

# The Alliance News

December 2013



Illinois Self-Advocacy Alliance



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## 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

## SAVE THE DATE

### GOING HOME RALLY

**Wednesday, March 26, 2014**

**Illinois State Capitol      Springfield, Illinois**



Living in the community offers people with disabilities the opportunity to be productive and social, live close to family and friends and enjoy an overall improved quality of life. 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.

Make plans to join with other self-advocates, family members, supporters and allies to share the message of Going Home with legislators.

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

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# The Alliance News

## PATH TO TRANSFORMATION 1115 WAIVER

### GOVERNOR'S OFFICE SEEKING OK FOR MASSIVE NEW WAIVER

Part of The Alliance's mission is to let self-advocates and their allies know about changes happening in Illinois. Governor Quinn's office is working on a big change.

Many people with developmental disabilities living in Illinois get CILA or home-based support. Those services are paid for by the government. The United States government pays half, and the Illinois government pays half. The United States part is paid for by something called a Medicaid waiver.

Right now, the state of Illinois has nine Waiver programs. Three of them are in the Division of Developmental Disabilities:

- Adult waiver (for CILA and Adult Home-Based)
- Children's support waiver (for kids' Home-Based)
- Children's residential waiver (for children's group homes)

The other six waivers in Illinois are for

- People who are elderly
- Children who are medically fragile/technology dependent
- People with brain injuries
- People with physical disabilities (the Div. of Rehab Services' Home Services program)
- People with HIV and AIDS
- Supportive Living Facilities which provides housing and services to people with physical disabilities and the elderly.

Governor Quinn's office wants to combine all of those waivers into one "super-waiver". They call it the Path to Transformation Waiver.

Illinois has hired a large consulting company called Health Management Associates to write the waiver. They are going to be writing it very fast. The formal proposal is to be made to the U.S. Centers for Medicare and Medicaid Services (CMS) by February 15, 2014. After that, it will be up to Illinois' Central Management Services (CMS) to approve or deny it.

The proposal is to take away all of the current waiver programs and create this Path to Transformation 1115 Waiver. The federal government would continue to pay Illinois the same total amount of money they are currently paying for the nine waivers. The state says it will be good because Illinois will be able to decide how to give out those funds. Some people are afraid that people with developmental disabilities will get less than they do now.

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# The Alliance News

## Speak Up and Speak Out Rewind

### **GOVERNOR'S OFFICE SEEKING OK FOR MASSIVE NEW WAIVER (continued from previous page)**

Health Management Associates wants input from people about what they want. The Alliance wants self-advocates to share their opinions. There are a two ways you can do this:

1. Call, write, or visit your legislators and talk to them about it so they can help figure out what to do. If you don't know your legislators, you can look them up at [www.ilga.gov](http://www.ilga.gov).
2. Join The Alliance for the Path to Transformation Waiver Webinar on Tuesday, January 7, 2014 at 1pm. Your input will be directed to Health Management Associates, the consulting company Illinois has hired to write the waiver. Register for the webinar by logging on to <https://attendee.gotowebinar.com/register/2746202168846918657>. You may also e-mail Krescene Beck at [krescenebeck@gmail.com](mailto:krescenebeck@gmail.com) for the direct link.

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### **This Year at SUSO: Our "Putting the U in the Community Presentation**

~ Megan Norlin, Local Group Coordinator

Happy December everybody! Some of you may know that the annual Speak Up and Speak Out Summit took place in Springfield last month. I always look forward to SUSO, and Krescene Beck and I had a great time speaking about individual advocacy, money management, and social security. We had a little help from Kaylee Raymond. She is a real expert in all things related to social security, and very clearly explained the differences between Medicare, Medicaid, SSI, SSDI, and DAC. She took some time to address some rumors about SSI, and she even talked a little bit about Ticket to Work. Social Security can be really hard to understand, and I sure am glad we had someone like Kaylee to help us. She did a great job, and it was wonderful to meet her. Thanks Kaylee!

Along the way Krescene and I made sure to keep our audience on its toes. We asked everyone to check themselves by asking themselves questions like "Do I have SSI, SSDI, or both? Do I get Medicare or Medicaid? How much money do I make? Who takes care of my checks?" Now of course, we did not ask everyone to share this information out loud. It was more of an audit, or a checklist for people to look at and take home, so they could begin to take more control over their money and their lives. The best part about the presentation, though, was hearing everyone's questions and comments. You guys asked some real stumpers, which is what we love to see!

SUSO makes be more and more hopeful about the future every year, and it's great learning and growing with you all. I know I learned a lot! If you missed SUSO this year, don't worry. We'll be sure to put our presentation up on our website for all to see at any time. That's all for now. We'll see you next month, and until then Happy Holidays! Keep Advocating!



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## Advocacy Connections

### SEARCHING FOR SELF-ADVOCACY WORD SEARCH

[SARN Memo from November 20, 2013]

Check out this word search that uses words about self-advocacy

[http://selfadvocacy.us6.list-manage.com/track/click?  
u=67fb25e0bdb57880aab85ce63&id=e3f0bc034f&e=3c343464b1](http://selfadvocacy.us6.list-manage.com/track/click?u=67fb25e0bdb57880aab85ce63&id=e3f0bc034f&e=3c343464b1)

Make copies and use it at your next self-advocacy meeting, bringing one puzzle for each self-advocate. Find and circle the words about self-advocacy and rights. You can also make your own word search by visiting [www.armoredpenguin.com](http://www.armoredpenguin.com).



### e-Buddies Pen Pal Program

e-Buddies is one of the eight programs offered by Best Buddies International. e-Buddies is an e-mail pen pal program that provides opportunities for e-mail friendships between people with intellectual and developmental disabilities (IDD) and their peers who do not have IDD.

e-Buddies is a fun and safe way to make a new friend. Each participant is matched in a one-to-one e-mail friendship, and matched pairs are asked to exchange e-mails once a week for at least one year. Matches are made based on similar age, gender, geography (i.e. participants will NOT be matched with someone from the same state/province), and shared interests.

e-Buddies fully appreciates the risks involved with online communication. For that reason, they have a multi-layered approach to minimize risk and ensure the safety of our participants.

e-Buddies is open to anyone with an e-mail address who is 10 years old and up. All participants join via our online application. Participants with IDD can sign up individually, or in groups through a special education class or a support service agency. *e-Buddies is ALWAYS free of charge for participants with IDD.*

e-Buddies provides individuals with IDD an opportunity to develop new friendships while acquiring much needed computer skills. For volunteers, e-Buddies is a unique opportunity to change a life and make a friend. The benefits of that are immeasurable.

Learn more by visiting [www.ebuddies.org](http://www.ebuddies.org).



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## People, Power, Passion, Possibilities Webinar

Please register for **THE ALLIANCE: Looking To The Future** webinar on  
December 11, 2013 at 10am by visiting

<https://attendee.gotowebinar.com/register/8908319429141304066>

The Alliance needs your input! Join with Alliance staff as you share YOUR ideas on

1. What are you passionate about?
2. What do you want your community to know about you?
3. What do you want the state of Illinois to know about you?
4. What do you want the world to know about you?

Your ideas will be gathered to assist The Alliance in planning events and activities in  
2014 and beyond!

For assistance in registering, please contact Krescene Beck at [krescenebeck@gmail.com](mailto:krescenebeck@gmail.com).



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