

Family Support Network

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June, 2019

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

Hello Family Support Network Family and Friends,

Thank you for another year of journeying this advocacy road with us. You have stayed at our side through the many twists and turns of events and we are so grateful for your commitment!

The Family Support Network is one of the major programs of the Arc of Illinois, 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.

The big picture for the disability field in Illinois is looking brighter. As reported in a recent Sun Times Editorial (June 2, 2019 - From 'impasse' to 'get it passed,' Illinois surges with stunning legislative session!), "The Legislature approved a new \$40 billion budget crafted by a new governor, Pritzker, with bipartisan support." Among the highlights listed in the Sun Times editorial we see, "Major increases for behavioral health, substance abuse, Autism, Early Intervention, DD services, senior services."

We all know how important funding is to get the services we need. But leadership is also critical. Additions to the Department of Human Services (DHS) leadership team have sent waves of hope and excitement through the Illinois DD community. The Arc of Illinois and the Family Support Network have worked closely in the past with many of these leaders and we know they are deeply committed to our issues and aware of our concerns. DHS's new Secretary is Grace Hou, a seasoned disability veteran who has served as Assistant Secretary of DHS (2003-2012). Ryan Croke is the Secretary's Chief of Staff. You may remember Ryan as Governor Pat Quinn's Chief of Staff in his final year in office and more recently as the Executive Director of INCIL. Other new appointments include: Kia Coleman, Assistant Secretary for Programs, previously the Deputy Commissioner of Behavioral Health, City of Chicago, Dulce Quintero, Assistant Secretary for Operations, previously at Erie Family Health/Humboldt Park, and before that Director of Operations for La Casa Norte, Rahnee Patrick, Director of the Division of

Rehabilitation Services, previously Director of Independent Living at Access Living. Theresa Eagleson was appointed the Director of the Department of Healthcare and Family Services, previously head of the Office of Medicaid Innovation at the University of Illinois. Governor Pritzker appointed Sol Flores as his Deputy Governor in charge of Human Services. Flores was the Executive Director of La Cosa Norte and a candidate for Congress in last year's Democratic primary.

FSN remains committed to helping Illinois individuals with I/DD and their families understand and navigate the state system. In December 2018, for the first time, early notification letters were sent out to 986 individuals/families. This was of great benefit to us and to them. We at The Arc **have started working with these families through Know Your Options events, webinars and contacting them directly with advocacy calls.** Early Notification letters were given to individuals and their families in the hope that this would provide them more time to plan for services. The Early Notification letters indicated that DHS



Shirley Perez
Executive Director,
Family Support
Network of Illinois

“FSN remains committed to helping Illinois individuals with I/DD and their families understand and navigate the state system.”

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Deb Fornoff
Director
Illinois Life Span
Program

“The Illinois Life Span Program fills the need for a place to go for information”

The Illinois Life Span Program (ILS) of The Arc of Illinois has been busy supporting people with intellectual and developmental disabilities, family members, and professionals in this field for more than 18 years. ILS fills the need for a place to go for information specific to services and supports for individuals with intellectual/developmental when you don't know where to go! We don't claim to know all of the answers but we will always do our best to connect you with resources to help.

ILS staff members answer calls through our toll-free line (at 1-800-588-7002), answer email inquiries, and participate in resource fairs, transition events, and conferences/trainings to reach out in person. ILS began with a website that provides information on important resources specific to developmental disabilities. That website has been updated regularly to reflect the changes in information available via the internet. Monthly webinars hosted by ILS and implemented two years ago are also an opportunity to share information on topics of interest. In the current fiscal year, a few of the topics covered in our webinars included:

- The Role of the Independent Service Coordination Agency (ISC) and Its Many Functions: PUNS and Transition to Community Based Waiver Services - presented by Juan Aponte from Community Alternatives Unlimited.
- Let's Learn About ABLE Accounts! - presented by JJ Hanley, Director of Illinois ABLE for the Illinois State Treasurer's office
- Partner, Help, Connect: How DSCC Supports Youth with Special Health Care Needs and Their Families -The University of Illinois at Chicago's

Division of Specialized Care for Children (DSCC) Illinois Life Span has four staff members, situated strategically throughout the state. Our staff members are all parents of adults with disabilities with years of experience in social and disability services, dedicated to helping others seeking information.

Rocio Perez is the most recent staff addition. She joined the Illinois Life Span (ILS) project in December 2018 and is a parent of a young adult with Autism. Rocio is a social worker and is bilingual (English/Spanish). She has worked in social service for over 25 years. Her professional experience in ID/DD include employment with Community Support Services and Community Alternatives Unlimited.



Rocio works part-time for the ILS Program and part-time for the Family to Family Health Information Center of The Arc of Illinois. She is focused geographically in the Chicago and the Chicago metro suburban area. For ILS, Rocio's responsibilities include answering ILS calls, providing outreach to the Hispanic/Latino community, representing the Arc of IL at various resource fairs and conferences, as well as establishing new community/agency contacts.

Rocio has been very busy in her first 6 months with us! She was involved with the planning and implementation for Grupo Salto's first bi-lingual conference in April 2019. She has established a relationship with the bilingual liaison at the Arc of Indiana and a contact with the office of IL

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

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anticipated that the recipients would be included in the next PUNS selection in late spring/early summer 2019, subject to the State's budgetary process. Now that we have a balanced budget we hope to see those actual PUNS selection letters being mailed out soon!

We are also pleased with the update in the Ligas consent decree around "reasonable pace!" The Ligas decree required that the Division enroll 3,000 new individuals from the PUNS waiting list in CILA and Home-Based services

over a six-year period ending in 2017, and that the enrollments continue "at a reasonable pace" after that. **Now all the parties and the Court Monitor have finally reached an agreement that "reasonable" means at least 600-630 individuals per year.**

The new Ligas implementation plan also says that PUNS selections "will be tailored such that by the FY2025 selection, no individual will wait on PUNS for over 60 months (5 years)." (For people on PUNS before age 18, the 60-month period

begins on the 18th birthday.)

Let me say this again to all of our families, friends and self-advocates. Our diversity, enthusiasm, and dedication when shared make all of our lives better. Thank you, FSN community. You keep our advocacy family strong!

Sincerely,

Shirley A. Perez
Executive Director
Family Support Network of Illinois

Representative Jesus Garcia. Rocio co-hosted a monthly webinar that featured Juan Aponte from CAU, director at a local ISC. Rocio has also completed two pre-recorded webinars in Spanish with Arc consultant Consuelo Puente that are available on the Arc of IL website and more webinars are expected to be completed by the end of the current fiscal year. Rocio also attended the Disability Policy Seminar in April and the Family Voices National Conference in May, both in Washington DC.

Missy Kichline joined ILS a year ago and lives in Godfrey along the Mississippi River, about 30 miles north of St. Louis, Missouri. In 2014 she began working for the Arc of Illinois as a Ligas Family Advocate. Prior to her work with the Arc, she worked for IMPACT CIL for 23 years. She is a former board member of the Arc of Illinois. Missy holds a BS in MIS from SIUE and a MAT. She is committed to expanding opportunities and supports for people with disabilities in community. Her middle daughter is a Ligas Class Member.



Missy has worked on the Illinois Life Span (ILS) team as the Outreach Coordinator for southern Illinois since 2018 and is responsible for providing trainings, informational presentations, collaborating with other organizations and assisting with Arc of Illinois events conducted in southern Illinois, assisting with ILS webinars, and answering the ILS statewide phone as needed.

Missy has provided collaborative trainings with The Alliance and will also be working with Transition Project grantees funded through the Illinois Council on Developmental Disabilities in the southern part of Illinois over the next three years. She recently attended a National Conference on Developmental Disabilities and Aging in Missouri.

Cindi Swanson lives with her family in Naperville and has been an advocate for people with disabilities since the birth of her middle son who has Down syndrome and is now a young adult. Cindi has her MSW in Social Work and works as a Resource Specialist for the Illinois Life Span Project. She started with ILS when it began 18 years ago and has remained an integral part of the program throughout the years. Cindi provides outreach in the suburban Chicago area and also answers phone inquiries regularly for ILS. Cindi works with the SEAT (Supported Employment Action Team) Project of The Arc of Illinois as well.



Cindi is a strong believer in the need for local advocacy. She is co-founder of Naperville Works, an organization created to increase capacity for the employment of people with developmental and other disabilities in Naperville. Her husband, Art, is a founder of We Grow Dreams, a greenhouse

The Arc of Illinois The Arc Illinois

Executive Director, Meg Cooch,

is well into her third year of heading up The Arc of Illinois. She has lately been able to proudly acknowledge that The Arc is fully staffed for the first time during her tenure. This is an achievement in itself, but Director Cooch is always thinking in terms of how much more this organization and all of its programs can achieve for individuals with I/DD and their families, how much more effectively we can advocate by expanding partnerships, and how we can continue to reach out to every corner of the state. Her special talent for public policy keeps The Arc in the midst of important debate in the disability field and keeps us in the forefront when it comes to educating decision makers about issues critical to people with disabilities and their families. Our Director's energy and commitment to exploring alternative ideas keeps The Arc on track but outside of the box, where it belongs.



Meg Cooch
Executive Director
The Arc of Illinois

opened by a group of parents to provide opportunities for job training and employment for their children and others with disabilities. Cindi also happens to have a visual impairment so can speak to many important transition and other disability issues from a personal perspective.

Deb Fornoff is the ILS Director and lives in Washington in central Illinois. Deb's advocacy began with the birth of her younger son who has Down syndrome and is now a young adult. Deb has been with the ILS Program for more than 16 years. She has an MS in Education, Counselor Education, and her disability advocacy work started with work as Systems Point of Entry and Parent Liaison roles for her local Early Intervention system, and then working with the Family Support Network under Charlotte Cronin. Deb was on the Illinois State Advisory Council for the Education of Students with Disabilities for 6 years, serving as Transition Committee Chair. She also served on the Board of Directors for the Heart of Illinois Down Syndrome Association and Family Matters Parent Training & Information Center. Deb is currently part of the Illinois Statewide Transition Conference Planning Committee as well.

Deb and her colleagues at ILS love the work that they do and are eager to assist others who are looking for information to make life better for the people with disabilities in their lives! Please take a few moments to check out the Illinois Life Span website at www.illinoislifespan.org and give us a call a 1-800-588-7002 if we can be of assistance at any time! Looking forward to talking with you!

The Ligas Family Advocate Program

The purpose of the Arc Ligas Family Advocates 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 (DHS/DDD), Prioritization of Urgency of Needs (PUNS) as a result of the Ligas Consent Decree. Family advocates will 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 Arc of Illinois is excited to be funded through the (NOFO) Notice of Funding Opportunity grant for FY2020! We are a state-wide program that is staffed by a Program director and two Ligas Family Advocates. All staff members in addition to being professionals also have experience in navigating the DDD system on behalf of a loved one!



Mary Dixon Northern Ligas Family Advocate



Mary Dixon
Northern Ligas
Family Advocate

The Ligas Family Advocate for Northern Illinois assists individuals selected from the PUNS whose Independent Service Coordination (ISC) agencies are Community Alternatives Unlimited (CAU), Suburban Access and DayOne PACT. The Ligas Family Advocate Program is funded through a grant from the Department of Human Services to help adults with I/DD and their families who are selected from the PUNS connect with each other and learn about their options through the Home and Community Based Services Medicaid Waiver and the ICF/DD program. Highlights of the year as the Ligas Family Advocate (LFA) for northern IL from 6/1/18 to 5/31/19 include:

- Nine “Know Your Options” events were held for individuals selected in June 2018 and those notified in December, 2018 of the PUNS selection to occur in 2019. These were well attended and provided individuals and their families an opportunity to learn about available services through the waiver. The events brought together families served by a common ISC. Representatives participating included staff from CAU, Suburban Access, DayOne PACT, and Service, Inc., numerous service providers, representatives from area Centers for Independent Living, respite providers and representatives from the Northeastern IL Agency on Aging.
- Three of the “Know Your Options” events were co-sponsored with the Corporation for Supportive Housing and held at permanent supportive housing locations, providing an opportunity for individuals and family members to tour apartments and learn how an affordable apartment and individualized supports could meet their needs.
- Professional development opportunities throughout the year included: an October event in Skokie sponsored by the Center for Independent Futures: “Creating Housing & Support Options for Individuals with Disabilities”; the April Disability Policy Seminar in Washington D.C.; the May “Targeting Autism Forum” held in River Forest; a May “Peer Exchange” for advocates and DDD staff from IL to meet with advocates and DDD staff from Missouri to learn how Missouri addresses the housing and service needs of their I/DD population, sponsored by the Corporation for Supportive Housing; and also in May, the “National Aging with DD Conference” held in St. Charles, Missouri.
- Sharing the work of The Arc of Illinois with individuals and families at events throughout the year was also a highlight. These events include: The Special Olympics Resource Fair at Soldier Field in July, the Parents of Exceptional Children Resource Fair at Rowan Park, Chicago in September, the Mayor’s Office of Disabilities Resource Fair in October, the Will/Grundy Transition Conference in Joliet in April and many others.



KYO event in Skokie

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Megan Mutti Central and Southern Ligas Family Advocate



Megan Mutti

Central, Southern
Ligas Family
Advocate

The Ligas Family Advocate for the Central/Southern (C/S) region joined the Arc of Illinois team in mid-September 2018. It has been an eventful year, with family engagement and training opportunities.

The LFA team

has worked together to develop some educational tools to assist families as they navigate the Adult Developmental Disability system in Illinois. Additionally, more than 55 families have sought support through the C/S advocate, most anticipating HCBW funding in the summer of 2019. These connections, at the heart of the LFA program, focus on individualized support, education, and advocacy.

Know Your Options Informational sessions occurred throughout downstate, with events in Bloomington, Red Bud, Peoria, Champaign (2), Rockford, and Germantown Hills. The events have been well attended, ranging from 13 to 65 participants. We have welcomed self-advocates, parents and guardians, siblings and professionals, all who have generously shared their experiences, hopes, needs and frustrations during our events. Partnerships with DD providers and school districts have expanded, and we welcomed the assistance of Community Choices in Champaign, Champaign Unit 4, the Arc of WBO in Rockford, the Regional Office of Education in Bloomington, the Human Service Center in Red Bud, and the ACES Family group in Germantown Hills. Additionally, visits with Central Illinois Service Access and CCRPC took place in an effort to build connections for families seeking services through the HCBW program. Lastly, in May of 2019, the Next Steps program invited our program to speak about core changes to the PUNS system, IDD services, and basics for families.

The Ligas Family Advocates partnered

to develop the Ligas Informational Call-in series, which invited individuals with IDD and their families who were recently selected from PUNS or were anticipating summer 2019 selection, to call in and participate in a structured Q&A taking place over the course of several weeks. The calls focused on a basic introduction to the HCBW funding system, key resources for families, and discussion around areas of interest to the participating families. All of the calls were well attended, and the program will expand to a webinar call-in series in the Summer of 2019, targeting individuals who have begun planning for services after receiving a funding award letter from DHS.

LFA Family Advocates, seeing the need for additional written resources for families, developed several core informational presentations focused on understanding options and support programs, self-advocacy, accessing local resources, and participation in planning. Additionally, the LFA program developed a flow chart of HCBW services and a comparison of DRS and HCB waiver services. All of these tools will be available to families as they plan for service and support utilization following receipt of a DHS Early Notification letter.

The C/S LFA enjoyed the opportunity to partner with the Self-Advocacy Alliance and several members of the Arc of Illinois team to co-facilitate one of a series of self-advocacy trainings. The trainings took place at several locations throughout the state, with the C/S advocate presenting on Legislative Advocacy at KCCDD in Galesburg, IL. There were more than 30 self-advocates actively participating in the event, all with an interest in speaking up about their own experiences and needs.

The Central/Southern LFA continues to build connections with community partners. Participation on the Central Illinois Transition Planning Committee has been a welcome introduction to local efforts aimed at young adults participating in transition-based programs. Statewide training, including the Speak Up, Speak Out Conference (Springfield), the Transition Conference, the Central Illinois Resource Fair (Peoria), the Arc of Illinois Annual Conference (Alsip), the Going Home Rally, a Wrightslaw training event (DeKalb), and two Ligas Family Advocate Know Your Options events (Oak Lawn and Chicago) all provided a strong base of information regarding DD services in the state.

We continue to work with families in the central and southern regions who consistently identify some key barriers to services. Individuals have shared their difficulties in accessing CILA group home programs and Community Day programs close to their home. Additional challenges include gaps between school-based services and adult DD programs, an information gap for families during the transition years, and the ongoing need for multiple and varied ways for families to receive training and support about adult services. The LFA program continues to work to assist families in self-advocacy efforts around these issues, while providing training and support on service navigation.



Know Your Options in Bloomington

Family Transition Project

2018-2019 Year in Review



Katherine Hamann
Director
Family Transition Project

From the beginning, the Family Transition Project has been intended as a source of information about community living for individuals in state operated developmental centers (SODCs) and their families, but also as a source of hope, advocacy, and support from the unique perspective of self-advocates and families who have left the closed world of large institutions and ventured out into the larger world of their chosen communities. There is rarely anything smooth about this process. We advocate for individuals with intellectual and developmental disabilities (I/DD) and their families but often they return the favor. They learn from us but we also learn a tremendous amount from them – past histories, hopes and dreams, barriers and challenges to making the transition. We support each other in exchanging information and making connections with other advocates, professionals, and families who can help us break these barriers and meet these challenges. That’s why FTP has always been a “project” and not a “program.” We approach everyone with respect and professional courtesy, but we don’t have a set program that follows a predictable course. We try to help self-advocates and their families locate what they need, but also we hope to help them discover things they might not have known they need. This might sound warm and fuzzy, but it’s also gritty and real. Families contact us with tough real world issues that challenge the ability for a successful transition to happen. We are there to support them in their journeys.

Because the Family Transition Project is under the umbrella of The Arc of Illinois, we partner extensively with all of the programs of The Arc, especially the Family Support Network, Ligas Family Advocates Program, and Illinois Life Span. We can’t say enough about having the expertise of so many knowledgeable colleagues to draw on, not to mention their willingness to take time out of their busy schedules to help. They are a thoughtful and compassionate group with a lot of firsthand experience confronting the same issues self-advocates and their families encounter.

In the last year, the FTP family has grown. We are

now working with four Arc Transition Mentors – Susan O’Connor, Robert Rowley, John Porter, and Robert Peterson. All four of them have lived in SODCs and now are living successfully in homes in the community. When we wrote about them last year they had just experienced their first training/brainstorming session. Since then they have been all over the state speaking about their experiences. A few highlights – Mentors testified in meetings on the need for sex education for people with disabilities (in regard to Representative Will Davis’s House Bill 3299), they taught a class to a group of graduate students at Rush University, they did self-advocacy training with The Alliance for several self-advocate groups at SODC’s, they had a keynote address at the Speak Up and Speak Out Summit, they met with two directors of HFS (Healthcare and Family Services) – Director Bellock and her successor, Director Eagleson, they hosted a roundtable discussion at The Arc of Illinois Leadership Conference, they assisted with a number of Arc/Alliance trainings in self-advocacy and legislative advocacy around Illinois, they spoke at the rally at the Going Home Coalition Advocacy Day, and they have had a number of meetings with legislators. Our Mentors mentor decision makers, but they are mentors on a more personal level. Because of their role with FTP, friends

“We advocate for individuals with intellectual and developmental disabilities (I/DD) and their families but often they return the favor. They learn from us but we also learn a tremendous amount from them ”

and colleagues see them in a different light, as role models. Within the agencies that support them, individuals and professionals have asked them for help and asked them to speak about what they do. As they head into their annual brainstorming session again, we can’t wait to see what they do next!

The Family Transition Project has always had a close connection with the Going Home Coalition. Thanks to a generous grant from the Illinois Council on Developmental Disabilities, the Going Home Coalition now has a fulltime campaign manager, Nafia Lee. Ms. Lee has great credentials, energy, and advocacy experience in the disability field in Illinois. She was an intern in Governor Quinn’s office when the push for rebalancing started, so she understands the issues and the need to expand community capacity. FTP will still be involved with

Family Transition Project

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Going Home, but it's wonderful to have a new colleague who can devote her full attention to growing and developing the Going Home Coalition and increase its scope.

FTP is my passion, but many of you know that (like many Arc employees) I have a sister, Margaret, with I/DD who transitioned from 63 years in SODCs and has now lived in a CILA very successfully for the last 11 years. She is the reason why I feel so strongly about community living. In the past year we have struggled with her age-related issues and in spite of all my experience I felt unprepared. It was yet another reminder of what so many families go through. We and our loved ones are aging and this is an area where community services need to become more robust. Several of us from The Arc attended the Aging with Developmental Disabilities Conference in St. Louis this May and we came away with one thought – I/DD services and supports need to be more flexible for the different stages of a person's life. Natural changes need to be accounted for in planning for services and in serving people with I/DD. This is something The Arc as a whole will be thinking about and we at FTP will be thinking about when we work with self-advocates and their families.

We continue to bump up against barriers of all kinds. One that we weren't familiar with until recently was the presence of non-certified units on SODC campuses. These are units that have the same staff members, same administrators, and same location as the rest of the SODC but are not certified by the Department of Public Health. This means they don't receive Medicaid match dollars and are not overseen by the Department of Public Health, unlike the rest of the SODC. The Arc of Illinois asked Senator Laura Fine to sponsor a bill (SB2086) that would close all of these SODC uncertified units and make sure that the people who live in them transition safely either to the community or to a certified unit in the SODC. The bill has not advanced, but talks have opened with DHS about the situation. This is yet another example of how we learn from families who are on the frontline.

Learning about barriers to transition is painful but it's the only way we can learn how to get past them. Hidden barriers make a successful transition impossible. But just for a moment, let's look at what's at stake and what gives us hope. Some of the differences between community living and living in an institution may seem small to someone who hasn't experienced them. But they are huge. Our Arc mentors, and many other individuals and families we have spoken with in the last year emphasize the importance to them of making their own choices, from changing jobs, to not having to spend time with people they don't want to be around, and whom to date, to the smallest details of what they want on their toast and which shoes to wear – all decisions that most of us take for granted. Every day we talk to people who are living in the community, making more choices, discovering new interests and talents and feeling empowered. And this makes everything we do worthwhile!

Contact information for this program:

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Katherine Hamann, Arc's FTP Project Director pictured with the Arc Transition Mentors!



We're on the Web!

See us at: www.familysupportnetwork.org



Illinois Department of Human Services

Division of Developmental Disabilities

Redeterminations have and continue to be an issue for many of our families. In an effort to provide some clarity DDD has posted a DRAFT Information Bulletin on Medicaid Redeterminations for review and comment on their website. Below is a summary of the draft the full draft can be viewed at: <http://www.dhs.state.il.us/page.aspx?item=117939>.

Draft Medicaid Redeterminations

For individuals receiving DD Waiver services, there are two (2) annual redeterminations which need to be completed. Those being:

1. The Level of Care Redetermination (“Clinical”) and
2. The Medicaid Benefit Enrollment and Medical Renewal Process (“Medical/Cash/SNAP”).

The purpose of the Level of Care Redetermination is to conduct a level of care/Waiver eligibility redetermination for continuing eligibility of services to everyone in the three (3) DDD Waivers. The purpose of the Medicaid Benefit Enrollment and Medical Renewal Process is to maintain uninterrupted eligibility for Medical, Cash and SNAP benefits in order to continue receiving DDD Waiver services.

ISC agencies are the Conflict of Interest free service coordination (service coordinator) entities and are essential to Illinois Developmental Disability service system. Service coordination includes maintaining the PUNS database, conducting Pre-Admission Screens, providing Individual Service and Support Advocacy to people in a DDD Waiver and providing service coordination to Bogard class members. It also includes, but is not limited to, conducting outreach, **servicing as the front line for information and assistance to help individuals and families navigate the system**, ensuring informed choice, developing and monitoring a person’s Plan, linking individuals to services and addressing problems related to outcomes and quality.

Process and Procedures:

(1) The Level of Care Redetermination (Clinical)

The process for completing this Redetermination is as follows:

At least annually, a service coordinator will conduct a level of care/Waiver eligibility redetermination for continuing eligibility of services to everyone in the three (3) DDD Waivers. This redetermination is for waiver claiming and is summarized and documented on the Redetermination of Medicaid DD Waiver Eligibility form (IL462-0952; formerly the DD-1213.1).

The annual level of care redetermination can be performed during the time of the annual review of the Personal Plan; however, the redetermination must never be allowed to expire. If the redetermination and the Personal Plan process cannot be scheduled during the same time, the Independent

Service Coordinator (ISC) must perform the redetermination on or before its next due date, regardless of the timing of the Personal Plan process. The timeliness of the redetermination is of critical importance, as it will be monitored by the federal government: Centers for Medicare & Medicaid Services (CMS), and state government: the Illinois Department of Healthcare and Family Services (HFS) and The Illinois Department of Human Services (IDHS) Division of Developmental Disabilities (DDD). No redetermination may be allowed to become out of date, it must be completed within 365 days of the date on the most recent Determination of Intellectual Disability or Related Condition & Associated Treatment Needs (DDPAS-5) form (IL462-4428) or the Redetermination of Medicaid DD Waiver Eligibility form (IL462-0952), documenting the need for an ICF/IID level of service (sometimes referred to as active treatment for developmental disability). The IL462-4428 or IL462-0952 must be maintained in the individual record. Not only will the ISC complete and document the Level of Care Redetermination, the ISC must also report the annual redeterminations in the Reporting of Community Services (ROCS) system.

(2) Medicaid Benefit Enrollment and Medical Renewal Process (Medical/Cash/SNAP)

The process for completing this Redetermination is as follows:

The individual, guardian or approved representative will receive two (2) Illinois Medical, Cash and SNAP Redetermination Notices in the mail every year. The notices contain a return address from the Illinois Department of Human Services (IDHS), Family and Community Resource Center (commonly known as FCRC or local office) or the Illinois Department of Healthcare and Family Services (HFS). These are the two (2) Illinois entities which handle Redeterminations. It is crucial the individual, guardian (if applicable) or approved representative complete and return the *Medical, Cash and SNAP Redetermination Notice* within the specified time frames in order to avoid interruption or loss of Medicaid status and Waiver services. The form used for this process is titled “Medical, Cash and SNAP Redetermination Notice” (IL444-1893).

- a. The first mailing from HFS is a notice the redetermination date is approaching and the *Illinois Medical, Cash and SNAP Redetermination Notice* will arrive in approximately two (2) weeks.
- b. The second mailing from HFS contains the actual *Illinois Medical, Cash and SNAP Redetermination Notice*. This form

Family to Family Health Information Center



Faye Manaster

The Arc of Illinois Family-to-Family Health Information Center (F2F) will be starting our fourteenth project year on 6/01/19. We are part of a network of F2Fs in each state and every U.S. Territory.

When our project began in 2006, we were one of only six F2Fs in the country. We are funded by the U.S. Department of Human Services (HHS), Maternal and Child Health Bureau (MCHB), Division of Services for Children with Special Health Care Needs (CSHCN).

All F2F staff members are parents or family members of persons with disabilities and/or chronic illnesses. We serve families and professionals involved with children and youth up through age 21, with any disability/chronic illness/special health needs anywhere in Illinois.

Highlights of this past project year (6/01/18-5/31/19) include:

- Our Annual Healthcare Conference held on 9/14/18 with record attendance and very positive

reviews. We are now preparing for the 2019 conference on 9/12/19.

- Rocio Perez joined The Arc's team in 12/18, serving as the Bilingual Outreach and Information Specialist for F2F and the Illinois Life Span Project.
- We were invited to compete and awarded a one-year grant from United Health Care (UHC) to serve Illinois families of CSHCN insured by UHC. We have just commenced training of our newly hired consultants, and received our first intake call on 5/23/19.
- Two emerging family leaders from Illinois were awarded scholarships from Family Voices National to attend the Annual Conference in Washington, DC on May 8-10. Together with Rocio, they formed our Illinois delegation for this intense experience. The awardees are Claudia Partido, Hope for Hemophilia and Kimberly Haynes, Illinois Federation for Children's Mental Health.
- One of our new publications, Family Guide to Medicaid Managed Care Appeals was published in the Winter 2019 issue of The

Illinois Pediatrician: <http://www.familyvoicesillinois.org/wp-content/uploads/2018/10/Family-Guide-to-Medicaid-Managed-Care-Appeals.docx101818.2docx.pdf>.

- We continue our collaboration with the Illinois Chapter, American Academy of Pediatrics, Committee on Children with Chronic Illness and Disability and focus on policy and systems issues specific to our state.
- We now have a direct Spanish-language telephone number 708-218-1958, in addition to our toll-free number 866-931-1110.
- We commented on last year's Illinois Maternal and Child Block Grant Application and Annual Report, as we do yearly: <http://www.familyvoicesillinois.org/wp-content/uploads/2019/02/2018-8-Block-Grant-Comments.pdf>

We look forward to hearing from you in the coming year!

Contact information for this program:

Faye Manaster, M.Ed.

866-931-1110

familytofamily@thearcofil.org

www.familyvoicesillinois.org

IDHS Division of Developmental Disabilities

continued from previous page

will already contain the individual's name and date of birth; it will also contain a barcode in the upper right-hand corner. To complete the redetermination process, the individual, guardian (if applicable) or approved representative must:

- Complete the preprinted *Illinois Medical, Cash and SNAP Redetermination Notice*.
 - Attach any verifications and/or documentation requested.
 - Sign the form.
 - Return the form and any verifications and/or documentation by the date indicated on page 3, #11 of the form.
- Cash and SNAP Redetermination Notice, the ISC should assist as needed. A provider agency can also assist the individual, guardian or authorized representative in completing and returning the form.



The Arc of Illinois Family to Family Health Information Center Illinois Health Care Coverage Options and Benefits Information for Children and Adults with Disabilities Conference

September 12, 2019

8:00 a.m. – 3:30 p.m.

Doubletree Hotel

5000 West 157th St • Alsip, IL 60803

**CEUs for Professionals
Limited Stipends for Families**

For more information: familytofamily@thearcofil.org

The mission of the Family Support Network (FSN) is to unify individuals with disabilities and their families to advocate for funding, services and community resources that strengthen and support the individual and the family directly by responding to their individual needs and empowering them to live in their own homes. The Family Support Network further seeks to ensure the continuation of all individual supports throughout the life span of the individual. As our society continues to depend on the active engagement of family caregivers for the support of individuals with I/DD, it is essential to meet the needs of those caregivers, so they can continue providing care in the community. The alternative for individuals with I/DD should not be more costly and unwanted institutions. Resources and information are all too often unavailable to those who need it the most.

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

The FSN/Ligas 7th informational seminar was a great success – thanks to all that attended! Special thanks to our Presenters: **Sherri Schneider**, President of Family Benefit Solutions, Inc. Her presentation helped us to explore the who, what, and when of the four major government benefits and how they change over a lifetime.

Brian Rubin, Special Need Trust Attorney, his presentation focused on the Pre-Selection letters, ABLE, Special Needs Trust, ISC changes, PUNS categories changes...and so much more!

Tasha Whiteside, Director of Illinois Operations, ACCESS\$, her presentation helped us to understand the services offered by the State's Fiscal Agent as well as what to expect with the pending (EVS) Electronic Verification System.

Ronnie Cohn, Ligas Court Monitor provide and update on Ligas and **Kathy Ward**, Acting DDD Director updated us on the latest in the DDD World.

FSN has reached and shared information to over 10,000 people which included families, self-advocates, providers, and other organizations state-wide. These activities were conducted via telephone conferences, emails, presentations, website, Facebook page and webinars including in person meetings.

July 1, 2018 – June 20, 2018, 4,542 users visited our website with over 10,991 page views, and 5,381 sessions. We conducted 80 one on one advocacy sessions, which involved helping individuals navigate DHS's website, address issues with ISCs, Medicaid issues, providers and attended staffing with families. FSN participated in 10 legislative outreach events, Arc staff and families attended the 2019 Disability Seminar in Washington DC and was able to connect with over 900 advocates. Please find a few pictures from some of our 7th FSN/Ligas Informational Seminar, state-wide know Your options and training events as well as pictures from Washington DC Disability seminar.

Troy Markert joined the Arc of Illinois Family Support Network as our Family Advocate Specialist, we have been able to assist families with unique situations, especially in downstate Illinois. He has attended numerous events around the state. These events have allowed him to reconnect with Independent Service Coordination agency staff to build relationships on behalf of families. These relationships are critical in our role of advocating for families and individuals with intellectual disabilities. He has participated in conferences conducted by the Arc, where he has had an opportunity to listen and learn from a number of professionals that will directly assist in our efforts to assist individuals with disabilities. His efforts have strengthened our advocacy on behalf of families and self-advocates.



He continues to work closely with the Program Director to support individuals and families to navigate the complex service system, educate and reach out to families especially focused on mid and downstate Illinois, and encourage improvements to



Sherri Schneider
March 21, 2019



TBCoC Volunteers
March 21, 2019



Arc/FSN/Ligas staff
March 21, 2019



Brian Rubin
Keynote Speaker
March 21, 2019

the service system where appropriate. Troy can be reached at Troy@thearcofil.org

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 connections) and a community system of services that promote the well-being of families and their adults/children throughout their lifespan.

Shakari Asbury, Family Support Network Assistant and Liaison

Shakari continues to interact with families and self-advocates who call the FSN/Ligas office looking for support and resources. She worked with and assisted in getting individuals registered for the Know Your Options May 7th in Joliet. She represented the Arc at the Open your heart to Autism Walkathon at Proviso West High School located in Hillside, IL. This event was hosted by Debra Vine (Answer Inc.) This was great exposure for her as she continues to expand her outreach events. She shared information about the programs of the Arc with over 400 people who attended this event, including legislatures. She was able to meet other vendors and donors and of course be part of a great cause. In honor of Mental Awareness, she attended an Open House for Envision Unlimited. This home is designed as an option for individuals who may need an alternative other than hospitalization.



She continues to support the Family Support Network Director in Partnering with a minimum of three organizations and connect with families who have loved ones not receiving services to share information. FSN continues to develop our relationship as we partner with Chicago Land Autism Connection, (CAC), and Answer Inc., Parents of Extraordinary Children in the 10th ward and South Chicago Parents and Friends. FSN presented February 6, 2019 in collaboration with Good Shepherd to the Speed Family group of 30 participants in Chicago Heights, IL.. Shared information with families about PUNS, respite, Medicaid and navigating the state system. Presented on 2 / 16/ 2019 at Chicagoland Autism Parent group of 38 participants. Topics included Puns, Medicaid, resources on navigating State system, ISCs role, and video on options. 2/21/2019 was a vendor and shared information with the Answer Inc. with 40 participants/

families on the west side at Loreto Hospital about navigating state system and PUNS. 3/14/2019, presented to South Chicago Parents and Friends, 36 families and staff on Home Based services, SDA, and natural supports and options.

Shakari along with FSN Director participated in 8 statewide conferences or advocacy groups. 7/17/18 presented at the DHS New Provider Orientation; 8/20/18, Self-Directed Statewide conference in Lombard; 8/29/18, Stakeholder meeting with Meridian, and on 9/28/18 participated in the Support Wavier webinar. 10/18/2018 - presented at DayOne/PACT Parent Support group; 10/18/2018 participated in Clearbrook's Statewide expo; 10/29 -10/31/2018 participated in Speak Up Speak Out in Springfield and 11/14/2018 participated in Rudolph and Hope School resource fair.

On September 26, 2018 in conjunction with the Ligas Family Advocate Program, FSN hosted a one-day conference at Park Lawn Activity Center in Oak lawn, IL. The success of this event was measured by using evaluation/surveys. The event included professional speakers from Access the fiscal agent for Illinois. A panel discussed Self Directed Assistance which included an ISC representative, SDA representative and a representative from DHS. FSN participated in the 7th Annual Clear Brook Expo. The Expo was held on Thursday, October 18th, from 8:45am-2:00pm, at the Avalon Banquet Hall in Elk Grove Village. Family Support Network's second one day conference was held in conjunction with the Ligas Family Advocate Program at The Heritage Banquet Facility, 1500 west 95th Street, Chicago, IL, March 21, 2019. The success of this event was measured by using evaluation/surveys. There were 200 participants registered for this event.



Disability Policy Seminar Washington April 8-9, 2019





Phil Milsk

Legislative Update with Phil Milsk

ARC OF ILLINOIS LEGISLATIVE REPORT JUNE 11, 2019

The following bills that may be of interest to the Arc community have passed both houses of the Illinois General Assembly. The Governor has already signed the budget bill, the budget implementation bill and several others. Most bills have not been sent to the Governor yet. Approximately 600 bills passed both houses this year.

SENATE BILL 1814

(Stears, G. Harris) This is the State Fiscal Year 2020 Budget Implementation bill. It includes (1) a 3.5% rate increase for community-based agencies serving individuals with intellectual disabilities, all or part of which may be used for wage increases, (2) Medicaid coverage for ABA therapy prescribed for children with autism, and (3) Early Intervention (IDEA Part C) eligibility for children 0-3 who have elevated lead levels beginning July 1, 2020.
Status: Public Act 101-0010, effective June 5, 2019.

SENATE BILL 262

(J. Cullerton, G. Harris) State budget for Fiscal Year 2020 beginning July 1, 2019. Arc's Life Span program was funded at the same level as FY 2019, and the Autism Program received an increase of \$500,000 over FY 2019. The bill is over 1,500 pages.
Status: Public Act 101-0007, effective July 1, 2019 unless otherwise specified.

HOUSE BILL 62

(G. Harris, J. Cullerton) Capitol projects legislation. Some specific grants in this bill are for several community-based I/DD service providers for various capital improvements.
Status: Sent to the Governor

SENATE BILL 2087

(Fine, Mussman) Creates a Customized Employment Pilot Program under the Department of Human Services Division of Rehabilitation Services serving individuals with

intellectual disabilities, developmental disabilities or similar conditions resulting in a most significant disability. Requires the Pilot to include at least 4 sites in the State. Requires person-centered planning, geographic and participant diversity, and involvement of certified staff. This is an Arc of Illinois initiative.
Status: Passed both Houses.

HOUSE BILL 3483

(Gabel, Fine) Amends the Department of Human Services Act to update the section governing the "cross-disability database" by calling it the "PUNS" and making other changes regarding the administration of the PUNS. This is an Arc of Illinois bill negotiated with the Department.
Status: Passed both Houses.

HOUSE BILL 3299

An Illinois Guardianship and Advocacy Commission bill supported by the Arc of Illinois and many advocacy groups, individuals and families. The bill requires persons admitted to a developmental disability facility and receiving habilitation to have access to sex education, related resources and treatment planning that supports his or her right to sexual health and healthy sexual practices and to be free from sexual exploitation and abuse. Requires that individuals be assessed, including consideration of medical, psychological and psycho-social evaluations. Requires that the individual's decision-making capacity to consent to sexual activity

and the developmentally appropriate materials and resources must be determined by the treatment team in consultation with professionals who have knowledge of the individuals and the guardian. Provides that the Department of Human Services shall approve course materials.
Status: Passed both Houses.

SENATE BILL 1321

(Stears, G. Harris) An omnibus Medicaid reform bill that includes some Medicaid Managed Care reforms and also requires the Department of Healthcare and Family Services to conduct a review within 90 days of the effective date to determine whether and how to implement a streamlined redetermination process for certain beneficiaries including persons with I/DD receiving waiver services. This bill was the product of a large bipartisan Medicaid Working Group that worked throughout the session.
Status: Sent to the Governor

SENATE BILL 111

(Morrison, Willis) Amends the Insurance Code to require coverage for dental anesthesia to individuals diagnosed with autism spectrum disorder up to age 26 (now age 19).
Status: Passed both Houses.

SENATE BILL 190

(Morrison, Carroll) Provides that if a State agency requests an open competitive eligible list from the Department of Central Management Services, the CMS Director shall also

provide to the agency a Successful Disability Opportunities Program eligible candidates list. Effective January 1, 2020.
Status: Passed both Houses.

SENATE BILL 726

(Morrison, Morgan) Creates a trainee program for persons with a disability in State Government beginning on or after July 1, 2020. Requires each agency with 1,500 or more employees to offer at least one position per year to be filled by a person with a disability, as defined by the Americans with Disabilities Act. Allows, but does not require State Constitutional Officers and agencies with fewer than 1,500 employees to participate in the program. Provides that the trainee position shall last at least 6 months and require the trainee to participate at least 20 hours per week. The program will be administered by the Department of CMS.
Status: Passed both Houses.

HOUSE RESOLUTION 214

(Hoffman) Requires a performance audit of the Department of Human Services' NOFO process that resulted in the awarding of new contracts for ISCs.
Status: Adopted

HOUSE RESOLUTION 410

(Gabel) Commemorates the 20th anniversary of the Olmstead v. L.C. decision by the United States Supreme Court in 1999.
Status: Adopted.

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



July 17, 2018 DHS New Provider Orientation



July 21, 2018 Special Olympics



Aug. 29, 2018 Meridian Stakeholders Meeting



September 26, 2018 KYO • Oak Lawn



October 2, 2018 Autism Conference



Oct. 3, 2018 DHS Support Waiver Mtg



October 12, 2018 Center for Independent Futures



October 13, 2018 MOPD Resource Fair



October 18, 2018 Clearbrook's 7th Annual Home Based Expo



October 26, 2018 Statewide Transition Conference



November 8, 2018 Arc of IL Conference



November 30, 2018 Planning for the Future



December 13, 2018 KYO • Country Club Hills



December 19, 2018 KYO • Elgin



January 3, 2019 KYO • Wheeling



Feb. 7, 2019 Leadership Forum • Lisle



Feb. 16, 2019 CAC Meeting



Feb. 19, 2019 KYO Meeting • Homewood



March 12, 2019 March Madness Special Needs Info Fair



March 14, 2019 South Chicago Parents and Friends



April 13, 2019 Transition Conference



April 18, 2019 KYO • Red Bud



April 30, 2019 KYO • Bloomington



May 4, 2019 Walkathon Proviso West Hillside

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!



Nafia Lee
Going Home
Coalition Mgr.,
The Arc of Illinois

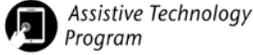
Nafia Lee is the Going Home Coalition Manager for the Arc of Illinois. In addition to recruiting and engaging current and new members for the coalition, she will help coordinate coalition members' participation in developing a public policy framework and messaging strategy which captures the Coalition's priorities. Some of the tasks associated with succeeding in this endeavor include hosting legislative coffees, regional meetings throughout the state, and partnering with other groups in order to push forward the Coalition's agenda items.

The Going Home Coalition is a network of self-advocates, family members, and community leaders. Our goal is to create truly person-centered and responsive programs and systems that reflect people's desires and support needs by increasing investment in community services, ending the waiting list of services and rebalancing the

state funding away from institutional care.

Nafia has previously worked for the Arc of Central Alabama as a QIDP, an Employment Representative for the Marriott Foundation for People with Disabilities and a Program Leader for an adult day program at the Fox Valley Special Recreation Association and She also has a professional background in local government and nonprofit communications. Nafia participated in the prestigious James H. Dunn Fellowship program in the office of former Illinois Governor Pat Quinn as a press assistant when closures of some of Illinois' state mental health and development centers were introduced. Her interest in working in advocacy stemmed from the fellowship and she is thrilled to join the Going Home Coalition team in her current role.

Nafia is excited about working with self-advocates, partner organizations as part of the Going Home Coalition. Nafia hold a master's degree from the University of Illinois at Springfield in Public Administration. She also holds a Bachelor's degree in Communications from Bradley University.



Training Department

The Training department is fully staffed and ready for the next year of events! We saw an increase of attendees at our Annual Convention – we had 402 attendees, up from 322 for 2018’s event. We hope to continue seeing this trend.

We are very proud of The Arc of Illinois Assistive Technology Fund that continues to grow every year. In April, we hit the 600 mark of devices ordered for those in need of Assistive Technology. We have ordered 611 iPads and other assistive technology devices since the Fund started and hope to continue to do so for years to come.

We are very grateful this year for being chosen as the beneficiary of two fundraising events. The band Mumford & Sons, with a partnership with Deering Banjo Company, have been auctioning off custom-made banjos personally signed by the band, with the funds benefitting a local charity organization. With their March 29th show in Chicago, they selected The Arc of Illinois to be the beneficiary with the banjo selling for \$4,010! The second fundraising event was through HaHaMen, a faith-based improve team. With each monthly comedy show, a different charity is promoted to raise donations, with The Arc of Illinois chosen for their April show.

As we look into the new year, we are getting a new website to better serve our viewers and a new CRM (Customer Relationship Management) software to better engage with our Members.

This program 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

Ashley Farland

Ashley@thearcofil.org

The Arc of Illinois

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Together we can make a difference!



The Arc of Illinois • 815-464-1832

2019-2020 Schedule of Trainings/Seminars/Webinars

- ◆ **May 2, 2019** | *“Know Your Options”* | Rockford, IL
- ◆ **May 3, 2019** | Brian Rubin, J.D., Sherri Schneider & Benjamin Rubin, J.D., *“Planning for the Future for Children & Adults with Special Needs”*
Hosted by Center for Independent Futures | Evanston, IL
- ◆ **May 7, 2019** | *“Know Your Options”* | Joliet, IL
- ◆ **May 8, 2019** | Brian Rubin, J.D., Sherri Schneider & Benjamin Rubin, J.D., *“Planning for the Future for Children and Adults with Special Needs”*
Hosted by Elim Christian Services | Crestwood, IL
- ◆ **May 16, 2019** | *Going Home Rally* | Springfield, IL
- ◆ **June 16, 2019** | *“Know Your Options”* Schaumburg, IL
- ◆ **June 25, 2019** | *Accessing Supported Employment: Supported Employment Action Team*
Doubletree Hotel, Alsip, IL
- ◆ **September 12, 2019** | *“Illinois Health Care Coverage Options and Benefits for People with Disabilities”*
Doubletree Hotel, Alsip, IL
- ◆ **October 3, 2019** | *Autism Conference*
Doubletree Hotel, Lisle, IL
- ◆ **October 28-30, 2019** | *Speak Up & Speak Out Summit 2019* | Wyndham Hotel, Springfield, IL
- ◆ **January 28, 2020** | *“18th Annual QIDP Leadership Conference”* | Doubletree Hotel, Alsip, IL
- ◆ **February 5-6, 2020** | *“Executive Leadership Conference”* | Doubletree Hotel, Lisle, IL
- ◆ **March 19, 2020** | *“8th Annual Arc/Ligas Family Advocate Informational Seminar”* | Heritage Plaza, Chicago, IL
- ◆ **April 22-23, 2020** | *“The Arc of Illinois 70th Annual Convention”* | Doubletree Hotel, Lisle, IL



Family Support
Network of Illinois

Family Support Network

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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



Rev. T.D. Hughes

The Arc Family Support Network would like to say thank you to retired Pastor Emeritus Rev. Dr. Alan V. Ragland of the Third Baptist Church of Chicago for partnering with the Arc of Illinois. This partnership has allowed us to utilize the Heritage Plaza facilities to bring resources to an underserved community. Over the past 7 years we have shared information and resources with thousands of families, individuals and self-advocates. We are equally grateful to the new Senior Pastor, Rev. T.D. Hughes, he will continue this collaboration in the years to come.

Thank you!

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



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