



For the Hope and the How

1650 South Avenue, Suite 200
Rochester, NY 14620
starbridgeinc.org

Volume IV, Issue 4 • Winter 2018

Bridges

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

Direct Support Professionals

Direct Support Professionals (DSPs) are people who work directly with people who have disabilities with the aim of assisting them to become integrated into their community or the least restrictive environment.

Examples of DSP job titles include: Classroom Aide, Personal Care Attendant, Home Health Aide, Job Coach, Residential Habilitation Counselor, and Community Habilitation Counselor.

Direct Support Professionals
page 2-6

**Personal Perspective:
Interview with a Parent**
page 4

Webinars:
Fostering Social-Emotional Skills in Young Children
page 7

Understanding Challenging Behaviors in Young Children
page 7

Project SEARCH® Open House
page 7

Voices | A View from Where I Sit by Jeiri Flores

How do you define your own freedom? When you close your eyes and think about it, who else is there? Who else gets the privilege to share your journey? People with disabilities oftentimes find themselves having to share their time, space, and energy with folks who work for them as direct support professionals. And they are the people who help us fly! Is it always comfortable to have to share your most intimate moments with someone else? No, but with their support, we get to do things that we wouldn't otherwise do. We get to have a person with whom we can reminisce, eat meals and talk. It is a very fine line that we walk with our staff; but once we figure out our balance, sometimes our future is brighter because our definition of freedom morphs and we get the opportunity to explore the world a little more, take bigger leaps and ultimately live our best lives.



Voices | Interview with Julian Hiler by Jeiri Flores



Photo: danielsphotos

Q: Where do you live?

A: I have lived in my own apartment for almost three years now.

Q: What do you do for fun?

I go to church two to three times a week, go out to eat, ride around the city, go on mini trips and watch movies.

Q: Do you work? If so, what do you do?

A: Yes I work, but only per diem. I am a Peer Specialist at the Center for Disability Rights. I go out to nursing homes and help individuals come up with goals to get out of the nursing home and into the community.

Q: How many aides or supportive staff professionals work with you?

A: I have 24-hr aide service: three aides in total and one back up.

Q: What do they do for you?

A: All of my daily living needs and much more. Like they cook all my meals, help me get dressed, and make sure I get out into the community.

Q: How long have they worked for you?

A: All of them have been working for me for two years now.

continued on page 6

Direct Support Professionals

What Does a Direct Support Professional Do?

DSP work may include:

- Meal preparation, grooming, and toileting
- Medication administration
- Lifting and moving people to meet mobility needs
- Tube feeding, diabetic and wound care, oxygen administration

- Providing transportation
- Teaching personal care skills, money management, and social skills
- Supporting the delivery of physical and behavioral health services in both routine and crisis situations
- Forming close, trusted relationships with people who have disabilities and their families

- Respecting the human dignity and uniqueness of people they support and serving as advocates through the promotion of human and civil rights
- Understanding and communicating complex information via daily logs and progress reports

- www.bfair2directcare.org

15 Competency Areas of DSPs

What should a DSP be able to do? The next time you encounter a School Aide, Health Aide, or Community Habilitation Counselor, consider all the skills and knowledge they are using to do their jobs. The National Alliance for Direct Support Professionals outlines the following competency areas:

- 1. Participant Empowerment** - enhances the ability of the person to lead a self-determined life by providing the support and information necessary to build self-esteem and assertiveness; and to make decisions
- 2. Communication** - should be knowledgeable about the range of effective communication strategies and skills necessary to establish a collaborative relationship with the person
- 3. Assessment** - should be knowledgeable about formal and informal assessment practices to respond to the needs, desires and interests of the person
- 4. Community and Service Networking** - should be knowledgeable about the formal and informal supports available in their community and skilled in assisting the person to identify and gain access to such supports
- 5. Facilitation of Services** - is knowledgeable about a range of participatory planning techniques and is skilled in implementing plans in a collaborative and efficient manner

- 6. Community Living Skills and Supports** - has the ability to match specific supports and interventions to the unique needs of individual persons and recognizes the importance of friends, family and community relationships
- 7. Education, Training, and Self-Development** - should be able to identify areas for self-improvement, pursue necessary educational/training resources, and share knowledge with others
- 8. Advocacy** - should be knowledgeable about the diverse challenges facing people (e.g., human rights, legal, administrative and financial) and should be able to identify and use effective advocacy strategies to overcome such challenges
- 9. Vocational, Educational, and Career Support** - should be knowledgeable about the career and education related concerns of the person and should be able to mobilize the resources and support necessary to assist the person to reach his or her goals
- 10. Crisis Prevention and Intervention** - should be knowledgeable about crisis

prevention, intervention and resolution techniques and should match such techniques to particular circumstances and individuals

- 11. Organizational Participation** - is familiar with the mission and practices of the support organization and participates in the life of the organization
- 12. Documentation** - is aware of the requirements for documentation in their organization and is able to manage these requirements efficiently
- 13. Building and Maintaining Friendships and Relationships** - support the person in the development of friendships and other relationships
- 14. Provide Person Centered Supports** - provides support to people using a person centered approach
- 15. Supporting Health and Wellness** - promotes the health and wellness of all persons



Making a world of difference
in people's lives

- Adapted from
<https://nadsp.org>

Direct Support Professionals

Personal Perspective: Interview with a Direct Support Professional

The following interview is anonymous to respect the privacy of all those involved. The opinions expressed here are not necessarily those of Starbridge.

MS: How many people do you support per week and how many hours do you work?

DSP: I support four people and work 35 hours per week.

MS: How many years have you been a DSP?

DSP: Approximately ten years.

MS: Tell me about some of the rewarding aspects of the work you do.

DSP: I am naturally a caretaker, so it comes easy for me to care for people. I enjoy seeing people succeed, with or without my help, and to watch them grow. I enjoy having bosses who are supportive and understanding. It's important to me that my bosses respect people who have disabilities and treat them with dignity. I thrive working with this kind of direction, and so do my clients.

MS: What aspects do you find challenging?

DSP: Since I do care about people, it's challenging to separate my life at home from life at work. It's hard not to bring work home with me, in my thoughts and feelings. And I have found that if something is bothering me at home, it's important not to take that to work because my clients will pick up on it and be concerned about me.

Also, I have had bosses who are not supportive, and this job is extremely hard to do with a boss who doesn't support you. For example, if something challenging is happening with one of my clients, I need to be able to go to my boss and share that. I need their advice and perspective on the situation. Otherwise, I feel that I am totally alone in the situation. In fact, I left a previous job for that reason.

MS: Do you feel you have had enough training to accomplish all that your job requires? How could training be improved?

DSP: We're always doing different things, so sometimes I'm learning on the fly with a client if there's some

activity they would like to do, for example. Training can't prepare you for everything.

In residential, we get a lot of background information on the client, so I feel better prepared to work with them. Maybe the thought is that in residential, there is often a medical component, so there is more information given about the person to be sure their needs are met. I have found that in Com Hab, we don't get as much background information on the person, but I feel it is equally important to know about the client so we can work them. For instance, knowing ahead of time that they struggle with something in particular would be useful information.

Stress management training would be helpful too. It's a stressful job and I think that's why we are given generous vacation time. But knowing how to handle the stress week to week would be good.

More training for management would be helpful too: how to handle staff and how to be supportive; also, in residential, how to keep some conversations between the DSP and management confidential so that the client is not affected by challenging or negative situations. You might think that people with disabilities don't see how you are interacting with staff, but they do. We have to think about the environment that we are building. You want a nurturing environment all around.

MS: What are some of the things you do to avoid caregiver burnout? How do you take care of yourself?

DSP: Well, that's hard. I think that is something we need to be reminded of: to take care of ourselves. I try to take my vacation time and not feel guilty for it. My clients often want to know why I'm taking vacation and what I'm doing, so I have to remind myself it's OK to take vacation. Also, I try to save work for the work day and not take it home with me – I think that's really important and not easy.



MS: Does any of your work involve communicating with families of the person with a disability? If so, how would you describe your relationship with families?

DSP: Yes, it does. In residential, I will see families mostly around the holidays. In ComHab, I may see a family weekly or every six months at an ISP* meeting; it varies. The best situations are those with families that truly care for their loved one and want to be involved, but also realize that I have a job to do, and allow me to work with their loved one. That's what I'm there for is to help, and they support that. Sometimes there are families who are going through hard times, and they fight me in what I am trying to do, and that makes the job more difficult. There are some sad situations where families are struggling to care for their family member, and I have felt that I cared more for the person than their family does – that's really hard. I have dealt with some really tough family situations where there has been borderline abuse, and I wondered, "What do I do with that? How do I handle that?"

At the same time, I know there are maybe families that have had to deal with staff that have not been the best, and that makes them more uptight. I understand that.

MS: What advice would you give someone just starting work as a DSP?

DSP: I would say, try not take work home with you. And don't be afraid to voice your observations or concerns, but I know if it's not a healthy work environment, that's not always going to be possible or easy. But it needs to be possible; it needs to be OK. It makes for a better environment for everybody, especially for the people we serve.

*Individualized Service Plan; will be referred to as a Life Plan as of July 1, 2019

Direct Support Professionals

Personal Perspective: Interview with a Parent

The following interview is anonymous to respect the privacy of all those involved. The opinions expressed here are not necessarily those of Starbridge.

MS: How old is your child? Describe your child's needs.

Parent: He is 32 and has significant, complex medical needs. He is diabetic, so his blood sugars are monitored throughout the day. He has spinal issues and is in a wheelchair, so all of his transfers have to be handled by two people. He's asthmatic. He has no permanent teeth, doesn't chew, and has no gag reflex, so his food has to be chopped and soft, but not pureed.

He uses a device for communication and uses it pretty well except for when it comes to medical needs – he doesn't like to tell us when something's hurting or bothering him. He doesn't have a lot of feeling as far as pain goes below his waist, so we monitor for any falls or any mishaps and get x-rays. He's in remission from leukemia, so we do body checks twice a week for any lumps, bumps or bruises.

He's legally blind. He's losing weight, so we have to make sure he is on a high calorie diet. He's got severe osteoporosis, which complicates everything. We have to watch for his breaks and anything that happens. He has severe scoliosis as well as rheumatoid arthritis in his spine.

MS: Are there any DSPs you remember as being outstanding in caring for your child?

Parent: Yes! I've had one that literally saved his life. The DSP noticed that my son wasn't acting right, that he just didn't look right. The on-call nurse and the manager weren't concerned, but the DSP called me right away. So I got over there, rushed him to Emergency, and he was so dehydrated, they put him in the Intensive Care Unit. The doctor said, if they had put him to bed, he would have never woke up. He doesn't present like everybody else when they're sick. This DSP was fairly new and didn't have any medical background – she just knew that something wasn't right. Right now,

we have a DSP who's also really good with my child; she always lets me know when something is up.

MS: How do you approach a DSP about a problem you may perceive in your child's care?

Parent: Most of the time I have to approach them when dinner is being prepared. For instance, the other day I walked in and he had toast on his plate. Well, because he has no teeth and can't chew, that would have caused choking. So I took it away. You have to be very gentle with the DSPs because they have to follow a lot of rules and regulations, and it's very scary for them. They know if they mess up, they could be fired. So I showed them and said, "This is dangerous for him, so let's learn how to do this. Let's not get upset. Let's use this as a teaching experience." And it calms them right down. It really relieves their anxiety. If there's something else of concern that isn't an emergency, but that needs to be addressed right away, I take it to the agency, and I have them talk with the staff. If it's really something I'm uncomfortable with, I take it to upper management.

MS: How would you describe your relationship with your child's DSPs?

Parent: It's really good right now; it's awesome. Prior to the last three months, it wasn't so good because there were a couple of staff who were really triggering his PTSD. I ended up putting a tape recorder in his room. The manager and the assistant manager realized what I had done, and they didn't like it so much. I had been talking with them about the issue, but nobody could figure it out because it was taking place behind my son's closed bedroom door. But the Justice Center determined that evidence from the tape recorder

proved abuse. So those direct care workers left, and new people are there, and we're doing really well. It's taken awhile to rebuild that trust and not give up and to really work with them.

When the relationship is working, it's really important to tell DSPs, "I really appreciate everything you're doing. I can't commend you enough for your patience, for everything that you're doing, not just for my son, but for everyone at the house." That goes a long, long way. It's not just about pay; it's about recognition and about validating their concerns; it's about praising them for everything they do right, not just about things that have to be corrected.

MS: In what areas do you think there needs to be more training?

Parent: Everybody is trained on the agency's expectations and what OPWDD's expectations are. What they don't know is that there's a person there, not just somebody with a disability, but somebody with a history. My son has a life. He has a family: aunts, uncles, cousins. He has done so much in his life. So I think it's important that they know that so that they can know him and talk to him. People with disabilities have life experiences like everybody else, but they can't always voice it. So if the DSPs know who he used to be by watching videos that I have provided of him, they realize he used to walk. He used to do a lot he can no longer do. So it's not just about his medical needs: it's about him as a person, an individual that has dreams, expectations and wants, just like everybody else.

And parents, we're the constant. We've been there for 32 years. So we know the past, the present, and can anticipate sometimes the future. Families know their loved one best.

"It is really hard for people in direct care to see their power. They often see themselves as the least powerful person in the organization so they forget that they are often the most powerful person in the life of somebody with a disability." -Dave Hingsburger

Direct Support Professionals

Personal Perspective: Interview with Neil Cavalieri, Starbridge Community Living Manager

MS: Describe the training of DSP managers. What do you need to know in order to manage DSPs?

NC: There is a lot of collaboration that takes place between my supervisor and myself because the nature of our program can have different challenges on a daily basis. In my experiences as a DSP manager, I would say you would need to know how to problem solve and troubleshoot. In most situations, DSPs just need some general guidance to help them problem solve (i.e. schedule changes, issues/concerns with the individuals they serve).

MS: In an ideal situation, what is your relationship with DSPs? How do you cultivate trust with the DSPs you are managing?

NC: I always tell the staff that I supervise: "I would never ask you to do something that I wouldn't or haven't already done." That helps build trust right away and lets them know that I won't put them into a situation they are uncomfortable with. I try my best to allow my actions to speak louder than my words, so they have an example to work from. An ideal relationship between a DSP and a DSP manager is one that has a mutual respect.

We had a person who moved out into the community about a year ago, and she was working with one of our staff. The person purchased new furniture and some of the furniture that was delivered needed to be put together. The Com Hab staff and I arranged a time to meet at the person's apartment to assist with putting the furniture together. This person did not have a lot of natural supports and was very anxious about her move and new apartment. This simple gesture of collaboration made it a good experience for her. In this situation, I felt it was good for me to work alongside the staff and allow my actions to speak for themselves and vice versa. There is much mutual respect that comes from experiences like this.

MS: How do you help resolve a problem a DSP may be having with a person under their care?

NC: My approach is to talk the concern/situation out with the staff; because most times they have the answer – they're just looking for someone to bounce ideas off of. From there I would offer suggestions/next steps for the DSP. Depending on the situation, I will step in and make the necessary phone calls, set up a team meeting, or even schedule a time to visit the individual.

MS: What are the main responsibilities of managers in an emergency situation?

NC: Responsibilities for emergency situations can vary from program to program, because some are certified sites and have different requirements. Speaking from a Com Hab Manager perspective, my responsibilities are to make sure that both the individual and staff are safe. When we initially welcome a person into our program, we develop a "Safeguards" section on their plan for any staff working with that person to refer to. This section contains important information regarding medical/behavior concerns along with actions steps if a situation were to arise. There have been a few instances where I have actually relieved a staff from a visit because



Stock Photo

of some type of emergency. For example, during a Com Hab visit recently, the counselor's car was hit by another vehicle during a visit. I drove to the accident scene to assist the counselor with anything they needed at that time and actually transported the individual to his doctor so the staff could take care of her car.



Resources

National Alliance for Direct Support Professionals, <https://www.nadsp.org/>

The Direct Support Newsletter, <http://www.vitacls.org/client/newsletter.aspx>

"You Just Don't Do That!" Drawing the Line Between Direct Support Staff and People with Disabilities, by Stephanie Ioannou, Service, Support and Success: The Direct Support Worker Newsletter, Volume 1: Issue 13, <http://www.thefamilyhelpnetwork.ca/wp-content/uploads/2013/03/ssss-boundaries-direct-care.pdf>

Direct Support Professionals

Reporting Abuse and Neglect

What happens if a DSP or family member reports abuse or neglect to agency supervisors and/or quality assurance personnel, but the concern is ignored? If a concern is not addressed appropriately at the local level, you can call the New York State Justice Center.



The Justice Center operates a centralized, statewide toll-free hotline and incident reporting system that receives and tracks allegations of abuse and neglect 24 hours a day, 7 days a week. Reports can be made by service providers and others who are "mandated reporters", as well as by anyone who witnesses or suspects the abuse or neglect of a person with special needs.

To Report Abuse: TOLL FREE: 1-855-373-2122 Free language services available.

Dial 7-1-1 for NYS Relay Service and give the operator 1-855-373-2122. If a report involves an emergency situation, please call 911.

If you need to report abuse or maltreatment of a child by a parent or other person legally responsible for that child, or by a day care program, please call the NY Statewide Central Register of Child Abuse and Maltreatment at 1-800-342-3720.

- <https://www.justicecenter.ny.gov/>

#BFair2DirectCare: Continuing the Fight for a Living Wage

#BFair2DirectCare is an initiative to raise wages for New York State Direct Support Professionals. Currently, DSPs in NYS earn on average between \$10 and \$13 per hour.

#BFair
2DirectCare

"We are the voice of 130,000 New Yorkers with developmental disabilities who often cannot speak for themselves.

#BFair2DirectCare is also 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.

These professionals, who carry out such diverse tasks as helping people eat to administering medications, need and deserve a living wage for the work they do. Otherwise, our system of caring for persons with developmental disabilities, created in the wake of the 1970s scandal at the state's Willowbrook facility, risks collapse as direct care workers seek better wages in fast food restaurants and big box stores.

Almost all funding for these agencies comes from government, at rates set by the government."

Want to learn more about progress in this initiative or find out how to get involved? Please see: <http://www.bfair2directcare.com/#home>

I Needed My Caregiver to Keep Me Alive. She Exploited That Power.

It's important to be aware that abuse can happen by direct support professionals. Please see the following article to learn about one person's experience:

I Needed My Caregiver to Keep Me Alive. She Exploited That Power, by Hannah Soyer.

-<https://www.rootedinrights.org/i-needed-my-caregiver-to-keep-me-alive-she-exploited-that-power/>

Voices |

Interview with Julian Hiler

continued from page 1

Q: Do you think they were prepared to be working with you?

A: No. I was in desperate need at the time and kinda just started off with one of them and then worked my way up to the three I have now.

Q: What do you like about your interactions with your aides?

A: They treat me like I'm one of their own. I never have to worry about going without.

Q: What don't you like?

A: I don't know because they've been doing it for so long, we have a routine now.

Q: If you could give advice to a new aide, what would it be?

A: Don't be so quick to get mad with your clients because they're not what you're used to. Take time to get to know them and figure out what they like and don't like especially if you're considering this to be your long term job.

Q: What advice would you give someone with a disability who is in the process of hiring supportive staff?

A: Make sure you hire someone that you trust and is willing to deal with you on your good and bad days.

Starbridge Workshops, Conferences & Special Events

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



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 by email to mschaertel@starbridgeinc.org – we'll choose one or two to include in the next issue!

Project SEARCH® Open House

**Jan. 16, 12 to 2 pm,
Jan. 17, 6 to 8 pm**

The Summit at Brighton
2000 Summit Cir Dr.
Rochester, NY 14618

Visit the Adult Project SEARCH® at Jewish Senior Life internship program. Meet interns and staff to learn about the exciting opportunities offered. Learn how an internship can prepare you for paid work. Obtain information to apply for the 2019-2020 program. RSVP to Shawna Boynton at Sboynton@heritagechristianservices.org, (585) 405-1639

Opportunities to **GET INVOLVED!**

Do you have a story or information to share? We'd love to hear from you! Email mschaertel@starbridgeinc.org

New York State Partners in Policymaking®

Learn/Advocate/Lead

Please visit:
www.nyspip.org.



Webinars

Fostering Social-Emotional Skills in Young Children

February 7, 2019 | 7:00-8:00pm

While every child develops social-emotional skills at a different pace, there are milestones to watch for between birth and 8 years old. Join us as we talk about social-emotional developmental milestones and the social skills children need to develop confidence and positive self-esteem in their early years. Starbridge is pleased to partner with Beth Grier-Leva and Barbara Wischnowski of the Regional Early Childhood Direction Center to discuss developmental milestones and supports available to families with young children.

This event is presented via webinar, and is not broadcast in our office. To participate you must have access to a computer at another location – your home, office, or other facility.

To register, go to the event on our calendar at www.starbridgeinc.org/events

Questions? Call Registration at 585-224-7399.

Please request special accommodations at least two weeks before the event.

Understanding Challenging Behaviors in Young Children Webinars

February 13, 2019, Part 1; February 28, 2019, Part 2 | 7:00-8:00pm

When you are tired, frustrated, scared or overwhelmed, how do you let someone know? For young children, they often don't have the vocabulary or self-awareness to express their needs. Their behavior is their way to communicate with the adults in their lives. So what can adults do to support children with challenging behaviors and hopefully prevent or decrease behaviors in the future?

Join us for a two-part webinar to look at: Factors that influence young children's behavior; What differentiates typical from challenging behavior; What adults can do to prevent challenging behaviors; Factors adults should consider in responding to unwanted behaviors; Strategies to promote positive behaviors – at home and at school

Starbridge is pleased to welcome Jennifer Rymanowski, PhD, BCBA-D, Midwest Regional Special Education Technical Assistance and Support Center. We encourage families and service providers who work with children ages 3-6 to sign up today!

This series is presented via webinar, and is not broadcast in our office. To participate you must have access to a computer at another location – your home, office, or other facility.

To register for these webinars, go to the event on our calendar at www.starbridgeinc.org/events

Questions? Call Registration at 585-224-7399.

Please request special accommodations at least two weeks before the event.

**Starbridge Business Hours:**

Monday to Friday,
8 AM TO 5 PM

Location:

Wolk Campus of the
AI Sigl 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:



My son, Nick, has needed direct support professionals in his life from an early age. Whether it was his one-on-one aide in elementary school, the classroom aides in high school, or his current job coach, Nick's DSPs have provided the necessary support to participate in the least restrictive environment at school and to participate fully in his community.

For me, one of the most important roles they have fulfilled is that of communicator between home and school or work. Since Nick can't always communicate his experiences to me very well, I have depended on a partnership with the DSP to let me know how things are going. Early school daily communication notebooks from Nick's one-on-one aide let me know things like: how Nick participated during circle time, if he ate his lunch, if he had homework, and if he made any new friends. Today, an occasional text from his job coach lets me know things like: he needs to fine-tune a skill, how he treats customers, how he relates to his boss, and how he advocates for himself.

Through the years, Nick's DSPs have displayed many excellent qualities. They have been person-centered in their approach; understood Nick's strengths and needs and respected him as an individual; acted as bridges to teachers, classmates, community members, and co-workers; helped Nick to discover new ideas and abilities. For their hard work and commitment to his growth and development, I will be always be grateful to the DSPs in Nick's life.

Wishing all of our readers happy holidays and a happy, peaceful 2019!

Maria Schaertel