



THE ADVOCACY CENTER  
Putting People First

# The Bridge

*Connecting individuals with disabilities and their families with resources, support and information*



## UPFRONT & PERSONAL:

### Nina Loan

By Monique Baran

When my daughter, Nina Loan, was born 24 years ago, attending and graduating from college was not even a dream that my husband and I had for her. She has Down syndrome and has always been included in her neighborhood schools and classes. We felt she would be successful if she would go from school to a supported job. Just before she graduated from high school at age 19, our local Arc of Yates joined in partnership with the Penn Yan School District and Keuka College to start the D.R.I.V.E. (Diversity, Responsibility, Inclusion, Vision, and Experiential-learning) Program, a program for both school age and adult students with intellectual disabilities located on the Keuka College campus.

D.R.I.V.E. offers students with intellectual disabilities the opportunity to attend school in an

age appropriate setting. All D.R.I.V.E. students are fully integrated into the campus of Keuka College. Students attend at least one college class each semester. In addition students receive instruction in academic skills and a variety of life skills topics.

In the program, Keuka College students serve as peer mentors to D.R.I.V.E. students. They assist students to attend college classes and to assimilate into campus life.

As with any college student, the goal of D.R.I.V.E. students is to obtain meaningful employment upon graduating from the program. Thus work study experiences are an important aspect of D.R.I.V.E.

Nina spent five years at Keuka College in the D.R.I.V.E. Program. She participated in a variety of college classes along with peer mentors who helped her with her class work and projects. The professors were very welcoming and inclusionary. Her last college class was Introduction to Physical Therapy. For her class project, Nina prepared a PowerPoint presentation on what it is like to have a disability. Go to [www.driveprogram.org/category/college-classes/](http://www.driveprogram.org/category/college-classes/) and scroll to the bottom of the page to see her project. Her classmates found it to be very illuminating and they felt this would help them in their future careers.

During her years on campus, Nina became independent with her schedule and navigating around campus. She attended concerts, sporting events,

movies, and religious events along with peer mentors. The peer mentors would often eat lunch or hang out with her and her fellow D.R.I.V.E. students. Nina also did an internship at Peebles, our local department store, to help her with job skills.

At Keuka, person-centered planning involved meeting at the beginning of the year to plan her schedule, monitoring her progress, and then meeting again with Nina at the end of the school year to see what changes Nina wanted. Person-centered planning was especially important this past spring, with Nina leaving college. There were many conversations with Nina, individually and in groups, until we came to a plan that Nina wanted and that was doable.

Because of her experiences at Keuka College, Nina is independent in getting around Penn Yan on foot or on her bike. She has entered a NYS OPWDD (Office for Persons With Developmental Disabilities) job training internship which will lead to a job at a local business. Nina's sister, Carol, recently graduated from college. Who would have known 24 years ago that we would have two college graduates in our family?

## What's Inside...

This issue of *The Bridge* highlights  
**Person-centered planning**





# Is there an Advocate in the House?

**QUESTION: I am concerned about all the changes happening with the People First Waiver. How does this affect my child's services?**



**Janet Austin**  
Director of Individual  
Consumer Services  
The Advocacy Center



**Gretchen Jackson**  
WNYADD Advocate  
(Western New York  
Advocacy for the  
Developmentally  
Disabled, Inc.)



**Janet:** It's good for people to be aware that there are changes going on. I would caution people not to be overly anxious about it. The system is going through a re-design. It doesn't mean the services are going away.

What they are talking about is taking our current system of provision and moving it into a managed care model. So much has to occur for that to happen...I think it is a ways out. The intent is to make the system easier and more person-centered. But at this point, we don't know what that will look like.

**Gretchen:** We certainly need to look outside of traditional services because the whole People First Waiver, is in some respects, going away from the traditional models. But it's important for parents to understand they are not looking to take away services but to possibly deliver them in a different way. Their responsibility is always going to be to care for people with developmental disabilities, but it is

up to individual families to help pull the direction it is going in.

**Janet:** I think what parents need to focus on -- for their young children, children in school or children in a postsecondary setting or adult children-- is not to focus on services but what types of support your child needs. Moving forward, each person will be assessed individually. So look at your loved one, figure out what his or her needs are, and help build community around your child.. using what's out there, natural community supports. Use whatever supports you would use for children that don't have disabilities.

**Gretchen:** I see the People First Waiver as an opportunity for people to focus services more around what the individual wants, instead of fitting into traditional services. So I see that as being very positive. But I also feel that it's really important for parents to stay involved in the process, that they are very well informed by: connecting with other parents, both individual parents and parent groups; doing internet research; being knowledgeable about the OPWDD (New York State Office for Persons with Developmental Disabilities, <http://www.opwdd.ny.gov/> website and how to access information there. It's important for parents to give input along the way through hearings and participation in local groups because this is an opportunity to help design the direction we want this to go in.

Everybody is going to have strong viewpoints about what is best; parents need to develop their own viewpoints and not be swayed. But get views from all different ways, so they can develop their own to help support their child.

It is important for the individual's voice to be heard- that's what person-centered is all about. Give your child many different experiences so that when she is asked what she wants to do, she has the experience to draw from, to make a decision about.

**Janet:** So focus on your child's needs now. If you haven't done person-centered planning, do that. Be able to document what they need, why, and what you are doing to support them. I would like to see person-centered planning begin when the child is 3 or 4 years old. Begin by developing a portfolio or a vision book of what interest areas, experiences, successes and challenges your child has. It's really about taking a look at the individual and what support systems they have, what works in their lives and with their values.

**Gretchen:** With your vision and person-centered planning, I would be sure that the outcome of that planning will allow the child to participate in activities that will achieve that vision. Start at the very beginning, no matter what age your child is, to look at activities he or she can be a part of.

Make sure that your person-centered planning is a well-done process and not just a check-off list. Make sure the activities involved are related to the person-centered plan!

**Janet:** It's our job as service coordinators, the people that provide services, to help people make informed choices. But is also your job as parents to make sure that you have enough information.

# Advocacy Center Upcoming Events & Workshops

## **BULLYING:** Intervention Strategies

**Wednesday, January 16, 2013,  
10:00 am – 12:00 pm**

The Advocacy Center, 590 South Avenue, Rochester, NY 14620  
Presenter, Julie Buick, Parent Education Specialist and Trainer

Bullying is an increasingly serious problem in schools. Parents, teachers, and children need help and support in knowing how to respond. This workshop introduces participants to definitions of bullying, how to recognize it, and how to respond to it both at home and in school.

**Register by January 11, 2013 (Limited Space)**, Family members, \$15; Professionals, \$25. To register and pay online, locate this event on our website calendar: [www.advocacycenter.com](http://www.advocacycenter.com). Contact Colleen Brown at (585) 546-1700, ext 267 or [brown@advocacycenter.com](mailto:brown@advocacycenter.com)

## **Opportunity to Participate in a Study on Friendship**

### **Perspectives on Friendship**

Many students with severe disabilities are now included in public schools, but families and teachers often report that they still do not have friends. In this study we will “start at the beginning” by investigating how parents/guardians and special and general educators think about and make meaning of the concept of friendship.

<http://www.parentcenternetwork.org/assets/files/national/Newsline/BUFriendshipStudy.pdf>



## **Winter Workshop Series – free for parents and family members**

### **Creating Your Advocacy Notebook January 30, 2013 10:00am-12:00pm**

This workshop provides you with the skills, knowledge, and resources to maintain the documentation and records needed for effective advocacy. Participants will leave equipped with a notebook, handouts, reproducible forms, correct educational and legal terms, and greater confidence in communicating with the whole team.

### **ABCs of a School Meeting February 12, 2013 10:00am-12:00pm**

Parents and professionals are invited to attend a variety of school meetings. Participants in this workshop will learn how to get the most out of a meeting and how to be an involved team member before, during, and after a meeting. The workshop will offer suggestions on partnership essentials, such as being prepared and knowledgeable. The ultimate goal is for the parent and school to work together for the benefit of the child's education.

### **Effective Communication February 26, 2013 10:00am-12:00pm**

Do you come away from educational or staff meetings not saying what you intended? Or feeling as though your viewpoint is misunderstood? Do you listen to what other team members say? How do you respond? Communication is key to effective partnerships. Participants will strengthen their collaborative skills by learning effective communication strategies. Topics include verbal and non-verbal expressions, styles of communication, and team building.

All workshops will be held at:  
The Advocacy Center, 590 South Avenue, Rochester, NY 14620  
Workshops are FREE to family members, and you may register for one or more workshops.  
Register online via our calendar at [www.advocacycenter.com](http://www.advocacycenter.com) or by phone at 585-546-1700 ext. 399

## **Nominations for**

# *Community Awards*

## **accepted year-round!**

Do you know someone who stands out in service and commitment to people with disabilities? Or maybe a self-advocate whose work and life direction you admire? The Advocacy Center now accepts nominations for Community awards year-round. Award winners are honored at our annual fundraising event. Don't miss the opportunity to honor a special parent, teacher, community member, or self-advocate! Please contact Rick Wright for further information at (585) 546-1700 or [wright@advocacycenter.com](mailto:wright@advocacycenter.com).

## Interview with Kathy Giordano

Co-author of *A Family's Quest for Rhythm*, *Living with Tourette, ADD, OCD and Challenging Behaviors*, talks about writing her first book, with Maria Schaertel

### A Family's Quest for Rhythm

Advocate Kathy Giordano has co-authored a book with her son, Matthew, entitled, *A Family's Quest for Rhythm*:



*Living with Tourette, ADD, OCD and Challenging Behaviors*.

Kathy shares the ups and downs of her family's experience as well as what and who helped along the way.

Matthew Giordano contributes two chapters, revealing his experience with honesty and humor. Learn how even as a young boy Matt advocated for himself at school. He and his family then discovered his amazing drumming ability not only alleviated his symptoms but helped others as well.

Matt's father, Tony Giordano, shares his experiences too.

Please visit [www.afamilysquest.com](http://www.afamilysquest.com) to learn more and to order a copy.

### Interview with the author

Find out how and why this parent and advocate decided to write and publish her experiences in raising a child with difficult behaviors.

*Families have told me that the book has helped them understand how to support their child while also providing an inspirational story with a positive outcome. Our intention in writing was to let families know that they are not alone and to help families who have children with difficult behaviors. It's extremely heartwarming hearing that we have achieved that goal.*

Click here for the full interview: <http://www.advocacycenter.com/news/2012/12/20/kathy-giordano-co-authors-book-with-son-matt>

# Person-Centered Planning

As opposed to system-centered or disability-centered planning, **person-centered** planning puts an individual's unique needs, interests, and preferences in the driver's seat.

Visit the Cornell University Person-Centered Planning website to learn all about it. It includes:

- an overview of the person-centered planning process
- a self-study course covering the basic processes involved
- a quiz section to help you focus on areas you may need to cover more thoroughly
- readings and activities for you to use on your own
- links and downloadable resources. <http://ilr-edi-r1.ilr.cornell.edu/PCP/>

## Person-Centered Planning Action Steps

### Step 1: Choose a facilitator

A facilitator needs to be a good listener, work creatively to shape the dreams of the individual, discover the capacities within the individual and within the community, and be a community builder. A facilitator can be a family member, school staff member, a service provider, or a consultant. It is helpful if facilitators have previous experience or training on conducting person-centered planning.

### Step 2: Design the planning process

The first meeting can be used to develop the personal profile or history of the individual. This can take a couple of hours. Parents/families and the person with a disability will:

- Develop a list of people they want to invite, sometimes called a Circle of Support, based on their: knowledge of the person and family; Ability to make this process happen; Connections with the community; and Connections with adult service providers (if they will be involved in the future).
- Identify a date and time for the initial meeting and other follow-up meetings.
- Determine the place that will be the most convenient for everyone, especially the person with a disability.

• Discuss strategies that increase the participation of the focus person, the person with a disability.

• Decide who will take a lead in gathering information during the meeting and what person-centered process will be used (PATH, Essential Life Planning, It's My Life, or another).

• Develop a history or personal life story or profile of the focus person by everyone sharing past events in the person's life. The focus person's parents and family may share the largest amount of this information. Critical events, medical issues, major developments, important relationships, and more may be shared.

• Describe the quality of the focus person's life by exploring the following: community participation, community presence, choices/rights, respect, and competence.

• Describe the personal preferences of the focus person. Include both likes and dislikes to get a complete picture.

• Send invitees (Circle of Support members) the personal profile.

### Step 3: Hold the meeting: Implementing the person-centered planning process

• Review the personal profile and make additional comments and observations.

- Identify ongoing events that are likely to affect the focus person's life such as conditions that promote or threaten health.
- Share visions for the future. Through brainstorming, imagine ways to increase opportunities.
- Identify obstacles and opportunities that give the vision a real-life context.
- Identify strategies and action steps for implementing the vision.
- Create an action plan. Action plans identify what is to be done, who will do it, when the action will happen, and when you will meet again.

#### Step 4: Planning and strategizing at the follow-up meetings

Work the action plan. Implementing the plan can require persistence, problem solving, and creativity. Periodically bring the team together again to discuss what parts of the plan are working and what parts are not. Once more, identify what is to be done, who will do it, when the action will happen, and when you will meet again. Make sure that at each follow-up meeting the team:

- Establishes the time, place, of the follow-up meeting;
- Establishes the list of participants;
- Lists all activities that occurred in the past;
- Lists all of the barriers/challenges that occurred;
- Brainstorms new ideas and strategies for the future;
- Sets priorities for the next agreed upon time period.
- Establishes renewed commitment by those participating;
- Lists five to ten concrete steps for each person to follow;

#### Always celebrates the successes!

-Adapted from Mount, B. & Zwernik, K. (1994). *Making futures happen: A manual for facilitators of personal futures planning*. Minnesota Governor's Council on Developmental Disabilities.

## Young Adult Participation in the Planning Process-

### Factors that encourage participation from the focus person:

- Speaking directly to or directing questions toward the focus person.
- Verifying or checking with the focus person on the meaning of his or her answers, responses and suggestions before moving on.
- Speaking at the focus person's language level. By rephrasing words or concepts that were abstract, the focus person participates more productively and remain engaged in conversation.
- Waiting for a response from the focus person. When the facilitator allows the focus person time to formulate and produce an answer, other family members and friends are less likely to jump in, and the focus person is less likely to rely on them for answers.
- Using accommodations to support the focus person's understanding and communication. These include pictures, visual or auditory clues, technology, or any other concrete techniques that facilitate communication.
- Following the focus person's lead to change the subject, take a break or talk more about a topic.
- Setting and maintaining a positive tone.
- Setting aside fears and concerns while the vision is developed. When parents and others feel that their fears and concerns will be addressed during action planning the focus person can be encouraged to speak about their plans for the future and expand upon them during the building of the vision.

### Factors that decreased participation:

- Using jargon: words or phrases that were unclear to the focus person.
- Using the third person: speaking about the focus person to the group.
- Using patronizing language: correcting or talking about the focus person in a way that causes the student to lose face or become embarrassed.

-Excerpts from *Building Authentic Visions: How to Support the Focus Person in Person Centered Planning, Research to Practice 15* by Jean Whitney-Thomas & Jaimie Ciulla Timmons. Originally published: 3/1998

## Person-Centered Approach

Person-centered planning is typically used in Transition, the process of getting ready for adult life or life after high school. But the person-centered approach can be used for anybody, at any age, including people who don't have disabilities.

### ...For younger children

- Document your child's activities and interests.
- Create a vision statement for your child's future. Consider what activities, attitudes, skills, and values you can help your child develop to work towards that vision.
- Teach your child to express his likes and dislikes through speech, art-making, and role-play.
- Give your child choices. Show that you value her ability to decide what she likes.
- Provide opportunities to try different activities. Respect your child if he indicates he is not interested, or not ready, for the activity. Try something else.
- Find or create activities that support your child's interests and strengths.

## Carol Blessing discusses Person-Centered Planning



### **How did the idea of person-centered as applied to individuals with disabilities come about? Where did it all begin?**

Person-centered planning, as I have come to understand it through conversations with those who “invented” it, came about with the thoughtful intention to redefine the social perception and status of people who were labeled as “disabled” – or more explicitly “not like us.” It was never intended to be adopted into the disability service delivery system, but rather to be used as a way to surface the voice of the person and their allies around hopes and dreams for a meaningful future and to use this understanding to advocate for use of resources that created the pathways and addressed the barriers that would otherwise prohibit people from experiencing and expressing life through typical activities and relationships. At its heart, person-centered planning has always been centralized around the ideals of citizenship.

### **What part do you play in encouraging discussion and practice in this area?**

A few years ago I would answer that my part in this work is to try to share the theory and practice processes with others in ways that honored and respected the integrity of the work of person-centered planning as John O’Brien, Beth Mount, Jack Pearpoint, Marsha Forest and others intended it. I would have called myself a trainer, or a facilitator.

I have been deeply influenced by the thinking and writing of Margaret Wheatley. She has this marvelous question that stopped me in my tracks a year or so ago and continues to shape the way I now answer this question. She says: “How do you call yourself? Have you chosen a name that is large enough to hold your life’s work?”

Today, I see my role in this area as creating the opportunity and the

experience for people to reconnect with what has brought most of us to the field in the first place. To awaken what has been made dormant or lulled to sleep by inviting people to remember first personally and then together the soul of this work and to listen to it with what Beth Mount has called the “eyes and ears of the heart.” Now I think of myself more of a Learning Journey Guide. I create intentional space for people to come home to the soul of their work and to go forth armed with tools of insight and wisdom and compassion and courage to take on the status quo.

### **Tell me about the new Citizen-Centered Leadership Development initiatives. How is this an extension of your previous work?**

The Citizen-Centered Leadership Development work is one kind of response to requests for training in person-centered planning. Today, many organizations say that they offer person-centered services, but really what they offer is good customer-driven services. If we are really honest with ourselves about this, people who rely on the service system really don’t get too far from it when the delivery system is leading person-centered planning and practice. Michael Smull says that we have gotten very good at providing better paid supports but that we have not figured out how to really support people away from a significant dependence on the service system. People, by and large, are no more involved in typical community settings than we can point to a decade or so ago. Sure, there may be more community programs but they are disability programs, not the kind of experience most of us who have not been caught in the disability world experience.

So while I have always tried to bring applied learning to the theory of person-centered work in my previous

endeavors, it was always from a place of passing information back and forth and believing people would “get it.” The Citizen-Centered Leadership Development initiative ([www.cclds.org](http://www.cclds.org)) is not and should not be considered a training program. It believes that people don’t need to “get it” because they already “got it.” It says to participants: you matter, you are wise, you are powerful, you are a leader. It challenges participants to make the work first an inside job by engaging them in reflective practice and next to make the work a shared effort...to bring a minimum of two learning partners along for the journey. One of the learning partners must be someone who experiences the label of disability on a daily basis. It says, together we are traveling this road and no one knows better where it needs to take us than you. We also connect participants in a given semester together through storytelling, shared experience and peer learning. The material that makes up the CCLD series isn’t what we are needing to learn, that’s the easy stuff and it’s there as a vehicle when it can be useful. The real learning and the real work is taking the journey. That’s a big leap from being a trainer who used to show up with a bag of tools!

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Carol Blessing, LMSW, faculty, Cornell University’s Employment and Disability Institute within the School of Industrial and Labor Relations. Currently serves as Project Director for the New York State Office of Mental Health Career Development Initiative.

## Dad's Corner

### Daniel Sr. and Daniel Jr.

By Daniel Fluellen, Sr.



My son, Daniel Darrell Fluellen, Jr. (12), and I have a very strong loving father and son bond. To look at us together many would say, especially my wife Barbara, that we could be twins. She would tell you that our mannerisms are exactly the same. We walk the same. When we are watching television we hold our heads to the side the same. Our sense of humor also is identical. He and I will laugh at things that nobody else finds funny. If I am in the same room as he and he starts laughing, I'll start cracking my funny bone too. My wife tells me on numerous occasions that she will see us sleeping and Daniel and I are both lying in the same positions. If I turn over to my right side, she looks in the next room and he has turned to his right. Hey what can I say the son is supposed to take after his father.

Many have asked why do I believe that we are so close?

To look at Daniel, Jr. you would not think that there is anything wrong with him. However, he has Chrons Disease. On top of that he has numerous food allergies. He is allergic to all milk products, wheat, eggs, soy, nuts, corn and etc. If you know anything about that, it has not been easy for him. He has been though things that many adults would never go through including, at his young age, having had 8 colonoscopies and nearly 100 doctor visits. Today he is living a healthy happy life.

Before Daniel Jr. was born my wife and I both had busy work related lives. I was concerned how we were going to take care of a child with our work schedules. I prayed and asked the Lord God what to do. HE led me to quit and take a different significantly lower paying job so that I could work in the evening and take care of my son while my wife worked during the day. Notice I did not say baby sit. And it was the best decision that I could have ever made.

It is my belief, that a father must make countless selfless sacrifices to ensure that everyone in the family unit has a happy and wholesome way of life. Not just providing for the family financially, even though that is a part of it. But by showing that he loves them, of course to the wife, but especially to his children. For there is no love like a father's love.

## Self-Advocates

Person-Centered Planning is all about you. It's about planning for your future. Here are some things to think about:

- What do you like to do?
- What don't you like to do?
- Who is important in your life?
- What is your favorite place?
- What are you good at?
- What do you need help with?
- Who do you like to hang out with?

Want to learn more? Check this out: A workbook just for you: *It's My Choice*, by William T. Allen, Ph.D. You can find it online: [http://www.mnddc.org/extra/publications/choice/Its\\_My\\_Choice.pdf](http://www.mnddc.org/extra/publications/choice/Its_My_Choice.pdf) or ask for a free paper copy by writing to: Governor's Council on Developmental Disabilities Dept. of Administration, 370 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155 or call Toll Free: 877.348.0505 TTY: 651.296.9962 Fax: 651.297.7200

## From the Editor

I want to share with you this glimpse into survival and resiliency in action:

*I have to take a lot more hits in life than most people. That's my life. But it doesn't mean I can't achieve the things in life that I want. In some ways, Tourette's has taught me many skills that I can use to achieve those things better and quicker than others. I can take a hit and know how to keep pushing forward. I've gained a greater understanding how to approach life and people in a caring, understanding and compassionate way, which can help with relationships. In many ways, my Tourette's has helped me a great deal to become an even better and more successful person in life than if I didn't have Tourette's.*

-Matt Giordano,  
*A Family's Quest for Rhythm*

*Maria Schaertel*, Editor

## Resources

**Person-Centered Planning Education Site.** Employment and Disability Institute, at Cornell University's School of Industrial and Labor Relations <http://ilr-edi-r1.ilr.cornell.edu/PCP/>

### **Making Futures Happen**

Beth Mount, Kay Zwernik [http://www.mncdd.org/extra/publications/Making\\_Futures\\_Happen.PDF](http://www.mncdd.org/extra/publications/Making_Futures_Happen.PDF)

**\*\*\*It's My Choice**, by William T. Allen, Ph.D. Choice of: Audio file, PDF version, text version, Spanish text version and a new editable PDF workbook. **All formats available at:** <http://www.mnddc.org/extra/publications.htm>

### **Citizen-Centered Leadership Development Research and Learning Center**

Homepage: <http://www.citizencenteredleadership.org/>



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## Newbie Notes

### Get to know the Family School Partnership at The Advocacy Center!!

Have a question about special education? This link will take you to a form at our Family School Partnership website where you can ask your question. <http://www.specialedparentcenter.org/contact.php>

Need to write a letter but don't know how to get it down on paper?? Don't reinvent the wheel – here are samples for you to use right at the Family School Partnership website: <http://www.specialedparentcenter.org/en/28/sample-letters>

For any questions you may have regarding your child with a disability, please contact The Advocacy Center (585) 546-1700 and speak with our intake receptionist. She will direct you to information or refer you to the appropriate contact.



This newsletter is published by The Advocacy Center  
590 South Avenue Rochester, NY 14620  
(585) 546-1700 1-800-650-4967  
[www.advocacycenter.com](http://www.advocacycenter.com)

Funding is partially provided by a Family Support Services Grant by the OPWDD (Office for Persons With Developmental Disabilities) and by the U.S. Department of Education, Office of Special Education and Rehabilitative Services.

Publication within this journal of articles and information should not be considered an endorsement by The Advocacy Center and/or the funders.

EDITOR: Maria Schaertel  
EXEC. DIRECTOR: Paul Shew  
DESIGN & PRINT: Sarah Stein

This issue underwritten by



**James C. Traylor, ChFC, ChSNC**  
Special Care Planner, Financial Services Professional  
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