

73RD ANNUAL CONVENTION

Reimagining Expectations

April 19-20, 2023



Wednesday, April 19, 2023
10:45 a.m. - 12:15 p.m.

“My Disability Roadmap for an Inclusive Life” **Presented by Dan and Samuel Habib**

Before Samuel Habib was diagnosed with a disability at age 1, the Habib family rarely thought about the inclusion of people with disabilities. Since then, they have advocated for Samuel’s inclusion nearly every day – in their schools, city, and even in their extended family. Now Samuel is leading the advocacy charge for his own life. Samuel, 21, is a student at his local community college in Concord, New Hampshire. In high school, Samuel was on the school yearbook staff, the school television station, and played “Unified Sports” track, basketball, and soccer. Samuel is working towards a career as a multi-media storyteller in film and other mediums. Yet he still faces challenges on many levels due to his rare GNAO1 neurodevelopmental disorder, including periodic seizures, movement disorders, hospitalizations, fatigue and the inaccessible homes of his extended family and friends. **Samuel and Dan Habib will share their new short film, My Disability Roadmap, and discuss how they have tried to build a culture of inclusion in their family, school district, and community, and plan for a full adult life as Samuel enters his 20’s.**

Thursday, April 20, 2023
10:45 a.m. - 12:00 p.m.

“Federal Policy and Individual Advocacy - A Place for All ”

Presented by Marty Ford



Marty Ford is one of the nationally recognized leaders in federal public policy affecting people with disabilities, with over 35 years of experience in long term services and supports, Medicaid, and Social Security disability issues. She has testified numerous times before Congress, has been a resource to the press, and a mentor to many throughout her years of work on behalf of people with IDD. What many people do not know is that the inspiration behind her years of tireless advocacy is her brother, Jud, and her family’s journey to support him at home when the common

recommendation by physicians was to send him to an institution. Marty will share her family’s journey to support Jud, including how this impacted her career trajectory, and how The Arc has impacted the lives of many as a result of her work. Afterward, Marty will sit down with Amie Lulinski for Q &A.

THE ARC OF ILLINOIS 73RD ANNUAL CONVENTION

WEDNESDAY, APRIL 19, 2023

8:00-9:00 am	Registration, Continental Breakfast Visit with Exhibitors, View Art Exhibit			
9:00 - 10:00 am Breakout Sessions	Session #1 (Live Streamed) Mary Dixon Rocio Perez Shirley Perez Greg Walkington <small>The Arc of Illinois</small> <i>“The Programs of The Arc: How Can We Support You?”</i> The programs of The Arc of IL can provide robust supports including education, advocacy, resource connections, and funding for technology and training. Participants will be introduced to the program components, mission, and key resources.	Session #2 Zareen Kamal <small>Start Early</small> Alison Liddle <small>M Street Pediatric</small> <i>“Equity in Early Intervention (EI): An Innovative Approach”</i> Learn about disparities children and their families are experiencing within our Early Intervention system, and efforts to increase access to services including a pilot study connecting NICU babies to EI.	Session #3 Katie Arnold <small>University of Illinois at Chicago</small> <i>“What Adults with IDD Say about Sibling Support”</i> Hear what adults with IDD have to say about the companionship, emotional, instrumental, and informational supports that they get from and give to their brothers and sisters.	Session #4 Susan Gardner Kristen Noonan Adam Rapacz Josh Vanwyk <small>Envision Unlimited</small> <i>“It’s a Beautiful Day in the Neighborhood”</i> <i>Envision Unlimited’s Neighbors Program</i> Envision Unlimited is bring Community Day Programming to a neighborhood near you. We are stretching our focus to empower our members where they live. Independence is within reach.
	Sesión #5 En Español (Transmisión en Vivo) Josephine Mueller Megan Forristall <small>Administración del Seguro Social</small> <i>“Descripción General del Seguro Social por Discapacidad Social y la Seguridad de Ingreso Suplementario”</i> La presentación brindará una descripción general del Seguro Social por Discapacidad y la Seguridad de Ingreso Suplementario (SSI), incluidos los requisitos de elegibilidad y el proceso de solicitud. La presentación también destacará los servicios en línea del Seguro Social.	Session #5 - Presented in Spanish <i>“Overview of Social Security Disability and Supplemental Security Income”</i> Presentation will provide an overview of Social Security Disability and Supplemental Security Income (SSI) including eligibility requirements and application process. Presentation will also highlight Social Security online services.		
10:00-10:30 am	Break			
10:30-10:45 am	Welcome: Leanne Mull, Board President, The Arc of Illinois (Live Streamed)			
10:45 am - 12:15 pm	KEYNOTE PRESENTATION: <i>“My Disability Roadmap for an Inclusive Life”</i> Presented Virtually by Dan and Samuel Habib (Live Streamed)			
12:15 - 2:00 pm	Lunch 1:00 - 1:45 pm PLENARY SESSION: Legislative Update (Live Streamed)			

Please visit the Annual Convention Sponsor & Exhibitor Hall

<https://www.thearcofil.org/73rd-annual-convention/>



We hope you enjoy The Arc of Illinois 21st Annual Art Exhibit & Contest.

<https://www.thearcofil.org/73rd-annual-convention/>

Browse and enjoy all the marvelous art work on display from April 13 - 20, 2023

Cast your vote on your favorite work of art! All artists will receive a ribbon and certificate!

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2:00 - 3:00 pm Breakout Sessions	<p>Session #6 (Live Streamed) Tyson Bedford William Bedford Kimberly Johnson Caroline O'Hara Kish Pisani National Disability Institute</p> <p>"The Faces of Financial Wellness"</p> <p>Learn from self-advocates and family members the impact that financial wellness education has had on their daily lives.</p>	<p>Session #7 Beth Marks Jasmina Sisirak University of Illinois at Chicago</p> <p>"Rethinking Health Promotion: Virtual Coach HealthMatters Program"</p> <p>This presentation will focus on community health promotion efforts during and after pandemic. Evidence based HealthMatters Program and a virtual delivery of the program will be discussed and ways to participate will be described.</p>	<p>Session #8 Megan Forristall Social Security Administration</p> <p>"Overview of Social Security Disability and Supplemental Security Income"</p> <p>Presentation will provide an overview of Social Security Disability and Supplemental Security Income (SSI) including eligibility requirements and application process. Presentation will also highlight Social Security online services.</p>	<p>Session #9 Carole Rosen Sabrina Wyman The Arc of Illinois</p> <p>"Systems Advocacy and the Legislative Process "</p> <p>This presentation will discuss how to: register to vote (and its importance), look up legislators, prepare an elevator speech, arrange a meeting with your legislator, and fill out a witness slip, as well as give an Illinois Session update.</p>
	<p>Sesión #10 En Español (Transmisión en Vivo) Angélica Dávila Amalia Montoya Luis Ovalle Miguel Saucedo Grupo Salto</p>	<p>"Panel de Padres y Hermanos"</p> <p>Este panel compartirá la perspectiva de padres y hermanos sobre cómo es vivir realmente con alguien con autismo. Cada uno de ellos tiene funciones, presiones y experiencias únicas para compartir. Aceptar el autismo no es fácil. Hay barreras del idioma, problemas familiares y resentimiento de ser desplazado por las altas necesidades del individuo con TEA. La expectativa de este panel es brindar información y orientación a las familias, especialmente a las de padres más jóvenes de niños con TEA.</p>		<p>Session #10 - Presented in Spanish "Parent & Sibling Panel"</p> <p>This panel will share the parent and the sibling perspective on what it is like to live with someone with Autism. Each of them has unique roles, pressures, and experiences to share. It is the expectation of this panel to give families especially those of younger parents of children with ASD information and guidance.</p>
3:00- 3:30pm	Break			
3:30 - 4:30 pm Breakout Sessions	<p>Session #11 (Live Streamed) Ron Clewer Gorman & Company Carole Rosen The Arc of Illinois Adam Wiser Illinois Self Advocacy Alliance Kim Zoeller Ray Graham Association</p> <p>"Housing: Innovative Solutions for People with Developmental Disabilities"</p> <p>Creating innovative, accessible, affordable, and integrated housing for people with developmental disabilities is one of the cornerstones for them to be living a person-centered and fulfilling life in the community. Join the panel to discuss unique options amongst the changing landscape of housing for people with developmental disabilities in Illinois.</p>	<p>Session #12 Brian Rubin Benji Rubin Rubin Law, A Professional Corporation</p> <p>"Special Needs Trusts, ABLE Accounts, Letters of Intent, and Related Topics"</p> <p>Brian Rubin, a parent, and Benji Rubin, a sibling, of Mitchell Rubin who has Autism, will present the basics of special needs' planning, including special needs trusts, ABLE accounts, selecting the future team of trustees and guardians, impact of divorce and law-suit settlements, educating the extended family, letters of intent, and many related topics.</p>	<p>Session #13 Diane Compton Parent Erin Compton Self-Advocate Susan Hoekstra SD103</p> <p>"Reimagining the IEP and Transition Process Without Intellectual Disability Bias"</p> <p>Are IEPs unintentionally preserving intellectual disability bias? A student, teacher, and parent look at the legacy of intellectual disability testing and how it is still limiting students' independence and potential.</p>	<p>Session #14 Megan Mutti The Arc of Illinois</p> <p>"Exploring Family Experience in Developmental Disability Supports"</p> <p>Families transitioning from school-based supports to adult developmental supports step into a new and complex system requiring the development of knowledge and advocacy skills different than those utilities in the school system. While the system continues to work toward improvements in quality of service, family experience remains under explored and under-utilized in systemic improvement processes. This presentation will focus on family experiences, barriers, and successes as they seek person-centered, individualized supports for their loved ones within the adult IDD system.</p>
	<p>Sesión #15 En Español (Transmisión en Vivo) Alejandra Griffet Sarah Isaacs María Esther Rodríguez Jill Tompkins Illinois Early Intervention Clearinghouse</p>	<p>"Superando desafíos: recursos para ayudar a las familias a abogar"</p> <p>Utilizando recursos e historias personales, empoderaremos a las familias para que aboguen por los servicios para los niños pequeños. Las familias se irán con información del Centro de Intervención Temprana de Clearinghouse de Illinois y los mensajes inspiradores de la madre y defensora, María Esther.</p>		<p>Session #15 - Presented in Spanish "Overcoming Challenges: Resources to help families advocate"</p> <p>Using resources and personal stories, we will empower families to advocate for services for young children. Families will leave with information from the Illinois Early Intervention Clearinghouse and the inspiring messages from parent and advocate, Maria Esther.</p>
4:30 - 5:00 pm	Visit with Exhibitors			
5:30 - 7:00 pm	<p>Awards Reception Stay and enjoy light appetizers, watch a performance, and meet other Convention attendees. The Arc of Illinois Annual Convention Awards will be presented to the winners.</p>			

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THURSDAY, APRIL 20, 2023

8:00-9:00 am	Registration, Continental Breakfast Visit with Exhibitors, View Art Exhibit			
9:00 - 10:00 am Breakout Sessions	Session #16 (Live Streamed) Claire Cook Haley Phelps <small>DSCC</small> Erica Stearns <small>The Arc of Illinois</small> "Division of Specialized Care for Children (DSCC) and Family Advisory Council" Learn more about the population served and programs offered by the Division of Specialized Care (DSCC). Leaders of the Family Advisory Council (FAC) share how centering the patient/family perspective has contributed to enhancing the experience and resources offered by DSCC.	Session #17 Sunita Patel Benji Rubin Theresa Versaci Lea Whitney <small>SIBS</small> "Our Journey through the Pandemic - Stories of Home and Survival" After two years of surviving and persevering through the pandemic we have become better and stronger advocates for ourselves and our siblings. We will share what we learned and how we can support each other no matter the challenging times we are living in. We know more than ever that siblings need support and resources. Through our stories and resources we will share how we help each other and prepare for the future. This session will be interactive, fun, and allow plenty of time for questions.	Session #18 Natasha Croff Kimberly Johnson Jada Thompson <small>National Disability Institute</small> "Financial Wellness: Credit Matters & Protecting Your Identity" Learn the basics of credit reports, what makes up a credit score, how credit profiles are used, and why credit is important. This session also covers protecting your identity and avoiding scams.	Session #19 Suzanne Aaron Ruth Aguilar Tiffany Steinhauser <small>The Arc of Illinois</small> "Answers to Transition Questions and PUNS Benefits & Resources" The Illinois Life Span Program and the Ligas Family Advocate Program receive numerous calls each year with questions about transitioning to adulthood. We will discuss those top questions and topics, and will also share information about the services available once pulled from the PUNS database.
	Sesión #20 En Español (Transmisión en Vivo) Jose Ovalle Matie Ovalle <small>Grupo Salto</small> Rocio Perez <small>The Arc of Illinois</small> "Qué Hay en el Futuro de su Hijo" Mantener unida a la familia es importante en la cultura latina/hispana. Sin embargo, llega un momento en que, de manera realista, debido a la salud o la edad, esto puede no ser posible y es un tema delicado. Únase al panel para discutir la propia experiencia de los padres, los hijos que viven separados de la familia, la planificación futura de los padres (testamentos, POA, fideicomiso para necesidades especiales), éxitos, barreras y participación de la familia extendida, si corresponde. Dar espacio para que las familias compartan sus preocupaciones y se apoyen mutuamente.			Session #20 Presented in Spanish "What's in Your Child's Future?" Keeping the family together is important in the Latino/Hispanic culture. However there comes a time, when realistically due to health, age, this may not be possible and is a sensitive issue. Join panel to discuss parental experience, their children living apart from family, parent future planning (wills, POA, special needs trust), successes, barriers, and extended family involvement, if any.
10:00 - 10:30 am	Break			
10:30 - 10:45 am	Welcome: Amie Lulinski, Executive Director, The Arc of Illinois (Live Streamed)			
10:45 am - 12:00 pm	KEYNOTE PRESENTATION: "Federal Policy and Individual Advocacy - A Place for All " Presented by Marty Ford, followed by conversation with Amie Lulinski (Live Streamed)			
12:00 - 1:45 pm	Lunch 1:00 - 1:30 pm PLENARY SESSION: Sarah Myerscough-Mueller, Interim Director, Division of Developmental Disabilities, DHS (Live Streamed)			

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THURSDAY, APRIL 20, 2023

1:45 -
2:45 pm
Breakout
Sessions

Session #21
(Live Streamed)
Ronnie Cohn
Ligas Court Monitor
Barry Taylor
Equip for Equality

"Ligas Consent Decree Update"

The *Ligas* Consent Decree is providing opportunities for people with I/DD to receive community services. In this session, *Ligas* Court Monitor Ronnie Cohn and *Ligas* lead counsel Barry Taylor of Equip for Equality will discuss Phase 2, with a major focus on people moving off the PUNS list, the reasonable pace aspect of the Decree, the gap of services for people with physical accessibility needs, higher behavioral needs and higher medical needs, along with the concern about the State's handling of crisis and placement of class members in SODCs. The current compliance review will also be discussed.

Session #22
Stephanie
Sideman
CSH

"Housing for You! The IL Statewide Referral Network"

Are you interested in living in your own home in the community? Learn about the Illinois Statewide Referral Network, a pathway to supportive, affordable housing across our state.

Session #23
Diane Compton
Parent
Erin Compton
Self-Advocate
Teresa Parks
Illinois Guardianship and Advocacy Commission

"Let's Learn About Supported Decision-Making"

Supported Decision-Making (SDM) is an alternative to guardianship for adults with IDD who need help in making decisions. This presentation will provide the legislative background of the SDM Act, key components, and examples of SDM in practice. The presentation will also include a family who will share their current experiences related to the decision-making process on guardianship.

Session #24
Ruth Aguilar
Erica Stearns
Greg Walkington
The Arc of Illinois

"Expectations vs Reality: Reimagining and Redefining 'Quality of Life' (Caregiver Panel)"

Greg, Erica, and Ruth are caregivers with diverse backgrounds who share struggles and successes. Together, they will take you on a storied journey to discover how to reimagine your expectations.

Sesión #25
En Español
(Transmisión en Vivo)
Maria Castillo

Family Resource Center on Disabilities
Consuelo Puente
Family Matters Parent and Training Information Center

"Toma de Decisiones con Apoyo"

En esta presentación, los participantes aprenderán sobre la toma de decisiones con apoyo como una alternativa a la tutela para personas con discapacidades intelectuales o del desarrollo.

Session #25
Presented in Spanish
"Supported Decision Making"

In this presentation participants will learn about supported decision making as an alternative to guardianship for individuals with intellectual/developmental disabilities.

2:45 -
3:00 pm
Break

3:00 -
4:00 pm
Breakout
Sessions

Session #26
(Live Streamed)
Nisha Baiju
Macey Jones
DHS/DRS

"Overview of HSP Assessment & Home Services Program Waivers"

This presentation will cover a review of HCBS programs and waiver services, Determination of Need (DON) assessment from referral to eligibility process, updates on the process of transitioning to sister agencies, and benefits of using of smart home technologies.

Session #27
Brian Rubin
Benji Rubin
Rubin Law, A
Professional Corporation

"Alternatives, One Size Does NOT Fit All: Supported Decision Making (new Illinois law), Powers of Attorney, and Guardianship (Plenary and Limited)"

Brian Rubin, a parent, and Benji Rubin, a sibling, of Mitchell Rubin who has Autism, will explain Guardianship (Limited and Plenary), and the alternatives, including Supported Decision Making (new law), Powers of Attorney, and related matters.

Session #28
Kim Fisher
Illinois State University
Tia Nelis
TASH

"Social, Civic, and Political Participation Using Technology"

This session will share research on how Illinois residents with IDD use technology to connect with friends/family and engage online. We will also share how Going Home Coalition members used technology to advocate during COVID-19.

Session #29
Susan Kahan
UIC Institute on Disability and Human Development

"Creating Trauma-Informed Environments at Home"

Trauma impacts the whole family. This presentation will discuss restoring feelings of safety, control, and connection for the individual and for the family by creating trauma-informed environments at home.

Sesión #30
En Español
(Transmisión en Vivo)
Dr. Cesar Ochoa-Lubinoff
Rush Children's Hospital

"Como Entender y Ayudar a Personas con Autismo que Tienen Problemas de Conducta"

Se explicara el diagnostico y tratamiento de los principales problemas emocionales y de conducta que afectan a personas con autismo. Presentaremos diferentes intervenciones para ayudar con su conducta en la casa y en la escuela.

Session #30
Presented in Spanish
"Understanding and Supporting individuals with Autism who demonstrate behavioral concerns"

The diagnosis and treatment of the main behavioral and emotional concerns affecting individuals with autism will be explained and discussed. We will present different interventions that can be implemented to help with behavior at home and school.

4:00 pm

Pick up Auction items



The Arc of Illinois 73rd Annual Convention

"Reimagining Expectations"

April 19 - 20, 2023

COST & REGISTRATION

Registration Fees for Participants are:

In Person

Both Days

- ☐ Professional Member.....\$ 275.00
- ☐ Professional Non Member\$ 335.00
- ☐ Family/Self-Advocate Member.....\$ 200.00
- ☐ Family/Self-Advocate Non Member.....\$ 240.00

Single Day Registration:

- ☐ Professional Member.....\$ 200.00
- ☐ Professional Non Member\$ 260.00
- ☐ Family/Self-Advocate Member.....\$ 145.00
- ☐ Family/Self-Advocate Non Member.....\$ 185.00

Virtual

Both Days:

- ☐ Professional Member.....\$ 175.00
- ☐ Professional Non Member\$ 225.00
- ☐ Family/Self-Advocate Member.....\$ 130.00
- ☐ Family/Self-Advocate Non Member.....\$ 160.00

Single Day Registration:

- ☐ Professional Member.....\$ 130.00
- ☐ Professional Non Member\$ 180.00
- ☐ Family/Self-Advocate Member.....\$ 95.00
- ☐ Family/Self-Advocate Non Member.....\$ 125.00

Indicate which days you will attend:

- ☐ Wednesday ☐ Thursday

Please let us know if you will be participating in the following:

- ☐ The Awards Reception
- ☐ The Spanish Breakout Sessions

To register: Email, mail or fax this form along with

This is a hybrid event.

Virtual Attendees: You will receive your Zoom link and reminders starting one week before the Conference. Only the presentations marked "Live Streamed" will be available for virtual attendees.

In Person Attendees: The Convention is located at:

Doubletree by Hilton
3003 Corporate W Dr
Lisle, IL 60532

The Arc of Illinois has reserved a block of rooms at the conference rate of \$119/night. Room reservations can be made directly by calling 630/505-0900. Reservations are under the Code "CTA." **The cut-off date for the block of rooms is March 28, 2023.**

If financial restrictions prevent you from paying full registration, consumer stipends for self-advocates and families are available through funding from the Illinois Council on Developmental Disabilities by contacting The Arc of Illinois at 815-464-1832 ext 1010.

REGISTRATION FORM

INSTRUCTIONS: One form per person, please print legibly. Your name and agency will appear on your name tag as it appears on this form. Check your registration options. Mail completed form to: The Arc of Illinois, 9980 190th St., Suite C, Mokena, IL 60448. Make checks payable to The Arc of Illinois. You may fax this form to 815-464-5292 and send the fee with the hard copy of this form in the mail. You may also register online at www.thearcofil.org/events.

Name: _____

Job Title: _____

Agency: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____

E-mail: _____

NOTE: We must know of any accommodation requests, including dietary needs, at least two weeks prior to the convention. Please tell us your accommodation needed here:

Not a member? Introductory Annual Membership discount for when you register for the Convention.

Yes, sign me up:

- ☐ New Family/Individual Member for \$20
- ☐ New Professional Member for \$40

TOTAL ENCLOSED: _____

METHOD OF PAYMENT:

____ Check enclosed payable to The Arc of Illinois

____ P.O. or State Voucher #

____ Charge to my Credit Card

Name as it appears on credit card:

Card Number: _____

Expiration Date: _____ **CVV Code:** _____

Billing Zip Code: _____

Card Holder's signature:

CANCELLATIONS & REFUNDS Participants canceling their registration 72 hours in advance will be entitled to a credit or refund. No refund or credit will be given for cancellation less than 72 hours before the conference.



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Annual Convention
April 19 - 20, 2023



Featuring the 21st
Annual
Art Exhibit

Call The Arc if you would like to participate!

SILENT AUCTION AND EXHIBITS

The Silent Auction and Art Exhibit will open Thursday, April 13th at 12 pm noon and remain open until Thursday, April 20th at 3 pm.

Visit the Exhibitor Hall for more information on our Sponsors and Exhibitors,

<https://www.thearc.org/73rd-annual-convention/>

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CEUs/CPDUs/Training Hours

10 CEU's available for Clinical Professional Counselor, Clinical Social Worker, Nursing Home Administrator, Social Worker, Occupational Therapist & Assistant, Physical Therapist & Assistant and QIDPs.



"Reimagining Expectations"