

The Alliance News

Issue #90

September 2019



Check Out the Newest Feature to The Alliance Newsletter...



Self-Advocacy Spotlight!

In Self-Advocacy Spotlight, a self-advocate interviews others, including staff, about:

- What self-advocacy means to them
- Tell about a time that you spoke up
- Share your gifts, talents, hopes, dreams
- Tell how they support self-advocacy

Check out Self-Advocacy Spotlight on page 2 of the newsletter.

Our Vision

Our vision is for self-advocates to work together to get the support we need and 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.



Illinois Council on
Developmental
Disabilities

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

Illinois Self-Advocacy Alliance

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Self-Advocacy Spotlight!

My name is Thomas Cochrane and I am a self-advocate and member of Vocational Voices self-advocacy group.

To me, self-advocacy means helping me learn new things and helping others and giving. I am good at sports; I do Special Olympics basketball, bowling, and football.



Self-Advocate Interview: Utopia

"Self-advocacy means setting goals and working on them. I speak up about abuse when I see people being abused. I hope to get a job."

Self-Advocate Interview: Lavell

"Self-advocacy means speaking up for myself and help people speak up. Also going out in the community. I spoke up at the Speak Up and Speak Out Summit. I like to DJ and I'm a dancer."

Self-Advocate Interview: Rico

"Self-advocacy means learning about rights and about myself like what I want. I go to my staff when people are not treating me right. I'm good at working and I want to get a job and career, and I like going places."

Staff Interview: Tavea

"Self-advocacy means advocating for those who can't advocate for themselves and need a helping hand. I support self-advocacy by being involved with the self-advocacy group Vocational Voices by supporting fundraisers and attending meetings."

Staff Interview: Elizabeth

"Self-advocacy means to know and understand your rights as an adult. I support self-advocacy by advocating for those whose rights may have been violated and they can't speak up about it. I am also the co-advisor for the agency's self-advocacy group (Vocational Voices)."

Stay tuned for next month's Self-Advocacy Spotlight!



TCRC's (Tremont) Self-Advocacy Certification Immersion Team!

The Alliance recently spent two days with self-advocates and staff at TCRC (Tremont) to start them on their Self-Advocacy Certification journey!

The first day was spent learning with and from each other while participating in "Speak Up for Self-Advocacy" and "Self-Advocacy Matters!" presentations. On the second day, the Self-Advocacy Certification Immersion team met to develop an Action Plan to increase self-advocacy and self-advocate involvement over the next year.

Congrats to TCRC for starting their journey; we can't wait to hear and see how the culture of self-advocacy is growing!



NATIONAL DISABILITY EMPLOYMENT AWARENESS MONTH RESOURCES

National Disability Employment Awareness Month (NDEAM) takes place annually each October. This year's NDEAM theme is "The Right Talent, Right Now." It emphasizes the essential talents and skills people with disabilities contribute to America's economic success. This message especially resonates in an era when historically low unemployment and global competition are creating a high demand for skilled talent.

Visit www.dol.gov/ndeam to access the media kit, download posters, and find other resources to celebrate NDEAM throughout October and all year long.

"I've Got a Job...Yes! Now What?" Webinar

Tuesday, September 24, 2019 at 10am CDT

Register at

<https://attendee.gotowebinar.com/register/4813282975579454477>

You just got a job which is awesome, but you did not talk about the support you need to be successful at your job. This webinar will help you think through as well as to speak up and speak out in asking for what you need to be successful.

"Individuals with Hearing Loss and Deaf Culture"

Tuesday, October 22, 2019 at 10am CDT

Register at

<https://attendee.gotowebinar.com/register/8849894725732485899>

Hearing loss can be a big deal, no matter how much a person can or cannot hear. What are important things to know about individuals with hearing loss? Many individuals may not realize that some individuals with hearing loss identify with Deaf Culture. Let's learn about the different types of hearing loss, along with some basic about Deaf Culture. This presentation welcomes questions, so please feel free to BRING YOUR OWN QUESTIONS. health conditions in a variety of positions.

Registration is now open for Speak Up and Speak Out Summit 2019!

October 28 – 30, 2019

Wyndham City Centre (formerly Hilton Hotel)

700 East Adams St.

Springfield, IL 62701



To learn more or to register, please visit

<https://www.speakupspeakoutsummit.org/>

Community Conversations About Healthcare

Community Choices (Champaign) has been engaging with local civic organizations, government entities, influential individuals, and community groups through a series of community conversations. These conversation roundtables were jumping off points for people with disabilities to take on leadership roles in attending organizations and entities.

The result of the Community Conversation with Healthcare Professionals is a one-page guide to be used in offices of doctors, dentists, counselors, etc. It can also be used to prepare for an appointment with any healthcare professional.

**THE HEALTHCARE PROFESSIONALS' GUIDE
TO WORKING WITH PATIENTS WITH DEVELOPMENTAL DISABILITIES**




GOAL	WHAT PATIENTS CAN DO	WHAT HCPS CAN DO	WHAT SUPPORT PEOPLE CAN DO
HCPS UNDERSTAND THAT I HAVE A ROLE AND VOICE IN MY HEALTHCARE - IT'S MY BODY	Make a list of questions ahead of time (prioritize items before you come) Give a list of questions/topics to the tech when you are just starting an appointment Bring a medicine list or pill bottles - this saves lots of time for other issues and conversation Write down symptoms experienced and when ahead of time	Communicate to the patient that you are there for them Encourage the patient to be honest	Ask the patient before hand how they want you to be involved Let the patient explain who the support person is and why you are there Help the patient prepare for the appointment Help review with the patient after the appointment
HCPS ADJUST TO HOW I COMMUNICATE AND RESPOND IN A WAY I CAN UNDERSTAND	Find a communication style that works for you and practice how it can help at an appointment Bring communication tools with you Help HCPS understand why you are using a communication support and how it works Request a 30 minute appointment and explain that a communication need is a reason for it Use automated systems to send messages to providers ahead of appointments (48-72 hours ahead)	Use pictures to help explain things Use notes to record important information about the patient's communication preferences - bring in the support staff to help make this possible OK a 30 minute appointment when people need more time to communicate Connect with nurses and other office support people about when someone might have communication needs Ask patients if they need more time to process or consider options Slow down and explain things using plain language without being patronizing. Be patient and kind Let the patient know that you understood what they are saying or communicating	Help the patient prepare for the appointment Talk with the patient about supporting them to use an online communication portal Use automated systems to send messages to providers ahead of appointments (48-72 hours ahead) Take notes during the appointment Help review with the patient after the appointment
HCPS FOCUS ON ME AND USE MY SUPPORT PEOPLE AS A RESOURCE NOT A STAND-IN FOR ME	Make sure the doctors know who they have permission to talk to Let the clinic know that you will need someone or some support during your appointment - have them add it to an appointment note	Find a way to talk to the patient alone and ask them what they want Ask the patient who you have permission to talk to Help other HCPS when a patient and support person might not agree on something Be open with patients about when and why support people can and cannot be present	Ask the patient before hand how they want you to be involved Let the front desk or office staff know you are available to support someone Let the patient explain who the support person is and why they are there

PLEASE UNDERSTAND HOW MY DISABILITY COULD AFFECT MY CARE, BUT TREAT ME LIKE ANYONE ELSE.

Check it out at <http://www.communitychoicesinc.org/community-conversations.html>. There is even a blank guide you can download and fill out for yourself!



The Alliance and The Arc of Illinois Fall 2019 Regional Training

“Speaking Up and Speaking Out for Yourself, Your Friends, and Your Community!”

Join the Illinois Self-Advocacy Alliance (The Alliance) and The Arc of Illinois for a day of learning and advocacy.

Trainings are free and will begin promptly at 10am and end at 2pm; lunch is included!

Register at <https://thearcofillinois.salsalabs.org/alliancetrainings/index.html> or contact Krescene Beck at the Alliance at krescenebeck@gmail.com or 618-806-9431.

August 28, 2019
Meadowdale Center for Learning and Innovation
2281 West 11th Street
Springfield, IL 62761
Registration Limit – 70

September 11, 2019
Joliet Community College
1301 West 1st Street
Joliet, IL 61731
Registration Limit – 70

September 25, 2019
Rockford Mass Transit District
725 N. Lyford Road
Rockford, IL 61101
Registration Limit – 45

September 26, 2019
Access Living
115 W Chicago Avenue
Chicago, IL 60610
Registration Limit – 70



October 9, 2019
Effingham Public Library
200 N 3rd Street
Effingham, IL 62421
Registration Limit - 35

October 10, 2019
Kaskaskia College
27210 College Road
Centralia, IL 62801
Registration Limit – 70

This regional training was developed under an investment by the Illinois Council on Developmental Disabilities (ICDD).





Welcome to Community Connections, where we share awareness, information, and celebrations relating to the disability community.

Famous People with Disabilities – October Spotlight



Stephen Hawking (1942 – 2018)

Stephen Hawking was diagnosed with ALS (Amyotrophic Lateral Sclerosis) at the age of 21 but he didn't let that stop him! He used a wheelchair and a computerized voice system. Steven graduated with a doctorate in physics and mathematics; he was a professor as well as an author of several books. His family includes three children and three grandchildren.

Learn more about Stephen Hawking by visiting www.hawking.org.uk.

Disability Inclusion Awareness Ideas for October

- Check out the NADS (National Association for Down Syndrome) at www.nads.org.
- Consider purchasing a NADS sign to put in your yard or at your agency to show your support.
- Register to attend the NADS fashion show on October 28th or plan your own fashion show in celebration of NADS.

Don't be afraid to "think outside of the box" and come up with your own Disability Inclusion Awareness Ideas for the month. Let The Alliance know what you did by emailing us at info@selfadvocacyalliance.org.

Disability Inclusion Awareness in October

- National Disability Employment Awareness Month (NDEAM)
- Down Syndrome Awareness Month
- Learning Disabilities Awareness Month
- National Bullying Prevention Month
- Dwarfism Awareness Month
- World Cerebral Palsy Day - October 6
- World Day of Bullying Prevention - October 7
- World Blind Day/World Sight Day - October 10
- World Mental Health Day - October 10
- Spina Bifida Awareness Day - October 25

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.

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