



# The Voice of Freedom



CNY Grassroots Regional Organizing Program (GROP) Newsletter

Volume 3, Issue 5

## Personal Stories: Jenn Seybert

My life was not always as exciting as it is now. I spent my entire school years in self-contained classrooms for the retarded. We were taken out for our "specials" such as art, adaptive physical education, music, and, on good days, we would join the rest of the school for programs in the gym. The most exciting time of my day was to take the lunch count to the cafeteria and notes to the office. I was never included in an academic setting and what I learned I learned from home and TV.

After I aged out of the school system, I was placed in a sheltered workshop where I put paint sets together, wires in a bag, and so forth. I spent three days a week there and the other two days in a day program that taught me life skills.

All this time I knew I could communicate but no way to express it. My frustration raged in me and my behavior was not the best. I kept watching these people I was with, seeing how productive they could be in society if only given a chance. In the day program I learned to make a bed, over and over and over...Each day I identified a penny, nickel, dime, and quarter, month in and month out. I matched colored teddy bears to colored cards, I colored pictures torn out of a coloring book; I can make toast with my eyes closed...need I go on?

That door opened for me on July 18, 1995, when I was evaluated for Facilitated Communication (FC)

and my silence was broken forever. From that day forward, I have been able to demonstrate my capabilities and intelligence. Not only was the label of being retarded removed...the label of having intelligence was attached.

After months of sharing my locked thoughts to those whom I entrusted in typing with, I began to include the world outside of the glass bubble I lived in, to explore it.

Being able to sit with my Circle and share dreams that have been part of me for so very long, typing them on my computer and having my thoughts read for all to hear, my



Jenn Seybert

person-centered planner writing my thoughts on paper using colored markers for



clarification, and my Circle brainstorming on how to make my dreams become a reality, is one exciting mountaintop high! For example...I wanted to know if there were other beings like myself who used FC to communicate. My mentor and a woman from the agency I chose to support me and find my place in life, agreed to seek others and in a few weeks, a small group was meeting and I named them "The Lonesome Doves."

Because I never got to experience any academics in my high school years, I wanted to go to college. I love learning and am hungry for knowledge. My Circle met many times as we figured out how to make this happen. I chose Penn State University and became a matriculated student there after building my courses semester by

semester. By the time my father accepted a new position in Central New York, I had earned 33 credits and transferred them into Le Moyne College.

I also discovered that reaching out to help others became my first and foremost love in my life. Besides reaching out to others through keynote addresses, I have given trainings and workshops for the Pennsylvania State OMRDD. Topics included Autism, Facilitated Communication, Self-Advocacy and Self-Determination, Dependence/Interdependence, etc.

I actually had a Circle of Support and a Self-Determination piece in place, long before PA provided the funding. Networks for Training and Development supported me in PA. At that time, my county MH/MR, where I resided, did not have the experience or in-depth knowledge that the Networks had.

I was the first in PA to access Self-Determination funding and when we moved to Central New York, I had to begin the process all over and locate those who were working in that project. Steve Smits met with my family and I, and connected us with Doris Moore and a service coordinator.

New York was just beginning with the Self-Determination pilot and since I was the first applicant, it took 18 months to receive funding. My new Circle is still evolving as it changes with people moving in and out of my life.

My Self-Determination dollars go for hiring Bridge-Builders to link me to the different communities we visit. This can be a museum, theater-arts, or some other community event being offered. I use the "Y" for therapeutic swimming.

This is the first time I experienced a Start up Broker. He works hard and is quite thorough in all areas. I find him to be helpful and creative and I am most pleased.

Self-Determination and Circles of Support are wonderful. Folks with disabilities are sometimes seen as society throw-a-ways. I like watching them discover that they have choices by using their voice in how they want their lives to look like. They have choices with whom they want to live with, when and what they want to eat and sleep, and whom they want to hire to help them everyday. This is a blessing and exciting to observe and personally experience.

Along with being a seasoned presenter, I have been published in several books, my keynote addresses have been published in journals, I have done presentations at conferences in Michigan, Miami, Boston, New Hampshire, Pennsylvania, and here in New York. I traveled with three other individuals with autism to Bolton, Liverpool and Manchester, England, to re-light the fire of Facilitated Communication, and we were successful!

I graduated from Le Moyne College on May 21, 2006 with my BA in Psychology and

proudly wore a gold braid draped around my neck and over my gown as I was inducted into the Psi Chi National Honor Society for Psychology majors.

I am currently taking my first graduate class at Le Moyne College, am a new member of the SANYS Speakers Bureau, represented the self-advocates of CNY at the Community Leadership Retreat in October, 2006, and I work as an associate and Consultant for Networks for Training and Development, Philadelphia, PA. I've also participated as a presenter in trainings with Doris Moore, Deb Bojarski and fellow peers, on Circle of Supports, Self-Determination, and Self-Advocacy.

My goal is to attend graduate school and receive my MS in Counseling. I wish to counsel those with Autism to help them work through their emotional issues and develop trust outside of themselves.

All of this came about because I was taught to dream. As each dream became a reality another took its place. There have been many twists and turns in my life and the journey has not always been smooth, but because of Person-Centered Planning, Circles of Support and Self-Determination, my life continues to evolve with me deciding the path.



## SANYS/OMRDD COMMUNITY PARTICIPATION RETREAT "ADVANCING THE VISION"

On October 16-18, the Marx Hotel in Syracuse was the site for a statewide conference co-sponsored by the Self-Advocacy Association of NYS and OMRDD. The aim of the conference was to bring together people from every region and statewide leaders to discuss strategies to bring about opportunities for full participation in all aspects of community life. There were over 100 people in attendance, including Commissioner Maul and his senior staff and the SANYS Board of Directors. It was an exciting, stimulating forum that provided great ideas and motivation to advance this vision regionally and across the state.

The retreat built on the successful SANYS/OMRDD 2004 retreat where a statement was written that described a vision of full community participation. The statement envisioned a time in NYS where people with developmental disabilities will live fully included lives with the supports needed to experience all aspects of community life, will reside where and with whom they choose, and will have a broad range of opportunities for employment, volunteer activities or other interests.

A team from the Central New York region was selected to represent various groups interested in advancing the

vision. Our team was comprised of Steve Smits, DSO Director; Jenn Seybert, Self-Advocate; Ro Vargo, family member; Mary Handley, Cazenovia College professor and community member at large; and Sara Wall-Bollinger, Enable. The team represented the ideas and priorities of the interest groups from the region and will lead follow up activities that will carry forward the strategies formulated at the forum.

A highlight of the retreat was the "success stories" told by people who have achieved their dreams of full community participation. The stories were real experiences in residential living, working, and becoming a full member of the community. These stories, including several from our region, were inspiring and motivated the conference attendees even further.

Another highlight was a presentation by the Arc of Monroe County on the concept of "social capital." Social capital refers to the network of associations, relationships, and supporters that everyone can develop to enhance their full participation in community life. A young woman from Rochester who has gained a lot of "social capital" through her work was featured and her story was very moving.

The conference featured three occasions for small group discussions to brainstorm ideas to advance the vision. People talked about approaches to help bring about more opportunities for people and more acceptance by the

community at large. Each regional team was asked to outline how it would go forward after the conference to bring others into this work on community participation. The Central team thinks that we will need to broaden the involvement of others throughout our region in this discussion with more people from the various interest groups, including direct support staff. We thought that the first step to achieving more community participation is truer person-centered planning. We said that we have to think of all aspects of community life and look for alliances with the community to open these up to persons with developmental disabilities. As examples of this we mentioned more opportunities for college experiences and more participation on committees and boards. We felt that in going forward we have to set specific and targeted goals so as to move beyond generalities.

The consensus is that the retreat was highly successful and inspires us to move on with enthusiasm. The team will be convening a steering committee to work out a local plan that builds on the ideas generated at the retreat.

Steve Smits  
Director of Developmental  
Disabilities Service Office



## Self-Advocacy Group Updates

The **Broome DDSO Self-Advocates** received the Self-Advocacy Group of the Year award by SANYS at the Annual Conference in September. The President of the Self-Advocacy Group was part of the management team at the Commissioner's Retreat in Syracuse this month. Other self-advocates managed the registration table for the retreat.

The **Springbrook Self-Advocates** are currently in transition and are looking for a new advisor. Linda Stager has recently been promoted to Assistant Director. Congratulations to Linda and we look forward to meeting the new advisor.

The **Speak-It Self-Advocates** postponed their dance a couple of weeks ago because of the dinner dance that we held in Syracuse. They rescheduled their dance for the following week, which is a fundraiser for the group. The group's also continuing to look for a new advisor. In addition, the group continues to discuss issues around developmental disability services.

The **USA Self-Advocates** are having a Halloween party and they are planning their annual Thanksgiving dinner for November 15th. The group has also decided to get involved with the Marine Corps' Toys for Tots. They want to get at least a truckload of toys. The group has also decided to adopt a family for Christmas, so they

will be busy getting gifts to give to their family.

The **Self-Advocacy Network** is continuing to raise money with their bottle drive. The group spent a lot of time working on the Fall Harvest Dinner Dance. The President is taking turns with the Vice President in chairing meetings. This is giving the Vice President some valuable experience. The self-advocates are also looking into hotels for the annual conference.

There is a **Consumer Advisory Committee** in Herkimer and Dan, Nicole and Michael have been invited to their meeting on November 20th. We are very excited about meeting this new group of self-advocates!

The **Self-Advocacy Council** in Oswego has a small membership of three to five individuals. Their advisor, Pat Rush has left ARISE and Jim Cronk is temporarily acting as an advisor until a new advisor is chosen. Jim is currently the Treasurer of this group. He also works for ARISE. Jim recently put an article in the ARISE Newsletter in the hope of reaching out and recruiting new members. Their Newsletter goes out to about 400 individuals. Jim said that if they get more individuals interested, he would like GROU to come out and do another presentation.

The **North Country Self-Advocates** has been busy in October. During the month the SA group went to a retreat at Dodge Pond in Degrasse, NY. They met with other SA groups from St. Lawrence and Franklin Counties, and spoke with NYS

Assemblywoman DeeDee Scozzafava about transportation issues. Also, in October the Watertown Daily Times interviewed three North Country self-advocates and published an article about the group and the community issues they are working on.

The **Go-Getters Self-Advocates in Cortland County** has begun to meet again on a biweekly basis. Their numbers continue to grow. They currently have 13 active members. The group has already been discussing what they would like to work on this year. The first thing on the agenda is the election of new officers. Their elections are occurring on November 16th.

The Go-Getters are working on trying to get the local taxi companies to lower their fares for those who cannot afford such a costly expense and addressing the issues of unsafe crosswalks.

In addition, they have been working with others in Cortland County to try and get more accessible public transportation for all parts of the county, including nights and possibly weekends.

The Go-Getters assisted with a survey that was created and distributed to people who utilize the transportation. It was an informational questionnaire asking about peoples thoughts on night and weekend transportation being available. In conclusion to this, there was an article in the Cortland Standard recently that spoke of a grant that First Transit applied for to complete



this necessary needs assessment to see where the services are lacking in the county. The Go-Getters are proud to know that they had a hand in this.

Lastly, there is a bunch of the advocates who are working on their personal stories with the hopes of completing them in the near future.

## Fall Harvest Dinner Dance, October 27th



### A WORD FROM THE REGIONAL COORDINATOR

It doesn't seem possible that it has been six months since I have been working for you here in the Central Region. In that time, I've most enjoyed the time I've spent getting to know those of you whom I've met so far, and watching the amazing work you do to advocate for yourselves and others. Through Speakers Bureau, Real Choice, AmeriCorps, Self-Determination and the Grass Roots Organizing Project, you have committed not only to achieving your own dreams, but also to helping your fellow self-advocates in achieving theirs as well. You do this through your efforts to educate members of your local communities, your service providers, and your government officials. You also show your commitment by keeping your Self-Advocacy groups strong and exciting. Nicole and I hope to visit each and every group over the coming months to meet more of you and to learn how to best support your efforts. Until then, keep advocating.

Dan Flanigan, Regional Coordinator

### *Kudos Corner*

The Self-Advocates want to send a special thank you to Cyndy Colavita for coordinating the Fall Harvest Dinner Dance on October 27th (see page 5 for pictures). It was a great event, with wonderful decorations, great food, a chance to network and the opportunity to kick up our heels and dance the night away. Thank you, Cyndy, for making this great event possible!!!

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