



The Voice of Freedom



CNY Grassroots Regional Organizing Program (GROP) Newsletter

Volume 3, Issue 4

Personal Stories: Cheryl Clark

Hello my name is Cheryl Clark and I am a self-advocate. Since I became an advocate and now live in the community, I have seen many obstacles in the community such as inaccessible public bathrooms. One time, in Old Forge, I had to use a bathroom that wasn't accessible at all and there weren't even any grab bars to hold on to. That experience made me very uncomfortable because I had to have someone help me.

These experiences made me want to fight for changes. Also the stores in my community were not

even accessible. I had to write to one store to get the aisles widened. Once I had to climb up the steps on a public bus with someone's assistance

because the bus was not accessible. This was hard for me because I use a wheelchair. So I told a friend to help me write letters. These letters were about how important accessibility was and about ADA legislation. As an advocate, I also had to write letters to our congressman and governor because they wanted to cut funding in a day treatment program that I attended. Thank

goodness they realized what they were doing to me and others with disabilities and

decided not to make those cuts.

I lived at the Rome institution from the age of 5 till I was almost 18. It was very, very hard,

because you couldn't do what you wanted. It was very structured. You had to do what you were told, and you had no choice in the matter. You couldn't even choose what you wore. No choice on what I wanted to eat, and what time I went to bed. They had you in bed at 8 o'clock at night. I was also an advocate while I lived in the Rome institution. I served on the Human Rights Committee there. Even though I advocated for things to change, not many changes ever happened.

After the institution, I went into Family Care. It was better, but I wanted my own apartment. I also wanted my own life. I wanted to be in charge of my own life. Next I moved into a community residence, and I lived there for 9 years. In 1992 they finally realized that I didn't belong there anymore. In 1993 I finally moved



into my own place because I advocated for myself, and somebody finally listened to me.

I've been in my own apartment now for almost 13 years, and I love it! I have a cat and a boyfriend. I do what I want such as go shopping, go to the movies, listen to music and go to bed when I want to. I make my own appointments. I have a job with the Rome Self-Advocacy Speaker's Bureau that I absolutely love! A group of advocates and I give presentations in the community so people will learn about us, and understand that we are also people who deserve a normal life just like everyone else.



Cheryl Clark

Self-Advocacy Group Updates

USA Self-Advocates are not planning to attend the State SA Conference. The group chose to attend just the regional conference for financial purposes. The self-advocates planned a camping trip at Green Lakes State Park on August 8, 9, 10 and 11th. Self-advocates from The Self-Advocacy Network are going to meet USA on the 10th for a picnic and to camp overnight. It looks like they will have a great time. USA was able to make \$400 through a raffle. The \$400 went towards planning their camping trip.

Speak-It Self-Advocates are planning to send a couple of people to the state conference. The group held their annual meeting at an ice cream parlor and they have a picnic planned for next month. Some of the self-advocates are planning on participating in the community forum on October 21st with the DDSO.

The North Country Self-Advocates donated money to the city of Watertown Fire Department to purchase a Thermal Imaging Device. A fire captain is going to attend their meeting in September to demonstrate how the camera works. The group is also inviting

candidates for Jefferson County Sheriff to address the group prior to the November election. Six members of the group are attending the State SA conference. The Jefferson Rehabilitation Center has invited Chester Finn to be a keynote speaker at their annual banquet in December. Several of the North Country self-advocates decided to join JRC, thereby becoming eligible to attend the banquet and hear their friend's speech!

The Broome County Self-Advocates opened a Delaware County SA office in Walton this past June and held an open house. Another SA office is open and in Chenango. An open house is pending due to the recent flooding in the area. The self-advocates published their quarterly newsletter in July and the group is planning a dinner dance fundraiser for August 18.

The Self-Advocacy Network is doing a bottle drive to raise money for different events. The self-advocates went to a Syracuse Chiefs game in July. The group is also doing a raffle with the Information Station at the DDSO. The SA Network is planning a picnic with the USA self-advocates on August 10th at Green

Lakes State Park, and some members will stay overnight with USA members. Some self-advocates are planning to attend the State SA conference in the fall.

The Oswego Self-Advocates will be meeting on August 18th. The group is currently looking for a new advisor. They have a few people interested and then members will be possibly voting on who they want. Two members were interested in attending the state SA conference, but were unable to get someone to take them this year. They're hoping that next year they will be able to attend.

The Oneonta Self-Advocates have gotten together informally over the past couple of months, but with vacations and camping, the group has not been very active. Three members and Linda Steger are planning on attending the state SA conference. The group has decided to move forward with approaching the Arc about benefit time for those who work in the workshop. The group also wants to advocate for better wages.

The Go-Getters Self-Advocacy Group has taken off the summer due to camping & other vacations. The group will begin meeting again in the fall.

Hearings on Aversive Behavioral Interventions

There are public hearings being held around the state on aversive treatment to children who have behavioral issues. VESID issued regulations under the New York State Education Department on aversive behavioral interventions for children with difficult behavioral issues. The regulations mostly talked about establishing positive behavioral intervention for children. However, there was a "child specific exception" where in some cases the regulations could allow for aversive intervention.

Aversive behavioral intervention is really abusive because it allows school professionals to do things like hit, slap, pinch, apply electric shock therapy to the skin, spray with noxious inhalants, withhold sleep, withhold food, withhold fluids, and so forth. Many children in New York State are being sent to Massachusetts and are receiving this type of aversive treatment.

SANYS Board of Directors presented a statement at a hearing in Albany. Following are some excerpts

from the Association's statement:

"We believe there is no place for aversive behavioral interventions in schools or in any facility providing support or services for people with disabilities. The use of electric shock therapies to the skin, hitting, slapping, pinching, excessive restraint, seclusion, the use of foul smells, and other inhumane treatments should not be allowed under any circumstances. We believe that no individual should be subjected to such indignities and that no teacher or staff person should be expected to inflict these treatments on anyone they support."

"We believe in the use of positive behavioral practices that treat people with respect and dignity and give students and their families hope for the future. We believe in person centered planning and individualized supports."

"We feel the State Education Department should have a zero tolerance policy on aversive behavioral interventions. In summary, SANYS challenges all New York State schools and agencies involved in the education of children with disabilities to:

1. Reject policy that

allows placement of students in any facility that uses aversive behavioral intervention.

2. Develop a plan to move all students with disabilities placed in out of state residential schools back to New York State with the supports they need to live at home or as close to home as possible and to receive an education as close to their home communities as possible."



SANYS Annual Picnic

The Rome Speakers Bureau is hosting a picnic at Walsh Center in Rome. It will be on September 20th, from 11 to 2 p.m. For more information, you can call Nicole Spear at 315-473-5080.

Self-Advocates Picnic/Camping at the Green Lakes!

By Mario Alexander and Perry Whittico

On Thursday, August 10, members of the Information Station and the SA Network joined the USA group (self-advocates in Utica) for a picnic at Green Lakes State Park. There were about 20 people who came. We had a **BLAST!**

MARIO: I personally enjoyed the delicious ribs that Cyndy had promised to cook for me. Boy, I was happy! I even got to take the leftover ribs home with me and ate them the next day. My friend, Janufa, also came to the picnic and joined us too. It was very nice to have my friend there.



Mario and his friend, Janufa

I would like to say thank you to my good friend, Agnes, for taking me to the picnic. She invited me to take a ride with her using

her transportation service (ABLE) so I could come. Thank you, Agnes!

I didn't want to come to the picnic when I first heard about the event because I had a dentist appointment on that day. Cyndy made me come! I am happy that she did. Cyndy persuaded me to reschedule my dentist appointment and to join the picnic. It was okay to change the schedule, and I am happy that I could come to the picnic. I also got to talk to people like Rachael Zubal, whom I never met in person (We have spoken on the phone many times).

PERRY: The picnic was very well-organized, although at times it was confusing for me because there was too much going on, but it all worked out at the end.

There are many people who deserve our thanks for making this event happen, such as all the drivers who took people down to the Park. But there are two important people who particularly deserve our special thanks. They are Cyndy Colavita and Rachael Zubal from the Center on Human Policy. They made sure that there was enough food and drink for everybody. They also made sure that people had a good

time by keeping the activity level high. Cyndy did an especially outstanding job—as always—of decorating the place real nice. It surely looked like a nice vacation place by the beach!



A very organized picnic tables!

Me, John, Samantha, Louie, and Cyndy stayed to camp for the night. We cleaned up after the picnic, donated the leftover food to people who were camping there, moved to our camp site, and there we played the golf game! It started as the USA group challenging our group. I decided to keep a close eye on the game instead of playing, but John Sacco played it well and so did Cyndy. It was a lot of fun especially toward the end. The USA group beat us by two points.

Cyndy cooked us a nice breakfast (Menu: Orange juice, bacon and eggs) the next morning. I would love to do it again next year and

hopefully we'll get a cabin next time so I won't have to sleep on the ground!



Relaxing by the beach

Is there someone you think should get a copy of our newsletter? Let us know! Write to us:

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More About The CNY Regional Grassroots Regional Organizing Program (GROP)

GROP is a program developed by the Self-Advocacy Association of New York State. GROP helps to promote the self-advocacy movement in NYS and the CNY Region is involved in many activities including:

- Assisting in the development of Self-Advocacy groups in the region
- Training of Self-Advocates, Self-Advocacy groups and advisors
- Providing presentations to Self-Advocacy Groups, service organizations and at conferences
- Helping Self-Advocacy groups to strategize on disability issues and assist groups with letter writing and position statements
- Providing Medicaid Service Coordination training to Self-Advocates and agency service coordinators
- Providing disability awareness presentations to communities, schools, and service organizations in collaboration with other SANYS projects

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Kudos Corner

On September 14th Michael Kennedy and Doris Moore will each receive an award from the New York State Developmental Disabilities Planning Council. Michael will receive an award on "Substantial Influence on the Lives of Others" and Doris will receive an award for "Promoting Self-Determination in New York State." Congratulations to Michael and Doris! We are so proud of you!

We would like to acknowledge the support of the Center on Human Policy, Law, and Disability Studies. Distribution of this newsletter is supported by the Center's subcontract with RTC on Community Living at the University of Minnesota.

GROP QUOTE OF THE MONTH:

"You must learn from the mistakes of others. You can't possibly live long enough to make them all yourself."

—SAM LEVENSON

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