Family Support Network

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June 2021

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

Hello Family Support Network Family and Friends,

The Family Support Network closes this year on a note of deep gratitude to our families, selfadvocates, and supporters, all of whom have generously shared their experiences, frustrations, needs, and successes throughout this very challenging year. While the pandemic presented deep difficulties, it also exposed opportunities for connection and advocacy that would have otherwise gone unexplored. The Family Support Network focused on expanding outreach, connecting with the most isolated and underserved members of our community, and developing effective and progressive educational and advocacy offerings. While it did not seem possible in the early days of the pandemic, we now look back with pride, for the challenges that we faced forced us to grow and adapt and shift our perspective to one of possibility and problem solving. We look forward to continuing on that path in 2021-2022, and we welcome your partnership in that endeavor.

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

Our Arc of Illinois team is in the process of some major changes this year. Executive Director, Meg Cooch, left at the end of March to join the DHS DDD Division, as Deputy Director Ligas Consent Decree. We thank her for her years of leadership at The Arc and wish her well in her new role. Of course we will continue to work together on making the DDD System responsive to the needs of the Illinoisans we all serve. Our new Executive Director, Amie Lulinski, began her work at The Arc of

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Illinois on June 1st, 2021. Amie is no stranger to Illinois or to the developmental disability system. She brings a wealth of knowledge and expertise as well as enthusiasm for the work and a heart for the challenges that face people with intellectual/developmental disabilities and their families. We know you will enjoy meeting Ms. Lulinski. Please find a more detailed introduction to her later in this newsletter.

Four Arc of Illinois team members are retiring this year, at the end of June. At some point you may well have met one or all of them. Janet Donahue has worked for the Arc of Illinois for twenty-eight years. Her reputation as Director of Development is formidable. She excels in planning and managing numerous Arc events and trainings that happen every year, down to the smallest detail. We often have attended outside events and wished they had a Janet to keep them running smoothly! But we know that her secret passion is for the Assistive Technology program she started and has shepherded so successfully that it has supplied approximately 800 people with disabilities with the devices they need to access the world around them. Cindi Swanson has worked with the Illinois Life Span program for over 19 years, making presentations and answering calls from people with all kinds of questions



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."

The Arc of Illinois is pleased to welcome its new Executive Director, Amie Lulinski, PhD, FAAIDD.



Amie Lulinski Executive Director The Arc of Illinois

Amie, who was born in Chicago and raised in the south suburb of Sauk Village, has worked with and for individuals who have IDD and their families since 1995 when she began her career as a Direct Support Professional at The Arc of McClean County after graduating from Illinois Wesleyan University with a BA in Psychology. Since then, she has served in various roles in Illinois, Missouri, and the Washington, DC metropolitan area including Individual Service Coordinator, ICF/ID Administrator, Senior Research Specialist in Developmental Disabilities at the Institute on Disability and Human Development at University of Illinois at Chicago, and Director of Rights and then Director of Research and Evaluation at The Arc of the United States. Most recently, Amie served as Project Director for the State of the States in Intellectual and Developmental Disabilities for IDD supports and services at the University of Colorado. Prior to relocating to the DC metro area to work at The Arc of the United States national office, Amie served as Secretary of the board of The Arc of Illinois as well as a long-time member.

In addition to job-related duties, Amie has served in voluntary roles including board member-atlarge of the American Association for Intellectual and Developmental Disabilities (AAIDD) where she also received the distinction of Fellow of AAIDD for her contributions to the field. She has served as a member of the Planning Committee for the National Goals in Research, Practice and Policy Conference, chair of the Managed Care Task Force for The Arc of Illinois, and a peer reviewer for professional journals, conference proposals, national grant competitions, and awards committees.

Amie earned a Master's in Disability and Human Development in 2008 as well as a PhD in Disability Studies in 2014 from University of Illinois at Chicago, Department of Disability and Human Development where her research interests included deinstitutionalization, the home and community-based Medicaid waiver program, and mental and behavioral health needs of people with IDD.

Amie says she is honored, humbled, and excited to return home to Illinois to serve in a leadership position on behalf of and alongside people with IDD and their families as well as support equity and inclusion of leaders with IDD in a system that is responsive to the needs of the diverse tapestry of Illinois stakeholders. Amie recognizes the importance of the roles of self-advocates and families in systems change and looks forward to maximizing opportunities for selfdirection and purchasing power of people with IDD. She will live in a Chicago suburb with her husband, Bill Norris, and their dog Maxine (Max).

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

continued from front page

and information needs. Her experience and her kindness have improved many people's days. Missy Kichline has worked in the field of disability services and supports for over thirty years with seven of those years at The Arc of Illinois in both the Ligas Family Advocate Program and Life Span. Her tenacity and her calm strength have given many people encouragement. Faye Manaster has been a member of The Arc of Illinois team since 2006. Faye's career spans more than 40 years in the fields of special education, family support, early intervention and public health. Her knowledge has been a source of inspiration for members of the Arc team and beyond. All four of these Arc team members will be deeply missed. Their value to the organization has been priceless.

Changes are always a little disconcerting. We all know that nothing in the disability community stays the same from day to day and that there is always a need to bring our issues into the spotlight. The Family Support Network is here for you. Our job is to keep abreast of changes and to stay ahead of the curve whenever possible. We can't do this without your support, your information, your thoughtful questions and concerns. So please keep them coming! One thing we have all learned in this last year is how critical good communication is. We are here to share information and we will always share hope! Thank you for your trust in us, as it makes our jobs fulfilling every single day.

Sincerely, Shirley Perez, Executive Director, Family Support Network

Illinois Life Span (ILS) Program

The Illinois Life Span Program (ILS) of The Arc of Illinois began twenty years ago to address the need for information related to advocacy, services, and supports for people with intellectual and developmental disabilities of all ages, throughout Illinois. We continue to be the "go to" disability information resource for people with disabilities, family members, care-givers, and professionals. Although we don't claim to have all the answers, we will always do our best to connect people who reach out to us to helpful resources!

ILS provides information in a number of ways, including through the resources available on our website at www.illinoislifespan.org. Questions can also be submitted by email via our website, and ILS staff are available to answer calls by phone at 1-800-588-7002 during regular business hours Monday through Friday.

ILS has been hosting Monthly Lunchtime Webinars since 2017, focusing on Illinois resources, supports, and services for families that include a loved one with IDD. 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 and recorded webinars are available under the Monthly Webinars tab.

There are currently five staff members on the ILS team. Faye Manaster, Cindi Swanson, and Missy Kichline all work part-time to provide information to people who contact us at for help and they are also all retiring at the end of June, 2021! We would like to acknowledge and sincerely thank these three amazing professionals and advocates who graciously stayed on with us through the Covid-19 pandemic. Cindi, Missy, and Faye have devoted decades to the work of The Arc and have generously shared their knowledge, their personal experience as parents, and their professional expertise with both those who reached out for help and their co-workers at The Arc. They will be greatly missed!

ILS Team - Retiring . .



Faye Manaster has been a member of The Arc of Illinois team since 2006, when The Arc of Illinois Family to Family Health Information Center received its initial grant. Faye's motivation to get involved with healthcare advocacy was based on the challenges she faced in raising her daughter as an uninsured child with multiple disabilities and medical challenges. Faye's daughter is now 39 years old, and continues to benefit from the changes and improvements

in both medical care and the evolution of programs and policies for persons with disabilities. Faye's career spans more than 40 years in the fields of special education, family support, early intervention and public health.

Faye served as the Project Director for our state's F2F through the end of 2020, when she retired and transferred to part time for the Illinois Life Span Program (ILS). ILS has been grateful for the partnership with Faye for many years and having her on staff for these last several months has been invaluable to us! Thank you, Faye, for sharing your wealth of knowledge, your extensive and lived experience, and your time with us!

From Faye: "Working on The Arc's team of predominantly family members and friends of persons with disabilities around the state continues to be phenomenal. Together, we have connected with literally hundreds and hundreds of families around the state each year and developed numerous fact sheets for families in both English and Spanish. We have provided trainings around the state for families and professionals, expanded our partnership for both program and policy matters on the state and local levels, and developed our F2F Family Stipends for inperson as well as virtual training events. Assisting and supporting families in our large state, together with my Arc colleagues is one of my proudest lifetime accomplishments. As I prepare for my retirement, I want to leave you with this message. We are here to help you, so please reach out to us. Remember that you are not alone. "



Cindi Swanson has been with the Illinois Life Span Program from the beginning of the program in 2001! Although there were a few minor interruptions in her Arc tenure during times of budget difficulties, Cindi was committed to helping other families and to doing that through the work of The Arc of Illinois. Cindi's is likely the voice you heard when you called ILS, and her decades of advocacy in the IDD service system gave her unique expertise in

guiding families to the information and resources they sought. Cindi and her husband, Art, helped start We Grow Dreams – a greenhouse and work experience opportunity for youth with disabilities in DuPage County. Cindi also started a disability advisory committee with her local State Representative.

Cindi and Art have a young adult son, Adam, who has Down syndrome – the impetus for their hard work on these issues over the years. They have built a full and integrated life for Adam and they do that currently from the State of Nevada, where they recently moved to be near their other children.

From Cindi: "When our son Adam was born, we realized we were not in Kansas anymore. Our family dug into learning everything there was to learn about disability, policy, law. As time went on, we learned The Arc is a leader and as a social worker/advocate I wanted to work for the organization.

Every time the Illinois Life Span phone rings I know I am touching the heart and soul of a family member or a professional who has dedicated their life to helping people with disabilities. That recognition helps me help them be the best advocate for their loved one. It is truly sacred ground we stand on when we do this work.

It has been an honor to work with a most professional, compassionate staff of people and to walk hand in hand with the consumers we assist."



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's knowledge, experience, her unending energy and enthusiasm for helping others, and her sense of humor will be sincerely missed!

From Missy: "Some 30 years ago my middle daughter was born. I quickly realized I needed to learn A LOT of new stuff!!! Along the way I have been fortunate to have great mentors, colleagues, bosses and dear friends. My experience with the Arc of Illinois started with serving on the Board of Directors. Then moving to the newly formed Ligas Family Advocates Program. And finally working for the Illinois Life Span. The Arc of Illinois is the leading organization in the field of IDD in the state of Illinois. It has been an honor to work for such courageous, smart, dedicated individuals. Thank you."

ILS Team Members . . .



Rocio Perez, the Assistant Director for Outreach, is also an integral part of the Illinois Life Span team. Rocio is located in the Chicago area, and is bilingual in English and Spanish. Rocio has greatly expanded our reach to Spanish speaking families statewide through outreach events, webinars, and making sure that information from The Arc is available

in Spanish. Rocio is also the parent of a young adult who receives disability services/supports. We are very grateful to have Rocio and her expertise as part of our team! You can reach Rocio by email at Rocio@thearcofil.org.



Deb Fornoff is the Director of the Illinois Life Span Program and is also a long-time team member at The Arc of Illinois. Deb and her family live in central Illinois. She and her husband are parents of an adult son, Brad, who has Down syndrome. Deb encourages everyone to take a look at the wealth of information available on the ILS website (www.illinoislifespan.

org) and invites all to join one of our monthly webinars if you haven't already! Look for the upcoming topics under the Events tab at www.thearcofil.org. Please contact the ILS staff any time with questions at 1.800.588.7002! Deb can be reached at deb@thearcofil.org. We all look forward to connecting with you!

The Ligas Family Advocate Program

The purpose of the Ligas Family Advocate Program is to provide family-to-family support for individuals and their families who are selected through the Illinois Department of Human Services, Division of Developmental Disabilities (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. We are funded by the Illinois Department of Human Services Division of Developmental Disabilities.

The Ligas Family Advocate Program continues to expand in our outreach to families and self-advocates in Illinois. The department is now bilingual and we are able to reach Hispanic families with consistency. The Northern LFA, Ruth Aguilar, contributes to the team with her personal

and extensive professional experience, as she previously worked as both an Individual Service Coordinator and Self-Directed Assistant. We are thrilled to see the expansion in outreach that has allowed us to serve many Spanish speaking families and self-advocates. Moreover, the addition has fostered new connections with organizations in Illinois and in other states nationwide, including Parents of Extra Ordinary Children and the Epilepsy Foundation. The LFAP strives for diversity and inclusion, we are proud to say that we are moving in the right direction. Many documents, presentations, meetings and one-on-one advocacy calls are now being conducted in English and Spanish. We respect and embrace all cultural backgrounds and promote acceptance and inclusion towards a better and brighter future. The LFAP program provides support and advocacy to individuals seeking adult developmental

LIGAS REACH

- Facebook: 8,114
- Website users: 1,840
- Sessions: 1,298
- Page views: 2,674
- Letters to Individuals selected to apply for services: 1,571
- 1st & 2nd letters to Early PUNS Notification Recipients: 3,122
- Webinars/trainings/Online events: 60
- Telephone calls: 2,107

disability throughout Illinois.

Our educational offerings, whether oneto-one or in a group format, focus on understanding adult I/DD service and support options under the Medicaid Home and Community Based Waiver, system navigation, and residential and in-home supports. The LFAP program sent out 1561 letters of introductions to families and individuals seeking support and education as they begin the process of preparing for services after being selected from PUNS in July 2020. We also continue to work with families and individuals that received an

Early Puns Notification letter in December 2020. As we move into the summer of 2021, we look forward to partnering with these families as they begin planning their course for community supports and inclusion.

We will continue to find creative ways to connect with families, conduct trainings online and in-person (when safe to do so), share information, and mange concerns raised by families and self-advocates.

Contact information for Ligas Family Advocate program:

Shirley Perez Program Director Shirley@thearcofil.org Megan Mutti Central/Southern Senior Ligas Family Advocate Megan@thearcofil.org Ruth Aguilar Northern Ligas Family Advocate <u>Ruth@</u>thearcofil.org

Northern Ligas Family Advocate



Ruth Aguilar

This year has been very rewarding and full of positive interactions, I started my job as the Northern LFA at the beginning of 2021 after overcoming the struggles of COVID-19. Although, I felt uncertain about the future, The Arc of Illinois opened its doors to me and I not only found a career, I also found a tremendous network of support and professionalism. Since day one, I was able to jump right into my duties. To this date, I have interacted with close to 400 families and self-advocates out of the 800 letters that were sent out back in

December 2020 to the three ISCs that I work with, as part of the Early Notifications from PUNS. I have established positive relationships with the Independent Service Coordination Agencies at Suburban Access, Service Inc. of Illinois Region E, and Community Alternative Unlimited. I have participated in numerous virtual conferences and meetings tailored to inform people that anticipate the PUNS selection.

Some of the biggest impacts that make my days at work is the fact that I am able to serve families in two different languages; English and Spanish. I feel so happy and useful when my Director Shirley Perez asks me to assist a family in Spanish. The moment that a person knows that I can speak in their native language, they feel relaxed and feel more confident to share about their lives. On the other hand, I proud to say that I have been given the opportunity to make connections with organizations in Illinois and across the United States with invitations to present about our strategic work on behalf of people with Intellectual and Developmental Disabilities. I am confident to say that my job to inform and advocate is already making a difference in the families because they have expressed their gratitude in multiple occasions. I look forward to continue the service and advocacy in my community.

Este año ha sido muy gratificante y lleno de interacciones positivas. Empecé a trabajar como Defensora de las Familias Ligas de la Región Norte de Illinois después de sobrevivir al COVID-19. A pesar de que me sentía insegura sobre mi futuro, The Arc of Illinois me abrió sus puertas y no solo encontré una carrera, también encontré una tremenda red de apoyo y profesionalismo. Desde el primer día, recibí mis casos de trabajo. Hasta el día de hoy, he interactuado con cerca de 400 familias y auto defensores de las 800 notificaciones de PUNS que fueron enviadas en diciembre del año pasado. También he formado conexiones positivas con las agencias de coordinación independiente tales como Suburban Access, Service Inc, Region E, y Community Alternative Unlimited. He participado en numerosas conferencias virtuales y juntas dedicadas a informar a las familias que esperan la selección de PUNS,

Algunas de las cosas que me alegran el día, es el saber que puedo asistir a las familias en dos idiomas -Inglés y Español. Me da gusto cuando mi Directora Shirley Pérez me pide que ayude a las familias Hispanas. En el momento que las personas saben que se pueden comunicar conmigo en su idioma natal, se sienten más confiados y me cuentan su historia. Por otro lado, me siento orgullosa de que he tenido la oportunidad de establecer relaciones con otras organizaciones en todo el estado de Illinois y a nivel nacional. Me han invitado a dar charlas sobre como The Arc promueve sus estrategias de trabajo para las personas con discapacidades del desarrollo e intelectuales. Me siento segura de que mi trabajo de informar y abogar está haciendo la diferencia en las familias. Y lo sé cuándo ellos me expresan su agradecimiento. Estoy emocionada de continuar sirviendo y abogando por mi comunidad.

Central/Southern Senior Ligas Family Advocate



While the past year has looked and felt significantly different, technology has allowed our program to continue to connect with families and individuals in need of education and support as they pursue adult supports. Families and selfadvocates generally viewed the contact with the LFAP program favorably and indicated that their understanding of options increased significantly following phone consultation.

Megan Mutti

The majority of families that have engaged have been seeking Home-Based Supports and Services. Families sought information regarding program rules/regulations, roles and responsibilities of a parent as a PSW, community day service programs, and clarification regarding transitioning from Home-Based Supports to CILA supports should family or individual need/circumstance change over time. Families also sought information regarding transportation, particularly as it applied to DHS programming. Numerous Early Notification families are currently receiving DRS Home Services hours, and much of the consultation for these families has focused on the differences between the programs and a review of the DDD v DRS Comparison Tool.

We have grown our virtual capacity and our confidence around the zoom platform, much through trial and error! We are facilitating monthly statewide Know Your Options programs, and regionally we have seen ISC specific representation by both ISC staff and families seeking services. It is encouraging to see the connections that can be made, particularly in more rural areas of the state, as families have become more comfortable utilizing online platforms. We have enjoyed the invitation to regularly facilitate a short program on family centered care for the DHS DDD New Provider Training, and it is always exciting to see the vision and enthusiasm that new DD providers have for the work they are pursing.

Families in Central and Southern Illinois report familiar barriers, all of which are compounded by the pandemic. Difficulty in finding PSW's, frustration at accessing accurate information, concerns around making decisions that will be effective in both the short and long-term for their loved one, and Medicaid application frustrations top the list. Families have also shared their need for robust respite supports, which are difficult to come by on a consistent basis in many areas of the state. Not surprisingly, access to mental health supports for individuals with IDD remains a difficult challenge downstate.

We enjoyed the opportunity to participate in the Disability Policy Seminar and the Arc of Illinois Annual Conference. With the current separation of staff across the state, these opportunities to connect and learn have become more welcome and meaningful. That said, we look forward to being back in person with the families we support and our colleagues soon!

Family Transition Project

Annual Update - June, 2021



Katherine Hamann

It is impossible to ignore the obvious, and not start by saying that the last year and a half has severely tested the Family Transition Project, just as it has tested all of us. Now that re-opening is beginning in earnest, many of us have begun to examine the losses of the pandemic. We will not minimize or ignore them, but this FTP update is going to be a report on hope. This single word – hope - has defined the work of the FTP (and the Family Support Network and The Arc

of Illinois) from the beginning. Some years ago, your FSN Director, Shirley Perez, and I talked about "second best." We were visiting an agency that has accomplished a lot for people with intellectual and developmental disabilities (i/ dd) and heard about many of the shortages they had and lack of funding for new equipment and staff. Afterwards, we wondered to each other why people with i/dd always seem to get "second best" when we live in a society of such unprecedented wealth. We believe in hope. We believe that people with i/dd deserve to have what they want and need to live a full life and we believe that that life should not have to be "second best." This is what we advocate for. It doesn't mean that we don't all have to compromise sometimes, but we always have that high standard to look up to. If nothing else, the pandemic has taught us how small differences in services and supports for people with i/dd can make huge differences in their lives and we will continue to advocate for systemic improvements, but also for small individual improvements.

Although we are happy to redirect calls about students transitioning from high school to adult life, the Family Transition Project is focused on one specific group of people with i/dd - people who live in large institutions and want to transition to community life. We offer support to this group and to their families. We have received calls from selfadvocates living in state operated developmental centers (SODCs) and, most often, from their loved ones. We will help individuals and families make connections with the agencies and individuals who can help them. We will offer advocacy and information and a listening ear. This can mean attending meetings with individuals and their families. It can mean making calls for them and (pre-pandemic) it has meant making one-to-one visits as well. It has also meant connecting families with other families who have experienced the same transition challenges. We work with families for years sometimes. At the moment, for example, several families are unsure about community living because of past experiences, but we will continue to keep the lines of communication open with them and advocate for their loved ones in the SODC. FTP is different every single day because we want to be responsive to your needs.

What are some of the positives of the last year? Annoying as some may find the technology, virtual meetings have made it possible to keep in touch with individuals and families all over the state. Less traveling has actually meant more time to spend with families, even if we are talking on the phone or on a computer screen. Even during the pandemic, hopeful transitions have continued to happen. The Illinois Department of Human Services/Division of Developmental Disabilities has been a good partner in sharing our information with people who are ready to transition from SODCs and their families. We continue to work with them to find new ways to connect with families. We also keep them apprised of trends and concerns we observe and they have been responsive. Our FTP Mentor Program is also going strong. We now have six self-advocate mentors who have lived in SODCs and can share their firsthand experience of life inside the SODC and outside, in the community. The Mentors have met regularly online and continue to advocate for community life. In the last year they have testified in a legislative hearing, given several interviews to the Media, spoken at numerous conferences and meetings, and offered peer support. Our colleagues at the other programs of The Arc of Illinois are a wonderful resource to us and we thank them for their teamwork, which never missed a beat, pandemic or not.

Thank you. Katherine Hamann Director, Family Transition Project

Contact information for Family Transition Project:

Katherine Hamann

Work Cell: 708-465-2827 Office: 815-464-1832 x1019

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ARC MENTORS!

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



The Arc of Illinois Family-to-Family Health Information Center (F2F) will be ending its sixteenth consecutive Project Year on 5/31/21. Our project is funding 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 a 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.

The biggest news of the year is the retirement as of 12/1/20 of Faye Manaster, founder and Director of F2F for 16 years. Faye's extraordinary talent and advocacy continues in her current position as an Information Specialist for the Illinois Life Span Program of The Arc of Illinois. New F2F Director, Mary Dixon, is grateful for Faye's continuing mentorship and welcomes the opportunity to serve families with children with any disability, chronic illness or special needs. Mary has a J.D. from Valparaiso University and a Certificate in Health Disparities Research from the UIC School of Public Health, Health Policy and Administration. Prior to taking the position as F2F Director, Mary assisted individuals selected from the PUNS and their families as the Northern Illinois Ligas Family Advocate.

Here are some of the highlights of the major accomplishments over the past year, which emphasize our approach to serving and supporting children and youth with special health care needs (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 and evolve under Medicaid Reform and the Affordable Care Act.

- Beginning in January, 2021, the F2F is offering monthly Healthcare webinars, all with captioning in Spanish available, throughout the year on topics of interest to families with CYSHCN. To date webinars have been offered covering: Community Health Centers/Federally Qualified Health Centers; ABA Therapy and II Medicaid: School-Based Health Centers, Marketplace Plans and UIC's Specialized Care for Children Programs. Upcoming webinars, July -November include Illinois Medicaid Managed Care, the IL Attorney General Health Care Bureau, the Division of Developmental Disabilities Childrens' Waivers with DDD Director Allison Start and the Persons with Disabilities Medicaid HCBS waiver with DRS Director Rahnee Patrick.
- 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 convene an Annual Health Care Conference featuring expert speakers on trending public, private and Marketplace insurance issues through a CYSHCN/disabilityspecific lens. In 2020 Annual Healthcare Conference was held virtually in 2020 and our pending September 1st 2021 Healthcare Conference will be virtual a well. This year our Annual Conference will feature information about state and federal benefits, as well as panel discussions on caregiver supports, behavioral health and telehealth and a child COVID vaccine update.
- In June, the first ever F2F Health Information Center Spanish language Healthcare Conference was launched in three parts during June, 2020.
- We continue to expand and update our virtual library of Illinois-specific family-friendly health fact sheets and brochures, with both English and Spanish versions.

- The F2F is the state affiliate office of Family Voices, a national grassroots network organization of families and friends of CYSHCN. As such, we applied and were granted funding to offer Telehealth Trainings and assist families with barriers some experienced to accessing care. Thanks to Maria Castillo, F2F Telehealth Consultant, trainings were offered in Spanish as well as English.
- 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.
- As a member of Protect our Care -IL we participate in the Access to Healthcare subcommittee with organizations throughout the state working collectively to improve IL health care systems.
- We also serve professionals statewide, via telephone, through numerous training and outreach events and social media.

Family to Family staff and consultants are themselves parents of persons with 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.

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

Mary Dixon, Director

Toll-free: 866-931-1110 Español: 800-588-7002 Office: 815-464-1832 x1017 mary@thearcofil.org

Assistive Technology Program - Training Department

The Training Department went virtual this year with great success! While we miss being in person and connecting with everyone, hosting virtual conferences and webinars has allowed us to reach a wider audience. Transportation and scheduling were no longer a barrier for families, selfadvocates, and professionals to attend a conference. As we start to move forward with the State opening back up, we will remain cautious and continue to put the health and safety of everyone in our community at the forefront in planning for future events. However, once we do offer in-person events again, we'll also offer a virtual option. The new normal of virtual conferences has shown us the great benefit of offering a hybrid event.

Thanks to The Illinois Council on Developmental Disabilities (ICDD) for their continued support. Not only did they partner with The Arc of Illinois on the COVID-19 DD Relief Fund grant, but they also expanded The Arc of Illinois Consumer Stipend Program to cover the cost of assistive technology for individuals needing to connect during the pandemic. Through this, we've been able to help 145 families across the state. This expansion is now over with no remaining funds available. ICDD also provided the funding for the Speak Up and Speak Out 2020 Summit as a virtual, 5-day event!

This past year The Arc of Illinois fundraising was very successful, including many Silent Auctions and donations. Huge thanks to all our donors this year!

There are some changes to The Arc of Illinois staff. Janet Donahue will be retiring at the end of June after 28 years. Her passion and commitment are evident in the work she has done for The Arc of Illinois, including starting the Training Department and creating The Arc of Illinois Assistive Technology Fund. Janet has helped countless self-advocates, families, and professionals to ensure everyone has the ability and right to live, work, play, and love in their community.

The Assistive Technology Department is staffed by:

Janet Donahue

Janet@thearcofil.org Director of Development

Becca Schroeder Director of Training 815-464-1832, ext 1018 Becca@thearcofil.org

Additional Arc staff:

Karin Ulstad Office Manager Karin@thearcofil.org

Special *thank you* to Sandra E. Heidt, for helping out in The Arc's office while Karen was out on leave!

The Arc of Illinois

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The Family Support Network (FSN) Program

The Family Support Network works to uncover the resources, funding, and services needed to help people with developmental disabilities live fulfilling lives in their own homes. By focusing on the needs of both family members and individuals, we help break down barriers to clear the way for long-term success. We are a state-wide staffed by a Program Director, Family Liaison and Family Advocate Specialist.



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

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 with core partners. In these challenging times we are happy to have Shakari respond out to our families and provide resources and support. Sharaki@thearcofil.org

HOW WE HELP:

We make finding family services flexible and easy, using personal and professional experience to bring lifestyle benefits and support to all.

Inform - We connect the dots to the right resources opening doors to smart choices.

Educate - Education brings everyone together, uniting families under informed plans of action.

Support - Help individuals live at home on their own with guided support.

OUR MAIN GOALS:

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

FAMILY SUPPORT NETWORK AIMS TO:

Keep Families Together - until the person with a disability chooses to live independently.
Empower Caregivers - to meet the many needs of their family member with a disability.
Improve Support - to families while minimizing the need and the cost of out-of-home placement.
Allow Family Participation - in integrated leisure, recreational, and social activities.

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: 10,250	Website engagement:	Training (one-on-one): 121
Number of Electronic newsletters: 12	Users: 5,593	Organizational Partners: 8
Electronic Newsletters Reach: 10,119	Website Page views: 3,747	Telephone calls (approximate): 1276
	Website Sessions: 2,113	Other Outreach events/Conference: 12
	Webinars/Training: 38	

Two State-wide Virtual events were hosted by FSN:

The first event was held on October 30, 2020, with 426 participants, Statewide Best Practices and Home Based Services Conference featuring:

Keynote:

John Agosta, Executive Vice-President Human Services Research Institute (HSRI) Yoshi Kardell, Policy Analyst

Derek Hedges, Medicaid Waiver Unit Andrea Medley, Strategic Planning, Department of Human Services, Division of Developmental Disabilities

Tasha Whiteside, Illinois Program Director Aces\$

Mary Dixon and Megan Mutti Ligas Family Advocates

SDA Provider: Eliza Jones - QIDP/SDA ClearBrook

HBS Participants: Michelle McFarland Jose Ovalle

ISC Patty Obrien - Suburban Access The second event was held on March 24, 2021, with 478 participants 9th FSN/Ligas Informational Seminar featuring:

Keynote: Allison Stark, Director Illinois Division of Developmental Disabilities

Sherri Schneider, President Family Benefit Solutions

Ronnie Cohn Ligas Court Monitor

Brian Rubin & Benji Rubin Rubin Law

Amy Newell, Executive Director Arc of Winnebago County



Thank you to our Exhibitors & Sponsor of the Arc FSN/Ligas 9th Informational Seminar:



CONGRATULATIONS TO ALL OF THE 9TH FSN/LIGAS INFORMATIONAL SEMINAR WINNERS



THE FIRST 2 PROFESSIONALS TO REGISTER: Kristen Feld and Elizabeth Hage from Clearbrook

Michael Kors card holder Envision Unlimited: Kate Spade



Elizabeth Hage Michael Kors Card holder **WINNER**



Rose Beal Envision Unlimited - Kate Spade **WINNER**



Donated Prizes

Linda Hall Hand Held Coach Purse **WINNER**



Legislative Update with Phil Milsk

Summary of Key 2021 Disability-Related Illinois Legislation as of June 10, 2021

The following bills have passed both houses of the General Assembly unless otherwise stated. Please note that these bills are not law yet, and this summary may not include every bill that might be of interest to our readers. "Effective immediately" means that the bill will become effective when (if) the Governor signs it. These are bill summaries only. Anyone who has questions about these bills or other bills that are not listed may contact the Arc of Illinois. You can read the full text of any bill filed in the General Assembly at www.ilga.gov.

Phil Milsk

BUDGET

SB 2800

(Harmon/Welch) is the FY 2022 budget bill. It also covers FY 2021 supplemental appropriations and capital projects. The bill is over 3,000 pages long. DD grants for FY 2022 through the Department of Human Services including Life Span, Best Buddies, Dental grants, Autism Program, etc., start on p. 369. Our understanding is \$170 million is appropriated to implement the Guidehouse Report on DD rates. We also believe there is funding recommended by the Division of DD to cover the cost of allowing CILA residents to retain their post-tax earned income. This was an initiative of the Arc and IARF in SB 1978 and HB 292. This bill was sent to the Governor on June 10,2021.

SB 2017

(Harmon/G. Harris) is the FY 2022 Budget Implementation bill. It is over 800 pages long. The language with regard to ID/DD rate methodology and wage increases is on pp. 106 for community based service agencies and pp. 222-223 for ID/DD facilities.

EMPLOYMENT

HB 2616

(Yang-Rohr/Fine) would exempt from the State Procurement Code acquisitions by State agencies of assistive technology, adaptive equipment, adjustments, modifications, repairs and replacement parts to accommodate employees, customers and job applicants in order to reduce delays to enhance compliance with the Americans with Disabilities Act. The bill was an initiative of IATP and was endorsed by the State Task Force on Employment and Economic Opportunities for Persons with Disabilities. Effective immediately.

HB 292

(LaPointe/Fine) would allow a CILA resident to retain all after-tax earned income from employment or community day services starting July 1, 2021. It would also modify the membership of the State Use Committee, including the addition of a member representing a statewide disability-focused advocacy group. This bill is currently in the House Amendment for concurrence with Senate Amendment No. 1, which changed the effective date to July 1, 2021.

PUBLIC SAFETY

HB 2784

(Cassidy/Peters) creates the Community Emergency Services and Support Act (CESSA). Provides that 9-1-1 call centers and other emergency services must coordinate with mobile mental health and behavioral health services established by the Department of Human Services so that, when appropriate, mental health or behavioral health services will be provided to individuals as an alternative to law enforcement involvement.

SB 921

(Morrison/Carroll) creates an advisory committee under IEMA to address emergency disaster responses in coordination with State and local emergency response plans and with a focus on equity, including addressing the needs of persons with disabilities. A report is due from the committee by July 1, 2022.

HEALTHCARE

SB 2294

(Gillespie/G. Harris) is an omnibus Medicaid bill developed by the bipartisan Medicaid Working Group. On p. 167 of the bill a new Supports Waiver Program for Young Adults is authorized. This was an Arc of Illinois initiative (see SB 2292 sponsored by Sen. Scott Bennett) that was presented to the Working Group. The language that ended up in SB 2294 was negotiated with the Department of Human Services, and we plan to continue our discussions with the Department regarding this waiver program specifically and generally about services to young adults who have not been selected off of the PUNS.

HB 3308

(Jones/N. Harris) is a comprehensive telehealth bill that was neaotiated with the insurance industry by a new Coalition to Protect Telehealth led by the Illinois Hospital Association and other medical and advocacy groups. The bill deals with various issues including insurance reimbursement practices, reimbursement parity, coverage mandates, patient and provider protections (for example, patients and providers are not required to show hardship or an access barrier to in-person care before telehealth services will be covered). The bill covers private insurance only, not Medicaid, but current Medicaid telehealth policies will remain in place and further discussions are planned with our State Medicaid Agency, DHFS. The bill includes authorization for telehealth services in the Early Intervention program.

SB 500

(Barickman/T. Bennett) amends the Illinois Anatomical Gift Act by providing that a hospital, physician, surgeon, procurement organization or other person shall not, solely based on an individual's mental or physical disability, deem the individual ineligible to receive an anatomical gift or organ transplant, deny medical or other services related to an organ transplant, refuse to refer an individual to a transplant center or related specialist for an evaluation or receipt of an organ transplant, refuse to place an individual on a waiting list or place on a lower position on a waiting list than the individual would have been on if not for the individual's disability, or decline insurance coverage for any procedure related to the transplant and recovery. Requires compliance with the ADA.

SB 1592

(Fine/Welter) amends the Insurance Code provisions covering autism spectrum disorders and habilitative services for children to ensure coverage if therapy services are provided in a location other than the home or clinical office setting if clinically appropriate for the child.

EDUCATION

HB 40

(Hurley/Cunningham) provides that a student with an IEP who turns 22 years of age during a school year shall remain eligible for special education through the end of that school year. Currently students lose eligibility on their 22nd birthday. Effective immediately.

HB 2748

(Ness/Koehler) allows any student with an IEP who has turned 22 years of age during the COVID-19 pandemic and has had their in-person instruction, programs or services suspended for at least 3 months to continue their eligibility through the 2021-22 school year. The bill does not apply to students who have moved out of the district that was responsible for the student's last IEP. Effective immediately.

HB 3950

(LaPointe/Fine) amends the Dual Credit Quality Act by adding language regarding high school students with disabilities having access to dual credit courses offered by community colleges and using the accommodations provided in their IEPs/504 plans as long as they meet the dual credit course eligibility requirements. The bill also amends the Public Community College Act by referencing access to for-credit and non-credit courses by students with disabilities using their IEP/504 plan accommodations. Finally, the bill amends the School Code section on transition services by adding language regarding participation of students with disabilities in Career and Technical Education programs and services, and also adding language on potential goal areas under the general category of independent living skills. Effective immediately.

HB 41

(Stuart/D. Turner) provides that, prior to the placement of a child in an outof-state special education facility, the school district or other agency or court placing the child must offer to the child or parent/guardian the option of placing the child in a comparable Illinois facility, if any. Requires annual review of any out-of-state placement. Effective immediately.

HB 219

(Carroll/Gillespie) builds on regulations adopted by the State Board of Education in April, 2020, governing the use of timeout, isolated timeout, and restraints in schools. Like the rules, the bill eliminates the use of mechanical and chemical restraints as behavioral interventions in schools. It allows prone restraints under very limited circumstances for one additional school year. It aspires to eliminate timeout, isolated timeout and all restraints within 3 years by requiring the State Board of Education to develop benchmarks and each school district that uses these interventions to adopt 3 year plans. It requires the State Board of Education to impose progressive sanctions for violations and allows the State Board to issue grants for the training and use of trauma-informed practices if funds are available. It allows a parent or guardian whose child is subjected to one of these interventions to request a post-incident review meeting. Like the rules, the bill requires documentation and reporting of each incident and defines terms. If the bill is signed into law, the State Board's rules will need to be amended. Effective immediately.

HB 2425

(Crespo/Koehler) would extend the deadline to September 30, 2022, for Chicago Public School parents/ guardians to file State Complaints with the State Board of Education with regard to special education violations found by the State Board of Education during its public inquiry into CPS in 2018. The current deadline for filing complaints is September 30, 2021. Effective immediately.

HB 26

(Mah/Pacione-Zayas) amends the School Code to ensure that content available through a third party online curriculum that is made available to an enrolled student or the public through a school district over the Internet be accessible to persons with disabilities. Requires the State Board of Education to ensure that online curricula meet Level AA of the World Wide Web Consortium's Web Content Accessibility Guidelines.

HB 290

(Hirschauer/Villa) amends the School Code to require the State Board of Education, in consultation with the Department of Human Services, to provide parents and guardians of students with disabilities copies of DHS' guide, "Understanding PUNS" each year at the annual IEP review meeting held for the student. The guides would be provided through the local school district. Effective immediately.

SUPPORTED DECISION MAKING

HB 3849

(LaPointe/Feigenholtz) creates the Supported Decision-making Agreement Act. This is an initiative of the Illinois Guardianship and Advocacy Commission ("GAC"). The bill authorizes a supported decisionmaking agreement between an adult with a developmental or intellectual disability ("principal") and another adult ("supporter"). Disqualifies certain individuals from acting as a "supporter". The bill requires the GAC to develop training and educational materials for principals and supporters, including, but not limited to, sample agreements. Provides that the agreements may cover everyday life decisions including obtaining food, shelter or clothing, taking care of physical and emotional health, managing financial affairs, finding work, applying for public benefits, assisting with self-advocacy and helping with school. The bill provides that the supporter is permitted to assist with decision-making, not to make decisions.

GUARDIANSHIP

SB 80

(Tracy/Costa Howard) amends the Probate Act regarding guardianships over persons with disabilities to (1) allow the appointment of separate guardians over the person and over the estate of the individual if in the best interests of the individual, with certain exceptions; (2) allow the appointment of co-guardians if in the best interests of the individual if the co-guardians agree to serve together, subject to certain exceptions; (3) requires that the notice of rights to the individual must include the right to ask the judge to appoint only a limited guardian if the individual believes they are capable of making some of their own decisions; (4) allows for the award of guardian fees based on certain factors. Makes other changes.

Precious Moments with Janet .















Saying Thank You to Janet Donahue

Janet is retiring after 28 years of dedicated service to The Arc of Illinois and the families that we serve. There are no words to describe what you mean and have meant to The Arc of Illinois and the staff. We just wanted to take a few moments and say "Congratulations on a job well done!" You have been an inspiration, sounding board, resource and always that go to person that we knew that we could count on down to the very last detail.

It is our hope that you will finally get the opportunity to enjoy your life with your husband, children, grandchildren and of course your dogs. May your life be blessed and filled with love, happiness and joy.

We love you! ~ Shirley Perez

Dear Janet - Big congratulations on your retirement! You will be truly missed at The Arc but I am so happy for you! I will think of you enjoying the sunshine, hanging out with your fur babies, and just generally having a wonderful, relaxing life! I know how hard you work and it will be a change for sure. Take care and thank you for your friendship and support at The Arc of Illinois all of these years! Have fun and be well! Love ~ Deb

Janet -Congratulations on such a well-deserved retirement! I knew as a Ligas Family Advocate how much Shirley appreciated you and learned how much I do now as Director of F2F. Despite having too much on your plate since Meg left, you helped me with all questions -big and small -always finding time to reassure! I am happy to know you'll be kicking back at your home in Missouri and finding time to relax and explore new adventures. You have been the mainstay of The Arc for so long. I know Phil will miss you too! All the best ~ Mary

Your dedication to The Arc of Illinois and the

people that they serve is inspiring. It was a pleasure working with you and learning from

you. Enjoy your time with Rocky & the girls!

Dear Janet:

To Janet,

the most.

BIG shoes to fill!

It has been a true pleasure getting to know you and work together through the years. I'm so happy that our paths crossed many times and am hopeful that they will cross again. Enjoy your well-deserved retirement. You are amazing and will be missed by many! Wishing you and your family the Congratulations on your retirement Janet!

absolute best in this next chapter of life. Love, Michelle Arnold

On your retirement everyone appreciates you for your hard work

My best wishes ~ Ruth

and dedication. May your new journey

every moment and have so much fun.

Thank you for your service with

made a lasting impact on people

with intellectual & developmental

providers and other partners and

allies. Thanks for putting up with

once making me feel like they were

ridiculous – and for always sharing

your institutional knowledge. Your

resourcefulness is what I will miss

The person who will be responsible

to pick up where you left off has

With much gratitude ~ Nafia

my myriad of questions, never

The Arc of Illinois. You have a

disabilities, families, service

bring you, life satisfaction. Cherish

Ms. Janet, I am sad to see you go, yet very grateful for all of your hard work! It has been a wonderful journey working at your side, witnessing your amazing work here. You will be truly missed! I wish you and your family nothing but the best and thank you for being a kind spirit to me. Sincerely ~Shakari

Best wishes for your retirement. It's been a privilege to be your colleague! Really appreciate your expertise and commitment to The Arc of Illinois. Your outstanding skills have made all the difference. I've learned a lot from working with you since 2005 when we did the grant application that launched F2F!!

Best Wishes ~Sarah Chavez

Janet, Congratulations on your retirement! Your commitment to the Arc of IL is unmatched and you have made amazing things happen. Thank you for your many contributions to families and self-advocates through your 28 years with the Arc. Wishing you the very best in this next chapter.

Best wishes ~ Megan Thank you Janet for helping The Arc of Illinois get to where it is today. You have been an endless source of information anytime I had a question, and have been so willing to share the knowledge you've gathered over the years. It's been great getting to work with you on the trainings and events. You have done an amazing job with putting together and running our Annual Convention and making sure it runs smoothly. I hope you enjoy your retirement, you've earned it! ~ Karin



I want to thank Janet for her many years of passion and commitment to people with disabilities, families, community organizations and The Arc staff and volunteers. Janet's unique leadership and vision helped to build The Arc from the ground up. She identified barriers to people participating in events and trainings and worked to open doors so more people could have access to critical services and supports. Seeing a need for people to be able to access assistive technology, she built The Arc's Assistive Technology Fund from scratch. She listened to families about what they needed to know to be advocates and helped to train and inspire thousands of people through many The Arc trainings she created. Without Janet's hard work and willingness to help, The Arc would not be the advocacy and support organization it is today. I consider it my honor to have been able to work, learn and grow from her experience. Congratulations Janet on your retirement! I am so happy to celebrate you with The Arc Family. ~ Meg Cooch

Janet Donahue epitomizes all that The Arc represents. Her sincere belief of The Arc's core values has enabled her to embark upon a career with great distinction. It has been my pleasure to call her a dear friend and valued colleague. Her retirement is well earned and I wish her the very best. Well done, Janet! ~ Tony Paulauski

Ianet.

Thank you for ALL of your hard work. Wishing you a wonderful and relaxing retirement! ~ Rocio

Janet, It has been a pleasure working with you during my short time with the Arc. Your ability to manage complex needs will be greatly missed but I also want to wish you the very best in your new venture! Hope to see and hear from you in the future. ~ Trou

Janet – Congratulations on your many years of service to The Arc of Illinois, but especially to the individuals and families we support. Your work has impacted so many lives for the better. I will never forget the first time I saw you at Speak Up and Speak Out and I realized how much your heart was truly in everything you do. Blessings and good wishes on the road ahead! -

~ Katherine



Arc Family Support Network

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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 of The Third Baptist Church of Chicago for our continued relationship in reaching the underserved community.

Unfortunately, in 2021 due to COVID-19 restrictions we had to host our 9th FSN/Ligas Informational Seminar online. We are eagerly looking forward to the day when we can safely resume this event in person at the Heritage Banquet Facility.

Through this partnership utilizing the Heritage Plaza Facilities, we have been able to bring sources to the South Side of Chicago. Over the past several years prior to the pandemic we have shared resources with thousands of families, individuals and self-advocates. Looking forward to better days! Non-Profit Org. U.S. Postage **PAID** Permit No. 28 Tinley Park, IL

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.