

A Quarterly Newsletter of the National
Alliance for Direct Support Professionals

Frontline Initiative

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Is it Paperwork? or, is it the Person?

Many agencies have undertaken person-centered planning processes to assist in better understanding each individual with disabilities who receives support. These processes typically have two parts: (1) understanding a person as a person, including their past and what is important to them; and (2) identifying what kind of better future for the person is worth work-

ing for. Many of these processes take time. Some take the form of interviewing people significant to the individual, visiting people and places the individual used to know, or involving group processes. Often not all the Direct Support Professionals (DSPs) who support an individual are involved in these meetings or interviews.

As staff leave and new staff come into a

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Get out of the paperwork rut. See story on page 10.

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Frontline Notes

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Every Direct Support Professional (DSP) across the country should know how to effectively and accurately document, and why documentation is important when supporting individuals with disabilities. This issue of *Frontline Initiative* addresses the documentation process in its many forms such as, writing daily notes about how you are supporting an individual with disabilities, charting goals and objectives, and writing in staff communication logs.

All DSPs spend some part of their work day communicating through writing, or documenting. Howard Miller's article, "Is Documentation a Necessary Evil?" suggests DSPs could make use of task analysis based on a step-by-step approach to any task by making a list of the steps a person would take to be successful at accomplishing their routines. Another approach to effective documentation is to create a portfolio with the person you support and help them record how they participate in each step of their goal using pictures, "to do" lists, and notes from phone contacts. Angela Amado's article, "Is it Paperwork, or is it the Person?" reminds us about the importance of documentation from a person-centered approach — doc-

umentation becomes the person's living history while DSPs come and go. Traci LaLiberte's article, "Doing Documentation "Write," covers the "how to's" of documentation with hints and tips about how to write case notes effectively and accurately. Finally, DSPs should read the article on Health Insurance Portability and Accountability Act (HIPAA) and the importance of protecting information and data privacy. It is "need-to-know" information.

We also chose to include an article on DSPs in the Netherlands in this issue to acknowledge that a credentialing process and recognition for the work of DSPs is important worldwide. Finally, John Rose's article, "DSPs: Building Bridges to Community, Choice, and Safety" offers advice on minimizing risk while promoting safety, choice, and self-determination.

After reading this issue, take some time to think about the documentation you do every day at work. What is really required by rules and regulations? What is necessary and what is helpful? When you write about the person you support, is it respectful and accurate? How do you protect the person's privacy?

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Frontline Initiative is available in alternate formats upon request.

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 an NADSP State Contact, please contact one of the NADSP Co-Chairs (listed above).

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.

The "Write" to Privacy

Dear Seth and Cliff,

I am a brand new Direct Support Professional and my supervisor keeps telling me about something called data privacy. I am not quite sure what this is. Can you tell me what data privacy is? Why should I be concerned about it? Is it really important for me to know what it is? How does it affect the people I support? Can you help?

—Data Entry Confusion

Dear Data Entry Confusion,

Have your bank and store credit card companies sent you privacy mailings yet? They should have. All personal information that is shared needs to be kept confidential — no ifs, ands, or buts, without written authorization by the person you support and if need be, their legal representative. The concern, especially in this day and age, is that personal information can be used

against the individual (e.g. an insurance company finds out you are HIV positive and will not accept your application; your credit card numbers are used for bogus purchases.) Personal information in the wrong hands probably can hurt you in some manner. For the people you are supporting this is also true. Your job as a direct support professional is to protect the person's privacy by keeping personal information from falling into the wrong hands.

— Seth

Dear Data Entry Confusion,

Data privacy means privacy; you should not discuss information about the people you support with anyone outside of work. As part of your job you get to know very private and personal information about the people you support. If you need to release this information, you should obtain written approval from the person in question or their guardian. Data privacy involves a person's life and needs to be protected. If everyone knows what the person you are supporting is doing, that person may not be willing to carry out his or her goals and objectives. You should respect their privacy as much as you respect your own.

— 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.

Is Documentation A Necessary Evil?

Few people would question the importance of documenting the services they provide to people on the job as a Direct Support Professional. If done correctly, documentation reduces errors in the administration of important medications. Documentation assures that people provide supports to individuals with disabilities in systematic and consistent ways. Documentation verifies that companies receiving public funds are spending them correctly for appropriate services. “Documentation” is unquestionably necessary. But, is it a necessary evil?

Documentation certainly has its “evil” aspects. People who could be providing supports are instead spending their precious time recording sometimes innocuous information. Employees are compelled to document bowel movements, menses and other highly personal information, intruding on the privacy of those they support. The adage “If it’s not recorded, it didn’t happen” is so entrenched in our minds that companies may emphasize recording information over actively supporting people. This is, unfortunately, not an unusual situation.

Most provider agencies must maintain licenses in order to continue offering supports to people with disabilities, yet the act of complying with documentation requirements may actually restrict their ability to offer adequate supports. This is especially true when funding is tight and staff-to-persons served ratios are lopsided.

Ironically the amount of record keeping staff are required to do is often related less to rules and regulations than it is to our own

overprotective tendencies and failure to understand the reasons for documentation in the first place. One must exercise a well-cultivated sense of balance when dealing with documentation.

Here are some things to remember and practical steps to take —

1. Avoid writing compliance objectives in individual program plans.

I always wondered why people kept repeating this phrase when talking about programming, “Never set achievement criterion

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at 100%. It’s a set-up for failure.” What part of crossing the street safely, I thought, would you not want a person to learn? Which step in self-administering a medication, or lighting a stove, or getting to the YMCA, would you want a person not to learn?

Then I got it: these people weren’t talking about teaching others new things, they were talking about compelling people to do things that they already knew how to do!

If you look at many individual program plans, you’ll find “compliance objectives” (e.g.

Howard will carry out all steps of his morning routine 75% of the time). Hey, *I* don’t carry out all of the steps of *my* morning routine 100% of the time either!

So, what’s the fuss? Well, if you’re butting heads (and documenting the encounters) over whether someone makes their bed in the morning or puts their clothes away in the evening, you are definitely wasting staff (and the person’s) time.

Instead, just set-up the routine on a chart or graph, or have a reminder in a little book. Have the person monitor their own daily routines. Check the room from time to time. Have a celebration when the week is done and all the squares are red (or purple). People will get in the habit of minding their own affairs. Empower the individuals you support.

2. Use task analysis as much as possible.

Many people see the use of task analyses as a retreat to the dreaded “medical model.” Task analysis is a method in which you break a task down into smaller steps and teach the person to learn the larger task by completing the various steps. Adversity toward task analysis is a case of guilt *only* by association. Task analysis forms provide a baseline and measure progress toward skill acquisition, while assuring that everybody teaches skills the same way all the time.

The task analysis should help the individual being supported to learn the skills they want to learn

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DSPs Building Bridges to Community, Choice, and Safety

Strong forces, in the form of liability concerns, funding constraints, Health Insurance Portability and Accountability Act (HIPAA) mandates, and ongoing workforce issues are testing human service providers. Smaller state budgets and bigger regulatory demands are leaving providers with fewer dollars and staff with which to manage risk at a time when the wisdom of expanding choice and opportunity has never been clearer.

At the same time, providers are striving to broaden the opportunities of individuals with disabilities to make decisions and participate in community life. Providers must strike a balance between choice and risk for individuals who long for more opportunities to make choices based on their personal preferences. The exposure to risk continues to grow, along with the provider's duty to manage it.

A sound risk management process pursues quality outcomes while ensuring a reasonable degree of safety. It relies on competent Direct Support Professionals (DSPs), frontline staff, and self-advocates to minimize risk and educate the community. Together, they weigh options and make *informed* choices based on ability, desire, and degree of preparation. With this process, outcomes are more likely to be positive, leading to increased knowledge, competence, and self-esteem. These are the tools that DSPs and people who receive supports use to build bridges to the community and inclusion. Without them, outcomes can be disappointing or even disastrous.

When Bad Things Happen, the Community is the Jury

If members of the public were polled, many would agree with the *idea* that persons with mental health, cognitive, developmental, or a combination of disabilities have a right to be employed, have intimate

When it comes to life situations...members of the public often decide that people with disabilities are best kept on a bland diet of limited activities and close supervision.

relationships, vote, attend schools, shop in stores, use public transportation and join recreational clubs. When it comes to life situations, however, those same members of the public often decide that people with disabilities are best kept on a bland diet of limited activities and close supervision. They think that by keeping human service recipients "experience-poor," they will also keep them safe. They overlook the fact that this would also bar such individuals from participating in most of the activities that society itself has identified as essential to making life worthwhile.

This contradiction is most apparent during a court trial that may follow an incident or accident involving a person with a disability. Jurors drawn from that uninformed public often find providers responsible for not providing a safe environment for individuals with disabilities. They may not realize that their decisions also promote more restrictions on activities and diminish community support for inclusion.

While we need to understand public perceptions, we must remember that they are indeed perceptions. With accurate information, the public, including jurors, lawyers, and judges, may ease their concerns and change their opinions. Efforts to deliver that information must be both coordinated and comprehensive if they are to succeed. The goals of such efforts are to discourage the use of judicial remedies that can restrict choices and opportunities, and to disperse the information that will promote safety, choice, self-determination, and the right to risk.

Steps Providers Should Consider

The task of educating an entire community sounds huge, but there are solutions. It begins with identifying risks and selecting the best options to manage them. In reducing the risks surrounding people and their activities, the most powerful tools are training and education. Plan to include staff, individuals being supported, and the public in your educational campaign.

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The DSP's Role

In addition to specialized training, the role of DSP and frontline staff demands high levels of stress tolerance, patience, and strength of character. Trained and empowered DSPs are more likely to be competent, motivated, and qualified for their complex tasks. Even in the face of smaller budgets, providers can do much to enhance DSP performance and morale —

- Schedule in-house sessions on stress management.
- Provide behavior support workshops, which can give staff alternatives to using restraints, etc. when working with individuals who have challenging behaviors.
- Offer brief talks by the Agency Safety Committee (OSHA requires providers of a certain size to have a Safety Committee in place) on topics relevant to your program and population.

Ongoing training, skill standards, a code of ethics and public relations and communications protocols are vital to a DSPs support system and should be in place to guide DSPs' decisions and actions. DSPs must also understand the philosophy and mechanics of the Individual Risk Management Process (IRMP) if they are to effectively support individuals with disabilities in their pursuit of choice.

It is important to convey staff appreciation and approval —

- Initiate a staff recognition day or employee-of-the-month program.
- Have a mentoring program to acknowledge senior DSPs and support less experienced staff.
- Recognize and support DSPs in an effort to enhance their status and image within your community.

All of these suggestions are low or no-cost ways to improve focus and tell staff that what they do matters, and that they do it well.

The Self-Advocates Role

Remember the old ad, “An educated customer is our best customer”? It might have well been written for human service providers. Educated individuals with disabilities are prepared and self-aware and therefore safer. Individuals who participate in personalized programs with suitable supports and realistic goals can suc-

All of these suggestions are low or no-cost ways to improve focus and tell staff that what they do matters, and that they do it well.

ceed. Documenting each individual's plan regarding abilities and preferences is a useful risk management practice. Here, again, providers can turn to in-house resources to boost safety awareness —

- Deliver reminder sessions on using public transportation, managing medications, job and household safety, etc.
- Sponsor discussions on choices, interpersonal relationship rights of the people being supported, and other topics.

All of these will reinforce formal training and help individuals with disabilities enjoy positive experiences and minimize the severity of any

negative ones. Staff and the individuals being supported will also be better equipped to participate in the next step of the campaign.

Taking it to the Streets

A well-planned public relations campaign will show the community exactly what staff and individuals with disabilities have achieved with support. The only way to relieve public concerns and replace public perspectives with facts is to *show* the public the connections among right to risk, self-advocacy, bridges to the community, and ways in which people with disabilities can improve their own quality of life and that of the community. For example, maybe a local paper would write a news article about a person with a disability visiting residents at a local nursing home or helping to maintain a local park.

The more people who participate in community education, the better, but educated self-advocates and trained, motivated DSPs are your best ambassadors. They can carry first-hand information to schools, civic organizations, community leaders, the media, and special interest organizations. Among those groups are the judges, lawyers, jurors, teachers, and employers who have the power to affect your organization's future and the lives of those you support. As the people you support educate the public, they will also gain experience and forge contacts that lead to inclusion and safety.

Through such grassroots activities your ambassadors can identify the community's “Gatekeepers” and solicit their support. Gatekeepers are rich in social capital and often hold the keys to acceptance and risk reduction.

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In Action: Community Skills Standards

Time Management and Documentation

I have been a floor supervisor at the local supported work program center for almost five years and I have really learned a lot. I used to dread the end of my shift because it meant hurrying up and getting the people I support ready to go home. Once everyone was gone and I had everything put away and counted, I would have to sit down and write something in each person's daily log for the program manager's monthly review. I needed to record how their day went and if there were any incidents. I also had to remember to write or call their family or group homes to make sure they were aware of any problems. I sometimes spent an hour or more just documenting in log books. My supervisor did not understand why it took me so long to do the daily logs and why I never had the individual production and piece rate counts ready when she wanted them. I kept telling her I just wanted to make sure what I wrote in the logs was accurate.

In one of our meetings I asked why all the logs had to be done at the end of the shift. I would be able to get done sooner and be more accurate if I could spread logging out over my work day and not wait until the very end. She did some checking and told me that we could try this to see if it would make better sense. I looked at the list of people I worked with and realized that by staggering their breaks and with a little help from the floor job coach I could get most of the logs done by sitting with the workers one-to-one when they were on break and asking them how their day was going. We have a quiet little corner in the break room where no one else can

hear what we are talking about so I do not have to worry about privacy issues. In the beginning, I was surprised when a couple of the guys wanted to know what I was doing and when I told them they said they never knew I had to keep notes on them. We laughed and I asked them what they wanted me to write in their logs. They told me, and then

My supervisor did not understand why it took me so long to do the daily logs and why I never had the individual production and piece rate counts ready when she wanted them. I kept telling her I just wanted to make sure what I wrote in the logs was accurate.

I read to them what I had written. This system of log writing really works out well — they get one-on-one attention which really helps me build a good working relationship with each of them, and I get my logs done in a timely manner. I even get to learn about the kinds of jobs they want to work on. This was really helpful to the community support employment manager who is continually on the lookout for jobs in the community. Now when it

comes to the end of the shift I have time to talk to the workers before they leave for home. They tell me jokes and once they are on their way home I get the work area cleaned up and leave for home in no time at all. My supervisor has asked supervisors in the other production areas to consider doing their daily logs in the same way because she gets better information about how the people we support are doing and what kinds of jobs they want in the community. I am glad this is working for all of us.

Community Supports Skill Standards

Competency Area 12: Documentation

The community support worker is aware of the requirements for documentation in his or her organization and is able to manage these requirements efficiently.

Skill Standard C: The competent community support human service practitioner learns and remains current with appropriate documentation systems, setting priorities and developing a system to manage documentation.

Time Management and Documentation

As a DSP, think of ways in which you can involve the people you support when you are writing the required daily logs. Is there a way to have them tell you about what their day was like from their perspective? Can you read to them what you are writing about them?

Protecting Privacy

DSPs and the HIPAA Standards

Health care professionals, Direct Support Professionals (DSPs) included, have always had a duty to protect the privacy of the people they support. A new federal law, the Health Insurance Portability and Accountability Act, known as HIPAA, adds to that duty a legal obligation. HIPAA sets new federal privacy standards and defines what kind of health information is protected.

Protected health information is any health information that can be linked to an individual. Protected health information includes a person's written health record, whether on computer or on paper; billing information from health care and human service providers; and spoken information about that person's condition.

Protected health information is protected from unauthorized use. In general, those who have access to an individual's protected health or billing information may disclose only the minimum information necessary for the intended purpose. An improper disclosure of protected health information may result in criminal or civil legal actions.

A Few Facts

- HIPAA gives patients and people supported by DSPs more control over their health information. In hospital settings, for instance, patients, parents, or guardians must be asked if they object to the release of their protected health information before they can be listed in the public directory.
- HIPAA does not prevent health-care providers — doctors, nurses,

and so on—from discussing patients' cases; it only restricts them from discussing cases where others might overhear the conversation.

- HIPAA generally gives patients and the people supported by DSPs the right to examine and obtain a copy of their own health records, case notes, and other data collected by providers and to request corrections.

via computer by those who have no need to see them.

This is just a brief introduction. HIPAA, its privacy rules, and other aspects of the law are complicated. For more information, see <http://www.hhs.gov/ocr/hipaa/assist.html>.

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Health, program plans, and treatment records should not be easily seen in or easily accessed via computer by those who have no need to see them.

- A typical health plan or health-care and human service provider is required to tell patients and people being supported by DSPs about their privacy rights under HIPAA — and how their health program or billing information can be used.
- Health care and human service providers need to keep safe the protected health program and billing information of patients and people being supported by DSPs. Health, program plans, and treatment records should not be easily seen or easily accessed

Doing Documentation “Write!”

Documentation has become an extremely important aspect of Direct Support Professionals’ (DSPs) work responsibilities over the past several years. DSPs are held accountable for what happens during the time that they are at work and providing supports to individuals with disabilities. One of the ways that supervisors, administrators, and government funding agencies keep DSPs accountable is through documentation. Therefore, it is essential that DSPs understand how to effectively document activities and incidents.

There are three critical components in effective documentation: 1) clear and concise content; 2) documentation completed in a timely manner; and 3) adherence to the seven basic rules of documentation. If a DSP is successful in following these three components, then the high quality of their documentation will contribute to the best possible support.

Clear and Concise Content

Clear and concise content must be at the forefront of a DSP’s mind when they begin to write information. Clear documentation is information that is recorded in a way that is easy to understand, straightforward, and uncomplicated. Concise documentation is information that is expressed briefly, while capturing all the facts and descriptions necessary for the reader to understand what occurred. There are two types of information recorded in documentation: objective documentation and subjective documentation. Objective documentation can be described as “just the facts.”

In this part of your documentation, you would answer the following questions —

- **WHO** is involved? This might be the person receiving supports, someone providing supports, a family member, etc.
- **WHAT** happened? This is a brief description of what took place or didn’t take place, such as an individual participating in a community event.
- **WHERE** did the activity take place? It is important to be as specific as possible. For example, if you are documenting an accidental fall, it is essential to describe where in the home the person fell (i.e. at the bottom of the stairs that lead to the basement) and not just that they fell in the home.
- **WHEN** did the activity take place? Document the month, day, and year, as well as the time of day that you are making your documentation. Be sure to include AM or PM as part of the time.

Subjective documentation is the aspect of documentation where you, the DSP, can include your opinion. *always* indicate that this is your opinion. In this part of your documentation you would answer the following questions —

- **HOW** something happened. This is a description of how you believed that the event or incident took place.
- **WHY** something did or did not happen. In this area, you could make the following statement: “In this DSP’s opinion, Harry

appeared to hit co-worker in frustration after this writer told him that his mother called to say she would be late to pick him up.” In this example, it is the DSP’s *opinion* that Harry was frustrated, but it isn’t a fact (objective documentation).

Complete in a Timely Manner

In addition to ensuring that your documentation is clear and concise, you must also be aware of the need to complete documentation in a timely manner. Documenting an incident or activity *immediately* (or soon as possible) after it occurs is optimal. Remember, if you don’t document that something happened, there is no record that it occurred. For example, if a person you support hit their head but told you they were fine and you failed to document the incident, and later that night they fell unconscious while with another DSP was providing supports, that DSP couldn’t tell the doctor of the earlier injury and the person’s medical care would be compromised. In contrast, documenting something that hasn’t happened yet isn’t good either. A DSP may think that they have a little extra time in their day and so they may want to do their medication documentation early so that after they give a person their medication the documentation will be done and they can leave for the day. This type of documentation is fraudulent and wrong. It is documenting something that has yet not occurred. Imagine if, following this documentation, the DSP forgot to give the medication. Other staff

Continued on next page

members would see the documentation and believe that the person did receive their medication. This could have serious results. *Never* document something before it happens.

Adherence to the Seven Basic Rules of Documentation

The last of the three essential components of good documentation is that the DSP follows the seven basic rules of documentation. These rules help to ensure that documentation is accurate.

1. Write in dark blue or black ink. Do not use erasable pen or pencil because someone could change what you have written.
2. Write legibly. Take your time and write neatly. The best information in the world is not useful if no one can read it! Don't use abbreviations unless they are common in your agency and approved by your organization. Unknown abbreviations can make documentation difficult to understand.
3. *Always* sign what you have written. This is your way to ensure that others know what you have and have not documented. *Never* sign something that someone else has documented and *never* document information on behalf of someone else.
4. Be sure to include the full date with each documentation entry. This includes the month, day, and year.
5. Document the time of your entry. Be sure to indicate if the time is AM or PM.
6. If you make an error in your documentation entry, simply draw a line through the error and place your initials next to it. *Do not* erase a mistake or cover it with

Wite-Out.[®] This rule helps to ensure that the entry is your own and that no one else has altered it (i.e. using white out).

7. Use all the lines in the documentation log or book so that nothing can be inserted ahead of your entry. Do not leave room for someone else to document information. If they need to document something out of chronological order they can indicate that in the margin of the book. If there are unused lines in the documentation log or book, draw a single line across them so that nothing can be added.

These seven basic rules are easy to remember and follow. You may even want to cut out the simplified list below and post it in a visible location as a reminder. Most importantly, remember that the support provided to the people you support after you leave for the day may depend upon what you have written, so make sure that it is clear, concise, timely, and accurate!

Traci LaLiberte, M.S.W., is a Community Program Associate at the Institute on Community Integration. She can be reached at lali0017@umn.edu.

The Seven Basic Rules for Accurate Documentation

1. Write in dark blue or black ink.
2. Write legibly.
3. Sign each documentation entry.
4. Date each documentation entry.
5. Document the time of your entry. Don't forget to include AM or PM.
6. Draw a line through errors and initial. Do not erase or cover with Wite-Out.[®]
7. Do not leave unused log space blank. Draw a line through unused space.

From, "Doing Documentation 'Write,'" *Frontline Initiative* newsletter, v. 5 no. 4.

A Daring Decision

The Dutch Direct Support Professional

It is common knowledge that Direct Support Professionals (DSPs) in the United States lack an indispensable ingredient. Whether one works for a large company or for a smaller organization, the same scenario unfolds before one's eyes. Should one assist in a small home, in a setting supporting people with challenging behaviors, or in a program supporting people with mental health issues, one often witnesses the painful turnover of DSPs. Having been actively involved in the lives of people with disabilities for over twelve years, I can testify to the same sobering conclusion. Individuals being supported resent having staff come and after being trained, decide to leave. Rather, they like stability. They love to relate to the DSPs they have come to trust. They hate when bonding relations with caregivers are severed.

An Attractive Alternative

An inviting model of support is found in the Netherlands, the tiny country of my birth. Over a century ago (1891), a group of dedicated people formed an "Association for the education and care of idiots and backward children." Its members were moved by the plight of Dutch children with disabilities, many of whom were then bound to furniture or locked up in outhouses or attics. Together they started a small institution on an estate belonging to the Knights of St. John — first for boys and, as it grew, also for girls.

Education

Before individuals can become direct caregivers in the Netherlands, they

must be properly educated. During three years of training, they take courses in medication and hygiene, in human relations, and, above all, in comprehensive care giving; only those with seven years of education may administer medications. Prior to receiving their diploma, they pass an internship, which enables program directors to determine whether or not candidates are suitable for their vocation and applicants to assess if they really like their future

Individuals being supported resent having staff come and after being trained, decide to leave.

employment.

The more education one acquires (one can even branch out into psychiatry), the more readily prospective caregivers can expect good financial rewards. Once trainees have obtained their diploma, they are deemed authorized and thus competent in all areas of this profession, including how to administer tube-feedings. In other words, the Dutch model permits greater initiative on the part of the caregivers and demands less supervision by administrators since the responsibility lies as much with the workers as with those placed in charge. Staff members are, further, encouraged to adopt the values of the people they support, and to help make where

they live not just a house, but a home. Rarely are residents exposed to disruptive changes in staff.

Employment

Among the young entering this field of employment in the Netherlands are more women than men. According to one trend, women tend to get married after awhile, raise a family, and then return to this vocation on a part-time basis. While there is a growing shortage of competent workers — more in the cities (where wages in other professions are more alluring) than as yet in the provinces (where a slower pace of life appeals to some) — there exists a large pool of experienced mothers willing to help out as needed while their husbands take care of the children in the evening. Each home, I was told, tries to accommodate the part-timers in their choice of hours — either early in the morning or in the evening. This solution has very few cases of last minute "sickness" and "no show no call" incidents.

Rewards

Before the Dutch changed their national currency from the guilder to the Euro, the nearly common European coin, employment for caregivers in the Netherlands was winsome. After this unsettling change, their life, and that of many other Dutch citizens, has become more expensive, while the wages have remained more or less the same. A single caregiver still enjoys a comfortable life, a married couple less so, and a family with one child needs to look for a part-time job to make monthly ends

Continued on next page

meet. Many caregivers, however, consider their work a way of life rather than merely a paid job.

Funding

The Dutch government pays a big part of the financial costs for the support of people with disabilities (though it does not dictate how each organization administers that support). Since the Dutch have a national health insurance policy, which covers all Dutch citizens including individuals with disabilities, all medical expenses are paid by, as the Dutch lovingly call their government, “Father.” Each adult with disabilities pays only a small amount to cover some of their costs. Fund raising is limited to special projects, such as taking a person on an extended outing.

Conclusion

As I am writing this article, I wonder how long it will take the United States to require comprehensive training and state certification of DSPs. I also wonder when our nation will recognize that the profession of care is worthy of fitting pay and deserves the same public respect as do other professions in America.

Ralph W. Vunderink is a senior lecturer in philosophy at Aquinas College, Grand Rapids, Michigan, and is a retired caregiver of Spectrum Community Services. For more information about direct care in the Netherlands, please contact Ralph at vunderal@aquinas.edu.

The Tools of Human Service Worker

Carpenters use tools. Chefs use tools. Dentists use tools. So what tools do human service workers use?

Your tool is YOU! The whole, entire, physical being of you! Your heart, your brain, your voice. Your eyes, your ears, your body.

You use your heart in your work daily. In fact, such a big heart is what drove you to human services in the first place! It provides you with compassion but not pity, sensitivity without overreaction, acceptance without judgment, empathy even when lacking understanding.

Your brain senses the entire situation and separates how to take action or just leave it be; decides when to be right or do right; considers what motivates another’s action or inaction.

Your eyes watch 360 degrees, make observations of behavior, antecedents and consequences, show acknowledgment.

Your voice calms, not incites. Tone reflects respect, not humiliation; your words connect, not disconnect. Whispers are intimate, not stabbing.

Your ears listen beyond words to feelings and emotions: fear or comfort, desperation or depression, joy or reluctant acceptance.

Your face reacts to all of these, expressing confidence and safety.

Occasionally a forced poker face can save a potentially bad situation, covering your own bewilderment, fear, insecurity, shock, or humor.

Your body is balanced and paced, its proximity can intimidate or reassure.

Your arms enfold another while erasing all trepidation or loneliness.

Ultimately, your hands are all-powerful. Slowly reaching out an open palm to another who instinctively grasps it, says that they’re not alone, we are all only human, with all the limitations and frailties, and that you will walk with them through this human condition.

© Linda La Pointe, MRA, author of *The New Supervisor: Strategies for Supporting and Managing Frontline Staff* available at www.thetoolbox.org. Used with permission.

Your tool is YOU!
The whole, entire,
physical being of you!
Your heart, your brain,
your voice. Your eyes,
your ears, your body.

Alliance Update

Greetings from your friends at the National Alliance for Direct Support Professionals.

Much of the “buzz” in our recent meetings and conversations has been about choosing policy and organizational directions for the future. After meetings in Chicago last May and Minneapolis in July, members are focused on several key initiatives for the coming months.

A top priority is moving from our informal coalition structure to a fully incorporated non-profit entity. Our volunteer members have been busy with the task of creating and reviewing the mission, procedures, and by-laws that are essential to making this change. It will be an exciting new phase for NADSP and we expect it will help us to make an even greater contribution to the direct support workforce. Big kudos to John Rose of the Irwin Siegel Agency for the thankless task of “herding the NADSP cats” toward achieving this organizational goal.

We’ve had much positive feedback and requests for the *NADSP Code of Ethics* (see the following page to order). With that interest we’ve also seen a rising demand for technical assistance in applying this code in the everyday life and work of agencies and the Direct Support Professionals (DSPs) they employ. In response, the NADSP members have identified the development of a *Code of Ethics* tool kit as a key action goal in the coming year. We encourage anyone who has created fun or innovative ways to teach, use, or disseminate the at the grassroots level to share this information with the development committee (e-mail: Taylor@hsri.org).

Another primary policy goal is to make sure that our recently published *Moving Mountains* workforce covenant is widely distributed to employers and that we begin to publicly recognize those employers who have committed to the workforce support principles it describes.

On the national front the

The United States Department of Labor has issued apprenticeship guidelines for the “direct support” role and has extended an increasing amount of in-kind and fiscal resources to “jump start” apprenticeship programs throughout the country.

NADSP is witnessing a significant rise in awareness and commitment to improving work conditions for DSPs. Several state Developmental Disabilities Councils, including Ohio, Kansas, West Virginia, Mississippi, and Arkansas, have made important investments in projects supporting the creation and demonstrating interventions that will have a positive impact on DSPs. The

United States Department of Labor has issued apprenticeship guidelines for the “direct support” role and has extended an increasing amount of in-kind and fiscal resources to “jump start” apprenticeship programs throughout the country. For example, they sponsored a *New England Regional Conference on Direct Support Apprenticeship* that took place last summer, provided a grant of \$100,000 to the Ohio Alliance for Direct Support Professionals to promote apprenticeship activities, and provided advice and technical assistance to coalitions in Massachusetts, Kansas, Ohio, and Wyoming on how employers create and register an apprenticeship development program.

Policy leaders in other organizations are also working to make a difference. Several national human service associations (ANCOR, Arc, AAMR, AUCE, and NADSP) have formed a coalition to speak in one voice on important policy matters. This group, known as the DDQC (Developmental Disabilities Qualities Consortium) facilitated the development of an important conference in February sponsored by the Administration on Developmental Disabilities where direct support was a key theme. The DDQC is also planning a joint summit in 2005. The Center for Medicare and Medicaid Services is also funding research and demonstration activities focused on direct support. While that funding is still too limited for the extent of the current problems, it is a step in the right direction. Finally, NADSP serves as the advisory

Continued on next page

panel to several important research efforts involving direct support.

As time goes by, more people are joining NADSP on the exciting but difficult journey to better conditions for the direct support workforce in America. We hope you will too.

Tribute to Marianne Taylor

As of January 1, Marianne Taylor is no longer the co-chair of the NADSP. Tony Thomas, liaison NADSP from Ohio, has agreed to be co-chairperson with Cliff Poetz and Mark Olson. The entire NADSP Steering Committee and NADSP membership wants to take this opportunity to thank Marianne Taylor for her outstanding efforts to advance the concepts of direct support practice *as a profession*. It is with this deep appreciation that we recognize Marianne's work and dedication to DSPs around the country. She will continue her work with the NADSP as our legislation and policy advisor and continue to travel the country helping states and regional entities develop sound practices and programs that directly impact the quality of the services we provide. Marianne, we THANK YOU!!!

Co-chairs: Mark Olson
Cliff Poetz
Tony Thomas



Code of Ethics Materials for DSPs

This series of materials is based on the Code of Ethics for Direct Support Professionals. 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

Brochures: 25 brochures \$15.25,
100 brochures \$45

Posters (18" x 24"): \$10.50 each

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Is it Paperwork? or is it the Person?

continued from cover

person's life, important information about an individual is lost.

The information obtained about a person through these processes is often rich and vital and helps DSPs really understand that person as a person. For instance, in one group home there was a woman named Janet who was often quite aggressive — she had hit staff, other people who lived there, and put holes in walls. The DSPs who worked in that home primarily saw the woman as her behavior, and that behavior ran the whole home. If Janet was having a bad day, the whole home had a bad day. If Janet had a good day, everyone did. Interviewing her family about her past through a person-centered planning process, however, really helped Kate, the program coordinator, understand

the woman better. Kate came to understand how traumatic Janet's past had been — how often she had been moved from home to home, from institution to institution. Janet had often been tied down, and been given medications to control her behavior, which had given her terrible reactions. In one of the most terrible times in her life, Janet was in constant horrible pain for a year, and was acting very badly because of the pain. Her mother had to do a lot of work to find out what was the real cause of Janet's behavior. Once she found out that it was a medical issue causing the pain, she started working on getting the institution to do what was really a very simple resolution. But, it took them a whole year to do it, with Janet in pain the whole time!

When Kate left the family home after interviewing Janet's parents,

she had a new sympathy for what Janet's life had been like and a brand-new understanding of Janet as a *person*, why she acted as she did, and what was important to her. Even though Kate had known Janet for ten years and had thought she knew everything about her, after the meeting with her parents, Kate said, "I never knew Janet's life was so hard." The staff started supporting Janet in different ways — helping her have more control over daily decisions, meeting more community members as friends, expressing her interests like country line dancing and flowers, and getting a job at a florist shop. The problem behavior almost completely disappeared.

How can that understanding of a person as a person be documented and passed on so all current and new staff understand Janet that way and

Continued on next page

Working together to pick out some pictures of my favorite things.





Understanding the person, including their past and what is important to them, helps plan a better future.

how to support her? It would need to be written down or otherwise documented in some way so it could be shared. “Paperwork” would be much more than just papers — it would be an avenue to helping Janet have the life she wanted.

Here are some ways different agencies have used to document a person’s past and their interests —

- Make a videotape telling the story of a person’s life that all new DPS’s have to watch when they start working with that person.
- Complete posters that graphically show different themes in a person’s life — their interests and their past. However, it’s important to have a written or videotaped explanation of the poster, as the symbols and pictures are not always understandable.
- Show photos of favorite activities and people — but again, it is important to have a written or taped explanation.

The second part of person-centered planning is also important to document. As persons with disabilities are supported in pursuing their interests and dreams, it is also important to pass on important information and progress to others supporting that person. For instance, let’s say a DSP named Mary takes Janet country line dancing, to volunteer at the library, to church, or to a Jaycees meeting. Perhaps Mary knows who the important people are in the church who really know Janet and her family, and where Janet likes to sit. Perhaps Mary knows which officers of the Jaycees really like Janet and who help her get signed up for activities. Mary probably knows what Janet can order something to eat and drink when she goes to line dancing, and which lady at the library is most helpful to Janet.

Ideally, that information is documented for others who might end up taking Janet if Mary is sick,

or if Mary leaves the agency. Ideally, if Mary left and a new DSP named Lily started, Mary would take Lily to church or to the Jaycees meeting and introduce Lily to the people there who are important to Janet. Mary would also explain the “informal rules” of the group — such as what part of the meeting is for meeting and what part is for eating, how you need a partner for horseshoes and how to get the best partner.

Documentation is also important for the interdisciplinary team — the parents/guardians, case manager or social worker, and everyone else who plays an important role in the person’s life. Without on-going effective documentation, the richness of a person’s history may get lost.

Angela Novak Amado, Ph.D. is a Research Associate at the Institute on Community Integration at the University of Minnesota. She can be reached by phone at 651-698-5565 or by e-mail at amado003@umn.edu.

NADSP Moving Mountains Commitment Certificate

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

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DSPs: Building Bridges to Community, Choice, and Safety continued from page 7

No provider can promise that people with disabilities and DSPs will not suffer harm or be harmed through their own or someone else's actions or failure to act. No one expects them to make such a promise. What providers *can* do is use every available tool to reduce exposures, manage risks, protect individuals and DSPs, mitigate the negative effects of any untoward event, and investigate any event extensively and use the results to prevent future occurrences. Regardless of the people served, providers can use bridge building to achieve a variety of results.

John Rose is Vice President of Risk Management for the Irwin Siegel Agency. He can be reached at 2johnrose@excite.com.

Frontline Resources

The Community Support Skill Standards: Tools for Managing Change and Achieving Outcomes

By Taylor, Bradley, & Warren from The Human Services Research Institute

Contains competency areas for essential for Direct Support Professionals. It includes a skill standard devoted to competencies that DSPs should practice around documentation. Order by phone at 617-876-0426 or visit at <http://www.hsri.org>.

The College of Direct Support www.collegeofdirectsupport.com

The College of Direct Support offers an on-line curriculum covering a variety of topics important for training Direct Support Professionals. It's documentation course provides the

learner with a thorough understanding of why it is important to record specific activities or events, different types of documentation, ways of effectively completing documentation, and the importance of maintaining confidentiality in documentation.

Ten Topics for the New Direct Care Provider

By Michael True, M.Ed.

Each of the ten areas is covered in a fully self-contained packet (individual files on CD), including training objectives, questions for discussion, pre- and post-tests, and administrative supplements which can be adapted for use in your program. Subjects include: abuse and neglect, active treatment, basic documentation, behavior management, communicating, confidentiality, consumer rights, an intro to de-

velopmental disabilities, incident reporting, and training techniques. Product and ordering information can be viewed at www.qualitymall.com or at <http://www.ilresources.com/Truenergy.htm>.

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and should always be individualized. Develop task analysis by observing where the person will perform the task. Draft a step-by-step guide for the task as you would perform it.

Once the steps are in place, cue the person who's going to be learning the skill to "make a hamburger" or "clean the living room" and see what they do. They may get a long way into the task before they need a single prompt! This is a good thing. Re-order *as the person did them* and then use this list to support the person in learning the task.

3. Never document "programs" anecdotally.

Somewhere people started thinking that numbers were evil if they were used to document programs. It seemed that if you developed a goal for a person that taught them to do something they really wanted to do (e.g. "Bob wants to

go to Branson and hear Donny and Marie") it was much harder to document it numerically!

But it's really not that tough to document reaching a dream. Think about all of the practical, functional steps along the way that *could* be learning experiences —

- Calling travel agents
- Checking the internet
- Checking the paper
- Making an itinerary
- Making reservations
- Banking for the trip
- Buying clothes for the trip (watching the Weather Channel?)
- Packing
- Etc.

Interestingly, each step that Bob takes toward his dream vacation would produce notes, brochures, lists, articles, etc. — a quantity of documentation the gathering of which would *not* keep one employee

away from active treatment for more than a minute! Put these "documents" in a portfolio or album. Throw in the pictures of Bob with Donny and Marie. Goal achieved!

You'll notice that survey-approved documentation was kept in the example above. The person was actually working on a real outcome. Staff direction *and* documentation was kept to a minimum, empowerment to a maximum!

This is what should be getting documented! Let's make life easier for DSPs by making it possible to professionally and directly support people.

Howard Miller is the director of training for REM Minnesota, part of the Mentor Network, Inc. and can be reached at hmill@reminc.com.

Visit the DSP Web site at <http://rtc.umn.edu/dsp>

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