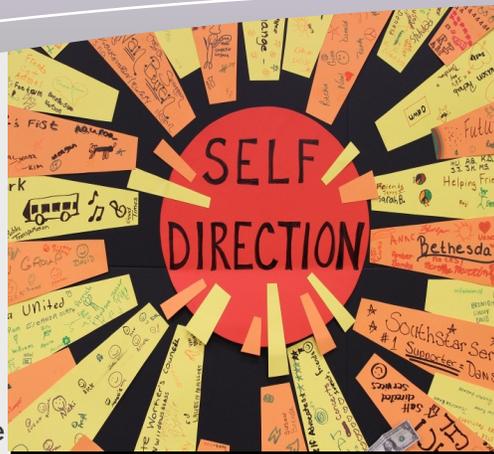


The Alliance News

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Illinois Self-Advocacy Alliance

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.

Mission

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

The Alliance is proud to be an Initiative of the Illinois Council on Developmental Disabilities

The Alliance Goes On!

We recently learned that The Alliance was awarded funding from the Illinois Council on Developmental Disabilities! This means that the work of The Alliance will continue through September 30, 2017. During the next four and a half (4 1/2) years, the goals of The Alliance are to

- establish an active network of 50 self-advocate leaders and 25 local/community groups throughout the state
- make one (1) state policy change on employment
- support fifteen (15) local/community groups in conducting a local event
- train fifty (50) self-advocates to be leaders
- have fifty (50) self-advocates in leadership positions
- make one (1) state policy change on an issue selected by self-advocates
- develop a strategic plan to establish local/community self-advocacy group control.

The Alliance looks forward to being part of your self-advocacy journey!

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The Alliance News

Self-Advocates Speaking Up



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH. EDUCATION. SERVICE

Envisioning the Future: Allies in Self-Advocacy

Envisioning the Future: Allies in Self-Advocacy is a report summarizing what was learned across a series of nine regional planning summits held in 2011-12 to discuss what was happening in organized self-advocacy efforts around the United States led by or including persons who have intellectual/developmental disabilities (I/DD). Each summit was attended by state-based teams that included persons with I/DD who identified as self-advocates (both youth and adults), along with representatives from the state's Developmental Disabilities Council, its University Center for Excellence in Developmental Disabilities, its Protection and Advocacy agency, and its I/DD State Services Agency. The following four goals were used to structure each summit meeting and also to organize the final report:

1. Assess what was currently happening in the states in self-advocacy – the support structures, activities, accomplishments, and challenges;
2. Plan next steps to strengthen and enhance current efforts at the state level;
3. Develop recommendations for actions needed at the national level; and
4. Develop policy recommendations that can lead to a stronger, more effective, and long lasting self-advocacy movement across the country

Read the entire report by logging on to

www.aucd.org/docs/publications/self-advocacy_summits/2012allies_report_web.pdf

Stop Bullying Now!

~ Terah Green, State Action Coordinator



The Alliance staff are working on a bullying workshop called Stop Bullying Now! Many self-advocates have shared that they have been bullied and want to know more about stopping it.

The workshop is about stopping bullying towards people with disabilities; it will cover what is bullying; why some people may bully others; how being bullied can affect people; and ways to speak up against bullying. The workshop will also discuss why it is hard to stand up to bullies. I have seen people with disabilities being bullied and how badly it can affect someone. I know that bullying is happening to other people and that is why The Alliance is creating this workshop so that we can take steps to stop bullying altogether so it will stop hurting people. We all need to work together to stop bullying!



The Alliance News

Managed Care Update

Managed Care Update: February 2013

~ Megan Norlin, Local Group Coordinator

Happy February! The implementation of Phase Two of Managed Care began February 1, 2013. Phase Two involves getting everyone on Medicare and Medicaid to receive healthcare either through IlliniCare or Aetna. Phase Two also involves providing long-term services for people with different types of disabilities other than intellectual and developmental. DD waiver services are to be included in Phase Three, which is supposed to begin in 2014.

This switch to Managed Care is going to be a long and complicated process. One of the most common questions people are asking about phase two is, "How will all of this be monitored?" For starters, each person under Managed Care is supposed to be assigned a "care manager," which is something like a case manager for health care. A good care manager is supposed to make sure you get all the health care services that you need. Care Managers are also supposed to make sure that the people they serve don't receive any unnecessary health care procedures. Each Managed Care Organization (MCO) must have a process in place for managed care recipients to file grievances, or complaints, should they ever be dissatisfied with the quality of their health care. MCOs must also have a process for filing an appeal, should a managed care recipient ever be denied a service they truly need. As of right now, the Department of Healthcare and Family Services has developed a list of standards to help make sure Managed Care Organizations are doing their jobs properly. The Department of Healthcare and Family Services (HFS) is looking for feedback on this list, which can be found here: <http://www2.illinois.gov/hfs/SiteCollectionDocuments/ICPHQLPM.pdf>. Send HFS as many questions as you can think of. Here are a few to get you started:

I live in _____. Can you give me a list of Managed Care Organizations in my area?
How many people on your staff will be responsible for monitoring healthcare?
If a MCO is not doing what I want and need, what will be done about it? How long will it take?

As we learn more about Managed Care, I encourage you to ask as many questions as possible. Like you, The Alliance is learning as Managed Care is implemented; we keep you posted on ways to make sure your voice is heard. As always, if you have any questions, please feel free to contact me, and I'll do my best to answer them.



The Alliance News

Disability Awareness and Employment



How to Get Businesses to Include People with Disabilities

~ Tara Wickey, Community Organizer

Think about the last time you were in a business. Could you get into the door easily? Did the staff talk directly to you? Did the staff give you extra time and support if you asked for it? Did the business have employees with disabilities?

Why does this matter? Here's why:

- 1 in 5 Americans has a disability

- 30% of families in America includes someone with a disability

- People with disabilities are loyal to brands and products that support disability-related causes

- People with disabilities have \$200,000,000,000 to spend on whatever they want every year!

JJ's List is known for thinking outside the box. JJ Hanley is the founder, and she believes that when people speak with their money, businesses listen. JJ's List helps you tell businesses what you think of their service towards people with disabilities. By putting a business review on the JJslist.com, you are advocating for people with disabilities and making a listing difference. Every review makes a difference! Recently, a young woman with a disability posted that she had trouble getting into her local bank even though a sign on the door said it was accessible. The bank's executive vice president read the review and did something. He made sure that people could get in and out of the bank, and even spoke with the young woman to thank her for sharing. That wasn't all. The bank's executive vice president made sure that employees from all eight bank branches went to disability awareness trainings! Employees learned how to better serve customers with disabilities and how to interact comfortably with fellow employees with disabilities. The bank even joined the Disability-Aware Business Directory on JJ's List. Because the young woman took the time to write a review, the bank now knows about disability awareness and is more open to hiring people with disabilities.

The best part is that every time a review is posted, volunteers with disabilities build their skills by notifying that business. Reviews are coming in from 23 states and word is spreading. It's fast, easy and free to post a review so let your voice be heard!

The next time you visit a business, check it out. Is it disability-aware? Let others know and let the business know by posting your reviews on www.jjslist.com.



The Alliance News

Advocacy Opportunity



SAVE THE DATE

GOING HOME RALLY

Wednesday, April 10, 2013

10.30am gathering with Rally beginning at 11am

Illinois State Capitol at the Lincoln Statue

Springfield, Illinois

"I get to go on more outings, especially shopping and going out to eat where I live now. I am treated with more respect, I get more time to talk with staff, it is quieter because there aren't so many people around and I have better friends now."

~ David B., Decatur, IL, on what it is like to live in the community

People with disabilities can choose where they want to live and can be closer to family and friends. Anyone can live in the community with supports and services. In 2012, Governor Quinn introduced the Rebalancing of the Developmental Disability System to offer people with disabilities the opportunity to live in a community of their choice. The disability system has been studied extensively and the national trend is to downsize state institutions and invest in a community system that offers people with intellectual and developmental disabilities equality, opportunity and improved quality of life.

Learn more about Going Home by visiting us at www.goinghomeillinois.org. Find and "like" Going Home on Facebook at Going Home: A Full Life in the Community.

**Watch for more information on the Going Home Rally
in upcoming issues of The Alliance newsletter.**



The Alliance News

Texting To Include 9-1-1

911 TEXTING MOVES TO REAL WORLD

~ William Jackson

Jan 07, 2013



The move to bring text messaging into the nation's 911 emergency call systems has speeded up in the last year, with several statewide text-to-911 pilot programs, agreements by major carriers to make 911 texting a reality nationwide by 2014 and proposed rules from the Federal Communications Commission that would require all carriers and service providers to enable text services.

In many of the nation's public service answering points (PSAPs) the majority of 911 calls already are being made from mobile phones, requiring updates in an emergency call scheme that was designed for tethered telephones in the legacy wireline system. For many cellular users, texting has become as common as voice calling, if not more so, putting pressure on 911 systems to further adapt to this new reality.

Moving text onto 911 systems also would provide benefits for the 40 million speech and hearing impaired, who now must use special equipment to communicate with 911 answering points via non-voice messages. "We propose to require all wireless carriers and providers of 'interconnected' text messaging applications to support the ability of consumers to send text messages to 911 in all areas throughout the nation where 911 Public Safety Answering Points are also prepared to receive the texts," the FCC wrote in a notice of proposed rulemaking released in December 2012.

The proposed FCC rules are based on an agreement reached in December between major wireless carriers and public safety organizations to begin providing text-to-911 service nationwide. The most commonly used protocol for texting today is Short Message Service (SMS), and the carriers will use SMS-based text in their initial deployments.

As the FCC proposal notes, enabling text-to-911 is a two-sided effort. Local PSAPs, which are run by state and local governments, must have the ability to receive text messages delivered by carriers. A number of states have begun putting programs and infrastructure in place to enable this service for local jurisdictions.

Read the entire article at

http://gcn.com/articles/2013/01/07/911-texting-moves-to-real-world.aspx?s=gcntech_080113



The Alliance News

Advocacy Opportunity



Center for Disability Rights, Inc.

Helping People Help Themselves

Nothing About Us Without Us! Tell Congress and the President to Include People With Disabilities on the Commission on Long Term Services and Supports

The deal that averted the “fiscal cliff” created a new Commission to look at long term services and supports. The Commission will be charged with developing a plan for the establishment, implementation, and financing of a comprehensive, coordinated, and high-quality system that ensures the availability of long-term services and supports for individuals in need of such services and supports. The Commission will be made up of 15 people appointed by the President and Congressional leaders and are supposed to represent the broad range of groups affected by or interested in these issues.

TAKE ACTION below to tell the President and Leaders in Congress that ADAPT and NCIL need to be represented at the table!

www.capwiz.com/rochestercdr/issues/alert/?alertid=62355696#.UQMDRbkWPqM.facebook



Find SACNI (McHenry County) on Facebook at Self Advocacy Council of Northern Illinois

Find The Network (Alton) on Facebook at Impact CIL

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The Alliance News

Medicaid Consumer Alert

Reduction in Number of Prescriptions Filled Without Prior Authorization for Medicaid Consumers

~ Amber Smock, Director of Advocacy at Access Living



One of the challenges presented to Medicaid consumers through the SMART Act last spring is the reduction of the number of prescriptions that can be filled without prior authorization. The target number of prescriptions was set at four. The state has been operating at a limit of seven (7) for some time and beginning Monday, February 4, 2013, the limit is set at five (5) prescriptions.

Here is a statement from Illinois Health and Family Services:

Effective February 4, 2013, the department will reduce the number of prescriptions that can be filled in a thirty-day period without prior authorization from seven to five. In addition, the department will begin to phase-in prescriptions for patients residing in long-term care facilities (LTC), including participants residing in community-based long-term care settings.

Here are links to the notices sent to providers and pharmacies:

Long Term Care Provider Notices page – <http://www.hfs.illinois.gov/ltc/>

Pharmacies Provider Notices page – <http://www.hfs.illinois.gov/pharmacies/>

Medicaid consumers ~ please be alert to this change. The change is the result of efforts to reduce waste in the Medicaid system by making sure prescriptions are properly authorized, but of course the flip side is that there are many Medicaid consumers who rely on more than four, more than five, more than seven prescriptions year in and year out, and requiring pre-authorization could create undue burdens for many. Advocates are hard at work fighting for a system that will work for everyone, but in the meantime do please make sure Medicaid consumers you know are aware of this change.