

Illinois Self Advocacy Alliance

The Alliance News

Issue #82

January 2019



SAVE THE DATE!

The Alliance and The Arc of Illinois Spring 2019 Regional Training

Join The Alliance and The Arc of Illinois to learn about self-advocacy, the developmental disability service system in Illinois, legislative advocacy, and more! Trainings are free and will begin promptly at 10am and end at 2pm; lunch is included!

February 26, 2019
Davis-McCann Center
5 North 14th Street
Murphysboro, IL

March 5, 2019
KCCDD
2015 Windish Drive
(Unit 8 on Lowrey Drive)
Galesburg, IL

March 19, 2019
Memorial Center for Learning and Innovation
228 West Miller Street
Springfield, IL

March 20, 2019
Knights of Columbus
100 S. 129th Infantry Drive
Joliet, IL

March 26, 2019
Knights of Columbus
15 N. Hickory Avenue
Arlington Heights, IL

**Registration is limited to 75 at each location.
Watch for the flyer and registration coming soon!**

Illinois Self-Advocacy Alliance
PO Box 666 Park Forest, IL 60466 618.806.9431
Email: info@selfadvocacyalliance.org
Website: www.selfadvocacyalliance.org
Find us on Facebook at Illinois Self-Advocacy Alliance

Our Vision

Our vision is for self-advocates to work together to get the support we need to live the life we want in the community.

Our Mission

Our mission is to speak up for ourselves and each other while working together to make changes in our communities and in Illinois.

Our Focus

Our focus is on empowering people to speak up about what they want and need, don't want and don't need, action plan their goals and participate in advocacy at the personal, agency, community and statewide levels.



Illinois Council on
Developmental
Disabilities

This newsletter was developed under an investment by the Illinois Council on Developmental Disabilities

WE NEED YOU! TO MAKE IT HAPPEN

WE NEED YOU... to contribute to The Alliance newsletter each month. Share your ideas, hopes, dreams, success stories and challenges with The Alliance. You can submit an article, a poem, a piece of artwork, photography, write a column, or ask a question.

Let us know if you have any questions. Submit your content to info@selfadvocacyalliance.org.

HCBS GUIDE: YOUR RIGHT TO A COMMUNITY LIFE (for self-advocates)



The Home and Community Based Services (HCBS) Settings Final Rule is a federal policy change announced by the Centers for Medicare and Medicaid Services (CMS) in January 2014 to make sure that people with disabilities have the kinds of services they need in their communities. The Rule sets requirements for where and how Medicaid HCBS are provided to ensure that people receiving services through Medicaid HCBS waiver programs have full access to community life. This means that services should be provided in the most integrated setting possible, and must provide opportunities for integration and access to the community, choice, individual rights, and independence.

Throughout the planning and implementation process to comply with the Rule, states will ask stakeholders for input about the services they receive, the places where services are provided, and changes that could be made to help them get the community lives they want. Some people with developmental disabilities may need assistance to think about how their services could better support them in their communities and to advocate for their right to a community life.

This guide prepares you for HCBS advocacy with information about the Rule and tools to share about your experience receiving services.

Find the guide at

<https://c-q-l.org/files/2018Documents/CQL-HCBS-Advocate-Guide-2018.pdf>.



Keep up with all the exciting news in between monthly newsletters by finding and liking The Alliance on Facebook at Illinois Self-Advocacy Alliance.



"I Can Be Safe Online" Webinar Recording Recorded Live on Thursday, January 10, 2019



Do you use social media? Email? Dating websites? The internet is a great way to learn and to connect but it can put your safety and privacy at risk. Let's learn together about staying safe online.

Check out the recording at

<https://register.gotowebinar.com/recording/4132296046250096386?assets=true>

"Assistive Technology and Why It's Important!" Webinar Thursday, February 21, 2019 at 10:00am CST



Assistive technology is defined as products, equipment, and systems that enhance learning, working, and daily living for persons with disabilities. Let's learn about assistive technology of all kinds, from low to high tech and why it is important in all areas of life including school, work, play and independent living. Assistive technology is for all ages and disabilities!

About the Presenter

Susy Woods is the Public Policy and Education Liaison for the Illinois Assistive Technology Program (IATP). In this job she attends I.E.P. and 504 meetings with families to support them from Early Intervention through College and works on policy at the state. Suzy has recently been appointed to the Springfield Disability Commission.

Please register for Assistive Technology and Why It's Important! at:

<https://attendee.gotowebinar.com/register/3280292182332909059>

After registering, you will receive a confirmation email containing information about joining the webinar.

HCBS GUIDE: SUPPORTING THE RIGHT TO A COMMUNITY LIFE **(for family members, support staff, allies)**



The Home and Community Based Services (HCBS) Settings Final Rule is a federal policy change announced by the Centers for Medicare and Medicaid Services (CMS) in January 2014 to make sure that people with disabilities have the kinds of services they need in their communities. The Rule sets requirements for where and how Medicaid HCBS are provided to ensure that people receiving services through Medicaid HCBS waiver programs have full access to community life. This means that services should be provided in the most integrated setting possible, and must provide opportunities for integration and access to the community, choice, individual rights, and independence.

Throughout the planning and implementation process to comply with the Rule, states will ask stakeholders for input about the services they receive, the places where services are provided, and changes that could be made to help them get the community lives they want. Some people with developmental disabilities may need assistance to think about how their services could better support them in their communities and to advocate for their right to a community life.

This resource prepares you to assist those you support to advocate for the community lives they want and share their experiences receiving Home and Community Based Services.

Check it out at

<https://c-q-l.org/files/2018Documents/CQL-HCBS-Supporter-Guide-2018.pdf>.

The Alliance Staff Contact Information

Tara Wickey Project Director
Project Director
tara.advocacy@gmail.com

Jae Jin Pak
Project Specialist
jaejinadvocacy@gmail.com

Mike Brown
Regional Self-Advocacy Specialist
mikebrown@ctfillinois.org

Krescene Beck
Organization Director
krescenebeck@gmail.com

Tracey Wyant
Project Specialist
traceyalliance@gmail.com

Robyn Carpenter
Regional Self-Advocacy Specialist
robynadvocacy@gmail.com



The Progress Center for Independent Living is excited to announce...

A NEW YOUTH TRANSITION PROGRAM



The Youth Transition Program will equip young people with disabilities with independent living and job readiness skills.

If you are young person, disabled, and enrolled in an academic program, Progress Center invites you to sign up for a new program designed to empower youth to navigate life after high school and college.

- This new program will cover:**
- Disability History
 - Disability Rights
 - Independent Living Skills
 - Financial Literacy Skills
 - Job Readiness Skills
 - And More

- Eligible young people must:**
- Be between 14 and 21 years old
 - Be disabled
 - Be enrolled in an academic program
 - Not have an active case with the Department of Rehabilitation Services of Illinois

Partner with Progress Center & take charge of your future!

Progress Center for Independent Living
 7521 Madison Street
 Forest Park, Illinois 60130
www.progresscil.org
 708-209-1500



Progress Center is the Illinois Center for Independent Living that serves suburban Cook County. Governed and staffed by people with disabilities, Progress Center equips people with disabilities with the tools to be independent in their own communities.

For more information on the Youth Transition Program, please contact:

Courtney Harfmann
 at
charfmann@progresscil.org
 or
 (708) 209 1500 Ext. 26

Kim Liddell
 at
kliddell@progresscil.org
 or
 (708) 388 5011

HCBS (Home and Community Based Settings) Videos

States, support providers, self-advocates, families, and others are continually working to ensure that the tenets of the HCBS Settings Rules remain strong throughout the human services system. To support stakeholders in these efforts, we've compiled a number of videos and resources that provide information and guidance.



HCBS Overview

Watch an overview video about the Home and Community Based Settings Services rule and its various components.

<https://www.youtube.com/watch?v=xnbtb5Jpz7c&t=30s>



About the Rule

View essential information about how the rule will promote choices, independence, and community for people receiving supports.

<https://www.youtube.com/watch?v=8sJl-LF5ufg>



Residential Settings

Find out about the various requirements placed on providers involving residential settings.

<https://www.youtube.com/watch?v=sjy334aMXXk&t=8s>



Rights Restrictions

Learn about the impact of the HCBS Settings Rule on rights restrictions and modifications for people.

https://www.youtube.com/watch?v=Vg5DA_ouOwY&t=18s



A Call To Action

Discover how to share information about the rule for providers and people receiving supports.

<https://www.youtube.com/watch?v=m-MzRKsvCGE>

Meet Three Graduates of Illinois' Partners in Policymaking (PIP) Program! ~ Tracey Wyant, Project Specialist



PIP is a program designed to teach people with disabilities and family members how to advocate for the changes and services that they need in order to live the life they want. It requires participants dedicate one weekend a month for 8 months to attend classes to expand advocacy skills. Classes included supported living, assistive technology, employment first, school inclusion, person centered planning, customized employment, and how to talk to legislators and others who are in power to bring about change. Each month homework is assigned and must be completed by the following month. Participants must complete a graduation project and present it at graduation in order to receive a diploma.

Meet three self-advocates who have recently received their PIP diploma:



Brian Antczak lives in Pontiac, IL. He belongs to the LCAA (Livingston County Advocates in Action) advocacy group and has worked on many advocacy projects.



Melissa Justus lives in Mattoon, IL and is a founding member of CTF Illinois Advocacy Center in Charleston. She is an outspoken advocate and presenter.



John Bellot is from Pontiac, IL, and is an active member of LCAA (Livingston County Advocates in Action) advocacy group. John is a member of The Alliance's Board of Directors

How did you hear about PIP?

Melissa: Someone emailed my staff and they approached me and asked if I might be interested.

John and Brian: Our advocacy advisor read the flyer at our advocacy meeting and asked if anyone was interested.

What about PIP made you want to take on such a task?

Melissa: I always enjoy learning new things and taking on new task. I enjoy getting to know different people.

Brian: I have a passion for advocacy work and have enjoyed learning more ways to advocate for myself and others

John: I enjoy learning about new things and finding ways to speak up for things that are important.

Was there anything that surprised you?

Melissa: How children in special education classes today are being left out of things that their other classmates may be doing.

Brian: I never knew about the TASH organization and all the advocacy work that they do. How the PUNS list works surprised me. I didn't know that so many people are still awaiting services.

John: The history of how individuals with disabilities were treated surprised me. People with disabilities used to be used as a circus act and were treated very bad.

What would you say is the hardest part about PIP?

Melissa: It's long class time and so much information coming at you all at once. It's very fast paced.

Brian: The homework. It is a lot of work and a lot of information to take in

John: The homework and the length of the classes. We take breaks but it still is a lot of stuff to take in and learn.

Why do you feel that PIP was important?

Melissa: I felt like I wasn't alone in my advocacy work. Meeting many people who had the same desire as I did was really nice.

Brian: I feel like PIP really teaches people how to be strong advocates and the things that they learn they can take out to their communities and bring about real change.

John: I think PIP is very important and really helps parents learn how to advocate for their children. There is so much they need to learn.

What was the most important thing you took away from your PIP experience?

Melissa: Confidence. I took a role in one of our role-playing activities where I would lead the crowd in chanting for customized employment. I was scared at first, but people supported me and it was really fun.

Brian: To continue to do advocacy work throughout my community.

John: To be a better advocate.

Any advice to someone who might be interested in attending PIP?

Melissa: Pay attention, it's going go fast

Brian: You think you know a lot about advocacy, but after PIP you find out there is so much more you need to learn.

John: It's hard and easy to get overwhelmed. Ask for help when you need it.

The next session of Partners in Policymaking will begin in September 2019, with recruitment beginning April/May. Watch upcoming issues of The Alliance Newsletter for a Partners in Policymaking webinar presented by Melissa, Brian and John!