

**A publication of the National
Alliance for Direct Support Professionals**

Frontline Initiative

Volume 9 • Number 3 • 2011

Building successful partnerships

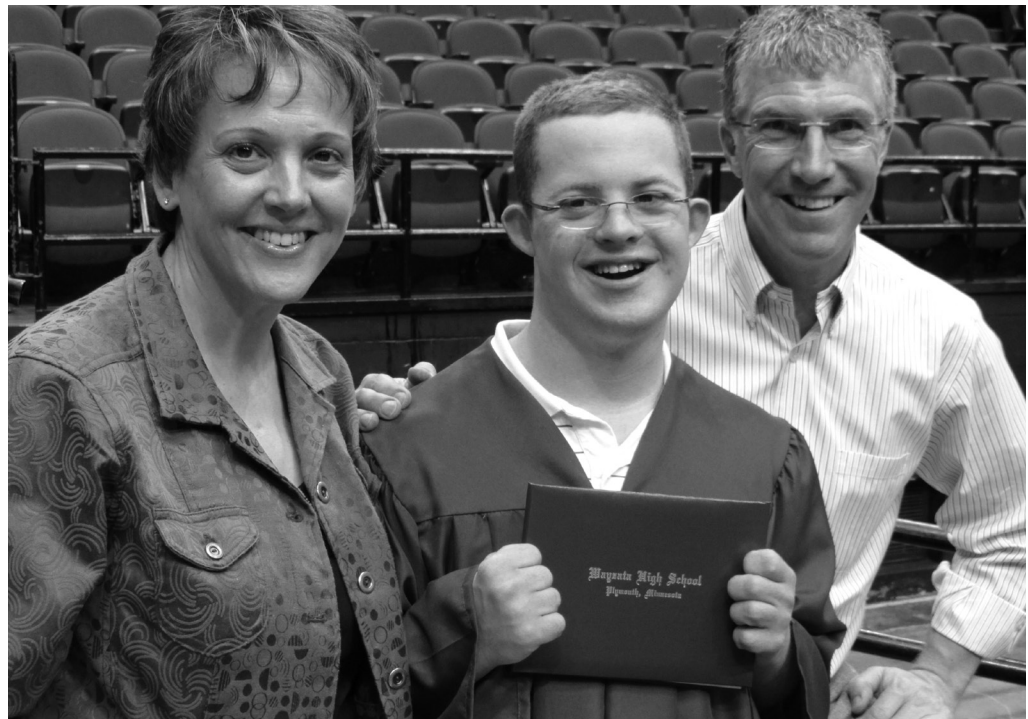
A family's story of working with DSPs

Beth and Kurt Lidell, and their three sons, Michael, Jeff, and Nate, work together as a cohesive team to create a support plan that will best meet Nate's needs, a nineteen year old who has Down syndrome. We interviewed two members of the Lidell family, Beth and her eldest son, Michael, to share their powerful story of how family involvement has helped in building strong

partnerships with the Direct Support Professionals (DSPs) who support Nate in their family home.

As Beth emphasized, communication is key. Honesty and trust is really at the core of the relationship between the DSP and the family. The Lidell family respects the people that come into their home, and expect DSPs to respect their home, their family, and who they are.

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**Working with Families
Frontline Initiative**

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Frontline notes

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Welcome to our *Frontline Initiative* on Working with Families. Nationwide, nearly 58% of people with intellectual and developmental disabilities receiving support live with a family member. Therefore, it is important for us to consider how our work in supporting individuals influences, and is influenced by, their families. As Direct Support Professionals (DSPs), we can work towards helping individuals thrive within the context of their families, providing support to both individuals and their families.

A growing number of DSPs are working in families' homes and in community-based settings. DSPs Debbie Fogg and Lupe Robles offer inside perspectives of what it is like to support individuals in their families' homes. Though challenging at times, they describe their experiences as meaningful and significant to their work. Leslie Merriman reflects on what it was like to grow up with a sister with Down syndrome, and shares her important perspective as a sibling and family member.

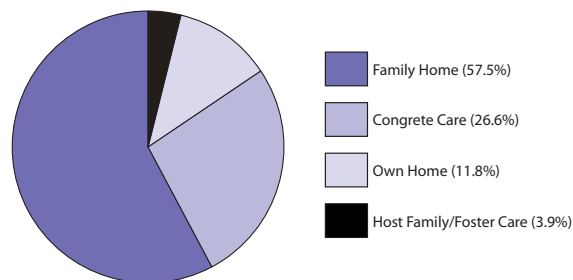
Being an effective professional requires working with and supporting entire families. In an overview of family systems theory, Jennifer Reinke discusses how we can use theoretical concepts to better understand the families we work with.

Some organizations are moving towards a new model of supporting families. Executive Director of the ARC of Westchester, Ric Swierat, shares insights he has learned through talking with professionals in this work. He highlights important themes that are likely to be useful for DSPs, and explores the connection between working with families and the NADSP Code of Ethics. Verónica Guzmán, Family Support 360 Coordinator at the ARC of King County, explains a model that serves as a one-stop center for supporting entire families impacted by intellectual and developmental disabilities.

We hope you will enjoy this issue as you learn more about providing individual support in a family context.

~ The editors

Number of people with intellectual and developmental disabilities receiving each of the four types of support as of June 30, 2009



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Frontline Initiative is available in alternate formats upon request.

NADSP update

By Joseph M. Macbeth

This past September, NADSP achieved an important milestone when we completed our transition from the Research and Training Center on Community Living (RTC) at the Institute on Community Integration, University of Minnesota. On behalf of NADSP we want to thank RTC for their vision, commitment, leadership, and ongoing support that helped make this organization a reality.

As most of you know, National DSP Recognition Week was September 11–17. On September 15th, I had the pleasure of attending an event in Columbus, Ohio that was organized by our Ohio Chapter – OADSP. The room was filled with nearly 400 DSPs from across the state who came together for some learning, laughter and celebration. As we greeted attendees, I was so pleased to see the genuine gratitude and appreciation from these dedicated professionals. To say that this day was inspiring would be an understatement. I left Columbus thinking, “if we could duplicate this event in every state, then THAT would be a DSP Recognition Week”.

According to the American Network of Community Options & Resources (ANCOR), the organization that has taken the lead on pulling Recognition Week together, twenty-nine state Governors had also proclaimed September 11–17 DSP Recognition Week. We hope that this trend continues and we improve on these numbers for next year. I believe that all DSPs should be recognized for their vital contributions to the lives of people

with disabilities — not for one week, but every day of the year. Enhancing the status and recognition for DSPs remains one of the most important parts of our work at NADSP.

On another important note, NADSP is one of fifteen founding organizations of the Alliance for Full Participation (AFP) and we played an important role in the “Summit 2.0: Real Jobs — It’s Everyone’s Business” that was held in Washington D.C. in mid-November. The Summit brought together a true cross section of all those of us who believe in the importance of integrated employment for people with disabilities. The goal of AFP is to double integrated employment by the year 2015 and this will not be possible without the efforts of strong and competent DSPs who often assist people in finding and keeping jobs.

Our work is challenging. We need to continue to build partnerships with self-advocates, their families and service provider organizations. We also need to expand credentialing and career ladder opportunities for those of you who are committed to making direct support a career and not just a job. And lastly, we need you to help us spread the word about NADSP and our important contributions to the field of intellectual and developmental disabilities services. After all, where is quality measured, if not our interactions with those we support?

Joseph Macbeth is the Executive Director of NADSP. He can be reached at jmacbeth@nadsp.org or 518-449-7551.

**Building successful partnerships:
A family’s story of working with DSPs**
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What is it like to have DSPs come in and out of your house/life? How has your everyday family life been affected?

Michael: We have had DSPs coming and going since Nate was three. At that time I didn’t get that attached to DSPs just because they weren’t there for me, they were there for Nate. I am now more involved with DSPs and have grown to appreciate those who stay. Instead of, “Oh whatever, I’m Michael, nice to meet you,” it’s “I’m really sad that you’re leaving. Good luck with your next job”.

Beth: I think my biggest struggle is just to find DSPs who stay around and who are really invested in my son and don’t just see it as a part-time job. We stayed away from making a “revolving door” of staff for the benefit of my other children. It’s really hard so sometimes we went without staff just to take a break. We did what a lot of people are told not to do, we incorporated them into our family. We had one DSP that stayed with us for six years. We would take her with us if we went on a vacation or to the cabin and we bought her birthday and Christmas presents. We just really treated her as a family member. For her to be in our home, we needed to incorporate her into our family for our other children so it wasn’t seen as an employee or just somebody who comes and goes. By incorporating her into our family, it made it more of a natural thing. We try to do this with all of our DSP staff but this

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An interview with Lupe: Reflecting on experiences with families

By Susan R. Copeland

Lupe Robles became a Direct Support Professional (DSP) seven years ago when her niece was born with Down syndrome. She volunteered in local residential facilities for people with developmental disabilities in her hometown in Mexico when she was in middle and high school. This experience interested her in working with people with disabilities. Lupe now provides support services for people with disabilities in their own family homes. She enjoys this because it allows her to build a connection with individuals and their families.

Lupe got to know other families who also had children with developmental disabilities through providing respite services for her niece. Some of these families began asking her if she could also provide respite for their children. Her reputation for providing excellent support grew over time and she now provides respite care for young children with a range of developmental disabilities. She has been a respite provider for most of these children for many years.

Lupe most often provides support in the children's homes. However, she has gotten to know their families so well over the years that sometimes they bring the children to her house and she provides respite services there. She also hosts barbecues for the children and families she supports at her own house. She feels strongly that it is important for the children she supports to have an opportunity to get to know other adults and

children outside of their families. Bringing families together is one way to do this. Lupe has seen her own children's understanding of disability grow as they get to know the children she supports.

Each time Lupe begins to work for a new family, she interviews the family and makes sure that the information she has received from the agency is accurate. She asks

Lupe feels strongly that it is important for the children she supports to have an opportunity to get to know other adults and children outside of their families.

the families to provide a schedule of their child's activities, and information on the child's interests, likes/dislikes, and other needs. She uses that information to create unique activities and supports for each child.

Lupe mentioned that the most important thing a DSP needs to do in supporting a child in his or her own home is to build trust with the family. She has noticed that most families will stay in the house during the first few visits. They only feel comfortable leaving their child alone with her after they trust her. Therefore, she works hard to create a sense of trust with each family.

Lupe has experienced only a few challenges in providing direct support in families' homes. Handling challenging behaviors can be difficult since she works with younger children. It has been important to discuss each family's expectations for handling behaviors early on and to share her management style with the family. Lupe has found this approach to work well and she has experienced only one conflict between a family's expectations and her own during her seven-year career.

It is clear that Lupe loves her job. Supporting children and their families gives her great satisfaction and joy. Though it takes patience and caring to be effective, she recommends working as a DSP in families' homes.

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Family Support 360 Program

A holistic approach

By Verónica Guzmán

Many programs supporting people with intellectual and developmental disabilities (I/DD) focus on the individual. Other programs focus on caretakers and family members separately. The Family Support 360 Program focuses on supporting the needs of the entire family. These services are provided through a one-stop center.

So how do we support the needs of an *entire* family? As a Direct Support Professional (DSP), you know that it is challenging enough to assist a single person. At The Arc of King County & Spokane, we struggled with this question. We found that we needed to ask families to prioritize their needs. In our program, we depend on staff we refer to as Navigators.

Navigators are persons uniquely assigned to a family. They share the family's same culture and language. They guide and support families to address their top three concerns. Navigators meet with families. They help them develop a comprehensive *Family Centered Plan*. A *Family Centered Plan* is basically a plan of action. The family and Navigator set objectives and specific tasks. This is in order to address the family's unique needs. Navigators do not provide direct services such as employment, housing, financial help, or therapies. Instead, they help families gain access to information and relevant sources of support. They connect families with government services and community networks. They are also connected to families from their same communities. These are families who also have a

family member with I/DD.

Cultural differences play a huge role in the Family Support 360 Program. For example, in the Somali community the word *autism* does not exist. Somali Navigators have found that they need to explain what autism means to families in different ways. They will describe the characteristics of autism. They will introduce fami-

For example, in the Somali community the word autism does not exist. Somali Navigators have found that they need to explain what autism means to families in different ways.

lies to other Somali families who care for children with autism. They will also provide them with information. This includes videos that explain the disorder in a family friendly way. What may seem like denial may simply be a disconnection between different cultures. Somali families tend to have a better understanding of an autism diagnosis when they receive an explanation. The explanation should include references to their own culture.

Our recent program data points to common areas of concern across all groups. The primary con-

cern of families is education. They are also concerned with health and financial stress. Many African American families report not receiving adequate educational services. They report the need to access early intervention services. They also need adequate school-to-work transition plans. African American Navigators work hard to connect families to services that "fill-in the gaps."

Latino and Vietnamese Navigators work closely with new immigrant families. Navigators encourage them to participate in their children's Individualized Education Plan (IEP). Some Vietnamese immigrants in the program feel scared to send their children with I/DD to school. Latino parents tend to feel grateful that their children with I/DD can attend school. In most cases, this is the first time the child with I/DD attends school.

Parents don't know what their rights are. They often do not know what questions to ask. They need support to participate in a school system that is overwhelming. Through Family Support 360, The Arc of King County and Spokane aim to empower families in the diverse communities. This is our mission to create change at a local and system's level.

Verónica Guzmán serves as the Family Support 360 Coordinator for The Arc of King County, WA (www.arcofkingcounty.org). She can be reached at 206-829-7027 or vguzman@arcofkingcounty.org.

For more information about Family Support 360 programs across the country, visit <http://www.addfamiliesupport360.org>.

Family systems

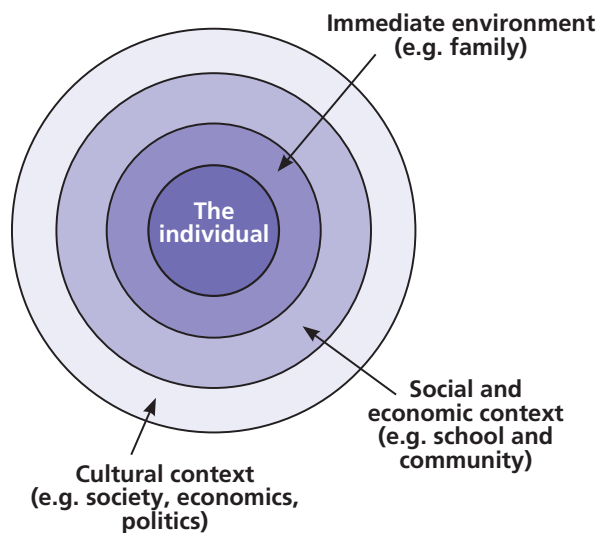
A theoretical approach

By Jennifer Reinke

Our work as Direct Support Professionals (DSPs) often focuses on the individual. It often does not focus on the family as a whole. I wonder why this is. Ask any mom, dad, or sibling. You could also ask a grandparent, aunt, or uncle. I assure you they will agree that disabilities affect the entire family. Because disabilities affect *entire families*, it is appropriate to use a family systems lens. Family Systems Theory offers some ways to understand any family unit. This is regardless of culture or race. It is regardless of religion or family structure. It is also important to consider how our own families influence the way we provide support to the individuals and families we work with.

Please consider the following concepts from Family Systems Theory. They can be used to better understand the families we work with.

- **Holism** — Holism is the idea that the whole is greater than the sum of its parts. This means



recognizing the entire family as a unit rather than simply looking at each individual. It also means considering *all* aspects of family's lives. This includes their resources and religious beliefs. This includes stressors and the communities in which they live. I think this is the most important concept to keep in mind.

- **Interdependence** — Interdependence means that family members can function independently. It also means that they depend on each other for some things. Interdependence is often difficult in families of children with disabilities. Sometimes people with disabilities may be entirely dependent on others for their basic needs.
- **Hierarchy** — There are many subsystems within the greater family. Parents, siblings, and various generations are subsystems. Each subsystem has different amounts of power and influence. This affects the entire family. For example, parents

generally have more power and decision-making authority than children. However, the nature of a child's disability and their related needs may alter the amount of power and influence.

- **Boundaries** — The boundaries of a family system are important. Boundaries help define who is *in* and who is *out*

of the family. Families impacted by disabilities tend to have open boundaries. This may not necessarily be by choice. There are typically many therapists, caregivers, and other specialists involved. They come in and out of their homes and their lives. As DSPs, we can be sensitive to families' desired boundaries. We can be respectful of their time and space together as a family.

- **Equifinality** — Equifinality is interesting to me. It means achieving the same goal through different routes. For example, some children with disabilities have difficulty sleeping through the night. A common goal for their parents is for their children to sleep through the night. Parents can choose from a variety of different options. These are all in hopes of reaching the same goal. Options may include behavioral techniques such as token systems or relaxation techniques. Other options could be medication or a change in the child's diet. Regardless of the chosen treatment, parents have the same goal of their children being able to sleep through the night. What are some goals of the individual's family that you support? How are you supporting these goals?

Jennifer Reinke, M.A., LAMFT, CFLE has served as a DSP for five years and is currently a Graduate Research Assistant at the Institute on Community Integration at the University of Minnesota. She can be reached at rein0281@umn.edu.

A moment in their shoes

By Debbie Fogg

Sit back and think for a moment. Imagine the following scenario: You have to surrender your entire life over to an individual. You may know this person or it could be a total stranger. Take a minute and ask yourself these questions: How are my needs going to be met? Am I safe? Am I going to get hurt? How is this person going to take care of me? Can I trust this person?

Now imagine those same questions when leaving your loved one. This could be a person you know, a person someone referred to you, or a complete stranger. These thoughts and feelings are only the beginning of what a parent or guardian experiences. Parents and guardians need time to adjust. Often they are the primary caregivers to their family member with a disability. Some families are lucky to have natural supports, or other people who are able to assist in the day-to-day care or provide some respite. Parents go through a process of learning to trust others and learning to let go. Allowing for others to provide support is difficult for parents and guardians because they have been doing it all their life.

It is important for Direct Support Professionals (DSPs) to keep a few things in mind. Putting yourself in parents' shoes gives you an



understanding and compassion to provide the needed support. Listening to the parents or guardians can show them you are hearing their concerns and will give their

loved one the best support possible. Families are a great resource and have a wealth of information about the individual you will be supporting. DSPs can learn more by

talking to families, making home visits before providing support, and researching any information that will help families feel more at ease. This is a great way for DSPs to learn about the individual and provide the best support possible.

Debbie Fogg is a DSP Independent Provider and a sub contractor with the State of Ohio. She can be reached at ru2cdeb@yahoo.com.

“Parents go through a process of learning to trust others and learning to let go.”

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one really stands out as a great memory for our family.

How do you communicate your expectations to DSPs?

Beth: Where I really focus on is how I expect their interactions to be with Nate. I expect them to be a “helper friend” and engage Nate in the community and learn from them, not just a person babysitting a 19 year old. I also lay out examples of what I do expect and what I don't want. For example, I don't want DSPs on their cell phone texting or talking with their friends. I have found what happens is DSPs sit on their phones and text or talk with their friends while Nate just sits there. Or shopping with Nate, which he hates, but they see it as an easy way to get their errands done.

Would you describe something a DSP did that demonstrated they really understood your family?

Michael: I'll use the DSP that was with us for six years as an example just because she had the biggest influence. Her name was Heather. When she came in, she came from a very strong Christian background, which is something that is important to us. She was a college student going into early education, she really understood kids, and she had the patience to really get along with Nate. The first couple of months she would ask questions just to make sure she was doing everything the way we expected. Then it evolved to a point where she knew Nate's routines just as well as we did. She knew the foods that he liked or

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A home for my mother's baby

By Leslie Merriman

My very first memory of Lindsay was seeing my parents crying after they'd gotten home from a doctor appointment. I was seven and Lindsay would have been around one. That's when they found out she had a disability. From then on, life was different. Not bad, just different.

I spent the next years of my life explaining Lindsay to my friends and sticking up for her around strangers. People were cruel. I learned to determine my relationships with others by their reactions to my sister. If people were kind to her, I liked them. If they appeared cautious and put off, I distanced myself from them.

Lindsay is the reason I have spent the past 22 years working for an agency that supports people with developmental disabilities. They also support my sister. I convinced my parents to allow Lindsay to move into a group home. It was hard on them at first. My mom did a lot of crying. But having her live in a house with her peer group did wonders. She thrived. She accomplished more than my parents ever thought she could and more importantly — she was happy. When Lindsay would spend the night back with my parents, they'd find her the next morning packed with her bag ready to leave for home, her home. I know it hurt my mom's feelings but I reassured her that this was exactly the way she should want Lindsay to be. Still, I think my mom was secretly hoping Lindsay would beg to stay home with her!

My father passed away 4 years ago. At 86, my mom is pretty amazing. She still drives and still worries about her 55-year-old daughter, Lindsay. With all her aging issues, I've taken on more responsibility for Lindsay. I've become her medical power of attorney, so I get the calls when something happens and then report to my mom. At first this bothered my mother, but now I believe she is thankful to be out of that role.

My mother would often get upset when Lindsay came for a visit and her hair wasn't cut or her clothes weren't quite right. Now I make sure she looks her best when visiting. Lindsay knows she might have to change her clothes for these visits. But more often than not she's learned what to wear. I sometimes get disappointed that her Direct Support Professionals (DSPs) don't pay more attention to that area. But I have to pick my battles and defend group home life to my mom, telling her that the most important thing is that Lindsay is safe and happy. Having worked ten years in direct care, I understand the job.

One time when I went to pick up Lindsay, I observed her DSP playfully teasing with her, chasing



her down the hallway. Lindsay was laughing, the DSP was laughing. It brought tears to my eyes. It's what I want for Lindsay. I know it's what my mom wants for her, too. A place where she feels comfortable and safe. A place where she feels loved. A place that's home.

Leslie Merriman is the Executive Assistant at Welcome House, Inc. in Ohio. Her email address is lmerriman@welcomehouseinc.org.

DSPs working in community support settings

Lessons from the field

By Ric Swierat

The direct service profession has gone through significant changes over the last decade. There has been a shift from institutional-type group homes and sheltered day programs to community-based services. This is a huge success for the people we support and their families. However, this shift is also presenting new challenges for Direct Support Professionals (DSPs).

One challenge is that we no longer have supervisors observing the direct contact between the DSP and the person receiving services. Direct support is provided in private homes and/or community settings. It is provided outside of group living environments. This is particularly true of those DSPs who provide family support.

The role of the DSP is evolving as service settings change and these new support environments are creating challenges for DSPs. I asked DSPs responsible for in-home and respite programs about their experiences with families and the people they support. I have also considered my own conversations with families who are receiving services. There are a number of themes that have surfaced —

- DSPs feel isolated from peers
- DSPs and families disagree on best support strategies
- DSPs face challenges with communication between families and DSPs
- DSPs recognize a family's unique culture
- DSPs understand family dynamics

Based on these themes, I have identified some of the skill sets that the DSPs highlighted. Let's look at these skills within the context of the NADSP Code of Ethics.

NADSP Code of Ethics

Integrity and Responsibility

As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.

- **Open and positive communications as a cornerstone of building relationships:** The most skillful and successful DSP understands that he or she is entering a private home and private lives. Therefore, it is important to begin with appropriate steps. This involves creating an expectation of open and honest communications with the family. Each DSP provided stories about this. They work closely with families to develop a plan of support together.

Relationships

As a DSP, I will... recognize the importance of relationships and proactively facilitate relationships between the people I support, their family and friends.

- **Navigating personal relationships and recognizing family strengths:** Families may make different decisions than the DSP as a way to minimize conflict. This means they may allow for the wrong dietary intake. Families may change medication routines. They may make choices

that may be different than DSPs. The skilled DSP recognizes that families most often do the best they can, just as DSPs most often do the best they can. Families may enjoy learning new strategies from DSPs just as DSPs can learn from the families they work with.

Respect

As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.

- **Being sensitive to the unique needs of the individual and family:** A big part of this job is relationships. I heard this from many of the interviews. Remember to step back. Understand the family dynamics. The successful DSP starts with getting to know the person and the family.

This arena of work and supervision is still evolving. DSPs work in community settings, supporting families and individuals in their homes. There are often new challenging interactions to face. DSPs need the support and training to manage these situations. Talk to a DSP who you believe is successful in his or her work. Ask that person about the lessons that she or he has learned. From DSPs, we will learn what training and support they need.

Ric Swierat serves as the Executive Director of the Arc of Westchester, New York. He can be reached at 914-495-4619 or rswierat@westchesterarc.org.

NADSP supporting & affiliate organizations, state chapters and contacts

We would like to acknowledge NADSP Supporting Organization members for their generosity and ongoing dedication to the goals and mission of NADSP.

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- Crystal Run Village, Inc.
- NYSACRA
- Research & Training Center on Community Living, University of Minnesota
- Rise, Inc.

Supporting organizations: \$500 level

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- Schenectady ARC
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- SECOH
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- The Adirondack Arc
- The Arc of Rensselaer County
- The Arc of Schuyler County
- The Arc Otsego
- The Center for Family Support
- The Resource Center

Affiliate organizations: \$200 level

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- Bona Vista Programs, Inc.
- Community Residences, Inc.

- Connections of Moorhead
- Delta Projects, Inc.
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- Miami Cerebral Palsy Residential Service Inc.
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- Seven Counties Services
- SPEAK, Inc.
- St. Amant Community Residential Program
- The Arc of California
- The Arc of Somerset County
- The Arc of Southside
- The Arc of Steuben
- The Emmaus Community of Pittsburgh
- The Epilepsy Foundation of Long Island, Inc.
- Western New York Training Consortium

State chapters and contacts

As a membership organization, NADSP requires the involvement of its members to share information on DSP issues, achievements and directions. Chapters and contacts do this important work in concert with NADSP. We encourage the involvement and participation of DSPs in leadership roles at both the local and national levels.

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Frontline resources

Sibling Support Project

<http://www.siblingsupport.org/>

This national program trains service providers on how to create community-based peer support programs for young siblings; increasing parents' and providers' awareness of siblings' unique, lifelong, and ever-changing concerns.

Parent to Parent USA

<http://www.p2pusa.org>

Provides emotional and informational support for families of children who have special needs.

The Rosalynn Carter Institute for Caregiving

<http://www.rosalynncarter.org/>

Focuses on supporting individuals and caregivers coping with chronic illness and disability across the lifespan as well as limitations due to aging.

Beach Center on Disability: Family Quality of Life

http://www.beachcenter.org/families/family_quality_of_life.aspx

Focuses on family quality of life and helps families or family support personnel identify family strengths and priorities for support.

Book: Working with Families with Young Children with Special Needs. R.A. McWilliam, PhD (Editor)

ISBN-10: 1606235397 | ISBN-13: 978-1606235393

Presents research-based best practices for serving families of children with special needs from birth to age 6. This book offers information, support, and coaching for people that work with families with children with special needs.

Video: Listening to Families: Building a Family Partnership

<http://www.childdevelopmentmedia.com/working-with-families/20917p.html>

Addresses strategies to build a family and professional partnership. Strategies include having a conversation rather than an interview, sharing power by letting the family do the talking, focusing on family members' strengths, asking open-ended questions, and encouraging expression of different viewpoints. Experienced family consultants meet with families from African-American, Hispanic/Latino, and European-American backgrounds from all income levels.

NADSP membership form

DSP level \$10/year

If your state has a NADSP chapter, you will receive dual membership in the state chapter and NADSP.

DSP

Other individual level \$20/year

If your state has a NADSP chapter, you will receive dual membership in the state chapter and NADSP.

Frontline supervisor Self-advocate Family member

Other professionals (please specify)

For professionals working in community human services, such as social workers, administrators, and healthcare professionals

What is your profession? _____

Affiliate level \$200/year

For individuals, agencies, providers, associations, and NADSP state chapters who wish to demonstrate a commitment to support the efforts of DSPs.

Individual Organization

Supporting organization level \$500/year

For individuals and organizations dedicated to advancing the interests of DSPs and the people they support at a national level.

Individual Organization

Sponsoring organization level \$2000

For individuals and organizations dedicated to advancing direct support as an accepted profession at the national level and participation on the NADSP Advisory Committee.

Individual Organization

Make checks payable to NADSP. To pay by credit card, visit www.nadsp.org/membership

Mail membership form and payment to:

NADSP, 240 Washington Ave. Ext., Suite 501, Albany, NY 12203

Name

Organization

Address

City State Zip

(_____) _____ - _____
Phone

Email

Total enclosed \$ _____

Frontline Initiative

240 Washington Avenue Extension
Suite 501
Albany, NY 12203

**Building successful partnerships:
A family's story of working with DSPs**
continued from page 7

didn't like just as well as we did. So the more time that was spent, the more familiar she became with Nate's routines and preferences. The biggest success was that Nate became really attached to Heather and looked forward to when she was scheduled and felt like he had a friend coming over to be with him. Friendships were something that was missing from Nate's life. Nate looked forward to seeing his *friend* Heather versus the *DSP* Heather.

Beth: Heather was like a dream come true, she was unbelievable and I called her my angel from heaven. If Nate was having a hard time, she would come and get me. If I was busy with one of my other kids, she would take my place there. Or, if I was busy cooking, she would do that so I could go tend to Nate. It wasn't like "here's my role, here's your role". It was more like "I'm here to support the family," and I wish every DSP could understand that.

Michael, why is it important to you to be involved in your brother's support team?

Michael: He's my brother. As a family, we really do know what's best. Obviously, there's a mom relationship and everybody listens to mom; nobody argues with mom. That can be a bit intimidating at times for new staff. They don't always feel like they can express concerns or something they're frustrated with like a routine or something they just don't get. They may not always feel comfortable going to our mom because that's like going to "mama lion". So it's easy for me to step in as the brother, it's more of a casual relationship. It offers that dichotomy of mom being the one who makes the rules, runs everything, does all of the scheduling as the big boss. Then there's me who is the intermediary and can go through the little details, provide that personal support, and provide that unique perspective of a brother relationship versus a mom and son relationship. That is really important because Nate doesn't need a second Mom.

What would you say to a DSP who is interested in working in a family's home?

Beth: It takes a higher level of responsibility and maturity to work in a family home because DSPs have a lot more freedom. Families need DSPs who are self-motivated, responsible, reliable, and honest. Also, I think DSPs need to look at 'is this a good fit for me?' If a family smokes and you don't like cigarette smoke, then that is a really important thing to consider. In my family, we're Christians and we put it right out there. Some DSPs may be uncomfortable to be in an environment where we play Christian music and watch certain TV shows. It is important for DSPs to really understand who they're working for and what that family's values are, to find out if it's a good fit or not.

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