

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

Hello Family Support Network and Friends!

As we close out the year, the Family Support Network (FSN) is filled with excitement and gratitude for the incredible momentum of collective advocacy that is upon us. On May 16, 2024, our FSN Director joined a committed group of self-advocates, families, allies, educators, professionals, service providers, government officials, and directors in "Engage Illinois" - a pivotal effort to redesign how Illinois supports its citizens with disabilities in living a full life in the community.

While there is still so much work to do, we are grateful that the final budget was signed by the governor in early June. This budget adds about \$400 million to the proposed budget announced by the Governor in February. The additional \$400 million includes a wage increase of \$1 per hour for ID/DD community based Direct Support Professionals, additional funding for summer youth and after school programs, additional funding for domestic violence programs and a pay raise for community care programs. (Read more in Phil Milsik – legislative update)

FSN remains grateful for our incredible, ongoing partnership with families across the state. One of the top concerns that families who self-direct their services continue to share with us is the impact that "decreasing purchasing power" is having on individuals using Home-Based Services.

When rates for services are increased on the Provider side, it decreases the ability of individuals to purchase services because the formula for HBS is set in statute and the dollar amount in the individuals' budget does not change to match the rate increase. FSN is keeping a close eye on this concern and looking for ways to advocate for change.

We continue to work together with families to advocate, explore, and connect around the needs and interests of families in the developmental disability system in Illinois. In collaboration with our community partners, programs of The Arc of Illinois, and FSN staff, we have kept our focus on our core goals of keeping families together, empowering caregivers, improving support options, encouraging family participation, and making a positive difference within the disability community.

Our 12th Informational Seminar in March was a great success. We were deeply gratified by the turnout and the lively participation of attendees. Experts in the disability field shared their knowledge regarding the Ligas Consent Decree, Future Planning, family stories and key updates were shared by Director Tonya Piephoff from the Division of Developmental Disabilities. We are grateful for the many professional partners who allow us to provide engaging and vital information year after year. Mark your calendars, as we anticipate another fantastic event in the Spring of 2025.

As we look ahead to the new year, we are filled with a renewed sense of purpose and determination. With your continued partnership, we will build upon the momentum of 2024 and work tirelessly to create a more inclusive and accessible Illinois for all.

Thank you for your unwavering dedication to the Family Support Network and the individuals and families we serve. Your compassion and commitment are truly inspiring, and we are honored to have you as part of our community. Connect with us online at [Family Support Network | Arc of Illinois Disability Assistance & Support \(thearc.org\)](https://thearc.org/family-support-network).

All the Best,
Shirley Perez
Family Support Network/Family Advocate Program Director

June 2024



Shirley Perez

Family Support
Network/Family
Advocate Program
Director

The Arc of Illinois

"One of the top concerns that families who self-direct their services continue to share with us is the impact that "decreasing purchasing power" is having on individuals using Home-Based Services (HBS). When rates for services are increased on the Provider side, it decreases the ability of individuals to purchase services because the formula for HBS is set in statute and the dollar amount in the individuals' budget does not change to match the rate increase."

Special Interest Articles

Message from The
Arc of Illinois Board
President.....2

Illinois Life Span
Program.....3

Family Advocate
Program
.....5

Family Transition
Project.....12

Legislative
Update.....19

Message from The Arc of Illinois Board President



Kimberly Johnson

Board President of
The Arc of Illinois

After an extensive search process led by members of the Executive Committee, we are pleased to announce that Samantha Alloway has been selected as Executive Director, beginning June 16, 2024. We are confident that the organization's success and impact in achieving its mission and vision will continue to flourish under her leadership.

Please join us in welcoming Samantha!

Samantha M. Alloway is an accomplished and influential leader, known for her expertise in government relations, advocacy, and human services.

In her most recent role as Director of Government Relations for the Little City Foundation, Samantha demonstrated exceptional leadership skills.



Samantha Alloway

She led cross-functional teams and effectively aligned policy strategies and services to benefit the community. Samantha is also a member of the Illinois Women's Institute for Leadership Training Academy, class of 2024. This prestigious membership highlights her commitment to personal and professional growth, and it positions her as a promising leader with a forward-thinking mindset for the state of Illinois.

Samantha has served as a CASA/GAL for Kane County, advocating for the rights of children in the foster care system. Additionally, she has worked as an advocacy coordinator and operations manager at Lazarus House, providing support to unhoused individuals. Samantha is also a certified Domestic Violence and Sexual Assault advocate through the Illinois Coalition Against Domestic Violence.

Academically, Samantha has excelled in her studies. She holds a certification in legal justice studies and achieved a remarkable 4.0 GPA, ranking in the top one percent of her class at Rasmussen University. Furthermore, she earned a Bachelor of Arts in Communications and Sociology from Northern Illinois University.

As a mother of three sons, Samantha encountered a pivotal moment when her middle child was diagnosed with Autism Spectrum Disorder at the age of three. This deeply personal experience has driven her to become a passionate advocate for disability rights. She has emerged as a highly effective and influential communicator, successfully engaging with families, participants, and legislators at both the federal and state levels. Her journey is a testament to resilience and triumph, having overcome cancer and becoming a lead canvasser for the American Cancer Society. This experience ignited her passion for advocacy and politics.

Born on the North side of Chicago and a lifelong resident of Illinois, Samantha has a deep connection to this state, and true passion and commitment to the I/DD community. Her unwavering belief in the power and possibility of change makes her an exceptional motivator. In this role, her mission is to revive determination and unity throughout our industry, while expanding The Arc's mission across the state of Illinois!

Thank you,
Kimberly Johnson
Board President, The Arc of Illinois



**Rocio Perez,
MSW, LCSW**

Director of
Illinois Life Span
The Arc of Illinois

The Illinois Life Span Program is the Information and Referral division of The Arc of Illinois. We cover a wide range of topics and find our passion in helping families navigate these services. We also work closely with other Arc programs such as the Illinois Family to Family Health Information Center (F2FHIC) and the Family Support Network (FSN) to offer seamless service to families who may have questions that require a deeper dive with complex support or medical needs.

The Illinois Life Span team is made up of Rocio Perez, Director of Illinois Life Span, and three regional Information and Resource Specialists: Tiffany Steinhauser in Central Illinois, Suzanne Aaron in Northern Illinois, and in November 2023 we welcomed our newest team member Vicki Borlin, from Southern Illinois. Faye Manaster remains a vital part of our team and provides information and research for our team and our callers. Our regional coverage allows each team member to become familiar with local resources in their area. Tiffany, Rocio, and Suzanne are certified Community Resource Specialists for Aging and Disabilities (CRS-AD) through the Alliance on Information and Referral Systems (AIRS).

Some of the questions we answer include guardianship options and alternatives, how to apply and keep federal and state benefits such as SSI/SSDI & Medicaid Waivers, how to apply for the PUNS, getting respite, what services cross state lines if moving to a new state with a loved one with disabilities, and how to connect with a special education advocate. If we are not able to answer your question, we refer you to the program within The Arc of Illinois or the outside agency/office that can help.

We provide this assistance in several ways. Our statewide Helpline, (800) 588-7002, is staffed Monday through Friday. You can also contact us through our website, www.illinoislifespan.org to submit your question. Our staff also maintains an online Resource Directory, updates an Events calendar, and develops fact sheets on several topics.

In collaboration with F2FHIC, we help Illinois families and professionals stay up to date on important and timely topics through our monthly online seminar series. These services are all offered free of charge, thanks to funding from the Illinois Department of Human Services/Division of Developmental Disabilities.

As of April 30, 2024, Illinois Life Span has responded to 1,000 inquiries this fiscal year, which includes phone calls, emails, and responses after outreach events. We have participated in 48 in-person community outreach events and have hosted 13 webinars. We updated the popular Comparison of Adult Medicaid Waiver Programs DDD v DRS Fact Sheet (which is available in English and Spanish) and have added two new Fact Sheets to our resources: Grief Resources for People with IDD, and Puberty & Adolescence Resources for Individuals with IDD (also available in English and Spanish). To date, 33,100 individuals have been touched by the Illinois Life Span Program via our website, our helpline, and webinars we have hosted.



**The Arc Fact
Sheet Book**

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



**Folleto de Hojas
Informativas de The Arc**

ESCANEAR EL CODIGO QR PARA RECIBIR
EL FOLLETO EN SU TELEFONO





Tiffany Steinhauser, M. Ed

ILS Info & Outreach Specialist

Tiffany joined the ILS team in September of 2022 as Information & Outreach Specialist for Central Illinois. I enjoy my work at The Arc for different reasons than most. She states, "I am a 24-year veteran special education teacher that left the full-time classroom in May of 2022. I knew I needed to help our desperate parents and families in a different way than teaching in a classroom would allow." Tiffany says, "The connections I make with

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



Vicki Borlin

ILS Info & Outreach Specialist

Vicki joined the team in November 2023 as a mom and an advocate and have been trained by the most knowledgeable people in the world of disability services in the state. She states, "Being an outreach specialist has been the most rewarding job I have ever had. Navigating the world of therapies, IEPs (Individualized Education Programs), evaluations, and transition to adulthood can be lonely."

Vicki says, "With The Arc of Illinois and the incredible knowledge of the ILS team, I feel I can tell people they do not have to navigate the disabilities world alone. In my personal life, I know so many parents of, and people with disabilities, and this position allows me to help people I care about. I love helping people who call or write to us for advice, and I look forward to learning more each day."



Suzanne Aaron

ILS Info & Outreach Specialist

Suzanne joined the ILS team in July 2021 as the Information and Outreach Specialist for Northern Illinois.

She states, "It is my calling and my life's passion to help people navigate the world of disability services. I understand firsthand how overwhelming, confusing, and complicated it is.

Being able to answer a question, provide a resource (or several) and simply listen is one of the most satisfying parts of my job." She says, "I am truly humbled to have the opportunity to assist families, caregivers, self-advocates, and professionals by directing them to the services that are available to support them. The depth of knowledge that is within this team and the entire staff of The Arc of Illinois means that help is just a phone call away."

Suzanne has worked in the disability advocacy and family support field since 2008 and is a 2018 graduate of Illinois' Partners in Policymaking. She has also navigated disability services in Indiana, Ohio, and Illinois. She has a special understanding of moving services across state lines. Suzanne is also navigating the Transition to Adulthood years currently, and she has a special interest in this area!



Faye Manaster, M. Ed

ILS Info & Outreach Specialist

Faye has been with The Arc of Illinois for over 13 years. Her unique qualifications include over forty years of professional experience in the areas of special education, family support, early intervention, and public health. Faye is the parent of an adult daughter who is deafblind and has cerebral palsy. She became involved as a volunteer with Family Voices, Inc., Family to

Family's national umbrella organization, in 1992 based on her experiences as the parent of an uninsured child with multiple special healthcare needs.

The Family Advocate Program (FAP)

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

For the last ten years, The Arc of Illinois has developed and managed the Family Advocate Program, meeting all program goals while growing the program into a support system that educates and supports families and self-advocates who have received Early Notification for an anticipated PUNS selection, those who received an invitation to apply for the Medicaid Home and Community Based Waiver, and those who have experienced difficulty/barriers in accessing required supports and services. The FA program workload has increased due to the second year of the DDD selecting children from the PUNS list. We are excited about these selections and hopefully continued selections into the future. The FA Program is working with the division to address the need for additional funding to meet the need of the increased demands of the program. Additional resources will allow the FAP to continue to provide accessible programs focused on assisting Ligas Class Members and their families in understanding the state requirements and benefits before, during, and after a PUNS selection.

As a bilingual program, the FA Program connects with self-advocates and families in several ways, including written invitations be a part of our community, one-to-one consultations, closed-captioned online

trainings, monthly Know Your Options webinars, follow-up communications, distribution of our newsletter (News You Need to Know), bulletins, and updates from DHS/DDD. Furthermore, we will continue to tailor educational resources to the individual needs of each family we serve. Marketing materials will be available in both English and Spanish. Families for whom technology is a barrier we offered phone consultations, correspondence via US Postal Service, and in-person meetings as appropriate.

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

As we move into the summer of 2024, we look forward to partnering with over 1,101 families who will receive invitations to apply for Adult Wavier Services; and individuals selected to apply for the Children Support Wavier. We will continue to find creative ways to connect with families, conduct training online and in-person, share updated information, and manage concerns raised.

Ligas Reach

- Facebook: 19,100
- Website users: 2,809
- Sessions: 4,096
- Page views: 4,617
- Letters to Individuals who receive Early PUNS Notification Recipients: 2,024
- Number of Consults, Webinars/trainings/Online events: 90
- Telephone calls: 2,500

Contact info for The Arc Family Advocate Program:

Shirley Perez
Director
Shirley@thearcofil.org

Ruth Aguilar
Senior Northern FA
Ruth@thearcofil.org

Annie Bruno
Central/Southern FA
Annie@thearcofil.org

Shakari Asbury
Chicago, Southwest FA
Shakari@thearcofil.org

Senior Family Advocate



Ruth Aguilar,
QIDP
Senior Family
Advocate

As a Senior Family Advocate, Ruth is deeply inspired by the opportunity to empower families and make a meaningful difference in their lives. Over the past year, she has been humbled by the privilege of working alongside the incredible team at The Arc, building invaluable interagency partnerships, and participating in over a hundred events to connect families with the information and resources they need.

The most rewarding aspect of her role is the personal satisfaction she derives from the appreciation expressed by the families she has had the honor of supporting. Witnessing the impact of her work and the difference it makes in the lives of those she serves is truly what drives her forward.

Looking ahead, Ruth is particularly passionate about expanding the Hispanic outreach efforts. She recognizes the significant gap in services for underserved communities, and she is committed to breaking down language and cultural barriers to ensure that all families have access to the support they deserve. If you share this vision, you are welcome to reach out so that we can collaborate on innovative strategies to empower minority communities and make a lasting impact.

Español

Como defensora principal de la familia, Ruth está profundamente inspirada por la oportunidad de empoderar a las familias y marcar una diferencia significativa en sus vidas. Durante el año pasado, se sintió honrada por el privilegio de trabajar junto al increíble equipo de The Arc, construir asociaciones interinstitucionales invaluable y participar en más de cien eventos para conectar a las familias con la información y los recursos que necesitan.

El aspecto más gratificante de su función es la satisfacción personal que obtiene del aprecio expresado por las familias a las que ha tenido el honor de apoyar. Ser testigo del impacto de su trabajo y la diferencia que marca en las vidas de aquellos a quienes sirve es realmente lo que la impulsa hacia adelante.

De cara al futuro, a Ruth le apasiona especialmente ampliar los esfuerzos de extensión a los hispanos. Ella reconoce la importante brecha en los servicios para las comunidades desatendidas y está comprometida a derribar las barreras lingüísticas y culturales para garantizar que todas las familias tengan acceso al apoyo que merecen. Si comparte esta visión, puede comunicarse para que podamos colaborar en estrategias innovadoras para empoderar a las comunidades minoritarias y lograr un impacto duradero.

Central/Southern Family Advocate



Annie Bruno,
LCSW, QIDP
Family
Advocate

Annie joined The Arc of Illinois in September 2023 as the Central & Southern Illinois Family Advocate. Since her start, Annie has provided 1:1 personalized consultations with over 160 families, including those that have received Early Notification letters and PUNS selection letters. It is evident that the Family Advocate program fills a specific niche in the system – serving as a sounding board and cheerleader throughout the ups and downs of securing services for individuals with I/DD.

Families are seeking connection and understanding as they navigate an incredibly complex and challenging system. As a Family Advocate, Annie serves as a vital partner to families in this process, mediating concerns and answering complex questions. Through collaboration with, and support from, the Independent Service Coordination agencies, Annie has worked with families to alleviate barriers and support the needs of individuals with I/DD.

Central/Southern Family Advocate

Our Family Advocate presentations (including our monthly Know Your Options webinars) and outreach events have fostered a connection for many families and professionals with The Arc of Illinois. Annie has presented to parent groups and fellow professionals on her new role at The Arc, what services we can offer, and specific hot-button topics like the Children's Support Waiver. Annie was grateful to have the opportunity to present at the Autism Society of Southern Illinois's Annual Conference in Carbondale this year, creating several new connections.

Annie says, "It is with immense awe and admiration that we say thank you to the families that are working tirelessly to better the world for their loved one. We are honored to be in your corner."

Someone You Should Know



Annie Bruno resides in Champaign, Illinois where she was born and raised. She began working with individuals with disabilities at a young age, serving as a peer mentor in the adapted P.E. class in high school. Annie went on to attend the University of Illinois at Urbana-Champaign, where she graduated with both her bachelor's and her master's degrees in social work. During her time at U of I, she held a leadership position in the student chapter of Best Buddies and completed semester-long internships at both the Autism Program, as well as a therapeutic school for children with autism. Annie's first professional role was serving as a Service Facilitator through the Home-Based program at a local disability provider agency. She went on to work as an ISC (Independent Service Coordinator) for many years, eventually supervising a team of 10 full-time staff covering four counties.

Annie is grateful to have landed at The Arc of Illinois, an organization she has held in high regard for many years. In her free time, Annie enjoys being outdoors with her husband Josh and her dog Sprout. She craves a summer day at the beach, cooking with fresh veggies from the garden, and seeing a new movie in theaters (with popcorn, of course).

Contact info for the Family Advocate Program:

Shirley Perez
Program Director
Shirley@thearcofil.org

Ruth Aguilar
Senior Family Advocate
Ruth@thearcofil.org

Annie Bruno
Family Advocate
Annie@thearcofil.org

Family to Family Health Information Center



**Susan Agrawal,
PhD**

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

You may have seen the meme showing a parent of a child with a disability falling in a hole. She gets a wide range of unhelpful advice from doctors, state agencies, and charities on how to get out of the hole. But it is the response from another parent of a child with a disability that is most useful: "I'm here! I'm coming down there with you. I've been here before. I know how to get out and I won't let you do it alone."

That is the premise of Family-to-Family. We are family members of individuals with disabilities or serious medical conditions, as well as experts on disability and medical systems. We understand because we have also lived it. And we want to help you because we know how challenging it is.

The Family-to-Family (F2FHIC) Health Information Center is a program for children from birth through age 21 with disabilities and special healthcare needs that is housed at The Arc of Illinois. We also serve as the state affiliate for Family Voices. Each state has a Family-to-Family as part of a grant from the Health Resources Service Administration, Maternal and Child Health Bureau. Illinois' program was one of the first in the nation and has been in operation since 2006.

The heart of the F2FHIC program is assisting families of children with any type of disability or chronic medical condition to navigate healthcare and disability systems. We provide one-to-one consultations with families via phone, email, Zoom, and messaging. We also provide the same assistance to professionals who care for this population of children.

The past year brought many changes to the F2FHIC here in Illinois. Director Mary Dixon retired after many years of assisting families across the state. We wish her all the best in her retirement! Susan Agrawal began training in the fall and took over as director in the new year.

Susan's background includes lived experience with her daughter Karuna, who had multiple disabilities and passed away at age 11. She brings with her a wealth of knowledge about children who are medically fragile or technology dependent, as well as special expertise in children's Medicaid and Medicaid waivers.

In addition to individual assistance, F2FHIC provides training through webinars, outreach events, and other presentations. F2F continues to host joint webinars with Illinois Life Span on a wide range of topics including Siblings, Secretary of State Services, Domestic Violence, Developmental Pediatricians, Shirley Ryan Ability Lab, WIPA, Adapting the Holidays, Sexual Abuse Prevention, Act Early, REV UP Voting for People with Disabilities, and the Illinois Assistive Technology Program. F2FHIC also hosted a virtual healthcare conference in the fall with presentations on Medicaid benefits and redeterminations, health benefits for immigrants, SSI and SSDI, Medicaid managed care, Medicaid waivers, and the ACA Marketplace.

We were delighted to meet lots of families at outreach visits to Chicago and suburban schools and at the Chicago Autism Expo. We presented trainings or presentations for LaRabida Children's Hospital, Illinois Disability Rights Coalition, Association of Maternal and Child Health Programs Bridges Podcast, Illinois Spina Bifida Association, The Arc of Illinois Annual Convention, Family Voices National Convening, and to several state and federal legislators.

Family to Family Health Information Center

Part of the F2FHIC program is staying up to date on state/federal policy and advocating for children with disabilities. In this capacity, we participated in three broadcast news stories, reviewed documents for the American Academy of Pediatrics, evaluated a behavioral health algorithm through Google for the state of Illinois, partnered with Legal Council for Health Justice on individual and systemic legal changes for children, and worked with the Division of Specialized Care for Children to provide direct assistance to children with home nursing care. We regularly attend state meetings and partner with other advocacy organizations to make sure the family voice is always included.

Our ongoing advocacy efforts include pushing state plan Medicaid to provide personal care services to children, improving the Medically Fragile Technology Dependent (MFTD) waiver, advocating for children in Division of Rehabilitation Services (DRS) waivers, promoting waitlist reductions, and increasing the availability of autism services.

Finally, our webpage received a fresh look with many new resources added. We have also livened up our presence on social media. Take a look at our [webpage](#) and [Facebook page](#) and let us know how we can improve even more!

We look forward to serving more children, families, and professionals in the next year. Please let us know how we can assist you!

Email: Susan@thearcofil.org

Phone: 1-866-931-1100 or

1-815-464-1832 x1017

Español: 800-588-7002

Congratulations, Mary Dixon, JD!



In December 2023, we wished farewell to the former Director of the Family to Family Health Information Center, Mary Dixon, JD. While we are excited for Mary's next chapter, we will miss her cheery disposition, willingness to collaborate, and ability to dig into complex issues. We are grateful to Mary for her 5 ½ years of service at The Arc of IL supporting people with disabilities and their families and wish her all the best in retirement!



Going Home Coalition



**Carole Rosen,
M.A.I.D., C.A.P.S.**

Going Home
Coalition Manager

REV UP Illinois

As its mission states, [Going Home Coalition](https://www.goinghomeillinois.org/)¹ (GHC) continues to, “advocate to create systems change, transition away from institutional living through increasing community capacity, and empower fair and equal choices and opportunities for people with intellectual and developmental disabilities.”

Within the last year, the Coalition has grown its diverse membership base from 50 to over 300 statewide participants and continues to welcome new members. We are comprised of self-advocates, family members, non-profit members, service provider agencies, consultants, universities, allies, and other advocacy organizations and have greatly expanded our outreach.

[Come join us!](#)² Going Home Coalition's advocacy continues meetings with legislators, state organizations, and leaders with government oversight. This past year included Going Home Coalition meetings with Senator Julie Morrison, Equip for Equality's Laura Miller and Stacey

Aschemann; Office of the Inspector General, Inspector General Charles Wright, 708/377 thought leaders; Lynn Canfield, Mike Murray, Vicki Niswander, and Dr. Kim Fisher, DDD/IDHS staff – First Assistant Deputy Governor Ryan Croke, Chief of Staff Meg Cooch, Director of The Division of Developmental Disabilities Tonya Piephoff, and Sarah Myerscough-Mueller, HFS Senior Advisor for Long Term Care.

Going Home Coalition continues to present at Arc of Illinois events, webinars, and radio programs and provided resources for the CBS documentary, [“No Place Like Home: People with Disabilities' Fight to Stay Out of Institutions.”](#)³

Earlier in Spring, Going Home Coalition launched a 9-module [legislative advocacy series](#)⁴ which will be rerun in the Fall. Over 60 Going Home Coalition members have indicated interest in meeting with their legislators! Going Home Coalition continues to advocate for the remaining [1,603 residents](#)⁵ in institutions to be transitioned into community residential settings. GHC advocated for raising DSP wages which has now been written into the budget as a \$1.00 per hour increase starting in January of 2025.

Upcoming meetings will explore the development of innovative, supportive, diverse, and inclusive housing alternatives to group homes, shortening the amount of time spent on wait lists to receive critical services, redirecting and/or increasing investments from the state to IDD community supports from funds earmarked for SODCs, and mitigating the risks of re-institutionalization for those with IDD living in the community.

Going Home Coalition acknowledges with gratitude member organizations, participants, and additional contributors who graciously and generously donated this past year and participated in our first virtual comedy fundraiser with Patti Vasquez, Pamela Schuller, and Tina Friml. We are also tremendously appreciative of continuing funding through The Coleman Foundation. Going Home Coalition has also been awarded funding through The Grassroots Project administered by Human Services Research Institute (HSRI) with funding from the Administration for Community Living (ACL) Grassroots Project to continue our much-needed advocacy work.

Your Advocacy Matters!

Most Sincerely,

Carole Rosen

Going Home Coalition Manager

<https://www.goinghomeillinois.org>

¹ <https://www.goinghomeillinois.org/>

² <https://www.goinghomeillinois.org/join-us/>

³ <https://www.youtube.com/watch?v=N3sQ4-Bkdac>

⁴ <https://www.thearcofil.org/legislativewebinarseries/>

⁵ <https://www.dhs.state.il.us/page.aspx?item=82095>



REV UP Illinois

REV UP Illinois' mission is to build the power of the disability vote through increasing civic engagement in the disability community and improving the accessibility of elections.

REV UP stands for “Register, Educate, Vote, Use your Power!”

The Coalition, comprised of individuals and organizations will offer participants opportunities to engage in presentations on voter education and registration, voter registration events, polling place accessibility audits, dissemination of accessible voting information, and other grassroots initiatives to empower the disability vote.

In 2023, REV UP presented over 2 dozen in-person and virtual statewide events for transition programs, parent's groups, day service programs, and The Arc of Illinois' events such as the Speak Up and Speak Out Summit (SUSO).

Presentations in state operated developmental centers have created ongoing success in registering people to vote and getting resident's other important documents in order. This year, REV UP Illinois has been present at the IDHS Community Resource Fairs in the Choate, Murray, Ludeman, Kiley, and Shapiro State Operated Developmental Centers and will be on-site at upcoming events at Mabley, and Fox.

Enthusiastic attendees of Chicago's 2023 Disability Pride parade were excited to pose with REV UP signs, including a group photo with Chicago [Mayor Brandon Johnson](#). The Arc of Illinois's 2023 REV UP grant extensively expanded its breadth of outreach. Data estimates that more than 260,000 people had access to voting information through presentations and radio interviews.

This year, REV UP Illinois participated in The Arc of Illinois 2024 Annual Conference and presented at the on-site The Arc of Illinois Executive Forum Leadership Conference. We were also on-site for the Special Olympics Summer Game, and Chicago Abilities Expo. REV UP Illinois will also participate in this summer's Chicago Disability Pride Parade.

This year, Disability Voters Right Week (DVRW) will take place September 9th through 13th, 2024. Highlights of last year's Disability Voters Rights Week included proclamations by [Governor Pritzker](#) and Chicago Mayor Brandon Johnson. The pictures taken at last year's Disability Pride Parade were edited into a [video](#) for DVRW and used on The Arc of Illinois's and Going Home Coalition's social media platforms. Illinois State Board of Elections also partnered with The Arc of Illinois around Disability Voter Rights Week creating a bilingual [accessible voting resource guide](#).

Reach out to admin@thearcofil.org to participate in REV UP Illinois activities and access disability voting resources! We'll include you in our upcoming REV UP Illinois kickoff meeting.

Take the words of American activist Fannie Lou Hamer to heart when she said, “If you don't vote, you don't count.”

Your Vote Matters!

Most Sincerely,
Carole Rosen
REV UP Illinois

<https://www.goinghomeillinois.org>

Carole@thearcofil.org

815-464-1832 x1027

The Family Transition Project Annual Update 2024



Greg Walkington

Director of
Family Transition
Project
The Arc of Illinois

The Family Transition Project (FTP) supports individuals with I/DD (intellectual and developmental disabilities) and their families undergoing transitions from state operated developmental centers (SODCs) into the community. We believe these individuals deserve to be listened to with respect and compassion, offered helpful information and meaningful connections to navigate the system, and supported by other individuals and families who have had similar experiences. It is a simple vision, but one that we have found extraordinarily successful. Newer self-advocates and their families have valued the opportunity to talk with other seasoned self-advocates and family members who have already transitioned from an SODC to the community. Individuals that transitioned from an SODC can help self-advocates and their families identify barriers to community and help provide solutions. The Family Transition Project will provide support to them along their journey. If asked, we stay with them providing support even after their move.

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

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

We would like to take a moment to thank the Family Transition Projects six mentors James Elliott, Susan O'Connor, Robert Peterson, John Porter, Hector Renta, and Robert Rowley. They have all lived in SODCs and made successful transitions to the community. All six of them are active advocates for community living. They talk openly about the benefits and challenges of the transition and this authenticity is what makes their words so powerful. The Family Transition Project would not be able to do its work without their help. Their words and experiences are invaluable to the program, and they do a wonderful job telling their stories.

The Family Transition Project Annual Update 2024

The mentors have attended Community Transition Fairs and trainings at SODC's to tell their stories about community living. The mentors have made many friends participating in the SODC Transition Fairs and trainings. The Family Transition Project Director has also received several calls from people living in SODC's wanting help with issues and help to explore a transition. We have had contact with over three hundred individuals living in SODC's and want to learn more about community living. FTP staff will be participating in Transition Fairs in June and July of 2024. The Department of Human Services is planning on hosting Transitions Fairs in the future and the Family Transition Project staff will be there to share information about community Living.

We are also participating in a new organic group lead by parents called Engage Illinois. This group has gathered leadership in the field from all areas. Participating in these meetings for change are parents, the Department of Developmental Disabilities, providers, advocacy agencies, representatives from special education as well as other stakeholders.

The Family Transition Project is extremely excited about continuing our work into the future with individuals from SODC's wanting to learn about Community Living.

Please visit The Arc of Illinois' website at <https://www.thearcofil.org> and view the Family Transition Project and the Operation Welcome Home webpage. Greg Walkington, FTP Director can be contacted at Greg@thearcofil.org.

Family Transition Project (FTP)

<https://www.thearcofil.org/about-us/programs/family-transition-project/>



FTP Mentor Brochure



Operation Welcome Home

<https://www.thearcofil.org/operation-welcome-home/>



The Training Department



Becca Schroeder

Director of
Development
The Arc of Illinois

The Arc of Illinois recently held the 74th Annual Convention. The Arc of Illinois was thrilled to host this year's convention in Bloomington-Normal, IL, and still provide a virtual option. As a statewide organization, it was great to see professionals, families, and self-advocates who might otherwise not be able to attend conferences located in Northern Illinois. It was a wonderful opportunity to connect with individuals in person. We are grateful to our sponsors, exhibitors, speakers, and volunteers for sharing their time and expertise. And a special thank you to Secretary Quintero and newly appointed Chief of Staff, Meg Cooch.

We look forward to continuing to provide virtual, hybrid, and in-person events throughout the year, sharing the latest information, resources, and best practices. Stay tuned for more information next year as we celebrate the 75th Annual Convention and the 20th Annual Speak Up and Speak Out Summit.

Walk with us at the [2024 Chicago Disability Pride Parade](#) on Saturday, July 20th!



If interested in walking with The Arc of Illinois or SUSO, please contact Becca Schroeder at Becca@thearcofil.org or 815.464.1832 x1018.

Save the Dates!

Stay tuned for more information in our Event Update emails.

Virtual Events

- **Healthcare Conference** - September 2025
- **Speak Up and Speak Out Summit** - October 9-11, 2025
- **Fall Conference** - Fall TBD
- **22nd Annual QIDP Conference** - January 28, 2025
- **13th FSN/Ligas Informational Seminar** - March 2025
- **75th Annual Convention** - May 2025

Ongoing Virtual Events

- **Know Your Options (English)** - First Thursday of every month, 12:00 – 1:00 p.m. on Zoom
- **Conoce Tus Opciones! (Español)** - Cada Primer Viernes del mes a las 12 del medio día.
- **ILS & F2FHIC Lunchtime Webinar Series** - 2nd Thursday of the Month
- **Operation Welcome Home Quarterly Webinar Series**

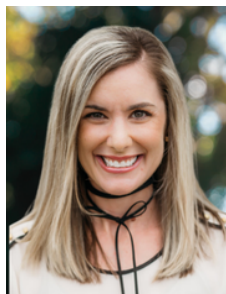




Kim Swanson
Events & Outreach Coordinator

Kim Swanson is the Events & Outreach Coordinator. Kim has previously worked at the American Cancer Society as a Senior Coordinator, supporting many events raising money for the fight against cancer, including athletic events and galas. She loves volunteering wherever needs to help make a difference.

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



Heidi Booth, MBA

Marketing & Communications Manager

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



Karin Mentzer
Office Manager

Karin is at the core of The Arc of Illinois team, providing support and guidance as the Office Manager. Karin assists families and professionals in connecting with the appropriate program of The Arc of Illinois, processes applications,

and notifies all recipients of the assistive technology and consumer stipend programs, provides technical assistance with projects, manages the membership database, and assists in coordinating events and managing the webpage.

There's Strength in Numbers.

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

**Your Membership Matters!
Join Our Voice!**



The Family Support Network (FSN) Program

The Family Support Network works to uncover the resources, funding, and services needed to help people with developmental disabilities live fulfilling lives in their own homes. By focusing on the needs of both family members and individuals, we help break down barriers to clear the way for long-term success. We are staffed statewide by a Program Director, Family Liaison and Family Advocate Specialist. We are funded by the Illinois Department of Human Services, Division of Developmental Disabilities. FSN has reached and shared information to over 40,000 people, using various formats. Our reach includes families, self-advocates, providers, professionals, stakeholders and organizations state-wide. We look forward to continuing to strongly advocate for families and self-advocates in Illinois.



Troy Markert
Family Advocate
Specialist

Troy is our dedicated, well respected Family Advocate Specialist with over 25 years of experience in troubleshooting issues that families face. He continues to fill a significant 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 continue to expand, increasing the resources that can be offered to families in need of information and support. In his role, he continues to be a critical resource working with the ISCs, Division of Developmental Disabilities, and families to address and come up with solutions to very complex issues. Troy has strengthened our ability to effectively advocate on behalf of families and self-advocates. Please continue to reach out to Troy at Troy@thearcofil.org.

Family Support Network aims to: **Keep Families Together**

until the person with a disability chooses to live independently

Empower Caregivers

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

Improve Support

to families while minimizing the need and the cost of out-of-home placement

Allow family Participation

in integrated leisure, recreational, and social activities

Make a Positive Difference

in the lives of people with disabilities as well as the lives of family members



Shakari Asbury

Part-time Family
Advocate/Family
Support Assistant

Shakari is coming into her 6th year at The Arc of Illinois. Her time is split between working as an assistant in the Family Support Network Program and a part-time Family Advocate for the Family Advocate Program. In her role she connects with families daily through email inquiries, phone calls,

and in-person outreach events. FSN is always happy to investigate and advocate for individual/families in situations that may be deemed complex. Shakari participated in the 12th Annual Informational Seminar, which was a huge success! Resources were provided to families that are not always readily located when it comes to navigating the I/DD system in Illinois. Outside of the annual event FSN staff participated in the 74th Annual Arc of Illinois Convention, The Answer Inc. 17th annual walkathon and assisted in webinars for the Family Advocate Program. If you haven't done so, please be sure to sign up for our online webinars or in person conferences by visiting The Arc of Illinois website, www.thearcofil.org. Contact Shakari at Shakari@thearcofil.org.

Our Main Goals

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

The Family Support Network (FSN) Program

FSN Engagements by the Numbers

FSN has reached and shared information to over 40,000 individuals, including families, self-advocates, providers, and organizations state-wide. We look forward to continuing to advocate for families in Illinois.

- Facebook page: 9,195
- Number of electronic newsletters: 12
- Electronic newsletters reach: 24,257
- Training (one-on-one): 145
- Organizational partners: 8
- Telephone calls (approximate): 1,600
- Other outreach events/Conference: 16

Website engagement:

- Users: 2,084
- Website page views: 2,839
- Website sessions: 2,514
- Webinars/training: 32

Four State-wide Virtual events were hosted by FSN:

The first event was held on July 27, 2023, with 335 registered participants.

Home-Based Basics, Process, & Common Concerns

Derek Hedges
Medicaid Waiver Unit Manager

Mike Vespa
Department of Human Services, Division of
Developmental Disabilities, PUNS

Tasha Whiteside
Illinois Program Director, Aces\$

Shirley Perez
Director Family Support Network,
The Arc of Illinois

The second event was held on August 24, 2023, with 240 registered participants.

Derek Hedges
Medicaid Waiver Unit Manager
Updates for Families new to
Home-Based Supports

Shirley Perez
Director, Family Support Network,
The Arc of Illinois

The third event was held on September 13, 2023, with 210 registered participants.

Tasha Whiteside
Illinois Program Director,
ACES\$ Services: Navigating Payroll
and EVV

The fourth event was held on March 26, 2024, with 475 registered participants.

12th FSN/Ligas Informational Seminar featuring:

Keynote:
Tonya Piephoff, Director,
Division Developmental
Disabilities

Brian Rubin, JD, Rubin Law
Benji Rubin, JD, Rubin Law
Ruth Aguilar, QIDP, Family Advocate
and Family member
Laura Miller, Equip for Equality
Ronnie Cohn, Ligas Court Monitor

Kimberly Johnson, The Arc of
Illinois Board President
Tasha Whiteside, Illinois Program
Director, Aces\$
Scott Nixon, Life's Plan Inc.

Thank you Sponsors, Exhibitors, and Donors of The Arc FSN/Ligas 12th Informational Seminar



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



The Answer, Inc - 501(c)(3) not-for-profit organization, provides support, resources, education, recreation, and advocacy for families in the greater Chicago area that are challenged with supporting family members with Autism & Developmental Disorders. In addition to providing essential resources & services for parents and caregivers, our agency strives to help contribute to the continued growth, educational and recreational inclusion for the children and relatives specifically impacted.

<https://theanswerinc.org/mission>



Chicagoland Autism Connection - 501(c)(3) not-for-profit organization is a volunteer family wrap-around support group that provides resources and events for the entire family. Through our support group meetings, trainings/workshops, and social/recreational events our organization is committed to "Building Community" for individuals living with ALL disabilities in underserved communities. Chicagoland Autism Connections supports the Chicago proper area and the surrounding suburbs.

<https://www.chicagoautism.org>



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

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



The Department of Human Services is one of Illinois' largest agencies, with more than 13,000 employees. Illinois created IDHS in 1997, to provide our state's residents with streamlined access to integrated services, especially those who are striving to move from welfare to work and economic independence, and others who face multiple challenges to self-sufficiency. IDHS is proud of its diversity, efficiency, and the services that the agency and its community partners provide to Illinois citizens.

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



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

Congratulations to all of the 12th FSN/Ligas Informational Seminar Winners:

First Family Member to Register

Ali and Saeedeh Bagherian
(Coach Male socks & Coach hand bag)

First Professional to Register

Tracy Hellner
(Kate Spade bag & earrings)

First Self-Advocate to Register

Curtis Harris
(\$50 Gift Card)

Trivia Winners

Rebecca Curran
Nickie Myers
Brittnei Monreal
Ryan Mueller
(\$50 Gift Cards)
Morgan Sanders
(Coach bag & earrings)

Organization with the most Registered Professionals

Envision Unlimited
(Kate Spade purse & Belle bag)

Door Prize

Rosario Carrillo
(Vera Bradley blanket and umbrella)

Legislative Advocacy Update



Sabrina Wyman

Advocacy
Legislative
Coordinator

What another great year of legislative advocacy at The Arc of Illinois! We had a record number of respondents to our annual public policy priorities survey, allowing us to better understand and advocate for families and individuals with disabilities throughout the state.

This information allowed the Public Policy Committee (PPC) to create our 2024 priorities. The PPC meets every other month outside of session and monthly during the Spring Legislative Session. We provide up-to-date information on legislation that we are watching. The PPC and our entire advocacy membership were incredibly active in their efforts this past Spring, filling out witness slips and contacting their legislators. Our advocacy team met weekly with the They Deserve More Coalition regarding an increase in pay for Direct Support Professionals (DSPs). We are thrilled to have received a \$1 an hour wage increase for DSPs.

The Arc of Illinois, along with many other advocacy organizations and self-advocates, worked tirelessly to pass the Dignity in Pay Act and phase out subminimum wages. While the Dignity in Pay Act did not end up passing both houses, we made significant progress this Spring and passed the House with a bipartisan vote. Hopefully this fall, during Veto Session, the Senate will work on the Dignity in Pay Act.

We hope to continue our growth in legislative advocacy even more in the following year.

2024 Spring Session Legislative Update with Phil Milsk

Spring 2024 Disability Legislation Summary

BILLS THAT PASSED BOTH HOUSES

The following bills passed both houses of the General Assembly and will be sent to the Governor.



Phil Milsk, JD

Legislative
Consultant

SB 251 (Sims, Gordon-Booth)-Budget Bill

Senate Floor Amendment #3 is the State Fiscal Year 2025 budget bill. Makes appropriations and re-appropriations for operating expenses, capital expenditures and other purposes for the State Fiscal Year beginning July 1, 2025. It also adjusts various Fiscal Year 2024 appropriations. The final budget adds about \$400 million to the proposed budget announced by the Governor in February. The additional \$400 million includes a wage increase of \$1 per hour for ID/DD community based Direct Support Professionals, additional funding for summer youth and after school programs, additional funding for domestic violence programs and a pay raise for community care programs.

The budget includes funding for the creation of a Department of Early Childhood, which will include the Early Intervention program, a new child tax credit that applies to children under age 12, additional funding for homelessness prevention, and emergency funding for migrant services in the Chicago area. State funds for Early Intervention were increased by \$6 million, as proposed by the Governor.
Last Action: Passed the House 65-45 on May 29, 2024.

HB 4959 (Gabel, Sims)-Budget Implementation Omnibus

Senate Floor Amendment # 2 became the State Fiscal Year 2025 Budget Implementation bill ("BIMP"). This is an omnibus bill that makes various statutory changes that align with the implementation of the new budget. This bill includes language authorizing a \$1 per hour wage rate increase for direct support personnel and other frontline personnel for community-based providers serving people with intellectual or developmental disabilities. The new rate is subject to federal approval of any relevant Waiver amendment and applies to services provided on or after January 1, 2025. At least 75% of the funds must be provided as a direct base wage increase. The remaining 25% may be used flexibly by providers for base wage increases. (See, HB 4959, Senate Amendment #2, pp. 40-41). Last Action: House Concurred with Senate Amendments 1 and 2, 62-46 on May 29, 2025.

HB 4959 (Gabel, Sims)-Budget Implementation Omnibus

Senate Floor Amendment # 2 became the State Fiscal Year 2025 Budget Implementation bill ("BIMP"). This is an omnibus bill that makes various statutory changes that align with the implementation of the new budget. This bill includes language authorizing a \$1 per hour wage rate increase for direct support personnel and other frontline personnel for community-based providers serving people with intellectual or developmental disabilities. The new rate is subject to federal approval of any relevant Waiver amendment and applies to services provided on or after January 1, 2025. At least 75% of the funds must be provided as a direct base wage increase. The remaining 25% may be used flexibly by providers for base wage increases. (See, HB 4959, Senate Amendment #2, pp. 40-41). Last Action: House Concurred with Senate Amendments 1 and 2, 62-46 on May 29, 2025.

SB 3268 (Aquino, Gabel)-Medicaid Omnibus

This is the omnibus Medicaid bill that represents the session-long work of the bipartisan Medicaid Working Group. Last Action: Passed both houses on May 26, 2024.

The legislation includes the following:

- Creates a 24-hour CILA per diem reimbursement for up to 20 days when a resident is temporarily absent due to medical treatment or for other medical reasons such as hospitalizations or admission into a rehabilitation facility or nursing home that have been recommended by third party medical personnel. Requires the 24-hour CILA to hold the bed for the resident during the medical absence. Begins January 1, 2025. The new per diem reimbursement is in addition to the current occupancy factor policy set by DHS-Division of Developmental Disabilities. This was an initiative of the Jewish Federation of Chicago and had been House Bill 3344 (Ness). (See SB 3268 pp. 201-202.)

- For services on or after January 1, 2025, requires the Department of Healthcare and Family Services to pay negotiated, agreed upon administrative fees associated with implementing telehealth services for people with intellectual or developmental disabilities who are receiving CILA residential services. Provides that the implementation of telehealth services shall not impede the choice of any person receiving waiver services, and requires the Department to ensure that persons or their guardians must request to opt-in, and that this must be included in the individual person-centered plan. Further provides that for people who opt in, the telehealth service shall not be used for the convenience of staff and shall not replace primary care physician services. (SB 3268 pp. 234-235).
- Prohibits prior authorization or utilization management controls under Medicaid fee-for-service or Medicaid managed care for drugs prescribed for mental illness under specified conditions. (See, SB 3268, pp. 202-203).
- Effective January 1, 2025, and subject to federal approval, increases the reimbursement rates by 7% for providers of private nursing services for medically fragile and technology dependent children. (See, SB 3268, p. 96).
- By January 1, 2025, requires the Department of Healthcare and Family Services to apply for Home and Community-Based Services State Plan amendment and any federal waiver necessary to reimburse legally responsible family caregivers as providers of personal care or home health aide services for persons who are medically fragile and technology dependent. To qualify for reimbursement a legally responsible family caregiver must be a certified nursing assistant or certified nurse aide and must provide services to a medically fragile relative who is receiving in-home shift nursing services coordinated by the University of Illinois at Chicago Division of Specialized Care for Children. (SB 3268, pp. 211-212).

HB 340 (Mussman, Villivalam)-IEP Meeting Materials

This bill changes language in the School Code currently requiring school districts to provide parents with written materials that will be discussed at their child's IEP meeting at least 3 school days in advance of the meeting. The change would require the written Notice of IEP Conference sent to the parents to include the exact date when the written materials will be provided or made available to the parents. The purpose of the bill is to address reports of frequent non-compliance with the 3 school day disclosure requirements. This was an initiative of the Legal Council for Health Justice and Access Living. Last Action: Passed both houses on May 15, 2024.

HB 5276 (Ness, Koehler)-Transition Planning/Assistive Technology Needs

The bill requires post-secondary transition planning for a student with a disability to include consideration of the student's post-secondary need for assistive technology services and devices. This is consistent with a U.S. Department of Education guidance document on assistive technology issued in January 2024. The Illinois Assistive Technology Program was the lead proponent of this bill.

Last Action: Passed both houses on May 23, 2024.

HB 5354 (Ness, Fine)- Customized Employment

Amends the Customized Employment for Individuals with Disabilities Act that was enacted in 2020. The bill would extend the Customized Employment program under the Division of Rehabilitation Services of the Illinois Department of Human Services. The program was scheduled to expire at the end of 2024. It adds a new definition of "Customized Employment" and requires implementation in compliance with standards developed by the Workforce Innovation Technical Assistance Center through a grant from the U.S. Department of Education. This was an initiative of the Illinois Assistive Technology Program with support and technical assistance from the Illinois Council on Developmental Disabilities and Marc Gold and Associates. Effective January 1, 2025.

Last Action: Passed both houses on May 16, 2024.

SB 3753 (Fine, LaPointe)-Admissions to SODCs; Progressive Sanctions

The first part of the bill addresses the conditions that must be met for a person to be admitted to a State-operated Developmental Center for persons with developmental disabilities. The conditions include: (1) the person must be at least 18 years old; (2) the person and the person's guardian, if applicable, have received, attempted to receive, or received education about community-based services and supports; (3) the person meets the intermediate care facility level of care definition; and (4) the person meets all clinical eligibility requirements including having an intellectual disability as defined in the Mental Health and Developmental Disabilities Administrative Act.

The bill further states that upon admission to a State-operated Developmental Center, the facility must complete at least annual reviews of the person's clinical need for continued services to determine whether the person's needs are able to be met in a less restrictive setting. Comprehensive and integrated assessments must be used to assist in determining the level of care and services needed by the person.

Under the bill, all persons have the right to know their service and support options and to be provided with the opportunity to learn about the full spectrum of care including the range of living options. The interdisciplinary team must assist the person and the person's guardian to identify placements that are able to meet the person's needs. The person's support plan must include services to address identified needs if the person is clinically determined to no longer meet the intermediate care facility level of care or be at risk of harm to the person or to others.

The second part of the bill provides that the Division of Developmental Disabilities of DHS may impose progressive sanctions on providers that "fail to comply with conditions specified by rule, or contract agreement, as determined by the Department." Sanctions include, but are not limited to, payment suspension, loss of payment, enrollment limitations, admission holds, removal of persons served by the provider, or other actions up to and including termination of contract, certification revocation, or license revocation.

A provider may appeal a sanction in writing to the Department of Healthcare and Family Services within 30 days of receipt of the sanction. A provider may request reconsideration of a discharge by DHS-Division of Developmental Disabilities within 10 days after receiving the written notification of discharge.

Last Action: Passed both houses May 24, 2024.

SB 857 (Fine, Katz Muhl)-DHS Office of Inspector General

This bill makes some clean-up changes to the Department of Human Services Act concerning the powers and duties of the Office of Inspector General (OIG). In addition, it requires the DHS OIG to conduct unannounced site visits to each facility at least annually "for the purpose of reviewing and making recommendations on systemic issues relative to preventing, reporting, investigating, and responding" to abuse, neglect, exploitation and material obstruction of an investigation. It requires the Inspector General to issue a written report to the DHS Secretary and the facility director including conclusions and recommendations and requires the facility to submit a written response within 45 days. Effective January 1, 2025. Last Action: Passed both houses on May 9, 2024.

SB 3201 (Toro, Kelly)-Police Training on Autism

Requires the Illinois State Police Division of the Academy and Training to provide training for State Police officers on the nature of autism spectrum disorders and in identifying and appropriately responding to people with autism spectrum disorders. The training must be made available to all ISP cadets and officers. Amends the Illinois Police Training Act to provide that the minimum in-service training requirements that a law enforcement officer must satisfactorily complete every 3 years includes training on autism-informed law enforcement responses, techniques and procedures. Requires the Police Training Standards Board to update the training from time to time to conform with national trends and best practices. Effective January 1, 2025. Last Action: Passed both houses on May 24, 2024.

HR 818 (Mussman)-Medicaid Advisory Committee

Urges the Medicaid Advisory Committee of the Department of Healthcare and Family Services to examine and make recommendations that will expand the network of Medicaid enrolled specialty providers, including, but not limited to, dentists, anesthesiologists, occupational therapists, and phlebotomists, for people with autism. The issue of Medicaid network adequacy for people with developmental disabilities was raised this year in SB 2655 (Murphy, Mussman). After SB 2655 passed the Senate and advanced out of the House Human Services Committee, this resolution was filed as an alternative to creating a new task force through legislation. Last Action: Resolution Adopted on May 24, 2024.

BILLS THAT COULD BE CONSIDERED IN VETO SESSION OR IN THE LAME DUCK SESSION

SB 458 (Walker, Mussman)-Use of Timeout and Restraints in Schools

The bill would extend until August 1, 2027, the requirement that school districts, non-public special education schools and special education cooperatives submit a report each year to the State Board of Education on the progress made toward achieving the goals and benchmarks established by the State Board on the use of isolated time out, time out and restraint. Extends until June 30, 2026, the requirement that the State Board issue a report to the General Assembly on the progress made by school districts, non-public special education schools and special education cooperatives to achieve goals and benchmarks. This initiative of Equip for Equality was a House floor vote away from passing before the Spring session ended.

Last Action: Re-referred to the House Rules Committee on May 31, 2024.

HB 793 (Mah, Harmon)- “Dignity in Pay” Act/Phase out of the Sub-minimum Wage

An initiative of the Department of Human Services with support from the Governor’s office to phase out the sub-minimum wage for people with intellectual and developmental disabilities by January 1, 2030. The bill would also increase the Personal Needs Allowance for people in CILA from \$60 per month to \$100 per month with an annual cost-of-living adjustment based on the annual adjustment for SSI benefits. This bill is very likely to be considered by the Senate during the Fall session or the lame duck session in January. Last Action: Passed the House 78-30-3 on May 23, 2024. Referred to the Senate Assignments Committee on May 24, 2024

SB 3499 (Holmes)-End-of-Life Options Act

This initiative of the ACLU of Illinois would authorize a qualified patient with a terminal disease to request that a physician prescribe aid-in-dying medication. The bill contains, among other things, definitions, procedures and forms, and describes the responsibilities of physicians. Last Action: Assigned to the Senate Executive Committee on February 28, 2024, and placed into a Subcommittee on End of Life Issues.

SB 3166 (Koehler, Ness)-School Student Records Availability

This was an initiative of the Guardianship and Advocacy Commission to make special education records permanent (destroyed after 60 years) instead of temporary (kept for 5 years). The purpose is to ensure that people seeking adult home and community-based waiver services have access to the information necessary to establish eligibility. The bill was amended in the Senate to limit it to the Summary of Performance, a document that some students with IEPs who exit high school must receive. The bill, as amended, passed the Senate, but was held up in the House due to school management opposition, concerns about privacy and other issues. We anticipate that there will be efforts to resolve the issues during the summer and fall and move the bill forward during Veto Session if an agreement can be reached. Last Action: Re-referred to the House Rules Committee on May 10, 2024.

BILLS WE MONITORED THAT DID NOT ADVANCE

HB 4613, HB 4444, SB 2758-Bills Seeking to Address the Right of Wards to Marry.

SB 2663 and HB 4275- Bills to Expand the Use of Supportive Decision-making Agreements.

Meet the Barraza Family:

An Inspiring Story of Resilience and Compassion

The Barraza family is a true testament to the power of love, dedication, and community. Led by the indomitable spirit of Jose, Anita, and their three children, Diana, Carolina, and Danny. This family has faced immense challenges with unwavering courage and resilience.

At the heart of the Barraza family are their two teenage children, Diana and Danny, both of whom have multiple disabilities. Yet, instead of letting these challenges define them, the Barraza's have embraced them, working tirelessly to ensure that Diana and Danny have access to the resources and support they need to lead meaningful, fulfilling lives.



"Their story is a testament to the power of the human spirit and a reminder that even in the face of adversity, hope and love can prevail."

Whether it's navigating the complexities of the healthcare system, advocating for their children's educational needs, or simply creating moments of joy and connection, the Barraza family approaches every obstacle with a steadfast determination and a deep well of compassion. They are always on the move, seeking out new opportunities and resources to enrich the lives of their loved ones and those around them.

What sets the Barraza family apart is their unwavering commitment to one another and to their community. They are a shining example of what can be achieved when a family comes together, pooling their strengths and supporting each other through thick and thin.





Family Support
Network of Illinois

Arc Family Support Network

9980 190th Street | Suite C
Mokena, IL 60448

Office: 815.464.1832 x1032

Phone: 708-331-7370

Email: Shirley@thearcofil.org

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

Shirley Perez, Director

Troy Markert, Family

Advocate Specialist Shakari

Asbury, Part-time Family

Advocate/Family Support
Assistant

AMPLIFY YOUR IMPACT.

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

Scan to
Join Us



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