The Arc of Illinois



February 11, 2019



Presenter:

Meg Cooch – Executive Director
The Arc of Illinois

meg@thearcofil.org

815.464.1832





Agenda

- What the Arc Does
- Policies Impact People with Disability
- Policy Change Admin & Legislative
- The Arc of Illinois Legislative Priorities
- Telling Our Stories Building Relationships
- Get Involved!



The Programs of the Arc of Illinois



Mission

The Arc of Illinois
is committed to empowering perso
with disabilities to

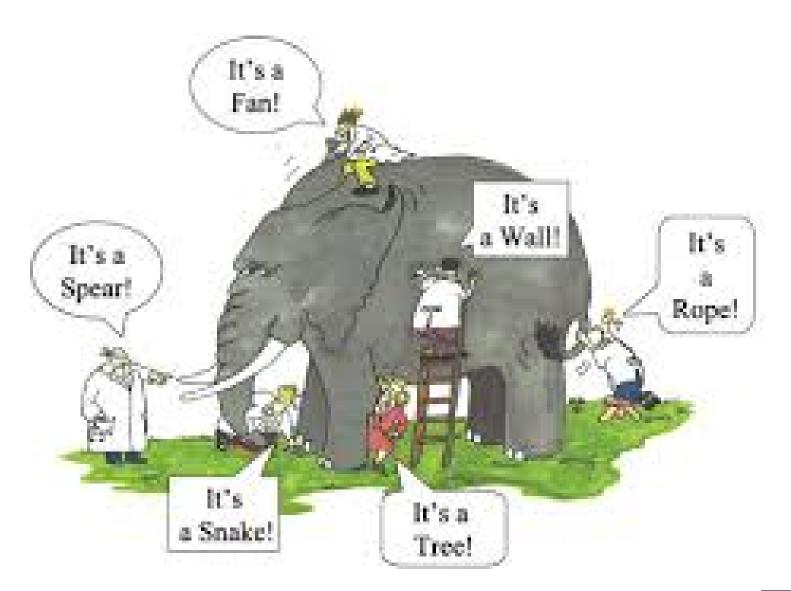
achieve full participation
in community life
through informed choices



Just a Bit of History

- •Families were the genesis of The Arc movement in 1930s-50s
- Movement grew organizations
- •Public policy was always critical!
- The Arc was involved in all of the major issues affecting people with disabilities from that point on
- •The Arc of Illinois works with 40 agencies and their thousands of individuals and families and nationally with the Arc of the US more than 800 organizations







The Arc of Illinois

- Policy and Advocacy
- Information and Resources
- Support for Self and Family Advocacy
- Training and Education
- AT Fund
- Consumer and Family Training Stipends

To learn more about the work The Arc of Illinois, go to www.thearcofil.org

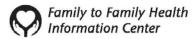




Information & resources across the life span

The Illinois Life Span Program provides information and resources on advocacy, supports and services for individuals with intellectual and developmental disabilities of all ages, their family members, and other stakeholders across the state via website and toll-free help line.

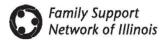
Deb Fornoff, Director www.thearcofil.org/illinoislifespan illinoislifespan@thearcofil.org 800.588.7002



Information & resources for families of children under 22 $\,$

The Family to Family Health Information Center, the Illinois affiliate of Family Voices of Illinois, provides information and resources specifically for families of children and youth with any disability, special needs and/or chronic illness. We focus especially on healthcare and benefits issues.

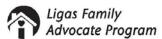
Faye Manaster, Director thearcofil.org/familytofamily www.familytofamily@thearcofil.org Toll Free: 866.931.1110 (English) / 800.588.7002 (Español)



Support for individual & family advocacy

The Family Support Network supports individuals and families advocating for individual funding, services and community resources that meet individual needs and are key for independent living.

Shirley Perez, Director www.thearcofil.org/familysupport familysupport@thearcofil.org 708.331.7370



Information & support for the PUNS waiting list

The Ligas Family Advocate Program works with the State of Illinois Independent Service Coordination agencies and providers to ensure that information about all available options for services reaches consumers over 18 years of age and their families.

Shirley Perez, Director www.thearcofil.org/ligasfamilyadvocates ligasfamilyadvocates@thearcofil.org 708.331,7370



Family Transition Project

Support in transitioning to community living

The Family Transition Project supports individuals and families who want to explore the possibilities of community living, for those currently living in large institutions.

Katherine Hamann, Director thearcofil.org/familytransition familytransition@thearcofil.org 708.465.2827



Stipends to attend conferences

The Consumer and Family Stipend Program provides financial assistance so that individuals or their family members can attend a conference of their choice — provided the conference is related to intellectual and developmental disability issues.

Lee Ann McQuen, Director www.thearcofil.org/stipend stipend@thearcofil.org 815.464.1832



Assistive Technology Program

Assistive technology access

The Assistive Technology Program funds the purchase of assistive technology for individuals with intellectual and developmental disabilities who have an evaluation from a qualified provider and do not qualify for AT through Medicaid, Medicare or private insurance.

Janet Donahue, Director www.thearcofil.org/assistivetech assistivetech@thearcofil.org 815.464.1832



Training Department

Training in advocacy

The Training Program offers educational conferences and trainings for self-advocates, family members, and professionals.

Janet Donahue, Director www.thearcofil.org/training training@thearcofil.org 815.464.1832



The Arc Reach Last Year

- •More than **80,000** connections on website and facebook
- More than 3300 people supported over the phone
- Outreach to more than 15,000 people
- •Trained almost **1,300** people at a total of 10 one day or multiple day conferences
- More than 800 people attended monthly webinars
- •266 people received consumer and family stipends
- •Since the start of the AT fund in 2015, more than 500 families have been helped.



Public Policy & Advocacy Efforts

- Long History of Legislative Efforts
- Arc Public Policy Committee
- Legislative Agenda State & Federal
- New Supported Employment advocacy
- Get involved in advocacy Arc member, advocacy network, rallies, action alerts



Join The Arc Family

- •Make your voice heard Advocate with us for policy change, funding and legislation.
- •Be a part of community Get support and learn from other families.
- •Access resources when you need them Gain valuable online and program resources.
- Learn and network Receive discounts on training and conferences.
- •Connect to The Arc of the United States Join a national network, and get news and resources from across the US.
- •Make a difference Be a part of protecting rights and advocate for improved services.

The Arc

Membership Benefits

- Discounts on trainings& conferences
- Online resources, materials & video from trainings
- Quarterly members-only webinars
- Weekly emails on federal /state policy & advocacy
- Networking opportunities with individuals, families & professionals
- Regional meetings for members
- Participation in a team advocating for change in community living



If You Want...

- Information and resources regardless of age Illinois Life Span
- Information and resources specifically for kids with health/medical concerns
 Family to Family
- •Information, resources and support for individuals who have been pulled from the PUNS waiting list _____ Ligas Family Advocates
- •Further support for advocacy problems Family Support Network
- Attend Training/Conference Consumer Stipend
- •Make Connections Arc Trainings

The Arc

Public Policy & Systems Advocacy

WHAT ARE THE SYSTEMS AND WHY SHOULD WE CARE?

Important Systems Impacting People with Disabilities

Medicaid

Medicare

Social Security

State Depts/Divisions including:

Department of Human Services (DHS)

Division of Rehabilitation Services (DRS)

Division of Developmental Disabilities

Illinois State Board of Education

Transportation

Local and community issues



Illinois Facts

Almost **20,000** people receive Home and Community-Based Services

1,667 people living in 7 State Operated Developmental Centers (SODC)

4,764 people living in Intermediate Care Facilities for Developmentally Disabled ICFDD's (FY18 estimate)

22,585 people attending Day Services

19,089 people waiting for services (7,500 actively waiting)



Illinois Behind the Times

Illinois is second only to Texas in the number of people it houses in institutions (1667 in SODCs)

50th - Illinois has the highest percentage of people with I/DD who live with 7+ people than other state

47th - Illinois' rank nationally in funding services that promote community inclusion

55.5% - Illinois spending on community services compared to national average (the national average is nearly twice what Illinois spends)

Ligas Consent Decree and NB vs Norwood

Transition Plan to Implement Home and Community Based Services settings rules still not approved



Decision Makers

State and federal decision makers can make policy that can impact people with disabilities include elected officials and administrative/state employees

<u>Legislators/Governor</u> – Pass and sign bills, Appropriations/Spending <u>Administration Officials/Governor</u> – Implement bills, write rules, have leeway to interpret and implement change



Change Can Come In Many Forms

Legislation – ADA

Administrative – Dept of Ed Roll Back of Rules, State Implementation of Waiver

Legal - Olmstead



Ligas V. Hamos



In 2005, Stanley Ligas and David Cicarelli and 7 other people filed a class action lawsuit, and now you may have some other options. Six years later, in 2011, the state of Illinois and the people in the lawsuit reached an agreement called a Consent Decree. This Consent Decree supported Mr. Ligas' desire to move. He and Mr. Cicarelli now share a home in the community.

Ligas

The *Ligas v. Hamos* lawsuit was filed on July 28, 2005, on behalf of individuals with developmental disabilities who were residing in private, State-funded facilities(ICFDDs) of nine or more persons or who were at risk of being placed in such facilities. Plaintiffs sought placement in Community-Based Settings and receipt of community-based services.

Reasonable pace of movement off the PUNS list (averaging 900 people pulled a year)

State found out of compliance and has been directed to among other things focus on rates for community services.



How Are You Connected with Policy Makers?





2018 Election



New Administration

IN CHARGE OF SETTING THE AGENDA,
IMPLEMENTING LEGISLATION, WRITING RULES —
WHERE THE RUBBER MEETS THE ROAD

Key Leaders – Among Others

Governor

Lt Governor

Appointees:

- >HFS Theresa Eagleson
- > DHS
- > DDD
- **DRS**
- **ISBE**



^{*} don't forget public employees!

Alphabet Soup of Departments







State Legislature

State House and Senate

Big changes:

118 House Members – 74 D, 44 R,

New Legislators: 30

59 Senators - 40 D, 19 R,

New Legislators: 12

Leadership:

Speaker Madigan

Minority Leader Durkin

Senate President Cullerton

Senate Minority Leader Brady



Calendar – ilga.gov

- Legislature runs from January to May
- > Additional Veto Session in Nov
- Lame Duck in January following an election
- Budget must be passed by May 31 statutorily

Start of Session: January 29

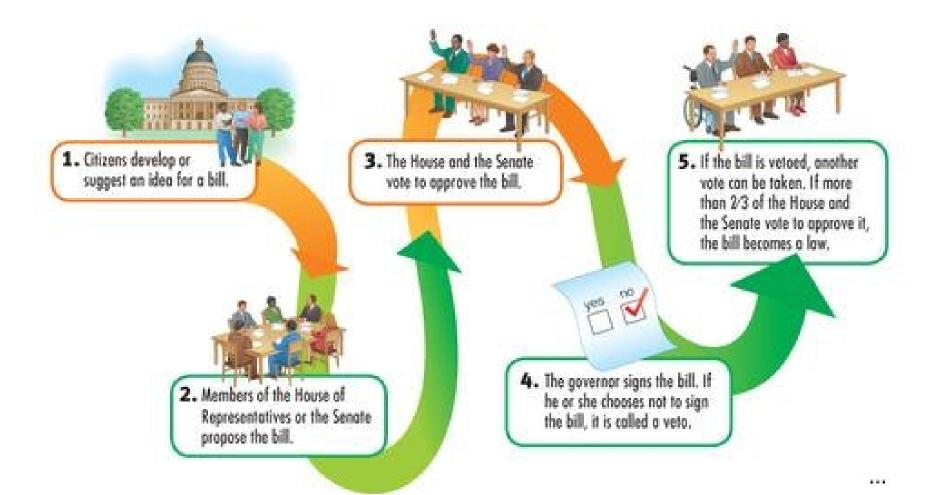
Filing Deadline: Feb 15

Governor's Budget Address: Feb 20

End of Session: May 31



How a Bill Becomes a Law





Legislative Process

- The Arc collects policy ideas in Sept-Oct to address in session
- Bills begin being crafted and sponsors found in Dec and January
- ➤ Bill drafts must be reviewed by LRB (legislative reference bureau) and put into legislative language with deadline around Feb 1.
- ➤ Bills must be filed by Feb 15 in order to be considered.
- ➤ Bill starts in either or both chambers must be assigned, heard and voted out of committee (toward end of March). Opportunity to submit witness slips (ilga.gov) in support or opposition as well as testimony.
- ➤ Bills are voted on and must pass one chamber around end of April.
- Then the process is repeated in the other chamber. If a bill passes both houses, it is sent to the governor to sign.
- ➤ Governor can sign, veto, amendatory veto or let become law without a signature.

The Arc

Budget Process

- ➤ Budget follows a similar path:
- ► Feb 20 Budget Address
- >Appropriations Committees consider changes to the governor's budget
- ➤ Votes in both House and Senate
- Budget is ideally signed by the Governor
- ➤ If no budget after May 31, passage requires three fifths majority.



Keep Up with the News

- The Arc of Illinois Membership and Advocacy Network
- Chicago Tribune
- Springfield Journal Register
- Capitolfax.com
- Facebook sites (The Arc, IPADD, Family to Family)





Visiting Your Legislators

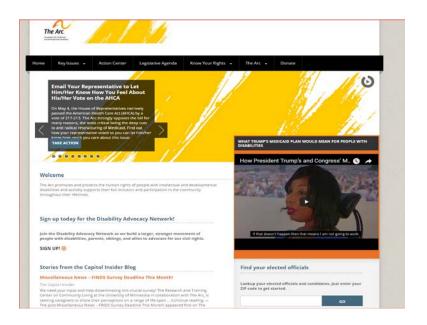
In Springfield (usually Tuesday-Thursday – check the calendar)

In District

- Individual meetings
- Constituents Services
- Emails
- Town halls
- Legislative breakfasts



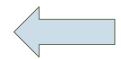
How do I find my legislators?



Go to

http://cqrcengage.com/thearc/?6

Plug in your zipcode and a list of your Federal, State, and Local representatives will come up.





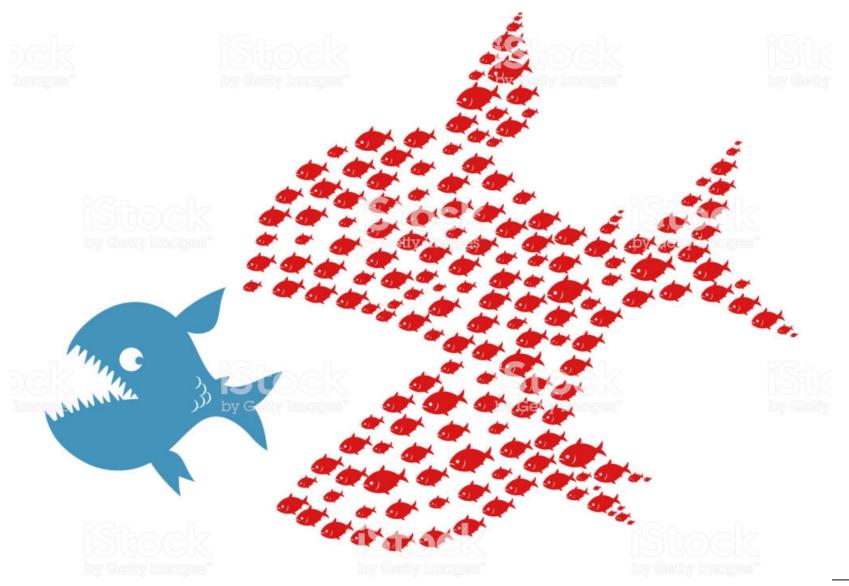
You can also look at: https://www.illinoispolicy.org/maps/

For 550 S. Plum, Palatine:

HOUSE DISTRICT 54: Thomas Morrison (R)

SENATE DISTRICT 27: Ann Gillespie (D)







The Arc of Illinois 2019 Key Issues

- Support a wage increase for frontline staff/DSPs to above \$15 per hour.
- •Continued funding for the **DD grants** including Life Span, the Autism Program, Epilepsy, Best Buddies and Respite.
- From our SEAT Advocacy work, create a customized employment pilot project in DRS
- Improve communications and transparency through the PUNs waiting
 list
- Extend a task force on disability and criminal justice system
- Address the issues of homes/units not certified by DPH on institutional campuses



Other Advocacy

- >Increase minimum wage
- Budget funding generally
- > Address Medicaid redetermination issues
- Increase the Personal Needs Allowance
- Create an assistive technology pilot
- ➤ Make the state a better employer of people with disabilities a couple of bills
- Improving access to providers through early intervention



Administrative Issues

DDD

Independent Service Coordination Agencies Consolidation/Transition

PUNs category changes

Changes to people's ability to move within waiver services from homebased to CILA

Proposed rule changes

Person centered planning

DRS

WIOA implementation

Transition age youth and employment



Key Questions

What we wanted changed? How we want it changed?

Who can change it?

To Do: Write down 1-3 systems changes you want to see made



Telling Our Story: Why Creating Relationships are Important!

Building Relationships with Policymakers

Advocacy is about relationships & sharing stories!

You want to make friends with policymakers when you don't need friends!



Hook, Line and Sinker: A Way to Prepare to talk with Policymakers



Your stories and experiences are the most powerful tools for change. Sharing them effectively with professionals, legislators and other advocates can make a big impact.

This is a process that was developed by the Sibling Leadership Network.



Your Story

Hook

*Your name, something about you and/or your family member



Line

- *Your concerns
- *Your story
- *Statistics



Sinker

- *What you want changed
- *How you want it changed





The Hook: Details about you and your family

I live in your district and I am the parent of a young adult with Down syndrome. He lives at home and receives funding for services through the Home and Community Based Waiver Program for Adults - a program funded by Medicaid. Without this funding that provides Personal Support Worker services, my son would have a much smaller life. This funding allows him the opportunity to volunteer and enjoy his community with the support he needs. Without this funding, I would not be able to work. Our financial situation would not allow him to have the experiences he has now.



The Line: Your main concern



I am contacting you to share my deep concern regarding proposed cuts to Medicaid. This will most definitely have an impact on my son's life as well as other individuals with disabilities, the elderly, and folks with low income who will not receive adequate health care or services without Medicaid.

In Illinois where we also have ongoing and serious budget issues, any cuts to Medicaid will be particularly devastating.



The Sinker: What you want



Please vote "no" on any bill that limits or decreases funding for Medicaid in Illinois. These cuts would result in loss of and limitations to services for Illinois residents who need that help! I would be happy to talk with you more about my concerns and the importance of this funding to my son and others. Please let me know if you have any questions or need any more information at any time.

Thank you for your time and consideration of my sincere concerns.



Prepare Your Story: Activity

Take 5-7 minutes to complete the hook, line, and sinker worksheet

Pair with someone to each share your stories for 10 minutes (5 min each).





HOOK





LINE





SINKER





Tips to Remember:

- 1. Always be polite.
- 2. Say thank you.
- 3. Be prepared and keep your story straight.
- 4. Never make up an answer.
- 5. Expect to have 10-15 min only.
- 6. Be patient.
- 7. Ask how you can help them.



From the Connecticut Health Policy Project.

From http://www.cthealthpolicy.org/toolbox/advocacy/tips.htm



Who Needs to Hear Our Stories?





Everyone!

Elected Officials:

- Congressional Delegation House and Senate
- State Representative and Senator
- Governor/Administrative leadership (DHS, HFS, DDD, DPH, DRS)
- County boards
- Mayors
- Other local officials

Non elected key stakeholders: State associations, other disability and not coalitions

Appointees: Committees/advisory councils/task forces



The Time Is Now To Speak Up to Legislators

- Letters, faxes and emails
- Telephone calls
- Face-to-face visits with elected officials
- Hearings (attend and/or testify)
- Public meetings/Townhall meetings
- Phone and email "trees"
- Fundraising events
- Call them out on social media
- Sign up for their newsletters
- Become active participants/leaders in state trade associations
- Serve on state-wide committees and boards





Call to Action: What will YOU do within 24 hours?



What Can You Do to Help?

- Support people around you
- •Be a connector share information!
- Educate yourself trainings, conferences, webinars
- Introduce yourself to your local and state legislators
- Advocate for issues you care about
- Volunteer with local Arc chapters (see our website)
- Volunteer with the Arc of Illinois events (contact Meg)
- Join the Arc of Illinois Membership and/or Advocacy Network



Contact The Arc of Illinois

The Arc of Illinois – Administrative Office 20901 S. LaGrange Road, Ste. 209 Frankfort, IL 60423 815-464-1832 www.thearcofil.org

Illinois Life Span Program 800-588-7002

www.illinoislifespan.org

Family to Family Health Information Center 866-931-1110

www.familyvoicesillinois.org

Family Support Network and Ligas Family Advocate Programs 708-331-7370

www.familysupportnetwork.org www.ligasfamilyadvocateprogram.org

Family Transition Project 708-465-2827 www.goinghomeillinois.org

The Arc of Illinois
is committed to empowering persons
with disabilities to
achieve full participation
in community life
through informed choices



Thank You & Questions

Meg Cooch 773-558-5136 meg@thearcofil.org





How is Information Provided?

- www.illinoislifespan.org
- **1**-800-588-7002
- □ Deb@thearcofil.org
- Monthly Lunchtime Webinars



Illinois Life Span







- Provides information and resources for families with kids with disabilities, special needs or chronic illness (not just intellectual and developmental disabilities but other complex health needs);
- Support families in all issues but especially healthcare and medical issues;

F2F Website: www.familyvoicesillinois.org

Phone: 866-931-1110 or 815-464-8247

Email: family to family@thearcofil.org





WE PROVIDE ADVOCACY AND SUPPORT

- Supports and educates families to navigate the state system to obtain services as well as utilize natural supports.
- Supports families with more in-depth problem solving through relationships and contacts
- Provides individual and systems advocacy training to families
- Connects families with legislators
- Hosts at least two state-wide conferences and participate in more than ten each year.

- Family Support Network Program provides education and community awareness regarding disability issues as related to lack of services regarding housing, families' responsibilities, and employment options.
- We also provide advocacy and legislative training to teach families how to advocate for funding.





- Provides family to family support for individuals and their families who are selected through the Illinois department of Human services, Division of Developmental Disabilities (DDD) Prioritization of Urgency of Needs (PUNS) as a result of the Ligas Consent Decree.
- Provide consistent information about all options including ICFDDs state-wide
- Connect families with other families
- Share creative ways to utilize funding for Home Based and CILA services

708-331-7370 - Office

Email: Shirley@thearcofil.org





Family Transition Project

- Supports individuals and families who want to transition from institution to community;
- Provide information and resources;
- Provide transition mentors who can speak to their own experiences moving from institution to home;
- Meets one on one with self-advocates and their families by phone, email, or in person – whatever is most helpful. We are here to listen and learn their histories, their needs, and their concerns.





Consumer Stipend Program

- •Supports people with intellectual and developmental disabilities and family members/guardians to attend conferences, trainings and other educational opportunities through a stipend structure.
- Funded by a grant from the Illinois Council on Developmental Disabilities.
- •How much can I apply for?
 - \$400 per person per year
 - 🔲\$700 per family per year







The goal of the Assistive Technology Program is to enhance and improve the quality of life for persons with intellectual/developmental disabilities by providing opportunities for individuals to receive technology to help with education, employment, community living and independence.

Who can apply?

- Illinois resident
- A person with an intellectual or developmental disability
- ☐ Maximum amount funded is \$500

How do I apply?

- Complete application form and return to The Arc of Illinois
- □ Include a copy of an evaluation/assessment to show the need for the assistive technology device and what type of device is needed.





Training Department



The Arc of Illinois 815-464-1832 2018-2019 Schedule of Trainings/Seminars/Webinars



- ♦ August 21, 2018 Lunchtime Webinar (Supportive Housing with CSH) 12:00-1:00 p.m.
- ◆ September 11, 2018 Lunchtime Webinar (Community & Residential Service Authority with Director, Debbie Smith) 12:00-1:00 p.m.
- ◆ September 13, 2018 "Illinois Health Care Coverage Options and Benefits for People with Disabilities"

 Doubletree Hotel, Alsip, IL
- ◆September 26, 2018 "Supported Employment Action Team Summit" Hilton Hotel, Lisle IL
- ◆ September 28, 2018 Brian Rubin, J.D., Sherri Schneider & Benjamin Rubin, J.D., "Planning for the Future for Children & Adults with Special Needs" Hosted by The Arc of WBO, Rockford, IL
- ◆ October 2, 2018 "The Arc of Illinois Living With Autism Conference" Hilton Hotel, Lisle, IL
- ◆ October 30-31, 2018 "Speak Up and Speak Out" Wydnam Hotel, Springfield, IL
- ◆ November 8, 2018 "A Day of Government Benefits and How NOT to Lose Them" Presented by Sherri Schneider, Brian Rubin and Scott Nixon Doubletree Hotel, Alsip, IL
- ♦ November 30, 2018 Brian Rubin, J.D., Sherri Schneider & Benjamin Rubin, J.D., "Planning for the Future for Children & Adults with Special Needs" - Hosted by Community Choices, Champaign, IL
- ◆ January 29, 2019 "17th Annual QIDP Leadership Conference" Doubletree Hotel, Alsip, IL
- ◆ February 6-7, 2019 "The Arc of Illinois Leadership Conference" Hilton Hotel, Lisle, IL
- ◆March 21, 2019 7th Annual Arc/Ligas Family Advocate Informational Seminar- Heritage Plaza, Chicago, IL
- ◆April 24-25, 2019 "The Arc of Illinois 69th Annual Convention" Hilton Hotel, Lisle, IL
- ♦ May 3, 2019 Brian Rubin, J.D., Sherri Schneider & Benjamin Rubin, J.D., "Planning for the Future for Children & Adults with Special Needs" Hosted by Center for Independent Futures, Evanston, IL
- May 8, 2019 Brian Rubin, J.D., Sherri Schneider & Benjamin Rubin, J.D., "Planning for the Future for Children and Adults with Special Needs" Hosted by Elim Christian Services, Crestwood, IL

Check out <u>www.thearcotil.org/events</u> for the latest events!

