

A Quarterly Newsletter of the National
Alliance for Direct Support Professionals

Frontline Initiative

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Public Policy It's Everyone's Business (Including Yours)

Imagine your life if you had a disability. Imagine every aspect of your life being controlled by rules and regulations. Rules that dictated where you live, who you live with, choices you can make, and even who can support you. This is the reality for millions of Americans with disabilities. Government has enormous impact on the lives of people with disabilities. Their services and supports are almost entirely underwritten by taxpayer dollars. Government — or rather, public policy — affects who can access supports, the types of sup-

ports they can receive, and how supports must be provided.

Public policy affecting people with disabilities has different dimensions, two of these are lawmaking and funding. Lawmaking, or legislation, is the framework for rules and administrative decisions that affect how services are provided to individuals with disabilities. Funding or budgeting is the dollar amount attached to the carrying out of the laws. It has long been observed that the budget — rather than laws or regulations — is the truer

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Cliff Poetz mingling with legislators. See the story on page 12.

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Frontline Notes

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We hope you all have enjoyed Spring springing and Summer activities. In addition to flowers and warmth, the spring and summer seasons bring along another important annual occurrence — the end to the legislative session throughout the country. Your state may have a unicameral (one house) or bicameral (two house) system may meet yearly or every other year; may be predominately Republican or predominately Democrat or evenly divided, yet in all of these circumstances, you can have a voice in what happens at the Capitol. Lawmakers are interested in the opinions of their constituency — the people who vote them into office each election cycle. Because of this, your opinion is desired and needs to be heard! Although this issue will hit your desk after the current legislative session ends, it will be important to read, learn and begin to develop your action plans now so you will be ready when the next legislative session begins this Fall. Start a dialogue with legislators who are back in their home districts for the summer waiting to hear from constituents on issues of importance. Develop a new relationship with them so they become keenly aware of issues that they will be called upon to make decisions about next session. Call them and invite them to meet the people you support as a DSP. If it is an election year in your state, get to know the candidates and what they stand for. Learn the issues that are important to them and let them know what issues are important to you.

In this issue we will focus on the nuts and bolts of public policy —

what it is and how to go about influencing it. We will also hear from people just like you who have gone before their legislatures to testify about the importance of the direct support profession and other disability-related issues. Public policy is also influenced through other means, and we will learn more about lawsuits and efforts at administrative changes (such as the apprenticeship program) which will also affect DSPs.

Our next issue will focus on DSPs who have gone above and beyond the call of duty to support people with disabilities in times of natural disaster and emergency situations — floods, terrorism, and other occurrences. We will also talk about the important role DSPs have in supporting people in the aftermath of tragedy — even if we weren't in New York City, Washington D.C., or Pennsylvania, many of the people we support were still affected by the tragedies that happened there last Fall. What can we do to help people overcome their emotional trauma after a disaster? If you have a story to share about supporting someone through a difficult time, please consider submitting an article — it doesn't have to be long, and we are willing to help with writing. Your stories are important and make *Frontline Initiative* a better publication.

Remember those who show up make the rules — get involved! Write letters to your local paper. Lobby a legislator.

Happy lobbying,
The Editors

NADSP Member Organizations and State Contacts

Frontline Initiative is a product of the National Alliance for Direct Support Professionals. The NADSP is a collaboration between 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
- JFK Jr. Institute for Worker Education
- 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.
- 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, University of Pittsburgh, School of Social Work
- Reaching Up
- Self-Advocates Becoming Empowered
- TASH
- United Cerebral Palsy Association

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Join NADSP and Represent Your State

For information on NADSP membership or becoming a NADSP State Contact, please contact one of the NADSP Co-Chairs (listed above).

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Frontline Initiative is available in alternate formats upon request.

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.

Take the Challenge

Dear Seth and Cliff,
I've been a DSP for 10 years. I have been considering changing jobs lately because of the low pay and the frustration I feel trying to get services for the people I support. I love my job and I've decided I would like to try and make a difference in another way before I give up. I don't know how to start trying to change laws about pay for DSPs and other issues related to the people I support. Where could I go to work with other people who want to lobby and learn more about the system?

— Thank you,
Not Giving Up

Dear Not Giving Up,
There has never been a better time for you and your colleagues to join the National Alliance of Direct Support Professionals (NADSP)! Your concerns are right on target with the goals of the NADSP. Check our member organizations and state contacts in our quarterly newsletter, Frontline Initiative.

You can see us on the Web at <http://nadsp.org>. Find your state contact and see how you can help. Between your job and your new found self-advocacy, you will be too busy and excited to even think of another profession. We don't want to lose you and you have valuable knowledge and skills that can be used to make change for all DSPs.

— Seth

Dear Not Giving Up,

First, I think you need to go to your agency and tell them your involvement with your legislature will benefit them as a provider. Give them the opportunity to tell you what their concerns are and they will be more likely to pay your registration fee, give you paid time off and mileage reimbursement for a day at the Capitol. Another thing to think about is bringing a self-advocate that you support with you. Going to lobby with a self-advocate allows you to build a relationship with those you support, and gives them an opportunity to lobby for issues that are important to them. I encourage you to take on this challenge. The lawmakers do not know what you need unless they are told and you are the expert on what is important to DSPs. In order to get support and information, contact your state office of Arc. They may have groups that get together to discuss the issues that are in the legislature and you can get on an action alert network so that you can be informed about the issues that concern you and the people you support and their families.

— Cliff

Ask Clifford and Seth

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

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

DSPs in Action

Lobbying to Make a Difference

Those who play the game make the rules. Remember your backyard games when you were a kid? Your own modified version of baseball, soccer, Frisbee, football, tag, or hide-and-go-seek. You created rules to adapt the game to the quirks of the playing field (yard, street, or park), the number and skill of the other kids, and the materials you had at hand. Do you remember that the kids who were biggest, most skilled, or who owned the ball, had more influence over the rules than anybody else? Welcome to politics.

Have you ever complained about the circumstances you have to deal with? The lack of funding for essential programs? The numbing ignorance of public policies? You sit there fuming at the stupidity of state legislators or other policymakers, wondering what they were thinking. I bet you've heard or even said something like, "They don't know anything!" You may have even used language that is, well, less than polite. Hmm . . . If they don't know, shouldn't someone tell them? You may need to begin playing the game yourself. Welcome to lobbying.

Lobbying generally refers to influencing the decisions of policy setting bodies, such as Congress, state legislatures and city councils, though there are other decision-makers who might deserve your attention. Agency policies and procedures, as well as regulations that give life to laws, are appropriate targets of lobbying. Because many of the decisions that affect your work are made there, and because you can

have significant impact on these decisions, the focus of this piece will be on working with a state legislature.

As a citizen you have many opportunities to make your voice heard. A simple e-mail, phone call, or personal letter to your legislator is a good start. Still, some of you may want to make a more substantial

You sit there fuming at the stupidity of state legislators or other policymakers, wondering what they were thinking.

commitment to influencing public policy. Even if you are not involved as a full-time lobbyist, you can participate meaningfully in the political process.

So what do you need to know in order to be effective at playing this game? That's a tall order for a short article. This article will to introduce you to some basics, and then suggest a few ways for you to add to your understanding.

Understand That You Need to Work With Others

As interesting and devoted as you are, acting alone will not get you very far. You are much better served by working in collaboration with

others who share your same goals. The more you are organized, the more effective you are likely to be. So, when I say "you," I am not just referring to you as an individual, but to all of "you" who are DSPs letting legislators know your issues. Get support and help from your co-workers, DSPs from other agencies, and activists in other organizations. Consider collaborating with self-advocates or other advocacy groups.

Understand the Process

You need to understand how the legislature in your state works. Each state will have its unique features, like Nebraska's unicameral legislature and New Mexico's meeting schedules. Except for Nebraska, each state has two chambers, usually a Senate and a House or Assembly. So even though the general process is pretty common, you will want to learn about rules that govern such things as how legislation is drafted and introduced, how it is voted on, and the roles and responsibilities of each chamber. To learn more about the legislature in your state, check out the internet. Almost every state legislature has a Web site packed with information.

Understand the Basic Steps

- **Legislative session:** find out when the legislature begins its session, the time it considers legislation, and how long the session is likely to last.
- **Drafting and introduction of legislation:** This is the first step in the process, preparing legislation and offering it for consideration.

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Proposed legislation is commonly called a bill. This process is often called introducing a bill.

- **First reading, assignment of bill to a committee:** Once a bill has been filed, it is formally read into the record and assigned to one or more committees. For example, a bill related to health and human services funding would be assigned to the Health and Human Services Finance Committee, which renews funding proposals for the Department of Human Services, the Department of Health, the Council on Disabilities, the Veterans Homes Board, and all health-related licensing boards and ombudsman offices.
- **Committee hearing:** The bill is then heard in committee. The committee members (legislators) may hear testimony on the bill from people who have interest in it. This could include you. Committee members may change or amend the bill in committee. Generally a bill must be approved by the majority of the committee in order for it to continue throughout the process. If it is not, it is usually dead. This is commonly referred to as “died in committee.”
- **Floor action:** After passing out of committee, the bill is considered by all the members of the chamber (e.g., Senate, House, or Assembly). Consideration is demonstrated by the members voting for or against the bill. The bill can be amended here as well. It has to receive the majority of votes from the whole chamber to keep going.
- **Action by the other chamber:** Once it passes one chamber, the process is repeated again in the other chamber (if there is one).

Get to know
legislators. Learn their political philosophies, areas of interest, and status among other legislators. You also want to learn which districts they represent and as much as you can about their personal background.

- **Concurrence of amendments and conference committees:** A bill might be amended in the second chamber. If the members of the chamber that first heard the bill don't agree to these changes, a conference committee, made up of members from both chambers, is appointed to work out an agreement. Conference committee is when bills often die, since it's unlikely that the two chambers can come to agreement on their differences.
- **Governor's office:** Once the bill passes the legislature, it is sent to the governor to sign. If the governor vetoes the bill, the legislature may have a chance to override the veto. Usually this requires the support of two thirds (overwhelming majority) of the members of each chamber.

Whew! That's just a skeleton outline. There may be sub-committees involved, special ways to revive “dead” bills, several public hearings,

preliminary votes, and other fun and games. Two things are important to understand. First, with all these steps, it is not easy to get legislation passed. Second, you can influence the outcome at any point in this process.

Understand Your Players

Get to know legislators. Learn their political philosophies, areas of interest, and status among other legislators. You also want to learn which districts they represent and as much as you can about their personal background. The more you know about them, the better able you will be to relate to them. Of course, you especially want to know what they think and feel about your issues.

Understand the Language

Just what is a *bill*, when is *cloture* used, and if legislation is *engrossed*, does that mean it is messy? DSPs have their own language about the work that they do. So does the legislature. Fortunately, most legislatures provide a glossary that helps you understand what people are saying. For example, a bill is a proposal calling for a new law, a change in current law, the repeal of current law, or a constitutional amendment. *Cloture* means the closing or limitation of debate in a legislative body especially by calling for a vote, and *engrossed* means the current text of a bill or resolution which includes or incorporates all adopted amendments to the title and/or text.

Understand Regulations

You may have to register as a lobbyist if you intend to spend time trying to influence legislation, even if you are not paid to do so. Also, be aware that there are certain limits on

lobbying for tax-exempt, non-profit social service agencies (those with the IRS designation as 501(c)(3) organizations). There is a common myth that these organizations cannot lobby. The fact is, they can and should. However, there are limitations. Federal law limits the amount of time and resources an organization may devote to its lobbying efforts. You will have to look into the substantiality and expenditure tests based on your exempt status. Each state may have specific limitations which you should know about. Check with your state's Campaign Finance and Public Disclosure office or IRS office for specific information. Non-profits are not allowed to engage in partisan or candidate campaigns and may not use government funds, grants, or contracts to lobby.

Understand Sources of Influence

Influence flows from the power of an idea, the power of those who offer ideas, and the power of relationships. You have access to all these types of power. Yes, though other people may have more, you do have some at your disposal. The more you can show that your idea is compelling and that you are backed by a well organized group that can provide campaign workers or command money, media attention, or votes, the better off you will be. If you and your allies have developed personal relationships with a number of lawmakers, you will have more ready and receptive access. Finally, there is the matter of credibility. It is your greatest individual asset, and it is based on three things —

1. Your credibility as a person. For example, can you be trusted?

2. The credibility of your information. For example, is it timely and accurate?
3. The credibility of your power base. For example, can you mobilize other people in support of your position?

Understand the Need to Set a Legislative Agenda

Do you intend to support or defeat legislation? Are you going to develop new legislation, influence proposed legislation, or modify legislation in process? Which legislation are you really going to work on? Realize that legislation is only one approach to making changes. Be sure that making a change in law is what you want. Many legislators are impatient with those who seek legislative change when simpler methods would do.

Understand That you Need to Start Early

Regular legislative sessions start in January and most end by May. However, if you begin your work in January or only deal with the legislature while it is in session, you are too late. You need to begin conversations with supporters and legislators months in advance. Spend the summer visiting with your legislators while they are back in their home districts, or better yet, invite them to your place of employment so they can see what DSPs are all about and meet the individuals you support.

Understand how to Increase Your Effectiveness

Essentially, lobbying involves your talking with legislators to convince them to support or oppose legislation. So, you have to be willing to talk with legislators as well with as

other people who talk with legislators. You will want to continue to improve your ability to communicate. Be prepared with your information and be clear about what you are asking. Anticipate arguments so that you can preempt or counter them. Discover and use possible areas of common ground or interest. Demonstrate that your position is based on a strong command of the issue. Let the listener know your position, your professional expertise, and your experience. Some other things —

- **Get known.** Once legislators know you they will pay more attention to your calls, letters, and opinions.
- **Observe the body in action.** Attend a few sessions or committee hearings so that you become more familiar with the process.
- **Decide who to approach.** Lobby supporters first to alert and activate them; lobby “undecideds” next. Do not lobby strong opponents. You are unlikely to change their minds, and you might increase their active opposition.
- **Get to know key staff people.** Key staff may be more accessible and they often shape legislators’ opinions.
- **Prepare fact sheets.** In *one* page summarize the cost and impact of responding to or ignoring your issue.
- **Anticipate the likelihood of compromises.** Rarely will you get everything you want. Be prepared with what you can compromise and what you can't.
- **Use testimony to strengthen your case.** Participating in legislative hearings gives legitimacy to your

DSP Perspective

Telling it Like it Is

When Debbie, my supervisor, first asked me to testify before the Human Services Sub-Committee of the State House of Representatives, I was pretty scared. I am not an outspoken person and that seemed like a really scary thing, going up in front of all of those people. But I just looked back at all the years I have been working and prepared a letter of how I felt about our profession and about the people I have worked with.

I guess I decided to do it because of all of those people. I don't think anyone realizes that after working with people, they become a part of your life, like family. I decided that it is important for people to know my experiences so that people know what people with disabilities need. Before I got into this profession, I didn't even realize there were this many people with disabilities living in the community. I also decided that it was important for legislators to know that I have worked for 15 years and get 10 bucks an hour. You can make 15 bucks an hour making donuts in my town. Other people need to know this. They have to know that this isn't a nine-to-five job. It takes a lot of dedication to learn how to support the people I work with. And they have to know that the reason we do it isn't because of money, but because it's more than a job, the people I support are my family. So, when I decided to tell the story of who I have worked with, Debbie promised to help me through the experience. I wrote a letter about some of the needs of the people I support and I was ready to testify.

I was scared all the way through the testimony. However, it was worth it. The legislators were cooperative and they really understood us when we told our stories. They seemed interested and asked us important questions like why we stay for such little money. This made it a good experience, definitely one that I will never forget. Here is the testimony that I gave to my state's House of Representatives:

Testimony before Human Services Sub-Committee of the House Finance Committee Public Hearing on MR/DD Budget, March 8, 2001

Hello, my name is Mary Winchell. I want to thank you for putting more money in the MR/DD budget. This and the proposed budget language will allow raises for direct care staff.

I've worked for HAVAR, Inc. for 14 years. Working for and with people with disabilities is both a reward and a challenge. Some of the challenges are the long hours that I put in and the times I work over, just to accomplish

consumer needs. Many times I give up personal time to help individuals accomplish goals when there is no other staff available to work.

When I work with people with mental retardation in their homes, I need to make sure their needs are met, problems are solved, lend an ear when someone needs to talk, and try to explain things so they understand the choices and explain the consequences of decisions.

I want to tell you about my work with a woman I will call Dorothy, who is a 70-year old with mental retardation. I provide live-in supports for her. When I first started to work with Dorothy, about fourteen



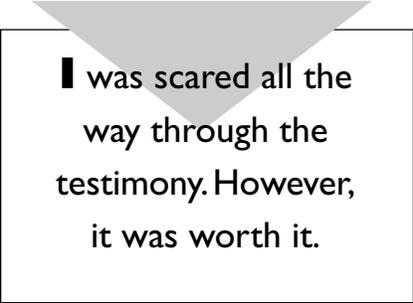
Mary Winchel, left, speaking out for DSPs in Washington D.C.

years ago, she wouldn't wear clothing or go outside her bedroom. She had been kept locked in a closet and was afraid of leaving her home. She had had violent outbursts in her earlier life and people were afraid of her. Now, as a result of working with her daily and the care that she receives, she is a happy woman.

Dorothy needs help in every aspect of her life. I help Dorothy get up in the morning, toilet herself, take a shower, wash her hair, help select her clothing and get dressed and ready for the day. Since Dorothy can't protect herself, I make sure the temperature of the water of her shower is safe before she gets into the shower. If she wants a meal cooked, I will cook it for her. I make sure, if she is doing something in the kitchen, that there are no accidents. I drive her where she needs to go, whether it is shopping or errands or visiting her sister.

Dorothy struggles to keep weight off, so what she eats is important. I research what foods are healthy for her to eat, and then suggest those for her meals. From these healthy foods, we have developed a special menu that includes healthy snack items. This way, Dorothy is not so hungry that she wants to snack on foods that aren't good for her. We make up a menu together of what she would like to eat, and then we shop for groceries together. It is very hard to maintain her weight so this helps her stay healthy and maintain a healthy weight.

Another area of health concern for Dorothy is her balance. She often is thrown off balance and can fall easily. It is important that I



I was scared all the way through the testimony. However, it was worth it.

watch and assist as she makes the transition from sitting to standing or when she gets into bed, that she does it safely. A staff person is always with Dorothy to make sure that she is safe from falls that could cause serious injury.

I make many late night calls just to reassure the people I work with that everything will be okay. Also, while in the home, especially when there is more than one person I provide services for, there is an extra need for attention. One may feel you are spending too much time with the other, and problems can arise. It's really hard to split time between them, especially when one may have more needs. The other person is more independent, but she still longs for your attention.

There are also many rewards. The smiles and joy you see on the faces of people when something that they really want actually happens, or they accomplish a goal they have been working for. Also, the self-satisfaction of knowing you have had a part in helping and improving someone's life for the better. It's the little things that are rewarding—the thank you's and the joys of the job.

Many people are leaving this profession due to the changing

economy — the need for a higher wage to meet our own personal needs. I personally wish to stay in the profession, but if we don't get an increase, I may have to take this route myself.

I have enjoyed my job for many years, but times are changing for me, and needs are changing. It's not that I mind the extra work I do, but it's hard to afford some of the extras for Dorothy when I pick up the tab. The long hours worked, the time given up from my family, to help in times of need — these must be compensated, so I appreciate your assistance in this budget so that I may continue to provide services to Dorothy.

Dorothy, and the other people that I serve, also deserves to keep the staff people who are important to her.

In closing, this raise is desperately needed and I thank you for keeping it in the budget.

Mary Winchell is a DSP working for HACAR, Inc. She can be reached at 740-594-3533.

Agency Perspective

Public Support Needed for DSPs

Tony Thomas, the Ohio Liaison for the NADSP, gave companion testimony to Mary Winchell's testimony. Tony's testimony highlights the importance of legislative action supporting direct support professionals, giving an agency perspective.

March 8, 2001

Testimony of Tony Thomas

Mr. Chairman, members of the committee, my name is Tony Thomas. I am the Executive Director of Welcome House in Cleveland, Ohio. We are a provider of services to individuals with Mental Retardation and Developmental Disabilities (MR/DD), serving over 100 persons with disabilities in the Cleveland area. The services we provide include habilitative services to persons residing in group home settings, supported living services to person residing in apartments, and in-home support services to persons still living with family.

I am here today as the Ohio liaison to the National Alliance of Direct Support Professionals (NADSP). This is a national effort including members and organizations that represent individuals, families, providers, government and others to mention a few. This national group has the support of the leading disability organizations including —

- Self advocates
- American Network of Community Options & Resources (ANCOR)
- National Organization of State Directors of Developmental Disability Services

- American Association on Mental Retardation (AAMR)
- The Arc
- United Cerebral Palsy (UCP)
- President's Committee on Mental Retardation (PCMR)
- Several university-affiliated training programs that specialize in services to individuals and issues related to MR/DD

We cannot think anymore about expanding services to persons with MR/DD without thinking about the implications of where we will find the staff to support such an effort.

- Center on Residential Services and Community Living
- Council for Standards in Human Services Education
- Representatives of State Departments of MR/DD
- Council on Accreditation of Rehabilitation facilities (CARF)
- Association for Persons in Supported Employment
- Consortium for Citizens with Disabilities
- And many others.

In Ohio, we are pleased to have a statewide effort (the Ohio Alliance of Direct Support Professionals) with many of the same kinds of individuals and groups represented; including individuals, families, the Developmental Disabilities Planning Council, ARC, OPRA, County Boards of MR/DD, and others. While I am here today to talk to you about the importance of direct care wages and stabilizing the workforce, I want you to be aware of the depth and the breadth of work that is underway nationally and here in Ohio.

The availability of staffing to serve individuals with MR/DD is a complicated problem that can't be solved with a single or uniform solution. Across the nation, and here in Ohio, there are a variety of efforts to address the problem in a variety of ways. The National Alliance of Direct Support Professionals, including the Ohio Alliance of Direct Support Professionals, is working on a range of efforts related to training, ethics, supervisory issues, research into the problems of recruitment and retention, and more.

For today, I want to focus on the issue of direct care wages and the need to stabilize the workforce. We cannot think anymore about expanding services to persons with MR/DD without thinking about the implications of where we will find the staff to support such an effort. In the past we have said it is essential to expand services to persons with MR/DD by creating more community living options and helping people achieve and experi-

ence community living. Without a suitable and more appropriately compensated workforce and expansion efforts will be severely compromised.

Attached to my testimony is a summary of information from other states. The issue of direct care staffing and wages is reaching crisis proportions in many states across the country. Legislatures and state government officials are taking action to address the wage issues. I'd like to highlight a few examples —

- *Arizona* providers are experiencing turnover rates of 70 to 150%. Litigation is pending.
- *District of Columbia*: Deputy Mayor announced proposed legislation for wage increases for direct care workers.
- *Illinois*: Governor Ryan pledged his support for wage legislation that will be introduced as a supplemental appropriation.
- *Maine*. Key legislative leaders have sponsored legislation to provide a 4% increase in wages.
- *California* has litigation pending which alleges that the disparity between institutional and community-based service providers is a violation of the ADA.
- *Maryland*: Legislation will close the gap between state institution wages and community wages over a three-year phase in.
- In *Massachusetts*, the legislature provided a 3% increase and has introduced legislation to provide a wage of no less than \$12.89 an

hour without health insurance and \$11.89 with health insurance.

- *Montana*: The Governor's budget includes a direct care wage increase of 4.65% and 9.28% for FY '02 & '03 respectively.
- *Nebraska*: The Governor recommended an additional \$7.3 million dollars for wages.
- The *New Jersey* legislature authorized a \$1 per hour increase for a cost of \$56 million dollars.
- *New Mexico* received an \$11 million dollar increase, with a target wage of \$10 per hour for direct care wages.
- *New York*: Governor Pataki is proposing a 3.52% increase for the community service waiver providers.
- *Pennsylvania*: The Governor announced an increase of \$41.3 Million for recruitment and retention; in addition to 2% cost of living increase.
- *Washington State*: Legislation is being considered to increase wages \$1 per hour.
- The *Wisconsin* legislature provided \$8.3 million in funding for direct support staff salaries.

In closing, safety and well being cannot be assured if there is no one there to assist individuals or if there is so much turnover that the staff never truly understand the individuals' needs. States across the country are addressing the issue of direct support staff wages for individuals receiving MR/DD services. We need

your leadership and support to do the same. Thank you for the opportunity to address you today. I would be glad to respond to any questions you have.

Tony Thomas is the Ohio liaison for the NADSP. He can be reached at 440.256.2330 or tthomas@welcomehouseinc.org.

Consumer Perspective

Rocking the Boat

I've been going to the legislature for 30 years. It began when I was living at a "mini-institution." The agency that ran it wanted to open a group home. Although ARC was behind us and the state supported it, the agency still wanted me to testify to say that I wanted the group home to open. It was scary at first, but the DSPs that worked with me helped me prepare what to say and calm my nerves.

After the group home opened, there were about ten of us who would go around and talk at town meetings, trying to get support for opening more group homes. Back then, people didn't want group homes in their neighborhoods and this was one of the greatest barriers.

In 1973, Senator Kennedy heard about our group and asked me to come to Washington D.C. The director of the agency that ran the group home helped me prepare three pages of testimony. Many people didn't want me to say the things that I said because it was seen as "rocking the boat." But I spoke in front of all those people, and I've been speaking ever since.

I have worked on legislation that provided funding to put names on the graves of all of those people who died in the institutions that have only been marked by their case number. I have lobbied for a public apology for the treatment people with disabilities received in the institutions. Right now we are working for getting a \$2000 bonus for DSPs who stay more than a year and continue their education. I look forward to working on legislation that will speed up background

checks on DSPs so they aren't working for 6 weeks before the background check is cleared. The Individuals with Disabilities Education Act (IDEA) is up for re-authorization and the family opportunity act is very important in helping families get in-home support.

Many people didn't want me to say the things that I said because it was seen as "rocking the boat." But I spoke in front of all those people, and I've been speaking ever since.

Some of this has not been easy, but it is so gratifying to see DSPs along with self-advocates make such a big difference in so many of these issues. We can talk about our personal experience, things that they may know nothing about. They hear from the Department of Human Services, the providers, and the state, but they need to hear from the experts: DSPs, self-advocates, and family members. We are the only ones who can determine if the money is being spent appropriately and if people have what they need.

So, I encourage all of you to get out there and tell the legislators what you need: pay, benefits, time off, education, and certification. If you do decide to advocate for yourself and the individuals you support, here are a few simple tips —

- Take time to prepare with other self-advocates, decide what you are going to say, and practice, practice, practice.
- Give the legislators good information. If you don't have the information that they ask for, tell them you will be able to find someone who does.
- Always be neat and wear clean clothes.
- Make sure to keep your appointment when you have one with a legislator.
- It would be good to join the local Arc. They usually have a handle on what is going on at the local legislature.
- Be on time.

Good luck, and see you at the capitol!!!

Cliff Poetz is a self-advocate and co-chair of the NADSP. He can be reached at 612.624.0060.

What is an Apprenticeship Program?

The 21st century holds many challenges for the workforce as we see industries with skilled workers and leaders approaching retirement age at increasing rates. As we look at the current challenges of recruitment and retention, the human service industry must identify approaches that not only benefit the situation today, but also prepares for the future.

Apprenticeship is one concept that provides a time tested training program that has benefited industry over the centuries. Mark Floretta, St. Louis Apprenticeship Representative, describes apprenticeship programs as, "... world-class training systems that provide a structured education and career pathway for the future. Apprenticeship ensures employability and provides committed workers with required knowledge and skills for the workforce of the future." Today there are over 850 apprenticeable occupations which shows that apprenticeship training benefits both employers and employees. The DSP workforce now joins the list of apprenticeable occupations, providing human services agencies with a new tool for recruitment and retention efforts. The U.S. Department of Labor points out the following benefits of apprenticeship programs —

Benefits to Apprentice/Employee

- Paid employment while training
- Increased wages as skills and training progress
- Higher quality of life and skills versatility

DSPs are a vital part of the 21st century workforce and need to advocate for funding to increase training opportunities and wages...

- Portable credentials recognized nationally and often globally

Benefits to Apprentice Sponsor/Employer

- Decreased employee turnover
- Enhanced problem-solving capability and versatility of workforce
- Increased productivity by cultivation a highly-skilled and knowledgeable workforce
- Enhanced employee relations by developing a collaborative commitment to achievement
- Attraction of high-quality applicants who are motivated to succeed
- Increased national and state recognition

Apprenticeship is not designed to be quick fix for retention and recruitment problems. However, it is an opportunity for human service agencies to make a commitment to the future of the direct support workforce and quality services.

As human service agencies approach the apprenticeship process they move toward creating learning environments. Floretta states, "Today's workplace requires a new

kind of worker – one who excels at solving problems, thinking critically, working in teams and constant learning on the job. The future workforce must offer challenging, relevant education and meaningful work-based learning experiences in their communities." To pursue this endeavor, human service agencies must begin a dialogue with state and national legislators to increase the availability of grants and training funds to this field. DSPs are a vital part of the 21st century workforce and need to advocate for funding to increase training opportunities and wages for a highly skilled, professional human service workforce.

With the recognition of direct support as an apprenticeable occupation, human services agencies across the United States have the opportunity to implement apprenticeship programs, which are voluntary, nationally recognized and provide a selection process to train employees that show true dedication to the field. To establish an apprenticeship program any agency or group of agencies must contact their local Bureau of Apprenticeship and Training Office and/or State Apprenticeship Council. At that time your local apprenticeship representative will walk you through the process of establishing an apprenticeship program.

More information on the apprenticeship process can be accessed from the following Web site: www.dolta.gov/atels_bat.

Sherrill Wayland is a training specialist at St. Charles Community College, St. Charles, MO. She can be reached at swayland@stchas.edu.

Litigation Affecting DSPs

Policy changes happen not only through legislative action and administrative changes but also as a result of court decision.

Two unprecedented lawsuits have recently been filed in federal court. They bear watching because how they are decided may have important ramifications for DSPs. Both lawsuits (*Ball v. Biedress* in Arizona and *Sanchez v. Johnson* in California) raise similar issues. In a nutshell, the lawsuits contend that low state payment for community services cause people with disabilities not to be able to receive the services they need. In the *Ball* lawsuit, it is argued that Arizona's payments for personal assistance services are not high enough to attract individuals to provide the services. Persons authorized to receive personal assistance are going without because they cannot find individuals willing to provide services at the price the state is willing to pay. In the *Sanchez* lawsuit, community provider agencies argue that low payments leave them no choice but to pay very low wages. Therefore, these providers are unable to meet their obligation to provide services to individuals. In both cases, the plaintiffs directly tie low payments to problems in recruitment and retention.

These lawsuits revolve around the consequences of low payments for people with disabilities. They have been brought on behalf of individuals who are eligible for and authorized to receive Medicaid-funded services in the community but have had to go without services because of lack of workers.

The federal courts may enter the picture because there are federal laws that bear on the delivery of disability services. Both lawsuits are based principally on two federal laws —

1. Federal Medicaid law contains a requirement that a state's payments be sufficient to attract enough providers to meet the needs of Medicaid recipients. In each of these lawsuits, the plaintiffs contend that each state's

In some of these cases, the issue of payments has arisen because of concerns that, even if states are directed to stop wait listing individuals by expanding services, payments may not be high enough to attract sufficient providers.

- low payments violate this requirement because individuals are going without the services they are otherwise entitled to receive.
2. Title II of the Americans with Disabilities Act requires that governmental entities operate their programs for people with disabilities in a non-discriminatory fashion and make services available to people with disabili-

ties in the “most integrated setting.” In each lawsuit, the plaintiffs argue that low community payments have the effect of forcing people to seek institutional services or prevent institutionalized persons from being served in the community.

The *Sanchez* lawsuit also argues that workers in California's state-run Developmental Centers are paid substantially higher wages than community workers and consequently, California is not operating programs for people with disabilities in a non-discriminatory fashion because it is favoring institutional services over community services.

The lawsuits ask the federal courts to rule that the states are in violation of these federal laws and order them to change their payments so that people with disabilities can access the services they are authorized to receive in the community.

The effects of low state payments on the access of individuals to community services may come before federal courts in other ways. For example, over the past three years, there has been a flurry of “waiting list” lawsuits challenging state policies that lead to individual having to wait for Medicaid services rather than receiving them right away. In some of these cases, the issue of payments has arisen because of concerns that, even if states are directed to stop wait listing individuals by expanding services, payments may not be high enough to attract sufficient providers. In some states, provider organizations are considering joining these

lawsuits as plaintiffs in order to put payment issues on the table.

How these lawsuits will be decided is difficult to predict because federal courts have not dealt with these specific issues in the past. It is not entirely clear how the courts will interpret the relevant federal laws. For example, it is uncertain whether a violation of the Americans with Disabilities Act can serve as the basis for a court's ordering a state to increase spending. Similarly, proving that a state's payments are the cause of people going without services is not necessarily a simple proposition.

It also is uncertain when rulings will be made in these cases. For example, the Sanchez lawsuit will not go to trial until sometime later this year. Rarely does this type of litigation move along quickly in the federal courts, especially when the courts find themselves in relatively uncharted territory.

(A quick update arrived just as we are going to press. Re: Ball, there is nothing new to report. Re: Sanchez, the only noteworthy recent event is that on 6/7/02 there was a hearing on the plaintiffs' motion for summary judgment. But the Court won't rule on that motion for a couple of months. New litigation filed in March 2002 *Pennsylvania v. Department of Public Welfare* "contends that Pennsylvania has depressed payments for ICF/MR services and held down waiver funding by predicating funding levels on depressed, inadequate compensation of direct care workers. As a result, the plaintiffs contend that they are unable to furnish an appropriate level of services to the persons they serve due to high staff turnover and workforce instability." This information is from the *Status*

Report: Litigation Concerning Medicaid Services for Persons with Developmental and Other Disabilities, June 12, 2002, by Gary A. Smith (see page 18).

Gary Smith is Sr. Project Director involved in several HSRI projects concerning services for people with developmental disabilities, including the Core Indicators Project and the Quality Inventory Project on behalf of the Centers for Medicare and Medicaid Services. Before joining HSRI, Gary served fourteen years as Director of Special Projects for the National Association of State Directors of Developmental Disabilities Services. He can be reached at 503.885.1436 (ext. 17) or gsmith@hsri.org.

Public Policy, continued from cover

measure of how committed government actually is to a policy's objective. For example, many states have enacted laws to create family support programs, but there are marked differences among the states in the extent to which they fund family support. Some states have adequately funded these supports while other states have not.

Policymaking within disability services takes place continuously in many different ways. Policy is made when a state legislature acts on the budget. It is also made when Congress enacts federal laws, or when executive branch agencies issue rules or make decisions concerning payment rates, or when local human services boards adopt new purchase-of-services policies.

Policies are the end products of processes that start with decisions about what will be considered, continue with securing input and

information about potential changes, and ultimately result in decisions. Affecting policy starts with placing a topic on the "agenda." How the topic is addressed hinges on many factors, including who is "at the table" and whether policymakers become convinced that a change will have positive results. Policymaking has a "work" dimension — identifying alternatives and the potential effects of choosing one alternative rather than another. Too often, policymaking processes seem intimidating. Policy issues are frequently complex and there is no doubt that many have "knowledge" dimensions. However, at the end of the day, policymaking fundamentally is the result of the give-and-take among people in search of solutions to problems.

What does all this have to do with DSPs? DSPs are directly affected by public policy. Their pay and benefits depend on budget decisions. Requirements for credentialing and training affect what positions they will qualify for. There is absolutely no doubt that the quality of service for people with disabilities depends on the skills and commitment of the workforce that supports them day by day. Policy changes which ensure that there are skilled and competent workers to support individuals with disabilities often do not make it to the agenda or are postponed. Keeping these issues on the front burner depends on the extent to which DSPs engage in the policymaking processes. DSPs are fundamentally concerned that, at the end of the day, the outcome of public policy is that people with disabilities are well supported in

Continued on page 16

their communities. DSPs possess enormous expertise and insight concerning how supports actually affect the lives of people with disabilities, and therefore understand how to improve their quality. They can make enormously valuable contributions along many dimensions. But in order to make these contributions, DSPs must engage in the policymaking process.

It is vital that DSPs are at the policy making “table” to address the issues that affect people served and to speak out for issues that affect them personally. Being a part of the decision making process and taking part in the discussions can have great impact on what issues will be acted upon. It is important to offer concrete proposals and make positive contributions to resolving broader issues.

DSPs are sure to be welcomed to the policy making table. Disability policymaking has become more open and inclusive as self-advocates, families, and DSPs have come together with policymakers who are interested in obtaining input and information from everyone involved. Collaborative policymaking is more commonplace, but there is still a long way to go. Some states and localities are better at fostering collaboration and inviting participation than others. Learn about what is going on in your state and local area and look for opportunities to participate. Do not be bashful or intimidated! The simple fact is that being involved in the policymaking process is fundamental to addressing a host of very hot topics such as assuring and improving quality, expanding access to services, providing consumer-directed services, and enhancing direct support wages and opportunity for

education and training. DSPs have valuable contributions to make along these lines. You will bring welcome expertise and insight to the table.

There is no doubt that becoming engaged in policymaking requires a commitment of time and energy. Many major policy changes have been the result of the sheer perseverance of families and advocates. There is no doubt that DSPs face many challenges in this regard. Taking time off work is difficult and DSPs, like everyone else, have many other responsibilities. Undoubtedly, in order to engage in the policymaking process, DSPs will need to network among themselves to share responsibilities and assignments. This is not easy, but it can be done. The enactment of family support legislation in many states can be traced back to family members building networks and coalitions among themselves in support of such legislation. DSPs can also build networks and coalitions that will foster changes in legislation.

In addition, finding out what is happening with public policy and networking with others are both enormously aided by the Internet. Information can be spread rapidly via e-mail groups at no cost. State agency and advocacy groups have Web sites that can be scanned regularly. Where there is a will, there is a way.

Public policy concerning people with disabilities is everyone’s business — including yours. Policies will be better as a result of your active engagement in policymaking processes. Please do not be bashful. Get involved and stay involved.

Gary Smith is Senior Project Director involved in several HSRI projects concerning services for people with

developmental disabilities, including the Core Indicators Project and the Quality Inventory Project on behalf of the Centers for Medicare and Medicaid Services. Before joining HSRI, Gary served fourteen years as Director of Special Projects for the National Association of State Directors of Developmental Disabilities Services. Gary can be reached at gsmith@hsri.org.

DSPs in Action, continued from page 7

issue and your organization. Coordinate testimony with your allies. Tailor your presentation to the legislators you most want to influence. Make distinct points using a combination of personal experiences and factual information. Things to touch on: your interest in the bill and how you arrived at your conclusions; who will benefit; who will be hurt by inaction and how; and cost efficiency of your position.

Entering into the legislative arena is exciting and meaningful. It can be a little scary and confusing too, especially when you first get started. The best way to get going and to learn more is by working with someone who already knows what they are doing. State and local chapters of the Arc, a national organization of and for people with intellectual disabilities and their families, will likely have people familiar with the legislative process in your area.

Working on political campaigns is a rather simple and interesting way to get involved. You come to know legislators and their staff and supporters. These people can give you some guidance and introduce you to others. Public interest groups like the League of Women Voters and Common Cause can provide

direction. Attend town meetings where legislative representatives invite the public to speak out on issues.

Of course you can do a little reading. Newsletters of advocacy groups will give you information on current concerns. Special publications dealing with legislative matters are commonly available. You can read the political section of the newspaper to learn more about the current debates. A couple of books dealing with political involvement are: *Affecting Change: Social Workers in the Political Arena* by Haynes and Mickelson, and *Lobbying for Social Change* by Richan.

Finally, you can explore the Internet. Each state has its own Web site with valuable links. One specific site I'd recommend, that gets you to all of the state legislatures, is that of the National Conference of State Legislatures at www.ncsl.org.

Poorly crafted public policies are a problem. Like any problem, you can decide to let this problem persist, you can hope it will correct itself on its own, or, you can do something about it. What are you going to do?

(* Note: for the purposes of this article the term "lobbyist" has the meaning of a person getting their voice heard on an issue they feel strongly about, or advocacy. Any citizen can talk to a legislator to have their voice heard. This is different from a "professional" lobbyist who is paid to represent a particular point of view for a business or organization.)

Mark Homan is the Arizona representative of the NADSP. He can be reached at 520.206.6958 or mhoman@pimacc.pima.edu.



Code of Ethics Materials for DSPs

This series of materials is based on the recently-developed Code of Ethics for Direct Support Professionals (DSPs). Brochure provides the entire text of the Code; poster and wallet card provide a quick-reference version.

- Wallet cards:** 25 cards \$8.25, 100 cards \$28
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- Posters (18" x 24"):** \$10.50 each

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Frontline Resources

Status Report: Litigation Concerning Medicaid Services for People with Developmental Disabilities

by Gary A. Smith, HSRI

Over the past several years, people with developmental disabilities who receive services in institutions or don't receive services at all because they are on waiting lists have taken their cases to court. This *Status Report* describes lawsuits that have been filed on behalf of individuals seeking to access Medicaid services in the community. It is available online at <http://www.qualitymall.org/online/litigation.html>.

Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators

By DeWayne Davis, Wendy Fox-Gage,
and Shelly Gehshan

<http://www.ncsl.org>

This report profiles efforts by states to reduce the use of large facilities to serve people with developmental disabilities. It was prepared for state legislators to brief them about the Supreme Court's Olmstead decision and the steps that states can take to support deinstitutionalization in their state. The report may be viewed on the NCSL Web site at <http://204.131.235.67/programs/health/Forum/pub6683.htm>. To order a hard copy, contact —

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The Oaks Group

<http://www.oaksgroup.org>

The Oaks Group is a stakeholder organization of parents, consumers, advocates, educators, service providers, and other professionals who believe persons with developmental disabilities should be fully included in the mainstream of community life. The Oaks Group Web site provides considerable information about its activities and resources of value to stakeholders. There is also an e-mail discussion group where people from around the country share ideas concerning community inclusion. For more information, contact —

Bill Coffelt, President

The Oaks Group

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Pollock Pines, CA 95726

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E-mail: oaksgroup@aol.com

Web: <http://www.oaksgroup.org>

Disability.Gov Web Site

<http://disability.gov>

Disability.Gov is a one-stop Web site that pulls together information concerning topics related to disability from many federal agencies into a single location. Topics include children and youth, choice and self-determination, civil rights and protections, college and adult education, disability statistics, emergency preparedness, employer resources, employment, health, housing, in-

come support, media resources, recreation and travel, self-empowerment, tax credits and deductions, technology, and transportation.

Monday Morning in Washington, DC

Jackie Golden, Editor, and
Dora Blaino, Co-Editor

This free weekly e-newsletter, published by the Inclusion Research Institute in Washington, D.C., details information of importance to parents, children, and individuals with disabilities. Topics include legislation, U.S. government programs and services, and general announcements of importance concerning people with disabilities. To subscribe send an email to MMWDC@inclusionresearch.org. For more information, contact —

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RADAR@AAMR

www.radaraamr.com

RADAR@AAMR identifies and tracks key issues and emerging trends in developmental disabilities at the national, state, and local levels. Data is gathered from more than 150 national, state, and local newspapers. Every two weeks, abstracts summarizing important issues are delivered to the disability network through RADAR Reports.

Alliance Update

The Code of Ethics is Launched

The National Alliance for Direct Support Professionals (NADSP) celebrated the release of the NADSP Code of Ethics at its semiannual “face to face” meeting in Anaheim, California. We would like to thank Alliance members, TASH, (What a great conference!), and ANCOR for providing us with meeting space and the other amenities that made our time in Anaheim both enjoyable and productive.

The Code of Ethics (see page 17) is an excellent product that must quickly get into the hands of those providing supports. It is just one of the Alliance’s efforts to enhance the status of Direct Support Professionals (DSPs). In fact, while pursuing the development of an ethical standard, we have also been collaborating with the U.S. Department of Labor to make direct support an apprenticeable occupation. What is this going to do for us in the future? That is a question Alliance members

asked themselves when the first draft of an apprenticeship program proposal was presented by our friends at the Department of Labor in the great State of Missouri. It was exciting to us that the Department of Labor sees the work we do to support people in achieving their life goals as an occupational requiring recognition. With that occupational recognition comes the expectation that practitioners have skills, standards, and ethics, which is what the NADSP is all about. So when we were asked to review this initial proposal we made sure these components were a part of the final product. Through both classroom curriculum and on-the-job training we hope that the apprenticeship program leads the DSP towards the mastery of the skills needed to provide the best support possible. It is my pleasure to announce that the U. S. Department of Labor has approved the NADSP and now

recognizes direct support as an apprenticeable occupation.

To the NADSP, its state contacts, and DSPs throughout the country, this means that we can begin discussions with each State’s Department of Labor about the development of a support system to make apprenticeships happen. If you wish to get involved in the development of this process on a local level, contact your NADSP state representative listed on page 3. If you do not have a state representative but would like to pursue apprenticeship development contact one of the chairs for more information on becoming a state contact.

Mark Olson is co-chair of the NADSP and works for Arc Hennepin-Carver in Minneapolis, Minnesota. He can be reached at 952-915-3617 or olsonmark@archennepin.org.

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