

Bridges

Provides information and support to people with disabilities, their families, and the community to connect with the HOPE and the HOW.

What's Inside...

This issue of *Bridges* highlights

Person-Centered Planning



👉 **Person-Centered Planning**
Page 3

👉 **Events and Workshops**
Page 6

👉 **Dear Advocate**
Page 7



👉 **Opportunities to Get Involved**
Page 7

👉 **Resources**
Page 7

👉 **New York State Partners in Policymaking®**
Page 7

👉 **From the Editor**
Page 8

Voices | A View from Where I Sit

Editor's note: Jeiri Flores is a strong, passionate Puerto Rican disability rights activist from Rochester, NY. She earned her Bachelor's Degree in Sociology and African-American Studies at SUNY Brockport in 2014. Welcome to Jeiri, who will be writing our Voices column going forward. We're happy to have her on board with *Bridges*!



Jeiri Flores

Is it "person-centered planning" or is it "person-centered living"? If you had to describe your life out loud to someone else, how would you do it? What would you say? If it was to be classified under a specific model or program, what would it be called? Would there be any specific requirements that needed to be completed to be a participant in that model or program? People with disabilities are often asked these questions in one way or another; they are asked to describe their world as if it were a movie. At any given time they are expected to know more about themselves than their non-disabled peers. For example, they could be asked what services are they receiving, who pays for those services, do they have any friends, do they want friends, what is their diagnosis and how does it affect them; honestly the list could be endless. This became more and more apparent to me as I set out to choose a self-advocate to interview who could highlight person-centered planning. I realized that a non-disabled person would never be asked if they lived a person-centered life.

With that being said, I selected a self-advocate who lives a person-centered life. Below you will meet Jonathan "Jon" Ayla who is passionate about living his best life.

Voices | Interview with Jonathan Ayla

by Jeiri Flores

Q: If you had to describe yourself to a complete stranger, how would you describe yourself?

A: I am 29. Hispanic, Puerto Rican. I was born in Rochester. I am an angry, passionate progressive, not liberal, not conservative progressive. I'm right in there with Bernie Sanders. At times I can be the life of the party.

Q: Have you always lived in Rochester?

A: I was born in Rochester and then spent what amounts to a few years of vacation time in Puerto Rico in between grade school and high school.

Q: What's your disability?

A: Cerebral Palsy. It's not all that obvious, but it's still there. And that's the thing: people always see disabilities when they are obvious, not when they're not. They'll see someone like me, it's like "okay there may be something about you, but you don't have a disability." But I do.

continued on page 2



Voices | Interview with Jonathan Ayla *continued from page 1*

It frustrates me because disabilities don't have to be obvious to be there.

Q: What's your support system like? How do people support you?

A: I have my mother. I have my sister, and I have my uncles and cousins in Ohio. My mother supports me with unconditional love. My sister gives emotional support on social media. Every time I am going through something, I can always count on her for comfort. However, she is in Seattle now, which makes seeing her face-to-face quite difficult.

Q: What are some of your goals?

A: To contribute overall to society. That means it can be something as little as socializing to community service.

Q: What's your favorite place to serve?

A: Oh I'm versatile. I don't really care where it is. As long as people appreciate the efforts in community service, I'm perfectly happy. I've volunteered at the Open Door Mission and Rochester Area Interfaith Housing Network in the past.

Q: What do you do day to day?

A: Day to day I usually study for Monroe Community College or read and react to political stuff because I am a politics guy. Politics sink deep right into my life, so now I'm going to sink deep right back into it. I mean everything is political now. No matter what someone does, others will put political spins on it. A few examples of this are some people's thoughts on the *Black Panther* movie, and the many reactions to the Miles Morales version of *Spiderman*. *Wonder Woman* and *Captain America* have also had similar responses. Plus, the reasons why some companies or some people are what they are have a lot to do with politics. Companies will do whatever to maximize their profit regardless of their employees and will support any political candidate

that will let them get away with such actions.

Q: After MCC what is your next step? What do you want to do?

A: The next step for my career is going to be to do some political interviews and for educational purposes is going to be to get the next degree somewhere, maybe at U of R or RIT. I'd like to interview Governor Cuomo about the \$15/hr minimum wage, his stance on subminimum wages, and the Community Integration Act. I mean, is he COMPLETELY for or against the Community Integration Act, or does he agree with some parts of the Community Integration Act, but not others?

Q: How do you make plans for yourself? Do you decide what you want to do?

A: Yes. And it is mainly spur-of-the-moment. Any activities that I want to do, I would want to do right away. There is no planning weeks ahead for me. Example, Last week, I went to see *Black Panther*, which has deserved all the hype it has now, on notice of no more than three hours.

Q: What kind of services do you receive?

A: Well, I do have Medicaid and on Thursday someone comes to my house and we do activities together like community service or any other activity. For example I like hanging out at the Rec center with people from CDR and playing basketball,

working out, and marveling at the artistry on display at the Pieter's Family Life Center.

Q: How do your services help you accomplish your goals?

A: It increases my self-confidence. It reassures me that there is something good I can offer to society.

Q: Five years from now, where do you see yourself?

A: In five years, I may still be in Rochester, hopefully working towards my masters'. People are going to be like "domo arigato (thank you) Master Jonathan."

Q: If you were talking to another advocate, what advice would you give them?

A: To reach for their goals - first identify what their goals are, and then step by step how they're going to reach them, and then do it.

Q: Would you say you're a self-advocate?

A: Yeah, using social media has provided me an avenue to advocate. One of my favorite ways social media does this is that it helps people find other people who are going through the same issues and have many similar beliefs. I'm also getting more confidence in myself, so I produce a better quality of work and quality of advocacy.

(Note: This interview is a transcription and some answers are edited for brevity and clarity.)

Here is one group's attitude about person-centered planning.

Self-Advocates' Pledge

I am IMPORTANT

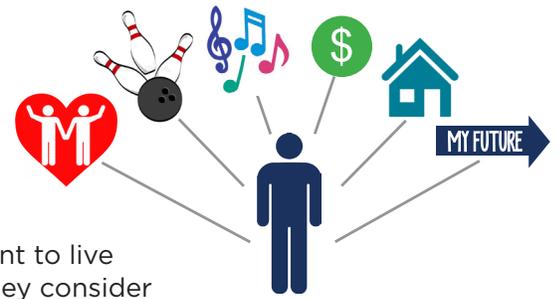
I KNOW what I want

I will WORK HARD to get what I want

I am RESPONSIBLE for the choices I make

Adapted from a pledge of the Santa Barbara Council for Self-Advocacy

Person-Centered Planning



What is Person-Centered Planning?

- Seeks to listen, discover and understand the individual
- A process directed by the person that helps us learn how they want to live and what supports are needed to help them move toward a life they consider meaningful and productive
- Empowers the person by building on their individual abilities and skills, and building a quality lifestyle that supports the person in finding ways to contribute to their community.
- Considers other factors, such as health and wellness, during the planning process.
- Helps to set a direction while providing positive motivation
- Increases the likelihood of achieving the desired outcomes that are most important to the person receiving supports.

Adapted from OPWDD - https://opwdd.ny.gov/opwdd_services_supports/person_centered_planning



What is the Purpose of Person-Centered Planning?

- To look at an individual's strengths and needs
- To assist the person in gaining control over their own life
- To increase opportunities for participation in the community
- To recognize individual desires, interests, and dreams
- Through team effort, develop a plan to turn dreams into reality

Steps to Achieving a Person-Centered Plan

Step 1: Choose a facilitator

A facilitator needs to be a good listener, able to work creatively to uncover the dreams of the individual, discover the capacities within the person 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 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).

Leaders in Person-Centered Thinking

◆ Beth Mount

My life work is devoted to the possibility that all people, particularly those with disabilities, are seen in the light of their capacities and potential.

◆ Michael Smull and Helen Sanderson

If people who use services are to have positive control over their lives, if they are to have self-directed lives within their own communities, then those who are around the person, especially those who do the day-to-day work, need to have person-centered thinking skills.

◆ John O'Brien and Connie Lyle O'Brien

The goal of the human services system should be to join forces with natural unpaid support networks (families, friends, neighbors, coworkers, citizen advocates, et al.) to create conditions and support for people with disabilities to live within their local communities.

◆ Jack Pearpoint and Marsha Forest

In services, staff are often directed to ensure people are kept healthy and safe; in person-centered thinking this is often referred to as being 'important for' someone. What is 'important to' the person and embraces the important people, places, possessions, rituals, routines, faith culture, interests, hobbies, work etc. which makes the person who they are.

Steps to Achieving a Person-Centered Plan

continued from page 3

- Develop a history, personal life story or profile of the person by everyone sharing past events in the person's life. The 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 person's life by exploring the following: community participation, community presence, choices, rights, respect, and competence.
- Describe the personal preferences of the 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 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.

A Parent's View of Person-Centered Planning

by Cindy Ferland

We always prayed that one day Christy would live independently. Person-centered planning was the answer. We gathered the largest team of invested individuals we could while Christy was still in high school and worked out a plan that was the perfect continuation of the road to growth that Christy had always been on.



Christy and sister, Hannah

Christy's daily schedule is what she chooses and because motivation is everything, she is growing by leaps and bounds. She enjoys horseback riding lessons, music lessons, using her gym membership, volunteering at the community center, and spending two days at SHINE, a creative arts program.

The independence and confidence that Christy has gained from the control she has over her future is amazing.

She now has a housemate and is adding new social and communication skills to her routine. The support team has changed a bit over the last four years, but we continue to be surrounded by people who care and are helping to look out for Christy's best interest.

As crazy as it sounds, it is so comforting to know that Christy needs us a little less these days.

Person-Centered Approach for YOUNGER CHILDREN

Person-centered planning is typically used during Transition planning, 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.

- 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 their likes and dislikes through speech, art-making, and role-play.
- Give your child choices. Show that you value their ability to decide what they like.
- Provide opportunities to try different activities. Respect your child if they indicate they are not interested, or not ready, for the activity. Try something else.
- Find or create activities that support your child's interests and strengths

Person-Centered Thinking vs. Non-Person-Centered Thinking

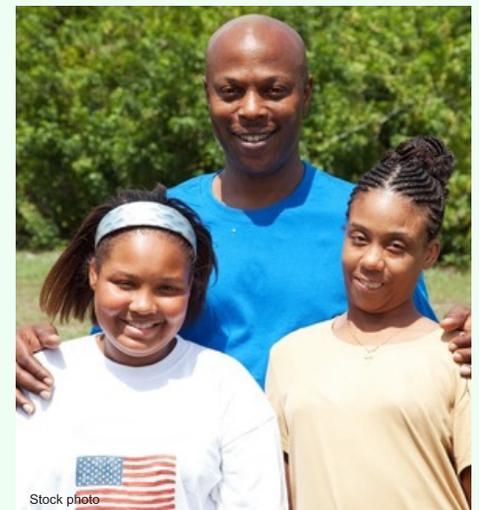
Person-Centered Thinking

- Specific examples of positive activities, experiences, and life situations to increase
- Plans reflect person's unique interests, gifts, and qualities, as well as the unique characteristics and life of the local community
- Emphasizes creative ways to develop and deepen personal relationships and community life

Non-Person-Centered Thinking

- Goals focus on specific negative behaviors to change or decrease
- Plans may look like "one size fits all"
- Little/no mention of personal relationships or community life

Excerpt from Beth Mount, Person-Centered Planning: Finding directions for change using personal futures planning



Starbridge Workshops, Conferences & Special Events

Check our website event calendar for updates! www.starbridgeinc.org/events

Creating a Life After High School Series

Tuesdays, April 17, 24

May 1, 8, 15

5:00-8:00pm

Monroe 2-Orleans BOCES,
3599 Big Ridge Road
Spencerport, NY 14559

This 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. 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. Dinner is provided each night.

Registration is required by 4/6/18. To register, call Christa Knaak at 585-224-7370 or 800-650-4967 ext. 370 or email cknaak@starbridgeinc.org

Disability Disclosure

May 12 from 10:00am-2:00pm

Happiness House,
731 Pre-emption Rd., Geneva, NY 14456

Families will explore why, when, where, and how to tell others about a child's disability. Self-advocates will learn that disclosing to others may help them recognize their strengths and gain skills and support. Participants will leave with a sampling of tools designed to facilitate disclosure.

Registration is required. This workshop is FREE to family members.

To register, please email jmundy@happinesshouse.org or call (315) 789-6828, ext. 7160.

A Family Empowerment Series

10:00am-2:00pm

Saturday, April 28

Corning Painted Post
Middle School Café
35 Victor Highway,
Painted Post NY, 14870

Saturday, May 5

Winfield Elementary School
Café
193 Winfield Street
Corning, NY 14830

Saturday, May 12

Corning Painted Post
High School Café
201 Cantigney Street
Corning, NY 14830

Join us in a series to support families in becoming effective advocates for their children's success in school.

This series is FREE to family members of children who have disabilities. **Plan to attend all three sessions to be an FES graduate!**

To learn more about the topics that will be covered, and to register, please go to the event calendar on our website at www.starbridgeinc.org or call Registration at 585-224-7399.

Registration is required. Registration deadline is April 24.

Light lunch and gas gift cards will be provided each day.



RTI/504/IEP: What's it all about?

April 30, 10:00am-12:00pm

Lincoln Branch Library
851 Joseph Ave., Rochester, NY 14621

When a child qualifies for special education services, federal law requires the development of a document called an Individualized Education Program (IEP). Some students may not qualify for an IEP, but may receive accommodations and modifications from a 504 Plan or may receive support through Response to Intervention (RtI). This workshop will explain the process for receiving supports and services through general and/or special education.

Light refreshments and a gas gift card will be provided.

Registration is required. This workshop is FREE to family members. **To register,** please go to the the RCSD Parent University website or call 585-324-9999.



Join us for a fun and meaningful evening— enjoy fine food, wine, music, and friends! Salute those who create positive change and be part of building opportunities in school, work, and healthy living for children and adults with disabilities and their families.

www.starbridgeinc.org/celebration



Question:

Can you give me ideas to prepare for my daughter's CSE meeting? I want to be a team player, not just a passive listener.

Answer:

Here are some tips you can use to prepare for the meeting:

- Find out how long you have to meet
- Write down your questions and concerns
- Prioritize your child's needs
- Set realistic goals as to what can be accomplished during the meeting
- Ask to meet with the teacher or school psychologist to go over any new testing prior to the meeting

Also, here are some ways to collaborate:

- Ask "What if" questions as a way to propose new ideas: "What if we gave Anna a five minute break?"
- Take notes
- Recap important points before the meeting ends
- Make sure everyone knows who is responsible for specific tasks
- Ask when the tasks will be complete
- Don't forget to say "thank you!"

- Laura Arrington, Family and Youth Education Coordinator

Do you have a question for one of our advocates, a topic or issue you'd like some guidance on? Submit your question on our Facebook page or email mschaertel@starbridgeinc.org - we'll choose one or two to include in the next issue!

Opportunities to Get Involved



Are you interested in wages that direct support professionals receive?

#bFair2DirectCare is the call to action to remind state leaders that the nearly 100,000 direct support professionals (DSPs) who work for not-for-profit agencies do this work on behalf of the state. Please see www.bfair2directcare.com for further information.

Do you have a story or information to share?

We'd love to hear from you! Email mschaertel@starbridgeinc.org

Resources

Pacer Center's National Parent Center on Transition and Employment
<http://www.pacer.org/transition/learning-center/independent-community-living/person-centered.asp>

It's My Choice publication by William T. Allen, Ph.D.
http://mn.gov/mnddc//extra/publications/choice/Its_My_Choice.pdf

NYS OPWDD (Office for Persons with Developmental Disabilities)
https://opwdd.ny.gov/opwdd_services_supports/person_centered_planning

Cornell University Person-Centered Planning Education Site
<http://www.personcenteredplanning.org/>

New York State Partners in Policymaking®

Learn / Advocate / Lead

New York State Partners in Policymaking® is hosting the **Partners 2018 Speaker Series**, a sequence of collaborative workshops on the topics being covered by the Partners in Policymaking® course materials. Recognized experts on the core topics of the Partners curriculum will present in person at these sessions around the state.

Partners Graduates and community members interested in the topic are invited to attend the events in person or online. Sessions are offered at **no cost** to current Partner members and Partner Graduates. Others pay a nominal registration fee of **\$25 for access to all 6 sessions, online or in-person!** For further information, please see <http://www.nyspip.org/speaker-series>





Starbridge Business Hours:

Monday to Friday,
8 AM TO 5 PM

Location:

Wolk Campus of the
Al Sigi Community of Agencies

Mail:

Starbridge
1650 South Avenue, Suite 200
Rochester, NY 14620

Phone: 585-546-1700

Fax: 585-224-7100

President/CEO:

Colin Garwood

www.starbridgeinc.org



1650 South Avenue, Suite 200
Rochester, NY 14620



Bridges

This newsletter is published by Starbridge
1650 South Avenue, Suite 200
Rochester, NY 14620
(585) 546-1700
1-800-650-4967
www.starbridgeinc.org

Funding is partially provided by a Family Support Services Grant by the OPWDD (Office for People 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 Starbridge and/or the funders.

EDITOR: Maria Schaertel
DESIGN & PRINT: On the Move Contracting Services - Maát Reed and Sarah Stein

From the Editor:



“I can just see Nick ushering at a movie theater, Geva Theatre, or RBTL (Rochester Broadway Theater League),” Nick’s service coordinator contemplated during one of Nick’s person-centered planning (PCP) meetings. Based on Nick’s interest in socializing along with his passion for music and performance, she shared her vision with the team.

The PCP facilitator turned to Nick and asked, “What do you think? Would you like to be an usher?” After she explained to him what an usher does, Nick responded “Yes!”

Then Nick’s aunt, another member of the team, chimed in, “I’ve always wanted to volunteer for RBTL. Maybe Nick and I could work together.”

And that simple, quick exchange is how it all began. Nick has been ushering for RBTL for six years with his aunt Lisa Schaertel. Before each show, Lisa reviews seat numbers in their section, so Nick has a chance to see where they are placed. Then when patrons come to the show, Nick is ready to show them to their seats. The other ushers know Nick and value his work, and Nick is proud to volunteer in his community. It’s a win-win situation.

I believe this is an example of person-centered planning at its best: it began with assessing Nick’s interests and ended with Nick pursuing an interest in the community.

Maria Schaertel