

Family Support Network

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June 2020

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

Hello Family Support Network Family and Friends,

How awesome is it, that I can greet you with the news that the Illinois General Assembly passed the FY21 budget. The budget includes a move to \$14.00/hour in our frontline wage reimbursement rates effective July 1st and a move to \$14.50 effective January 1, 2021, both of which were also included in the Governor's introduced budget. At the time of this writing the Department of Human Services (DHS) is awaiting clarification on legislative intent on the increases in wages. More information will be shared later in Phil Milsk's legislative update.

It has truly been a year of turmoil, but I like to begin with the good news and with thanks. It's especially important in times like these to stay focused on our mission, a mission that would never be accomplished without your commitment. We cannot thank you enough for your support, but we also appreciate your feedback. We are a resource for you, yet often you have information for us about resources, about barriers you have encountered, or suggestions about ways around those barriers. If you share them with us, they add to our store of knowledge and add to what we can share with each other and sometimes with decision makers as well. We also appreciate that many of you have answered the call when we've asked for help with specific projects. You are too many to name but you know who you are and you have our deepest gratitude.

The Family Support Network is one of the major programs of the Arc of Illinois, funded by a grant from The Illinois Department of Human Services whose Executive Director is Meg Cooch. With her direction and the support of our staff, Board, and volunteers, The Arc continues to lead the way in advocacy for people with Intellectual /Developmental Disabilities (I/DD) and their families statewide.

This program is state-wide and staffed by 3 people: a program director, an assistant/family liaison and a family advocate specialist. Each member of the team brings deep personal and professional experience to their work with families.

Families of children or adults with intellectual/developmental disabilities want the best for them. They strive to prepare them for the transition into adulthood, but often they face additional challenges, including daily stress, social isolation, and financial strain. The unexpected, like the novel coronavirus pandemic (Covid-19), can knock families even farther off course. Sheltering in place with a family member without the respite of a reliable daily routine or help from a regular support system, being separated for weeks from a family member who lives only a few miles away in a CILA, or struggling to figure out the in's and out's of stimulus checks or what to do if a family member needs to be hospitalized – all of these issues have come up in recent conversations with families who often feel more isolated than ever before. The uncertainty might be the most difficult factor. Jobs and lives on hold are difficult to process for both individuals with I/DD and their families. Through "Family Support" families are able to access a broad array of supports and services, including formal and informal supports (such as parent-to-parent

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Shirley Perez
Executive Director,
Family Support
Network of Illinois

“The Family Support Network seeks to ensure the continuation of all individual supports throughout the life span of the individual.”

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Meg Cooch
Executive Director
The Arc of Illinois

Meg Cooch, The Arc of Illinois Executive Director, is now in her fourth year of leadership at The Arc. Leadership has many aspects in her very responsible job. She leads the Arc team of dedicated staff members. She works with the Board of Directors. She has made a concerted effort to know Arc members and meets regularly with the Executive Forum – heads of Arc chapters. She knows many of our volunteers and also self-advocates and families who attend our events. And that’s just the beginning.

Director Cooch is familiar with leaders in many other advocacy organizations, too numerous to list. She converses multiple times a week with decision makers in the Legislature and in the Department of Human Services and other government agencies, as well as keeping in touch with the National Arc. But leadership is not just a matter of endless tasks. A leader is a visionary. Our Director’s vision allows for growth and flexibility (as in facing unexpected Covid-19 issues) but does not waver in bedrock beliefs.

We always know that she stands for the fullest participation in their own lives and full community engagement for people with I/DD and the funding and infrastructure needed to make this happen. Thank you, Meg, for your leadership.



Arc Board President with Arc Staff at Speak Up Speak Out
October 30, 2019



LFA, participating in the Alliance Arc Training
August 28, 2019



FSN, Director presenting at Ray Graham Series
September 19, 2019

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

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connections) and a community system of services that promote the well-being of families and their adults/children throughout their life span. Some of these services and supports may change in light of health and safety protocols and we are here to keep you updated on changes.

One bright spot is that DHS Secretary Hou and DDD Director Allison Stark, still in their first year in the job, are very open to hearing your thoughts on many topics such as visiting loved ones in

CILAs and how you think day services for your family members should work. This is a chance for all of us to speak up about what we would like to improve. (See our introduction to Director Stark and contact information later in the newsletter.)

As a result of Covid-19, the FSN will be partnering with the Ligas Family Advocate program to bring webinars, conferences and relevant educational forums to the intellectual/developmental disability community. As our society

continues to depend on the active engagement of family caregivers for the support of individuals with I/DD, it is essential that the FSN is fully staffed and prepared to address the increasingly challenging needs presented by the current pandemic.

Please know we’re happy to hear from you at Shirley@thearcofil.org. FSN Community – our strength comes from you. Thank you again for lifting us up. When we act together, We’ve Got This!

Thank you, Shirley A. Perez



Illinois Life Span Program

The Illinois Life Span Program (ILS) of The Arc of Illinois has been available to help people with disabilities, their families and caregivers, and professionals find information/resources related to intellectual/developmental disability (i/dd) services and supports for almost twenty years. ILS provides information in a number of ways, including through the website, which will be available in an updated format very soon at www.illinoislifespan.org. Questions can be submitted through the website and by email, and ILS staff are also available by phone at 1-800-588-7002 during regular business hours Monday through Friday to answer calls.

The ILS Program has been hosting Monthly Lunchtime Webinars since 2017, focusing on Illinois resources and services for families that include a loved one with i/dd. These webinars are generally held on the second Tuesday of the month from noon to 1:00 PM. You can sign up for webinars on The Arc of Illinois website Events page. Between July 2019 and May 2020, ILS has hosted 11 webinars for a total of more than 1,500 participants statewide! If you missed a webinar, you can find the recording and any handouts available on our "Monthly Webinars" page at <https://www.thearcofil.org/monthly-webinars/>.



Rocio Perez
Bi-Lingual
Information and
Outreach
Specialist

There are four staff members on the ILS team. Our newest staff member is **Rocio Perez**, our Bi-Lingual Information and Outreach Specialist. Rocio is located in the Chicago area and supports Spanish speaking families statewide. Rocio has been instrumental in expanding our reach to Spanish speaking families through outreach events, webinars, and information in Spanish from The Arc of Illinois. Rocio is also the parent of a young adult who receives disability services/supports. Rocio has been a wonderful addition to our staff and we are very grateful to have her expertise as part of our team! You can reach Rocio by email at Rocio@thearcofil.org.

Cindi Swanson is the ILS staff member with the longest history with The Arc of IL! She has been with the ILS Program, with a few brief pauses, since the beginning of ILS in 2001. Cindi has been an advocacy force in the DuPage county area since the birth of her middle son, who has Down syndrome and is now a young adult. Cindi is also blind, so she experiences disability herself. Cindi's is likely the voice you will hear when you call ILS, and her decades of advocacy in the i/dd service system have given her tremendous expertise in guiding families to the information and resources they are seeking. Cindi can be reached at cindi@thearcofil.org.



Cindi Swanson
Illinois Life Span
Staff Member



Missy Kichline
Information
and Outreach
Specialist

Missy Kichline is our Information and Outreach Specialist in southern Illinois. Missy has worked in the field of disability services and supports for over thirty years and is also the parent of a young adult who receives services/supports. Missy has been instrumental in reaching out to families and organizations in the southern part of Illinois to share resources and support with others on their advocacy journey. Missy also shares information with callers to ILS and looks forward to connecting with other families as part of the ILS team! Missy's email is missy@thearcofil.org

Deb Fornoff is the Director for the Illinois Life Span Program and is also a long-time team member at The Arc of Illinois! Deb and her husband are also the proud parents of a young adult son with Down syndrome who is the reason behind Deb's commitment to disability information/advocacy. They live in central Illinois. Deb can be reached at deb@thearcofil.org and encourages everyone to take a look at the information available on the ILS website (www.illinoislifespan.org) and please contact her or the other ILS staff if they can help with information any time! We all look forward to connecting with you!



Deb Fornoff
Director
Illinois Life Span
Program



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



The Ligas Family Advocate Program

The purpose of the 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), Prioritization of Urgency Needs of Needs for Services (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.

PROGRAM OVERVIEW

- Work one-to-one with families and self-advocates, those who are currently receiving waiver supports, those who have received Early Notification from DDD regarding upcoming PUNS selection, and PUNS selectees to explore opportunities available within the Medicaid Home and Community Based Waiver for Adults with Developmental Disabilities (DD)
- Explore options focused on personal goals, community inclusion, and independence with needed support services
- Provide education regarding the PUNS selection process, key choices, and needed resources
- Ensure a basic understanding of the two programs available to adults with developmental disabilities in Illinois (ICF/DD program and Home and Community Based Waiver Program)
- Connect to core DD resources.
- Family advocates address the needs of individuals with developmental disabilities and their families by providing information about, and options for, using community-based services for the developmentally disabled, including Home-Based Support Services (HBSS) and Community Integrated Living Arrangement (CILA) services to build full and integrated lives in their homes and communities.

The Ligas Family Advocates Program remains engaged and committed to partnering with families and self-advocates who are anticipating a PUNS selection this summer or who have been funded throughout the last several years. Though Covid-19 has presented a number of challenges, we have been able to effectively continue our work with families to ensure that they receive accurate, up-to-date information about their options and can explore all of their support service possibilities. Additionally, we are connecting families with vital resources related to Covid-19 and DD support.

The LFA program reach is significant and consistent. We reach out to families by mail, email, telephone calls, newsletters, educational webinars and social media. LFA's frequently work with families through 1:1 calls and conference calls, based on family need and preference. The LFA program has served individuals in all 102 Illinois counties.

LIGAS REACH

PUNS invitation introduction letters: 986 individuals selected for funding in 2019; LFA support services remain engaged

- 2019 PUNS, December, Early Notifications letters over 1500: 1250; ongoing support
- Ligas Family Advocate Facebook page: 19,555 views
- Ligas Family Advocate website engagement: 2844
- LFA Electronic newsletters: 18,145
- Know Your Options events: 15 Know Your Options events, 350 family participants
- Know Your Options webinars: 4 total Informational Webinar events, approximately 150 participants
- LFA Program brochure sharing: 2500
- Approximately telephone calls: 1500

Once families engage the LFA program, the services remain available throughout the time that they are seeking services and after they are in services for the purpose of troubleshooting barriers. We work closely with families who are overwhelmed, frustrated, and confused by the navigation of the developmental disability system in the state.

Families consistently share concerns regarding lack of choice in providers, limitations in CILA openings, lack of system capacity, the unclear process of shifting from HBS to CILA services, lack of independent living options outside of group home CILA's and a widespread inability to find direct support staff/personal support workers.

We work to connect families to one another, helping to build a network of communication and support among families seeking support services. The LFA program regularly partners with Independent Service Coordination agencies and developmental disability providers to share information and assist families in exploring local options and programs. Many of the families that reach out to the LFA program request assistance with navigating the complexities of the system, including building a relationship with their Independent Service Coordination Agency (ISC), understanding common barriers, and most importantly, taking the key steps necessary to ensure that the PUNS selection process addresses their unique needs and concerns. The LFA program is distinctive, in that it allows for long-term relationship building, is able to both prepare families for common difficulties and provide

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Mary Dixon
Northern Ligas
Family Advocate

Northern Ligas Family Advocate

This year has once again been gratifying and humbling to know that we can ease the anxiety and confusion many feel as they anticipate a PUNS selection through our one-to-one advocacy and through resources, including an updated Medicaid Q & A, a comparison of the DRS v. DDD waiver, and a Planning for DD Services document with many resource links. I have been excited to meet with providers I had not yet met

who presented with me, and ISC staff at our “Know Your Options” presentations, including Allison Stark, current DDD Director, who last July spoke at an event held at Myers Place -supportive housing, when she was CEO of a DD provider, Orchard Village.

I am also glad that our outreach to the 1500 or so people who received early notification of their 2020 PUNS selection in late December, through a webinar offered on multiple

dates/times that provided a helpful general introduction to services of the waiver. I am looking forward to the launch of our 2020 webinar series that offers in depth information on specific services of the waiver. We began the series on May 6th, with Lore Baker, CEO and President of the Association for Individual Development who offered her expertise on the topic of supportive housing –affordable housing where waiver funding is used for needed support services. I am also happy to be The Arc of Illinois’ representative on the state Task Force for the Protection of Individuals with Disabilities in the Criminal Justice System which had its first meeting in April.



Mary in Action presenting at a Know Your Options Event

The Ligas Family Advocate Program

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anticipatory guidance to help them fully participate in the planning process, and allows for work with families who have difficulties that arise well into their support service implementation.

Families have frequently shared feedback regarding program effectiveness, sharing their gratitude regarding the clarity of the information that we provide, the family-centered nature of interactions, and the accuracy of the education provided. The LFA program is a critical component in ensuring that families and self-advocates are able to access key information and resources that allow for implementation of developmental disability support programming that is person-centered, consistent, and a match to the needs of the individuals that we work with. With the partnership of the LFA program, families are able to plan more effectively, take the necessary steps to streamline the selection process, and reach out to local providers to explore available options within their community.

The LFA program is using numerous methods to connect with families on our roster, attempting to reach as

many as possible during this time of high anxiety. We have developed an informational handout that directs families to upcoming educational events and lists relevant Covid-19 resources, including those specific to the DD community. The information is being sent to all families who have linked up to the LFA program throughout the past two years.

ONLINE EDUCATION

- Accessing Affordable Housing, Wednesday, May 6, 2020 12:00-1:00 p.m.
- Home and Community Services Programs: Available Services, Wednesday, June 10, 2020 12:00-1:00 p.m.
- Residential Services of the Home and Community Based Waiver, Thursday, July 9, 2020 1:00-12:00 p.m.
- Community Day Services Programs, Thursday, August 13, 2020 12:00-1:00 p.m.
- Supported Employment Programs, Thursday, September 10, 2020 12:00-1:00 p.m.
- Host Family & Shared Living

Programs, Thursday, October 8, 2020 12:00-1:00 p.m.

- Behavioral and Mental Health Supports in the HCBW, Thursday, November 12, 2020 12:00-1:00 p.m.

Based on concerns from families, the LFA program developed a Healthcare Fact Sheet specific to communicating with and partnering with healthcare providers for individuals with IDD. The fact sheet is available for educational and advocacy purposed to all interested individuals and is being emailed to LFA linked families. The fact sheet focuses on navigating the current environment, ensuring that individuals with IDD and their families understand their options and can partner fully with providers in their care.

The LFA program will continue to find creative ways to connect with families, share information, and manage concerns raised by self-advocates. Our program is a critical component of the developmental disability system in Illinois, ensuring that families and self-advocates can access the support services they want and need as they seek safe, successful, inclusive community-based living options.



The Ligas Family Advocate Program



Megan Mutti
Central, Southern
Ligas Family
Advocate

Central/Southern IL Ligas Family Advocate

The LFA program in Central and Southern Illinois has continued to expand, serving families throughout the lower half of the state via individualized advocacy calls, educational events, and online trainings. One-to-one advocacy continues with December 2020 PUNS Early Notification families, and families selected in the 2019 PUNS pull continue to connect to discuss barriers/implementation concerns, or simply to be connected to appropriate DD resources. Know Your Options events

continue, both in implementation and planning. The events, which often include parents, self-advocates, DD professionals, and providers, are designed to provide comprehensive and accurate information about the Medicaid Home and Community Based Waiver Program. Families are provided with various written resources, opportunities to learn about the services of local providers, and connection to the LFA program following the event.

Families who have participated in one-to-one advocacy calls have received follow-up educational tools targeted at their unique needs and concerns. The LFA program has developed numerous advocacy tools (Residential Services Fact Sheet, Medicaid Fact Sheet, Healthcare Advocacy Fact Sheet, DRS v DDD Waiver Comparison, PUNS Flowchart, Introduction to Developmental Disability Services in Illinois) to assist families as they navigate the DD system in IL, all which are focused on understanding options, participating meaningfully in support service planning, and addressing common concerns and challenges.

Know Your Options events (7) were facilitated in numerous areas throughout the state, including Ottawa, Carbondale (2), Quincy, Peoria, Morton, and Lincoln. Several Independent Service Coordination agencies participated as event partners. Additionally, numerous online and call-in education opportunities specific to options under the Home and Community Based Waiver were offered for families and self-advocates. The participation rates were steady, with families enjoying the opportunity to discuss options, understand common barriers, and explore creative problem solving around utilization of waiver services and preparation for the selections process.

The Central/Southern LFA continues to work in partnership with families seeking information, support and education. Family support calls vary, with extensive follow-up via ongoing email support. Family support has focused on understanding the basics of navigating the adult DD system in Illinois, the role of core participants in the process (ISC, ACCE\$ Services, DD Providers, SDA, PSW/SDA), and deep exploration of potential support options once funding is in place.

Families report numerous barriers and concerns. High quality CILA group home access continues to be difficult for families, particularly in southern regions of the state. Some families are navigating overwhelming mental health challenges and have shared their great difficulty in accessing even basic mental health support; their concerns often focus on whether the individual with mental health needs will have developmental disability specific needs that are "enough" to qualify under the Medicaid Home and Community Based Waiver. Many of these families have gone years without adequate or consistent services. Families come to the LFA programs with general concerns about being approved for waiver services and many struggle to access school/evaluation records that may assist them, as their individuals are years out from graduating or completing transition programs. For families who would like to utilize home-based services, concerns often focus on finding qualified and reliable PSW staff if they choose to not take that role on as parents. Transportation barriers are a consistent theme, with challenges in both access and consistency.



Know Your Options in Peoria

Contact information for Ligas Family Advocate program:

Shirley Perez
Program Director
Shirley@thearcofil.org

Mary Dixon
Northern Ligas Family Advocate
Mary@thearcofil.org

Megan Mutti
Central/Southern Ligas Family Advocate
Megan@thearcofil.org

Family Transition Project

2019-2020 Year in Review



Katherine Hamann
Director
Family Transition Project

The Family Transition Project is thriving and it's great to take this opportunity to look back over the past year and see what we have accomplished and imagine what the next year could bring. Hope is the one word that is always in our thoughts – hope that people with I/DD (Intellectual/Developmental Disabilities) can transition successfully from SODC's (State Operated Developmental Centers) and other large congregate settings to a life centered around their own needs and desires, particularly the need to experience community living. This is the "transition" we're talking about when we refer to the Family "Transition" Project (FTP).

The novel coronavirus pandemic has certainly made more people question the SODC system. Infection can theoretically be a problem anywhere, but we cannot help but be aware that people who are not living in large congregate settings right now have a lot of other advantages.

Isolation and social distancing are more palatable for people who have easy access to computers and phones, who can take a ride in their own vehicles, who can look out the window and see neighbors, or receive packages delivered by family members and wave from

the doorstep or who can stroll through a lively neighborhood or do some yardwork or experiment with cooking something new or do paying work from home or work on a craft project with their housemates. These are things that people living in the community have been able to do even during the pandemic and that most people living in SODCs have not. Food for thought when you consider that staying connected to their communities is always a challenge for people with disabilities in the best of times.

What are a few highlights of the last year that give us hope for the future?

The Arc Mentor Program is an integral part of the FTP. The four Arc mentors have lived in both SODCs and homes in their communities of choice and they have a lot to say about their experiences. After two years, they have spoken at many venues. In spite of the cancellation of ten events that were long planned (thanks, mostly, to Covid-19), the mentors presented, co-hosted, or co-presented (or all three) at over twenty different events in the

last year alone. During stay-at-home-orders, they have still participated in webinars and meetings, and spoken at a press conference, a rally, and on the radio. They continue to find new ways to share their stories and in the next year they plan to help more self-advocates lift their voices and ask at least one new mentor to join them in the program.

Individual and family advocacy continue to keep us grounded in the issues that self-advocates and their families face every single day as they attempt to transition out of state operated developmental centers. Several successful transitions have made us hopeful this year, particularly when self-advocates met major challenges. We are all learning from even those experiences that weren't successful and right now a big source of hope is that the Department of Human Services is listening. We appreciate that both DHS Secretary Grace Hou and DDD Director Allison Stark are

keeping an eye to the future while coping with the crushing demands of fighting the coronavirus in SODCs and supporting the many community based facilities that are also working hard to keep everyone safe and well.

In the last year, the Family Transition Project has expanded visits to self-

advocates living in state operated developmental centers and is still in contact by phone and email with several individuals and their families as the SODCs remain temporarily closed to visitors. What's encouraging about this is the chance to see and hear firsthand how people feel about their lives in SODCs.

As always, our partnerships with the other programs of The Arc, and particularly the Family Support Network, are an incredible blessing to our work. Many other agencies and advocates have pointed us in the right direction and shared valuable resources with us and we thank them.

If you know someone (or their family) thinking of looking outside their state operated developmental center or if you know someone who has transitioned and would like to share their story, please check out the Family Transition Project page on The Arc of Illinois website (www.thearcofil.org), or call us at 708.465.2827 or 815.464.1832 x.1019, or just email me at katherine@thearcofil.org. Thank you.

“Food for thought when you consider that staying connected to their communities is always a challenge for people with disabilities in the best of times.”



Division of Developmental Disabilities



Allison Stark
Director, Division of Developmental Disabilities

Allison Stark, Director of the Division of Developmental Disabilities, DHS, has committed her entire career to serving individuals with intellectual and developmental disabilities. Allison most recently served as the President and CEO of Orchard Village, a nonprofit in the North Chicagoland area providing an array of community based services to individuals with I/DD. Prior to her 12 years with Orchard Village, Allison was a Program Manager at Resources for Living in Evanston, and a Home & Community Based Services Waiver Case Manager for adult Care Management in Lafayette, Colorado. Allison holds a Bachelor's degree from the University of Colorado, Boulder, and a Master's degree from the University of Chicago.



Sherri Schneider, Arc Board President, Allison Stark, DDD Director, IDHS Secretary Grace Hou, Arc Executive Director, Meg Cooch, Ligas/FSN Director Shirley Perez, Ashley Farland, and Shakari Asbury Arc staff, Speak Up Speak Out October 2019, Springfield

A mark of her leadership has been her constant communication with families, providers and stakeholders. We encourage you to reach out to her at: allison.stark@illinois.gov, she welcomes feedback.

Here is some great news for families and self-advocates shared in Director Stark's June 17, 2020 Communication to stakeholders:

PUNS NOTIFICATIONS

The Division is in the process of preparing PUNS selection letters to be sent out. We expect to send out around 1,589 PUNS selection letters the week of July 13. Most of the individuals who will receive selection letters previously received early notification letters in December 2019. We are currently working with the ISC agencies to finalize the list of individuals that will be included in this selection. For questions, please contact Mike Vespa, Manager for Program Development at Michael. Vespa@Illinois.gov.



Check out our new look!

www.dhs.state.il.us/page.aspx?

Thank you to our generous Vendors & Sponsor of the 2020 Online 8th Informational FSN/Ligas Seminar:

- ◆ **ACES\$ - Avenues to Consumer Employment Services and Supports** | Northern Illinois Office: 7820 Graphics Drive, Suite 106 Tinley Park, IL 60477; Central/Southern Illinois Office: ACES\$ 830 South Spring Street, Springfield, IL 62704 Toll Free Number (877) 223-7781 Website: www.mycil.org
- ◆ **Chicagoland Autism Connection** | www.chicagoautism.org
- ◆ **Community Services Options, Inc** | Telephone (773) 471-4700, Fax (773) 471-4770, TDD: 773-471-4772, Toll-Free: (888) 276-4467, www.cso1.org
- ◆ **Envisions Unlimited** | www.envisionsunlimited.org
- ◆ **Family Benefit Solutions** | (847) 279-8506. Email: benefithelp@aol.com
- ◆ **Genesee Lake School** | www.geneseelakeschool.com
- ◆ **Pace Bus** | www.pacebus.com
- ◆ **Rubin Law – Special Needs Legal and Future Planning** | www.rubinlaw.com
- ◆ **Chicago Public Schools** | www.cps.edu
- ◆ **NAMI South Suburbs Chicago** | www.namisouthsuburbsofchicago.org



The Arc of Illinois Family-to-Family Health Information Center



Faye Manaster

The Arc of Illinois Family-to-Family Health Information Center (F2F) will be ending its fifteenth consecutive Project Year on 5/31/20. Our project is funded by the federal Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs. We are 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 and/or special healthcare needs.

Here are some highlights of our major accomplishments over the past year, which emphasize our approach to serving and supporting CYSHCN and families:

- We maintain strong relationships with Staff members at the Illinois Department of Health Care and Family Services and the Illinois Department of Human Services, which enables us to support many families in navigating barriers, related to eligibility, enrollment, redetermination and access while systems change evolve under Medicaid Reform and the Affordable Care Act. Since March 2020, we are also collaborating and sharing numerous updates and changes related to the COVID-19 Pandemic which impact families of children and youth with special health care needed.
- We convene an Annual Health Care Conference, featuring expert speakers on trending public, private, and Marketplace insurance issues through a CYSHCN/disability-specific lens. Our highly successful Annual Healthcare Conference was held in September 2019, with over 100 attendees. Planning is now underway for our September 2020 conference, which be virtual.
- New this year is our first Spanish language Healthcare Conference, originally scheduled for 3/14/20. Due to the pandemic, we have rescheduled this as a virtual event to be presented in three parts during the week of June 22, 2020.
- 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.

- 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 CYSHCN and their families across state agencies.
- We also serve professionals statewide, via telephone, through numerous training and outreach events, and social media.
- This past year, Family Voices National invited us to apply for a grant from United Health Care to support Illinois families with UHC employment-based insurance to learn more about all programs of The Arc of Illinois and get help with resources and information specific to their families. This project, which contracted with two skilled Parent Mentor Consultants, ended on 3/31/20. Unfortunately, United Health Care discontinued this Pilot Project.

Our staff and consultants are themselves parents/ persons with special health needs, 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.

“We are part of a network of Family-to-Families...all run by experienced parents of children of all ages with disabilities and/or special healthcare needs.”

**Contact information for
Family-to-Family Health
Information Center program:**

Faye Manaster, M.Ed.

866-931-1110

familytofamily@thearcofil.org

www.familyvoicesillinois.org



The Family Support Network (FSN) Program

Our program partners with families and other support groups and organizations to provide support, education, and connection around developmental disability policy, legislative advocacy, and problem solving. We work in partnership with families who are experiencing difficulties navigating the developmental disability service system in Illinois.



Troy Markert joined the Arc of Illinois Family Support Network as our Family Advocate Specialist, bringing with him 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. Troy@thearcofil.org



Shakari Asbury, Family Support Network Assistant and Liaison. She continues to interact with families and self-advocates who call the FSN/Ligas office looking for support and resources. She works with and assist in getting individuals 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 as

we partner with Chicago Land Autism Connection, (CAC), Answer Inc., and Parents of Extraordinary Children in the 10th ward and South Chicago Parents and Friends. In these challenging times we are happy to have Shakari respond out to our families in a timely manner. Shakari@thearcofil.org

As a result of Covid-19, the FSN will be partnering with the Ligas Family Advocate program to bring webinars, conferences and relevant educational forums to the developmental disability community. As our society continues to depend on the active engagement of family caregivers for the support of individuals with intellectual/developmental disabilities (I/DD), it is essential that the FSN is fully staffed and prepared to address the increasingly challenging needs presented by the current pandemic. The Family Support Network will help meet these needs by providing accurate and timely education, information, training, and a network of support for individuals with disabilities, their family members, and the community of service providers, professionals, and policymakers who serve them.

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: **12,042**
- Number of Electronic newsletters: **17**
- Electronic Newsletters Reach: **15,133**
- Website engagement:
 - Users: **3,774**
 - Website Page views: **8,149**
 - Website Sessions: **3,886**
- Webinars: **5**
- Webinars/Training/Reach: **673**
- Organizational Partners: **8**
- Telephone calls (approximate): **987**
- Other Outreach events/Conference: **25**
- Material shared: **10,000**

With state funding, FSN will ensure that families in all parts of Illinois will have access to accurate information and training. During COVID-19 we will address these needs through various virtual events, using webinars, conference calls, one-to-one advocacy sessions, emails, newsletters, and in-depth problem solving by experienced advocates. When safe to do so, information and training will be provided through in-person presentations, and participation in expos and resource fairs state-wide.

Families and professionals continue to share feedback regarding their work with the FSN, as quoted below.

“Thank you so much for coming and sharing your wealth of information with our families. All that you shared was such good information coming from someone who has been in their shoes. Do not hesitate to call me if ever I can return the favor.”

“Thank you both for being such a positive force today for -----. I apologize if I was out of line at all. I admit that I get too emotional because most of what is said is untrue. We will start fresh and hope that things can improve while ----- is at -----.”

“Just want to thank you so much for attending the phone conference even tho you are a very busy woman and mom. You added so much to the meeting which I think they began to realize what they needed to do. You were the star.”

“Outstanding article in the Tribune.”

“Since we were a small family my siblings and I wished with all of our being that we could give ----- what she couldn't have. Legs that worked and speech to say all that we wanted to hear. Our mother always said [you can't miss something that you never had]. I believed that as a child, but I know better now. I sometimes feel that Mom and ----- siblings did a great injustice for ----- . She shared a great home with Mom, was happier than ever. We will continue to fight to make her whole and happy again. With what Mom said years ago, I know now that it is worse to miss something that you did have. I looked at her tonight, tucked in bed, clean, fed and loved, while with her eyes closed, she had a smile on her face. One day, perhaps she will do this in another home. With wonderful people like both of you, there is hope that this will happen. I know that you were the most genuine people on the line this evening Thank you for taking the time away from your families. We greatly appreciate it.”

“Hello my name is ----- and I am the CPS South Shore Area Parent University, Campus Manager. I received information and a verbal invitation to invite parents to this event by Mrs. Shirley Perez. Mrs. Perez was a phenomenal presenter at our Parent University a couple of weeks ago. She did a workshop in conjunction with the CPS ODLSS Team. I would like to partner with your organization and bring informational materials about our Parent University and network with other community resources that are attending. I am asking parents in our Network 12/17 schools to attend the event as well. I'm hoping I have such a response that I can rent a bus if I have at least 25 participants. Please contact me at your earliest convenience.”

*“Hi Shirley and Troy,
After 6 years of proposals, appeals and court appearances, last night we got the news that we won our latest appeal against DDD and that -----will get the bathroom modifications she needs. At times, the situation seemed truly hopeless, but, fortunately for -----, we had the support and encouragement of an amazing team and wonderful advocates who assisted us throughout this process, including the two of you. I want you both to know how grateful we are for everything you have done to help us achieve this victory. Shirley, you have counseled, advised and guided me on numerous occasions. You have rearranged your schedule to attend meetings with us. You have advocated on our behalf. You helped me to find the strength and the energy to persevere.*

“We very much remember you, and I'm glad you wrote the letter to the editor that, I believe, appears in Sunday's Chicago Tribune. I'm copying -----, who wrote our editorial about you and ----- and ----- did a great service. We're glad you read it. They have more coming. I believe their next installment appears in print Monday. That probably means it appears online Sunday or early Monday if it isn't posted already. Best of luck to you and your daughter. And please have a good Thanksgiving.”

Troy, the insight and advice you provided helped me to formulate strategies with our team--both for developing more effective proposals and preparing for the appeals process. Winning this appeal is a victory, not just for ----- and our family, but for all of the disabled individuals in Illinois who have been unfairly denied services and supports they need in order to live productive, meaningful and fulfilling lives. It is also a victory for the two of you. Your contributions were crucial to our favorable outcome.

“Dear Shirley and Shakari:

I hope your day is going well. I just wanted to take a moment to thank you for all the help you provided to B. M .and her family. She is finally settled in the new apartment. The issues were clarified with CHA. Everything should start running smooth. So, once again THANK YOU!! For helping me and this family to get a better quality of life. At the end of the day, these are the reasons why we are in this field, right?! SDA, QIDP”

You guys do so much for our community, from providing information and training to giving accurate information, to making referrals, to speaking up on behalf of those who need you the most.

Please know that your hard work, dedication and passionate commitment to improving the lives of people with disabilities in Illinois is both noticed and appreciated. Your positive impact is greater than you know. Keep doing what you do; you both do it so well.”

Sincerely, Parent



Phil Milsk

Legislative Update with Phil Milsk

Arc of Illinois Legislative Report June 2020

The General Assembly met on May 20-24, 2020 for the first time since March 5th. They passed more than 20 bills in 4 days. Keep in mind that the Governor has not signed any of the bills as of today, but is expected to sign them soon.

BUDGET

Budget legislation includes **SB 264**, a budget bill to fund operations for the fiscal year that begins on July 1, 2020, **HB 64**, a bill to fund capital projects, and **HB 357**, a budget implementation bill.

The budget for next year is essentially the same as the current year's budget, which is fortunate considering how bad the economy is due to COVID-19. To make up for the substantial loss of revenue since March, the State is planning to use a combination of federal loans and federal funding to balance the budget. The State plans to borrow up to \$5 billion from the feds, and is anticipating additional CARES Act funding from the second CARES Act, which is still under discussion in Washington. **SB 264** also authorizes spending of the CARES Act funds the State has received or is expecting from the first CARES Act, which was enacted in late March.

In regard to developmental disabilities, **SB 264** increases appropriations for the Home Services Program to accommodate a wage increase for personal assistants. It also appropriates funding to provide community-based services for additional members of the

Ligas class coming off of the PUNS. The non-Medicaid I/DD grants were either funded at the same level as in Fiscal Year 2020 or increased slightly. There is money appropriated to accommodate wage hikes for Direct Services Personnel (DSPs).

HB 357

The budget implementation of "BIMP" bill, raises rates to pay for the DSP wage increase. There are actually three increases, one for \$.26/hour that brings the hourly wage up to the Chicago minimum wage, a \$1.00/hour increase and an additional \$.50/hour increase in January. All of the increases are subject to federal approval of a State Medicaid Plan Amendment and of an amendment to the home and community based services waiver.

HB 64

Funds capital improvement projects and re-appropriates funds for many projects that have been appropriated funds in the past. There are some allocations for facilities improvements for provider agencies that serve intellectual or developmental disabilities. Anyone interested may download the bill in PDF format and do a word search to find specific allocations.

HEALTH CARE

SB 1864

An omnibus health bill that passed both houses during the short May session. One provision of the bill requires the Department of Healthcare and Family Services and the Department of Human Services to jointly apply for a federal waiver or Medicaid State Plan Amendment to allow remote monitoring and support services as a waiver-reimbursable service for persons with intellectual or developmental disabilities. The application is to be submitted no later than January 1, 2021.

EDUCATION

SB 1569

An omnibus education bill that addresses, among other things, remote learning days and blended remote learning days during public health emergencies. It also includes language on the rights of parents to be provided materials in advance of special education meetings, the right to receive logs of related services provided to their child, and parental engagement in the MTSS/RTI process.



Ligas Program Director at Know Your Options Frankfort, IL
September 26, 2019



Arc of Illinois FSN Director presenting on Transition Planning, February 14, 2020
partnering with CPS

Few pictures from some of our Arc /FSN/Ligas Outreach Events



Partners and Policy, November 22, 2019



Arc of Illinois FSN Director presenting at Richards HS February 5, 2020 – Partnering with CPS



Arc staff, board and Arc Mentors at Executive Forum, February 5, 2020



FSN Director and Secretary Hou, August 5, 2019



Know Your Options at Suburban Access led by Mary Dixon, February 18, 2020



FSN Director partnering with CPS Bouchet Elementary Math Science Academy Arc Training, February 13, 2020



FSN Director, Shirley Perez presenting at Partners in Policymaking in Bloomington, IL, November 22, 2019



LFA, Megan Mutti, Maureen Stover, DHS, Shirley Perez, Ligas Director at DHS's New Provider



Arc/FSN Presentation at Palatine Public Library, September 13, 2019



FSN Director with Greg Porter at Clear Brook's Expo-Avalon Banquet in Elk Grove



Know Your Options, September 12, 2019



Central/Southern LFA Megan Mutti and Northern LFA, Mary Dixon - Know Your Options at Myers Place in Mount Prospect, July 17, 2019



FSN, Director presenting at Ray Graham Series, September 19, 2019



LFA, Megan Mutti at Know Your Options at Service Inc. in Rockford, September 20, 2019



Esperanza in Brighton Park FSN Director with Rep Greg Harris, August 5, 2019



Arc staff and volunteers from across the state having a little get together time, December 11, 2019



The Going Home Coalition



Nafia Lee

Going Home Coalition Manager

The Going Home Coalition is a coalition made up of self-advocates, families, community service providers and allies across Illinois calling for re-balancing of the state budget to prioritize person-led services in the community instead of institutional care; ending the waitlist for services; educating people living in state-operated developmental centers about their right to live in the community through peer-led mentoring and help residents who wish to, to transition out in the community; and ensure data is being shared and collected about the acuity, level of care and cost of current service levels in the state.

The Going Home Coalition is pleased to highlight some of its accomplishments of FY19:

- Increased engagement and the number of participants in the Going Home Coalition - more robust participation in discourse
- Actively worked with the team to develop priorities for our "elevator

pitch" (e.g., The Going Home Coalition members and partners are able to go to a legislators and decisionmakers with a succinct message on what we changes we want in the state)

- Facilitated and will continue to facilitate multiple meetings between self-advocates and lawmakers to engage and re-engage current and past coalition partners/organizations - preparation for post-shelter in place activities (legislative coffees, meetings, etc.).
- Built rapport with stakeholders inside and outside the Arc of Illinois to identify up and coming leaders who can contribute to the coalition - led to opportunities for both the Arc and the coalition to increase its reach
- Collaborated with different constituencies of the Arc of Illinois and Going Home Coalition to increase communication and collaboration on initiatives - lead to other internal and external stakeholders reaching out to ask for assistance with coalition activities
- Met with Secretary Hou with Arc Mentors - highlighted many concerns about state-operated developmental centers and asked for data sharing

- Met with Director Stark with key leaders with the Going Home Coalition - led to closures of non-certified homes
- Represented the Going Home Coalition at the leadership retreat for the Illinois Network of the Centers for Independent Living (INCIL) - led to CIL engagement in coalition activities
- Represented the Going Home Coalition at the largest statewide self-advocacy summit (Speak Up and Speak Out) in 2019 - increased ongoing communication with advocates who attended now taking on leadership roles in the coalition
- Held the first-of-its-kind virtual Advocacy Day on Zoom - connected over 200 attendees with legislators and fellow advocates to engage in advocacy priorities in the thick of a national health emergency

We look forward to continuing engaging with lawmakers, administration officials and advocates to strengthen the reach and impact of our work and make Illinois an accessible, community first state. If you want to learn more about or join the coalition, please email me at nafia@thearcofil.org or call (815) 464-1832 x1027.

Someone You Should Know!

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



Rebecca Schroeder

Rebecca Schroeder joined The Arc of Illinois in January 2019. She previously worked at the McGaw YMCA Children's Center as their Admissions and Data Manager, where she was responsible for registration for over 1,000 families and worked with state agencies, the local university, and other organizations to help families receive financial assistance.

This experience has helped her as the Events/Marketing Manager at The Arc of Illinois where she continues to provide her expertise with marketing, training events and data management.

She is a graduate of Loyola University Chicago. Rebecca is a consummate professional, always reliable, calm when others would be flustered, and excellent in her work. All of the Arc staff appreciate this about her and we have come to count on her as an essential part of our team.

An added bonus, though, is her heart for our mission and her commitment to our goals. We are fortunate to work with her!

Thank you Becca for all that you do!!!!

Since last year, The Arc of Illinois has implemented our new CRM system with great success! This software system allows us to organize our contacts and send out emails, including our FSN and Ligas newsletters. The Arc of Illinois events are now available online for easy registration.

The Training Department was thrown for a loop at the beginning of the COVID-19 Pandemic. We switched gears and have started hosting virtual events, including a Planning for the Future seminar and the Going Home Advocacy Day and Rally. We are currently getting ready for our largest event, the two-day Annual Convention. This virtual event will host 3 keynote sessions, 3 plenary presentations, 24 breakout sessions, an online Silent Auction and Art Exhibit, and an online Exhibitor Hall. We are excited to offer this event in a new format in order to reach a wider audience across the State. Next up for virtual events is the 8th Annual Informational Seminar on June 18th and a webinar series in partnership with The Alliance.

Thanks to an investment from The Illinois Council on Developmental Disabilities (ICDD), The Arc of Illinois has funded 46 mini-grants that assist in filling gaps in services that people with developmental disabilities and families are experiencing due to the COVID-19 pandemic. We are thrilled for this partnership and look forward to seeing the impact these projects are having on the I/DD community.

We are her to serve! Please see a list of the recipients of the 46 mini-grant recipients.

The Assistive Technology Department is staffed by:

Janet Donahue

Janet@thearcofil.org
Director of Development

Becca Schroeder

Becca@thearcofil.org
Events/Marketing Manager

Additional Arc staff:

LeeAnn McQuen

Business Manager

Karin Ulstad

Administrative Assistant
Karin@thearcofil.org

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Making a difference when it matters the most!

COVID-19 DD Relief Fund

May 2020

Overview

In March & April 2020, The Illinois Council on Developmental Disabilities (ICDD) invested **\$385,000** with The Arc of Illinois to fund time-limited demonstration projects that assist in filling gaps in services that people with developmental disabilities (DD) and families are experiencing due to the COVID-19 pandemic. There was an overwhelming response to this funding opportunity with **138** applications received and **50** projects awarded. In total, **150,000+** people with DD across Illinois will benefit from this initiative.

The Purpose

- Respond to emerging needs of individuals with developmental disabilities and their families who have been impacted by the COVID-19 pandemic.
- Reduce the amount of anxiety and isolation for individuals with developmental disabilities through innovative projects.
- Build and maintain community capacity to support the short-term and long-term needs of individuals with developmental disabilities during the COVID-19 pandemic.
- Inform systems change efforts for future disaster preparedness and emergency response in Illinois and other states.
- Ensure people continue to engage with peers during this period of social distancing and isolation.

With funds from ICDD, Awardees are able to purchase:

- Art supply kits
- Resources
- Technology/Devices (iPads, TVs, Smart TV, etc.)
- Exercise equipment
- Personal protective equipment
- Online augmentative communication software
- Zoom licenses, and more

The Illinois Council on Developmental Disabilities (ICDD) was created under a federal mandate in 1974 as an amendment to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and is administered by the federal Administration of Developmental Disabilities. ICDD works to promote the independence, productivity, integration, and inclusion of those with disabilities into the community, ensuring that those individuals with developmental disabilities have the same opportunities as others in the community. This communication is supported in part by grant number CPDA 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, therefore, necessarily represent official ACL policy.

830 S. Spring Street, Springfield, IL 62704 | ICDD.Illinois.gov | (217)782-9696

Listing of Funded Projects

Statewide:

- The Arc of Illinois: Resources
- Blue Tower Solutions: Virtual meetings
- Chicagoand Disabled People of Color Coalition: Develop COVID resource list in English and Spanish
- Illinois Early Intervention Clearinghouse at the University of Illinois at Urbana-Champaign: Technology for loan program
- The Star Raft Project: Scripts and guides on developing a personal Star Raft, virtual training and coaching

North:

- Ada S McKinley: Technology
- Arc of Winnebago: Virtual art classes
- Arts of Life: Virtual programming, art supply kits
- Association House of Chicago: Technology
- Association for Individual Development: Technology
- Bethesda Lutheran Communities, Inc: Technology, enrichment packages
- Center for Enriched Living: Virtual programming
- Center for Independent Futures: Virtual activities
- Cherubim Developmental Training and CILA Programs: Exercise equipment
- Clearbrook: Technology
- Continuity Access Naperville: Virtual programming
- Evision Unlimited: Technology for telehealth demonstration
- GIGI's Playhouse: Technology
- Glenkirk: Technology, personal protective equipment
- Helping Hands: Zoom licenses, teletherapy
- Master Mix Academy: Online music technology and socialization
- Parents of Extraordinary Children: Technology
- Milestone, Inc: Share activity boxes
- Orchard Village: Technology purchase
- Ray Graham Association: Technology
- Cornerstone: Technology
- Shore Community Services, Inc: Technology, crafts, activities
- The Nora Project: Licenses for on line augmentative communication for students

Central:

- Abilities Plus: Distribute care and activity packages
- Camp New Hope: Virtual programming and sensory kits
- EPIC: Technology
- Human Services Center
- Marcfirst: Technology, activity boxes

South:

- Centerstone: Technology
- Coleman Tri-County Services: Technology, social activities
- Community Support Systems: Technology, activity kits
- Our Directions, Inc: Technology
- Human Resources Center: Technology
- Human Services Center: Smart TV
- Human Support Services: Virtual learning and recreation community

Cross Region:

- Achievement Unlimited: Activities, comfort items
- Community Living Options: Activities, comfort items
- CTF IL: Technology
- Francis House: Activities, comfort items
- Pioneer Concepts: Activities, comfort items
- Pinnacle Opportunities: Activities & comfort items
- Trinity Services, Inc: Activities, comfort items

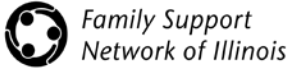
612+ devices have been purchased to bridge the digital divide allowing people with DD to connect with family, friends, agency staff, etc. through virtual programming made available by the above entities.

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Impact Stories

- Parents of Extraordinary Children (PExC)** is a volunteer lead organization serving people with DD and families on the southside of Chicago. In these unprecedented times, PExC has evaluated the current situation to determine how they can support families in a low income, majority Hispanic community. This funding is enabling PExC to provide wellness checks, Zoom group support sessions, as well as providing resources and information in Spanish. Additionally, PExC hopes to assist in addressing some inequities existing among lower income families of children with disabilities. Thanks to the award received from the COVID-19 DD Relief Fund, PExC can provide access to technology, internet service, and supports for those experiencing stressors and isolation due to remote learning and social distancing. In total, PExC will serve approximately 104 people with DD and families.
- Blue Tower Solutions, Inc.** is presenting through Zoom meetings to people with DD throughout the state. The first meeting reached over 100 and was called Self-Advocacy: The Basics and included self-advocacy at home during Covid-19. Another meeting featured a short video called "Captain COVID!" all about staying safe during this time of staying at home. All of the meetings feature paid self-advocates sharing their experiences and stories. An agency in Chicago is translating them into Chinese. The meetings take place, Tuesdays, Wednesdays and Thursdays at 1:30 and 3:00 and have games, prizes, and a lot of fun!

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

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



Rev. T.D. Hughes

The Arc Family Support Network would like to say thank you to Senior Pastor, Rev. T.D. Hughes for continuing the tradition of the Third Baptist Church of Chicago partnering with the Arc of Illinois. Due to COVID-19 we had to reschedule our March 19, 2020, 8th informational Seminar scheduled to be held at the Heritage Plaza , Bethune Room to an online event; we are looking forward to resuming this event in 2021, at the facility when it is safe to do so.

This partnership has allowed us to utilize the Heritage Plaza facilities to bring resources to an underserved community on the South side of Chicago. Over the past 7 years we have shared information and resources with thousands of families, individuals and self-advocates. We are excited to continue this collaboration in the years to come.

Thank you!

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.