Personal Perspectives

Interview with Jeiri Flores, Self-Advocate

What do you for fun?
I go to the movies for fun, I read and I occasionally enjoy an amazing nap. :)

Do you work? If yes, tell us about your work.
I do work, I work a couple of different jobs here and there but more regularly I work for Flower City AmeriCorps. I am serving my time with AmeriCorps at the Southeast Neighborhood Service Center where I assist with community events and city programs.

Do you volunteer? Where do you volunteer? What do you enjoy about it?
I do volunteer; there is not a consistent place I volunteer at right now but if people need me I’m there. What I enjoy the most is being able to help someone or an organization.

Do you go to school? If so, what is your favorite subject or activity at school?
I don’t currently go to school; I graduated college in 2014. My favorite subject then was a class I took where we dissected different social movements. It was one of my only classes where I could openly express my passion for disability rights.

When you were in college, how did you communicate your needs or any accommodations to professors or other school personnel?
When I was in college I had to cultivate a relationship with my professors, resident directors, resident assistants, and any campus staff that I encountered throughout my time on campus. I shared my frustrations, challenges, and needs with them; I was always open with them about my struggles on campus. I created a dialogue that hadn’t existed on our campus.

When you were in elementary school, how did your parents or family members advocate for your needs?
My mom has always been one of my biggest advocates. She never hesitated to tell people what I needed and if she didn’t agree with something they were saying, she told them that.

What is your dream for the future?
My dream for the future changes a little bit every day, but my dream for the future right now is to start a blog.

What does “self-advocacy” mean to you?
Self-advocacy is my way of life.

Can you offer any advice for other self-advocates to communicate their needs or desires to others?
Two things. One, don’t ever be afraid to ask for help; no one does anything alone. Two, you are the expert on all things about you, so don’t be afraid to express your wants, needs, and desires.
Ineffective Listening is Very Common:
You can probably think of examples when you have listened ineffectively or not been listened to over the last 24 hours. You can probably recognise the frustration and irritation when you know the person you are talking to is not listening to you. As listening is so fundamental to the communication processes it is important to try to avoid ineffective listening.

Here are things to watch for:

- You pay more attention to how you feel about the communicator and their physical appearance than to what they are saying. Perhaps you simply don’t like the speaker - you may mentally argue with the speaker and be fast to criticise, either verbally or in your head.
- Not focusing and being easily distracted, fiddling with your hair, fingers, a pen, gazing out of the window, or focusing on objects other than the speaker.
- Feeling unwell or tired, hungry, thirsty or needing to use the toilet.
- Identifying rather than empathizing - understanding what you are hearing but not putting yourself in the shoes of the speaker. As most of us have a lot of internal self-dialogue we spend a lot of time listening to our own thoughts and feelings - it can be difficult to switch the focus from ‘I’ or ‘me’ to ‘them’ or ‘you’. Effective listening involves opening your mind to the views of others and attempting to feel empathetic.
- Prejudice or bias by race, gender, age, religion, accent, and/or past experiences.
- Preconceived ideas or bias - effective listening includes being open-minded to the ideas and opinions of others, this does not mean you have to agree but should listen and attempt to understand.
- Making judgments - thinking for example, that a person is not very bright or is under-qualified so there is no point listening to what they have to say.
- Preoccupation - when we have a lot on our minds we can fail to listen to what is being said as we’re too busy concentrating on what we’re thinking about.
- Having a closed mind - we all have ideals and values that we believe to be correct and it can be difficult to listen to the views of others that contradict our own opinions.

- adapted from: https://www.skillsyouneed.com/ips/ineffective-listening.html

We asked our staff ‘What gets in the way of good communication between families and school staff? What can help?’ and here’s how they responded:

**Jean Tydings**

**Pre-meeting Preparation:**

- Ask yourself:
  - What do you wish to accomplish in the meeting?
  - What do you want your child to accomplish during the next school year?
- Develop an agenda for the meeting
- Write down questions you would like to have answered at the meeting
- Role play what might happen at the meeting
- Treat others the way you would like to be treated
- Take someone to the meeting with you
- Remember that you know your child better than anyone else

**During the CSE/504/Team Meeting:**

- Listen to other team members
- Use the agenda to stay on track
- Request a break if you feel you need one
- Check off your questions as they are answered
- Summarize the meeting if it has not already been done by someone else

**Norann Shiner**

“Always always re-read emails, text and letters before sending them. Ask yourself, “What would I think if someone sent this to me?” Sometimes it’s a good idea to have someone with no personal connection to the communication read it and give their input.”

**Maritza Cubi**

**Barriers to Effective Listening** is a resource Maritza often shares with families.

- adapted from: https://www.skillsyouneed.com/ips/ineffective-listening.html
Family-School Communication and Partnerships

Julie Buick

- Put things in writing when checking for clarification, requesting a meeting, asking for evaluations, or if there is a concern.
- Talk with a friend or someone unbiased prior to a meeting to help prepare you pinpoint specific concerns and action items.
- An agenda of the top 3-4 issues helps you to keep focused about the intent of the meeting and what you want to obtain as a result. It also helps show the team you value their time.
- For meetings, go with the intent to listen, to be open to possible solutions, to bring data that supports your concerns and to keep the focus on the child/student rather than making it about you or others in the meeting.
- The work a family does prior to the meeting can make the difference; ask for a team meeting prior to any 504 or CSE meeting. Talking with the team prior to the meeting also helps to build positive relationships, keeps the lines of communication open and helps everyone to avoid surprises.

From our website:
How Starbridge May Help You:

Starbridge Family Education Specialists and Advocates work with family members of students who have disabilities or suspected disabilities, who are looking for information, seeking support in addressing educational needs, and working to build positive family-school relationships. We educate and empower families to advocate on behalf of their children. Our goals are to improve educational outcomes and build positive family-school relationships.

Starbridge staff can help you understand:
- Federal and state laws and regulations governing the delivery of special education
- How to navigate school systems and policies
- Techniques to help you communicate effectively with the professionals delivering educational services your child needs
- Resources available to assist you, whether provided by Starbridge or other agencies

CSE personnel share advice for parents

We understand the mix of emotions parents may feel as they participate in a Committee on Special Education meeting, whether it is their first or their fifteenth meeting. However, parents are crucial members of the team. Parents know their child best and are their child’s best advocate. We encourage parents to come prepared to ask questions and to work collaboratively with other committee members. Only through teamwork can we work together to create an individualized learning program which can assist a child to achieve.

Julie A. Stark,
Coordinator of Special Education,
and Jason T. deJong,
Director of Pupil Personnel Services, Gates-Chili Central School District

To view workshops we are currently offering, go to our website calendar.

Starbridge webinar recordings on Communication and Partnerships include
ABC’s of a School Meeting and Advocacy Steps:
http://www.starbridgeinc.org/resources/webinar-recordings
Family-School Communication and Partnerships

Ready, Set, Go! Get a Positive Start this School Year

Family-teacher team building early facilitates the continuation of the good start through the rest of the year! Great suggestions for starting things off on a positive note when school begins!

Make a Folder about Your Child
Make a folder with a few pages of information about your child. This is a great place to put your child’s picture. Don’t use the regular school photo. Choose a photo of your child taking part in a favorite activity. This makes your child a real person and provides additional information.

Include a copy of your child’s IEP. While it may be tempting to go through it or highlight portions for the teacher, resist this impulse. This gives the teacher the respect of assuming she will read it and note important points.

Bring your own IEP copy with highlighted points when you meet with the teacher.
The teacher may notice and ask about the highlighted portions. This gives you the chance to reinforce important information, without seeming to tell the teacher how to do her job.

Add a page of information you may have gleaned from last year’s teacher. This is information teachers often do not get. Indicate what worked well with your child and any other positive points from that year. You might include 1 or 2 examples of your child’s work, either from home or last school year. Pick ones that highlight noticeable progress or special talents.

Answer questions.
Indicate your willingness to your child’s teacher to answer any questions she might have about your child. Provide your contact information, especially email. Many times this is the most convenient way for teachers to pass on comments or questions. It also provides documentation for your own files. If you provide phone contact information, include the best time to reach you.

Volunteer to help.
Ask about any needs the teacher has in the classroom, for volunteers, extra supplies, etc.

I used to hit some of the sales where supplies are crazy cheap and give the teacher a package of extra pencils, paper, glue sticks, paper towels, or facial tissues. Many times schools no longer supply these and teachers end up buying them out of their own pockets. Even if you bring in only a few things, it lets the teacher know you intend support, not conflict.

Write a Thank You Note
Follow your meeting with the teacher with a thank you note. Find at least one positive characteristic of this teacher to mention. Even if it is her great smile, or kind tone of voice, whatever you can find. Everyone has some positive things about them.

Introduce Your Child to the Teacher and the Class
Depending on your child and his characteristics, you may want to offer to come into the classroom early in the year to talk with the other students. This works best with the younger grades but can be valuable for both the teacher and the child.

I did this for many years, explaining that my son has autism, that he knows he has autism, that it was not catching, and some things they might see.

Follow-Up With the Teacher Throughout the Year
It’s always a good idea to meet with the teacher before school starts. Don’t hesitate to ask for a brief follow-up meeting 4 or 5 weeks into the year to go over progress. Ask how you might continue to provide support to the teacher. Again, refreshments never hurt!

Address Problems Immediately
Address any overt problems immediately. Be respectful when you voice your concerns.

If the teacher is the one noting problems, listen and ask clarifying questions. “I want to be sure I understand. I think you said…….” Paraphrase what the teacher said.

From Wrightslaw, by Debbie Larson
PTA Tips for Communicating With Teachers Effectively

• Offer to help by signing up to donate items or volunteer your time.

• Provide information that will help the teacher get to know your child as an individual. Include relevant information such as allergies, behavior issues (tendency to be distracted, for instance), learning issues, or changes in family life.

• Ask the teacher about expectations regarding homework and what to do if there are problems with homework.

• Find out the best way to contact the teacher. Ask for times when it is convenient to talk. Don’t expect them to be able to talk if you happen to be at the school and run into them.

• Write short notes (written or as an e-mail, if allowed) and follow up with a phone message to the school if you don’t get a response in a few days. Be sure to include your phone number and/or e-mail address.

• Be diplomatic, especially in e-mail. Choose words carefully and avoid criticizing the teacher.

• In e-mail communication, be brief, stick to the point, and don’t use animation, pictures or graphics. Stick to school-related information in e-mail.

• Be positive and curious. Open with phrases such as “Can we talk about...?” Use “I” statements such as “I’m confused about...” so you don’t put the teacher on the defensive.

• Don’t be afraid to talk to other school personnel if needed. A school counselor might be able to intervene if you are unable to communicate with a teacher.

• Be a partner in your child’s learning. Assist with homework, help your child learn time management skills, talk about school matters at home.

• Send a note of appreciation to the teacher when things go well in class (and mention this to the principal).

• It may be difficult to hear what teachers have to say if they deliver bad news about your child. Try to focus on solutions and work with the teacher to come up with a healthy plan to help your child learn.

http://www.pta.org/programs/content.cfm?ItemNumber=1758

Strive for progress, not perfection.
-Unknown

Walk in the School’s Shoes: Help them WANT to Help Your Child

As a parent, your ultimate goal is to educate school personnel so they want to help your child.

The most important ability to use in resolving problems with the school is to put yourself in the shoes of the people on the other side and answer these questions:

* How do they see the problem? (their perceptions)

* What do they feel and believe? (their beliefs)

* What do they want? (their interests)

* What are they afraid will happen if they give you what you want? (their fears)

**Creating a Life After High School Series**

Ready to Explore Possibilities?

*Creating a Life after High School* is a FREE five-session exploration program designed to help answer the many questions students and family members have as students enter the adult world, such as:

- Where will I live?
- What are the opportunities for learning?
- Where will I work?
- What will I do for fun?
- What agencies can help to provide support?

Join us Thursdays, Oct. 5, 12, 19 & 26 from 5:00 to 8:00pm and November 2 from 5:30 to 7:30pm

Dinner is provided each night.

The individuality of each student is valued and encouraged throughout the sessions.

At the end of this program, participants will apply for funds that will be used to support their future vision. PLEASE NOTE: Participants must attend all sessions to be eligible to receive payment.

Registration is open to all students in Monroe County NY, ages 15-21, who are living at home and who have established DDRO eligibility. A family member/guardian or family friend must accompany the student to all sessions.

Registration is required by Friday, 9/27/17. To register, call Christa Knaak at (585) 224-7370 or 800-650-4967 ext 370 or email cknaak@starbridgeinc.org.

Please request special accommodations at least two weeks before the first session.

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**Join us for the remaining events**

**Building A Vibrant Community: A Series on Self-Direction, Inclusion and Belonging**

**Show Me The Way Home**

September 27, 2017 8:00am-4:00pm
The Strong | National Museum of Play

This full-day conference will focus on a person-centered approach to creating housing for people who have Intellectual or Developmental Disabilities. To be sustainable, a good housing plan must be rooted in the individual's personal goals, address their needs, and identify and optimize their personal resources and public funding. We will follow the paths of two individuals seeking to live independently.

Fee: $99/person for full day; $59/person for half-day session
Fee includes continental breakfast and afternoon snacks. Lunch is not included in the registration fee. The Strong offers a food court and restaurant on-site.

**Supported Decision-Making: An Alternative to Guardianship**

October 21, 2017 8:00am-12:30pm
JCC Rochester, 1200 Edgewood Ave, Rochester, NY 14618

Supported decision-making is not a strange, new thing, but rather a process by which a person who has an intellectual or developmental disability can be supported in making decisions. People who have intellectual or developmental disabilities have a right to make their own choices and decisions, but may need more or different kinds of support to do so. Supported decision-making draws on our common experience of consulting or seeking assistance from others when we make decisions or choices. This session will discuss the movement of supported decision-making for people who have intellectual and developmental disabilities and how supported decision-making can be an alternative to guardianship.

Fee: $59 per person. Registration is required by October 18, 2017. Fee includes continental breakfast and materials.

For both events a limited number of scholarships are available for people who have disabilities, suspected disabilities, or their family members. Email events@starbridgeinc.org or call (585) 224-7248.

**Registration:**
Please visit our website for registration and further details.
2017 Education Conference
Restorative Practices:
Building Connections to Change Behaviors,
Repair Relationships and Improve Results

November 15, 2017 8:00am-4:00pm
Locust Hill Country Club, 2000 Jefferson Road, Pittsford, NY 14534

Challenging behaviors and discipline issues can get in the way of healthy, productive classrooms and schools. Research shows zero-tolerance discipline policies aren’t the solution. So what is the answer?

Restorative practices build healthy relationships and communities by addressing conflict and wrongdoing in a way that works to repair harm through connection, understanding, and growth. A team of experts—both local and national—will present.

Registration Fee:
$99/person. Registration fee includes light breakfast, lunch, snacks, and conference materials.

A limited number of scholarships are available for people who have disabilities, or their family members. Email events@starbridgeinc.org or call 585-224-7248 for more information.

Questions? Call 585-224-7248 or email events@starbridgeinc.org.

For further information or to register, please visit the website.

TASH – “The IEP is not a form” Campaign

seeks to protect the right to education for children who have disabilities.

“The IEP is not a form.” A quote from Chief Justice John Roberts in the Supreme Court’s Endrew F. v. Douglas County Schools opinion, in which the Supreme Court upheld a higher standard of education for students who have disabilities. 6.5 million students in America have an IEP.

For further information, see the TASH website, https://tash.org/the-iep-is-not-a-form-campaign/

TASH is an international leader in disability advocacy. Founded in 1975, TASH advocates for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. TASH works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates.

New York State Partners in Policymaking*

*Learn/Advocate/Lead

Partners in Policymaking is now accepting applications for the Spring 2018 class.

Apply now

Want to learn about NYS Partners in Policymaking?

Please visit: www.nyspip.org.
A low-tech, but effective tool: When Nick was in elementary and middle school, his one-on-one aide and I wrote to each other almost every day in a communication notebook. Since Nick couldn't speak very well, the notebook was a vital tool in letting me know how the day went. It also served as an important means for the aide to ask questions, get my take on Nick's behavior or other concerns, or celebrate an accomplishment.

I hope the communication tips in this issue will help empower you as you go forward this school year. Good luck to all our families!

Maria Schaertel