

A Publication of the National  
Alliance for Direct Support Professionals

# Frontline Initiative

Volume 14 • Number 2 • 2017

## Choice, direction, and control

How do I support these in my duties as a DSP?

Choice, Direction, and Control  
Frontline Initiative

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*Desiree Loucks Baer*

As direct support professionals (DSP), we support people every day to make informed decisions. How will people spend their time? With whom will they spend their time? How do they want to dress? How do they want to decorate their personal space? What and when do they want to eat? We support people to make large and small decisions about their lives. Supporting people to make informed decisions is one of the most important responsibilities we have as a DSP. We encourage people to have choice and control over their lives. We

also recognize that decision-making is a skill. We support people to learn and practice this important skill. This is especially important if they have had limited chances to do it in the past.

All people use supports to make decisions in their lives. When I recently purchased a car, I chose my husband and son to support me. They helped me to understand what I needed to know in selecting a car. They both have more knowledge about cars than I do. I used that knowledge to choose a car that would best meet my needs. I made the decision for myself, but I used the sup-

#FI4DSPs

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port of people I trusted to help me make a good decision. As DSPs, we have lots of opportunities to support the decisions that people make.

## Guardianship

Sometimes we work with people who have been appointed a guardian by the courts. When a person has a guardian, the court has determined that the person lacks capacity to make certain decisions for themselves. When a guardian is appointed, he or she has been given the legal responsibility to make decisions for the person. The decisions guardians make should be based upon what that person would decide if they were capable of making the decision. Courts can appoint a guardian to make different types of decisions. For example, they may make decisions about money or healthcare.

Guardianship may help protect a person from exploitation or harm. When a guardian is doing their job well, they always follow the person's expressed wishes. They engage the person to ensure they understand what those wishes may be. Guardianship can also have some negative consequences. Removing a person's rights may result in loss of independence, self-expression, and dignity. In some cases, it can result in exploitation of the person by the guardian.

## Supported decision-making

In the movement to help people with disabilities live more self-determined lives, people with disabilities and their families around the world have started to explore alternatives to guardianship. The United Nations Convention of the Rights of Person with Disabilities

has recognized Supported decision-making (SDM) as a tool that supports the decision-making abilities of people with disabilities. SDM is a series of relationships, practices, arrangements and agreements that are designed to assist an individual with a disability to make and communicate to others decisions about the individual's life.<sup>1</sup> The person exercises self-determination to the greatest extent possible. When making a decision where the individual has limited experience they choose people they trust, such as family members to support them. The people they choose may fill a specific role, such as helping to understand information relating to the choice to be made. Or, a supporter may also help communicate the decisions the person makes. Formal agreements can be developed between the person making the decision and the person(s) they choose as supporters. The agreement helps define (1) on what types of decisions they would like support, and (2) how that support should be given (e.g., providing information, communicating the decision). This can be used as a tool by the person when working with others. Professionals and others outside of the agreement may not understand or respect the person's ability to make decisions. Formal documentation of the agreement can ensure that the person maintains choice, direction, and control.

SDM is new to the United States. Texas and Delaware are the only states that currently recognize SDM agreements. However,

er, a handful of other states have statutes being considered in their state legislatures. A few states are trying SDM models with hopes of legal recognition in the future.

As a DSP, how can you support a person who is utilizing SDM? The key to SDM is the empowerment that comes with decision-making. Decision-making is a skill. Therefore, it needs to be taught, learned and practiced. It is important that as DSPs, you —

- Recognize that people make hundreds of decisions every day.
- Assist the people you support to practice making informed decisions as often as possible. Everyone has the right to make a bad decision.
- Support the learning that comes from those bad decisions.
- Recognize that the greatest learning can come from our mistakes.
- If you are supporting a person who has a guardian, respect the role of the guardian. However, remember your first allegiance is to the person you support. Help the person you support to communicate their expressed wishes and the decisions they want made on their behalf.

The support you provide as a DSP may be key to helping that person live a more empowered life.

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*Desiree Loucks Baer is Director of Program and Member Services at the New York State Association of Community and Residential Agencies (NYSACRA). She is working with the NYS Developmental Disabilities Planning Council Grant and CUNY/Hunter College to develop and pilot a supported decision-making model throughout New York State. Contact her at [desireelb@nysacra.org](mailto:desireelb@nysacra.org).*

<sup>1</sup> From "Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making," by R. D. Dinerstein, 2012, *Human Rights Brief*, 19, p. 8.

# Frontline notes

Peoples with intellectual and developmental disabilities (IDD) have not always had their choices, direction, and control over their own lives honored. In this issue of *Frontline Initiative*, we focus on how to support peoples' choice, direction, and control. Critical culture and policy changes are impacting the ways direct support professionals (DSPs) provide supports. Our aim in this issue is to make you aware of these changes. We also want to provide you with resources to help people make choices, take direction and feel control over their lives. This starts with helping people make day-to-day decisions in the ways we provide supports.

As DSPs, we are often driven by the successes of the people we support. Moments when people demonstrate choice, direction, and control are pivotal in our work. This is especially true when people have not often been given such options throughout their lives. Making choices and taking control is a skill. DSPs can support people to practice this important skill. As our cover story emphasizes, we can support people in making decisions. Even when people we support make a bad decision, we support them to learn from their mistakes. We can support people to become strong decision makers.

In this issue, we look at new federal regulations that emphasize peoples' choice, control, and direction. We examine guardianship.

We also discuss a newer option called supported decision-making. We provide resources DSPs and families can use to explore supported decision-making. People and their loved ones can use these to determine if supported decision-making may be right for them. We also include several stories about people with IDD who were supported to make decisions about their lives. We hope you are inspired by the great successes they experienced. Your role as a DSP is so important in the everyday decisions people make in their lives, both big and small.

DSPs support peoples' choice, direction and control in their routine and rituals. But we are often also present when people make larger decisions about the course of their lives. A person we support may be considering education or employment. They may be considering a relationship or pursuing a new hobby. Such experiences can change how a person feels about themselves. It can help them to be empowered to do things they didn't think they could do before. We support people in balancing risks and benefits in a person-centered way. Our role as community navigator is important in helping people reach their dreams.

~ The editors

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*Frontline Initiative* is available in alternate formats upon request.

# NADSP update

## It's Time to Roar!

By Joseph M. Macbeth

The stability of the direct support workforce has been a long-standing issue across disability service systems. The field is plagued with high turnover at a time when demand for additional direct support professionals (DSPs) to support disability and aging populations in the United States is peaking. An estimated one million new direct support positions will be needed by 2022. Growing demand, limited availability of training and education, and increased expectations and requirements make investment in this workforce essential. Traditional methods to address these issues have only resulted in small improvements. Now it's time to bring DSPs into the discussion. It's time to engage with them to speak for themselves.

We've just returned from our annual conference "The Third One" in Omaha, Nebraska. By all accounts it was a great success. Following The Third One was National Direct Support Professionals Recognition Week. DSPs were recognized, thanked, and appreciated in creative ways across the country. We, at the NADSP have created many research-based products. We have provided services to advance the knowledge, skills and values of the direct support workforce. The NADSP co-sponsored National Direct Support Professional Recognition Week. But, when you really think about it, have we made enough change? Sadly the data tells us, no.

During the introduction of our John F. Kennedy, Jr. Award for Direct Support Workforce Leadership & Advocacy, Amy Hewitt from the University of Minnesota took a moment to issue a call to action. Amy challenged the 250 people in the room to lead a campaign to call their elected officials and share their stories. In paraphrasing Amy, it's the DSP voices that will make a difference. It is not the voices of agency executives, researchers, trade associations or lobbyists. Change will come when the 2 million men and women who do this work get involved in their own cause.

As Amy said, "If every DSP called once a month and shared their story about what they do to support people with developmental disabilities – their needs and *the high-skilled nature of their job, the risks they take, the ethical decisions they make, the problem solving they have to do, and the autonomy they are required to work under* – it would make the MOST difference".

We at the NADSP heard Amy's call to action. Our public policy

committee will be creating an easy-to-use, online portal. This will have all the tools you'll need to make these important calls. This portal will include simple ways to find the names and contact numbers of all your elected officials. It will include important talking points about direct support work. It will include the challenges of supporting your own family on poverty-level wages. It will also include the rewards of having a job that assists people with disabilities to achieve meaning in their lives and be less reliant on public assistance. We want you to share your contributions in promoting the human and civil rights of people who have been ignored by society. Finally, we will send you information on the latest issues and topics that will affect the direct support profession. We will provide you with important talking points for you to use on your calls.

It's time to get engaged. It's time to hear direct support professionals roar.

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Joseph M. Macbeth is the Executive Director of NADSP. He can be reached at [jmacbeth@nadsp.org](mailto:jmacbeth@nadsp.org) or 518-449-7551.

A black and white portrait of John Raffaele, a man with short hair, smiling, wearing a dark long-sleeved shirt.

The GoToWebinar logo, featuring a stylized 'G' icon and the text 'GoToWebinar'.

The NADSP logo, which includes a map of the United States with the letters 'NADSP' overlaid.

### The conversation continues with John Raffaele!

Join John's webinar for an in-depth discussion about the stories in this issue. Go to [nadsp.org](https://nadsp.org) to find out more.

[Sign up to receive our email announcements of upcoming webinars and other information](#)



# Enhanced choice, direction, and control in services

## What does this mean to DSPs?



By Susan O'Neill

Enhanced individual choice, direction, and control over services were built into updates to Medicaid Home and Community Based Services (HCBS) program rules in 2014. These changes will influence how, where, and when DSPs work. Medicaid HCBS pays for the majority of publically funded services delivered to people with disabilities and older adults to help them live in the community. These updates were so large that states have been given years to come into compliance with them. Increasing a person's choice, direction, and control were central to the values driving these updates, primarily through using person-centered planning and the new expectations for what settings constituted community living. These new rules will impact the work of DSPs, and the lives of the people with intellectual and developmental disabilities (IDD) if properly implemented.

### Consider the following scenario

*Juan dislikes getting up at 5:00 a.m. but there is only one bathroom in the house. All three of the men who live there need to clean up before 7:30 a.m. At breakfast, staff offer him a choice of two kinds of cereal for breakfast. Juan picks one. He misses his mother's eggs and tortillas. When he is done eating, staff open the locked cupboard. They give him his medications, the hand brace that he wears at work, and a dollar of his money that they keep in the locked cabinet.*

*Juan watches TV. The staff help the two other men in the house. Juan thinks Joseph is okay but he really doesn't like Franklin. When Franklin yells at him, the staff tell Juan that he should go somewhere else. The three men attend a day program together. They put headphones into packaging. Juan is slow to come back from breaks because the work is boring. However, it's the only work that pays any money that he can do at the center.*

*After work, Juan is excited to see Jordan's car in the driveway. Jordan can play basketball as well as he can. When he asked, Jordan says he can only play for 10 minutes. Jordan has to help Franklin run errands. After dinner, Juan waits for Toulo, another DSP. Toulo gets the cleaning spray and broom out of the locked closet. Juan helps Toulo clean up. Juan must be in bed by 9:00 p.m. This is the time that staff go off duty. He has to be in his room after that*

*time. At his mother's, Juan went to bed when he wanted. Juan can't afford a TV so he listens to the radio until he falls asleep.*

Throughout his day Juan's choices and experiences are limited in ways that many of us don't experience. The changes in HCBS regulations expect service providers to support people to live as others without disabilities do. This means making decisions. It means having control over personal schedules. This includes what time to get up and go to bed. It includes when and what to eat. It means choices about who to live with and where. It means being able to fully use all areas of one's living space. It means having full access to one's possessions, money, and household items. It means being supported to seek interesting and lucrative work. These are all things that Juan and many others do not experience currently.

DSPs in this new era will find their work requires different skills from them. The emphasis is on supporting a person to make their own choices. It allows the person to be much more in control of their life. It is likely to be more seamlessly connected to natural supports. This means DSPs may not see supervisors or coworkers much at all. Instead their workday will be with the person supported and people he or she knows. DSPs may not have typical or routine schedules even if they work in employment supports. They will be creative about helping people make informed choices. They may

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# The Third One

## NADSP Conference 2017

place less emphasis on monitoring or limiting choices to keep people safe. They may be called upon to help identify what is working for people and what is not. This may be especially important in situations where the person communicates non-traditionally or without words. These changes continue the progression away from segregation and lack of choice common to institutional living. They are movement toward the full promise of inclusive, community living.

Ask your employer about their view of these changes and consider checking out your state's transition plan. State transition plans are available at: <https://www.medicaid.gov/medicaid/hcbs/transition-plan/index.html>.

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*Susan O'Neill is the Quality Director for the Research and Training Center on Community Living curriculum developed for DirectCourse ([directcourseonline.com](http://directcourseonline.com)). She spent 12 years in direct support and frontline supervision roles supporting people with development disabilities in community services. She is a family educator and supporter in the area of mental health. She is a guardian and friend to an adult with IDD and co-occurring mental health disorders.*

The Third One Conference in Omaha, Nebraska on September 9-10, 2017 was a huge success! Hundreds of DSPs from across the country came together to learn, collaborate, and celebrate. DSPs rang in DSP Recognition Week with a celebration on Saturday evening.



**NADSP Executive Director, Joe Macbeth with the recipients of the John F. Kennedy, Jr. Award for Direct Support Workforce Leadership and Advocacy: Marianne Taylor, Val Bradley, Amy Hewitt, and Regis Obijiski**



**Keynote speaker David Hingsburger, The community: What it is and what it isn't"**



More photos from The Third One



**Mark your calendars for  
The Fourth One in St.  
Louis!**

**Registration opens  
January 2018.**



# Opportunity at the Fab Lab

*By Robin Kusiak & Tim Haynes*

Randy is a man who receives support services through CLASS LTD in Independence, Kansas. He spends some of his time in the GOALS (Giving Opportunities to Adults for Learning and Success) Program at Independence Community College (ICC). GOALS is a program where people take mini courses in a college environment. The courses are aligned with their interests.

One class Randy enrolled in was the Road and Pedestrian Safety class. In this class, Randy was introduced to the Fab Lab and the capabilities of a three-dimensional printer. During a lesson on the importance of using crosswalks, Randy and his peers wanted to beautify their town by creating a crosswalk for the local park and zoo. For a project in class, he and his classmates decided to design and install one. This was a large project, but they were ready to do it!

They first needed permission from the Park Board. Randy and another student got permission from Board and City Council members for a spot on their agenda. As members of the city, they presented their project. Randy showed pictures of various crosswalks. His classmate spoke enthusiastically about their idea. Their teacher also attended for support, but only spoke if necessary. After their presentation, the Park and Zoo Board unanimously approved their idea.

Second, the students needed approval from the City Commis-



**Randy in the Fab Lab designing the stencil for the crosswalk**

sion. They also needed to make sure that their plans were in compliance with the city code. Randy, his classmate, and his teacher did a similar presentation for the City Commission. Again, they received a unanimous vote to proceed with their idea. Their plans were approved with appropriate measurement and legal placement for the crosswalk.

With their plan approved, the students needed to make a stencil. Since Independence is a small tennis town, Randy and his classmates wanted to use a tennis racket theme in the art they painted in the crosswalk. They would use the stencil to paint the crosswalk on the pavement. The Fab Lab's three-dimensional printer that was located at the college was an excellent place to start. Together Randy and his teacher went to the Fab Lab. They asked advice to create and construct the metal stencil. His teacher thought the tennis rackets should be slant-



ed with a net, but Randy tapped her on the shoulder. He shook his head "No" and made a large "X" with his arms. Instead, he communicated his own design. He added a ball at the top and a ribbon below the rackets. He got some help from Tim Haynes, the Fab Lab instructor. Tim provided some support. But ultimately, Randy created the crosswalk stencil from start to finish.

Randy has difficulty with speech. He does not use verbal communication with many people. He sometimes shrinks from challenges that are out of his "comfort zone." But, all this changes in the Fab Lab. In this place, Randy carries on conversations with Tim. He more confidently uses speech and gestures. Knowing Randy's insecurities with speech, it is amazing to witness how he comes out of "his cocoon" when he works at the Fab Lab with Tim.

Before this experience in the Fab Lab, Randy never worked on

*Continued on page 9*





**Randy and his artwork**

a computer. In fact, he showed no desire to use technology. In the Fab Lab, Randy is treated with respect and as an adult with creative ideas. His confidence level soars when he enters the Fab Lab. After his successes in the Fab Lab, Randy not only uses a computer, he now enjoys challenges and learning new things. Randy is now working on designing a mailbox in the shape of a race car. He learned the travel route from his Day Service Program to the Fab Lab. He also is learning his way around the Fab Lab. He can give directions to rooms, computers, and printers throughout the building.

Randy needed someone to believe in him and his dreams. He needed someone to give him an opportunity to make his dream a reality. He did not need someone to say, "Great idea. Some day." He also did not need someone to take up his dream for him and say, "Randy did it." Direct support professionals give options to people for accomplishing a task

beyond apparent limitations. They can use step-by-step motivators to progress toward the dream. They can provide tools for a person so they have a chance to succeed. They can help a person find new opportunities in the community. A DSP can encourage someone, like Randy, to use gifts they've never used. And, when a person achieves a dream, a DSP can celebrate their success with them and continue to encourage the person in using their new skills.

Randy says, "The Fab Lab is cool." There, he creates in ways beyond the barriers he has with language. His disability is not a barrier in the Fab Lab. When Randy completes a project, he thinks about what he's done. He says, "That's not bad." But the smile on his face tells so much more.

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*Robin Kusiak is the Education Coordinator at CLASS LTD in Independence, Kansas, an organization that supports people with intellectual disabilities. Robin works with staff*

*and persons served to train, teach, and model person-centered planning, rights and responsibilities. She trains in implementing positive behavior supports and other strategies to improve quality of life. Robin has over 15 years working in the field. She is certified as an Autism Specialist and Intensive Support Provider, a Mandt instructor, and a master trainer for Ohio DSPaths.*

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*Tim Haynes is the lab manager at Fab Lab at Independence Community College in Independence, Kansas. His daily responsibilities include machine maintenance, community outreach, member relations, and supervising staff. Tim's background is in community development and sustainable communities, but his entrepreneurial mindset was an asset for learning the Fab Lab's machines and software. In Tim's words, "I define quality of life not by being entertained, but by being involved. At Fab Lab ICC, I can be involved and make a difference in my community."*

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# Supported decision-making as an alternative to guardianship



By Robert D. Dinerstein

A well-known saying states, if all you have is a hammer, everything looks like a nail. Guardianship was the hammer for too long in the fields of intellectual and developmental (IDD) disabilities. Every time an adult with a mental disability needed assistance in decision-making, guardianship was seen as the solution.

For some time, there have been alternatives to guardianship for people with disabilities. Limited guardianship can help a person who needs some level of assistance in decision-making. But it does not require the guardian to make all decisions for a person. There are other alternatives to guardianship that allow people with IDD to maintain some control over their decisions:

- Healthcare proxies are documents that let a person name someone else to make health care decisions on the person's behalf if the person cannot speak for him or herself. Sometimes healthcare proxies have specific limits.
- A power-of-attorney is a legal document in which a person

authorizes another to make decisions on the person's behalf in a broad range of areas (financial, etc.).

- A representative payee arrangement allows someone to receive governmental benefits on the person's behalf and for the person's benefit.
- A direct deposit arrangement with a bank can make it easier for the person with IDD to make sure that funds can go directly into the person's bank account without running the risk of losing a check or having to travel to the bank to deposit it.
- A joint bank account with a friend or family member can permit the person with IDD to take advantage of the co-owner's access to the account to make it easier to enter into financial transactions.

These arrangements can allow a person being assisted to maintain choice, direction, and control while also receiving support.

One of the newest alternatives to guardianship—new to the US at least—is supported decision-making (SDM). In other publications, I have defined SDM as —

*Supported decision-making can be defined as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity. . . [These are] designed to assist an individual with a disability to make and communicate to others decisions about the individual's life. . . [S]upported*

*decision-making [relies] on peer support (for example, ex-users of psychiatric services for people with psycho-social disabilities), community support networks and personal assistance, so-called natural supports (family, friends), or representatives (pursuant to a representative agreement) to speak with, rather than for, the individual with a disability.<sup>1</sup>*

Central to SDM is the idea that all people have capacity to make decisions, although some people may need support to do it. *Equal recognition of all people* in the law means that people have the chance to make decisions for themselves. SDM is based on concepts developed in Canada, Australia, and Europe. SDM received a boost when it was adopted by the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) in 2006. The United States has not ratified the CRPD. But, SDM has become increasingly influential with legislators, courts, advocates, and legal commentators in the US.

There is a key difference between guardianship and SDM. In guardianship, the guardian is the decision-maker. The guardian is supposed to use input from the person under guardianship. In SDM, the person being assisted

1 From "Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making," by R. D. Dinerstein, 2012, *Human Rights Brief*, 19, p. 8.

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remains the decision-maker. The person is free to rely on their supporters or not. SDM is a way of providing decision-making assistance, but it does not allow someone else to take control of the person's life without their permission.

It is increasingly likely that direct support professionals (DSPs) will come into contact with people with disabilities who are using SDM. These relationships may require additional flexibility and investment of time from DSPs, since guardians may no longer be the points of contact. For some decisions, the DSP will need to interact with the person and one or more supporters. Different supporters may be called upon for different decisions. But if we are serious about the importance of person-centered planning and services, SDM should be embraced. DSPs can play an important role in making SDM a reality for the people they serve.

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*Robert Dinerstein is professor of law and associate dean for experiential education at American University, Washington College of Law. He has taught disability law courses since 1985, and founded the law school's Disability Rights Law Clinic in 2005. He has written and presented extensively on supported decision-making for people with disabilities. He testified as an expert witness on supported decision-making in the landmark Jenny Hatch case. He can be reached at [rdiners@wcl.american.edu](mailto:rdiners@wcl.american.edu) or 202-274-4141.*

## Credentialing Column

The DSP Credentialing Column shares the stories of direct support professionals (DSPs) who have completed a credentialing program. In this issue, John Raffaele, Director of Education Services for the National Alliance of Direct Support Professionals (NADSP) spent time with a cohort of DSPs who were working on their NADSP credentialing program DSP-C2 portfolios. They were talking with other learners who were beginning work on their DSP-C1 portfolio work samples. John extracted some quotes while listening to these incredible learners.

*"As I work on my DSP-C2 portfolio, I am so much more confident in my work. I also feel obligated to help the people who are learning and working towards their DSP-C1 portfolio. Helping them seems only right. I remember where they were at!"*

~ Cheryl M. DSP-C1

*"I face challenges in my work differently now. I have a better understanding of my important role as a professional. I always held the title, professional. Now I know what that means."*

~ Jerry F. DSP-C1

*"I now work with more confidence. I [work] with a sense of confidence and skill I did not realize I had before doing the credential."*

~ Nikki S. DSP-C1

### What is credentialing?

Credentialing is a process of receiving official recognition, including an authorized certificate for mastering and demonstrating professional standards of practice. The NADSP has identified and nationally validated the skills, knowledge sets, and ethical principles needed to be an effective DSP. They have organized these into a series of increasingly advanced levels of credential. Find out more information about NADSP credentialing programs on [www.nadsp.org](http://www.nadsp.org).

### NADSP Accredited Training Curricula

College of Direct Support (CDS)	The Academy for Direct Support Professionals–The Center for Disability and Development at Texas A&M University
U.S. Department of Labor (DOL)	
Relias Learning	
PATHS	The Training Collaborative for Innovative Leadership
North Dakota Community Staff Training Program	Star Services
ARC Broward PATHS Certificate Program	Human Services Program–Providers' Council (Massachusetts)
Open Future Learning	



# Supported decision-making

## Everyone can make decisions

By Jonathan Martinis  
& Jessalyn Gustin

How would you feel if you didn't have any control over your life? Or if you weren't allowed to choose what to do, where to go, who to spend time with, or whether to work? That feeling – frustrating and powerless – is what people with disabilities have faced for thousands of years. From Ancient Rome to America, courts have appointed people – called guardians or conservators – to make decisions in place of people with disabilities.

We're not saying that no one should have a guardian. If people truly cannot make decisions, even with help, they may need guardians. But, if people can make decisions for themselves, they should have the right to do so. When people have more control over their lives – more self-determination – they have better lives. One national study compared people with disabilities with similar abilities and limitations. It found that individuals without guardians were more likely to live independently, work, have friends, and practice their religion than those with guardians.<sup>1</sup>

Supported decision-making (SDM) is a way for people with disabilities to make their own decisions and control their lives. When people use SDM, they work with people they trust, who help them understand their choices so they



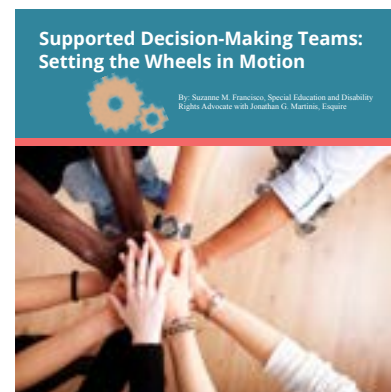
can make their own decisions.

Click the link<sup>2</sup> below to access a guide that can help people find out if SDM is right for the people to whom you provide support, their family members, or friends. It can help people create an SDM team, find people to be on the team, and work with the team to identify needs and provide support.

Direct support professionals (DSPs) can help people use SDM. The most important thing a DSP can do is presume that people can make decisions. Then, DSPs can help people think about where they need support, choose who will give that support and how, and communicate this information to the people and professionals in their lives.



Understanding, making, and communicating choices are key parts of everyone's lives. For people with disabilities, they are the most important parts of Person-Centered Planning. Person-centered values are at the heart of Dream Inspired Planning and developing a Culture of Coordinated Support, which we discuss below. By helping people with disabilities use SDM, DSPs empower them to make their own decisions, direct their own lives, play the central role in their service plans, and have the best chance to lead their best lives.



1 Human Services Research Institute, National Core Indicators Study. Available at: [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org) (statistics on guardianship provided by representative of HSRI).

2 Reprinted with permission from Francisco, S.M. & J.G. Martinis. (2017). Supported decision-making teams: Setting the wheels in motion. National Resource Center for Supported Decision-Making. Retrieved from <http://www.supported-decisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

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# Dream-Inspired Planning

*There are some people who live in a dream world, and there are some who face reality; and then there are those who turn one into the other.*

*~Douglas H. Everett*

We all dream. Our dreams motivate us. They help us decide what we want and need to do today, tomorrow, and into the future. Our dreams are as unique as we are. But we all might have dreams in common. We want to write a lifelong, personal story that reflects our strengths. We want a life that rewards us for having the courage to pursue our vision

of success. When we share our dreams with people we trust, they can work with us. They can dream with us. They can help us lead lives based on our abilities and preferences. We call this "Dream-Inspired Planning."

People with disabilities create and take part in many plans. Some examples are individualized education plans (IEPs), individualized

plans for employment (IPEs), individualized service plans (ISPs), person-centered plans, and plans for achieving self sufficiency (PASS). When these plans are connected to the person's dreams, it becomes easier to organize support and understanding among team members and across programs. Without dreams to unify them, plans are uninspired. They result in less motivation, commitment, innovation, and achievement.

Direct support professionals (DSPs) can play a key role in Dream-Inspired Planning. DSPs presume and support people's competence. They can help people communicate vivid and meaningful dreams. One way to do this is to help people create dream boards.

Dream boards are a universal tool. They are not just for people with disabilities. People make dream boards by writing words, drawing pictures, and attaching photographs or other memorabilia to a piece of paper. They attach and arrange the material in a way that represents or demonstrates their dreams and desires. In that way, people express their thoughts and aspirations visually. This encourages sharing, understanding, and collaboration.

Dream boards can start conversations with friends, family members, and service providers. They can lead to new opportunities for support, growth, and achievement. Even when a person's dreams are not tangible or possible, they communicate visions and values that can shape



Examples of a dream boards

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service plans. This can ensure that those plans focus on what is most important to the person. That way, the person's formal goals and objectives will be truly person-centered.

We have helped people and providers in several states create Dream-Inspired Planning projects. We know that identifying and communicating dreams can sometimes be hard work. Some people may have never been asked what they really want. They'll need support from people they trust. DSPs can help them come up with creative ways to envision, communicate, and move toward their dreams. That support can help people develop a roadmap that guides their journey through life. It can empower them to meet new people, have new experiences, learn new things, and dream new dreams.

## A Culture of Coordinated Support

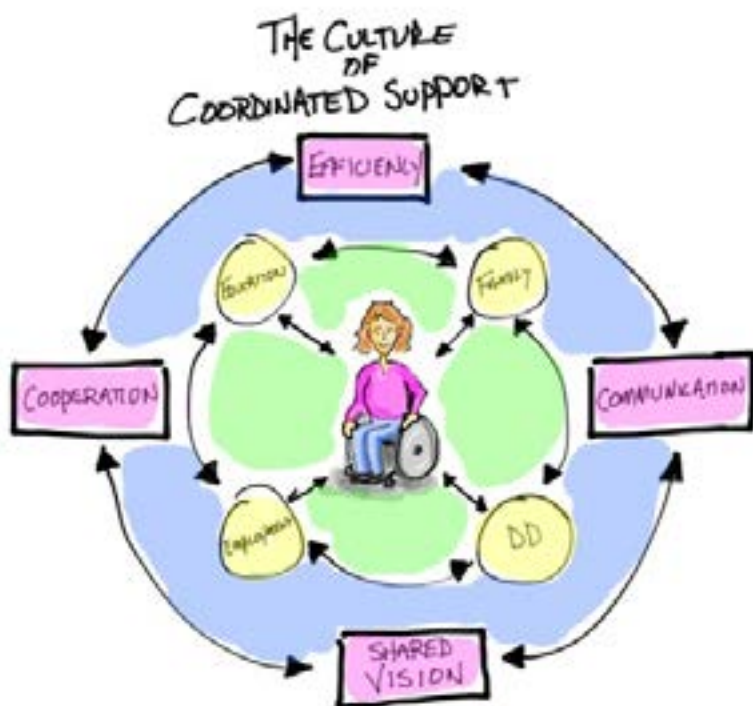
People with disabilities achieve better life outcomes when they work with their service providers to develop a Culture of Coordinated Support (CCS). Coordinated support teams use shared vision and values to develop goals and objectives based on the person's dreams, strengths, and preferences. Unfortunately, current, complex service systems may limit information and resources. When this happens, people spend too much time searching for who can provide services. As a result, they miss out on opportunities to develop and use appropriate, individualized supports.

In a CCS, people and providers develop a unified, person-centered vision and plan. The team adopts shared values, goals, objectives, and supports directed by the person. This is its "operating culture." Direct Support Professionals

(DSPs) should play a crucial role in this process. DSPs can ensure that the person remains at the center of the culture. They can make sure that the team's plans reflect and respond to the person's life, abilities, and preferences. They can also help providers coordinate their efforts. They can help eliminate the redundancies. They can eliminate "turf battles" that decrease effectiveness and waste resources. These efforts ensure that supports are more person-centered and effective. They empower the person to lead a more meaningful, independent life.

Because DSPs engage team members in varying environments, they can provide feedback to ensure that people's supports and services adhere to their dreams, goals, and values. For example, schools, vocational rehabilitation

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The Culture of Coordinated Support Model: people, families, and agencies working toward shared goals with shared responsibilities





**Supported Decision-Making balances self-determination and safety**

agencies, Medicaid Waiver providers, and Centers for Independent Living all must provide education, employment, and independent living supports. DSPs interface with these providers regularly. Therefore, they can encourage people and providers to work together to create a CCS where —

- People identify and communicate their personal dreams and goals to their family, friends, and service providers.
- People and providers develop a common set of values and vision for the person's supports based on the person's dreams and goals.
- People and providers create consistent, joint, cross-agency support plans, goals, and objectives that reflect the person's dreams and goals.
- Support plans identify the specific services each party will provide and how they will track progress and identify and implement change initiatives.

We have consulted on CCS

models in several states, including Vermont, which has convened the first task force designed to “transform practices in a way that brings a culture of collaboration” throughout state systems.<sup>3</sup> The states, agencies, and organizations that embrace CCS show a commitment to shared vision, coordinated efforts, and appropriate support planning and provision.

Great outcomes do not require more resources. People with support to share can help teams develop common vision and responsibility for service planning and provision in a way that maximizes effectiveness and minimizes costs. By encouraging and enabling a CCS, DSPs can help people and providers create truly person-centered plans and supports empowering full, independent, and meaningful lives.

*Jonathan Martinis is the Senior Director for Law and Policy of The Burton Blatt Institute at Syracuse University. Jonathan has over twenty years' experience*

*representing people with disabilities to protect their legal and human rights, including precedent-setting cases securing access to critical community-based services and Supported Decision-Making.*

*Jessalyn Gustin is the Program Director at Upper Valley Services in Bradford, Vermont. Jessalyn has been providing disability services in Vermont for over ten years, and has been recognized as champion for collaborative change initiatives. Her values and vision for communities that embrace and celebrate diversity has led to the development of innovative, person-centered service delivery systems, resulting in improved lives for Vermonters with and without disabilities.*

*Jonathan and Jessalyn are partners in Something Else Solutions, LLC. Together, they have presented to and trained thousands of people, professionals, agencies, and organizations about ways to support the dreams and goals of people with disabilities. Please feel free to email any questions or comments to [SomethingElseJM@Gmail.Com](mailto:SomethingElseJM@Gmail.Com)*

<sup>3</sup> See, <https://www.facebook.com/vtddsd/posts/1067901303303736:0>

# “She’s always proved me wrong.”

When Jim Ayres’ daughter, Jacque, was a child, services for individuals with developmental disabilities were limited in comparison to services available today. Today, Jacque is a 46-year-old woman living independently and thriving.

“I vacuum and clean my dishes. And, are you ready for this? My dad gave me new tablet and I can play bowling and Angry Birds,” Jacque said. “I love the birds.” Jacque was born with Down syndrome. She began receiving state-funded services at age five.

“It was the old era so when she was five she went to the training school,” Jim said. The training school was a facility that operated a day program for children with disabilities. It was separate from the public school that her peers without disabilities attended. “They hadn’t started inclusion yet, and that was her services,” Jim said. “I wish she would have been able to go to high school.”

At 18, Jacque began attending Perkins-Arthur, Keith and Surrounding Counties Developmental Services (PAKS). PAKS is a program that taught Jacque daily living and work-related skills. Later, she transitioned from living at home to living in a group home before moving into her own apartment.

When she moved to her own apartment, Jacque used supports that helped her live more independently. She knows her neighbors, and they know her. She does her own housework and laundry. Someone helps her with meals, and changing and mak-



**Jacque and her dad on Father’s Day**

ing her bed. She has additional safety and security measures in place. “She’s really very independent,” Jim said.

Jim said Jacque’s skill and independence levels have changed as the availability of services have changed and expanded over the years. These have supported her to be an integral part of the community. Today, Jacque receives specialized residential and vocational services from PAKS. Those services, as well as with support and help from family and friends, Jacque lives a full, meaningful life, her father said.

A PAKS support partner goes with her shopping, assists with meal planning, and helps her in her home. “And they get her out of the apartment,” Jim said.

Jacque’s days are spent in meaningful ways. She works part-time at the local Arby’s. “I help the customers,” Jacque said. “They like to talk to me.” On the

other days Jacque volunteers at the Women’s Resource Center and Court Appointed Special Advocates (CASA). Jacque has transportation to her jobs and on outings provided by her community support partners. She also enjoys riding her bike to work. “You have to wear a helmet and be safe,” she said. Recently, Jacque’s bike got a flat tire and a friend fixed it. “And you know that guy whose name is Rick? He fixed my bike. He’s a wonderful man,” she said.

Jim said, “I totally appreciate this community for the way they’ve accepted Jacque. Everybody’s friendly with her and it makes her life a lot more pleasant,” he said. Jim appreciates the changes in services his daughter has received, especially additional learning opportunities for Jacque. “The truth is I’ve always said she won’t be able to do that. No,

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# Information is power

## Self-Advocacy Online

we can't put her in an apartment by herself. We can't let her ride a bike. But she's always proved me wrong. Every single time," Jim said. "And that's a good thing."

The PAKS support partners have played an important role in supporting Jacque to live, work, and enjoy relationships with her community. Jacque's support needs and her goals have been identified, and they have been continually revisited throughout her adult life. As she receives day-to-day supports, the support partners have not made Jacque's choices for her. They support her to set the direction for her own life. In doing this, she has exceeded expectations. She continues to take control of her goals, benefiting from the support of her PAKS support partners.

*This article was adapted and reprinted with permission from Pierce, Mary. (2015). Adult Developmentally Disabled Services. Keith County News.*

*PAKS (Perkins, Arthur, Keith and Surrounding Counties) began serving young adults with developmental disabilities in 1968 in a sheltered workshop environment. Over the years, PAKS moved from services in congregate settings to individualized services. Today, services and supports are designed to be flexible to meet the needs of each person. Our mission is to encourage individuals to reach their highest potential by providing opportunities to live and work in the community. Facebook <https://www.facebook.com/paks.developmental> or email [paksds@allophone.com](mailto:paksds@allophone.com)*



John G. Smith

Everyone knows that information is power! In order to make good decisions and take greater control over their lives, people with intellectual and developmental disabilities (IDD) deserve access to clear, understandable information that affirms their preferences and opens up new options. Self-Advocacy Online (SAO) is designed especially for people with IDD. It has lots of information aimed

at helping people take greater control of their lives. It is presented in a way that is accessible and engaging. It was created by the Research and Training Center on Community Living with support from The Arc of the United States. All content is reviewed and edited by a panel of persons with IDD. When it's approved, it is enhanced with media to bring the ideas to life. As you read this article, I invite you to go to [selfadvocacyonline.org](http://selfadvocacyonline.org). See how this website might be helpful as you provide support.

### Learn about Self-Advocacy

First, click on "Learn about Self-Advocacy" ([www.selfadvocacyonline.org/learning/](http://www.selfadvocacyonline.org/learning/))

SAO currently has eight online lessons. The topics are helpful for both people with IDD and DSPs. Each lesson has about 20 screens. It takes 5-10 minutes to complete. The lessons available now focus on health and wellness, speaking

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**A Healthy Plate**

Learn about the different food groups and how to make healthy food and drink choices.

**Building My Relationships**

Learn about the qualities of a good friend and how to build lasting relationships in your life.

**Exercise**

Why it's important for everyone to play an active role in their own well-being and self-care.

**Taking Care of Myself**

Why it's important for everyone to play an active role in their own well-being and self-care.

Some of the lessons in "Learn About Self-Advocacy"



up, and getting organized to tackle the big issues that often hold back people with IDD. Click on a lesson that interests you!

DSPs can use this part of SAO together with the people they support. They can explore the interesting topics. All of the lessons have practical action steps DSPs could use. They can help people follow-up on what they have learned. We are always working on new lessons. We welcome suggestions for new topics.

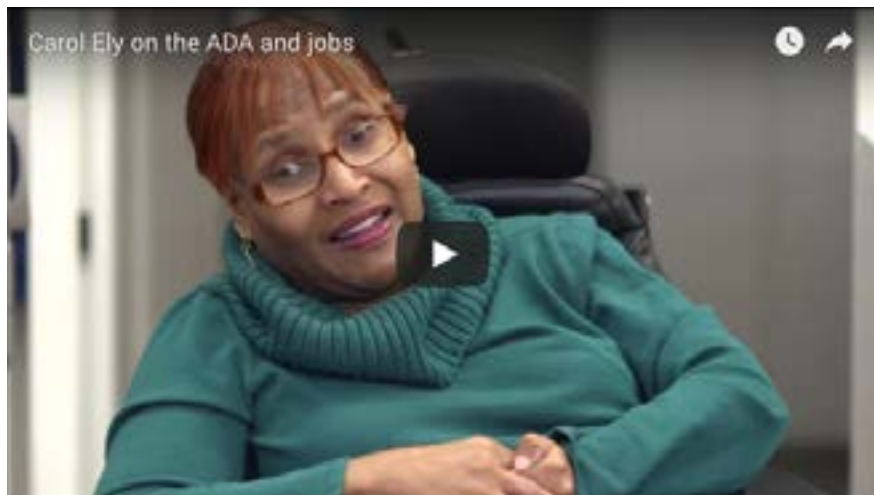
### View stories from Self-Advocates

Next, click on “View stories from Self-Advocates” ([www.selfadvocacyonline.org/stories/](http://www.selfadvocacyonline.org/stories/))

SAO has dozens of short, powerful video clips of self-advocates from all over the world. They talk about the issues they are passionate about. You can select from a list of topics that will narrow the videos to those that are most interesting. Topics from Olmstead to marriage, to working together and civil rights. You can find stories from self-advocates on so many topics!

We suggest that DSPs watch some stories along with the people they support. People find these stories engaging and inspirational. You can encourage the people you support to think about the stories they would tell. In the near future, we will be able to add anyone’s story to SAO as long as it meets some simple standards. You can begin by helping the person you support to tell or write their story.

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From the SAO Storywall: Carol Ely talks about the importance of the ADA and jobs for people with disabilities



Jeremy Beavers talks about relationships



Helen Bechold talks about living in the institution

## Find Self-Advocacy groups

There is more on the website than this. Under “Find Self-Advocacy Groups” (<http://www.selfadvocacyonline.org/find/>), we have information on more than 400 self-advocacy groups around the United States. If the people you support are members of a self-advocacy group, please check to make sure it is listed and the information is up-to-date.

## Research for all

Under “Research for All” (<http://www.selfadvocacyonline.org/research/>), there is information from recent research translated into simple language. It is supplemented with media to be clear and easy-to-understand.

The SAO homepage (<http://www.selfadvocacyonline.org/>) features a feed from our Facebook page. Our Facebook page is updated several times a week. It includes stories of the amazing and important things people with IDD are doing to make the world a better place.

Self-Advocacy Online is growing and changing. We hope to hear from you about what is working, and what seems to be missing. Please explore. Please share it with the people you support. Finally, send us your ideas.

*John is a coordinator at the Research and Training Center on Community Living at the University of Minnesota. He is interested in making important information accessible to everyone. Find out more about the Research and Training Center on Community Living by going to [www.ici.umn.edu](http://www.ici.umn.edu).*



An example of one of the knowledge translations from “Knowledge for All”

# Frontline resources

Learn more about the topics in this issue by visiting these websites.

## **NADSP Informed Decision-Making Curriculum**

[www.nadsp.org/informed-decision-making/](http://www.nadsp.org/informed-decision-making/)

This curriculum is a train the trainer product that focuses on how direct support professionals, and others, can best assist people they support in making informed choices and decisions. The HCBS Community Rule and person centered practices demand that we all help people with choice. This material will offer help in that regard to providers, families and anyone interested in informed choice.

## **Guardianship and Supported Decision-Making**

[www.supporteddecisionmaking.org](http://www.supporteddecisionmaking.org)

This is the National Resource Center for Supported Decision-Making. It has information, resources, model forms, education material, and more.

## **Quality Trust for Individuals with Disabilities**

[www.dcqualitytrust.org](http://www.dcqualitytrust.org)

The Quality Trust includes information for families and advocates to ensure that people have access to their communities of choice.

## **National Guardianship Association, Inc.**

[www.guardianship.org](http://www.guardianship.org)

The National Guardianship Association includes standards for excellence in guardianship, as well as other resources on guardianship.

## **The United Nations Division for Social Policy and Development on Disability**

[www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-six-from-provisions-to-practice-implementing-the-convention-5.html](http://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-six-from-provisions-to-practice-implementing-the-convention-5.html)

This selection promotes supported decision-making as an alternative to guardianship by the United Nations.

## **Council on Quality Leadership**

<https://c-q-l.org/files/2017Documents/CQL-2017-White-Paper-Supported-Decision-Making-In-The-US.pdf>

A link to the white paper (summary) on supported decision-making by the Council on Quality Leadership that was released this year. Provides state level information on policies pertaining to supported decision-making.

## **Tool: When Do I Want Support?**

<https://www.aclu.org/other/when-do-i-want-support-supported-decision-making-self-assessment-tool>

This tool helps people identify areas in their life where people can use supported decision-making.

## **Tool: Supported Decision-Making Teams: Setting the Wheels in Motion**

<http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

This tool provides an overview to help people and their loved ones to think through supported decision-making. It provides interactive tools to identify a supported decision-making team. It helps to establish team dynamics about meeting, supporting, and on-going support.

## **State Plans for Final Rule Compliance: HCBS Advocacy**

<https://hcbadvocacy.org/learn-about-the-new-rules/>

Find out more about home and community based services, and how states are implementing the new regulations from Centers for Medicare and Medicaid Services.

## **Texas Council for Developmental Disabilities Guardianship Alternatives**

[www.tcdd.texas.gov/resources/guardianship-alternatives](http://www.tcdd.texas.gov/resources/guardianship-alternatives)

Find out more about Texas, one of the only states that formally accepts a supported decision-making model as an alternative to guardianship.



# 2016-2017 NADSP

## benefits and membership form



Making a world of difference  
in people's lives

### NADSP credentialed professionals, individual and other professional member benefits

- Monthly Learning Annex Webinars
- Monthly Let's Talk Webinar series
- E-Blasts of information on NADSP events, presentations and opportunities
- Member only section of NADSP website – view past webinars, download COE screensaver, read past issues of the Frontline Initiative, online calendar of NADSP events and webinars.
- Discounted rates for Annual Conference registration Exclusive "Call for Participation" opportunity. You will have the exclusive opportunity to submit a topic for our Annual Conference's Networking Neighborhood. A select number of submissions will be selected to host a Networking Neighborhood session during our 2017 conference. (Conference registration is offered at the discounted member rate - all travel expenses are the responsibility of the presenter)
- Support an organization that supports DSPs

### Provider & non-provider organizations

- All of the benefits listed above
- 10% discounted training rate
- Link to your corporate website from NADSP website

### Memberships

#### ☐ NADSP Credentialed Professionals

*Free for the first year, \$10 every year after*

#### ☐ Individual Memberships • \$10

*DSPs, Frontline Supervisors, Self-Advocates & family members*

#### ☐ Other Professional Membership • \$50

*Social workers, administrators or healthcare professionals*

#### ☐ Affiliate Membership • \$200

*Individuals & organizations that wish to support NADSP who are not providers or employers*

#### ☐ Sponsoring Member Organization • \$2,000

*National & multi-state organizations, associations, businesses & stakeholders*

#### ☐ Supporting Organizations • Human Service

*Providers that employ Direct Support Professionals*

##### ☐ Level One • \$500

*1 to 50 Direct Support Professionals*

##### ☐ Level Two • \$1,000

*51 to 200 Direct Support Professionals*

##### ☐ Level Three • \$2,000

*201 to 500 Direct Support Professionals*

##### ☐ Level Four • \$3,000

*500 + Direct Support Professionals*

**TOTAL ENCLOSED**

Make checks payable to NADSP. To pay by credit card, visit [nadsp.org](http://nadsp.org) and click on "Membership"

**Mail membership form and payment to:** NADSP, 1971 Western Ave., #261, Albany, NY 12203 • phone / fax 844.44.NADSP

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