

A Quarterly Newsletter of the National
Alliance for Direct Support Professionals

Frontline Initiative

Volume 3 • Number 2 • Spring 1999

Supporting Self-Determination Through Self-Reflection

As someone who has many medical needs, but many dreams as well, I'd like to share with you what self-determination means to me, and how my situation demonstrates what a Direct Support Professional (DSP) can do to promote the self-determination of the people they support. For me, self-determination is expressed primarily in two ways: 1) speaking up for myself, and 2) learning more about my medical needs and how to cope with them on a daily basis. First let me share a little background about myself.

I have Prader-Willi Syndrome, diabetes and a developmental disability. Prader-Willi Syndrome is an eating disorder that was described to me as my brain telling me to eat constantly, but never telling me that I feel full. Every day I feel the struggles of having to watch what I eat and exercising every day. I have to use will power to help me control my urges. I feel better when I stick to my diet, and when my staff help me with these ongoing struggles by encouraging me to stick with it. Having diabetes, I also have to check



Heidi Maas shares her thoughts on how Direct Support Professionals can identify with the concept of self-determination.

Continued page 3

What's Inside

The Real Scoop	2
Caring for Waiting Babies	4
State-of-the-Art Definition	5
Member Profile: SABE	6
Breaking the Bonds of Substance Abuse	7
Alliance Update	8
Frontline Resources	9
How My Son got Wings	10
Subscriptions	11

The Real Scoop DSP Q&A

Editorial Information

Editor · **Tom Beers**
Supervising Editor · **Susan O'Neill**
Managing Editor · **Amy Hewitt**
Graphic Design · **Connie Burkhart**

Board Members

Pamela C. Baker
Long Beach, MS — FAAMR

Bill Ebenstein
New York, NY — Reaching Up

Gina Farrer
Provo, UT — Danville Services Corp.

Mark S. Homan
Tucson, AZ — Pima Community College

Sally Jochum
Lenexa, KS — DSP, Johnson County
Developmental Supports

Molly Kennis
Ft. Collins, CO — Martin Luther Homes
of CO, Inc.

Jerry Leismer
Wayne, MI — Wayne Community Living
Services

James Meadours
Baton Rouge, LA — SABE

Cynthia Mowris
Staatsburg, NY — DSP, Anderson School

Terri Niland
Rockville, MD — DSP,
The Arc of Montgomery County

Mark Olson
Eagan, MN — DSP, Owobopte Inc.

Steve Piekarski
Anoka, MN — Anoka County DD Unit

Rick Rader
Chattanooga, TN — Orange Grove
Center

Marianne Taylor
Cambridge, MA — HSRI

Ralph W. Vunderink
Wyoming, MI — DSP, Spectrum
Community Services

Marci Whiteman
O'Fallon, MO — Self-Advocacy
Coordinator

If you are interested in commenting on or contributing to Frontline Initiative, or in becoming a member of the editorial board, please contact —

Tom Beers, Editor
P.O. Box 13315
Minneapolis MN 55414
Tel. 612.624.0060

Welcome to *The Real Scoop*. Clifford is a self-advocate who has been politically active for years. He's ready to give you his spin on how to deal with issues that come up as you forge ahead in your role as a Direct Support Professional (DSP). Seth has been a DSP for too many years to count, and he loves to give advice. He may give you a hard time, but hey, it's for your own good! Clifford and Seth tackle this one with just a few suggestions. How would you handle this situation?

Balancing Wishes and Good Intentions

Dear Clifford and Seth,

I provide support for a woman whose family often has concerns for her that sometimes conflict with her wishes. She's her own guardian, but her family can still be very imposing.

How can I strike that important balance between the family's wishes for her and her wishes and concerns? This dilemma happens often and leaves residential providers feeling somewhat powerless to advocate for this person.

— *Terri in Kansas*

Dear Terri,

Since this individual is her own guardian, you must be firm about this legal status and help the family to understand that you are there both for her dreams and safety. It may help to clearly state what those dreams are and diplomatically ask for time and space to accomplish them. Provide the opportunity for them to be as involved or uninvolved as they want, but be

clear that you're moving on. Always maintain open communication channels. Also, you may want to ask your supervisor for training in negotiation skills. It is difficult to be in the middle, but remember that you're dealing with this woman's dreams.

— Clifford

Dear Terri,

Partnership and support of family is one of the most important aspects in a person's opportunity to plan and reach his or her goals. For the most part, a residential provider has a lot easier job when there is family involvement. However, as in many families, including my own, a family's wishes and dreams may emphasize different dimensions of their grown children. For example, some families are looking at long-term goals while their children are only looking at short-term ones, or vice-versa. Seek training from your agency on how to take the positive sides of all concerned to work short- and long-term goals that will make everyone who is constructively involved optimistic and supportive.

— Seth

Ask Clifford and Seth

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

Tom Beers
P.O. Box 13315
Minneapolis, MN 55414
Fax: 612.625.6619
Email: beer0025@tc.umn.edu

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

NADSP Member Organizations and State Contacts

Self-Reflection, continued from cover

my blood sugar four times a day and, again, I watch my diet carefully. My staff provide supports throughout all of this, but sometimes their eagerness to stick with the program has resulted not only in a clash of wills, but even a risk to my health.

For instance, one time I told staff that I didn't have enough to eat for breakfast, but she didn't listen. She told me she couldn't do anything about it and that I needed to stick with my diet. I left for work. I started feeling light headed and weak, my legs like jelly. I had to go to the staff at work to get something to raise my blood-sugar level. When I got home I was able to tell the supervisor what happened and she said she would take care of it. It has never happened again. Staff now support me by listening to me more carefully and responding to my needs. When that happens, I feel respected, self-confident and self-reliant. My situation is delicately balanced between what I want and what I need. DSPs need to be very sensitive to everything I say, whether it be something I want to do for fun, or how much I want for breakfast, and they need to work with me to find a solution.

I feel that, to be most effective, DSPs must not only be aware of my needs and wants but also their own. In the above situation about breakfast, the staff seemed callous, rigid, and almost oblivious to me. In this case and in many like it, the DSP's self-understanding may have affected how she understood and sympathized with others. Many people are rigid with others in areas

Continued back cover

Frontline Initiative is a product of the National Alliance for Direct Support Professionals. The NADSP is a collaboration of 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
- American Association of University Affiliated Programs
- 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
- CUNY Consortium for the Study of Disabilities
- Council for Standards in Human Service Education
- Human Services Research Institute
- Institute on Community Integration (UAP), University of Minnesota
- International Association of Psychosocial Rehabilitation Services
- National Association of State Directors on Developmental Disabilities
- National Association of State Directors of Vocational Technical Education
- National Center for 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, University of Pittsburgh, School of Social Work
- Reaching Up
- Self-Advocates Becoming Empowered
- TASH
- United Cerebral Palsy of America

NADSP Co-chairs

James Meadors

Self-Advocates Becoming Empowered
8326 Kelwood Ave., Baton Rouge, LA 70806
Tel. 504.927.0855

Mark Olson (Interim)

Owobopte Inc.
3195 Neil Armstrong Blvd., Eagan, MN 55121
Tel. 651.686.0405 ext. 148

Marianne Taylor (Interim)

HSRI
2336 Mass. Ave., Cambridge, MA 02140
Tel. 617.876.0426 ext. 330

State Contacts

Louisiana

David H. Belton, TRI*ADD Human Development Center
Louisiana State University Medical Center
New Orleans, LA 70119
504.942.8207
DBelton@HDC.lsumc.edu

Massachusetts

Marianne Taylor, HSRI
2336 Mass. Ave.
Cambridge, MA 02140
617.876.0426 ext. 330
mtaylor2@concentric.net

Michigan

Karen Wolf-Branigin, Wayne State University
Leonard Simons Bldg.
Detroit, MI 48202
313.577.7981
K.Wolf-Branigin@wayne.edu

Minnesota

Mark Olson, Owobopte Inc.
3195 Neil Armstrong Blvd.
Eagan, MN 55121
651.686.0405 ext.148

Missouri

Marci Whiteman
104-3 Old Hwy 40 #274
O'Fallon, MO 63366

New York

Bill Ebenstein, CUNY
535 East 80th Street - 4th floor
New York, NY 10021
212.794.5486
wiebh@cunyvm.cuny.edu

Ohio

Amy Gerowitz, Outlooks/ANCOR
3883 Blackwood Ct.
Cincinnati, OH 45236
513.793.1946
gerowitz@ix.netcom.com

Caring for Waiting Babies is Part of My Identity

My involvement in a pre-adopt foster care program is founded on my belief that all children deserve a good beginning in life. The purpose of my work is to provide care for an infant from the time of his or her birth until he or she is placed with a permanent adoptive family. The many aspects of this work provide me with a great variety of rewarding roles.

My primary responsibilities on a daily basis are feeding, clothing, and diapering, but I also have to work with others regularly including social workers, adoptive and birth parents, and other pre-adopt families. I serve as a liaison between the adoption agency for whom I work and other individuals involved with the child. I often accompany the infant to their new homes and provide the adoptive family with information about their child and maintain contact with the adoptive family as needed. The amount of time I care for a child varies widely as placement is dependent not only upon the decisions of the birth parents, but also on the availability of an adoptive family for placement.

One of my favorite responsibilities is the development of a “life book.” This involves collecting photographs and other mementos of the child’s early life. This book establishes a complete record of the beginning of a child’s life and is presented to the adoptive family when the child is placed.

My primary interest involves working with children with special needs. The children I have cared for have had a variety of difficulties ranging from challenges resulting from premature birth to health problems resulting from alcohol and drug abuse. Many times, people are reluctant to adopt a child with special needs. The adoption process can be long. I find it very rewarding to be able to be present for the child during this time.

Attitude is an especially important element of my work. With

“ I feel very fortunate to be able to care for children who are awaiting adoption. ”

respect to a baby’s care, my primary concern is that they receive the best care possible to get a good start in life. I am especially mindful that the children I work with are clean, well-dressed, and loved. I want the children to be viewed as valued persons, regardless of the circumstances into which they were born. I also

view my position as one in which I need to share the value of the work I do.

Being a pre-adopt mother has affected my life in many ways. First of all, I am willing to change my own life in order to care for an infant awaiting adoption. While many people may be unwilling to consider night feedings or toting diaper bags wherever they go, I am delighted to be able to provide this service. The people with whom I have regular contact expect me to have a baby.

Although I began this work approximately 10 years ago, when my daughter Catherine was in

preschool, my sense of satisfaction has been so great that I want to continue with it. Catherine also sees this work as important. She even comments on wanting to have another baby around, especially when she feels that it has been too long since we have had a child in our home. My role as a pre-adopt mother has gone from being something that I had only heard about to being the center of my identity. I feel very fortunate to be able to care for children who are awaiting adoption.

Jean Hoyt is a foster care provider for Lutheran Social Services of the National Capital Area. She can be contacted at 301.949.7356.

Since the composition of this article, Lutheran Social Services has expanded its supports delivery to include foster care in addition to pre-adopt care.

Watch for New Column — News From Syracuse

In the next issue of *Frontline Initiative*, *News from Syracuse* will premiere, featuring articles provided by the Center on Human Policy (CHP), the National Resource Center on Supported Living and Choice, at Syracuse University. Direct Support Professionals (DSPs) can often feel isolated in their work, and in many cases they may simply not have much information about important innovations or issues in the field. Many changes are happening, and many that will affect the role of the DSP. *News from Syracuse* will provide information focused on the latest changes in Direct Supports in the United States. The following are a few examples of the kinds of issues *News from Syracuse* will feature —

- Many agencies are converting from group homes and ICF/MRs to supported living approaches that have major implications for DSPs, ranging from increased isolation from other DSPs as supports delivery becomes more community focused, to having much more freedom in providing creative supports for individuals as they make the transition from large isolated facilities to personal, community living.

- As the field emphasizes social relationships and community building, DSPs are being called upon to play new roles in providing supports that develop natural networks among family, friends, and community.
- Many states are experimenting with self-determination, voucher, and subsidy approaches that place greater control over services in the hands of people with developmental disabilities and their families. This means that individuals have the opportunity to select and sometimes supervise their own support staff.

News from Syracuse will provide a handle for DSPs to grab onto as the world around them evolves and changes.

CHP is a policy, research, and advocacy organization involved in the national movement to ensure the rights of people with disabilities. The National Resource Center on Supported Living and Choice is funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research. To obtain more information, visit the CHP Web site at — soeweb.edu/thechp.

State-of-the-Art Definition:

Self-Determination

If you are a Direct Support Professional (DSP) who supports people with disabilities, you may be hearing more about promoting *Self-determination*, but you may not know exactly what it is or what it ought to look like in the lives of individuals. Self-determination is not the same as choice making, independence, or self-advocacy, but is made up of many different things. There are probably as many ways to think about it as there are people in the world. It refers to making plans and having ultimate control over both larger life decisions such as selecting a new place to live, or quitting a job, as well as everyday choices such as what shirt to wear, or who to receive help from when needed.

It is assumed for most people in our society that they have the ultimate right to control their own lives and therefore they are encouraged to do so at an early age. However, in our desire to protect people with disabilities, we have not offered them the same opportunities to live a life of their own choosing. A role for today's DSP is to give control over large and small life decisions back to persons with disabilities, but also to continue providing support based on helping each person achieve the lifestyle of his or her choosing. Finding this balance is part of the "art" of the DSP's job.

DSP Web Site

www.ici.coled.umn.edu/dsp

Check out the DSP Web site! It has a discussion board, an event calendar, information on NADSP activities, publications, and lots of useful links!

Self-Advocates Becoming Empowered (SABE)

Self-Advocates Becoming Empowered (SABE) is a national self-advocacy group that formed as a natural outgrowth of the self-advocacy movement. The mission of SABE is: "To ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes." Their vision is for "supporting self-advocates to speak up to gain their independence nationwide."

The self-advocacy movement was started by and for people with developmental disabilities because they wanted to advocate for themselves rather than having others, such as professionals, parents and other family members, and advocates with or without other disabilities, speak for them. As part of the broader disability rights/independent living movement, the self-advocacy movement is first and foremost a civil rights movement led by and for people with developmental disabilities. As with all social activism movements, self-advocacy started at the grass-roots level where local leadership was drawn upon to organize people to stand up and speak up in order to effect social change.

In 1990, self-advocates from around the United States met in Atlanta to talk about starting a national self-advocacy organization. Discussing the need for people to meet regularly to share and plan together, they wanted a national self-advocacy organization that would be for and by people with

developmental disabilities. The self-advocates decided to present their idea at the first self-advocacy conference, the *North American People First Conference*, hosted by Speaking for Ourselves of Colorado in the fall of 1990. People gathered after the formal conference hours, and eventually representatives from various national regions formed a steering committee to develop a proposal for implementing a national self-advocacy organization.

In September 1991, their plan was accepted by the participants of the *Second National People First Conference* in Nashville, Tennessee. Attendees had their first elections for board members, and SABE was formed as an official organization. In July 1994, the third national self-advocacy conference occurred in Alexandria, Virginia. SABE board members released their first position paper on community living at the conference. In that and ensuing years, SABE fought for its goals on several fronts —

- It has sought nationwide long-term care reform that promotes person-centered rather than provider-centered service system.
- *Campaign for Freedom Close the Doors* was founded as an ongoing endeavor to close permanently all institutions for people with disabilities.
- SABE developed a position statement about how self-advocates can support each other in the community.
- They have collected the stories of those who lived in public and private institutions.

- SABE produces a CD, *RESPECT*, that contains civil rights disabilities songs.

In its effort to promote the independence of those with disabilities, SABE asked several of its representatives how DSPs could support them in living more self-determined lives. Some of their responses were —

- Read to me, explain to me; don't use long words. Help people speak for themselves, and let them use their own words.
- Understand what you're saying and understand what the person is saying to you.
- Help the person get the supports they want and need.
- Be dependable. Be on time, and let the person know when you're not going to be able to be there.

Tia Nelis is chair, James Meadours is co-chair, and Mary Hayden is an advisor of SABE. Contact SABE at P.O. Box 105-CL, New Fairfield, CT 06812.

Breaking the Bonds of Substance Abuse Renewed Self-Determination

As a Direct Support Professional (DSP) in the field of adolescent substance abuse treatment, I have found restoring self-determination to be a key concept which is important for me to understand and implement. For adolescents to be successful in the outside world, they need to feel they have the ability to control their lives. Instilling this belief in an adolescent who has or is struggling with a dependence on alcohol and/or drugs can be an important step to his or her future success.

Adolescence is a period of development when individuals separate from their parents and create their own identity. When adolescents start to abuse substances, they stop the normal emotional developmental process. Consequently, when they stop using drugs there is a gap between where they should be developmentally and where they are chronologically. They often lack the confidence in themselves to believe that they can determine their own future.

There are several different ways to treat adolescent substance abuse. One way is a short-term residential program which usually lasts from 28 to 40 days and offers a chance to remove adolescents from their everyday setting and place them in a safe, drug-free environment. For many in the program, it will be the first time they have not had access to drugs on a regular basis in years.

Residential treatment takes away many of the day-to-day decisions that the person has to make because it is structured and most decisions are made for the adolescent by the staff. There are disadvantages to this when the goal is to promote self-determination among the youth because there are not many opportunities to make decisions and face

consequences either positive or negative. The DSP must work hard to help nurture as much choice making as possible given the setting.

Another option is having the adolescent attend three to five hours of counseling three to five nights a week. Self-determination is much easier for DSP to promote with this option because adolescents stay in their homes and school settings and continue to make decisions but there is structured time to address the issues around their

drug use. This enables the youth to test out new skills they have learned and receive support from peers and staff in doing so.

The DSP plays a crucial role in helping adolescents gain confidence in themselves to make decisions that will have a positive effect on their futures. As an adolescent begins to practice self-determination, usually several observable changes occur. Many times the youth will begin to discuss his or her future and what he or she wants to do. For many adolescents, drugs have taken away their hopes and dreams and left

them without plans or aspirations. Believing in themselves again, they begin to consider their futures. Another sign that an adolescent is beginning to practice self-determination is when he or she begins to discuss breaking away from drug-using friends; for most teens, their friends are critical to them and the thought of leaving them is overwhelming. When adolescents begin to see that staying away from drugs is about more than just saying "no" and they realize their drug-using friends are linked to their chances at sobriety, they are starting to take control of their lives and recover. As the adolescents take these steps, it is crucial that DSPs around them support their decisions. They cannot be forced into these decisions because adolescents will not follow through if they do not believe it is necessary for their sobriety.

The DSP must strive to create an atmosphere where adolescents are given enough choices so that they can see how these choices will affect their future, but not too many choices too soon so that they are not overwhelmed. Most adolescents want to have self-determination and the confidence in themselves that they can make the right choices. Often it is the DSP that needs to give that encouragement to the youth so that they may start down the road to self-determination.

Amy Brandhuber is a patient community facilitator for Cottonwood de Tucson in Arizona. She may be contacted at gbrandhuber@prodigy.net.

“
The DSP plays a crucial role in helping adolescents gain confidence in themselves to make decisions that will have a positive effect on their futures.
”

Getting Involved

Local Coalition Promotes Alliance Goals

The National Alliance for Direct Support Professionals (NADSP) has been working to develop local and regional coalitions of the NADSP and connect with existing coalitions that support the mission and goals of the Alliance. Through these networks we believe we will reach many more individuals who are concerned with the issues of the Direct Support Professional (DSP) workforce, and build our capacity to effect change, both on a regional and national level. This Alliance update will focus on the work and goals of one regional group, the Mid-Hudson Coalition (MHC) that exemplifies local efforts and activities that support the mission of the NADSP.

The Mid-Hudson Coalition, with its voluntary, paid membership of 35 agencies, 5 local colleges and more than 200 individuals, is a regional effort to improve quality supports for all people with special needs by elevating the stature of direct care to a profession in its own right. Its work includes representatives from a spectrum of service systems — developmental disabilities, mental health, child welfare, geriatric care and education — which began collectively addressing recruitment and retention issues related to direct care over 10 years ago. MHC examined salary schedules, benefits and work force demographics, and best practices in the United States and Europe.

According to the MHC philosophy, a career is defined by a specific education which generates a credible and portable credential. Therefore, the answer to recruitment and retention problems is a simple but long-term one: a new profession must be developed through education. If quality is defined at the

“
The answer to recruitment and retention problems is a simple but long-term one: a new profession must be developed through education.
”

point of service, then there must be a redirection resource to the point of service in order to ensure competence and a career commitment.

The MHC has focused its educational endeavors on three interrelated areas: 1) educational opportunities for direct care workers to increase both the quality and quantity of the work

force, 2) agency development to establish and welcome effective models of practice, and 3) governmental involvement with the regulatory agencies and legislators. To these ends the MHC has developed educational programs at the State University of New York (SUNY) at New Paltz and in several of the community colleges. The SUNY program is a bachelor degree in Sociology with a Concentration in Direct Care Practice (CDCP). The CDCP was developed in 1992 and modeled after Danish college education in social pedagogy (see *FI* Vol. 3, No. 1, Winter 1999 for more information on Social Pedagogy). The MHC raised funds to hire two professors from Copenhagen, Denmark to assist us in developing

the program in its first two years. By the fall of 1999, the MHC anticipates that five county community colleges will have certificate programs in direct care in place that are based on the nationally validated Community Support Skill Standards developed by Human Services Research Institute in Cambridge, MA. Currently, Dutchess County Community College has a 16-credit certificate and Ulster County Community College has an 18-credit certificate. To encourage the success of these programs, the MHC has provided partial scholarship and books/materials grants to students. The MHC also coordinates an annual conference for DSPs and sponsors two to three CEO/HR forums each year.

Effective systematic reform requires the commitment and work of many people in order to advance educational opportunities, career ladders, policy changes, organizational development, and compensation adjusted to levels of responsibility. In isolation, no organization can accomplish these types of educational and system-reform goals. The MHC thus seeks broader connections among the supports system. The NADSP is such an organization and MHC is pleased to be in alignment and affiliation with this national coalition.

The Mid-Hudson Coalition, Inc. may be contacted at P.O. Box 3805, Poughkeepsie, NY 12603 or 914.473.3000, ext. 363.

Frontline Resources

Tools for Change

This video-oriented series is an eye-opening, mind-expanding and life-affirming presentation of the self-advocacy movement from its inception to its current efforts to reform society for the betterment of all. Presentations made through music, drama, documentary footage, speeches, and discussion address such issues as the historical context of self-advocacy, the institutional warehousing of people, consumer advocacy, labeling and people-first language, social stereotyping and stigma, organizing political strategy, and self-determination. Setting out in bold relief how easy it is to take for granted personal freedom, *Tools for Change* provides an opportunity for one to see through the eyes of people with disabilities. *Tools for Change* is primarily designed to encourage and build up self-advocacy and social action among consumers of services, but DSPs would benefit greatly from the understanding provided by this series. The video series comes neatly packaged with workshop manuals, literature for distribution, and overhead and handout master copies, and the videos run approximately 15 to 30 minutes. Prices for modules range from the free "Lasting Leadership" module to \$199.95 for "Self-Advocacy: Freedom, Equality, and Justice for All." To obtain this resource or information about it, contact Kathy Sanders at 800-641-0059, or visionact@aol.com; fax: 651-641-4053 or Advocating Change Together, Inc., 1821 University Avenue, Suite S306, St. Paul, MN 55104.

Self-Determination for Youth with Disabilities: A Family Education Curriculum

Developed by B. Abery, K. Arndt, P. Greger, L. Tetu, A. Eggebeen, J. Barosko, A. Hinga, M. McBride, K. Peterson, and L. Rudrud

This 15-module curriculum was developed to teach families skills for supporting self-determination in their transition-age member with a disability. It is designed to be presented by teachers, community agency personnel, or other facilitators in a series of two-hour sessions addressing topics that include future planning, family meetings, values and goals, choice making, solving problems, resolving conflicts, personal advocacy, connecting with community resources, persevering through difficulties, and participating in political systems. It costs \$10. To obtain this curriculum, contact the Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455; phone: 612-624-4512; fax: 612-624-9344.

Human Services?... That Must be So Rewarding A practical guide for professional development, second edition

by Gail S. Bernstein

This well-written and straightforward book is what the title says and much more. Drawing on over 30 years of experience in human services, Bernstein offers not only her insight on the many difficult and common issues of direct support, but also shares the experi-

ences of 11 people from diverse backgrounds in human services. Each chapter includes practical information and exercises that can be applied to the workplace and to one's personal life. Interviews of the 11 also provide perspectives from people who understand direct support. Their comments are relevant to the respective content and often provides inspiration for those in human services. To obtain this 240 page trade paper edition, contact Brookes Publishing Co., PO Box 10624, Baltimore, MD 21285-0624, fax: 410-337-8539; phone: 1-800-683-3775 or internet: www.pbrookes.com, Stock # 3327, \$23.50.

Common Sense

This newsletter is dedicated to the promotion of self-determination in the lives of individuals. Published three times per year, its pages contain testimonials, current legislative policy information, editorials, letters to the editor, and other resource contacts regarding self-determination. Its articles represent a nationwide geographic distribution. *Common Sense* is also published by and linked to the Web site of the National Self-Determination Program Office: www.self-determination.org. Individual subscriptions for 3 copies in 1999 cost \$15 and for organizations \$30.

To obtain more information about *Common Sense*, contact Kim Sheridan at 614-777-1575 or ksherida@columbus.rr.com, or Thomas Nerney at 203-746-7801 or tomnerney@earthlink.net.

How My Son Got Wings

When my son David went into crisis as a teenager with Prader-Willi Syndrome, Essex County Association for Community Living (ECACL), a provider agency, did everything possible to accommodate him in their residential program. He moved to a group home where three others (two men and a woman) with extremely challenging behaviors lived. The woman, who also had Prader-Willi Syndrome, and David caused the bulk of the serious occurrences at the group home. They fought, stole, manipulated, and conned. They were like gasoline and lit matches together.

A year later in 1994, David told us at his annual support meeting that he hated the group home and wanted to move to a house of his own where he could live a quiet life with one roommate. He called it his dream. I called it my nightmare. What we had for him was far from perfect, but we thought it was the best we could ask for a young man like David given his behaviors and his problems with food. I developed a case of “parental *what-ifs*” —

- What if it doesn't work out and his spot in the group home is taken?
- What if he and his roommate don't get along?
- What if he has a blow-out and the lone staff can't handle him and care for the other fellow too?
- What if the neighbors don't accept these two individuals? And on and on.

Fortunately, David's direct support staff listened to him and assured me that it could work for

him. Shortly afterwards, I received a call from ECACL inviting me to go househunting for him. The staff was confident and excited about David's new life and how well it was going to work out. Their confidence and enthusiasm was catchy. I eventually found myself looking forward to his new house and not focusing on the “what ifs.”

ECACL proved to be creative and resourceful in meeting David's needs. They found him a house where he and a roommate could pay the rent and expenses themselves. They would share an afternoon staff and a sleep-over staff five days a week. During the weekdays they were at their work-places and each weekend both would go home to their parents. A friend of David had been on the waiting-list for housing, so this was going to work for them, and it was going to save the agency a great deal of staffing cost. David's dream of having a house became a reality.

David's primary staff came with him. She was already supporting David on his behaviors. Having developed a kind of Doppler radar, she taught him to leave the situation that made him angry well in

advance of a storm and to pound his pillow in anger.

Afterwards she taught him to voice his frustration and anger, a technique called “using my words.” It was not an easy feat, but in time he would point his index finger at us all and yell, “I'm pissed off and I am USING MY WORDS!”

This natural approach to supporting David had some setbacks. David learned to play staff at his home and work against us, his parents, and vice versa in an effort to get more from everybody. For example, when he was at our house he would complain that we weren't feeding him enough...that his day



David Blackman boards an Air Ontario commuter plane to visit his father in Nova Scotia, Canada.

staff gave him “monster portions” and let him rent slasher videos.

Everyone in David’s life (e.g., staff, we) agreed that David should have more control of his life, so we formed a team with him as our captain. Every Tuesday we meet at his house after work to discuss what is on his agenda, give him praise, and deal with the issues. With David at the lead, he communicates his wants and needs and we all are better able to support him. We still hold Tuesday meetings and feel they are the glue that keeps it together. After only three months, he calmed down and has been mellowing and

maturing. Disappointments that used to send him into a major blow-out now only get a question or two

and then a shrug of the shoulders. He is a walking miracle. He is, today, after four years in his house, nearly 23 years-old and a fine young man. He is a well-respected member of his community.

Every person is different and needs to be respected and heard. Every person needs to have a peaceful environment

to come home to each day. Every person needs wings. I cannot thank David’s frontline staff enough for taking the time to learn about his needs and his strengths and for

doing person-centered planning. These professionals were determined and extremely creative in their attempt to help David live his dream. He was not stuffed into a program and expected to fit. Instead, the program reflects his desires and needs — it’s alternative rock, a shaved head, leather jacket and the backwards Newsboy cap, weight lifting, lap swimming, Nike basketball shoes and working extra hard to earn extra money for a train trip, and self-esteem that won’t quit! All this didn’t just happen by accident. It has been encouraged and nurtured by people who care, DSPs, family and friends.

Ruth Tozer lives in Leamington, Ontario, Canada and may be contacted at toz@wincom.net or 519.324.0057.

“
Every person is different and needs to be respected and heard. Every person needs to have a peaceful environment to come home to each day. Every person needs wings.”

Subscribe to Frontline Initiative!

The cost of a one-year (four issues) subscription is only \$10.00. Orders of 20 or more one-year subscriptions are \$5 each. Subscriptions are year round and will expire one calendar year from the subscription order date.

Please type or print clearly

New Subscription Renew Subscription

Name _____

Organization _____

Address _____

City _____ State _____ Zip _____

(_____) _____ - _____ Number of newsletters _____ Total price \$ _____
Phone

Date of subscription (for office use only) _____

Make checks payable
to *Frontline Initiative* and mail to —
Frontline Initiative
P.O. Box 13315
Minneapolis, MN 55414
612.624.4512

Sorry, we are unable to accept credit cards or purchase orders for *Frontline Initiative*.

Self-Reflection, continued from page 3

where they themselves do not feel they are doing their best. Perhaps if she understood her own needs, she may have understood mine better and responded more appropriately.

I recently participated on a consumer empowerment panel where these types of issues were addressed. The panel shared a set of questions with DSPs which may help them during times when they struggle with consideration of a person's self-determination. These were the questions a DSP might want to ask him or herself —

- Are you struggling as a staff person to understand someone's choices? If so, ask yourself why you are having difficulty accepting that she is making the choices

she is according to her life experience and values, not according to yours.

- Do you find yourself feeling angry and frustrated with the person with a disability? Try to identify what it is about the individual's behavior that threatens you. (Remember that anger can interfere with your role as a support person.)
- With which person do you find it difficult to be compassionate? Why?

It is the challenge of the DSP to question and examine him or herself and ask how this self-understanding can affect the way they support me as well as affect my self-determina-

tion. As a person with various disabilities, I understand how a DSP may want to "protect" me, but I want to be in charge of my life.

Heidi Maas lives in Oakdale, MN. Lynn MacDonald, co-author, is an adult service coordinator for Arc of Anoka and Ramsey Counties and may be contacted at 651.523.0876.

Reprint Permission

For permission to reprint or reproduce any content of *Frontline Initiative*, please submit your request to —

Frontline Initiative
P.O. Box 13315
Minneapolis, MN 55414
email: one11001@tc.umn.edu

Include with your request your intended use for the reproduction and your contact information.

Frontline Initiative Newsletter

P.O. Box 13315
Minneapolis, MN 55414

Address Service Requested