# A Newsletter of the National Alliance for Direct Support Professionals

# **Of Two Minds**

• ne of the many Direct Support Professionals (DSPs) our family encountered over the past 26 years worked hard at developing a good relationship with us. In addition to the required annual and periodic review meetings, she would call us up and ask, "Well, how are things going?"

She would carefully listen to our responses as we talked about our son's support services. She would ask what was going well and not so well. Usually these conversations took less than 15 minutes, but, nonetheless, conveyed her concern about the quality of the supports being provided to our son with disabilities. After these conversations, more often than not, she would help us solve problems with his supports, especially when things were not going as well as expected. This act of keeping in touch and discussing our satisfaction with the support services our son received was very important in building our work-

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When our family has good DSPs supporting us, our lives are better.

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# Frontline Notes

Families are important to all of us. We depend on them for support, encouragement, and unwavering love. For people with disabilities, families are often the only support network that remains a constant in their life over time. Direct Support Professionals (DSPs) and Frontline Supervisors (FLSs) need to work closely with families in order to create the highest quality of life possible for people with disabilities. This issue of *Frontline Initiative* provides ideas that will help in this endeavor.

Barb Handahl helps us understand the role of families from a historical perspective in her article, A Family Celebration: Celebrating Change. She takes us back to 1968 when she started her career at the Faribault State Institution in Minnesota. Times were bleak, dark, and lonely for people with disabilities who were sent to live in the institution — away from their families. At that time DSPs were not encouraged and sometimes not allowed to have contact with families. That all changed when the institutions were closed and people with disabilities were reunited with their families. Today, the role of the DSP has changed and the partnerships they foster with families have enriched many lives.

In the article *My Three Wishes*, John Cox, a parent of a young daughter with disabilities, shares his wishes for in his daughter's life. We hope this article will help you find creative ways to make these three wishes come true for the individuals you support.

Dr. Condiluci and Melissa Rennie help us understand how someone becomes a part of the community in part one of this two-part article, *The Process of Cultural Shifting: Building Bridges to Community.* DSPs should review this article to learn more about the important role they play in creating successful bridges between the community and the individuals they support.

The *Alliance Update* gives us exciting news about the National Alliance of Direct Support Professionals (NADSP). It is officially incorporated! Now the NADSP has a stronger voice to help DSP initiatives across the country.

The article, ANCOR's National Advocacy Campaign, tells us about exciting new legislation, the Direct Support Professionals Fairness and Security Act of 2004 (H.R. 1264). It is important for DSPs and families to become familiar with this legislation and to educate their state representatives about workforce issues affecting people with disabilities.

There is much more information in this issue of *Frontline Initiative*. We hope you enjoy reading and sharing it with colleagues and find hints, tips, and ideas that you can use every day as you support individuals and their family networks.

The editors

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# NADSP Member Organizations and State Contacts

Frontline Initiative is a product of the National Alliance for Direct Support Professionals (NADSP). The NADSP is a collaboration among organizations who are committed to promoting the development of a highly competent human services workforce that supports individuals in achieving their life goals. The following are some of those organizations —

- Administration on Developmental Disabilities
- American Association on Mental Retardation
- Association of University Centers on Disabilities
- American Network of Community Options
  and Resources
- The Arc of the United States
- Association of Public Developmental Disabilities Administrators
- Association for Persons in Supported Employment
- CARF...The Rehabilitation Accreditation
  Commission
- Consortium for Citizens with Disabilities
- Council for Standards in Human Service Education
- Human Services Research Institute
- Institute on Community Integration (UCEDD), University of Minnesota
- International Association of Psychosocial Rehabilitation Services
- Irwin Siegel Agency, Inc.
- JFK Jr. Institute for Worker Education
- National Association of State Directors of Developmental Disabilities Services
- National Association of State Directors of Vocational Technical Education
- National Center on Educational Restructuring
  and Inclusion
- National Center for Paraprofessionals in Education
- National Organization of Child Care Workers
  Association
- National Organization for Human Service Educators
- National Resource Center for Paraprofessionals
- New Jersey Association of Community Providers
- President's Committee on Mental Retardation
- Program in Child Development and Child Care, School of Social Work, University of Pittsburgh
- Reaching Up
- Self-Advocates Becoming Empowered
- TASH
- United Cerebral Palsy Association

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#### Join the NADSP and Represent Your State

Contact one of the NADSP Co-chairs listed

above or visit **www.nadsp.org** 

# The Real Scoop

Welcome to *The Real Scoop*. Clifford is a self-advocate who has been politically active for years. He's here to give you his spin on how to deal with issues you face as you forge ahead in your role as a Direct Support Professional (DSP). Seth has been a DSP for many years, and he loves to give advice. He may ruffle your feathers, but hey, it's for your own good! Clifford and Seth tackle this one with a few suggestions.

## **Family matters**

Dear Seth and Cliff,

I am a DSP and the person I support lives at home with their family. Previously I was a DSP in a group home, and this is different. How can I better support the individual and the family? What should I know? What special considerations should I make if the family is culturally different from my own?

- Homebound

## Ask Clifford and Seth

### Dear Homebound,

It is important to learn the family routine, what the family needs from you, and what time you need to be there. You need to be sensitive to the family's needs and to work around them. You can learn more about their culture by talking with them and visiting the library. Ask them what you can do to make them more comfortable.

— Cliff

Dear Seth and Cliff,

How can I build a better relationship with the family I support? What are some simple steps that I can take?

- Call with Good News

### Dear Call with Good News,

The first step is to sit down with the family and find out what expectations they have; this will form the basis for your working relationship. If there is an evaluation, if the family was ever asked by the provider to evaluate the DSP, this will form the foundation for the evaluation criteria. It is important for both sides to have clear expectations. Again, sit down with the family and learn about their routine. Ask, how can I work into that routine?

— Cliff

Dear Homebound and Call with Good News,

I'm going to send you both to the library to take out a book which covers everything. "Community Supports for Aging Adults with Lifelong Disabilities" by Matthew P. Janiciki & Edward F. Ansello, published by Paul H. Brookes Publishing Company (2000).

Generally, you will be adapting to home environments, building bridges within and between community agencies, looking for clues for the persons interests and wants, and finally sharing the cultural beauty of your ancestry and of your consumers through activities of fun and learning. Whew, that's quite a list. Bottomline — show you care with respect and a smile and each day will be a relationship builder.

— Seth

Do you have a burning question about direct support, but don't know who to ask? Submit it to —

Frontline Initiative The Real Scoop P.O. Box 13315 Minneapolis, MN 55414

Tel: 612.624.0060 Fax: 612.625.6619 Email: mccul037@umn.edu

Please include your name, day phone for verification, and alias, if desired.

# **My Three Wishes**

When I was young, I remember dreaming about what I would wish for if I found the magic lamp. If offered the proverbial three wishes, I would often dream about what I would wish to have, what I would wish to do, and where I would wish to go. But what I would have wished for when I was eight, is not what I would have wished for on the day that my daughter, Kristina, was born with cerebral palsy and "significant" cognitive delays. Today, I am thankful that I did not have access to the magic lamp on that evening eleven years ago, because, what I would wish for now is not what I would have wished for then. After learning a great deal from my daughter and the rest of my family over the last decade, today...

1. I wish that Kristina will be treated as an individual — not pigeon holed as the end result of batteries of tests taken over the length of her life. I wish for her doctors, therapists, teachers, social workers, and aides to see that she is more than numbers on a graph or points on a line - that her tests measure what she may do, not what she will do. I wish that they would see the person that she is - so different from the dozens that they see every day, or the thousands they see every year. I wish that they would see the freckle faced, bony kneed, giggling little girl with all opportunities ahead of her, not patient/client #xxxxxx with all her limitations bound to her like shackles.

I wish that Kristina will have the tools she will need to live her life to the fullest. I wish that she will have an adequate education to prepare her for her life ahead, that she will have the equipment — computers, walkers, wheelchairs and braces — that she needs to function, and that she will have the community — friends, teachers, therapists, and aides — she will need to grow and develop to her greatest potential.

Today, I am thankful that I did not have access to the magic lamp on that evening eleven years ago. Because, what I would wish for now, is not what I would have wished for then.

3. Lastly, I wish that Kristina will be cared for as long as she lives — by parents while we are alive, and by a loving circle of friends when we are gone. I wish that she will be prepared to live in the community — wherever that might be, and able to make a contribution to society in a meaningful way to her. I wish that she will be prepared financially and emotionally to live her life fully, not to be dependent on her brother and sister, but able to have what she needs without worry to anyone for as long as she lives.

Some may question why I would not wish to change Kristina into a "normal" child. My other wishes would be unnecessary if I made that one wish. To those I would answer that I have grown to know that Kristina is normal. There is no other Kristina and could never have been. She was born just the way she was intended to be. No amount of wishing can ever change that, even if I wanted to. I cherish who she is now and what she will become, just as any proud parent would.

Reprinted with permission from www.fathersnetwork.org

John Cox is a sales supervisor in Los Angeles, California. His wife Shelley works for the HOPE Infant Family Support Program in Oceanside. In addition to Kristina, they have two other children: nine-year-old Kimberly, and six-year-old Travis. Kristina, now twelve, was born with cerebral palsy and other significant challenges.

# A Family Celebration Celebrating Change

For over 30 years, I have worked with people who have intellectual disabilities as a Direct Support Professional (DSP) in many capacities. My employment as a DSP began in March of 1968. The institution was referred to as the Faribault State School and Hospital. My title was Psychiatric Technician. Requirements for the job included six months of classroom education. I learned how to give bed baths and insulin shots, take blood pressures, and pass medications, and I learned a variety of psychological theories and human development models. My workday mostly involved bathing, feeding, changing clothing, passing medications, and cleaning. I preformed many janitorial tasks as well. This was a period of history when people with disabilities were called patients and their house was a hospital ward.

In 1968 white uniforms were required of staff, and we were told if we came to work with dirty shoe laces it was like wearing dirty underwear! Staff called each other by their last names — no first names were allowed. I can remember thinking to myself, "I can't believe I am in the same town that I grew up in and have lived in for over 18 years" - such an unreal sterile world within a few miles of my home, school, and community. At the end of my shift, I would anxiously drive off the institutional campus back into the real world, feeling sorry for those that I had left behind.

During my 21 years of work at this institution I experienced many changes, as did those who resided within the institution. As a young adult, I can remember asking myself, "What will be in store for the people who live in this institution next year?" I saw evidence of how their lives were ruled by bureaucracy. I watched as life changes occurred for people institutionalized in accordance with policy decisions made by people in the government. I was so happy that I had freedom to choose and have control over my

> At the end of my shift, I would anxiously drive off the institutional campus back into the real world, feeling sorry for those that I had left behind.

life, unlike those who were living in the institution at the time. The institutional environment brought sadness to my heart.

Families would come to visit their loved one at the institution usually on a weekends, when life was the most boring on the wards. When they arrived at the building, they were not allowed to come into the ward. They were told to wait in the reception area and we would bring their loved one out to them. They would visit in an area in the front of the building, go for a walk around campus, or go for a car ride. Rarely can I remember a family member visiting on the ward or unit. It was not encouraged. Often, management and professionals were nowhere to be seen. Institutionalized people had no friends to come and visit them. Their days were long and uneventful. Those of us who worked on weekends were responsible for more custodial care, with fewer scheduled staff.

We, the DSPs, had little relationship with family members. The person's social worker made the contacts and spoke on behalf of the person. A few people would receive mail from family members; it was always a happy moment. However, all mail was pre-opened by someone before it was given to the person for whom it was intended. In the late 1960's and early 1970's DSPs never reciprocated with a thank you note or a letter in return on behalf of the person. Family ties were minimal compared to those I experienced in my life.

Today in Minnesota, with the closure of the institutions, community living is now afforded to all people with intellectual disabilities who require out-of-home placement. As a result, many families have been reunited with their loved ones and are celebrating new and or closer relationships. Family members have an open door invitation to come and visit anytime they desire. Families are invited to many holiday parties and DSPs actively plan and provide support for people to go visit their family members at their home. Families are involved and given the opportunity to have more direct roles in their family member's life. Extended families are well

#### A Family Celebration: Celebrating Change, continued from page 6

acquainted with many DSPs and communication goes on regularly through telephone calls, mail, and outings together.

This transformation reflects a change in philosophy toward valuing everyone. We have come to understand that all people are unique and have gifts to share. We recognize and support the concept that every family member is important and requires close relationships. Sharing love and connectedness are essential human needs. We realize that each family member has a responsibility to his or her family as a member of that family. And we support all people to have and active family role in their life.

This is such an exciting time for those who have experienced many years of segregation in institutions. We are continually working towards communities where all people are seen as citizens, enjoying active, rich community and family lives. But as far as we have come, we have even further to go to reach full inclusion.

Barbara Handahl has worked as a DSP at the Faribault Regional Center for 21 years and for Minnesota State Operated Community Services, in Faribault, Minnesota, for the past 12 years. She is an advocate for creating inclusive communities where all people are seen as citizens with gifts to share within the communities in which they live. She can be contacted by phone at 507-210-0711. In Action Community Skills Standards

am a Direct Support Professional (DSP) who provides supports to three individuals in their homes. I divide my time between these three families and individuals for whom I provide support and find joy in their unique qualities and challenges. Because I work with three distinctly different families, I have had the opportunity to develop my communication skills and the set up expectations for working with families in a variety of ways. These skills have been developed through trial and error! It takes time and even some mistakes along the way to develop meaningful working relationships with families.

It has been important for me to understand both the family as a whole and each family member individually. I'll share a story that helped me grow as a DSP. While I was working at one home, the brother of Callie, the girl I was supporting, seemed to be having a hard time with all the attention Callie got from her parents and from DSPs like me. Josh, seven at the time, would often hide his sister's toys or hide my shoes when it was time for me to go home. It was easy for me to get annoyed at Josh's behavior and think about how he was getting in the way of the supports I was providing to Callie. After reflecting a bit I realized the Josh just wanted some attention from me and from his parents. I thought about how to provide the best supports possible to Callie while providing some sort of attention to Josh. I talked with the family and we tried a bunch of different things, but what finally worked was asking Josh to help me

provide supports to Callie when he wanted to. Josh was able to work with Callie and me on her speech program or just play with Callie. Josh was able to see the outcome of his involvement as Callie would make progress in her speech program and laugh when they were playing. By asking Josh to become more active in Callie's life, Callie and Josh both benefited by growing in their relationship. As a DSP I benefited too, because it became easier to provide supports to Callie. My working partnership with the family was strengthened because Callie's mom, dad, and Josh were all part of the solution. Along the way we built trust, respect, and clearer communication skills.

### Community Supports Skill Standards

#### Competency Area 6: Community Living Skills and Supports

The community-based support practitioner has the ability to match the specific supports and interventions to the unique needs of individual participants and recognizes the importance of friends, family, and community relationships.

Do you have a story you would like to share? Contact Nancy McCulloh or Michelle Trotter (see contact information on page 2) and we'll help share it with other DSPs. Contributors receive a year subscription to *Frontline Initiative*.

# Giving Voice Advocacy in the Human Services

We are not content to just talk about problems that face people with disabilities and ignore our ability to effectively engage in our professional roles. We have decided that awareness of harmful conditions must lead to action to change them. The National Organization for Human Services (NOHS) has made a commitment to forgo the seeming comfort of silence. At our most recent national conference in Nashville we decided to select an issue that affects those whom we support, deepen our understanding of it, and act to influence those whose policies and practices maintain the problem. We have decided to give voice to our knowledge and values on behalf of and in partnership with those whose voices are not often heard. Roughly translated from its Latin roots, "advocacy" means just that — to give voice. We have become advocates. This article presents a brief overview of elements of advocacy.

## **Basic types of advocacy**

"Advocacy" commonly refers to actions which speak for the interests of others. It is different from organizing, which brings people together to develop their own voices and power. Advocacy, however, may be an important step toward organizing or may use organizing in concert with other activities to change conditions.

Advocacy is generally expressed in three broad forms. *Policy advocacy* is directed toward making changes in public policy, often in the form of laws. *Cause advocacy* involves action "advocacy" on behalf of a class of people who are affected by shared conditions. *Individual advocacy* focuses on a situation affecting an individual or small group, such as a family.

# When is advocacy needed?

Although there are many different circumstances that call for someone to perform the role of advocate for a person with a disability, these are likely to fall into one of five categories —

1. The helping system is unable to

Advocacy reaffirms the value of the person, the value of our relationships with the person, and our professional values.

respond effectively because little or nothing is in place to benefit the person with a disability.

- 2. The rights of the person with a disability are being ignored or denied. This commonly occurs through the of information or withholding helpful and respectful responses.
- 3. The person's crisis situation does not fit routine response procedures.
- 4. The individual with a disability lacks sufficient knowledge, skill, confidence, or power to meaningfully assert her/his concerns without assistance.

5. The responding institution (e.g., human service agency) does not have a meaningful relationship with the person with a disability. The person and their issues are not real to the institution.

# Why advocate?

Like any other tool in our professional repertoire, advocacy allows us to effectively fulfill our professional responsibilities and purposes. More specifically, advocacy reaffirms the value of the person, the value of our relationships with the person, and our professional values. In fact, our ethics require us to advocate "for the rights of all members of society." Our own ability to function in accordance with our knowledge and values are hampered by conditions we may need to change. Further, advocacy prevents avoidable losses and discomfort and the additional expenditure of resources (including personal time and energy) required to restore the loss that occurs when attention is not appropriately given. We have a choice to become silent partners in maintaining conditions that exploit and demean — or not.

## Some basic considerations of advocacy

Advocacy is clearly a challenge. In the short term it may appear easier to develop the dubious skill of practiced inattention. Advocacy demands things from us that we may not feel prepared to give. Still, almost anything of value in human services will demand something of

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us. In part, our willingness to accept those demands makes this profession and its practitioners unique. There are many matters to which we need to give attention in order to become effective advocates. A few of them are —

- Confront your own hesitancy to act. Acknowledge that uncertainty can lead to inaction. Identify selfmessages that hinder your work and deal purposefully with them so that you can replace them with more powerful ones. "I'm afraid of what might happen....I really don't know enough about the situation....I really don't know what to do....People who are in charge are more important than I or the person with a disability..." What messages and actions could you construct to counteract these?
- Reaffirm your values and ethics.
- Recognize that you have a basic set of skills from which you can draw, including interviewing, problem solving, self-awareness, planning, observing, information gathering, and active listening.
- Involve people you support in the advocacy effort. Assist them in learning how to become more confident and skillful. Make sure that they agree to engage in advocacy, including an understanding of the likelihood of helpful and harmful consequences.
- Recognize common issues and link the people supported with one another or with someone who is better able to deal with cause advocacy.
- Assist people with disabilities in becoming teachers of others, including teachers of professionals.

## A few advocacy tips

I have selected from many tips I have on advocacy (A "Top Ten List"). I chose those that relate more, though not exclusively, to individual advocacy, because that's where many of us get our start.

- 1. Know your issue well. Be aware of areas where your knowledge is fuzzy. Do something about that. Don't pretend. Develop your "argument." That is, link facts and examples with a rationale for action.
- 2. Know the relevant rights, rules, and regulations. Vague understanding will lead to vague arguments. Be able to cite chapter and verse. Know how procedures work. If you choose to ignore them, do so on purpose and have a rationale for doing so.
- 3. Get a partner. You will feel more confident if you have a knowledgeable, friendly co-advocate.
- Get help. Get information and possibly involvement from relevant advocacy organizations and other organized groups.
- 5. Get a picture of what better looks like. Have a clear idea of how you would like the matter to be resolved. Stay open to alternative ways to solve the problem. Focus on interests, not just positions. Be creative.
- 6. Focus on the outcome. Do not get lured into a discussion of peripheral issues. You can perhaps acknowledge them for a future discussion, but return to the matter at hand and keep attention there.
- 7. Recognize and communicate awareness of legitimate interests. Be able to identify both your (and the person's) interests, as well as the interests of the

party to whom you are advocating (i.e., the target). Communicate this awareness so that the target knows you understand those interests.

- 8. Link the issue. Be able to connect the issue and its resolution to the mission, goals, statements, etc. of the target as well as to commonly held human values.
- 9. Use emotion appropriately. Be willing to inject emotion into your argument so that the target better feels the issue as well its importance to you. Avoid being purely rational or overly emotional.
- 10. Get clear agreements with timetables. Any agreement lacking specific outcomes to be produced by specific actions of specific people according to a specific timetable is fluff. Do not fall into the trap of accepting a promise to "take action" or "look into" the matter. Further, at the time agreements are made, you need to come to an agreement with the other party about what actions you should take if agreements are not kept. Keep the record straight by recording agreements.

Your decision to engage in advocacy will energize and deepen your professional commitment. Your decision to continue learning how to do it well will bring rewards that no attempt at accommodation can ever bring.

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# **ANCOR's National Advocacy Campaign**

# The Direct Support Professionals Fairness and Security Act

## About ANCOR

ANCOR is a national non-profit organization for private providers of supports for people with disabilities. ANCOR, the American Network of Community Options and Resources, strives to provide members with the most up-to-date information on issues that effect the work of Direct Support Professionals (DSPs). AN-COR also advocates for its member organizations in the area of public policy and legislation at the state and national level.

## National Advocacy Campaign

In 2001, ANCOR launched its' National Advocacy Campaign, a multiyear, multiple-strategy national public policy initiative to address Medicaid funding and workforce issues. The mission of the campaign was to obtain the resources to recruit, train, and retain qualified DSPs that will, in turn, enhance and promote community living and enrich the lives of Americans with disabilities. One of ANCOR's key strategies in this endeavor is lobbying to affect national public policy. During the summer of 2004, AN-COR did just that by working with both houses of Congress to develop bipartisan legislation to help address the crisis in recruitment and retention of DSPs. Contributing factors to the workforce crisis are ----

• DSPs that provide communitybased services and supports are often paid less than DSPs working for less desirable state-operated institutions. • Organizations providing services must work within the constraints imposed by policies of state governments, which establish the reimbursement rates for services available in the Medicaid program. Otherwise, the providers have to find sources of funding elsewhere, which is often impossible.

> Many DSPs find that they can earn higher hourly wages, and receive better benefits in far less demanding jobs in the fast food and retail industries.

• Many DSPs find that they can earn higher hourly wages, and receive better benefits in far less demanding jobs in the fast food and retail industries. This results in high turnover rates (from 40 to 75%) and poor supports for people with disabilities that directly affect their quality of life.

## The Direct Support Professionals Fairness and Security Act

ANCOR is grateful that Representatives Lee Terry (R-NE) and Lois Capps (D-CA) have taken the lead on bringing these issues to the forefront. On March 10, 2005 they introduced to Congress H.R. 1264 to address the crises in programs funded by the federal/state Medicaid program. The Direct Support Professionals Fairness and Security Act would take important steps to ensure that DSPs are paid wages that enable them to stay in their jobs and provide the critical services that people with disabilities rely upon.

This bill would amend the Medicaid program (Title XIX of the Social Security Act) to provide funds to States to enable them to increase the wages paid to targeted DSPs in providing services to individuals with disabilities. The program is designed as an option to states and would provide enhanced federal medical assistance percentage (FMAP) for five years to states to increase wages. It is designed to increase wages and eliminate the gap between wages paid to private employees and public employees in the state.

In order to receive the enhanced FMAP, states would be required to submit a five-year plan and must assure continuation of the increased wage rate after the five-year period. The state plan must be developed in conjunction with individuals with disabilities and family members, private providers, and direct support professionals.

The bill targets the increased FMAP to cover DSPs working for private employers who provide supports and services to people with disabilities who are eligible for and receiving Medicaid under the following state plan services: personal care option for personal assistance; rehabilitation option for rehabilitation or habilitation; home health

# ANCOR's National Advocacy Campaign, continued from page 10

services; home and communitybased services under Section 1915(c) or Section 1115 waivers; and intermediate care facility services for persons with mental retardation and related conditions (ICFs/MR).

The legislation provides for federal funding for state planning grants. It also mandates a Government Accountability Office (GAO) study on recruitment and retention and an Inspector General Audit of progress in reducing/eliminating the wage gap.

### **Personal interest**

Representatives Terry and Capps have personal insight and are committed to bringing the issue of low wages for DSPs and the inequity in wages between private and state employers to the forefront — Terry says, "It's the right thing to do."

At ANCOR's 2004 Governmental Activities Seminar, Terry urged ANCOR members to take their case to Congress and to invite other U.S. Representatives to co-sponsor the Direct Support Professional Fairness and Security Act of 2004. Terry also stressed the importance of adding a personal face to this issue and emphasizing what is at stake for people with disabilities, their families, and DSPs.

Representative Terry has a longstanding personal connection to this issue. Decades ago his father, a journalist, exposed the conditions in Beatrice, a Nebraska state institution. Representative Capps also has first-hand connection to the importance of quality support. Her late husband's aunt received supports from ANCOR member agency Mosaic of Omaha, Nebraska.

# **Make a Difference!**

# Use ANCOR's Online Action Center to Urge Support for H.R. 1264

The Direct Support Professionals Fairness and Security Act is introduced at a time when the Administration and many in Congress are

looking for ways to limit the Medicaid program. However, without enactment of the bill, people with disabilities will continue to have difficulties in acquiring the support they need. We need your support to make this happen!

### ANCOR's Online Action Center ANCOR has

made it easy

to contact your U.S. Representative and urge co-sponsorship and support for the Direct Support Professionals Fairness and Security Act of 2004. It takes less than two minutes! Go to ANCORs Web site at www.ancor.org and click on "ANCOR Action Center," then click on the Action Alert about the Direct Support Professional Fairness and Security Act of 2004 (H.R. 1264). There you can locate the list of cosponsors of the bill, and, by merely typing your zip code in the box in the alert marked Take Action Now and clicking on Go, you will be provided with the name and address of your Representative. You may use the text of the sample letter

Let's treat Direct Support Professionals with the fairness they deserve! Let's ensure that people with disabilities and their families have security in knowing that a quality, stable workforce is there for them!

provided, edit that letter to your own specifications, or type in your own letter text. Fill out the information requested on you as the sender,

> and then click to send the message to your Representative. You must provide your address in order to have your message emailed to your Representative.

By using ANCOR's online Action Center, you will receive a written report when your Representative co-sponsors H.R. 1264. A prepared thank you letter is already online for you to send

when your Representative co-sponsors the bill. In addition, ANCOR staff can retrieve reports on which Representatives have been contacted, number of contacts by state, and even who has sent the communication. That information makes it easier for ANCOR and the National Advocacy Campaign grassroots committee to focus its efforts on your behalf. Thanks to Missouri and Minnesota providers for making the most contacts to date!

So, take five minutes right now and go to ANCOR's Action Center and send your message on the Direct Support Professionals Fairness and Security Act of 2004 (H.R. 1264)!

# **Interfaith Disability Pre-Summit**

# Before Many Voices, One Vision: Alliance for Full Participation Summit 2005

### Tuesday, September 20, 2005

2:00–5:00 p.m.	Pre-summit gathering
5:00–9:00 p.m.	<b>Reception and dinner</b>

The Parish Hall, St. Margaret's Episcopal Church, 1830 Connecticut Ave., Washington, DC

(across the street from the Washington Hilton, site of Many Voices, One Vision: Alliance for Full Participation Summit 2005)



About Many Voices, One Vision On September 22-23, the Alliance for Full Participation will host a 2005 Summit:

On September 22-23, the Alliance for Full Participation will host a 2005 Summit: Many Voices, One Vision, in Washington, DC to bring together those committed to making the promises inherent in the Americans with Disabilities Act a reality. Over twelve hundred individuals are expected to attend to help craft a new strategic policy and social agenda in support of full participation, and to carry that agenda forward in their communities following the Summit. For more information, visit **www.allianceforfullparticipation.org** 

## Interfaith Disability Pre-Summit

The purpose of the Interfaith Disability Pre-Summit is to —

- 1. Discuss key issues the Summit will address and the ways that faith communities and networks can help address these issues with leaders of the sponsoring organizations of the 2005 Summit.
- 2. Identify key issues for the future of ministries and religious services and supports with people with disabilities and their families and share those with the leadership of the 2005 Summit.
- 3. Strengthen collaboration and networking among faith-based networks and organizations involved in disability ministries.

For more information about the Interfaith Disability Pre-Summit and to view sponsoring organizations, visit **http://www.aamr.org/Events/2005/presummit.shtml** 

Registration deadline is **September 1.** Cost is **\$30.** Complete the form below, and send with a check made out to —

> AAMR Religion and Spirituality Division c/o The Boggs Center P. O. Box 2688 New Brunswick, NJ 08903

Registration Form: Interfaith Disability Pre-Summit, Washington, D.C. • Tuesday, September 20, 2005

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City	State Zip Code
Organization:	
Email:	Phone:
Special needs:	
Please register	people @\$30 each for the Interfaith Disability Pre-Summit Total \$

# The Process of Cultural Shifting Building Bridges to Community, Part I

This article is based on a two-part theory, this is part one. The first part is that some ideas and customs in our culture stop individuals with disabilities from taking part in community life. The second part is that if we understand those cultural habits, we can use them to help those same individuals join their communities. This type of change is called "cultural shifting." As a Direct Support Professional (DSP), you are the agent of that change and the vital link between the people you serve and the communities they wish to join.

We use the term "cultural shifting" in this article to describe how someone becomes part of a community. In other words, when a new person, product, or idea is accepted in the community, a cultural shift has occurred. The process of cultural shifting is described more fully in my book, *Cultural Shifting* (2001) from which this article was taken.

## The idea of a bridge

The process of cultural shifting is best understood when we compare it to building a bridge. It's easy to see why we build bridges. We want to get from here to there. Figuring out how to build one can be much harder. The challenge of connecting people to community is the same. It's easy to describe what we want to do: we want to find ways for people who are "over there" (disconnected from their communities) to cross the "river" and come here (united with their communities.) The hard part is in making this happen when the "river" between the person and the community is really the community's way of looking at the individual who wishes to cross over.

This example gets easier to understand as we look at the ideas that have kept people with developmental disabilities outside the community. In my book, *Interdependence: the Route to Community* (1991, 1995) and Beyond Difference (1996), I commented on the traditional medical view that focuses on deficiency and dysfunction. The medical model says that the best way to get people with disabilities from

> Empowerment is a feeling we get when we are connected and respected.

one side of the river to the other is to try to change whatever is different about them so the community will accept them. The approach is popular, but it is not effective. We have moved people *into* the community but not really helped them become *part* of the community. Instead, the medical emphasis on differences spreads to the community, whose members come to devalue individuals based on their disabilities. In fact, many people see only the disability and have a very hard time seeing the person at all.

To consider persons with disabilities as the problem and "place" them in communities without exploring the cultures of those communities is like riding a train on a circular track. The train seems to be moving, but doesn't actually go anywhere new. This is not how culture shifts. If instead, we work to change the community's perceptions, instead each change would benefit all individuals who wish to cross the river.

This is why the idea of building bridges is so important. First, take a moment to think about how we just changed our own thinking. We now know that the river (which represents differences) is no longer the most important factor. Instead, we need to concentrate on gathering strong materials to build the bridge and finding a firm place on each side of the river where we can attach it. Now it is time to start thinking about what type of bridge we need to build and what materials we would need to build it. To do this, the change agent (the DSP) needs to think about four critical steps.

# Four steps to cultural shifting

A four-step process leads a culture to accept a person, product or idea. Unfortunately, the human service system seldom follows those steps when seeking inclusion for people with disabilities, but I believe that they will work. If you think back, you may have seen these steps in action. Companies use them to sell products, candidates follow them to be elected, and school boards promote policy changes with them. As we explore these steps, ask yourself if you have already used them with the people you support and how you might do so in the future.

The Process of Cultural Shifting, continued from page 13

# Step one – Find the passion or point of connection

The bridges we build to carry cars or trucks get their strength from steel and concrete. The bridge that we are building will get its strength from people — from their ideas, passions, and abilities. It is a "capacity process." In other words, we must identify all that is strong or good about the citizens with disabilities who will use the bridge.

This means we look for the following elements in them:

Passions Capacities Interests Hopes Dreams Skills Talents Hobbies Strengths

When we find any of these things in someone, they grow stronger. When we notice that someone is good at something or knows a lot about something, that person feels more pride and confidence in himself or herself. People like to talk about what they enjoy and this leads to empowerment. Empowerment is a feeling we get when we are connected and respected. Individuals can use their talents and interests to build bridges to the community and their feelings of empowerment will give those bridges strength.

Compare this with what happens when we focus on someone's problems or deficiencies instead. When that happens, the person tends to feel dis-empowerd. We never feel good about the things we cannot do or do not do well, but our system sets us up to look for those things in people with disabilities. We work hard to find people's differences and disabilities and develop individualized program plans (IPP) aimed at "fixing" those problems. We put far less effort into encouraging individuals to use their skills or interests to increase their independence.

This deficiency model causes people to think negatively and critically about themselves. This point of view can be very frustrating if the problem cannot really be fixed. In many ways, this model leads people away from empowerment. In fact, to focus on our problems is to invite negativity and poor self-image into

> The bridges we build to carry cars or trucks get their strength from steel and concrete. The bridge that we are building will get its strength from people from their ideas, passions, and abilities.

our minds. Imagine where a bridge of negative ideas, poor self-image, and frustration would take you!

The capacity process suggests the exact opposite. By looking for those things that are positive and strengthoriented, we can help people build on the capacities they already have and promote their importance to the community. Some people know their passions and interests. All we have to do is ask. With other folks, we have to dig. In the work we do, we may meet folks who have been so sheltered or who are so inexperienced that they do not readily display their passions. When people have been devalued and cannot seem to find their passions at all we must give them the time and space they need to identify those points of connection. People who want to discover themselves find it helpful to have input from those who know them best. Families or other relations have been invaluable for the capacity-building work we do.

Often this is a discovery process. This became clear to me when my wife and I spent a Saturday cleaning out our garage. As we found and removed old bikes, cameras, hockey sticks, baseball bats, a ballerina tutu, an old trumpet, and other items, I realized that all of these items were potential interests we were looking for in our children. We used the ones that appealed to our children to create bridges to community inclusion for them. Others became reminders of our search for materials to build those bridges.

Part two will be continued in the next issue of *Frontline Initiative*.

This article is based on the monograph Building Bridges to Community, the Process of Cultural Shifting written by Dr.Al Condeluci, Executive Director, UCP Pittsburgh. With his permission, it has been edited for Frontline Initiative by Melissa Rennie, Associate Director of Residential Programs, SullivanArc. Dr. Condeluci can be reached by phone at 412-683-7100 x 329 or by e-mail at acondeluci@aol.com.

# Alliance Update

Hello to all! We are writing today to give you some very good news. The National Alliance of Direct Support Professionals (NADSP) has been officially incorporated! I know it may not mean too much to the most of you, but this is a major step to fulfilling a dream of many of us. NADSP has operated over the past several years with the strong support of many organizations and individuals; especially Marianne Taylor, formerly of Human Services Research Institute (HSRI) in Cambridge, Massachusetts and Amy Hewitt, from the Institute on Community Integration at the University of Minnesota. Across the country many other individuals have supported the goals and mission of NADSP by participating in monthly teleconference calls, supporting positive direct support professional (DSP) legislation in their state, developing credentialing and certification programs for DSPs, and lobbying for DSP wage and salary enhancements.

By incorporating, NADSP can become both a clearinghouse and a facilitator of these efforts and indeed even help to sponsor some of these efforts nationally. Our Board of Trustees will be very small, numbering only seven, but we will actively develop working committees that support the ongoing efforts of this "new" organization. The trustees represent 5 different states (Minnesota, New York, Massachusetts, Missouri, and Ohio) and have equally diverse backgrounds (advocate, self-advocate, DSPs, insurance representative, agency director). We will meet monthly by phone to develop NADSP as the newest national organization in the disability field. We encourage open dialogue with our key constituents: DSPs and self-advocates. We will also meet quarterly by phone with our larger "steering committee." This latter group will be comprised of state representatives that have developed statewide chapters of NADSP or incorporated into statewide DSP advocacy.

We strongly urge you to consider not only developing a DSP initiative in your state but becoming affiliated with NADSP and becoming part of a growing trend to improve, recognize, and enhance the work of DSPs across this country. My sincere thanks to the very dedicated new trustees for NADSP: Mark Olson and Cliff Poetz, Minnesota; Regis Obijiski and John Rose, New York; Marianne Taylor, Massachusetts; and Don Carrick, Missouri. My sincere appreciation to these great leaders for their hard work these past several months and the ongoing support of the staff at the Institute on Community Integration, Research and Training Center on Community Living, at the University of Minnesota.

Tony Thomas is Secretary/Treasurer for the NADSP. See page 3 for contact information.

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# Use Frontline Initiative as a Training Tool!

Ask the DSPs you support to read one or two of the articles in *Frontline Initiative* before your next staff or team meeting. Then take 15–20 minutes at the meeting to talk about the articles. This approach creates a lively discussion and idea-sharing session and helps DSPs learn and grow from the ideas in *Frontline Initiative*. Try it and let us know what works and what doesn't.

### Sample questions

- What is one thing you liked best or learned from the article?
- 2. What is one thing didn't you like?
- **3.** What idea from the reading would you like to try to implement with the people we support?

#### Of Two Minds, continued from cover

ing partnership. One day she called to tell us that she would no longer be able to work with us and our son, as she had taken another job. It was time for her to move on. This was a very sad day and we realized that we would have to start all over to build a new relationship with someone else. Unfortunately, this is a reality of support for my son — that good people, who we learn to trust, respect, and communicate effectively with will at some point move on.

Over the past 26 years of parenting we have had relationships with many different people, including case managers, physicians, school personnel, Frontline Supervisors (FLSs) and DSPs. Some of these

relationships have been great, some okay, and some not so good. So why does this one DSP stick out as being memorable? Because she took time to listen, to get to know us, and to develop a partnership with us and our son. She made a personal connection by showing she cared about what was important. She respected who we were as a family and as individuals. She engaged and involved us in every aspect of planning and implementing support services. She openly, honestly, and effectively communicated about resources, supports, and services. She worked to make changes when change meant better supports for our son. She worked hard to gain our trust and told us that by developing a good relationship with us, it helped her



support our son better. I have always respected the lesson she taught us.

Likewise, as professional community human service providers, both my husband and I have worked with families and individuals with disabilities for over 30 years. We understand from two different perspectives (being parents of a child with disabilities and being DSPs) the importance of having quality relationships with the families and the individuals we support. We know that families play an

important role in the lives of people with disabilities. They are there when things are good and when things are not so good. They are often the only people who stay in the person's life as different support workers come and go. They know the person's likes, dislikes, and history better than anyone else. They are one of the most valuable resources DSPs and FLSs can have when it comes to learning and knowing about the person they support.

We have learned to value the differences families have — in culture and ethnic backgrounds, in beliefs and values, in socioeconomic status, in family histories, and in experiences with DSPs and FLSs. We know that it is essential to get to know these differences, appreciate them, and work with each family so we can provide the best supports, not only to meet the wishes of the individual we support but also to take into account the expectations of the family. We have learned that building and earning trust helps us provide better supports. We have learned to communicate honestly and effectively and we understand and respect the experience, expertise, and knowledge the family brings to the partnership as we all support the person with disabilities.

When I worked with my husband supporting individuals and families by providing independent living skills, one family, and in particular one dad, exemplified the importance of relationships. He and I both made a special effort to frequently keep in touch. He would call to get a regular update on his daughter's progress and to report both the good things he saw happening and the things he wished would change. We talked almost weekly and shared ideas about how supports were being provided and how they could be improved. We talked about what

was working and what was not. If we needed to make changes, we would include his daughter and wife in the discussion and plans. When his daughter wanted something different than what he and his wife felt was in her best interest, all of us were able to talk, laugh, and work through these disagreements as partners. It was so refreshing to work with him. He was always honest and straightforward in his communication with us. He shared opinions, stayed organized, kept an open mind, and asked us for feedback on how he could communicate better with us. He said by developing a good working partnership with his daughter's DSPs he knew she would get better supports. We developed our working relationship and partnership because we respected and trusted each other's points of view even when they were very different. Our common ground was staying focused on what was most important — making his daughter's life better.

As a result of these experiences, both as a parent and as a DSP, here are some ideas DSPs and families should consider when trying to develop their own working partnerships —

- 1. Understanding
- 2. Honest communication
- 3. Trust
- 4. Respect

### Understanding

Here are four suggested steps to develop greater *understanding* between DSPs and families —

1. Start by knowing who you are. Think about who you are and what you believe about culture, family, and disabilities. What you believe and value will color how you act and react to what others believe. You need to understand yourself before you can understand others.

- 2. Second, learn about what the other person believes and values. Ask what they believe about culture, family, and disabilities. Take time to reflect on the similarities and differences in your beliefs and theirs. Remember that past experiences, frustrations, and history color reactions in similar situations.
- 3. Third, acknowledge, clarify, and, most importantly, show respect for the ways in which you differ. Try to feel comfortable discussing these differences, but remember to emphasize the similarities in order to find common ground for your interactions.
- 4. Finally, begin to adapt how and what you communicate about your respective points of view. This will help both of you begin to collaborate, problem solve, and synergize about building the supports and services necessary to add quality and dignity to the life of the person you support.

### Honest communication

Honest communication is essential to a working relationship and partnership. Both family members and DSPs have to be able to communicate effectively and honestly or the relationship will be faulty. Honest and effective communication is accomplished through a series of conversations where each of you listens, reflects, clarifies, and practices exchanging ideas. One technique is asking each other open-ended question that can not be answered with a simple "yes" or "no." Ask about feelings, ideas, values, and reasons for the ideas that are being shared. Expect to disagree and know that by continuing to work on how things

are said as well as concentrating on *what* is being said it will make it easier to reach consensus. The focus in all communications should be how to improve supports and services for the person with disabilities.

### Trust

All relationships among families, individuals, and DSPs require an element of *trust*. Trust is earned. DSPs and family members can earn each other's trust by following through with what you say you are going to do. In other words, don't make promises you can't keep. Trust is earned by respecting each other. Trust should not be assumed by either the family or the DSP but rather worked at by every action you undertake.

## Respect

The final cornerstone in developing working relationships and partnerships is *respect* in all interactions. Respect, unlike trust, is given by both the DSP and family members to each other. It is given by recognizing and valuing each other's strengths, knowledge, and expertise. Respect is shown when communication and interactions remain positive and when both parties work toward mutual collaboration to resolve conflicts and solve problems together.

The individual being supported, their family, and their DSPs must and should continually work towards developing a working partnership in order to best support the person with disabilities.

Nancy McCulloh is a project coordinator at the Institute on Community Integration. She can be reached by email at mccul037@umn.edu.

# Frontline Resources

#### The Arc of the U.S.

1010 Wayne Avenue, Suite 650 Silver Spring, MD 20910 www.thearc.org 301-565-3842

The Arc is a national organization that focuses on people with mental retardation and related developmental disabilities and their families. It is the oldest family organization for people with disabilities, and it has been the most influential in terms of advocacy related to public policy. It has about 140,000 members who are affiliated through about 1,000 state and local chapters. The Arc sponsors a public policy forum each spring which provides thorough coverage of disability policy information and its Arc's governmental affairs newsletter contains the most recent information concerning public policy advocacy.

#### Federation of Families for Children's Mental Health

1101 King Street, Suite 420 Alexandria, VA 22314 www.ffcmh.org 703-684-7710

The Federation of Families for Children's Mental Health is a national parent-run organization focusing on the needs of children and youth with emotional, behavioral, or mental disorders and their families. The Federation is one of the newest family organizations but has already wielded extensive national influence on many aspects of educating students with emotional disabilities and ensuring comprehensive mental health services.

#### Family Village

familyvillage.wisc.edu/ index.html

Family Village, sponsored by the University of Wisconsin, provides extensive information for families of children with disabilities and professionals. Topics covered on the site include education, recreation and leisure, participation in religious communities, health issues, and cultural diversity.

#### **Beach Center on Disability**

University of Kansas 3136 Haworth Hall 1200 Sunnyside Avenue Lawrence, KS 66045 www.beachcenter.org 785-864-7600

This University of Kansas center's Web site offers research-based information on disability topics. The site features approximately 100 research articles/chapters are offered in three formats — brief overview, 2-3 page Research Highlights, and full text. Additionally, the Web site includes real stories, books and manuals, and links to a wide variety of organizations.

### Parent to Parent — USA

#### www.p2pusa.org

Parent to Parent — USA is the national consortium of local and state Parent to Parent programs. Parent to Parent programs provide emotional and informational support to parents of children with special needs, primarily through one-to-one matches of a "veteran" parent of a child with a disability with a parent who is experiencing challenges associated with disability for the first time. This Web site offers a map that provides the names of state and local programs and then contact information. There is also a section that summarizes the evidence-based practices related to Parent to Parent support.

#### Advocacy in the Human Services

Ezell, M. (2001). Belmont, CA: Wadsworth

Opportunities to engage in advocacy have increased due to changes at the federal level which are relegating more and more human service funding and decision-making to the state and local level. The purpose of this text looks is to give students and professionals a deeper understanding of advocacy practice in order to fully serve clients.

#### Understanding Generalist Practice

#### Kirst-Ashman, K.K., & Hull, G.H. (2002). (3rd ed.) Pacific Grove, CA: Brookes-Cole

This guide to general social work practice provides introductory knowledge and skills needed to work with individuals, groups, communities, and organizations. It has an excellent section on advocacy, including an examination of sets of assumptions, as well as tactics and techniques.

Special thanks to Ann Turnbull from the Beach Center on Disability at the University of Kansas for providing resources for this issue of *Frontline Initiative*. http://www.beachcenter.org



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# **NADSP** Moving Mountains **Commitment Certificate**

The Moving Mountains Commitment Certificate is a set of workforce principles developed by the National Alliance for Direct Support Professionals to encourage organizations and individuals to adapt policies and practices that result in a competent, committed direct support workforce. The NADSP seeks your commitment and asks you to move mountains within your organization by pledging to advance these principles. Certificate is metallic green and black. The size is 16" x 20" — perfect for framing! Cost: \$10

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# Attract and Recruit Quality DSPs

# with the Direct Support Professional Recruitment Toolkit

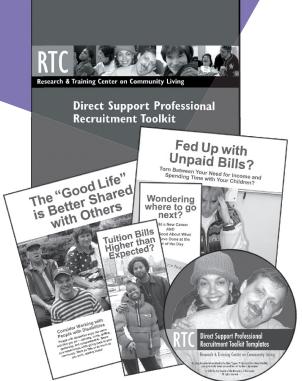
Finding DSPs who are competent and stay on the job is the greatest challenge faced by employers today. The *Direct Support Professional Recruitment Toolkit* is designed to help you create an exciting, dynamic recruitment plan that will attract a large pool of qualified applicants. The toolkit can be used by individuals, families, consortiums, and organizations — anyone who needs to attract, recruit, and retain quality DSPs.

The toolkit provides —

- Information on how to develop a marketing strategy and recruitment plan that meets your agency's unique needs.
- Information on where to find the people that make great DSPs.
- Samples of effective recruitment tools designed to reach target niche groups.
- A CD-Rom (PC & Mac compatible) with templates you can customize to produce eye-catching, professional-looking materials.

Cost: \$25.

Download the order form at http://rtc.umn.edu/wddsp/tools.html or call 612-624-0600.



#### Visit the DSP Web site at http://www.nadsp.org

# Frontline Initiative

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