



Dillion Pusatera

NADSNews

Newsletter for the National Association for Down Syndrome

November, 2014

Dare to Dream! NADS 2014 Conference

Joanne Schubert

28 Years ago, my son Nick was born with Down syndrome. Little did I know then that I would know A LOT now (about Down syndrome), and through it all, NADS has always been there along the way, disseminating the most current information, along with outstanding resources and invaluable family perspectives, through their newsletters, fundraisers, and conferences. When Nick was very young, I attended many of these conferences, and at that time, I remember each conference being a whirlwind of SO many workshops to attend, especially since my son was still young, and there was SO much to learn! We didn't have the internet back then, so the "dinner club" as we called ourselves (all of us moms, who had met at early intervention programs) would attend as many of the workshops as we could and gather up volumes of notes and handouts, and inevitably share them with each other at our next dinner club. I remember there being 700-800 people

that would come from far and near to learn more about the issues they currently faced or would face in the future, and how to help their child be the best they could be. Fast forward 20 years into this age of technology, and, while I am the first one to search the web to learn new information, attending a NADS conference is so much more rewarding and cathartic than a Google Search! Sharing some observations from now, as opposed to back then, the attendees seemed so much more comfortable, educated, and for lack of a better word....happy! Happy to be with other parents, families, educators, professionals, all having that something special in common with one another.

My main reason for attending the conference this year—I knew there was going to be a seminar on Supported Employment, and I had to overcome this fear I've had for much too long, that my son wouldn't have enough support to be successful in the workplace. We had been comfortable for too long in a job training program

that was going nowhere fast, and after 8 years of being his job coach, I was more than ready to retire! Nick seemed to always be the one that had trouble with transitions, but now it was his mother!

I was especially hopeful as I walked into the session on "Approaching the Age of Independence: A Parent's Guide to their Child's Employment," presented by Kristen Sheffield, of Parents Alliance Employment Project. There is just nothing like seeing a person talk about something they are extremely passionate about.... You know you have been somehow guided to be there, in this place, with this person, and to see this presentation. Especially when, after listening, and learning, you can actually envision your child in not just one job, but possibly many, with the care, guidance, training, and support of this organization. Years ago, I witnessed a job coach verbally abusing a young man with a disability, who was trying to vacuum the carpeting at one of

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Conference

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the local stores. That vision unfortunately held me captive for too long, and my willingness to allow my son the experience of a real job, out in the real world. Pat Loy, a parent of a son, Chris, with Down syndrome, gave valuable input on the benefits of supported employment as they related to her and her son, and his journey through various job opportunities found by Parent's Alliance. I left the session feeling extremely excited for my son and his potential future employment opportunities, and empowered with the knowledge that there really IS a job out there for my son, and he will get all the support he needs (as will we!). I'm fairly sure that I would not have had the same experience had I only researched supported employment on the internet! There are many supported employment agencies (SEP's) in Illinois; Parent's Alliance is one located in the Western suburbs of Chicago.

Another workshop I attended was "Increased Communication, Participation and Organization with Technology" presented by Dr. Pat Politano, from the UIC Assistive Technology Unit (ATU). We have an iPad for my son, and as many people know, the web is extremely overwhelming with choices, upon choices, upon choices of communication apps. Dr. Politano shared her favorite apps through her experiences of helping many individuals be successful communicators. THIS is exactly why

seminars are SO valuable! I was surprised to learn that one of ATU's services includes delivery and training of technology, in your home, if needed. Some of the specific areas include: adaptive equipment, augmentative communication, computer access, and home modification. Also, if you are interested in a particular communication device for your child, you can "borrow" it from them to try before you buy, as we did with the iPad. If you



Nick Schubert

are a Facebook user, more information on the apps and services provided are available at: facebook.com/UICATU, or on the Web: <http://uicatu.org/>. I was thrilled to learn that one of the apps recommended by Dr. Politano was Pictello. My son loves this app! It allows him to create digital books (with a little help from mom) about recent events, activities, vacations, sports, whatever his heart desires. If you know how to save your photos to One Drive, or some similar "cloud," you can create the books easily using all your own photos, or any images from the web. There is a small fee (\$19) for the app, but it is worth every penny. You can also use a synthesized voice, or your own. When using a synthesized voice,

each word is highlighted, as it is spoken, which also helps with word recognition. LOVE that feature! Unfortunately, the words can't be highlighted using your own voice. Another very helpful suggestion from Dr. Politano was to utilize YouTube to watch a video on how an app works before you buy it. I wish I had known that before I purchased some of the apps we have, and don't use!

As difficult as it is for my son to communicate, I could certainly tell he had a great time at the Teen and Adult Conference. I understand there were 50 attendees, and I'd like to thank all the amazing volunteers who helped to make that possible! I realized that at long last, Nick is beginning to understand that he has Down syndrome, and attending the Teen and Adult conference the last two years has helped him in that respect, despite how

many times we discussed it, over and over, since he was born. Yet another example of how Nick is on his own timetable, and no matter how much we want to rush him, he will do it when he is READY, and not one day, hour, or minute sooner! But the best part that makes our hearts sing, is that he continues to learn new things, and always amazes and surprises us, when we least expect it! Now if he could just teach his father and his brothers how to coordinate shirts and pants like he does for himself, I would be one happy wife/mom!

Thank you NADS for helping to provide current, invaluable information to parents, siblings, professionals, and the community, through your

Letter to Sean's Daycare

Cara Hunwick

Hi Friends,
October is Down Syndrome Awareness month and my mom read that the one great way to spread awareness is to write a letter to my classmates and their families and tell them what life is like for me and my family. So here goes....

My name is Sean Owen Hunwick and when I was born almost two years ago my parents were surprised to find out I had Down syndrome. At first they felt sad, worried, and scared. They didn't know any other families who had a child with Down syndrome and really wondered why them. They were scared that their life would drastically change and that my big brother and sister might not accept me. My mom thought she might have to quit her job to stay home with me because taking care of me would be so hard and different. They worried I would be sick and in and out of doctors and that I would have trouble making friends when I got bigger.

It turns out my parents were **WRONG**..... like super **WRONG**. Now my parents can't imagine life without me, just the way I am. Now, they have met many families with children who have Down syndrome and love talking and sharing stories about us.

Now, they realize my big brother and sister love me just the way I am. They love to crawl, climb, tickle, laugh, read, play ball and play peekaboo with me. They know I have Down syndrome and that I need help learning to do things, but it's really no big deal to them, just part of who I am.

Now, my parents know their life has changed, but only for the better. They still do **ALL** the things they used to do like going for walks, bike rides, trips downtown Chicago, family camp, going to the beach, pool, out to dinner, road trips to Michigan, and playing outside. I even hear my mom tell her friends that I have actually been the easiest of all three of her kids to take of: I sleep through the night, take a two hour nap every day, am super easy going, and almost always in a happy mood.

Now, my parents know

that having Down syndrome doesn't mean you're sick. In fact, other than one ear infection, I have never been sick. I go to the regular check-ups that all kids go to, with a couple extra appointments to check my hearing and vision every year. I

do have a small cardiac issue (PDA) that may need surgery, but overall I am a very healthy kid. I also have therapists that work with me each week to help me with my development. They have learned I **WILL** learn to do everything that other kids can do, I just have to work a little harder and it may take me a little longer.

Now, my parents are happy to report I already have lots of friends. I have been coming here to SchoolHouse ever since I was six months old and love all my friends here. I'm in the Toddler Room now and my parents were nervous about me moving over to that room since I'm not walking yet but I am having a great year and learning



Sean Hunwick

so much from my Toddler friends. Our SchoolHouse teachers are the **BEST** and help me learn and play with my friends everyday. They are a big part of my "team" and get so excited when I learn something new.

Thanks for reading! The best thing you can do to celebrate Down Syndrome Awareness month

is to share my story. If you know or meet another family who has a child with Down syndrome,

tell them about me and my happy family:)

Hugs,
Sean



conferences, newsletters and fundraisers. The amount of work that is done by volunteers, and just a handful of staff, is a true testament to the exceptional reputation and values NADS has established over the years, along with its unwavering continuous support of its families, young and old. ■

Quotes from the 2014 Teen & Adult Conference

"I learned how to make new friends and to dance with different people"

"I like to dance with my friends and I am so happy today."

(The dance with DJ) "It was cool and I like it because there is a lot of dancing and I bust the moves."

"It was epic fun dancing and shaking it on the dance floor."

"The best one I ever did"

"I love drama"

"I learned how to be confident, have a hero and to feel good about yourself"

"I learned how to express myself and be engaging"

"(HeartWords) was really great, and fun, I love writing."



A Dream Come True

Rachel Giagnorio (age 23)

It all started the summer of 2013 when my cousin Kelly gave me a "Bridesmaid" bag and asked me if I would be a bridesmaid in her wedding. I said, "Yes, yes, yes, a million times yes!!" Kelly was 5 when I was born and we have been best buds all of these years. I knew right away that this year was going to be so much fun. We went shopping at the House of Brides for the bride's dress and the bridesmaid dresses. It was a successful trip. The bride picked out a beautiful dress and we found the perfect bridesmaid dresses in watermelon pink with a sweetheart neckline to match the bride's dress.

My aunts and I were in charge of planning the bridal shower. I came up with a game called "How Well Do You Know the Bride?" and I helped make the party favors which included mini candy bars with the happy couple's picture on them. The next big event was the bachelorette party. This was held in Lake Geneva and on Friday night we had a personal shower and played some very funny and interesting games (if you know what I mean!). After that we went to a bar called "Hogs and Kisses." Luckily I am old enough, so I got to go along. I had a wine cooler and had lots of fun dancing. On Saturday we rented a pontoon boat and then went out to dinner. It was a great week-end that I will never forget.

On Friday July 25th I attended the rehearsal at the church and dinner at a restaurant where the bride gave all of the bridesmaids some special gifts for being in her wedding.

The big day has finally arrived. It is July 26th and at 11:00 A.M. my mom dropped me off at my aunt's house to get my hair done along with all of the other bridesmaids. We all dressed there and then the big black party bus arrived to take us to St. Alexander's Church in Villa Park. I was the first bridesmaid down the aisle and I walked slowly to meet my escort, one of the groom's very cute friends. The ceremony was absolutely beautiful and my cousin Kelly was so gorgeous she looked like Cinderella! After the ceremony we climbed back into the party bus and rode to the reception at Itasca Country Club. While we were on the bus one of the groomsmen opened a bottle of champagne and it spilled out like a waterfall all over the floor. We had to stop at Walgreens to get paper towels to clean it up.

At the country club we rode golf carts out onto the course to take some pictures. I had a fabulous time eating, chatting and dancing the night away. I know it was the best night of my cousin's life, but it was also the best night of my life.

When not being a bridesmaid, I work two jobs. I work at Homegoods and J.C. Penneys. I love working and my jobs are a lot of fun. I also like to go to Zumba, sing, hang out with friends, and dance. My favorite show is "Dancing with the Stars" (Go Derek!) I am also a NADS self-advocate and I enjoy telling people my story so that people can see that I am outgoing and I am just like everyone else. Doesn't everyone dream of being a bridesmaid? ■



New Study Shows Benefits of Inclusion for Language Development

A new study, "Peer Effects in Early Childhood Education: Inclusion," examined the effects of peers on language growth. The researchers, Laura Justice, Jessica Logan, Tzu-Jung Lin and Joan Kaderavek, compared the progress of preschoolers with disabilities who were placed with typically developing peers to that of preschoolers who were placed with peers who did not have strong language skills. The study concluded that children with disabilities clearly gained by being mainstreamed and that by the end of the year, they had made more progress in communication than the children who did not have the benefit of those strong language models. The study was published in Psychological Science on July 25, 2014 (www.pss.sagepub.com). ■

Sleep Apnea Study

A new study by researchers in the Sleep Research Unit at the University of Edinburgh concludes that one in three individuals with Down syndrome has moderate to severe sleep apnea, which is characterized by pauses in breathing during sleep. Sleep apnea can lead to daytime sleepiness and is also a risk factor for other medical conditions, such as high blood pressure. Treatments are available, but researchers estimate that currently only about 2% of adults with Down syndrome are being evaluated for the condition. For more information about the study, go to <http://www.digitaljournal.com/pr/1836613>. ■

DS-Connect

If you have not yet registered your child with the NIH's free health registry, DS-Connect (<https://dsconnect.nih.gov/>), you may wish to do so, especially if your child has any particular health issues. The registry helps to link individuals with Down syndrome to researchers, and you can request updates about new studies, treatments, and clinical trials. ■

Managing Behavior in Children with Down Syndrome

How Understanding Leads to Intervention: Development and Cognitive Processing

Mary Pipan, MD, Clinical Director, The Trisomy 21 Program at The Children's Hospital of Philadelphia

"No!" "Stop it!" "I don't know."

Arms folded, body and face turned away. Sitting on the floor, refusing to move. Fondly and frustratingly, this is often called "stop, flop and drop."

Psychologists refer to this behavior as "oppositional," or maybe even "defiant," but those descriptions often didn't fit with the smiling child I saw in front of me, eager to please and generally compliant. From the hundreds of children and young adults I have assessed, and from studies on development and cognition, I came to realize that these refusal behaviors needed to be interpreted differently in individuals with Down syndrome (DS). What they often really meant was: "I don't understand" or "I'm frustrated" or "I need help." And sometimes they meant: "Give me a minute, I'm not ready yet" or "I need to know what's happening next."

Effective behavior intervention requires an understanding of where the behavior is coming from, taking into account:

- the context,
- the person's level of abilities,
- their temperament,
- their experiences and how they learn best.

Individuals with Down syndrome are just that, individuals, and thus what works for some, may not work for others. The broad areas that help explain many of the behavioral challenges facing caregivers of individuals with DS

include sensory processing (discussed in the previous issue of *Down Syndrome News*, Spring 2013), development and cognitive processing (the focus of this article), and communication and social and emotional functioning, which will be discussed in a future segment.

As children's brains develop, they become capable of more and more complex movement and thinking. This development occurs in predictable sequences across the first 25 years of life. The timing of development varies widely among individuals with DS, and thus regular assessment of progress is necessary to help keep expectations reasonably challenging. As parents and caregivers push a child to accomplish to the best of her ability, expecting outcomes beyond her capability will frustrate everyone, and may result in refusal behaviors. For example, if a child is just starting to draw lines and circles, expecting them to copy letters does not make developmental sense. Refusal behaviors will also occur if you underestimate the child's capabilities. The child becomes bored and is ready to take on more challenging tasks.

Another common cause of refusal is when a child is capable of a new skill on his best day, but because the skill is still emerging and is not quite solid, he is easily sabotaged by stress, anxiety or anger. Similar to all of us, children with DS have different levels of frustration tolerance. Some will happily

fill out an entire math sheet, confidently writing numbers in the blank spaces. Others get to the first question they are unsure of, and put their head down, refusing to try anymore. For a child with a low frustration tolerance, tasks need to be approached carefully, starting with mastered tasks and then building momentum to try more challenging tasks.

Cognitive processing refers to how we take in information, put it together with what we already know, and then think through a response. Cognitive processing in individuals with DS is often characterized by longer processing times, more difficulty in flexibly switching from one thought to another, limitations in the amount of information that can be kept in mind at once, and difficulty with the organization of that information to make sense of the situation and then respond appropriately.

Some of us are visual learners, more effectively taking in information through what we see, while others need to read information, and others need to hear it. Individuals with DS tend to process visual information better than through language. Thus, we emphasize "talking in pictures" to help them process both simple information (what's going to happen today), and more complicated problem-solving (what to do when a friend ignores you). Visual supports have also been used very effectively

in children with autistic spectrum disorders, and often those same visually-based interventions can be used for individuals with Down syndrome.

Longer processing time requires that we wait longer for a response to what we've said or shown them. This is probably the most common situation where we see the "automatic no" response. Often, ignoring the refusal and waiting will work. "Patience is a virtue" is the needed mantra. Pressing too early may result in higher stress and more shut-down.

We are all required to move our attention from one thing to another, literally thousands of times a day. For example, while reading this article, you may have glanced at the clock, then to the TV, then back to the article. For some, shifting from thought to thought, and activity to activity comes easily. For others, including many with DS, the shift is harder. This difficulty shifting may also result in "getting stuck" on certain things, and having difficulty moving on. Transitions between activities or thoughts require preparation, effort and time. This is probably the second most common cause of the "automatic no" response. This can often be eased by warnings that the transition is coming, with a countdown, or with a transition song. (Who doesn't love Barney's clean up song?) Giving a child a heads-up as to what will be happening next can also

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SPECIAL OLYMPICS

Johnny Damme

Illinois Special Olympics 2014 Outstanding Athlete of the Year

John and Diane Damme



This year Johnny had the honor of being awarded the Outstanding Athlete of the year. The Outstanding Athlete Award recognizes a Special Olympics Illinois athlete whose achievements and commitment to their teams and individual sports exemplifies the purpose of Special Olympics. He was presented this award at the annual awards dinner at the start of the summer games at ISU. What an exciting experience watching Johnny being honored in front of all the other special awards recipients, Special Olympic, state and local dignitaries. Also in attendance were his coaches from the three programs he competes for, and of course, his family.

Johnny is an accomplished athlete and loves playing and competing in many sports, and as such, he competes for three Special Olympics programs:

- Oak Lawn Special Rec.
 - Softball , Swim, Alpine Skiing and Golf
- Orland Park Special Rec. – Soccer and Floor Hockey

■ Stagg High School – Basketball, Bocce ball, Track, Tennis and Unified Volleyball

In ten years of competing he has won over 40 medals in regional competitions and over 35 in State competitions for a total of over 75 medals along with numerous 4th place and participation ribbons. He plays ice hockey for the Tomahawks, is a certified scuba diver (two buddies required) thanks to Dive Heart, and is a member of the Boy Scouts of America. Thanks to the support of Mr. Syska, his coach and Drivers-Ed teacher at Stagg H.S., he just passed his drivers permit test. (I will be sending out warning messages when he gets behind the wheel.)

He has accomplished all this despite being born with a complete AV canal heart defect and had open heart surgery when he was 3 1/2 months old, never crawled and was almost 3 years old when he started to walk. We are so proud of him. ■



Christopher at WeatherTech

Two Worlds Collide

Pat Loy

Meet my son Christopher:

There are many things in life 34 year old Christopher enjoys. His family and friends, movies, music, and playing games on his PS3 are probably high on his list. I think he has every "Guitar Hero" and "Rock Band" game ever made. But keeping busy and having a full calendar makes Christopher truly happy. He lives from one special recreation event to the next and works an 8 hour shift, 3 days a week. Christopher has been working since he was 16 and has been at his current job at WeatherTech for almost 6 years.

WeatherTech are the folks who make those incredible car floor liners. Christopher takes his job very seriously and is proud of the work he does; he has several duties there but primarily packages part kits.

This is the story of how two important pieces of Christopher's world collided, work and recreation. Last summer Christopher qualified to compete in the downstate Illinois Special Olympics for powerlifting. Anyone familiar with Special Olympics knows this three day event is a big deal. So

Christopher requested the time off from work with his supervisor Ken. After the event, Ken sent me an email asking how he did in his competition. I told him he had received two silver medals and one gold medal for his division. Ken quickly responded and asked if he could share this with the rest of the staff. Of course I said yes and in fact I would have him bring in his medals the following day. When my husband picked Christopher up from work he noticed he was wearing his medals. He asked "Dude, have you been wearing these all day?" He said "No, just since 1:00." His dad asked "what happened at 1:00?" Christopher casually said "the party." We had come to find out that Ken had orchestrated a celebration for Christopher's accomplishment. As Christopher put it, they "had 3 huge cakes and everybody was there, office staff-production-maintenance-transportation department. Everybody!" As a parent I am comforted to know that Christopher is supported by his "work family" and treated as a true team member. ■

SELF-ADVOCATES

Self-Advocates at 2014 Chicagoland Buddy Walk



Jeannine Cleary and her son Peter and Linda Smarto with her daughter Julia working the popcorn table.



Selling raffles and working the craft table were: Alex Tello, Gina Rotondi, Julia Smarto, Michelle Anderson and Kelly Neville.

ABLE Act Update

A framework for the ABLE (Achieving a Better Life Experience) Act was approved by the Senate Committee on Finance on September 19, 2014. Leaders of that committee announced that they expect the bill to be taken up in the lame duck session of Congress, which starts November 12, 2014. The bill has been under consideration in Congress since 2006. It has widespread support, with 366 co-sponsors in the House and 74 in the Senate. They are hoping it will soon be approved, though it is unlikely to pass until a plan is developed to pay for its anticipated costs, which are expected to come to \$2.1 billion over ten years. ■

Self-Advocates Present at Resurrection Catholic Church



Self-Advocates Bridget Brown, Lindsey Pazerunas, Megan Niklas, Rachel Giagnorio, Julia Smarto, and Alex Tello at Resurrection Catholic Church in Wayne.

New Center on Technology & Disability

The federal Education Department's Office of Special Education Programs (OSEP) is launching a new Center on Technology and Disability. The Center will include an Assistive Technology library, a CTD Café, and a CTD Learning Center, with online courses taught by national AT/IT experts. For more information, go to www.ctdinstitute.org. ■

SAVE THE DATE:

NADS
Magic Show

JANUARY 25TH
ARCADA THEATER,
ST. CHARLES, IL



Social Security Disability Benefits: Can I Apply with Down Syndrome?

Lisa Giorgetti, Community Liaison, Social Security Disability Help

Applying for Social Security Disability benefits from the Social Security Administration (SSA), whether for yourself or your child, can be overwhelming, but understanding the application process can be helpful in obtaining support for your family.

SUPPLEMENTAL SECURITY INCOME

Supplemental Security Income (SSI) is a disability benefits need-based program that requires strict technical and financial criteria to be eligible. SSI serves elderly and disabled people who have low income or may have lacked the opportunity to work and pay Social Security taxes. The SSA determines financial need according to several financial limits, including ceilings for applicants' income and the total value of their assets. Those seeking SSI benefits will need to fit within these limits in order to qualify.

As of 2014, a single household cannot make more than \$720 per month in income and own more than \$2,000 in assets, excluding his or her home and one vehicle, while for a couple's household, the limits change to \$1,080 per month in income and \$3,000 in assets. An individual with Down syndrome can apply for SSI benefits on their own, or a child can apply through their parents' financial resources.

When applying for a child applicant, the parents or guardians will go through the parental deeming process, where the SSA will evaluate your household's financial resources. Only

a portion of the financial resources will be deemed towards the child, so even if you exceed the financial limits listed above, your child could still qualify (<http://www.disability-benefits-help.org/blog/parental-deeming-process>).

For disabled adult children to be eligible, their disability needs to have begun before they turned 22 and they must not be married. Despite being over 18 years old, he or she will be considered a child applicant because they will meet the technical requirements based on their parents' or guardians' Social Security earnings record.

MEDICAL ELIGIBILITY

The SSA keeps a guidebook of recognized disabilities, called the Blue Book, that would make an individual eligible for benefits. In addition to the financial or employment requirements, applicants need to meet the requirements listed for their disability in the Blue Book. There are separate listings in the Blue Book for adults and children. Down syndrome is listed by name under Congenital Disorders that Affect Multiple Body Systems in Section 10.00 for adults and Section 110.00 for children.

The adult listing requires the following criteria:

- Results of karyotype analysis confirming diagnosis.
- Doctor's notes stating that the individual has chromosome 21 trisomy and the distinctive physical features of Down syndrome.
- A physician's report stating that the individual

has Down syndrome based on the physical characteristics and evidence that they function at a level consistent with non-mosaic Down syndrome.

For children, a parent must present their child's case with the same information presented in an adult case, including: Karyotype analysis lab results, physician's confirmation, and physical characteristics and typical mental functions (<http://www.disability-benefits-help.org/disabling-conditions/down-syndrome-and-social-security-disability>).

That said, the SSA only names non-mosaic Down syndrome in the Blue Book because the severity of mosaic Down syndrome can vary and many people with the condition can live fairly unrestricted lives. In order to qualify with mosaic Down syndrome, you may have to do so by matching listings of associated symptoms of Down syndrome:

- **Congenital heart disease**
 - Section 4.06 (adult) or Section 104.06 (child)
- **Organic Mental Disorders**
 - Section 12.00 (adult) or Section 112.00 (child)
- **Hearing loss** – Sections 2.10 and 2.11 (adult) or Sections 102.10 and 102.11 (child)
- **Musculoskeletal Conditions** – Section 1.00 (adult) or Section 101.00 (child)

THE APPLICATION PROCESS

When starting the application process, you have the option of completing it online or in-person with a representative

from the SSA. However, applications for children must be completed in-person.

Before you begin, gather all medical and technical documentation needed for each step of the process. This includes:

- Medical records
- Doctor's notes
- Hospitalizations
- Treatments received
- A sufficient work history for SSDI or financial information for SSI

Keep in mind that there can be a bit of a wait time for a decision from the SSA. After two to four months or so, you should receive a decision. If your initial claim is denied, don't be discouraged or stressed. You may appeal the decision within 60 days of the notification. If you don't begin the appeal process within 60 days of the decision, you will have to start the application process over.

You may want to consider hiring representation to help you prepare all the required information effectively and present it to the SSA in a way that improves your chances of qualifying. Disability advocates and attorneys are specialists who understand best practices for the application process and the best way for you to qualify with your disability. Knowing ahead of time what will be asked of you before you begin the application will help greatly when going through the process. ■

Editor's Note: For more information, go to www.disability-benefits-help.org or www.ssa.gov/disabilityss/i/.

VOLUNTEERING

NADS Seeks Volunteers

NADS is looking for volunteers with communications/PR experience. We also need volunteers to assist with administrative tasks. If you are interested in helping in either of these areas, please contact Diane Urhausen at 630-325-9122 or durhausen@nads.org. ■

Parent Support Volunteers

Are you interested in helping new parents? NADS will be training a new group of support volunteers in 2015, and we are looking for mothers and fathers of young children who might want to serve in our parent support program. If you think you might be interested in mentoring other families and helping them get connected to local resources, please contact Ann Garcia, NADS Family Support Coordinator, at 630-325-9112 or agarcia@nads.org. ■

New Board Member

Welcome to new NADS Board member, Michelle Pusatera. Michelle is also a NADS Parent Support Volunteer and, as one of our Parent Speakers, has given many presentations at local hospitals. We are glad to have her on our board! ■

NADS Resource & Referral Service

Do you have a question about IEP's? Looking for a medical specialist, hard to find clothing, summer camps, adult programs or other resources? NADS offers a resource and referral service to help families with these and many other questions. We can refer you to appropriate programs or help you research your options. Just call NADS at 630-325-9112 and ask for Ann Garcia, the Family Support Coordinator. ■



FUNDRAISING

Yard Sign Fundraiser

Thank you to Peggy Delaney and KinderCare for this year's very successful yard sign fundraiser for NADS. A record number of families ordered an "I love someone with Down syndrome!" sign to display in their yard in honor of Down Syndrome Awareness Month. We are grateful for the hard work of Peggy and the staff at KinderCare in managing the sign distribution and for everyone who supported NADS and helped create awareness about Down syndrome by purchasing a sign. Many thanks to all involved! ■

Stand Up For Downs

We are grateful to Rob Snow and Stand Up For Downs for donating \$5,000 to NADS from his "Big Windy" comedy night in Elmhurst September 27. If you came to our recent conference, you may have seen Rob perform during lunch. We are glad he was able to join us for that event and very much appreciate his generous gift as well as the support he has provided to the Down syndrome community. ■

WeeVu App

NADS just joined the WeeVu mobile app, which allows you to donate a portion of your purchases to the charity of your choice. By downloading the free WeeVu mobile app, you will be able to shop and have WeeVu give back to NADS! To learn more, go to www.weevu.com. ■

Amazon Smile

NADS is an approved charity with Amazon's charitable donation program, Amazon Smile. You can go to smile.amazon.com, and if you choose NADS, Amazon will send us .5% of the total from eligible purchases—something to consider as you do your shopping this holiday season! ■

Penny Wars Fundraiser

Many thanks to third grader Maddie McKenna and her family for their donation to NADS from the Penny Wars Fundraiser Maddie organized between two classes at her school in Langhorne, PA. We appreciate their creative fundraiser and their gift. ■

NEW RESOURCES

The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities

Don Meyer and Emily Holl, editors
Woodbine House, 2014; \$21.95

Don Meyer, the director of the Sibling Support Project, partners with a licensed social worker to cover the concerns of siblings about the care of their adult brother or sister with a disability. This book includes questions drawn from surveys of hundreds

of siblings. The authors address topics such as future planning and taking care of yourself with practical information and advice. ■

Touch Math Adventures

TouchMath Adventures is an app series which teaches children math concepts, such as counting and addition, through adventure scenarios and mysteries to be solved. For more information about the apps or the Touch Math curriculum, go to www.touchmath.com. ■

Simple Smart Phone

A new smart phone is available for seniors and others who may benefit from a simpler version of smart phone technology. For more information, go to www.simplesmartphone.com. ■

Sign Me A Story

Sign Me A Story provides mobile apps which teach sign language through stories and videos. To find out more, go to www.signmeastory.com. ■

family album



Avery Strongs



Danielle Thomas



Katherine & Richard Jegen



Jimmy Petrillo



Riley Erdman



Kyle, Conor, Patrick & Sean Yerkes

We Need Photos!

Send your
Family Album
photos
to NADS!

shebein@nads.org



Graham Traynor, Tom Delaney, Stephen Yorga, Peter Vargulich, Steve Connors and Matt Adamczyk.

D.A.D.S. Update

On Sunday September 28th, members of the Chicagoland D.A.D.S. group enjoyed a round of golf at Twin Lakes Golf Course in Westmont IL. D.A.D.S. (Dads Appreciating Down Syndrome) is a group of fathers with a simple mission: to assist and support, through fellowship and action, the fathers and families of individuals with Down syndrome. If you are interested in learning more about the DADS group, visit chicagoland-dads.org.

The D.A.D.S. winter holiday party is scheduled for December 6th, 2014 - 7pm at Emmett's Ale House in Downers Grove. Dads and Moms are welcome to join us for a little holiday cheer. Please see chicagoland-dads.org for more details. ■

Managing Behavior

Continued from page 5

be very useful, with a visual schedule or a social story.

We are also required to problem-solve several times a day, quickly and efficiently. We take into consideration the pieces of information we deem relevant, usually from what we see and hear, keep that information in mind while we think about what we've experienced in the past, consider the consequences of what to do next, and finally respond, usually in the space of a minute or less. It's complicated!

Individuals with DS may have difficulty paying attention to all the relevant information, focusing only on one or two things. Their attention may need to be drawn to the relevant details. (Look at her face, is she smiling or frowning?) This will then influence how they relate that to their experience, in order to interpret the situation. Guiding them through the process of how to think through situations can help them

with the interpretation. (She is unhappy, you're right. What could have happened?) They then may have difficulty choosing an appropriate way to respond, and have trouble considering the consequences of their actions, before they act. (What do you think you could do: ask her if she's OK, or if she needs help? Bring her something to eat?) Some individuals will struggle with answering open ended questions. It may be more effective to give them multiple choice answers from which to choose. The use of visuals to help understand, especially for these multiple step processes, can be very beneficial. Figuring out where an individual's processing is breaking down takes detective work, but gaining this understanding will help problem-solve similar situations in the future. Also remember that problem solving gets even harder if stress or anxiety is present.

These differences in processing likely explain why so many individuals with DS thrive on predictable routines and structure. Indeed, they often impose their own routines and structure on the world around them, needing to control the physical structure (doors need to be shut, tables need to be clear), what happens next, or how activities must be done (I open the door and you walk through). We can optimize behavior and learning, and minimize stress, by structuring physical spaces appropriately, organizing activities in a predictable manner, and by building routines. Within these comfortable environments, we can more effectively teach flexibility and problem solving, thus averting future frustration behaviors.

Recommended resources:

FOR VISUAL SCHEDULES:

- iPhone Apps by Good Karma Applications, Inc.
- www.handsinautism.org, Visual Supports and Practical Tools
- www.do2learn.com, Visual Schedules
- http://lessonpix.com/articles/9/35/First+Then+Boards

FOR SOCIAL STORIES:

- www.thegraycenter.org, Social Stories Workbook, Comic Strip Conversations Author, Carol Gray

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