at its inception: individuals with I/dd (intellectual and developmental disabilities) undergoing transitions from state operated developmental centers (SODCs) into the community (and their families) deserve to be listened to with respect and compassion, offered helpful information and 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 found successful. Individuals and families have many professionals assigned to assist them through this process, but they cherish the opportunity to talk to openly with another family member who shares their perspective and can offer that unique support, whether in a one to one conversation or in a meeting. We will advocate for them when barriers are encountered and work with them to find the assistance they need. If I think of a single word for what we do it’s consistence. We are able to support individuals and their families consistently through the SODC transition process. We will still be there to listen when the transition is done. Even years later we check in to see how things are going or families check in with us with a new concern. This is the beauty of The Arc of Illinois team. We receive invaluable counsel from all of the other programs of The Arc. If a situation or issue is outside of our parameters, the staff of another program will step in. Often this help comes from the Family Support Network and we are so grateful to them, as to The Ligas Family Advocates, Family to Family, Life Span, and all of our wonderful colleagues. If our Arc team is unable to help, we will stick with a family until we find an agency who can help. Someone asked me recently, “Will you stay with me?” Yes, we will stay with you and offer consistent support. This is what we believe in and what we stand for.

Like a cactus blooming in the desert, hope springs up in unexpected times and places. Certainly it was a delightful surprise to start a new initiative of the Family Transition Project in the middle of another pandemic year. Thanks to a generous grant from The Aigner Foundation, we were able to begin Operation Welcome Home this year. OWH, as we call it, was designed to supplement the work of the FTP, specifically offering some support to people currently living in SODCs (and their families/guardians) who have expressed an interest in moving into the community. In spite of the pandemic, a number of people have still transitioned out, although staff shortages and COVID regulations have slowed the process down in the last couple of years. We have created an informational toolkit to list helpful resources. Stipends are available for those moving out of SODCs to purchase some items that they need for their new home in the community. There is a great deal of leeway in what can be purchased from furniture to a membership in an organization in their new community. The third part of OWH is a series of meetings specifically designed for SODC individuals who are on the list to move out and their families/guardians. These hour long meetings will feature guest speakers on topics important to anyone interested transitioning from an SODC and a chance to ask questions. Thanks to the Department of Human Services/Division of Developmental Disabilities Director Allison Stark, Tiffany Bailey, Deputy Director for SODC Operations, and Melissa Shaw, SODC Operations Transitions Coordinator, for promoting OWH so enthusiastically, facilitating contact with SODC families, and arranging speakers for the first four meetings. A number of professional staff in the Independent Service Coordination Agencies connected to the seven SODCs, and DHS and the Bureau of Transitional Services have begun to attend and to encourage families they work with to get involved in the meetings. If you know anyone who would be interested, please tell them check out the OWH page on The Arc of Illinois website (www.thearcofil.org). All of the meeting information is there, along with the toolkit and stipend application form.

I can’t close without mentioning the Family Transition Project Mentor program. Once again, six mentors have outdone themselves in finding opportunities to share their stories. James Elliott, Susan O’Connor, Robet 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. Please check out their information on the Family Transition Project webpage of The Arc of Illinois website.

This is my final FSN newsletter article as Director of the Family Transition Project. I’m retiring at the end of June. There are a multitude of people I wish to thank – all of the wonderful staff, board members and just general members of The Arc of Illinois, and countless amazing friends, supporters, and professionals from DHS and many other agencies who have supported me in this work. Just writing this, I am a little overwhelmed to think how many friends I have made on this journey. There are no words to express my gratitude to the individuals and families who have shared their triumphs and heartaches with me. Everything I have done is for them. I thank The Arc of Illinois Directors – Tony Paulauski, Meg Cooch, and Amie Lulinski – who have had faith in me and in the Family Transition Project. And I am almost speechless when I think of what I owe to the incredible Shirley Perez, FSN and Ligas Family Advocate Program Director, my mentor and friend, who has never failed in her support through every twist and turn. Thank you all.

Thank you,
Katherine Hamann
Director, Family Transition Project

Contact The Arc of Illinois
815-464-1832
email: Info@thearcofil.org

Family Transition Project
Annual Update - June, 2022
The Arc of Illinois Family-to-Family (F2F) Health Information Center ends its 17th consecutive Project year on 5/31/22. Our project is funded by the federal Health Resources Services Administration (HRSA), Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs. In April we were pleased to learn that we have secured funding for the next five year through 2027! 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.

We closed out 2021 with a December F2F Monthly webinar on the topic of Guardianship presented by Sara Hess, Senior Staff Attorney from Legal Council for Health Justice. All PowerPoints for our Monthly webinars and Annual Healthcare Conference are available on the F2F webpage: www.familyvoicesillinois.org

Here are some of the highlights of the major accomplishments over the past year which emphasize our approach to serving and supporting children and youth with any disability or chronic health condition, their families and the professionals who serve them:

- As of January 2022 we have offered Monthly Health Care Webinars on topics including: Care Coordination (DSCC), Mental Health Resources for Children and Youth - National Alliance for the Mentally Ill (NAMI) Illinois, Special Education -Parent Training and Information Centers in Illinois, Services for children with Deafblindness and DHS-Division of Mental Health Services for children who are Deaf, Hard of Hearing, Deafblind and Late-Deafened, Services of the Illinois Assistive Technology Program and will host a webinar in June on Respite services. All webinars offer real time captioning in English and auto-captation in Spanish.

- In 2022 we have offered F2F evening webinars in Spanish on topics of interest to Spanish speaking families of children with disabilities including in February and May on Illinois Medicaid programs

- We offer F2F stipends to support families and youth with registration fees, travel, and childcare expenses for health-related training events and conferences around the state.

- We continue to expand and update our virtual library of Illinois-specific family-friendly health fact sheets and brochures, with both English and Spanish versions.

- The annual Health Care Conference will take place virtually on 9/1/22 and will include speakers on SSI/SSDI and Medicaid, the Division of Specialized Care for Children - its programs and how children benefit from the Medically Fragile Technology Dependent (MFTD) Waiver through ILS colleague, Erica Steams, whose 2 children receive MFTD waiver services, Directors of DHS-DDD and DMH, and an update from the Illinois Children’s Mental Health Partnership and more.

- We continue to expand and update our virtual library of Illinois-specific family-friendly health fact sheets and brochures, with both English and Spanish versions.

- Together with our colleagues at the Illinois Chapter, American Academy of Pediatrics (ICAAP), we frequently 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. We drafted comments on the Child DD Support waiver, partnering with ICAAP that were submitted to DHS-DDD.

- We also serve professionals statewide via telephone, through numerous training and outreach events and social media.

Family to Family staff and consultants are themselves parents of persons with disabilities, so we let families who contact us for assistance know that they are not alone. With a combination of our own professional training and expertise, our personal experiences and our strong linkages with project partners, we always do our utmost to assist families in helping their children.

We look forward to connecting with you soon.

Contact information for Family-to-Family Health Information Center Program:

Mary Dixon, Director
Toll-free: 866-931-1110  Español: 800-588-7002
Office: 815-464-1832 x1017
mary@thearcofil.org
The Training Department was once again faced with the difficult decision about whether to continue to host virtual or in-person events. Although the prospect of in-person events originally looked promising, a Covid variant came along and derailed our initial plans. Even though we had wanted to be together in person, the removal of both physical and geographical barriers for our attendees has made our conferences possible to those who would otherwise have had challenges. Covid has certainly offered us a lens on how we can build our community through the use of technology and overcome any obstacle with resiliency.

In November 2021, a record number of self-advocates and allies attended the virtual Speak Up and Speak Out Summit (SUSO). The theme was “Building a New World with Independence, Belonging, Inclusiveness, and Respect.” Important topics discussed included epilepsy, Medicare and Medicaid Services, alternatives to calling the police in a crisis situation, how to prepare for a legislative meeting, the intersection of disability and race, employment, healthy relationships, and supportive housing. The chance to meet new like-minded people and learn new things is thrilling, so it is no wonder why SUSO is such a powerful event to so many. We are thankful to the Illinois Council on Developmental Disabilities (ICDD) for funding this event every year.

Our 72nd Virtual Annual Convention took place in April 2022. The theme of the convention was “Turning Silver Linings into Golden Opportunities.” The two-day virtual Conference was stacked with a masterful lineup of 4 keynotes, 21 breakout sessions, an online Silent Auction and Art Exhibit, and an online Exhibitor Hall. The theme of golden opportunities continues to resonate as access to technology opens doors for individuals with intellectual and developmental disabilities now more than ever.

The ability to reach a wider audience across the State continues to be imperative to The Arc of Illinois. As we plan for the future, we want to offer the option for our registrants to choose if they want to attend our events virtually or in-person. We hope there will be some exciting announcements this Fall for future events!

We are so excited to introduce you to the newest member of our Arc team, she is someone you should know!

Heidi joins The Arc of Illinois with over 15 years of experience in Marketing and Event Management. Her professional expertise has prepared her for the successful execution of events and outreach activities as well as marketing initiatives to build awareness and social media presence. 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 for all individuals with intellectual and developmental disabilities. She is dedicated to providing all people a happy and productive life to serve in our community.

Someone You Should Know!

The Arc of Illinois, through a grant from the Illinois Council on Developmental Disabilities, administers the Consumer Stipend Program and distributes consumer stipend funds to enable people with intellectual and/or developmental disabilities and their family members to attend conferences of their choice that are directly related to intellectual and/or developmental disability issues.

We greatly appreciate the investments from the Illinois Council on Developmental Disabilities (ICDD) for this program and there are still funds available. These funds can be used to help cover the cost of registration fees, child care, transportation, hotel, and more. This also applies to virtual trainings.

Additional Arc staff:

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

Traci joined the Arc 11/1/2021 as our Finance Director. As a CPA who has dedicated her career to serving non-profit organizations, Traci is devoted to helping mission-driven organizations maximize the impact of their dollars for the communities they serve. Throughout her career, Traci has become an expert on building highly effective finance teams with a commitment to efficiency, collaboration, and strong operating integrity. Traci attended Bradley University where she graduated with both a bachelor’s and master’s degree in Accounting. Outside of the office, you can find her gardening, experimenting in the kitchen and going on hikes with her family.
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 a statewide staffed 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 35,000 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.

Troy Markert
Troy has over 20 years of experience in troubleshooting issues that families face. He has filled a significant gap in family advocacy; increasing our ability to assist families with unique and difficult situations, particularly in downstate Illinois. Within his role, relationships with Independent Service Coordination Agency (ISC’s), families, and other developmental disability organizations have expanded, increasing the resources that can be offered to families in need of information and support. The addition of the Family Support Specialist role has strengthened our ability to effectively advocate on behalf of families and self-advocates.

Please reach out to Troy at Troy@thearcofil.org

Shakari Asbury
Shakari continues to interact with families and self- advocates who call the FSN/Ligas office looking for support and resources. She works with and assists in getting individuals scheduled for one to one conferences and registered for Know Your Options events. She continues to support the Family Support Network Director in Partnering with organizations and connect with families who have loved ones’ not receiving services to share information. FSN continues to develop our relationships with core partners. In these challenging times we are happy to have Shakari respond out to our families and provide resources and support.

Contact her 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 familial bonds.

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.

FSN Engagements by the Numbers
FSN has reached and shared information to over 30,000 people, including families, self-advocates, providers, and organizations state-wide. We look forward to continuing to strongly advocate for families and self-advocates in Illinois.

Facebook Page: 11,250
Number of Electronic newsletters: 12
Electronic Newsletters Reach: 11,119
Website engagement:
Users: 8,593
Website Page views: 3,747
Website Sessions: 8,113
Webinars/Training: 29
Training (one-on-one): 128
Organizational Partners: 8
Telephone calls (approximate): 1376
Other Outreach events/Conference: 14
Two State-wide Virtual events were hosted by FSN:

The first event was held on October 29, 2021 with 476 registered participants.
Statewide Best Practice and Home Based Conference featuring:

Amie Lulinski, PhD, FAAIDD, Executive Director, The Arc of Illinois
Updates and concerns about Family Support

Keynote:
John Agosta, Executive Vice-president, Human Services Research Institute (HSRI)
Derek Hedges, Medicaid Waiver Unit, Andrea Medley, Strategic Planning, Department of Human Services–Division of Disabilities
Tasha Whiteside, Illinois Program Director Aces$

Megan Multi, MA, QIDP, Senior Ligas Family Advocate
Family Centered Care – The Arc of Illinois

Eileen Morrissey, QIDP, Director of Family Supports Envision Unlimited

Wanda Sunlar, Program Manager, Independent Service Coordination Agency – CSO
Ruth Aguilar, Ligas Family Advocate, The Arc of Illinois

Home Based Support Services Participants:
Mr. John Stewart and daughter Maureen and Warren Groth

The second event was held on March 23, 2022 with 376 registered participants.
10th FSN/Ligas Informational Seminar featuring:

Keynote:
Allison Stark, Director Illinois Division of Developmental Disabilities

Brian Rubin – JD Rubin Law
Family’s Perspective on PCP:
Ruth Aguilar, LFA and
The Von Moore Family: Denise, Donese and Donnie

Barry Taylor, Equip for Equality

Ronnie Cohn, Ligas Court Monitor

Tara Ahern, Project Director Illinois Self Advocacy Alliance

Adam Wiser, Self-Advocate

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

Thank you to our Sponsor, Exhibitors of the Arc FSN/Ligas 10th Informational Seminar:

◆ Aces$ - Avenue to Consumer Employment Services and Supports
Northern Illinois office: 7820 Graphics Drive, Suite 106, Tinley Park, IL 60477
Central/Southern Illinois office: 830 South Spring Street, Springfield, IL 62704
Toll-Free Number: 877-223-7781 | Website: mycil.org/

◆ Community Service Options Inc. (CSO) promotes access, “choice” of service, options & independence to people with disabilities who reside in the City of Chicago through the provision of information, education, planning & service coordination.
6845 S. Western Avenue Chicago, IL 60636
Email: info@cs01.org | Website: https://www.cs01.org

◆ 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 www.rubinlaw.com
Buffalo Grove • Chicago • Old Orchard | 847-279-7999 | Toll-Free: 866.To.Rubin

◆ Envision Unlimited – For over 70 years, Envision Unlimited has served people with disabilities across all ages, abilities, and backgrounds. Today, our wide array of home and community-based programs benefit over 2,000 individuals across the state of Illinois. Envision provides day programs, community living services, employment services, a foster care program, and mental health services.
Central Office: 8 S. Michigan Avenue, Suite 1700 | Chicago, IL 60603
Phone: 312-346-6230 | Fax: 312-346-2218 | Email: info@envisionchicago.org, www.envisionunlimited.org

◆ Equip for Equality – 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) 20 North Michigan Avenue, Suite 300, Chicago, IL 60602
Contact Us: Phone: 312-341-0022 | 800-537-2632 (Voice) | 800-610-2779 (TTY)
CONGRATULATIONS TO ALL OF THE 10th FSN/LIGAS INFORMATIONAL SEMINAR WINNERS

DOOR PRIZE
Gloria Caldwell
($50 gift card)

TRIVIA WINNERS
Norm Perry
Andrea Buehler
Anita Barrzaz
Gloria Caldwell
($50 gift card)
Sweta Pandya
($75 gift card)

~ WINNER ~
Karina Villafuerte
First Family member to register
Kate Spade Purse
and Matching Wallet

~ WINNER ~
Rose Beal, Envision Unlimited
Hand-held Coach Purse
and Bracelet

FIRST SELF-ADVOCATE TO REGISTER
Curtis Harris
($50 gift card)

A Special THANK YOU to Katherine & James Hamann, Friends of the Family Support Network
Donated Amazon Gift Cards

A Special THANK YOU to Sherri Schneider, Benefit Solutions
Donated prizes

Family Support Network | June, 2022
HB 900 (Welch, Sims)
State Fiscal Year 2023 operating budget bill.
Public Act 102-0698, effective 4/19/2022.

HB 4700 (Harris, Sims)
State Fiscal Year 2023 budget implementation bill.
The language authorizing rate increases for community ID/DD providers and wage increases for DSPs and other frontline personnel, subject to federal approval, appears on pp. 484-485.
Public Act 102-0699, effective 4/19/2022.

HB 2775 (Ford, Villivalam)
Amends the Illinois Human Rights Act to make it a violation to discriminate in real estate transactions solely on the basis of an individual’s lawful source of income.
Public Act 102-0896, effective 1/1/2023.

HB 4343 (Harris, Gillespie)
Omnibus Medicaid legislation that includes several provision that benefit people with disabilities including:
1. Increasing the community spouse resource allowance;
2. Establishing a Certified Nurses Assistant Intern Program in various types of facilities including those licensed under the ID/DD Community Care Act.
3. Requiring the Department of Healthcare and Family Services (DHFS) apply for a State Plan Amendment that would allow it to include persons with disabilities and older adults in an ex parte redetermination process.
4. Requiring DHFS to investigate and report on by July 1 2022 on how it can streamline the enrollment process for the Medicare Savings Program and how it can align Medicare Part D Low-Income Subsidy and Medicare Savings program eligibility criteria, and streamline enrollment by July 1, 2023.
5. Subject to federal approval, requiring DHFS to waive the first $25,000 of any estate from an estate recovery claim, and providing that the State may expand the availability of undue hardship waivers.
Public Act 102-1037, effective 6/2/2022.

HB 4365 (Didech, Fine)
Establishes a process whereby a school district can request student-specific State approval for a private residential special education placement on an emergency basis so that the State will be have financial responsibility for the placement as a State-approved facility. Further, the bill provides that a private residential special education placement will be deemed State-approved if a due process hearing officer determines that the facility should be the student’s educational placement.
Public Act 102-0962, effective 7/1/2022.

HB 5196 (Morgan, Bennett)
DHS-initiated bill that establishes a uniform statutory definition of “developmental disability” with exceptions for the federal definition required to be used by the Illinois Council on DD and the definition applied under the Firearm Owners Identification Card Act.
Public Act 102-0972, effective 1/1/2023

SB 180 (Peters, A. Williams)
Creates the Legislative Accessibility Act. Requires the Speaker of the House and the Senate President to each appoint an accessibility coordinator.
who, in coordination with the Architect of the Capitol shall be responsible for addressing accessibility needs for their respective houses. Requires the General Assembly web site to include an email address where reasonable accommodations to meet accessibility needs of people with disabilities attending meetings, hearings, press conferences and floor proceedings at the Capitol complex can be requested. Creates a General Assembly Accessibility Task Force under the administrative control of the Architect of the Capitol. Public Act 102-0897, effective 5/24/2022.

SB 829 (Morrison, Stuart)
Amends the Election Code to require the State Board of Elections to provide a certified remote accessible vote by mail system for the November 8, 2022 General Election and all subsequent elections by electronic transmission to voters with print disabilities through which voters with print disabilities are able to mark and verify their vote by mail ballots. Public Act 102-0819, effective 5/13/2022.

*Since the bill was signed the Board of Elections has announced that the accessible vote by mail system is available for the June 28, 2022 Primary Election.

SB 3132 (Fine, Mussman)
A DHS initiative that would allow a spouse to be a Personal Assistant under the Home Services Program, subject to federal approval. Public Act 102-0826, effective May 13, 2022.

SB 3156 (Fine, Batinick)
Another DHS bill that makes several changes to the Mental Health and Developmental Disabilities Administrative Act with regard to the DSP Credential Pilot Program. Changes the name to Direct Support “Professional” instead of “person”. Provides that the program will be run by the DHS Division of DD or a Division partner. Provides that the program will begin in FY 2024. Public Act 102-0830, effective 1/1/2023.

SB 3215 (Bennett, Stava-Murray)
Amends the Property Tax Code to validate boards and levies created on or after January 1, 1994, and on or before the effective date of this bill that relied on conflicting language in the Community Mental Health Act, the Counties Code and the Community Care for Persons with Developmental Disabilities Act. Public Act 102-0839, effective 5/13/2022.

SB 3474 (Koehler, Avelar)
Amends the School Code to require school districts to provide informational material on ABLE Accounts prepared by the State Treasurer’s office to parents as part of a student’s annual IEP review meeting beginning in the 2023-24 school year. The material would be disseminated by the State Board of Education to school districts and be included in the IEP meeting documents provided to parents. Public Act 102-0841, effective 5/13/2022.

SB 3786 (Ellman, Avelar)
State Treasurer’s bill making several changes regarding ABLE Accounts. Adds “entities” as parties that can be designated beneficiaries. Authorizes Treasurer to require certification of authority from designated beneficiaries under penalty of perjury. Public Act 102-1024, effective 5/27/2022.

SB 3972 (Murphy, Mussman)
Creates a work-study pilot program for high school students to work at community ID/DD providers in direct support for credit. Purpose is to address the shortage of DSPs and interest high school students in the profession. Requires the State Board of Education to prepare a course curriculum by July 1, 2023. Public Act 102-0874, effective 1/1/2023.

SB 4006 (Bush, B. Hernandez)
Requires DHFS to submit annual reports to the General Assembly regarding access to ABA therapy services for persons diagnosed with autism spectrum disorder. Requires the Department of Public Health to develop and distribute education and outreach materials to inform and educate parents of children with autism spectrum disorder who are enrolled in Medicaid and eligible to receive relevant services and explain how to access the services. Sent to the Governor on 5/5/2022.
Saying Thank You to Katherine Hamann
Congratulations on your Retirement!

June 30, 2022

Katherine Hamann, Director of the Family Transition Project at the Arc of Illinois, and a treasured friend and colleague! It brings me great joy to say congratulations on your retirement! You are a committed advocate focused on building opportunities for community-based living for individuals with intellectual and developmental disabilities for over 30 years. As a younger adult sibling to Margaret, you became deeply involved in the disability advocacy system in the state of Illinois, highlighting the concerns and limitations present in the SODC system. Katherine, you have led the charge to ensure that individuals seeking community inclusion have the support, mentorship, and resources available to successfully transition out of the restrictive SODC system and into rich and robust living in the community of their choice. What an amazing legacy.

No one is more giving of her time, experience and passion than Katherine. Her energy and willingness to share has certainly made a positive difference in numerous lives and families. Enjoy your retirement Katherine. Please know that you have made a huge impact on so many lives!

Katherine, I wish you all the best as you, prematurely, begin your next chapter, retirement. You are one very special human being. To say that you are not replaceable would be a gross understatement. Words are simply inadequate to express my appreciation for all that you have done for our fellow families of individuals with I/DD. Be well, be safe.

Katherine joined The Arc of Illinois in 2010 and right from the start I saw what an incredible and warm person she is. And her passion for advocating for the rights of people with developmental disabilities was second to none. The story about her sister Margaret was very inspirational. Katherine truly cares about all people having the opportunity to live a full life in the community.

Retiring myself last June, I had the pleasure of working with Katherine for 11 years. She was always so willing to help whenever possible with any event or project we had going on in addition to doing her job. Thank you Katherine! Congratulations! I hope you enjoy your retirement and have many happy, healthy years with Jim to do whatever you would love to do! Best Wishes!

~ Meg Cooch

Congratulations Katherine on your Retirement! Your dedication and passion to ensuring self-advocates are living their best life is truly inspiring. Enjoy this next adventure and spending time with your family. It’s been wonderful working with you.

~ Becca

Congratulations Katherine on your retirement. Thank you for all your passion, energy, and compassion that you have brought to your work at the Arc. You have changed lives – for people who have been able to move into the community, for people who you have supported to speak their truth and educate others with their lived experience, for people who work for organizations supporting people to open their eyes to how to improve supports and finally for me! You educated me about institutions and community living through your personal story and your experiences with others. I know that even in retirement, you will continue to be the organizer and advocate you are naturally. Thank you for all your hard work. All the best!

~ Megan

Katherine has been an inspiration to many throughout Illinois. Her quite yet passionate advocacy that everyone deserves a full life in the community has been extremely effective. She and her sister’s story are a remarkable testament to her leadership. Well done humble servant. Another journey is about to begin. Lead on!

~ Tony Paulauski

Katherine, I am honored and humbled to have been able to work with you this year, and to have had the opportunity to learn about your sister and your family’s story. You have made an impact. Your work was and always will remain vitally important. May you have a restful and indulgent retirement!

~ Suzanne

Thank you for your dedication and passion! I will miss working with you. I hope you enjoy retirement to its fullest.

~ Rocio

Katherine - You are such a light. I enjoyed every conversation that we shared. Thank you for that. I wish you the best during your new journey. Enjoy every last moment, you deserve it.

~ Victoria

Katherine - Congratulations on your retirement! You have led with such authenticity and honesty, and your willingness to share your family’s story has been incredible. Thank you! Best wishes.

~ Megan

Ms. Katherine it has been a true pleasure to work with you, and though I’m sad that you’re leaving, I’m proud of you and will forever miss you!

~ Love Shakari

Congratulations on your retirement Katherine! When we met years ago, we were participating in the closure planning for House Developmental Center. At some point we became carpool buddies and got to know one another traveling for meetings. I recall thinking, “Wow, this person is amazing!” as I learned about you, your sister, Margaret, and the impact she had on your life – and, for us, your career trajectory. You have had a profound impact on the lives of those you have served over the years. That is evident in what the Transition Mentors had to say about the characteristics that the next Family Transition Project Director should have. They described you as: helpful, a good listener, patient, resourceful, kind, generous, understanding, outgoing, with a good personality. Katherine – you are one of a kind. Thank you for all you have done, and yet to do, on behalf of and alongside people with IDD and their families. I hope your find time in retirement to read all of those books you have and finally get some R&R. We will miss you!

~ Amie

Katherine, From the moment we connected in 2019 regarding my participation in Going Home Coalition Advocacy Day, I was so impressed by your thoughtfulness, helpfulness and kindness. Little did I know, our paths would cross in a much larger way these past few months when I became Going Home Coalition Manager. You have been instrumental to the success of the Going Home Coalition. We have relied on you for so much of your lived experience as a sibling to Margaret, your work experience in SODCs, as Family Transition Project Director, and additional knowledge you so graciously share with others. Throughout my time here at The Arc of Illinois, you have been there for me in so many ways. I am amazed by you! You are such a wonderful person!!!! I am truly grateful for our friendship and know that it will be lifelong and cherished. Wishing you my very best in your newest adventure.

~ Carole Rosen

Katherine - You are both a kind and thoughtful colleague and a fierce advocate on behalf of people with disabilities! I wish you a retirement full of blessings and happiness! Best of joy. I didn't need to spend much time with you to realize how wonderful of a self-advocate you are naturally. Thank you for all your hard work. All the best!

~ Mary Dixon

Katherine - A person with a great soul is always someone who shines the light human being you are. I wish you a retirement full of blessings and happiness! Best.

~ Ruth Aguilar

Congratulations on your Retirement! Your dedication and passion to ensuring self-advocates are living their best life is truly inspiring. Enjoy this next adventure and spending time with your family. It’s been wonderful working with you.

~ Becca

Congratulations Katherine on your retirement. You are a committed advocate focused on building opportunities for community-based living for individuals with intellectual and developmental disabilities for over 30 years. As a younger adult sibling to Margaret, you became deeply involved in the disability advocacy system in the state of Illinois, highlighting the concerns and limitations present in the SODC system.

Katherine, you have led the charge to ensure that individuals seeking community inclusion have the support, mentorship, and resources available to successfully transition out of the restrictive SODC system and into rich and robust living in the community of their choice. What an amazing legacy.

My friend you epitomize compassion: you are kind but firm, loving but focused, and strong but caring. Most of all, YOU are deserving of retirement. I wish you love, peace and joy in the next phase of your life. Your work lives on. Much love.

~ Shirley
Precious Memories with Katherine . . .
Arc Family Support Network
9980 190th Street, Suite C
Mokena, IL 60448

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

Let’s do together
what we can’t do alone!
Shirley A. Perez, Executive Director
Troy Markert, Family Advocate Specialist
Shakari Asbury, Administrative Assistant

The Arc of Illinois

Become a member of
The Arc of Illinois
Individual, Family, and Organizational Memberships

Membership Benefits:
• Discounts on Trainings and Conferences for staff, families, and self-advocates attending training opportunities
• Online Resources, Materials and Video from Trainings
• Quarterly Members-Only Webinars
• Weekly emails on Federal/State Policy and Advocacy
• Networking Opportunities with Individuals, Families and Professionals
• Regional Meetings for Members
• Participation in a Team Effort, Advocating for Change in Community Living
• Professional Certification Requirements
• Available CEU’s and CPDU’s for professionals

www.thearcofil.org/join-us/

2022-2023 FUTURE EVENTS
Visit our website for updates:
www.thearcofil.org select “upcoming events”

October 19 - 21, 2022
Speak Up and Speak Out Summit

November 1, 2022
New Fall Conference (name TBD)

October or November 2022 (exact Date to be determined!)
Home Based Boot Camp

January 24, 2023
QIDP Conference

July 2022 – June 30, 2023
Monthly Ligas Know Your Options

March 22nd or 23rd, 2023
11th FSN/Ligas Informational Seminar

April 19 - 20, 2023
Annual Convention

June 8 -9, 2023
Executive Forum Leadership Conference

We are proud to be one of the programs of the Arc of Illinois

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.