

A publication of the National  
Alliance for Direct Support Professionals

# Frontline Initiative

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Autism Spectrum Disorder  
Frontline Initiative

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## Illuminate! Advocate! It's Autism Awareness Month!

By Robin Hickey and Tom Harmon

The sixth annual World Autism Awareness Day is April 2, 2013. Autism organizations across the globe honor the day with programs and events to raise awareness about autism. Many places participate in the *Light It Up Blue* campaign and shine a bright blue spotlight to illuminate and advocate for autism.

The word *autism* comes from the Greek word *autos*, which means 'self'. It was first used in the early 20th Century to describe people that seemed to be

extremely isolated from other people. People that seemed to be in their own worlds.

Autism is a developmental disability. Its symptoms appear before age 3. The symptoms affect many different skills that develop from infancy to adulthood.

Autism is complex. You may have heard the expression: *If you meet one person with autism; you've met one person with autism.* This means that no two individuals experience autism in the same way.

Continued on page 3



**World Autism  
Awareness Day  
April 2, 2013**

# Frontline notes

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

Welcome to our *Frontline Initiative* issue on Autism Spectrum Disorder (ASD). An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. In honor of Autism Awareness Month, we bring you a variety of perspectives related to effectively supporting the unique needs of individuals with ASD.

Robin Hickey and Tom Harmon provide an overview of the characteristics of ASD and explain why autism is considered a spectrum disorder in our cover story, *Celebrate Autism: It's Autism Awareness Month!* Lynette Henderson, PhD, debunks some common myths associated with ASD. Information is provided on the Diagnostic Statistical Manual of Mental Disorders (DSM), including changes that can be expected. Jennifer Hall-Lande, PhD, shares practical direct support strategies that are related to the unique challenges experienced by people with autism.

For some Direct Support Professionals (DSPs), supporting individuals with ASD may be a completely new and unfamiliar experience. One DSP describes difficult first days on the job in the heartfelt story, *So, what got you into this field?* And Janice Eagan shares her insightful perspective as a parent, which you may find particularly meaningful as you consider the families you work with. You may also be moved and inspired as you learn about Maja Toudal's

perspectives of self-advocacy in *Aspie or NT? The pros and cons of acting neurotypical.*

Many individuals with autism need supports to be fully included in their communities throughout their lifespan. Such supports may include things like transition services or supported employment. Kris Foss from Ability Beyond Disability shares her organization's innovative model of employment for individuals with ASD, *Roses for Autism.*

Jennifer Reinke describes important federal and state policy initiatives around ASD, around ASD, and Annie Johnson Sirek discusses the barriers that adults with ASD face in accessing support through state Medicaid services.

There are many different beliefs about the cause(s) of and most effective interventions for autism. In this issue, we present some of these different perspectives and experiences. However, *Frontline Initiative* does not endorse any specific cause or intervention. Please note that the terms 'ASD' and 'autism' are used interchangeably throughout the issue.

We hope you will enjoy this issue as you learn more about supporting individuals with ASD.

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in peoples' lives



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[lisam@nysacra.org](mailto:lisam@nysacra.org)

Autism is a spectrum disorder. Spectrum means that people with an autism diagnosis have a wide range of characteristics and levels of ability. One person with autism may have mild characteristics while another person's may be severe. Sometimes people with mild symptoms are informally referred to as higher functioning though this is not a universally accepted term in the autism community.

Individuals with autism experience various levels of challenges in three areas —

- 1. Communication** — both verbal and non-verbal.
- 2. Social interactions** — such as difficulty in sharing feelings, understanding others' feelings, or holding a conversation.
- 3. Behaviors/routines** — such as repeating words or actions, obsessively following routines and schedules, and showing stereotyped or 'stimming' behaviors.

People with autism often have a co-occurring health condition. Common secondary conditions include sleep challenges, intellectual disabilities, seizures or anxiety disorders. People with autism also may have sensory issues. This may include over- or under-reacting to sights, sounds, smells, textures and tastes.

The cause(s) of autism are unknown. Some researchers suggest a combination of genetic and environmental factors. A range of therapies and interventions may help manage the characteristics of autism though there is currently no known cure.

Current statistics indicate that 1 in 88 children have an autism diagnosis and that autism is 4 to 5 times more likely to occur in boys than girls. These rates suggest that autism is on the rise. However researchers do not agree about reasons why. One theory is that autism is simply more prevalent now than in the past. Another theory is that pediatricians, families and educators are more aware of what autism is. Recognition of the early signs of autism may lead to increased diagnoses.

There are many places Direct Support Professionals (DSPs) can go for more information about autism. However, not all information is credible and reliable, particularly information online. One organization's website that is trustworthy is *Autism Speaks*. *Autism Speaks* is the world's leading autism science and advocacy organization. *Autism Speaks* is considered a very reputable source of information specific to autism. Here you can find facts about autism, current

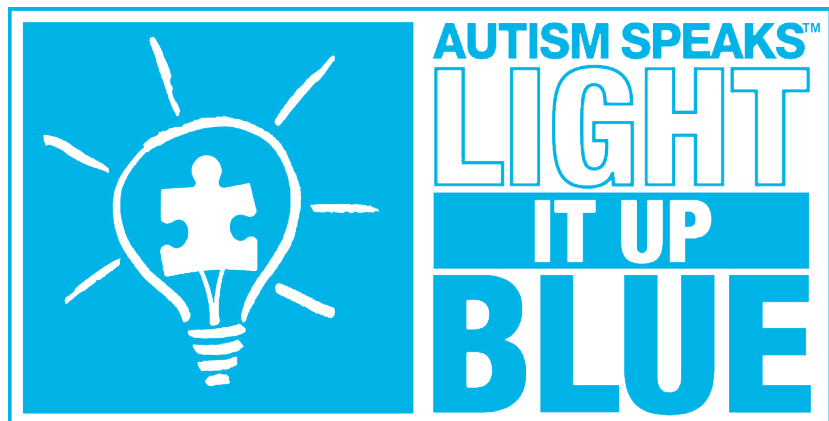
research projects and resources for families impacted by autism. You can also find resources specific to your state and zip code. Some of the resources provided include supports for adults with autism and legal information.

Gather information and share resources with the people and families you support. Keep in mind that every individual has different needs, interests, challenges and strengths. What might not work for one person might work very well for another. Celebrate the unique joys and accomplishments that people with autism have to offer!

For more information, visit [www.autismspeaks.org](http://www.autismspeaks.org).

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*Robin Hickey and Tom Harmon collaborated on writing this article. Robin Hickey has over 30 years of experience working in the developmental disabilities field. Ms. Hickey is also the parent of a son who has autism and other developmental disabilities. Tom Harmon serves as a FI Editorial Board member and can be reached at [tomh@nysacra.org](mailto:tomh@nysacra.org).*



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# NADSP update

## The winds of positive change

*By Joseph Macbeth*

In reference to a recent NADSP presentation about Ethics and Competencies, a Direct Support Professional (DSP) proclaimed, “Finally, the winds of positive change are here.” I’d like to borrow that theme for this update.

The winds are shifting in a positive direction for direct support professional development. Though this shift may take some time to bring about any real change. I have been an advocate for these initiatives for over a decade and can attest that decision makers in federal government, key states and others who can influence policy changes are finally beginning to feel the breeze.

One of the things that we are most excited about is joining forces with other stakeholder groups and the National Direct Service Workforce Resource Center (<http://www.dswresource-center.org/>) in the *Road Map of Core Competencies for Direct Service Workers* Project. The goal of this project is to assist federal agencies, states and employers in taking a more unified approach to competency development and training. This project represents a collaborative effort to strengthen the home and community-based direct support workforce. The stakeholders who have participated in this effort have reached consensus on a common set of core competencies that apply across the various sectors within the direct service workforce. These sectors include behavioral health, intellectual and developmental

disabilities, physical disabilities and aging services.

Why is this important? These cross-sector competencies are relevant to the work of both tenured and new DSPs. The competencies will guide the development of training, service delivery and performance improvement practices. The core competency set might also serve as the foundation for novel career ladders. New career ladders would validate the many competencies needed among DSPs across sectors of community-based long-term services and supports. It’s a really big deal for our advocacy work and we’ll keep you posted on how things are moving along.

Another area that we are watching very closely is managed care. Managed care is intended to reduce the cost of providing health benefits and improve the quality of care for the people we support. One of the things that managed care organizations will be trying to measure is the capacity and competency of an organization’s direct support workforce. Managed care organizations will be interested in how the direct support workforce will lead to better supports and less cost. For more than ten years, the NADSP has been advocating that a well-trained, skilled and ethical direct support workforce is the primary factor in quality service delivery. Now we are hoping that organizations that operate within a managed care environment can measure the outcomes of its DSPs and compensate them for demonstrated skills. This might take time

but it’s clearly going to bring positive change in how DSPs are viewed.

Lastly, I’d like to thank and say good-bye to our long time board member, Regis Obijiski. Regis needed to resign from our board of directors because he has recently taken a leadership position with the New York State Office for People with Developmental Disabilities. Regis was instrumental in the early days of the NADSP and has spent more than twenty years being a tireless advocate and voice for DSPs. He is a mentor to many of us. His steady, common-sense approach to dealing with big issues will be sorely missed. We are hoping that Regis will make even bigger change in implementing the Code of Ethics and Core Competencies across the state of New York in his new position. Please join me in thanking Regis for his tremendous work.

As you see, a shift is happening. More than anything, we need DSPs to take a more active role in this work. We need managers to support and empower DSPs to be better professionals and advocates. Ultimately, it’s about providing better supports for people with disabilities. We’re all in this together. Be part of this shift and help us strengthen the winds of positive change.

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

# Values and life skills I learned by responding to a newspaper ad

I have been asked countless times what got me into the field of intellectual and developmental disabilities (IDD). My explanation always starts off with, “Well, I needed a job in college...” Responding to a newspaper ad was the catalyst for a career that is both personally meaningful and professionally fulfilling. In hopes that other Direct Support Professionals (DSPs) will find my journey relatable, I will share my story.

I took a psychology course on learning and behavior. We applied the basic principles of behavioral therapy to pigeons. Over the course of the semester, my small group successfully taught our pigeon to ‘kick’ a ping-pong ball through a makeshift goalpost. I was fascinated! Later I saw the ad: *Wanted: Living Skills Instructor to teach individuals with autism valuable life skills*. I grew up with various disabilities on both sides of my family and I felt a strong calling to enter a helping profession. It seemed like it might be an ok fit; I might even learn about behavioral therapy techniques in the ‘real world’. I applied and got the job.

The position was at a group home. My role was to work with three men whose autism was considered significantly challenging. Jed, Nate, and James\* were only about a year or two older than me. Jed spoke very few words; what he did verbalize was echolalic in nature. Jed also had diagnoses of obsessive-compulsive disorder, anxiety disorder, and depression. Nate was nonverbal, did not reliably use the toilet, and

had a preference for not wearing clothes. Nate had frequent instances of self-injurious behavior (SIB). James had some words, and had a special interest in laminated magazine pictures. James also had epilepsy and wore a helmet.

I still wasn’t clear what autism was. I certainly wasn’t prepared for what happened on my first day. Nate had several toileting accidents and frequent and intense SIBs, James had a grand mal seizure and had slapped a DSP, and Jed sat on the couch for three hours perseverating on pizza. What had I signed up for? How was I supposed to teach the men ‘valuable life skills’?? I didn’t understand their behaviors and I wasn’t sure how to communicate with them. This was nothing like working with pigeons. After leaving my first training shift, I remember thinking, “I am *never* going back there.”

But something had happened. Something that, to this day, I can’t quite put into words. I had been changed. I went back for a second day, and a third, and a fourth. I worked there almost three years until I moved out of state.

As I got to know Jed, James, and Nate, I learned their interests and things they liked to do. Jed was a coffee guy and enjoyed taking showers in freezing cold water. James loved singing songs and purposefully calling DSPs by the wrong names. Nate had an amazing sense of balance and enjoyed the sensation of masking tape being ripped off of his skin. In partnership with my supervisor, I began to write programs to

promote positive behavior and help increase their independence. Just like breaking down the steps to teach a pigeon to kick a ball, I found that any skill could be broken down to very small, manageable steps. Who would have guessed that making coffee is really a 25-step process? Or that laminating pictures could be broken down to 20 different mini-tasks?

I often look back and think about how my initial experiences with individuals with autism were scary, confusing, and difficult at times. But I also found such joy and fulfillment in my work. Yes, I think I taught valuable life skills to Jed, James, and Nate. But I also learned to be open to the valuable life skills I would learn *from them*. Yes, I think I helped shaped their behavior and supported their independence. But, more importantly, my experiences with Jed, James, and Nate helped shaped the person and professional I have become. Patience, humility, person-centered thinking and acting, appreciation for diversity, and respect for humankind – all life skills that I didn’t expect to learn by responding to a newspaper ad.

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*The author would like to remain anonymous, and wishes to thank the Frontline Initiative editorial staff for giving this story a platform on which to be shared.*

*\*FI Editorial Note: The names used in this story have been changed to protect confidentiality.*

# Five myths about autism/ASD

By Lynnette Henderson

Myths have fascinated humans for centuries. Harmful myths about people with autism spectrum disorder (ASD) interfere with our positive interactions with them. Here are a few myths you may have heard about people with ASD and the evidence-based truths.

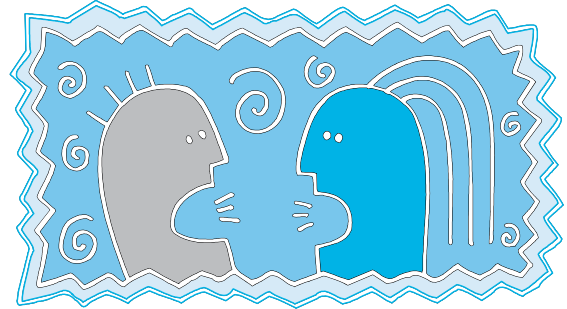
## 1. “Autism is a choice”

Communication is a key area of impairment in autism; the ‘right’ thing to say or do may not come naturally a person with ASD. Difficulties with social interaction are not due to orneriness, rudeness, self-centeredness, or a lack of caring for others. But family members and Direct Support Professionals (DSPs) can sometimes feel hurt or frustrated as a common response. During these times, it may be helpful to consider how this is the person’s best effort at saying or doing the ‘right’ thing in that moment. Remember that the person’s challenges stem from biological differences in the brain and he or she may have difficulty expressing feelings in a typical way.

## 2. “People with ASD can’t make eye contact”

Difficulty with natural eye contact may be one of the first signs of challenges with social communication. Eye contact may or may not come naturally to a person with ASD. It might be uncomfortable or anxiety producing. Some people with ASD may sneak peeks at your eyes or face. Others might stare. Some may follow ‘rules for required eye contact’. It may be

challenging for a person to listen and understand what you are saying while making eye contact at the same time. Eye contact varies widely based on the person and his or her preferences and experiences.



## 3. “People with ASD just want to be left alone”

There are introverts and extroverts with and without autism. As an introvert, one may find time with people tiring and need to be alone to recharge. As an extrovert, one may find people energizing and being alone draining. Differences in social interest are only part of the picture. Friendships also require social skills. A person with ASD may want to interact with others but may not understand how. Being alone may be a person’s easy or default setting. Remember that people with ASD can and do form loving relationships with family members, friends, and significant others.

## 4. “Vaccines or immunizations cause ASD”

There is a lot of controversy around what causes autism. Millions of dollars and hours have been spent researching and disproving links between vaccines and the specific ingredient thimerosal (removed from vaccines in 2001). There is no scientific evidence that vaccines or immunizations cause autism. But some parents may strongly feel differently. Their child may have

been vaccinated at the same time as when they began to notice developmental differences. As a DSP it is important know what the research says, but to also be sensitive to different beliefs around what causes autism. For more information, go to <http://www.cdc.gov/vaccinesafety/Concerns/Autism/Index.html>.

## 5. “Every person with ASD is a genius and has a special talent like the movie character Rainman”

People with all levels of intellectual ability can have ASD. That means there are genius-level people with ASD. There are also people with ASD who have intellectual disabilities. The special or ‘savant’ skills that *Rainman* showed are a natural outgrowth of his deep interests and autism-specific differences in brain organization. Your brain would also become highly specialized if you spent hours every day thinking about any one thing.

*Lynnette Henderson, Ph.D., is a Research Assistant Professor in Pediatrics. She is a Vanderbilt Kennedy Center Member and serves as the UCEDD Associate Director of Community Services. Lynnette can be reached at [Lynnette.henderson@vanderbilt.edu](mailto:Lynnette.henderson@vanderbilt.edu).*

# The DSM-IV-TR and DSM-5

## A primer for DSPs

Since the mid-20<sup>th</sup> Century, the American Psychiatric Association (APA) has published a tool to describe and differentiate various mental disabilities and their characteristics. This tool is the Diagnostic Statistical Manual of Mental Disorders (DSM). The DSM is periodically revised as society's understanding of disorders advances. The DSM-IV-TR is the fourth edition with text revisions, thus the *IV-TR* in its title. It was released in 2000. The DSM-5 is the fifth edition of the APA's classification system and will be released in the spring of 2013.

When the DSM-5 is released, the language and definitions from the DSM-IV-TR will still be in the records of the individuals you support. Many people may still use terms from the DSM-IV-TR during the transition to the DSM-5. Given

that you will likely come across both conceptualizations of autism, it is important to have an understanding of both the old and the new definitions.

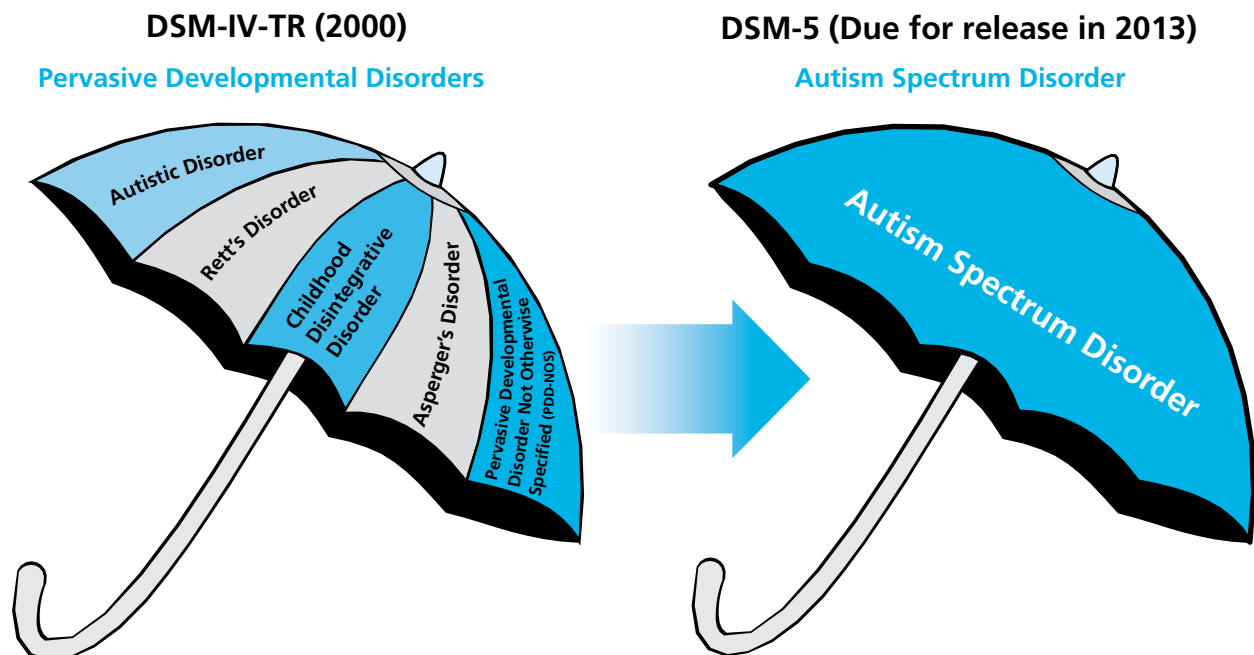
The DSM-5 will include 3 major changes related to autism. The **3 major changes** are —

1. The five subcategories of autism will be eliminated and included under the umbrella term *Autism Spectrum Disorder (ASD)*.
2. Severity levels of characteristics from mild to severe will be based on the amount of support needed (as opposed to a simple yes or no of presence of the characteristic).
3. Instead of the three deficit areas used in the DSM-IV-TR (communication, social, and behaviors/routines), the

DSM-5 will instead utilize two deficit areas: 1) social communication and interaction, and 2) restrictive, repetitive patterns of behavior, interests, or activities.

The APA has confirmed that all individuals who currently have an autism diagnosis under the DSM-IV-TR criteria will be able to retain the diagnosis. This means that no one with a current diagnosis will *lose* their diagnosis (or corresponding services) because of the changes in the DSM-5. However, individuals who currently hold these diagnoses may receive a different diagnosis when re-evaluated.

A person or family you support may be concerned about the DSM changes. You can help by sharing this article and more information from <http://www.dsm5.org>.



# Aspie or NT?

## The pros and cons of acting neurotypical

This excerpt was adapted from a column on the *Wrong Planet* website — an online community for people with ASD. The full article can be found at <http://www.wrongplanet.net/articles426.html>.

Maja is a 25-year-old singer/songwriter from Denmark. As a teenager, Maja received a diagnosis of Asperger's syndrome. This is her story.

Check out Maja's YouTube channel where she talks about Autism: <http://www.youtube.com/user/TheAnMish>.

By Maja Toudal

I'll keep my story somewhat short. Like many other Aspies, I've known since very early childhood that I was not like the other kids. I've felt different, weird, and it truly does feel like being on the wrong planet. Everyone else expected me to behave as them. For me, that was impossible. I'm fairly sure that any Aspie knows what it's like.

I think I first realized this when I was three- or four-years-old. I never went to special schools or had any help. I wasn't diagnosed until I was 16. So, not only did others expect me to act 'normal', I expected it of myself. It wasn't until I was 12 or 13 that I realized

that I would have to really work for it if I was going to achieve it. Also, it wasn't until then that I started wanting to be a part of society, after years of being bullied by classmates and teachers. So I worked at it. I observed and tried to repeat what the others did. I failed miserably.

When I was 17 or so, I was invited to play a role-playing game, which has since become much more focused on character play than anything else. And that is where I really learned something.

I see it as speaking two languages. To use a metaphor, I speak Danish and English. Danish is my native language, it's the language I grew up speak-

ing. Danish is good to be able to speak, because even though it's a small country, it's where I live. The relatively small number of Danish-speaking people mostly prefer to speak Danish. And many of them don't know English very well.

But many people in the world speak English, and most of them don't know how to speak a word of Danish. However, because I speak English so well, I'm able to share ideas with other people who speak English and befriend them. I'm able to translate Danish for them, and even – with those who are willing – am able to teach them a bit of Danish.

It's exactly the same with the languages 'NT' and 'Aspie'\*. There are many Aspies in the world, but most people are NTs. What I want to do with my life is reach out to the NTs and teach them to speak a bit of 'Aspie'.

*Maja Toudal started writing songs when she was nine and released her debut album, *Live, Acoustic & Stripped* less than a year ago. She has also released quite a few singles, available on her YouTube channel.*

Direct Support Professionals (DSPs) specialize in providing excellent support to individuals with disabilities through living out the NADSP Code of Ethics. Supporting individuals with ASD (and any other I/DD) also includes encouraging self-advocates to share their stories and perspectives. How might you help the individuals you support express themselves? Is it through writing? Through music or art? Could you help the individuals you support share their stories through movement or puppetry? Like Maja, everyone has a story to tell.

*\*FI Editorial Note: People with Asperger's sometimes refer to themselves as an 'Aspie'. This is generally considered to be an acceptable and positive term among people with Asperger's. Individuals with ASD also sometimes refer to people without ASD as 'neurotypicals' or 'NTs', which is another term commonly used and accepted throughout the ASD community.*

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# My experience parenting autism

## A journey of challenges and joys

By Janice Eagan

I can count on one hand all the words my daughter spoke before her third birthday. She never called us Mommy and Daddy and we generally referred to her as 'wild'. We often compared our situation to wanting a cat but instead going out and trapping a raccoon.

When doctors confirmed her diagnosis, I remember crying for several days. I felt as if she had died. A parent's dream of a future for her child was crushed by a simple word: *autism*.

June was a healthy and strong little red head born just one month premature. When June wasn't sleeping, she was crying. She almost never slept. June completely stopped looking at us when she was around 18 months old. She jumped off the back of the couch, climbed bookcases, and spun. We were in the emergency room for head injuries more times than I'd like to remember.

June loved to watch cartoon shows over and over again and also had a quick temper. She threw uncontrollable fits that sometimes lasted for hours. There are times I had to sit on her so she wouldn't hurt herself.

Tensions were always high. My husband and I fought a great deal and were at our wits end. We were tired and confused. We thought we were winners of 'The Worst Parents Ever' award.

When June qualified for state services at age two and a half, I ran out to the nearest bookstore and purchased a book on speech delays. It was while reading this

book that I found that June was possibly on the autism spectrum. I also learned there was a diet that worked for about half of the people who tried it.

My husband and I felt a wave of relief that we weren't the terrible parents we thought we were we might actually be able to help our daughter. We were afraid to medicate her at such a young age so we decided to try the gluten and dairy free diet\*. June began to make eye contact with us within a month or two. It was as if a fog had cleared away and she could finally see us!

June still didn't have any spoken words, but she began using some sign language that she had learned from watching Baby Einstein videos. We quickly graduated her to using the Picture Communication System (PECS). Before we knew it, the words started to come. Today as I write this, she talks to me endlessly.

It has been a long road these past 7 years. When we first received June's autism diagnosis, we were very afraid. We felt sad, lost and helpless. We were scared. We didn't know anything about autism outside of the movie *Rain Man*.

We are thankful for every therapy June has received. One of June's Early Intervention therapists, Rebecca, asked me to participate in June's sessions. Rebecca taught me how to carry over activities from the therapy session to our everyday life. I felt like I was an important part of June's program.

It is critical to include any willing family members in a person's support program. This simple step can help change parents' feelings of helplessness into feelings of empowerment and optimism of a successful future for their child.

June will always face challenges. She has heightened auditory and visual senses that sometimes interfere with her ability to focus in her environment. She occasionally wears a weighted vest to help her with those challenges. June is emotionally and socially behind her peers right now but her academics are two grades above and she is catching up socially.

June makes amazing progress with each passing year. We have worked hard to ensure a happy future for her. We hope she goes to college and possibly even gets married and has a family of her own someday. We are proud of June.

To our family, *autism* is just another word. It has its challenges but it does not mean the end of a dream.

---

*Janice Eagan is an Iraqi war veteran and mixed media artist turned stay at home mom who is working on perfecting Gluten-Free Casein-Free Soy-Free (GFCFSF) foods.*

*\*FI Editorial Note: Dietary changes are one approach to autism treatment. Specialized diets do not have the scientific support needed for widespread recommendation. Changes in diet might help one person with autism, but may not help another.*

# Autism insurance reform

## A political issue

By Jennifer S. Reinke

Autism is estimated to cost the United States \$126 billion a year. This suggests that we need to take action to address this critical public health issue. The goal of this article is to provide Direct Support Professionals (DSPs) with a summary of federal and state policies related to autism and provide suggestions for how DSPs can take action.

### Federal initiatives

There are several federal initiatives related to improving the lives of people with autism and their families. Here, we highlight two important Acts —

#### Combating Autism Reauthorization Act of 2011 (CARA)

President Obama signed the Combating Autism Reauthorization Act (CARA) of 2011, H.R. 2005 into law in September 2011. CARA authorized \$693 million in federal funding to continue these three important initiatives —

1. Developmental disabilities surveillance and research,
2. Autism education, early detection, and intervention, and
3. Interagency Autism Coordinating Committee (IACC), the primary advisory committee that coordinates all federal efforts concerning autism.

More information can be found at <http://www.govtrack.us/congress/bills/112/hr2005>.

#### The Achieving a Better Life Experience Act (ABLE)

The ABLE Act was written to help people with autism and other disabilities and their families save for disability-related expenses. If authorized, the ABLE Act would allow families to save money in tax-exempt accounts for things like future education, housing, transportation and employment support. More information can be found at <http://www.govtrack.us/congress/bills/112/s1872>.

### State Initiatives

Many advocates believe the best way to secure access to services for people with ASD is through mandated health insurance coverage. Thirty-two states have authorized autism insurance reform laws as of August 2012. All but eight of the remaining states have introduced or are proposing autism insurance reform laws.

The rules for health insurance coverage for people with ASD vary significantly among states. For example, individuals are covered up to \$36,000 a year in California. But there is no dollar maximum in Massachusetts or Indiana. Sometimes insurance coverage *within* a

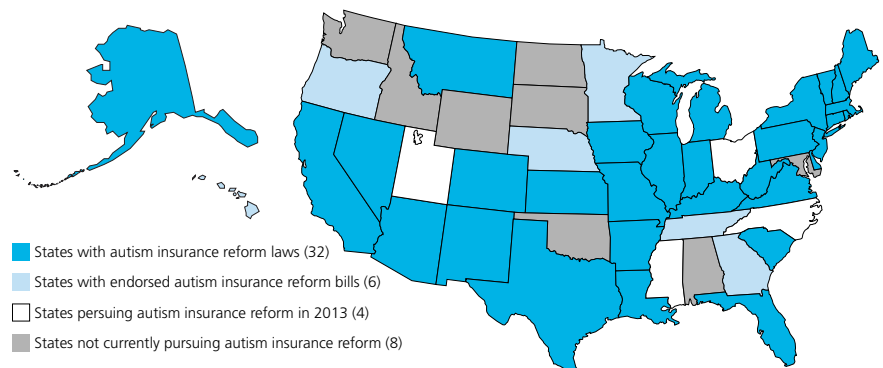
state might change depending on a person's age.

Health insurance coverage has improved in many states for people with ASD. But there is still a long way to go. Many states have not yet authorized *any* legislation around autism insurance reform. Insurance companies in these states are not required to pay for any behavioral therapies such as Applied Behavior Analysis (ABA). This leaves families with difficult financial decisions and limited treatment options.

The NADSP Code of Ethics calls DSPs to “advocate for laws, policies, and supports that promote justice and inclusion.” Answer this call by being knowledgeable about current initiatives in your state: <http://www.autismspeaks.org/advocacy/states>. Support any state legislation that would mandate coverage for behavioral therapies.

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Source: Autism Speaks. <http://www.autismspeaks.org/advocacy/states>

# Here's the latest!

## Research on services and supports for adults with ASD

### How do adults with Autism Spectrum Disorders (ASD) receive funding for the services and supports they need?

One of the main ways that adults with ASD receive direct support is through their states' intellectual and developmental disabilities (I/DD) service system. This system includes Home and Community-Based Services (HCBS) Medicaid waiver programs. This is often called 'the waiver' for short. The waiver is a primary source of funding services for people with I/DD and their families.

Adults with ASD often face barriers when trying to access services they need. Many are not eligible for the waiver and I/DD services. This can happen when a person does not have a co-occurring intellectual disability diagnosis. Or the person may have sufficient skills for performing activities of daily living. These are two common ways that states determine whether a person can receive services.

### What can help adults with ASD to access the services and supports they need?

Policymakers have worked to expand access to services for people with ASD. Some states have changed the eligibility criteria for receiving services. The policies label ASD as a 'related condition'. This implies that people with ASD may receive services because they face similar challenges or need similar supports as people with intellectual disabilities.

A few states have taken an even more promising approach

and have started waiver programs specifically designed for people with ASD. The new waiver provides more specialized services and supports based on a person's unique experience with ASD. Autism waivers for children are an important growing trend, but these waivers are less common for adults.

### What is important to know about the status of these services in my state?

Inclusive policies and targeted programs matter! States that have affirming HCBS policies for people with ASD make a difference. Research shows that those states are much more likely to provide services to residents with ASD. Without having these policies in place, a state may be making it *more difficult* for residents with ASD to receive needed supports.

You can help by contacting your local and state government representatives and policymakers in state human service departments. Tell them about your work. Discuss effective supports that adults with ASD need access to.

### What else does the research tell us?

There is a large proportion of *young adults* with ASD who currently use state I/DD services. Our systems must prepare for increasing numbers of adults with ASD. States need to develop plans to serve this population and their families across the lifespan.

It's also important to find effective ways to support people with ASD based on various levels

of *intellectual ability*. There are a significant number of people with ASD who have either a profound intellectual disability or no intellectual disability. This calls for state I/DD services to be specially designed to support these outlier groups.

Research also tells us that there are very few adults with ASD who use *communication aids or devices*. In part, this may be due to the many barriers around obtaining funding for devices and related repairs. This is troubling because communication can be particularly challenging for this population.

It's important for Direct Support Professionals (DSPs) to advocate for the use of effective communication technologies whenever necessary. Remember that communication is a human right! For more information, visit the *FI Issue on Technology* from 2011. Jolene Hyppa-Martin provides insight in the article, *The right to communicate: DSPs, communications, and technology* found here: [http://www.nysacra.org/nysacra/pdf/FI\\_Technology.pdf](http://www.nysacra.org/nysacra/pdf/FI_Technology.pdf)

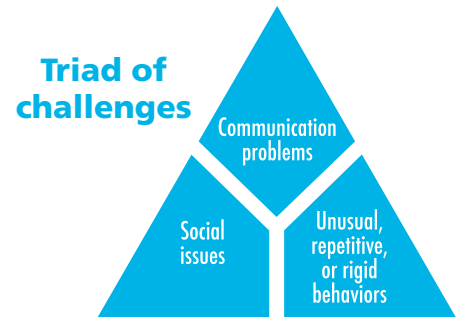
For further information, see this resource or contact the author.

Hewitt, A. S., Standliffe, R. J., Sirek, A. J., Hall-Lande, J., Moseley, C., Taub, S., Engler, J., & Bershadsky, J. (2011). Characteristics of adults with autism spectrum disorder who use adult developmental disability services: Results from 25 US states. *Research in Autism Spectrum Disorders*, 6(2), 741-751.

Annie Johnson Sirek, MSW, is delighted to serve as Editor of FI. She can be reached at 612-626-0535 or [joh02055@umn.edu](mailto:joh02055@umn.edu). Annie extends many thanks to the researchers who provided this information, the FI Editorial Board, and fellow DSPs.

# Strategies for supporting the unique challenges of ASD

As a Direct Support Professional (DSP), it is likely that you will support an individual with an autism spectrum disorder (ASD). It is helpful to conceptualize the support needs of the individual around the three core challenges: social, communication, and behavior issues. These characteristics may be referred to as the Triad of Challenges. Some of these characteristics may be mild. However, in some people with ASD, the characteristics may be severe. It is helpful to utilize support strategies around the Triad of Challenges in ASD. These core strategies will help promote success in working with individuals with ASD.



## Social issues

People with ASD often have trouble with socialization. They may not understand social rules and may experience challenges with social skills and social interactions. People with ASD may have trouble creating typical social bonds and maintaining social relationships. They may appear aloof or uninterested in social interaction. Eye contact may be atypical, and personal space issues are common. Social skills must be actively taught. Teaching is most effective when using concrete, rule-based social skill strategies such as —

- Rehearse and role play common social situations.
- Teach non-verbal social skills and social cues.
- Practice general social skills for cooperation.
- Teach appropriate social boundaries.
- Use visual tools such as social stories and visual cues to support social development.

## Communication problems

People with ASD may also have challenges with communication. Delayed or lack of verbal speech are common. Speech may have an unusual quality such as lack of tone, atypical rhythm, or inappropriate volume. Some people with ASD display echolalia, which involves repeating words and phrases. There are often difficulties with comprehension, and a lack of understanding of abstract or non-literal terms. To support individuals with ASD in improving their communication skills, DSPs can —

- Practice basic communication skills.
- Keep instructions basic, use fewer words, and break directions into smaller steps.
- Use visual supports or cues to support verbal directions.
- Teach use of signs, gestures, and picture cards for communication.
- Check often for understanding. Repeat if necessary.

## Unusual, repetitive, or rigid behaviors

People with ASD often display behaviors that are atypical, repetitive, or overly rigid. Some individuals with ASD may have an intense interest in a specific object, topic or activity. Transitions may be very difficult, and some individuals with ASD may have a noticeable preference for specific routines and rituals. Some individuals display repetitive body movements such as hand flapping, rocking, or finger flicking. As you support individuals with ASD that have challenges restricted or behaviors —

- Try to understand function or purpose of behavior.
- Teach concrete rules around behavior.
- Teach positive alternative replacement behaviors.
- Provide a clear schedule and consistent structure to the environment.
- Set aside appropriate times individual can discuss interest or engage in behavior in a safe manner.

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# “Roses for Autism”

## An innovative model of employment for individuals with ASD

Jobs, jobs, jobs. That is the hot topic that we hear echoed across our country. As Direct Support Professionals (DSPs) we have witnessed what the tough economy has meant for the people we support.

The unemployment rate is estimated at 88% for adults with Autism Spectrum Disorder (ASD). Autism Speaks has estimated that more than 500,000 young people with ASD will turn 18 over the next 10 years. These young adults possess a wide range of talents, prior experience and areas of interest.

Why, then, is the unemployment rate among people with ASD so high? They often experience challenges with communication and social situations. This can make it difficult for people with ASD to enter and navigate the workplace. Our job is to support people with ASD to overcome those challenges.

There are some promising practices and models across the country to do just that. One such model is *Roses for Autism*. This is a working rose farm in Guilford, Connecticut. The Pinchbeck family operated the farm for 80 years. A collapsing economy caused the business to close in 2008. A family friend and parent advocate approached the fourth-generation owner, Tom Pinchbeck, with an idea. Shortly after, *Roses for Autism* was born.

*Roses for Autism* is the first initiative of Growing Possibilities, a non-profit organization founded by Ability Beyond Disability. Individuals with a variety of abilities work together to grow, cut and package flowers. They market



**Wil Swartzell, e-marketing specialist, holds a bucket of his favorite variety of Pinchbeck roses – Forever Yours.**

the arrangements through social media and traditional advertising. The flower arrangements reach customers locally and throughout the country.

Wil Swartzell is an e-marketing specialist for *Roses for Autism*. Wil is a successfully employed individual with ASD. Wil was recently asked about his work at the Rose Farm. He said, “What I like most is the staff. We help each other out with our weaknesses, making each other our strength. What I don’t like are the computers. Only kidding! I work very hard to keep the computers in tip-top shape! I’d actually have to say that I don’t like the temperature. My working area is located right in front of a heater that is very over-reactive. I think the heater enjoys making my workday a reenactment of walking on the sun! But I’ve got a large fan at my desk so that helps a lot. Most of the time I’ll take a break in the cooler.”

It might sound like a simple solution but it demonstrates how creative approaches can help a person overcome barriers at work. A DSP can make a big difference by getting to know a person well.

A DSP can contribute ideas based on conversations with the person and through observation.

*Roses for Autism* also includes a Career Training Program (CTP). The CTP is for adults with ASD who are interested in finding meaningful work and living independent lives. People in the CTP learn skills that will help them to be successful in a variety of work settings. Some of these skills include working as a team, effective communication, customer service, marketing, agriculture and floral design.

*Roses for Autism* is an example of a promising model for businesses large and small. It shows that partnering with providers to successfully hire and retain individuals with ASD can help achieve business goals.

To learn more about *Roses for Autism*, please visit: [www.roses-forautism.com](http://www.roses-forautism.com).

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*Kristine (Kris) Foss is the Director of Human Resources and Workforce Development at Ability Beyond Disability, a health and human services provider located in Bethel, Connecticut. Kris can be reached at [kris.foss@abilitybeyonddisability.org](mailto:kris.foss@abilitybeyonddisability.org).*

# NADSP sponsoring, supporting & affiliate organizations, state chapters and contacts

We would like to acknowledge NADSP Supporting Organization members for their generosity and ongoing dedication to the goals and mission of NADSP.

## Sponsoring organizations

- American Network of Community Options and Resources (ANCOR)
- Crystal Run Village, Inc.
- Koinonia Homes, Inc.
- NYSACRA
- NYSARC, Inc.
- Provider Search, LLC
- Research & Training Center at the University of Minnesota
- Welcome House, Inc.

## Supporting organizations

- AHRC NYC
- Apple Patch Community
- The Adirondack Arc
- The Arc of Rensselaer County
- The Arc of Tennessee
- Block Institute
- Bost, Inc.
- Butler County Board of Developmental Disabilities
- Cardinal Hayes Home for Children
- Cardinal McCloskey Community Services
- Catholic Charities Disabilities Services
- Cedar Lake, Inc.

- Cerebral Palsy Association of New York State
- COARC, Inc.
- Grace Community Services
- Greystone Programs
- Hope House Foundation
- ICES, Inc.
- Jefferson Rehab
- Job Path, Inc.
- Larry McKinstry Services, LLC
- Laura Baker Services Association
- Mercy Home
- New Hope Community
- New Horizons Resources
- OAHE, Inc.
- Opportunity Enterprises
- Orange AHRC, NY
- Outreach MRDD Services
- Pathfinder Services
- Residential Resources
- The Resource Center
- SECOH, Inc.
- Services for the Underserved
- SPEAK (KY)
- SPIN, Inc.

## Affiliate members

- Adults and Children with Learning and Developmental Disabilities
- ADVANTAGE Healthcare Provider
- AHRC-NYC

- ARC Broward
- The Arc of Southside
- Cardinal Services
- Citizen Advocates, Inc.
- Community Support Services Inc.
- The Council on Quality & Leadership (CQL)
- DDI
- Eggleston Services
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- Haitian Americans United for Progress, Inc.
- Hampton Newport News Community Services Board
- Hope Association, Inc.
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- Life's WORC
- McComb Consulting & Government Relations
- Miami Cerebral Palsy Residential Services
- Regis Obijiski
- OPG, Inc.
- Parent to Parent of New York State (NYS)
- Passages, Inc.
- Presbyterian Homes & Family Services
- Rural Living Environments
- RWJMS/UMDNJ-The Boggs Center
- Self Advocacy Association of NYS
- St. Amant Community Residential Program
- Thumbs Up
- West Side Support Services
- WillGlo Services, Inc.

## State chapters and contacts

As a membership organization, NADSP requires the involvement of its members to share information on DSP issues, achievements and directions. Chapters and contacts do this important work in concert with NADSP. We encourage the involvement and participation of DSPs in leadership roles at both the local and national levels.

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### Virginia

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# Frontline resources

## Autism NOW: The National Autism Resource and Information Center

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

The Autism NOW Center is a clearinghouse of high-quality resources and information for individuals with autism, their families, and professionals.

## Autism Speaks

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

Provides a wealth of information about autism for families and professionals, such as autism apps, a video glossary, and state and local resource guides.

## DirectCourse: College of Direct Support

*Disability Intensive Course on Autism*

[www.directcourseonline.com/directsupport/](http://www.directcourseonline.com/directsupport/)

Hall-Lande, J., Perry, N., McCulloh, N., Sedlezky, L., Stenhjem, P., & O'Neill, S. (2009). Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.

## Quality Mall (search "autism")

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

Provides hundreds of links to autism-related resources, including books, websites, videos, and research findings.

## Book: A Beginner's Guide to Autism Spectrum Disorders: Essential Information for Parents and Professionals

*By: Paul G. Taylor; Publisher: Jessica Kingsley*

This book provides a starting point for anyone encountering Autism Spectrum Disorder (ASD) for the first time, and offers practical strategies for supporting individuals with ASD.

## Book: Ten Things Every Child with Autism Wishes You Knew

*By: Ellen Notbohm; Publisher: Future Horizons*

Written by a mother of a child with autism, this book describes ten characteristics common to many individuals with autism. Recommended for parents, teachers, physicians, and other service providers.

# NADSP membership form

## DSP level \$10/year

DSP

## Other individual level \$20/year

If your state has a NADSP chapter, you will receive dual membership in the state chapter and NADSP.

Frontline supervisor  Self-advocate  Family member

Other professional (please specify) \_\_\_\_\_

## Affiliate level \$200/year

For individuals, agencies, providers, associations, and NADSP state chapters who wish to demonstrate a commitment to support the efforts of DSPs.

Individual  Organization

## Supporting organization level \$500/year

For individuals and organizations dedicated to advancing the interests of DSPs and the people they support at a national level.

Individual  Organization

## Sponsoring organization level \$2000

For individuals and organizations dedicated to advancing direct support as an accepted profession at the national level and participation on the NADSP Advisory Committee.

Individual  Organization

Total enclosed

Make checks payable to NADSP. To pay by credit card, visit [www.nadsp.org/membership](http://www.nadsp.org/membership) (Discounts are not available with online payment)

### Mail membership form and payment to:

NADSP, 240 Washington Ave. Ext., Suite 501, Albany, NY 12203-0305

Name \_\_\_\_\_

Organization \_\_\_\_\_

Address \_\_\_\_\_

City State Zip \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

## Frontline Initiative

150 Pillsbury Dr. SE  
Pattee Hall, Room 204  
Minneapolis, MN 55455

Making a world of difference  
in peoples' lives

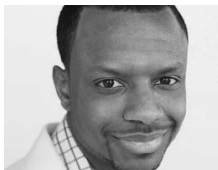


### Email my FI

Get *Frontline Initiative*  
sent to your email.  
Send your address to:  
[lisam@nysacra.org](mailto:lisam@nysacra.org)

## The many faces of autism

As you may already know (or have learned from reading this issue!), the characteristics of autism are different for each and every person. For example, some people may enjoy listening to music, while others may prefer quiet spaces with little noise. And some people with autism may have a fascination with bugs and insects, while others may have a fear of getting dirty. Remember the famous saying, *If you've met one person with autism, you've met one person with autism*. Here, we meet three people with autism who have unique strengths and challenges. How are each of these individuals similar to or different from the people you support?



**Meet Paul** — Paul is a 37-year-old mechanical engineer with Asperger's syndrome. Paul likes to figure out how things work, and often takes apart and puts back together computers, radios, and car parts. Paul lives with his wife and two children, and enjoys going to his kids' soccer games. Paul sometimes has trouble with understanding how other people feel, and is currently writing a book about his life as an engineer on the autism spectrum.



**Meet Cayden** — Cayden is a 7-year-old boy with autism. Cayden likes things that are green, Buzz Lightyear, and playing games on the iPad. Cayden doesn't like dark rooms or taking off his shoes, and gets easily frustrated with unorganized spaces, like when his little sister leaves toys all over the playroom. Cayden has an amazing memory, and can tell you all about Saturn's, Jupiter's, Uranus's, and Neptune's rings!



**Meet Jessica** — Jessica is a 15-year-old girl with Asperger's syndrome. Jessica enjoys listening to music, especially the Beatles. Jessica feels very anxious around doctors and sometimes listens to music during her appointments to help her calm down. Jessica is on her high school's swim team and is also a member of the photography and yearbook clubs.