

PLUS: UNITED STATES MILITARY SECTION



EXCEPTIONAL PARENT
MAGAZINE

DECEMBER 2019
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INSIDE THIS ISSUE:

ADVOCATING *as* A FAMILY
in THE COMMUNITY

PLUS:

LESSONS
from
OLMSTEAD

EP's ANNUAL ISSUE:

HOLIDAY
TRAVEL TIPS

FAMILY, COMMUNITY
AND THE

Holidays

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TOP TOY *and*
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ALSO:

MYTHS *about*
HIRING PEOPLE
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ON OUR COVER

As the year draws to close, and we draw our loved ones near, we know more than ever that families aren't "one size fits all" and neither is the support plan for caring for a loved one with a disability. EP's Annual Family, Community and the Holidays Issue features a myriad of articles and resources dedicated to finding that unique set of services that fits your family and your loved one's needs. Coverage begins on page 20.



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INFORMATION
AS TOOLS FOR POSITIVE
CHANGE FOR THE SPECIAL
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| | | |
|--|--------------------------|---------------------------|
| Editor-In-Chief | • Rick Rader, MD | • habctrmd@aol.com |
| Managing Editor | • Vanessa B. Ira | • vira@ep-magazine.com |
| Publisher | • Len Harac | • LHarac@ep-magazine.com |
| Vice President of Business Development & Sales | • Faye Simon | • fsimon@ep-magazine.com |
| Accounting | • Lois Keegan | • lkeegan@ep-magazine.com |
| Art Direction & Design | • Leverett Cooper | • lev@foxprintdesign.com |
| Information Technology Expert | • Ron Peterson | • ron@ep-magazine.com |

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Subscriber Services

1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012
subscribe.ep-magazine.com

Customer Service/New Orders

Faye Simon fsimon@ep-magazine.com
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Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative nomenclature.

— Rick Rader, MD

EP magazine neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.



Parachutes, Oranges and Clinical Trials

For those ID/DD clinicians in the trenches we have learned to rely on “our” version of the RCT... “Respect, Compassion and Thoughtfulness.”

When I was in high school,

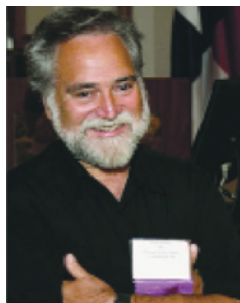
I was the student athletic trainer for the football team. I learned how to tape ankles, treat bruises, sprains, and athlete’s foot. Looking back, I was also a culprit in carrying out the coach’s practice of discouraging the players from drinking water during the summer practices leading up to the start of the season. Those were the days when, if you were injured, you heard the mantra of “walk it off.” I was under the guidance and tutelage of “Ol’ Doc” Greenberg, a cigar-chomping local GP (a general practitioner that we now call a FP or family physician) who served as the volunteer team physician. One of my chores was to slice oranges into four sections and give them to the players during half time. I could never really understand the medical value of having a quarter of an orange in the middle of a game and one day I asked Doc Greenberg why this routine was religiously adhered to. Chomping on his cigar, he shook his head and said, “We don’t want them to get scurvy now, do we?” His remark was of course sarcastic, an art form he was famous for.

It was sarcastic in that no one in the Flatbush section of Brooklyn was at risk for catching scurvy, and if they were, a quarter of an orange was not the treatment of choice.

The practice of giving oranges to prevent scurvy (a vitamin C deficiency disease) was “discovered” and pro-

moted by a Scottish naval surgeon, James Lind in 1747. Lind was appalled by the high mortality of scurvy among the sailors. More sailors died from scurvy than from battle.

Lind describes “On the 20th of May 1747, I selected twelve patients in the scurvy, on board the Salisbury at sea. Their cases were as similar as I could have them. They all in general had putrid gums, the spots and lassitude, with weakness of the knees. They lay together on one place, being a proper



the like. Two were ordered each a quart of cyder a day.” Lind went on to describe the various diets of ten of the sailors and then described the diet of two of sailors, “Two others had each two oranges and one lemon given them every day... The consequence

was, that the most sudden and visible good effects were perceived from the use of oranges and lemons, one of those who had taken them, being at the end of six days fit for duty.”

Although the results were clear, Lind hesitated to prescribe the use of oranges and lemons because they were too expensive (perhaps one of the first examples of cost cutting due to managed care). Instead, they opted for limes, which proved ineffective but gave birth to the nickname for British sailors, “limeys.”



SLICE OF LIFE: Scottish naval surgeon James Lind “discovered” that using oranges could prevent scurvy in 1747. Lind had been appalled by the high mortality of scurvy among the sailors, more of whom died from scurvy than from battle.

apartment for the sick in the fore-hold, and had one diet common to all, viz, water gruel sweetened with sugar in the morning, fresh mutton-broth, often times for dinner, at other times light puddings. Boiled biscuit with sugar, etc.” and “for supper, barley and raisins, rice and currants, sago and wine or

tions.

According to Dinethra Menon, “An RCT is a comparative, controlled experiment designed for finding useful information on efficacy (or costs) of one or two medical treatments in different patient groups.”

The three words represented by RCT pro-

Lind’s work with oranges was among the earliest prototypes for the “Randomized Clinical Trial” (RCT), the Gold Standard in evidence-based medicine for evaluating the effects of medical interven-

vide a simple explanation of the research design and methodology.

Randomized relates to how the participants are selected so that “chance” alone ascertains who receives treatments. This removes selection bias which, in turn, makes the results more reliable.

Controlled infers that the experimental environment that compares whether an intervention works to a control condition (either placebo or an alternative comparable intervention).

Trial design ensures intervention groups are treated the same. The results define the difference, if any, of outcomes between groups.

RCTs aim to find out which treatment is best by making a fair comparison between three variables. According to the Medical Research Council of England, these are “A new treatment and an existing treatment; two or more existing treatments and a new

treatment and no treatment, or a placebo (where there is no existing treatment).”

The first published RCT in medicine appeared in the 1948 paper entitled “Streptomycin treatment of pulmonary tuberculosis.”

RCTs are not without their critics. One sarcastic study was published in the British Medical Journal (BMJ) to assess the evidence for using a parachute to prevent death and major injury when jumping from a plane. Since the authors found no RCTs testing of the safety of jumping from an airplane with a parachute; they had to conclude, “As with many interventions intended to prevent ill health, the effectiveness of parachutes has not been subject to rigorous evaluation by using randomized controlled trials.”

Perhaps nowhere else in medicine is the debate of the utility and application of the

RCT is as hot as it is in the field of “developmental medicine.” For one thing there are few RCTs that address the unique health-care needs of individuals with intellectual and developmental disabilities. We very often have to extrapolate, extend, substitute and transpose the elements of an RCT to make it seem appropriate and applicable to our patient population.

And then there’s the “no proof that parachutes prevent death from jumping from a plane” position. We don’t know of any ID/DD RCTs that prove that treating a patient with dignity, respect and empathy impacts on the clinical outcomes of any given treatment. We don’t know that treating patients, specifically with an intellectual and developmental disability, with oranges and lemons will prevent scurvy. We seem to be successful with intuition, parental guidance, hallway consultations, communicating with our patients, feedback from direct support professionals and yes, from time to time, with a “Hail Mary pass.”

For those ID/DD clinicians in the trenches we have learned to rely on “our” version of the RCT... “Respect, Compassion and Thoughtfulness.”

For my money, if the jet I’m riding in is going down and there’s a spare parachute, I’m grabbing it; and on the way out, if there’s a sliced orange within my reach, it’s going with me. •

ANCORA IMPARO

In his 87th year, the artist Michelangelo (1475 -1564) is believed to have said “Ancora imparo” (I am still learning). Hence, the name for my monthly observations and comments.

— Rick Rader, MD, Editor-in-Chief, EP Magazine
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

CONNECT AND DISCOVER

Join EP’s Facebook Community



EP’s revamped Facebook page welcomes you to share stories, discover resources and connect with the special needs community.

Parents and families with members with special needs benefit greatly from meaningful interaction with peers facing the same challenges and joys. Facebook has provided the EP readership community with a convenient and effective platform to communicate, ask questions, promote events and share special moments.

Connect, Share and Discover with EP
www.facebook.com/exceptionalparentmag

Visitors can access the latest news and articles from recent issues of EP Magazine, and provide feedback and insight of their own.

EP’s Facebook page an open community group for parents, grandparents, family and friends of people with special needs family members. It’s an ideal place for both parents and professionals to share information and resources.

Parents, teachers, academics and professionals that are willing to help each other by sharing knowledge and resources are a vital part of the EP community. Like us today!

A portrait of Phillip Fiore, a man with dark hair, smiling, wearing a blue blazer over a light blue button-down shirt. He is positioned in the upper half of the frame against a dark, textured background.

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WHAT'S HAPPENING

STATE-OF-THE-ART SNOEZELN ROOMS AT ARC BROWARD



A LIGHT TOUCH: Snoezelen Multi-Sensory Environments are relaxing spaces that help reduce agitation and anxiety, but they can also engage and delight the user, stimulate reactions and encourage communication.

For persons who may be physically or visually impaired, deaf or hard of hearing, or struggle with language, communication or difficulties with motor skills, there are engagements designed for all users within a Snoezelen room, without restriction of age or ability.



The Haley's Joy Swing, is used to strengthen the vestibular system, the knowledge of where the body is in relation to other objects. Lying flat on the swing has been proven to improve mood, increase focus and calm our body's "fight or flight" response.

The multi-sensory environments have a soothing effect on their clients using calming sounds, captivating aromas and tactile experience of vibrations, vibrosonic sensations, and gentle movement designed specifically to engage and comfort someone experiencing high levels of anxiety or agitation, focusing on relaxation, development, stimulation and therapy, helping to improve the quality of life.

Two Snoezelen rooms have been installed at Arc Broward: a

large classroom designed to stimulate the senses and provide opportunities for interaction, where IBS participants can spend the day, as well as a smaller space more conducive to relaxation and calming when needed. For



The Abbotsford Chair reduces stress and restlessness with soothing vibrations and sounds.

more than 60 years, Arc Broward has worked hand-in-hand with our community, changing how people with disabilities and other life challenges are embraced and included.

This critical work ensures that people with disabilities not only live, learn, work, and play in their communities, but more important, thrive.

Through the manipulation of lighting, atmosphere, sounds and textures for the specific needs of the client at the time of use, the Snoezelen Multi-Sensory environment allows the individuals to organize and respond appropriately to the stimuli most suitable for them.



The Infinity and Beyond Panel features sounds effects and music in conjunction with shapes and colors that are controlled by push buttons, making it a great proponent of hand-eye coordination.

The addition of the Snoezelen rooms were made possible by the great generosity of the Taft Foundation, whose mission to improve the lives of children and adults with intellectual and developmental disabilities greatly aligns with that of Arc Broward, and in collaboration with Flaghouse.



The Fiber Optic Light Spray, safe to the touch, soothes through its vibrant blue color cascading from the ceiling, encouraging interactions that promote the use of motor skills and tactile sensory awareness.

WHAT'S HAPPENING

RARE DISEASE COMMUNITY CALLS ON CONGRESS & FDA TO ENACT LIFE-SAVING PUBLIC POLICY SOLUTIONS

Hundreds of rare disease advocates from around the country were recently brought to Washington, D.C. by the Rare Disease Legislative Advocates (RDLA), a program of the EveryLife Foundation for Rare Diseases (ELF). The group gathered in the nation's capital to implore Congress and the U.S. Food & Drug Administration (FDA) to take actions that will change the face of rare disease diagnosis and treatment forever.



SHOW OF STRENGTH: Rare disease community members from across the country gather at the Ronald Reagan Building during Rare Disease Week on Capitol Hill to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators.

“More than 30 million Americans are diagnosed with a rare disease, yet 93% of these rare diseases have no FDA approved therapies. This is unacceptable. The enactment of common-sense legislation is the only way to address this public health crisis and ensure that all rare disease patients have access to early diagnosis and lifesaving treatments,” said Julia Jenkins, Executive Director of ELF.

RDLA presented the RareVoice Awards to honor individuals who have demonstrated leadership in advocating for federal and state public policy solutions that benefit rare disease patients. Among those honored: United States Senator Roger Wicker (R-MS) and Representative Lucille Roybal-Allard of California (D-40).

“Every life matters and every voice deserves to be heard. We are here to ensure Congress and the federal agencies understand it is within their power to put into place life-saving solutions, giving every person with a rare disease the opportunity for safe, effective and affordable treatments,” concluded Ms. Jenkins.

Rare Disease Week on Capitol Hill brings rare disease community members from across the country together to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators.

In 2020, the week of events will start with the Rare Disease Congressional Caucus briefing, which will convene policy

experts and rare disease stakeholders to educate Congressional staff and the public on issues of importance to the rare disease community.

All events are free for patients, caregivers and other advocates but advance registration is required for each event. Please sign up for our email list at <https://everylifefoundation.org/newsletter-signup> or check RDLA on Twitter, Facebook, and Instagram for updates.



ABOUT THE EVERYLIFE FOUNDATION FOR RARE DISEASES:

The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science-driven public policy. The Foundation does not speak for patients, but instead provides the training, education, resources and opportunities to make patient voices heard. By activating the patient advocate, the Foundation believes it can change public policy and save lives.

WHAT'S HAPPENING

EVERYLIFE FOUNDATION IDENTIFIES PRIORITIES IN POLICY AGENDA

300+ rare disease patients and advocates were in Washington, D.C. to advocate for policies that will ease the physical, emotional and financial toll taken on patients by more than 7,000 rare diseases. At the recent Rare Disease Congressional Caucus Briefing, ELF outlined its public policy agenda, including several key priorities:

- **Calling on Congress to pass the Newborn Screening Saves Lives Reauthorization Act** (H.R. 2507 & S. 2158) (<https://everylifefoundation.org/newborn-screening>), that supports the screening of newborn babies in all 50 states for rare diseases. Currently, this legislation has expired, putting the health of newborn babies through America's most successful public health program at risk. The need for quick passage of the Newborn Screening Saves Lives Reauthorization Act, is epitomized by the story of Erica and Chloe Barnes. Erica lost her daughter, Chloe, to a rare disease. Had newborn screening been available to Chloe, her rare disease would have been detected at birth and treatment made available immediately. Instead, her mom faced heartbreak, a delayed diagnosis, and medical system unequipped for her family. She has since become a tireless advocate for newborn screening (www.minnesotaalumni.org/stories/university-to-form-rare-disease-advisory-council) and efforts to remove other barriers to proper healthcare through her work at the University of Minnesota.
- **Urging the FDA to establish an FDA Rare Disease Center of Excellence** (<https://everylifefoundation.org/fda-center-excellence>) as authorized by Congress' passage of the 21st Century Cures Act in 2016. The Center will help advance the pharmaceutical treatment pipeline for rare diseases, especially those (93%) that currently have no FDA approved treatment options.
- **The launch of a first-of-its-kind project** to measure the real economic impact that living with a rare disease has on patients, caregivers, healthcare providers, insurers, employers, schools, and other stakeholders. Results will be published in 2020, then shared with Members of Congress to help ensure that all cost considerations are factored into critical evidence determinations and public policy decisions.

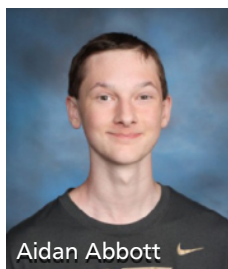
Two other patient stories highlight the need for common-sense legislation:

- **Isabel Bueso**, a native of Guatemala, came to the U.S. to participate in a clinical trial for mucopolysaccharidosis type VI (MPS VI), and for six years has become an advocate for rare diseases during treatment. Due to a change in federal immigration policy that eliminates the ability of patients from outside the U.S. to remain in America during clinical treatment, she is currently facing deportation. Courageous and undaunt-

ed, Isabel is working with members of Congress to seek a permanent solution for her and all rare disease patients affected by the new policy. Read more about Isabel's journey at <https://everylifefoundation.org/everylife-foundation-statement-on-uscis-action-on-deportation-requests-impacting-rare-disease-patients>

- **Aidan Abbott**, a 14-year-old teen from Slinger, Wisconsin, is working with Senator Tammy Baldwin (D-WI) to pass the Ensuring Lasting Smiles Act (www.baldwin.senate.gov/press-releases/ensuring-lasting-smiles-act-2019). Aidan was born with ectodermal dysplasia (ED), a rare congenital disease that affects hair, skin and sweat glands. Some patients with ED are born without many or all of their teeth and suffer collapsed jaws and facial deformation.

The Ensuring Lasting Smiles Act would ensure health plans cover medically necessary services related to a patient's anomaly or birth defect, including any serious dental and oral-related procedures that are necessary to maintain health and overall function. •



Aidan Abbott



Isabel Bueso

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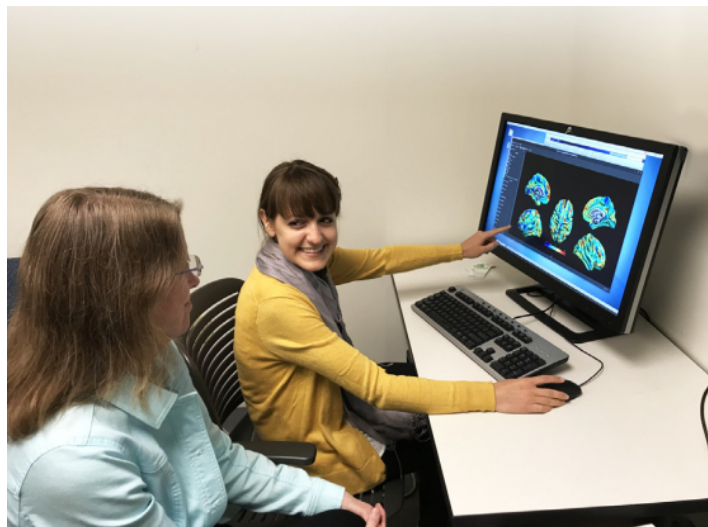
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participated & donated and wishes everyone Happy Holidays.**

NEW PRODUCTS

HOLIDAY CHILD'S PLAY

SIT TIGHT WEIGHTED LAP PAD

The Sit Tight Weighted Lap Pad helps children and adults improve their focus, attention span, and stay seated longer. The gentle pressure of the Sit Tight helps the user stay calm and focused. It is smaller than a weighted blanket and designed to stay on the lap while seated with use of its waist strap, that securely fastens around the back. The lap pad provides deep touch to the skin which is an effective tool to help your child stay in their seat and focus on their work whether it is circle time, home/school work, or mealtimes. To use, place the Sit Tight on the lap during meal time, sit and listen times, or resting times at home or at school. It features a strap that fastens around the waist to help ensure it will stay put while a child is seated. The strap is closed by a buckle and the size of the strap is adjustable. Children can also carry the Sit Tight across the room when a break is needed. The Sit Tight provides a little extra weight when a child takes a walking break. This can help improve their focus when they return to sit and work. Available in small, medium, and large.



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B-CALM HEADPHONES FOR KIDS

The b-Calm Headphone system is a noise reduction ear muffs system. This system features headphones with audio engineered "acoustic shield" tracks. These tracks feature designed white noise that makes typically distracting noises unnoticeable to the listener. It also features soothing nature tracks to help calm and recenter agitated students. The system can be used to help students block out distracting noises to help with focus or to protect kids from over stimulation. Individuals will love how disturbing noises are blocked and replaced with familiar and soothing sounds from nature and the world around them. Each b-Calm system includes a pair of headphones, ear buds, "acoustic shield" soundtracks, black carrying bag and an MP3 player.

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The ABLEDATA database of assistive technology (AT) and rehabilitation equipment contains information on more than 50,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for these pages by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by New Editions Consulting, Inc., is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: ABLEDATA, 103 W. Broad Street, Suite 400, Falls Church, VA 22046; phone: 1-800-227-0216; TTY: 703-992-8313; website: <https://abledata.acl.gov/>; email: abledata@neweditions.net; Twitter: [www.twitter.com/AT_Info](https://twitter.com/AT_Info); Facebook: www.facebook.com/abledata; Pinterest: www.pinterest.com/AT_Info/

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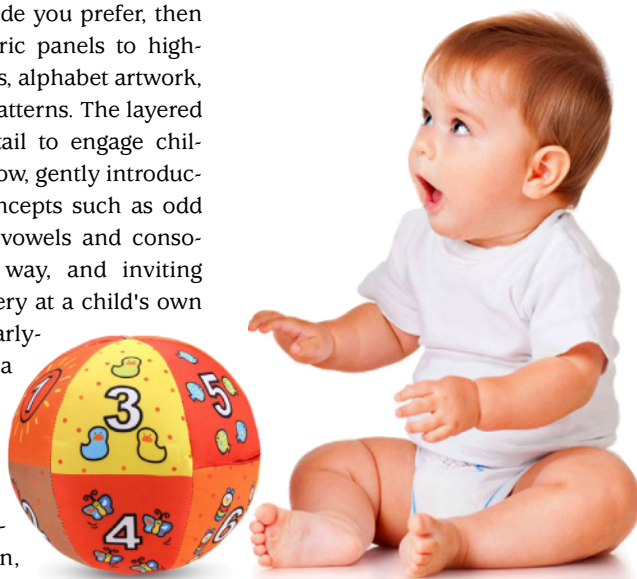
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“We hold these truths to be self-evident...” Children with disabilities can become healthy and successful adults

BY H. BARRY WALDMAN, DDS, MPH, PHD AND STEVEN P. PERLMAN, DDS, MSCD, DHL (HON)

All too often, we tend to live in the past, reflecting on experiences that were the norm in our earlier years. As we age (we the authors are in our mid 70s and 80s), the good ole days take on a glow of nostalgia (a sentimental longing or wistful affection for the past, typically for a period or place with happy personal associations¹). We are inclined to overlook the difficulties and hardships that existed in the long past supposed halcyon years. For example, developments in one area had dramatic impact on the way our ancestors lived.

“... the steam engine had been attached to milling machines and had been used to dramatically lower the cost of luxury cloth previously available only to the rich. That cloth was cotton. Until then, the clothes of the poor had been made of wool. Wool shirts and pants could not be laundered. They smelled deplorable. And they housed parasites (and) insects...”²

“...two chemists in France used a science still in its birth ... to develop techniques for mass producing the raw ingredients for another miracle product – a product that had previously been made by hand – soap. And soap took the health benefits of laundering to the next level.”²

AND IN OUR LIFETIME

In 1967,

“...there were more than a quarter of a million individuals (in the US) with mental retardation/developmental disabilities (MR/DD) in state institutions... (and) in psychiatric institutions... (By) 1997, the number of institutionalized residents with MR/DD decreased by 75

percent and 91 percent in psychiatric institutions. For more than three decades, changing social policies, favorable legislation for people with disabilities, and class-action legal decisions ... (have modified our understudying of the abilities of individuals with special health care needs).”^{3,4}

In 1988,

“...the true measure of a society lies in the way it treats its older, handicapped, and disadvantaged citizens. If this is true, the U.S. society still has a way to go.”⁵

In 1990,

“The (Americans with Disability Act) ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. The purpose of the law is to make sure that people with disabilities have the same rights and opportunities as everyone else. The ADA gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications.”⁶

In 1999,

“... the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services



AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

The American Academy of Developmental Medicine and Dentistry (AADMD) was organized in 2002 to provide a forum for healthcare professionals who provide clinical care to people with neurodevelopmental disorders and intellectual disabilities (ND/ID). The mission of the organization is to improve the quality and assure the parity of healthcare for individuals with neurodevelopmental disorders and intellectual disabilities throughout the lifespan.



FOR BETTER OR WORSE: For many, marriage is the keystone for joy and happiness. In 2014, the overall first-marriage rate for people ages 18-49 years was 71.8 per 1,000 persons; For people with disabilities it was much lower than for the general population, 41.1 per 1,000 persons.

are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.”⁷

In 2011,

Children with disabilities grow up:

- Sixty percent of young adults with disabilities reported having continued on to postsecondary education within eight years of leaving high school.
- Ninety-four percent of young adults with disabilities reported having been engaged in employment, postsecondary education, and/or job training during their post-high school period.
- Ninety-one percent of young adults with disabilities reported having been employed at some time since leaving high school, holding an average of four jobs.
- Fifty-nine percent of young adults with disabilities have reported living independently (on their own, primarily in a college dormitory or military housing).
- The participation rate of young adults with disabilities in any one of three types of social and community involvement activities - lessons or classes outside of school, volunteer or community service activities, and organized school or community groups - was 52 percent.⁸

YOUNG ADULTS WITH SEVERE DISABILITIES

Having held a paid, community-based job while still in high school is strongly correlated with post school employment success. In addition, being a male and having more independence in self-care, higher social skills, more household responsibilities during adolescence and higher parent expectations related to future work are associated with increased odds of employment after school for young adults with severe disabilities.⁹

MARRIAGE

Is the legal or formal recognized union of two people as partners in a personal relationship. For many, marriage is the keystone for joy and happiness.

In 2014,

The overall first-marriage rate for people ages 18-49 years was 71.8 per 1,000 persons. For people with disabilities it was 41.1 per 1,000 persons; much lower than for the general population. However, there are very wide variations in the rates of individuals with disabilities that marry.

- *15.5 per thousand for Blacks with disabilities in independent living arrangements.*
- *Whites and American Indians with hearing disabilities have marriage rates above the national average for individuals with disabilities.*
- *For every disability condition, Blacks with disabilities have the lowest marriage rates.*¹⁰

In 2012,

Should couples with special health care needs have children?

“Despite obvious difficulties placed upon children in a family with a disabled parent, I do not believe a couple in this situation should refrain from having children. There are many pros and cons in bringing up a family under these circumstances. Unfortunately I could never join my daughter on school trips, participate in any sports day or events of a physical nature; these were left for my husband to attend. However, being at home I was able to spend hours of quality time every day with my child which most working mothers aren’t afforded the opportunity. All those hours we spent together were precious and created a lasting bond between us. If I weigh up the good and the bad, I believe that for me the positive things have far outweighed the negative. If I’d known what lay in store, would I still have had a child? My answer is unequivocally “Yes.” I wouldn’t have missed out on having my daughter for the world.”¹¹

ON THE OTHER HAND

*"The children are endangered when, for example, the parents do not know how to hold or bathe the child safely, make the home environment safe, provide emergency first aid, or when to take the child for medical treatment..."*¹²

*"I'm not promoting forced sterilization for the mentally challenged, but shouldn't the rights of an innocent, vulnerable baby be taken into consideration, too? Shouldn't the emotional growth and safety of an inquisitive toddler be encouraged and protected? And as the child ages, doesn't he/she have the right not to be environmentally handicapped because his/her mentally challenged parents wanted a baby?"*¹²

*"A young couple with Down syndrome says they are ready for babies and marriage, despite the pleas from their concerned parents, who doubt their children are emotionally and physically ready."*¹³

*"The parents of 8-month-old Hunter and 4-year-old Christopher have lost custody of their children — not because they have harmed them, endangered them or neglected them... Rather, they have been told they are not smart enough to raise their boys and have fallen down a rabbit hole of trying to prove to child welfare authorities they are worthy parents, according to advocates and experts."*¹⁴

And your thoughts are...

In 1999,

"Having a disability shapes a person's life, but it not their total destiny."

– Senator Robert Dole¹⁵ •



ABOUT THE AUTHORS:

H. Barry Waldman, DDS, MPH, PhD is a SUNY Distinguished Teaching Professor, Department of General Dentistry, Stony Brook University, NY.

E-mail: h.waldman@stonybrook.edu

Steven P. Perlman, DDS, MScD, DHL (Hon) is the Global Clinical Director and founder, Special Olympics, Special Smiles and Clinical Professor of Pediatric Dentistry, The Boston University Goldman School of Dental Medicine.

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PREPARING FOR A LIFETIME OF EDUCATION

STARTING SCHOOL IS A BIG EVENT, BUT WITH A BIT OF PLANNING YOU CAN FACILITATE A SMOOTH TRANSITION.

Starting school is a big event for everyone. It represents a fast-paced period of growth, development and change. And to help ease the transition for children with special needs, there are certain steps that can help you prepare — starting with the Individualized Education Plan (IEP).

The IEP is an important legal document that will spell out learning needs, the services to be provided by the school and how progress will be measured. Over time, you'll gain more insight into your child's needs as well as abilities, which will allow you to adjust the IEP and any related financial plans accordingly.

BUILD BRIDGES WITH YOUR COMMUNITY

It is important to take the time to meet with your community leaders and establish rapport with the local school superintendent and staff. Community organizers may have more insight into financial aid and additional types of support to help with special needs care.

GET INVOLVED IN YOUR SCHOOL COMMUNITY

By getting involved with your school community, you may find other families and support groups in your area with similar experiences. Speak with your school's principal, special education teachers, and local community organizations for information on support groups and educational workshops. This is a great opportunity to extend your network of support and connect with other families and resources in your community.

REVIEW FINANCES REGULARLY

In the process of planning a lifetime of care and support, it's always a good time to review the finances that will support your future plans. At least once a year, you should review your financial picture to make sure your goals are being met. As your situation changes, you'll be able to develop a better idea of what resources may be needed. It's also a good practice to keep track of your spending, including any out-of-pocket expenses for your loved one's care. By planning and projecting for all scenarios, you may be able to cushion the impact of any unexpected scenarios, as they arise. Also, remember to budget for the rest of your family — and your retirement.

DETERMINE ELIGIBILITY FOR SUPPLEMENTAL SECURITY INCOME (SSI) AND/OR MEDICAID

Prior to a loved one turning 18 and reaching the age of majority, his or her guardian's income and assets will be used to determine eligibility for SSI and/or Medicaid. However, once an individual turns 18 and becomes his or her "own person," his or her own assets and income will be the determining factor. Since an individ-

ual's assets and/or income cannot be more than \$2,000 to qualify for critical government assistance programs, it's important to review all of your accounts, beneficiary designations, and titling to protect eligibility. Working together with a special needs planning financial advisor is one way you can ensure everything is in order.

CHOOSING A LEGAL GUARDIAN

As a parent, you are the walking encyclopedia for your child, and you know what's best for him or her. But what happens if you're no longer around to make those important decisions? Is there someone

you trust to step in and fill your shoes? While no parent looks forward to choosing and needing a legal guardian, it's an important safety net to have for children under the age of 18. Depending on your child's needs, he or she may need this type of ongoing help and guidance as an adult. If you feel your child will be unable to make important life, medical, and financial decisions on his or her own, choosing a guardian may be the best way to protect your child. Most states have their own legal requirements for what constitutes a legal guardian. In most cases,

the preference will be for an adult parent to take on the role or, if this is not possible, an adult sibling or a close family friend. Guardians are supervised by the court to prevent any potential abuse of trust.

ADDITIONAL TAKEAWAYS

- Medicaid and SSI aren't the only government programs available to your child. Spend some time online looking into additional community and state offered programs.
- In the process of planning a lifetime of continuous care for your child, don't forget to plan for your own retirement. A specially trained financial professional can help you address both and create a comprehensive strategy for your family.
- Remember the importance of successor caregivers and legal guardians. With a guardianship, your child could lose a great deal of independence, so it's best to carefully consider whether a guardianship is the most suitable option or if less restrictive alternatives would be more effective.

Most importantly, remember that you are not alone. You have access to specially trained financial professionals* to help you make important decisions and create a lifetime of continuous care. •

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ORGANIZATION SPOTLIGHT

BullyingCanada supports tens of thousands of abused youth with a robust network of volunteers who are trained in resolving and coping with these situations.

Myriad resources are made available to children and to school administrators across the nation.

COMBATING CRUEL BULLYING OF CHILDREN FOR OVER A DECADE

BY JAMES RYAN

This December, BullyingCanada will turn thirteen years old. Since its inception in 2006, by fourteen-year-old Katie Thompson (New) and seventeen-year-old Rob Benn-Frenette, O.N.B., BullyingCanada has been tirelessly working on supporting bullied youth throughout Canada.

Katie and Rob formed BullyingCanada out of frustration owing to a lack of resources when they experienced their extreme bullying. Still bearing the physical and emotional scars, they continue to support bullied youth, trying to make the world a safer, happier place.

These past thirteen years have been a time of significant progress, with bullying going from accepted and expected childhood behavior to becoming a public health issue. Yet, BullyingCanada still helps more than seventy-five-thousand youth each year. Because BullyingCanada operates on a case-management system—staying involved until the bullying situation has been resolved—they receive, on average, over one-thousand communications each day from youth in crisis from across the nation.

Though increasingly less tolerated, these incidences of bullying and extreme bullying are happening at alarming levels, and they can have devastating, lasting consequences for all involved—victim, bystander, and bully. Bullying can lead to issues with both mental and physical health.

Most of the calls BullyingCanada get can be described as nightmarish, but they're all certainly emotionally taxing. Those volunteers working on the support team endure a rollercoaster of emo-

tions on any given day. Rob Benn-Frenette shares some relatively recent stories:

"Though our calls aren't typically this grim, last year, I picked up the phone when a middle-schooler called BullyingCanada to ask that a final message be relayed to her parents when they got home, because she didn't want a younger sibling to find her first. She had slit her wrists and was hiding in her bedroom closet. Why? Because her tormenters told her to do so. Thankfully, we were able to get emergency personnel to her in time to save her life."



BullyingCanada is only national anti-bullying charity solely dedicated to creating a brighter future for bullied youth. What began as a youth-created website to bring together bullied kids and provide information on bullying and how to stop it is now a full 24/7 support service. On any day of the year, at any time, youth, parents, coaches and teachers contact BullyingCanada by phone, online chat and email for help on how to make their bullying stop. Its Support Team has more than 215 highly-trained volunteers.

After, he reached out to ask if we could meet for him to say thank you. We usually don't meet our clients (we had just over 76,000 last year), but I made an exception in his case. Speaking to him reminded me that this is why I do what I do."

"I remember another incident where a boy called us after seeing our television commercial; he was desperate to escape this torment. This six-year-old and I talked for about two hours—he told me his heartbreaking story about being bullied continuously, pushed and shoved on the playground, and continually teased. We were able to address and resolve his situation."



EVERY MOMENT COUNTS: The longer a child is bullied, the more likely they are to develop physical, emotional, and psychological scars that can last a lifetime. Resolving bullying situations involves directly facilitating communication between bullied kids, their tormentors, parents, teachers, school boards, social services, and police.

BullyingCanada supports these tens of thousands of abused youth with a robust network of volunteers who are trained in resolving and coping with these situations. Myriad resources are made available to children and to school administrators across the nation.

In addition to providing anti-bullying

posters, brochures, and other collateral, BullyingCanada gives hundreds of presentations at schools and community groups nationwide. These presentations cover a variety of topics for staff, volunteers, and students. Since starting this Youth Voices program, BullyingCanada has conducted more than 4,000 of these workshops.

BullyingCanada manages to do all of this, and more, on a limited budget that supports its volunteers with the necessary resources to provide the crucial help to bullied youth. If you need help or you wish to support this registered charity by donating or volunteering, please visit them online at www.BullyingCanada.ca or call (877) 352-4497.

Bullying is devastating, dangerous, illegal, and unacceptable. Don't be a passive observer, if you see it: say something.

If your child is experiencing bullying, contact their teacher(s) and their school – hold them accountable for behavior at school – and offer them access to support resources, such as those provided by BullyingCanada.”

ABOUT THE AUTHOR:

James Ryan is the Director of Public Relations for BullyingCanada Inc, which is Canada's premier—and first youth-created—anti-bullying charity. Founded by Rob Benn-Frenette, O.N.B., and Katie Thompson (Neu) in 2006, BullyingCanada has served hundreds of thousands of youth across the country by, among other initiatives, providing individual support, extensive resources, case management, scholarships, and presentations to schools and organizations.

BULLYING AWARENESS : TIPS FOR PARENTS

- Be involved
- Know what's going on and openly communicate with your child.
- Notice their moods and feelings.
- Be persistent
- Regularly ask about your child's friendships (keep in mind your child may describe bullying behavior without calling it that).
- Monitor their online activities and social media usage.
- Be on the lookout
- Keep an eye on their grades – investigate any major shifts.
- Notice if they're missing any important or prized possessions.
 - Be mindful
 - Listen without judgment.
 - Remember that it's not up to the child to fix the situation (if they could, they wouldn't seek help from adults).





Different Shades of the Holidays

Wherever you are in your life's journey and whatever your role, I hope my stories inspire you to focus on the merry and not the crazy side of the holidays.

Holiday experiences strike people's hearts unpredictably, the same way the pointer in roulette hits different outcomes. The season could be "the best of times," or "the worst of times." Celebrations can be a source of great joy, or stress, or both. What may be fun to one person may be distressing to another, depending on an individual's role, circumstances, and focus.

My recollections of holiday events unfold a breathtaking landscape of emotions, interactions, and insights. I want to share them with the community, hoping that we will be enlightened to be sensitive to the emotional needs of everyone during this season. The stories I picked reflect the stark differences in my status and situations in life.

AS AN INDIVIDUAL WITH VISUAL IMPAIRMENT

As a younger woman with visual impairment, I reveled in friends and family reunions, dressing up to the nines and assuming the life of the party. But blaring music, booming fireworks, or riotous yelling can transform me from a graceful social butterfly to a klutzy wicked witch. I would look the part if it were Halloween,

but if it were Christmas or New Year's, I'd be the Grinch or bad luck incarnate.

One Christmas evening after dinner, I was absorbed in conversation with a relative while sipping wine, when loud music suddenly blasted the room to signify the start of the merrymaking. Startled, I shot up from the couch. I fumbled to the coffee table to put down my glass, but disoriented and high-strung, my hand swept across the surface, knocking down all the glasses on the table. A squeal of frustration escaped my lips, alarming everybody at the party. Seized by embarrassment, I sped towards my bedroom to hide, but I clumsily smashed my face on the edge of the wall that led to my place of refuge. At that point, I was the center of distraction and a party pooper.

"There goes my effort to be invisible," I fretted.

The taste of blood touched my lips. It was oozing out of a vertical cut along the bridge of my nose. A family friend, a nurse, cleaned my wound. At my request, my folks



turned down the music. I re-joined the merrymaking despite the pain. On the lighter side, I was ready for Christmas as Rudolf the red-nosed reindeer.

AS A PRE-SCHOOL SPECIAL EDUCATOR

As a pre-school special education teacher, I took special care in preparing my students for the various holidays and events on the calendar. I showed them pictures and sounds that were symbolic of events (e.g., fireworks for New Year's Day in January) as I introduced the months of the year. This way, my students looked forward to the special days. I included the parents and the community in planning the celebrations to ensure that every child will enjoy, and families will not be burdened. To set their expectations, the children also acted out mock parties. But regardless of preparations, there was always that one child who felt intimidated in a crowd, became overstimulated by bright lights, or got scared at the sight of Santa. Previously, I would be emotionally charged myself, cod-

dling the child like it was the end of the world. But, over time, I learned that it was perfectly alright for these kids to do alternative activities. It's best to make a child feel that he or she's in a safe place around family and community, especially during festivities.

AS A MANAGER

Christmas carols bring back my best holiday memories when we were managing a massage livelihood for visually-impaired masseurs. We were a full house with about eighteen employees, some of whom had spouses and children living with us in the building. We were the nearest of kin for our personnel, and we wanted to give them an enjoyable holiday experience. We all agreed that the best way we could enjoy the yuletide season was through bringing Christmas cheers to everyone who welcomed us, especially to those who were lonely. So every night after work, we diligently practiced caroling. When we were ready, we serenaded our customers, residential institutions for people with special needs, and families who opened their houses to us, singing Christmas carols. The good deed brought fulfillment to our extended family. Since then, caroling became a tradition which we carried out every year.

AS A MOTHER WITH A VISUALLY-IMPAIRED DAUGHTER

Christmas of 2017 was my worst. Both my kids were out of the country. My son, a US Navy corpsman, was on sea duty and my daughter Jem who, like me, is visually impaired, was in Osaka, Japan, on a study abroad program. I had arranged for Jem to stay with a Filipino friend in Tokyo for the holidays during the winter break. The plan was for my friend to pick Jem up at a café in one of the busiest stations in Tokyo. My daughter took the bullet train to their meeting place on the 24th of December. A few minutes before Christmas eve, she called to inform us that she'd been waiting for hours, but nobody had approached her. I tried to get in touch with my friend but got no answer. My husband and I were in a panic, yet there was nothing we could do to help Jem.

"What a Christmas," I cried, as negativity doused my heart.

"Let's just hope for the best," my husband interjected.

His words were like magic! My heart instantly opened to the truth that there was hope, and hope is the meaning of Christmas! It was not only the celebrations and reunions, but a living, though yet unseen assurance that, eventually, all shall be well. And it became the merriest Christmas when Jem finally messaged us in the morning that she was safe in my friend's house.

AS A VISUALLY-IMPAIRED TEEN WITH THREE SIBLINGS ALSO VISUALLY IMPAIRED

Yes, you read correctly. We are four legally blind children, a tight community in and of itself, a whole unit of broken and hurting teenagers. Every year, after the traditional Christmas eve meal and gift-giving, our parents would go to bed and our only sighted brother would hang out with friends. We, on the other hand, were the restless shut-ins during the season. We couldn't drive, and there were no available means of public transportation, so we resorted to an underground drinking spree at home. My older brother always managed to buy gin and lime juice for the occasion secretly, and the four of us would drink ourselves to intoxication. We commiserated with one another's negative emotions. I enjoyed those no-holds-barred sessions because I could be myself and not worry about feeling inferior, or rejected for being different. I shared my stories about being treated like an outcast or the "strange one" in my social circles. I clearly remember always feeling relieved to discover that my story was also their story and that I was not alone in my lonely island.

Those times were my pre-advocacy days and the awakening of my heart to speak up for my community – individuals who, like me, are not disabled, but differently-abled. Such is the healing benefit of a community.

Wherever you are in your life's journey and whatever your role, I hope my stories inspire you to focus on the merry and not the crazy side of the holidays. Every holiday perspective, no matter how imperfect, has a redeeming nugget of wisdom, the real and lasting gifts of the season.

A WORD OF ADVICE

Increasing commercialization has debased our holidays. Giving and receiving gifts, lavish celebrations, and fancy get-ups, among other things, have been the focus of merriment. Consequently, stress and depression usually override excitement during the yuletide season. On this note, I would like to urge everyone to re-create our holidays. We aren't obliged to abide by traditions. Let's think about our priorities and the atmosphere we want to produce – and then plan for it. Come up with activities that will touch the hearts of friends and family. Why not give our loved ones something to remember during the gatherings, like the assurance that they are genuinely valued, hearty laughter, and warm fellowship as we bond during this season? If we want to give gifts that keep on giving, let's take the opportunity to make good memories.

Finally, Thanksgiving Day, the beginning of the holiday season, is an opportune time to reset our attitude. If, on this day, we could count our blessings instead of what we lack, we would have restructured our priorities. Let's be grateful for our joys that overshadow sacrifices, for our abilities that eclipse special needs, for the things we have and can share with a community that understands. •

HEARTSIGHT

Christina Llanes Mabalot is physically blind from aniridia, but has a vision. She enjoys touching people's lives to bring out the best in them. "Heartsight" explains her ability to see with her heart. Christina earned her B.A. degree and Masters in Education from the University of the Philippines, Diliman, specializing in Early Intervention for the Blind. She later received Educational Leadership training through the Hilton-Perkins International Program in Massachusetts, then worked as consultant for programs for the VI Helen Keller International. She has championed Inclusive Education, Early Intervention, Capability Building and Disability Sensitivity programs. She was twice a winner in the International Speech contests of the Toastmasters International (District 75) and has been a professional inspirational and motivational speaker. Christina is blissfully married to Silver Mabalot, also physically impaired, her partner in advancing noble causes. Their children are Paulo and Jem, who has aniridia. Visit leadershiptovision.com



ADVOCATING AS A FAMILY IN THE COMMUNITY

Advocacy in the community is a very important skill and one that takes time and preparation to develop, whether you are the parent of a child with a disability or an individual with a disability.

BY PAMELA AASEN

Both of my children have Usher syndrome type 1; they were born deaf, are progressively losing their vision and have severe balance issues. In the beginning my husband and I learned to advocate as their parents, but as they got older, we recognized the need to prepare our children to advocate for themselves. It was a process, and one we developed along the way.

Ethan and Gavin are 17 and 15 years old now. They participate in their IEP meetings, advocate for themselves with their teachers, and regularly present at schools, universities and charitable events to speak about their experiences and raise awareness about Usher syndrome. They are Student Ambassadors for Ava's Voice, an organization dedicated to empowering youth with Usher syndrome and to educate families and school communities. As my husband and I begin to take the backseat and watch them in action, we are reassured that they are confident young men who understand themselves and can communicate their needs.

In the beginning...

Our oldest son, Ethan, was born in 2001 in the Dominican Republic. My husband and I had been there for many years; with the beautiful weather, jobs we loved, and a relaxed lifestyle, we thought life could not be better. A child was a wonderful addition to our lives. However, my suspicions that Ethan had hearing loss began early. Of course, in the beginning, you want to believe you are mistaken in thinking there is a problem and hope to be proven wrong. My first lesson in advocating for my child was getting my husband on board. Thankfully, he was open and listened to my concerns. The next lesson was believing in ourselves as parents because it took a while to get the professionals to take us seriously. Finally, after months of frustration and worry, and knowing something was not right, we took Ethan to be evaluated in Florida when he was 10 months old. He was diagnosed as having a profound bilateral sensorineural hearing loss.

It was an emotional time, but Ethan was a baby, so it was up to us to advocate for him and make the decisions we thought were the best for our family. When we were presented with our options, we decided on cochlear implants. He was immediately fitted with hearing aids and we headed back to the Dominican Republic to prepare for his cochlear implant surgery in Miami at 13 months old.

Everything got much harder when we returned to the Dominican Republic. Being in a foreign country, we did not have any resources or support groups at our disposal. We diligently researched resources for children with hearing loss and cochlear implants. It was overwhelming and we quickly realized the next step in our advocacy journey was identifying our roles. My husband would take the research role while I would be responsible for implementing Ethan's appointment/therapy needs.

After Ethan's surgery, we made the decision to move our family to Canada. I'm Canadian and the access to universal healthcare made the most sense. We knew we had to do what was best for Ethan to maximize his speech and language development. In 2004, his brother Gavin was born in Toronto. Infant hearing screenings were available, so we found out at the hospital that he failed the screening. Given our experience with Ethan, making the decision and advocating for Gavin to get a cochlear implant was easy. Gavin was fitted with hearing aids as we started to prepare for his surgery at eight months old. It wasn't over yet though.

The next decision was immediately upon us as a second cochlear implant became an option. It wasn't automatic in 2005 like it is now with the research to support bilateral implants. There were certainly advantages to getting a second implant but were also told we should save an ear in case there was a "cure" one day. Again, we had our roles... as Ethan, Gavin and I attended audio-verbal therapy together, I talked to the professionals and my husband researched the benefits. We attended conferences and the family education days held by the Hospital for Sick Children. We again made the decision we thought was best and the boys received their second implants within six months of each other – Gavin at 18 months and Ethan at almost five years old.

We realized that part of being a good advocate for our children was doing the research and then being confident in the decisions made moving forward. We also

knew it was important for our children to be around other kids like them so we joined organizations for the deaf and hard of hearing. We became volunteer advocates and shared our story, on panels and through presentations, with parents who were facing the same decisions.

Elementary School...

The next big part of advocating for our children was keeping them in the loop. We started at an early age, talking to them about being deaf and how their "ears"

couldn't walk. There was something off with their vision, too; they couldn't find things that were right in front of them and they had difficulty seeing at night. My husband and I noticed they were clumsy, they fell all the time, they couldn't walk on uneven ground and they couldn't seem to coordinate the movements of their body. We described them as floppy; their first "official" diagnosis was "lax ligaments". We felt there was more to it; it still didn't quite fit so we again we had to trust ourselves as their parents. While we continued to advo-



GOOD SPORTS: Like any parent of a typical child, we put them in sports. They tried and loved them all... even if they weren't very good because of their balance problems. They worked hard on getting better, both by themselves and with their personal trainer. It paid off as they became athletes and developed a love for all sports; each eventually made travel baseball teams and currently are on their high school cross country and swim teams.



worked differently. We taught them how to change their own batteries and take care of their equipment. As soon as they started kindergarten, we had them talking to their classmates with help from their Teacher of the Deaf. They were asked to be on panels, talking to teachers about having a deaf or hard of hearing child in the classroom. They used it as a topic for speech contests in school. We strongly believed that talking to others would help them understand their differences while at the same time highlighting, for themselves and others, what made them special. Our goal was to build their confidence...and it worked. Some of their peers asked if they could have a cochlear implant!

During these early years, there were other concerns; as infants they couldn't hold up their heads, as babies they couldn't sit on their own, and as toddlers they

cate for a further diagnosis, we took them to occupational therapy and physiotherapy. Eventually, when Ethan was 7 and Gavin was 5, they were diagnosed with Usher syndrome type 1b.

I remember the feeling of relief with knowing that there was a known cause for their struggles and the devastation I felt with the diagnosis when I thought about their future. We certainly needed time to grieve but we also knew we needed to continue being their advocates and help them understand this new dimension. We talked to them about what having Usher syndrome meant; they would have to work harder at anything balance related and, like their ears, their eyes were also different, and they would need help at school.

They, in turn, continued speaking about their needs to classmates and teachers. We felt strongly that their diagnosis didn't

define them, but if they could embrace their differences through public speaking, they wouldn't feel any shame with the accommodations they needed to level the playing field with their typical peers.

So our efforts continued. Our family helped start a charity golf tournament to raise money for vision loss with the boys as the featured speakers. We spoke at special education classes at a local university. We nominated the professionals at the Hospital for Sick Children for a family-centered care award, and the boys presented the award to this group that was truly like our family. They even filmed an episode of a Canadian TV Show that raised awareness by showing a day in the life of children facing challenges.

Middle and High School...

In 2014, when the boys started middle school, we moved to New Jersey! Not only were they in the position of being in a new school and having to make new friends, they had to navigate a new country. This decision was not made lightly and, since they were on the path of advocating for themselves, we knew they needed to be a part of this major life decision that would take them away from all that was familiar. As their parents, we researched the schools, the health care, and made inquiries about the Usher syndrome community to provide all of us with the information we needed to make this decision. This is when we found the organization, Ava's Voice. We went for it and though it took time, our family adjusted and settled into our new lives. The boys had a level of confidence that helped them share their background with new teachers and peers. To boost that confidence, they participated in leadership activities like the Civil Air Patrol, and an annual leadership conference.

As the boys got older, we looked for opportunities to increase our advocacy at all levels. I got a job at the SPAN Parent Advocacy Network. We became active participants in Ava's Voice; the boys were part of student panels and spoke at schools, universities, workshops, conferences and charity events. At this time, it had evolved to be a family affair so when I had the opportunity to propose a presentation for the SPAN's Leadership Conference, we developed a presentation titled, "Advocating as a Family".

Along the way...

Throughout this time, though Ethan and Gavin were also attending doctor's appointments and therapy sessions, we knew that it couldn't all be about having Usher syndrome. There were family outings/trips to help them experience the world and build their vocabulary. We also wanted them to have visuals as their vision faded. And like any parent of a typical child, we put them in sports. They tried and loved them all... even if they weren't very good because of their balance problems. But they didn't give up. They worked hard on getting better, both by themselves and with their personal trainer. It paid off as they became athletes and developed a love for all sports; each eventually made travel baseball teams and currently are on their high school cross country and swim teams. They enjoyed swimming with their typical peers but commented that because of their fatigue level at the end of the day it was like they had practiced already for two hours and then had to have a two-hour practice with their typical peers.

When they lost more vision, we realized it was time to find a place where they could compete against other youth like them so they joined a Paralympic Club and participated in para events. For us, the idea

was to have many avenues open to them when one closed. Maybe they can't play baseball anymore, but they could join cross country. Para sports increased those opportunities and gave them the chance to compete against other visually impaired athletes.

All of these activities helped Ethan and Gavin build their confidence and knowledge of the world, but the final piece of the advocacy puzzle was providing them with role models – successful adults with Usher syndrome. They have met an author/motivational speaker, and a Paralympic athlete, both of whom have Usher syndrome. They have met blind engineers, teachers, and other professionals to give them a glimpse into the future that is possible for them. Through Ava's Voice they have attended a camp for youth with Usher syndrome, giving them peers they can relate to. So, now as we prepare to send our oldest son off to college, we are confident we have given them the tools to be successful. •

ABOUT THE AUTHOR:

Pamela Aasen is the parent of two children with multiple disabilities, and serves as the Director of the EHDl (Early Hearing Detection & Intervention) Mentoring and Family Engagement Project at SPAN Parent Advocacy Network. For more information, see <https://spanadvocacy.org/programs/ehdi>

TOOLS FOR SUCCESS : ADVOCATING RESOURCES



AVA'S VOICE
www.avasvoice.org



**HEARING LOSS INFORMATION
FOR FAMILIES**
(includes contact for each state)
**CENTERS FOR DISEASE CONTROL
& PREVENTION**
www.cdc.gov/ncbddd/hearingloss/families.html



**NATIONAL CENTER ON
DEAF-BLINDNESS**
<https://nationaldb.org>

RESOURCES FOR USHER SYNDROME



USHER SYNDROME COALITION
www.usher-syndrome.org



USHER SYNDROME SOCIETY
www.ushersyndromesociety.org



MARK'S MOMENTS TVO
www.tvokids.com/school-age/videos/marks-moments/ethan-and-gavin

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EDUCATION THROUGH SIMULATION

The law enforcement officers approach Gabby with care as she paces back and forth and tears little bits from the paper in her hands, dropping them to the floor.

Clearly upset, she avoids eye contact and

talks into her phone. The officers remain calm, gently defusing the situation while following Gabby's lead in conversation. Eventually, they make a connection and the tension eases.

The scenario is part of a training simulation for law enforcement officers in recognizing behavioral characteristics of autism and adaptive their responses in crisis situations to meet the needs of individuals on the autism spectrum. The program was developed by Johns Hopkins All Children's Hospital with a grant from the Cigna Foundation.

"Prior to this training, we are all ... This person is acting this way, so maybe I will have to go hands-on because they aren't listening to me. It may get escalated," said St. Petersburg Police Department officer Carla Ramos, who recently attended the training. "But with a person with autism, with this training, you realize you need to take a step back."

About one in 59 children is diagnosed with autism spectrum disorder (ASD). The training program teaches officers how to more effectively communicate with individuals on the spectrum and their caregivers. The goal of this training is to increase positive outcomes by enabling officers to successfully defuse crisis situations that may otherwise result in arrest or involuntary psychiatric hospitalization, says Lauren Gardner, Ph.D., administrative director of the Autism Program at the hospital.

"We have a responsibility to our patients with ASD to assure we are building first responders' awareness regarding their unique strengths and weaknesses, and advocating for their needs in the community across the course of their lifespan from childhood to adulthood," says Gardner, who completed a ride-along with local law enforcement officers when developing the training program.

Such training provides law enforcement officers with awareness of the behavioral symptoms and social impairments that may make an individual with autism more vulnerable to be considered a suspect.

For example, if an individual with autism does not respond to police when spoken to, avoids eye contact upon questioning, does not remain still, or tries to flee the scene, these behaviors may be misinterpreted as a sign of guilt as opposed to behavioral characteristics of ASD. When unaware of the social communications deficits and restricted, repetitive behaviors commonly associated with autism, law enforcement officers may mistakenly view these individuals as a danger to themselves or others. In the training program, officers are taught to recognize deficits in social communication that are commonly associated with autism, such as poor

eye contact, limited expressive language and impaired conversational speech skills. They also learn about repetitive behaviors such as hand flapping, unusual body movements, repetitive speech patterns, and intense interests.

"Autism is highly variable," says George Jallo, M.D., medical director of the Johns Hopkins All Children's Institute for Brain Protection Sciences. "Some may be severely impaired, whereas others have a mild form. The need for education is critical for all who care for these young children and adolescents as they need to

learn how to manage them in school, community or stressful situations."

Florida became one of few states that requires autism-specific training for

law enforcement officers after a 2016 incident in North Miami where a police officer shot an unarmed therapist who was protecting his client who had autism.

In the first 10 months, the Johns Hopkins All Children's program trained 314 officers from 23 different law enforcement agencies. The

training starts with a classroom session in the morning and then moves into interactive simulations that allow officers to practice how to communicate with an individual with autism in a variety of training scenarios that they are likely to encounter.

"This training is significant for the entire community as we are increasing the skill levels of our first responders in deescalating situations where they encounter a child, teen or adult with ASD," explains Jen Arnold, M.D., M.Sc., medical director of the Center for Medical Simulation and Innovative Education at Johns Hopkins All Children's.

"Hands-on, experiential learning, like sim training, greatly enhances the training process. Simulation is a safe place to make mistakes, explore how they occurred and learn how to prevent them in the future," she adds. "We are learning so much and excited to see the program grow to meet this important educational need for law enforcement across the state and even nationwide."•

ABOUT THE PROGRAM AND ITS DIRECTOR:



Dr. Lauren Gardner is the psychology internship director and administrative director of the Autism Program at Johns Hopkins All Children's Hospital. She has provided services for children and families with a wide range of concerns, including noncompliance, autism spectrum disorder, developmental disabilities, depression, anxiety and social skills deficits. Dr. Gardner's clinical interests include neurodevelopmental disabilities. She earned her doctorate degree from Indiana University Bloomington and completed an internship in psychology at the

University of Tennessee Professional Psychology Internship Consortium and postdoctoral psychology fellowship in developmental/behavioral pediatrics at the University of Tennessee Health Science Center (UTHSC) Boling Center for Developmental Disabilities. Visit HopkinsAllChildrens.org/AutismTraining to learn more about the training program.

TO PROTECT AND SERVE: (Opposite page and above) Lauren M. Gardner, Ph.D. leads Johns Hopkins All Children's autism program's law enforcement officer training in Autism Spectrum Disorder, May 10, 2019. The goal of this training was to increase knowledge and awareness of autism spectrum disorder for law enforcement officers with the St. Petersburg Police Department.



JUST IMAGINE WHAT COULD HAPPEN IF MORE EMPLOYERS WERE EDUCATED ABOUT THE CAPABILITIES OF INDIVIDUALS WITH DISABILITIES AND THE MANY ADVANTAGES COMPANIES COULD REALIZE BY GIVING THIS GROUP THE OPPORTUNITY TO DO EXACTLY WHAT THEY WANT TO DO: RETURN TO WORK.

MYTHS ABOUT HIRING INDIVIDUALS WITH DISABILITIES

BY DIANE WINIARSKI

Individuals with disabilities are frequently subject to discrimination during the hiring process, often because employer misconceptions throw up roadblocks to employment.

Smaller businesses can be particularly challenging for applicants, because those organizations may not have much experience employing individuals with disabilities and may not understand how reasonably their specific needs can be accommodated. Unfortunately, even many large employers hold onto some myths about hiring individuals with disabilities -- all of which disappear under closer inspection.

MYTH #1

INDIVIDUALS WITH DISABILITIES ARE LESS PRODUCTIVE.

Some employers shy away from hiring individuals with disabilities under the incorrect impression that their disability will prompt them to take more sick days or cause them to not work efficiently.

However, individuals with disabilities are the same as any other hardworking employee. They are highly engaged and eager to use their skills to benefit their team and their employer. They are motivated and determined individuals who frequently overcome challenges just to be at work each day.

Individuals with disabilities want to be able to support their families and have financial stability. We work with thousands of SSDI beneficiaries each year, and 52% of them say they want to go back to work if and when their condition improves.

At the end of the day, the employers who give individuals with disabilities the opportunity to once again work will receive numerous benefits from this untapped talent pool. For example, a 2018 study by Accenture, in partnership with the American Association of People with Disabilities, found that companies who hired people with disabilities had better business outcomes than their peers who did not have disability-inclusive work environments. These companies saw 72% more productivity, 45% better workplace safety, 30% higher profit margins, and 200% higher net income. The numbers don't lie.

MYTH #2

INDIVIDUALS WITH DISABILITIES AREN'T QUALIFIED.

It may surprise some business owners to know that the average SSDI beneficiary has more than 20 years of work experience and skills.

This is great news for any employer, but especially the person's former employer. Many SSDI beneficiaries are interested in returning to their previous company and position, if possible, and their former employer would be wise to rehire them.

Recruiting someone who is already familiar with the type of

work, has completed training, and has prior experience and industry knowledge can save companies a lot of time and money. Training Magazine found that the average cost of training a new employee in 2017 was \$1,886. But other studies suggest the cost could be higher: SHRM found it took companies an average of 42 days and \$4,129 to hire a single new employee.

In truth, many companies are missing out on a sizable job pool. There are thousands of people with disabilities who are qualified for jobs in today's economy, thousands of individuals with disabilities who are ready to be hired. The unemployment rate for people with disabilities is 6.9% – twice as high as the



national unemployment rate (3.2%) – and by overlooking these candidates, recruiters and employers are passing up on a huge portion of the labor market.

The real problem here isn't a lack of qualifications. It's that many employers and potential employees don't know where to find the next job opportunity or the right candidate.

Fortunately, Employment Networks (EN) can simplify the search. ENs like Allsup Employment Services (AES) are a part of the Social Security Administration's Ticket to Work (TTW) Program, and assist anyone who is receiving SSDI benefits to put together their plan and return to work.

The TTW program helps beneficiaries find new or related careers after they medically recover, and also protects their disability benefits while they seek employment. This allows individuals to test whether they are truly ready to return to work without having to sacrifice their SSDI and Medicare benefits. For their part, ENs work one-on-one to create an Individual Work Plan (IWP) that goes over the person's skills, abilities, limitations, employment history, interests, and goals so that ENs can match them with the right opportunities.

Sadly, only 30% of SSDI beneficiaries know about the TTW program. Very few employers know about it too, and they are unaware that they can use ENs to find the right talent, right now because of those IWPs.

Many employers also are unaware that the Americans with Disabilities Act (ADA) does not require employers to hire someone with a disability if they are not qualified for the position. The ADA protects against the discrimination of individuals with disabilities who are qualified for a job. Employers are free to hire whomever they wish as long as they don't make their decision based on disability.

It's equally important for people to know that under the ADA, a potential employer cannot legally ask someone if they have a disability before making a job offer.

If individuals are afraid of inherent bias, they should know that they are not legally required to disclose that they have a disability if asked in an interview. If a potential employer were to ask such an inappropriate question, an applicant could divert that question by asking, "Is that legal to ask in a job interview?"

Once an employer provides a conditional offer, the game changes and the employer can ask you more personal questions about your health, disability, limitations and capabilities, or even require that you have a medical examination. All of these requests are legally compliant, so long as the employer treats all candidates the same.

So long as employers play by these rules, there shouldn't be any problems. Ideally, employers are striving to be inclusive and give everyone a fair chance during the hiring process, as that is the best way to welcome these qualified, readily available employees.

MYTH #3

HIRING AN INDIVIDUAL WITH A DISABILITY WILL ADD EXTRA WORKFORCE COSTS.

Opening your doors to people with disabilities does not have to be costly. Employers are only obligated to provide reasonable accommodations to employees, and "reasonable" qualifies as any change or resource that doesn't force "undue hardship" on the organization.

The good news is that many accommodations are free. According to the Job Accommodation Network (JAN), under the U.S. Department of Labor's Office of Disability Employment Policy, 57% of accommodations come at no additional cost to businesses, and the rest are typically under \$500.

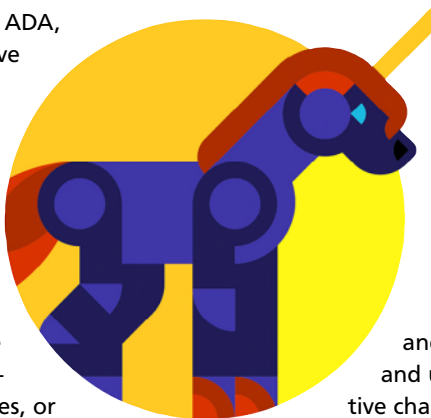
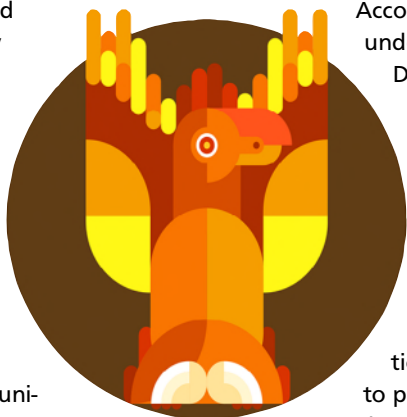
Most reasonable accommodations are fairly simple, such as standing desks, or Braille signage and ramps. Allowing for modified schedules, service animals, and remote work also count as reasonable accommodations.

Making these simple and low-cost accommodations are shown to be effective in allowing employees to perform their jobs, especially when the employer and employee have a discussion about what accommodations would help them the most. JAN also found that providing these reasonable accommodations is an investment with high returns. They discovered that companies who invested in their employees and provided them with the necessary tools to work were able to increase retention – cutting out the added costs of hiring new workers – and increase productivity. The companies also exhibited better relationships with their employees, saw greater company morale, increased attendance rates, and improved safety.

Clearly, employers have a lot to gain from hiring individuals with disabilities, especially since we have debunked the myths

that may be holding them back. Just imagine what could happen if more employers were educated about the capabilities of individuals with disabilities and the many advantages companies could realize by giving this group the opportunity to do exactly what they want to do: return to work. We could create a more diverse and inclusive work environment, and unlock progress that drives positive change throughout the entire U.S.

economy. •



ABOUT THE AUTHOR:

Diane Winiarski is the Director, Vocational Rehabilitation at Allsup Employment Services, a Social Security-authorized Employment Network created by Allsup, a provider of disability benefits representation.



LESSONS FROM OLMSTEAD

BY ERIC A. SWENSON

On November 1st, 2019, the Georgetown Journal of Poverty Law and Policy hosted its Volume 27 symposium. The event brought together luminaries of disability law, Supreme Court experts, direct service providers, and experts in housing, prisons, and data systems together with self-advocates to discuss the importance of the 1999 Supreme Court decision known as “Olmstead.” The opinion has been hailed as the disability community’s Brown v. Board of Education. It describes how a state or municipality might, and might not, be guilty of discriminating against people with disabilities who receive public services.

The Journal and I wanted this event to be a complement for a similar event at the Georgia State University. GSU had a two-day event with many speakers discussing this case and its implications. Our goal was to focus on some issues that are more associated with the Journal’s mission, which is fighting poverty through the law. With that in mind, we found volunteer speakers focused on the working conditions of direct support professionals and home health care aides; affordable housing shortfalls and related legal issues; and the criminal justice system and disability. Georgetown Law’s Supreme Court Institute sponsored a panel to discuss the supreme court case itself, following up on a GSU panel that discussed the representation of Lois Curtis and Elaine Wilson, the plaintiffs in this case.

I started this work in December 2017, during my first winter break from Georgetown University Law Center. I was exhausted from exams and could not face sitting at home wondering when the results would come out. Instead, I volunteered at DC’s landlord tenant court, talking to real people with problems related to their rented house or apartment.

I also wanted to read a case or two to keep practicing my new skills. I started by reading the *Olmstead v. L.C.* Supreme Court case. I knew this case's name before I went to law school because my family celebrated it and talked about how it could affect my brother and our family as well as others in our community. Even so, reading the actual case in the fog of a post-exam winter break was almost surreal.

It did not take more than two minutes after opening the case for something to pop out at me. The attorneys for the respondents (the people with disabilities) and the Solicitor General... they sounded so familiar. They were not my professors, but I recognized Michael Gottesman and Irving Gornstein because they are two of the many rock stars on the Georgetown Law faculty.

The idea started as just a wish to sit down and have a coffee with these two men. I cared because my brother was born with multiple and complex developmental disabilities. Charlie lived with my family until he was 26, which was almost his entire life. When I went away to college, I worked to convince the rest of his supported decision-making team that it was time to help Charlie live in a house of his own. By the time I graduated, he did.

“Change takes persistent work. I believe now that the ADA and *Olmstead* set the table for true belonging for citizens with disabilities, but the work of families still matters. We have love to give and expectations to set, and there is more work to do as advocates.”

I knew that sometimes he might not have someone to lay down with him in bed late at night to let him know that he was not alone. I also knew that he would have roommates his own age and would not have to live on our parents' schedules. Being integrated in the community meant more than living with our parents for his whole life, and then with my brother or me after our parents died. It also meant more than living in a safe place that addressed his every bodily need. Charlie always wanted to know people and make friends. He was disabled but he was curious. He liked being out and about. He liked to go



COMMUNITY SPIRIT: Charlie always wanted to know people and make friends. He was disabled but he was curious. He liked being out and about, to see and be seen. In other words, without knowing the law, he wanted to be the embodiment of the Americans with Disabilities Act's Integration Mandate.

swimming in a local pool where he could walk in waist-deep water. He liked to go to the local library to rent opera DVDs, or to go out for coffee, to see and be seen. When he was finally out on his own, his support staff figured out how to help him create a small dog-walking business. In other words, without knowing the law, he wanted to be the embodiment of the Americans with Disabilities Act's Integration Mandate.

I doubt that these Georgetown Law professors, even now, know how their work affected my life, my brother's life, and the lives of many others. Maybe some would politely suggest that the Supreme Court gave legal force to the cultural change that was already happening with the deinstitutionalization movement. However, I like to

believe that Prof. Gottesman and Prof. Gornstein's advocacy, along with the hard work of the Bazelon Center for Mental Health Law and the many advocates at Atlanta Legal Aid and at Protection and Advocacy organizations all around the country, led to a recognition that the ADA was not being correctly interpreted.

In January 2018, when I took my fledgling idea of a single panel reflecting on the case to the Supreme Court Institute's Director, Prof. Dori Bernstein, she encouraged the idea and gave me some goals. She said something along the lines of: "this sounds good, but why stop with us? A symposium might be a good idea."

Prof. Bernstein and I brainstormed from there. We dreamed big, we shared our sto-

ries, we strategized. I felt invigorated by our talk and newly confident that there was much more to law school than the exam results I was so anxiously waiting for.

I earned my way onto a journal. I learned more about Olmstead and revisited the project. The Journal formed a new board and my new Editor in Chief, Sarah Hainbach, liked our idea. She and I discussed how prevalent poverty is for some people with disabilities and the fact that fighting poverty tends to help people with disabilities. She trusted me to be the Symposium Editor and we got the support of the other editors to go forward with the plan.

Change takes persistent work. I believe now that the ADA and Olmstead set the table for true belonging for citizens with disabilities, but the work of families still matters. We have love to give and expectations to set, and there is more work to do as advocates. I know a lot of young people who have brothers and sisters with disabilities. Most of us work in whatever ways we can to make things better, whether we are practicing law or medicine or whether we are teaching or going to school or being a good citizen.

In the bad old days before the ADA, parents of children like my brother used to be

told: “You should institutionalize him. It will be better for your other children.” I hope that now parents are being told, “Do your best to include your disabled child in your family life and in school and help them live a full life in the community. This may well be wonderful for your other children.” People need to be given a chance. In any case, the law is clear, but we still have work to do to fulfill Olmstead.

Among the challenges we talked about during this symposium were:

- *The continued affordable housing crisis and the ways that a severe shortage of affordable, accessible, distributed housing leads to unnecessary institutionalization;*
- *The need for Bureau of Labor Statistics job category for direct service providers and for better wages to recognize the contributions of the home health care and personal assistant workforce;*
- *The need for expanded data to help states know what they are spending on various models of support so that they can find the most efficient and humane methods; and*
- *The problem of continued institutionalization of people with disabilities through the use of prisons, jails, and the school to prison pipeline.*

Our personal stories are inherently critical to our lives. What we decide to include in our story is critical to who we become as an adult. It is no different for our society. Thankfully, the Congress in 1990 and the Supreme Court in 1999 said that pushing people with disabilities into a setting that is inappropriate for them is illegal discrimination. What community integration means for you might be different than what it meant for Charlie and me. But make no mistake: it is because of my life with Charlie that I worked to make this event happen. Prof. Bernstein told me many times in moments of uncertainty over the last year and a half that this event would not have happened without me. To which I add: “Thank you, Charlie. I am glad you grew up at home with us and lived in a regular neighborhood with the help you needed. I am glad you were my brother.” •

ABOUT THE AUTHOR:

Eric Swenson is the Symposium Editor at the Georgetown Journal of Poverty Law and Policy. Eric was born in Minneapolis and has lived in Washington, DC, for nine years. The youngest of three brothers, he is an advocate for people with disabilities. He lived with his brother, Charlie, while growing up and worked to support Charlie’s independent lifestyle. Eric is in his last year of law school at Georgetown University Law Center in Washington, DC.

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS



WE RAISE MONEY FOR AUTISM RESEARCH... BUT NOT FOR OUR KIDS' SCHOOLS & SERVICE AGENCIES?

BY MICHAEL JOHN CARLEY

Many of us, as parents of spectrum kids, participate in “autism walks” or other events to raise money for autism research. But we don't volunteer anywhere near the same capacity for entities that directly impact our children – our kids' schools or service agencies. Why?

Well, the research walks are well-organized, their fundraising component is linked to spreading awareness, we're thanked adequately by the walk organizers (who engage us with empathy for our situations), the events are fun, we get to spend time with folks enduring similar experiences, and let's face it – our relationships with the schools and agencies that serve our kids can be contentious. We too often have to fight them to get what our kids need, deserve, and are legally entitled to. So given these parameters, our walking (infinitely more) for research makes sense.

But looking through another, perhaps painfully-obvious lens?

To start, there's that issue of “entities that directly impact our children.” Of the more than 1,300 funded research projects listed by the Interagency Autism Committee (IACC)¹ in 2014 (which is when I first looked into this issue for the Huffington Post,² a comparatively small amount of funding, as shown by the chart below, goes to towards “services,” and “lifespan” (two of the seven designated areas wherein autism research – specifically geared towards the living – is defined). Eight percent, to be exact.

The majority goes toward early childhood screening tools, or examining the biological, environmental, and genetic impact on autism with an eye toward causation and/or exacerbation. Furthermore, non-profit research orgs (with the exception of the Organization for Autism Research³) devote even less of a percentage to studies that would impact present-day families.

By 2016, the last year in which statistics were released in this format, little had changed (in fact, the 8% was reduced to 7%).

It also makes it extremely disingenuous, therein, for these organizations to tell us that walking for their walks will benefit our children, when most of the knowledge we'll gain from this type of research – nerve synapses and serotonin levels – may not impact a working class family with a child with autism... for 30 years!

That all said, the majority funding will result in worthy knowledge, research of a dramatically-higher scientific value than studies looking at educational strategies, or hypotheses that ask “How many spectrumites out there need housing?” The higher-brow knowledge will teach us about areas far outside the autism world – the human brain, environmental effects – even if it results in information that wouldn't trickle down in any meaningful way to the average, middle-class families for decades.

Part of the reason why our relationships with our kids' public schools and state-funded service providers are sometimes as volatile as they are has to do with the fact that these entities are too often dramatically under-funded. School boards that shudder at spending money on a child's individualized needs, to our sur-

prise, are not necessarily composed of bad people. Education budgets are continuously cut, especially in (mostly red) states that wish to see less overall government and public programs (such as the brainless “voucher system” in Wisconsin). Not coincidentally, these are states that usually produce little tax revenue. Public school employees have been through the ringer, operating without the same resources as others, and it shows. And until these officials don’t have to continuously base their decisions around what will have the least negative impact, they will not be able to muster the same smiles and programs as those enjoyed by walk organizers.

Service agencies even more so, with their horrific headlines of underpaid, uneducated and poorly-researched orderlies who become implicated far too often in the deaths of their residents (especially in my former state of New York). Often these are well-meaning but under-equipped organizations that, from top to bottom, simply cannot afford to hire good, qualified people. And even in the cases where they can, and a slimy CEO instead wishes to protect his high salary by skimming off the bottom? Greater funding would increase the accountability and monitoring of such agencies so that such misappropriation of funds would not go unnoticed.

As parents, we frequently assume that we should be primed for battle with these entities – we are not culturally conditioned to assist them – and too often this assumption is accurate. But if I learned anything in my pre-autism days at the United Nations, it is that economics rules almost everything. And one fiscal fact worth noting is that there is a class distinction here: Most autism research organizations were founded by parents of spectrum kids who have all of their service needs taken care of. Dare I say it, they are wealthier than most of us. And were they not, unmet service needs for their kids would be their top priority as well.

As non-wealthy parents of spectrum kids, we need to have a better understanding too, of the current explosion in autism research. There are significant scientific advances that are both fascinating, and that might even qualify as legitimate breakthroughs. But there is also trendiness – an existing notion that all

autism research is worthwhile. That notion is wrong. Due most likely to the actual researchers’ need for studies and publications to enhance their careers, the comparable gold mine available to them (when compared with 10 years ago), and the current hype surrounding autism research; some outrageous and/or redundant hypotheses stand a good chance of getting grants.

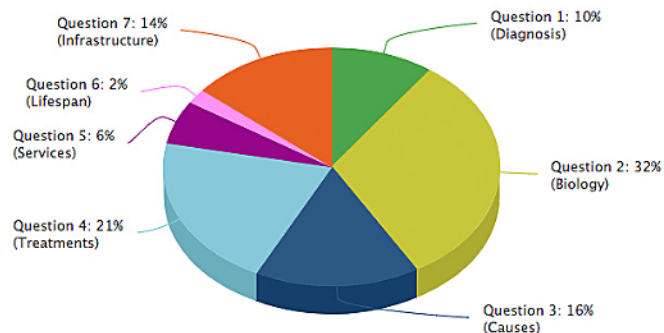
For instance, looking only at research announced in 2014 when I first studied this, why are we funding studies...

- Looking for a link between autism and vaccines by looking at aborted fetus tissue? (Vaccine theory was irreparably destroyed in 2007.)⁴
- Linking autism to genetics? (Uh, call me crazy, but didn’t we know this for certain over a decade ago?)⁵
- Showing autistic traits in parents?⁶ (Ditto.)
- Indicating that adults on the spectrum have a higher prevalence for suicidal thoughts?⁷ (Uh, when you’re from any marginalized group...?)
- Showing that older fathers carry greater potential for fathering spectrum kids?⁸ (Duh... due to the genetic component, if dad is socially challenged it might take him longer to find a mate.)

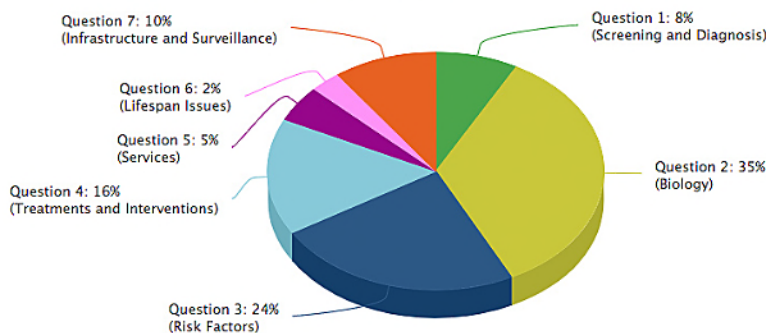
- Linking gut bacteria to problems,⁹ and broccoli to fewer problems?¹⁰ (While there may be autism-specific science in here, the idea that good things in our stomach making us feel, and therefore behave better, doesn’t strike me as worth the cost.)
- 9/24/14: One study reports finding 10 new genes¹¹ linked to autism. 10/30/14: Another study (link since removed) reported finding 24 new genes on top of the existing nine (did they miss the previously-mentioned 10?). And on the same day, 10/30/14 again: A third study reported finding 60 genes.¹² (Okay. Maybe good science, but it feels like no one would notice if we said we’d found 2,000 genes. Who’s keeping score here?)
- (My favorite...) Showing that children of women using selective serotonin reuptake inhibitor (SSRI) antidepressants during pregnancy were NOT at increased risk of autism?¹³ (I was losing so much sleep worrying about this one...)

Sigh... I could go on. Think of how many spectrum individuals could be given wonderful housing accommodations if the money from just one of these studies had gone to them.

ASD Research Funding by Strategic Plan Questions, 2014
Total Funding: \$309,873,907.00



ASD Research Funding by Strategic Plan Questions, 2016
Total Funding: \$364,435,254.00



STRATEGIC SLICES: It is disingenuous for autism research organizations to tell us that walking for their walks will benefit our children, when most of the knowledge we’ll gain from this type of research may not impact a working class family with a child with autism for 30 years.

The autism research community has fallen into a slippery slope – an ethical limbo wherein the money is high and the ideas are low, and the research community has shown no willingness to police itself and publicly call out its more charlatan brothers and sisters. And unfortunately, it is up to them to do so, not us. For as easy as it is for a dope like me to consider any scientific hypothesis a waste of time, only they can truly discern what studies will be valuable, and what studies merely capitalize on the fad of autism research, pad the bank accounts of clinical professionals, and benefit from our donations, tax dollars, or the miles we log on autism walks.

So, let's put economic focus on services and education, which is where the future of our kids – the ones living now – will be determined... unless, of course, we have the \$2.4 million that a child on the spectrum can cost¹⁴ through their lifetime. Easier said than done, I know.

Let's say you do have an awful relationship with that principal, or that executive director, one that contains years of fighting back and forth over the dollars spent on your child.

Well, imagine how that relationship, and your child's future might be altered if you surprised the daylights out of that individual, by walking into their office and proclaiming "I know you're strapped. Whether you like it or not, I'm organizing a fundraiser for you."

Inside, you can still feel the emotions of, or think to yourself, "YOU may not deserve it. But my kid does." •

ABOUT THE AUTHOR:



Michael John Carley is the Founder of GRASP, a school consultant, and the author of *Asperger's From the Inside-Out* (Penguin/Perigee 2008), *Unemployed on the Autism Spectrum*, (Jessica Kingsley Publishers 2016), the upcoming *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!*, and the column, "Autism Without Fear," which for four years ran with the Huffington Post but is soon to move to Neurodiversity Press. Dozens of past "Autism Without Fear" columns can be found by going to

www.michaeljohncarley.com/index.php/articles.html. And for more information on Michael John, or to subscribe to his updates, you can go to www.michaeljohncarley.com.

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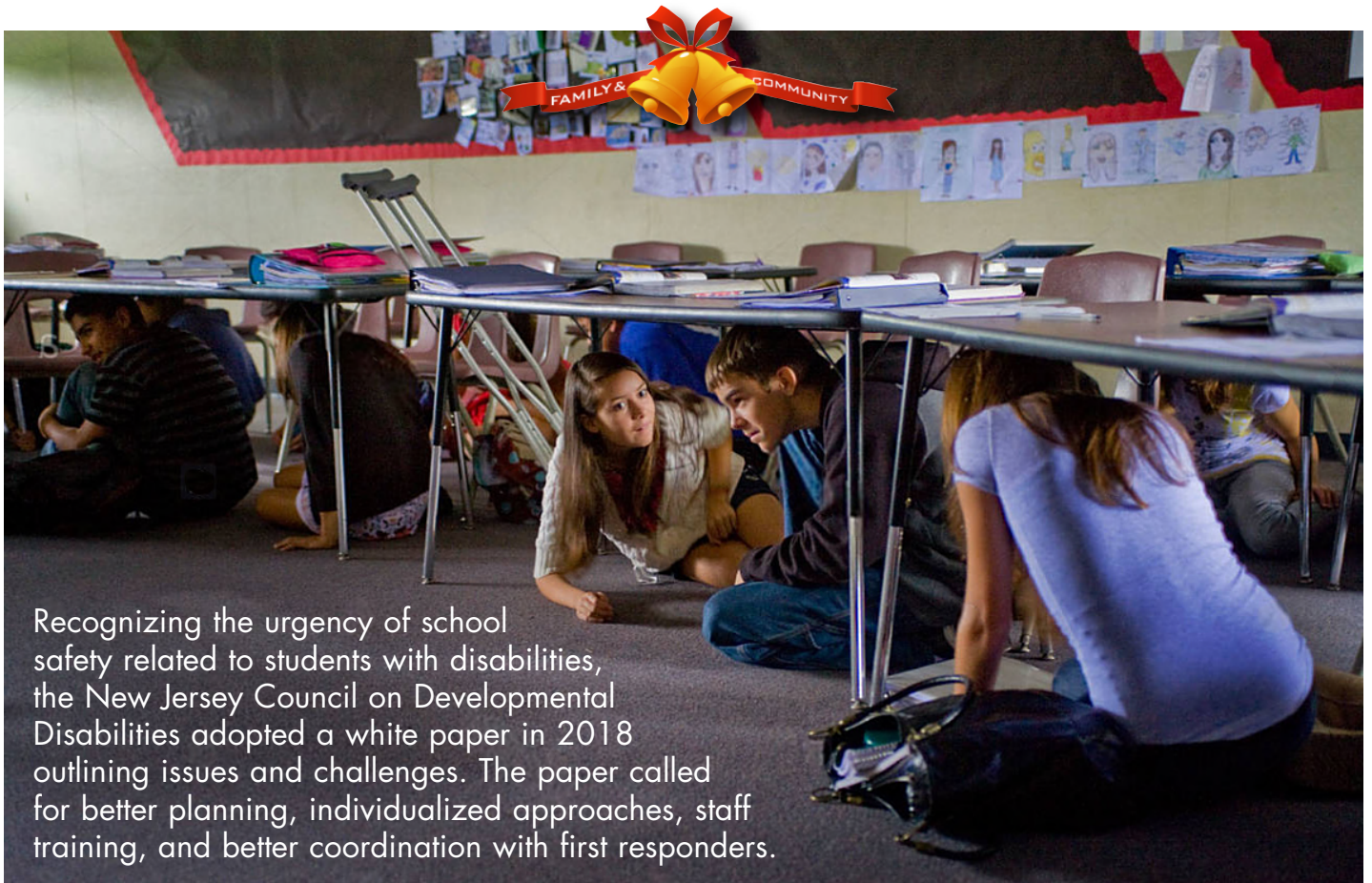
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SCHOOL SAFETY ISSUES AFFECTING STUDENTS WITH DISABILITIES

BY MERCEDES WITOWSKY

Most schools have comprehensive plans for emergency situations – fires, natural disasters, active shooters, terrorism, and the unplanned release of chemicals. Few have effective plans to address the complex, individualized needs of students with disabilities during emergencies.

Currently, there are no national models addressing the needs of students with disabilities in school-based crisis preparedness. As a result, most schools are not fully prepared to support students with intellectual and developmental disabilities (I/DD).

Many schools rely on an approach that forces students with disabilities to simply wait for help. Advocates agree: “sheltering in place” and waiting for help is not a comprehensive solution. It leaves students in harm’s way, and may be dangerous to other students and staff. In addition, door barricades and lockdown plans designed to keep children safe often ignore the needs of students with disabilities, who may have adverse reactions to alarms that overwhelm senses, difficulty processing instructions, or an inability to remain still or quiet.

RUN, HIDE, FIGHT

The Department of Homeland Security recommends a “run, hide, fight” strategy during active shootings. This calls for running away from the danger (when possible), hiding somewhere safe when you can’t run, and fighting back against a shooter (if running or hiding are not options).

not impossible—for some students. They must be taught the necessary skills and be provided with accommodations, including sensory, medical, and behavioral supports. For students who are unable to perform these skills, safety rests entirely with staff, who often lack effective training, supports, and time to coordinate response efforts.

“When I was in school my evacuation plan was to wheel myself into the ladies’ bathroom, go into the handicapped stall—the only place big enough for my power wheelchair, and turn around with my back to the door,” said Kevin Nuñez, vice chair, New Jersey Council on Developmental Disabilities. “I was told that if a shooter came in, the bullets would have to go through the metal door and my wheelchair before they hit me. I was told to wait there, alone, in the dark. That was the plan.”

NEW JERSEY’S REQUIREMENTS

In New Jersey, schools are required to have regularly-scheduled drills. They must address all hazards, fire, active shooter, and bomb threats. Since 2011, all New Jersey school districts have been required to have school safety and security plans. These plans are designed locally with the help of law enforcement, emergency



DESIGN FLAW: A “run, hide, fight” strategy is not useful for students with disabilities who may not be able to “run.” The “hide” aspect of this approach may require students to wait quietly in areas such as libraries, bathrooms, and classrooms until response personnel can assist them – even if these areas aren’t accessible or safe.

This strategy is not useful for students with disabilities who may not be able to “run.” The “hide” aspect of this approach may require students to wait quietly in areas such as libraries, bathrooms, and classrooms until response personnel can assist them – even if these areas aren’t accessible or safe. The “fight” strategy may also present challenges for students with mobility, intellectual, communication, and emotional disabilities.

“Run, hide, fight is not close to sufficient planning when considering students with disabilities or special healthcare needs,” said Peg Kinsell, policy director, SPAN Parent Advocacy Network, “The absence of school-wide evacuation planning for students with disabilities and special healthcare needs is a gross oversight.”

In addition, all students need certain “drill skills” in order to be safe during a school crisis including maintaining silence, following directions quickly, maintaining a position or location, managing feelings of stress/frustration without acting out, and managing schedule changes. Any one of these skills can be problematic—if

management, public health officials, and other key stakeholders. These plans must be reviewed and updated annually.

While state guidance on school safety addresses 91 specific planning elements, only one touches on the needs of students with disabilities, requiring schools simply “to accommodate students with disabilities.” While such plans must provide for the health, safety, security, and welfare of the school population, very little guidance has been offered in supporting students with disabilities.

FEDERAL REQUIREMENTS

Federal law mandates that every child with a disability receive a free and appropriate public education (FAPE) in the least restrictive environment. Children who experience difficulties in school due to physical or psychiatric disorders, emotional or behavioral disabilities, or learning disabilities are entitled to receive special services, modifications, or accommodations at no cost. This includes support for their ability to learn in school and participate in the bene-

fits of any district program or activity, including emergency preparedness and school safety plans.

Three federal laws apply to children with disabilities:

- 1) *Americans with Disabilities Act (ADA) of 1990 (amended 2008)*;
- 2) *Individuals with Disabilities Education Act (IDEA) of 1975 (amended 1997)*; and,
- 3) *Section 504 of the Rehabilitation Act of 1973 (revised 1978)*.

The ADA provides “a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.” Specifically, the ADA prohibits the exclusion of any qualified individual with a disability, by reason of such disability, from participation in or benefits of educational services, programs, or activities. This includes emergency response in a school safety crisis.

IDEA requires schools to provide an individualized educational program (IEP) designed to meet each child’s unique needs and provide the child with educational benefit. IDEA requires individual educational success planning for each student on a case-by-case basis through IEP development.

Some students who may be self-sufficient under typical circumstances may have other needs during an emergency. They may require additional assistance during and after an incident in functional areas, including, but not limited to communication, social, sensory, transportation, supervision, medical care, and reestablishing independence. A component of the IEP should consider the child’s individualized needs to ensure their safety during an emergency, including evacuation from a classroom and building.

Section 504 of the Rehabilitation Act protects students with a physical or mental impairment substantially limiting one or more major life activities. Often, children covered under Section 504 have impairments that either do not fit within the IDEA eligibility categories or may not be as apparent as those covered under IDEA. The Individualized School Healthcare Plan (ISHP) articulates the healthcare accommodations required for each student qualified for service under Section 504 regulation. The ISHP assists in the safe and accurate delivery of school healthcare services.

Last, Executive Order 13347, Individuals with Disabilities in Emergency Preparedness, was signed by President George W. Bush in 2004. It adds to existing legislative policy ensuring the safety and security of individuals with disabilities are appropriately supported. It also requires public entities to consider the unique needs of individuals with disabilities in their emergency preparedness planning.

Clearly, schools have a legal obligation to design plans for the individual needs of students with physical, sensory, intellectual, and other disabilities. Individuals who may lack understanding of a situation, and those who are unable to act quickly must also be accounted for. In addition to students, school personnel and visitors with disabilities also need protection.

School systems must have the capacity to move all students, staff, and visitors with disabilities to a safe location immediately during an emergency. Mitigation (the effort to reduce loss of life and property by lessening the impact of disasters) is a crucial part of emergency planning in schools and should never allow leaving anyone behind because of a disability.

MARYLAND’S EFFORTS

Currently, Maryland is the only state that specifically addresses the needs of students with disabilities in school safety laws. In 2017, Maryland passed legislation (<http://mgaleg.maryland.gov/mgawebsite/legislation/details/hb1061?ys=2017rs>) updating guidelines to “accommodate, safeguard, and evacuate” people with disabilities during a school emergency. The law further requires IEPs and 504 plans to address a student’s safety needs.

To further improve student safety, Maryland passed the Safe to Learn Act, which solidified school safety plans by mandating assessment teams and the training of school resource officers. To address students with disabilities, officers must receive sensitivity and de-escalation training. In addition, a representative from the state’s Protection and Advocacy agency, Disability Rights Maryland, (<https://disabilityrightsmd.org>) was appointed to serve on a committee at the Maryland Center for School Safety. In Maryland schools, students with disabilities are included in emergency plans. Teachers and resource officers must also receive training to ensure student safety.

NEW JERSEY’S CALL TO ACTION

On June 4, 2019, NJCDD convened a Summit on School Safety at the College of New Jersey. Bringing together a diverse group of stakeholders and thought leaders. The NJCDD took a leadership role in creating a forum to discuss issues, challenges, and best practices related to the needs of students with disabilities. The objective was to identify issues while generating tangible solutions to school safety for students with disabilities.

More than 70 guests from the public and private sectors participated in the Summit. Major stakeholders in New Jersey’s special education and emergency response communities were represented.

Recognizing the urgency of school safety related to students with disabilities, the New Jersey Council on Developmental Disabilities (NJCDD) adopted a white paper in 2018 outlining issues and challenges. The paper called for better planning, individualized approaches, staff training, and better coordination with first responders.

In response, the NJCDD released a comprehensive report, *School Safety Issues Affecting Students with Disabilities: A Call to Action*. (<https://njcdd.org/school-safety-issues-affecting-students-with-disabilities>) The report includes tangible school safety solutions for students with disabilities.

In addition, NJCDD worked with NJ Assemblywoman Mila M. Jasey (D) to introduce a bill (A5828). It requires documentation of students with disabilities’ needs during school security drills and emergency situations and in school security plans. It also requires staff training on the needs of students with disabilities in emergency planning. This legislation will ensure that all students can fully participate in schoolwide and building-based emergency response, including full mitigation, practice drills, staff training, and an evaluation process to identify obstacles.

We’ve only just begun to move the needle on school safety for people with disabilities – we still have much more work to do locally and nationally on this critical issue. •

ABOUT THE AUTHOR:



Mercedes Witowsky, Executive Director, The New Jersey Council on Developmental Disabilities (NJCDD) was named executive director of the New Jersey Council on Developmental Disabilities (NJCDD) during July of 2018. Witowsky began her career more than 30 years ago as a part-time direct support professional while earning her degree. She is also the proud parent of Anthony and Tina, a young lady with multiple disabilities.

THE GIFT THAT KEEPS GIVING ALL YEAR LONG

.....

This season, get your family and friends the 'ICON' edition of 'A Very Special Christmas,' the new collection in the best-selling series of holiday favorites featuring the most popular performances from previous collections plus six classic tunes from chart-topping stars.

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Special Olympics



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The following travel tips can help people with restricted mobility reduce their travel stress and successfully navigate accessibility issues associated with accommodations and transport.

PLANES, TRAINS AND BUSES

HOLIDAY TRAVEL TIPS FOR PEOPLE WITH LIMITED MOBILITY

BY KERRY RENAUD

Traveling during the holiday months of November and December – the busiest of the year – can be stressful for anyone, but is especially stressful for people with limited mobility. Last year, AAA projected that 54.3 million Americans would travel over Thanksgiving and a record-breaking 112 million during the year-end holiday season. This year could see even more holiday travelers. With the prime holiday travel season quickly approaching, there is a benefit to preparing and planning in advance for accessibility to ensure a smooth trip. The following travel tips can help people with restricted mobility reduce their travel stress and successfully navigate accessibility issues associated with accommodations and transport.

ACCOMMODATIONS

Whether a holiday traveler's plans include a vacation destination or a cruise, it is important to research accessibility and mobility assistance before booking accommodations.

Not every hotel, Airbnb or other type of accommodation is wheelchair and scooter accessible. Travelers should do their homework before booking accommodations to ensure in-room accessibility. Online sites like Expedia, Booking.com and Airbnb are beginning to address the concerns of people with mobility restrictions, with specific filters and options to help travelers determine the accessibility of hotel rooms, cruise cabins or houses.

Travelers booking directly with the hotel or cruise line – or with an online booking engine – should take the time to speak to a hotel

or cruise representative to ensure accommodations meet their accessibility needs. It is a good idea to research the availability of ramps, elevators, handicapped parking and other accessibility features. It is also important to ask questions to determine whether or not the room has an accessible shower, storage space for a scooter or wheelchair, grab bars around the toilet and shower, the option for a shower chair and the availability of accessible rooms on the first floor.

AIRPLANE TRAVEL

Airline travel poses challenges to people with limited mobility including maneuvering through crowded airports, enduring long waits at security checkpoints and dealing with baggage restrictions.

When booking a flight, travelers should let the airline know that they need assistance and should do this again when checking in for their flight. If traveling with a manual wheelchair, electric wheelchair or scooter, travelers should ask for their mobility device to be gate checked. This will allow the passenger to use the device right up to the plane's door before being transferred to an aisle chair. When gate checking their wheelchair, travelers should remove leg supports and cushions and bring them on the plane with them, so they don't get lost in transit.

When planning a flight itinerary, travelers with mobility issues should leave plenty of time between connecting flights to avoid rushing through crowded airports to make the next flight or missing the flight altogether.

Travelers with limited mobility should also consider renting a wheelchair or scooter at their destination to avoid the very real likelihood of damage to their mobility device in transit. "Between

January and August— the latest month for which data is available — U.S. carriers reported having mishandled at least 6,915 chairs. That's an average of 29 times a day.” This number is likely even higher as many passengers don't report damaged mobility devices to airlines or the damage is not immediately apparent.

Renting a mobility device can save travelers time and stress. If a traveler is going to need a wheelchair or scooter for their entire stay, it may make sense to rent a mobility device for the duration of their trip. Many companies make it easy and convenient to rent a mobility device, delivering the device directly to the traveler at their place of accommodation.

TRAIN TRAVEL

Train travel comes with its own issues for people with mobility challenges. Trains are known for confined spaces and limited room, making it important for travelers with restricted mobility to plan ahead to ensure an enjoyable trip.

Travelers should try to select the carrier that offers the most services tailored to their mobility needs. Some carriers offer a complete list of services – from boarding assistance to accessible sleeper cars – while others may offer only a few retrofitted cars with wheelchair tie-downs. It is a good idea to ask questions ahead of time so that travelers with restricted mobility have a complete understanding of accessibility options before making a final booking.

In particular, travelers should ask if their train car has doorways that are wide enough to permit access while seated in their wheelchair or scooter. Ideally, their room should have enough space to maneuver the mobility device on both sides of the door. The best accessible rooms have door handles, latches and other switches mounted at a height that permits travelers to use them while seated in their wheelchair or scooter. Train car restrooms should also be large enough to accommodate the traveler and their wheelchair along with an escort or attendant. If such a car is not offered, the restroom should at least be accessible to the traveler and their mobility device.

Travelers who have additional needs that require the services of an escort should ask their carrier about special rates and allowances. For example, some carriers require that escorts assist their travelers in boarding, disembarking and moving about the train -- regardless of whether the carrier

offers special boarding assistance. This is of particular importance if the traveler's escort is elderly or unable to assist in this manner.

In all cases, travelers with mobility issues requiring the assistance of an escort should be prepared to present valid documentation that supports the need for an escort (typically, a medical certificate, doctor's note or an ID card issued by a qualified organization). This requirement ensures that only travelers with the legitimate need of an escort are able to take advantage of this service.

Travelers should also ask their carrier if the departure and arrival stations are equipped with high-level platforms or wheelchair lifts, which will make boarding and exiting much easier.

Most carriers will do their best to accommodate special needs passengers and the extra luggage they may require, allowing travelers with limited mobility to check their scooter, wheelchair or powerchair at no extra cost. It is a good idea to talk with the carrier in advance about additional luggage requirements which will allow them to be more prepared and to make the boarding process as quick and pleasant as possible. Travelers making the decision to check their mobility vehicle should ensure they have made arrangements to rent a mobility device for stops along the way.

BUS TRAVEL

Buses are a lower cost travel option that can get a traveler to their destination for a fraction of the cost of flying or even taking a train. Because of this, buses are an excellent option for visiting friends or family over the holidays but can also bring challenges, especially for long-distance routes for those with mobility devices.

The first thing travelers will need to do before taking a bus trip is to research the bus company and their desired route. When booking a trip, travelers should let the bus company know they will be traveling with a mobility device and if they will be sitting in the wheelchair or scooter during the trip. Buses equipped with wheelchair lifts may have maximum weight and size limitations for wheelchair or mobility scooters and travelers should be sure to check this before booking. Travelers should also arrive early to allow the bus company to store their mobility device in the baggage compartment. Be sure to ask a customer service representative for a claim check.

NEW TECHNOLOGY AND SERVICE PLATFORMS

New technology in the form of Intelligent Personal Electric Vehicles (EVs) can also help people with limited mobility travel with more ease and independence this holiday season. Travelers considering renting a mobility device can rent these Personal EVs, which come equipped with an all-wheel drive system for maneuverability and easy transportability features to help make travel seamless in areas with heavy traffic flow like airports and theme parks.

Future holiday travelers with limited mobility may also be able to take advantage of new assistive technology in the form of autonomous wheelchairs. For example, WHILL, a manufacturer of Personal EVs, is currently conducting trials of autonomous wheelchairs in airports around the world. This service will allow passengers with restricted mobility to navigate more easily through the airport, providing additional independence and minimizing the need for assistance from a family member, friend or staff.

Mobility as a Service (MaaS) is another innovation that is making holiday travel more seamless for people with restricted mobility. MaaS is defined as the integration of various forms of transport services into a single mobility service accessible on demand. MaaS providers and platforms are on the rise in cities across the world and include platforms being created for people who require mobility assistance. Holiday travelers with restricted mobility can use these platforms to access worldwide rental, repair and mobility management services to help them travel seamlessly from their origin to final destination – whether that be at the airport, at their hotel, resort, or most anywhere else.

While travel, especially holiday travel, presents its own unique stresses and challenges to people with limited mobility, following the tips outlined above can help make holiday trips as stress free, seamless and enjoyable as possible. •

ABOUT THE AUTHOR:

Kerry Renaud is CEO and Managing Director of Scootaround – a personal transportation solutions company. With a goal of seamless travel experience for anyone with reduced mobility, Scootaround joined forces with WHILL – makers of the cutting-edge Model Ci and Model A Intelligent Personal Electric Vehicles (EVs) – to help improve the current mobility-as-a-service (MaaS) model and to evolve personal mobility and transportation.

Autism Live is a unique daily web show that provides news, resources and hope to the Autism Community. This free show is available online 24 hours a day, 7 days a week and is regularly viewed in more than 102 countries.



Viewers have the ability to interact by asking questions of experts, participating in contests or by sharing hope with others.

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TOP TOY & GIFT GUIDE 2019

INTRODUCTION

One in fifty-nine children in the U.S. has an Autism Spectrum diagnosis. Boys are four times more likely to be diagnosed with an Autism Spectrum Disorder. These are children who need great toys that are not only fun to play with but can also help them grow and develop important skills. This holiday season, *EP Magazine* is featuring excerpts from Autism Live's list of top toys and gifts in a wide range of categories and developmental levels to help you find the perfect gift to delight the loved ones in your life who are on the Autism Spectrum

BABY



Crawl About Butterfly

The Learning Journey

Top Therapist Award

Crawl About Butterfly is great for teaching little-ones joint attention, visual tracking and cause and effect. With fun lights and sounds, this is a fun toy that will motivate your baby to crawl behind it!



Sensory Bath Mobile™

Yookidoo®

Top Parent Award

Bath time is a great time for interaction and bonding. The Sensory Bath Mobile™ is a super fun toy that is ideal for making bath time fun, while working on early developmental skills.



Soothe 'n Snuggle Otter

Fisher Price®

Top Sensory Award

This adorable otter makes nap and bedtime reinforcing for small children. He's soft and emits soothing breathing sounds to help the child relax. What a great way to build self-soothing skills in a gentle, loving way!



This is Baby by Jimmy Fallon

Top Book Award

This is Baby, the third in the Jimmy Fallon baby books, hits it out of the park! With fun illustrations and easy, baby specific content these books are the perfect "first books" for your baby.



Bright Lights Soccer Ball™

Vtech®

Top Game Award

We now know that early ball skills lay the groundwork for later skills, like handwriting, balance and all hand/eye coordination. The Bright Lights Soccer Ball™ is the perfect solution, it's soft, grabbable and interactive! We especially love the washable feature, but make sure you remove the electronics first.



Jet Duck™ Create a Pirate

Yookidoo®

Oldie But Goody Award

This isn't your Grandmother's rubber ducky! Jet Duck™ Create a Pirate is a modern take on making bath time fun and interactive!



Babu Rocker

Mindware®

Top Stem Award

It's a rocking rainbow that offers a spectrum of play possibilities! Babu Rocker's modern twist on toy blocks deliver pure and simple creative play options for kids of all ages. Babu Rocker is a great toy to spark your baby's imagination and early engineering skills. Blocks, yes, but with a twist, or rather a curve! The learning is endless with this clever toy.



Gymotion® Robo Playland™

Yookidoo®

Top Toy Award

Yowza! This Gymotion® Robo Playland™ baby gym has it all! Maximize your baby's first months with this interactive, top of the line toy.

To learn more or to order toys or gifts from the guide visit <http://autism-live.com/ToyGuide>

TODDLER



LeapBuilders® ABC Smart House™
LeapFrog®

Top Therapist Award

Build, match, learn numbers and quantity! LeapBuilders® ABC Smart House™ is a workhouse that can teach so much to your child all while masquerading as pure fun! Leap Frog® is known for the research and educational expertise they pack into each toy, and it certainly shows in this fun filled interactive toy.



Band in A Box
Schoenut®

Top Parent Award

The Schoenut® Band in a Box is a superbly crafted box of musical toys that are a passport to pure fun. Your child will have jamming out, all while learning cause and effect, fine motor and visual motor skills. Pick up instrument and play along to add social skills to the list!



Shake & Match Shape Sorter
Hape®

Top Sensory Award

Shape sorters are an essential learning toy. They teach a variety of skills from hand eye coordination, matching, colors, cause and effect, problem solving etc. This well made Shake & Match Shape Sorter from HAPE® is an award winner because of the clever addition of flexible cords that keep shapes in unless you shake. Parents love this design upgrade, for easy clean up and more interactive play!

★ TOP TOY & GIFT GUIDE 2019



Touch And Teach Word Book™
VTech®

Top Book Award

This educational toy book for toddlers features 12 incredibly detailed and touch sensitive pages that help teach children over 100 words in six categories. Interactive reading is essential to building great readers. The Touch and Teach Word Book™ toy puts a world of reading in your toddler's hands. With countless ways to interact, your child will never be bored.



Button Button Belly Button™
Mindware®

Top Game Award

Button, Button, Belly Button™ is the perfect game to introduce your toddler to the wonderful world of board games. Have fun with the colorful game pieces that are perfect for little hands and growing minds. This game develops counting, matching and turn taking skills. Be ready to giggle and laugh as you build life-long skills with your child.



Walk Along Snail
Hape®

Oldie But Goody Award

The Walk Along Snail does double duty as a great shape sorter with a perfect pull toy. Develop gross and fine motor skills with quality wood toys in eye pleasing colors.



Crystal Village
WePlay®

Top Stem Award

This state-of-the-art building toy will launch your little engineer's imagination with superlative STEM driven play. Unlike other building toys the Crystal Village has no sharp edges, so have fun, play on the floor, build your heart's desire!



Hammer Away!
Discovery Toys®
Top Toy Award

We love Hammer Away! And it's not just us. Every child we tested this toy with LOVED it. In fact, even the teens and adults wanted to play with this toy. Gross and fine motor skills, hand eye coordination and cause and effect are all taught using this toy, but the fun is undeniable.

PRESCHOOL



My Little Farm™
SmartFelt Toys®

Top Therapist Award

My Little Farm creates a whole new world of interactive play for language learners! Little hands love to play with these soft shapes, matching them to the felt barn, while learning labels for a wide variety of language targets that are fun and relevant. Developed by an experienced Speech and Language Pathologist, it folds and stores easily, and grows with the learner.

To learn more or to order toys or gifts from the guide visit <http://autism-live.com/ToyGuide>

TOP TOY & GIFT GUIDE 2019 ★



Count And Learn Cookie Jar

The Learning Journey

Top Parent Award

Counting is fun with the super fun Count And Learn Cookie Jar. Playing with this talking cookie jar is a fun way to learn about numbers and counting from one to ten. The concept is simple, but children delight in playing with it over and over and that's what makes this toy a winner!

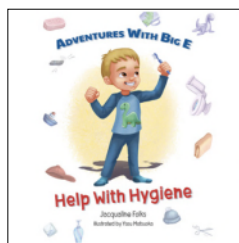


Glo Pals Liquid Activated Light up Toys

Glo Pals®

Top Sensory Award

The super awesome Glo Pals were inspired by a mom who wanted to make bath time more fun for her child on the spectrum. These light up cubes are attention grabbing and addictive. Use them in the bath, pool, or sink to create relaxing sensory fun.



Adventures with Big E: Help with Hygiene by Jacqueline Folks

Top Book Award

This is the book you need to add to your preschooler's routine reading. Adventures with Big E: Help with Hygiene teach your child all about important self-help skills. Your preschooler will love watching Big E brush his teeth, get dressed and take care of himself; they will want to join in the fun.



Heads Talk Tails Walk™

Think Fun®

Top Game Award

We love this game! The language it sparked was the icing on a cake that was filled with fun and laughter. Children as young as toddlers will enjoy vocalizing and physically recreating the animals they build within the game.



Spirograph® Jr.

Kahootz Toys

Oldie But Goody Award

Who doesn't love Spirograph®? But it can be hard for little hands that need work on fine and gross motor skills. Spirograph® Jr. is perfect with its easy grip pieces. Children will enjoy learning about shapes, colors and gears all while creating one-of-a-kind artworks!



Marble Works® Grand Prix

Discovery Toys®

Top Stem Award

We love a good marble run for its building and cause and effect lessons, but the Marble Works® Grand Prix has something extra! It has the ability to race marbles! This simple edition adds another layer of fun and educational lessons that will keep your child coming back for more.



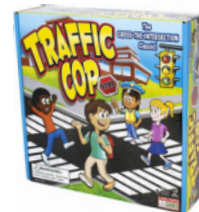
Plush Pretend Food Sets

PopOhVer®

Top Toy Award

PopOhVer® has reinvented the way we play with pretend food. We loved these soft, fabric foods and kitchen tools! We had hours of fun making pretend sandwiches, breakfasts, etc. People often overlook functional pretend toys but don't be fooled, this is play that is critical to social success later.

SCHOOL AGE



Traffic Cop

Endless Games

Top Therapist Award

Endless Games® has done it again! Traffic Cop is a great interactive way to teach safety, turn taking, sportsmanship and even planning, problem solving and perspective taking! Play on play dates or with the whole family on Game Night!



Emotiblocks Detective

Miniland

Top Parent Award

Miniland has come up with a great way to teach and reinforce understanding emotions in ourselves and in others. Choose one or all of their products to help teach your child to decode emotions and what others are thinking and feeling.

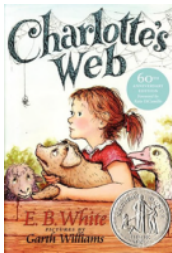
To learn more or to order toys or gifts from the guide visit <http://autism-live.com/ToyGuide>

TWEENS & TEENS



Club Squishy Surprise
clubsquishysurprise.com
Top Sensory Award

We are ADDICTED to these soft squishy toys and we love the idea of having a new reinforcer arrive each month! No one has been able to keep their hands off of these delightful toys!



Charlotte's Web by E.B. White
Top Book Award

Charlotte's Web is a children's novel by American author E. B. White and illustrated by Garth Williams. This classic is a must read for school-aged children. Read to, or with your child to share important concepts like having different abilities, overcoming adversity, building friendships and experiencing grief.



CLACK!™
Amigo Games

Top Game Award

CLACK! is a board game with constant action—every player plays on every turn. Perfect for children, fun for everyone! Fast and fun, CLACK! is super easy to play and a great way to help children work on fluency, processing speed, fine and gross motor skills as well as developing language. Magnets are safely sealed inside of the discs.



Magna-Qubix® 85-Piece Set
Valtech

Oldie But Goody Award

New to the Magna-Qubix® collection, Valtech's Magna-Qubix® 85-Piece Set was our favorite magnetic building toy because of the pleasing array of shapes and colors. There is no end to the things you can build with this ultimate set and the powerful magnets make it accessible to children with all levels of finger skills.



STEAM Inventor/Primer
Lux™ Blox

Top Stem Award

Lux™ Blox build fine and gross motor skills, problem solving, and complex cause and effect educational opportunities. And they are so much fun they are addictive! The new STEAM Inventor and STEAM Primer tubes are perfect kits to get your inventor started.



Genius Starter Kit!
OSMO

Top Toy Award

Osmo takes the interactive 2D world available on tablets and makes it a 3D experiential learning environment. Talk about capturing a child's imagination and giving it a place to grow! Osmo and their full line of products has creativity solutions for your tablet-driven child.



Dirty Pig™
North Star Games™

Top Therapist Award

We couldn't get enough of this unique card game that teaches problem solving, sequencing, consequences and perspective taking. Dirty Pig™ is a game you can play with your tween/teen and have a whole lot of good clean fun, while trying to keep your pigs dirty!



Light Stax®
The Lazy Dog Co.

Top Parent Award

Illuminated construction stacking blocks that use LED technology, Light Stax® bricks light up when connected to a power base or any Light Stax®. 100 percent compatible with Legos® and existing traditional building blocks, no special connectors or wires are needed. Parents and teens loved these building blocks that light up. Take building to a whole new level by adding the option of light!



Moosh-Moosh Plushies
MMG Brands

Top Sensory Award

Moosh-Moosh Plushies are the softest, squishiest, cuddliest plush buddies on the market today, the perfect fit for the sensory seeking tween or teen in your life. Their super cool shape and design make them more socially acceptable than the stuffed animals associated with childhood years.

To learn more or to order toys or gifts from the guide visit <http://autism-live.com/ToyGuide>

TOP TOY & GIFT GUIDE 2019 ★



A Wrinkle in Time by Madeleine L'Engle **Top Book Award**

While never mentioning Autism, this book features characters that will resonate with teens on the spectrum. Its themes of self-love and acceptance and difference as positive and powerful make this a great book for teaching self-esteem.



King of Tokyo™ **IELLO™**

Top Game Award

King of Tokyo features a 30 minute playing time and new artwork by Regis Torres, illustrator of King of New York! Other fun features: Space penguin included in the box! This is a great social game for tweens and teens who love creative group play but may not be ready for Dungeons and Dragons or The Gathering. Game play in King of Tokyo involves cooperation, problem solving, flexibility and more!



Eureka Crate Kits **KiwiCo®**

Oldie But Goody Award

KiwiCo® has taken the erector set of old and created one-of-a-kind kits that will ignite the imagination and inspire the inner engineer of your tween or teen. We love the subscription nature of having challenges arrive on a regular basis.



Coding **OSMO**

Top Stem Award

Kids love music, right? Now they can compose their own by arranging Osmo's Coding Blocks into patterns and sequences. So it's happy, hands-on play, and an awesome way to introduce Coding. Rock On! Kids can learn, create and experience in ways that are cutting edge.



Turing Tumble™ **Discovery Toys®**

Top Toy Award

This problem-solving game can be played solo or in groups and teaches the basic principles of coding. Our favorite thing about Turing Tumble™ is the clever "graphic novel" challenge book that comes with the game. Turing Tumble™ is a very unique game that will take your screen addicted teen and set them on the path to coding and building their own computer.

ADULT



Empower Poster **Craftastic®**

Top Therapist Award

Make this feel-good poster by choosing the empowering words that describe why you're wonderful and truly unique. Perfect gift for ages 8 and above.



Color Cob **Discovery Toys®**

Top Parent Award

Color Cob features game play that builds logical reasoning, problem solving, visualization, predicting outcomes and thinking several steps ahead. Different games promote progressive difficulty, patience, perseverance, observation, focus and fine motor skills.



Sensory Genius: Sensy Band™ **Mindware®**

Top Sensory Award

Soothing textured silicone is the secret behind Sensy Band's ability to calm and focus the mind. The bright orange band is easy to "slap" on and adjusts to any wrist size. When not worn, Sensy Band™ is fun and satisfying to bend and curl. The soft silicone bristles are irresistible to the touch.



Fall Down 7 Times Get Up 8 **by Naoki Higashida** **Top Book Award**

The proverb is "Nana korobi, ya oki" which means "Fall down seven times, stand up eight." It means choosing to never give up hope, and to always strive for more. This inspirational sequel to *The Reason I Jump* is a great, empowering read for adults on the Autism Spectrum with a message of self-acceptance and perseverance.

To learn more or to order toys or gifts from the guide visit <http://autism-live.com/ToyGuide>



Awkward Moment®
Resonym™

Top Game Award

This clever card game gives adults and opportunity to communicate about social cues and social situations in a fun and interactive format. Awkward Moment® does not “teach” a right answer to social situations, but rather creates a safe environment to discuss thoughts and feelings about what might be awkward.



Massive Googly Ball
Imperial Toys®

Oldie But Goody Award

The Massive Googly Ball is a great sensory toy for almost any age, but we have seen this toy light up adults of all ages and abilities. There is something both comforting and engaging about squeezing and pulling these super awesome toys!



3D Puzzles
Wrebbit™

Top Stem Award

There’s nothing quite like a puzzle to bring people together and create a low-key social experience. Wrebbit’s 3D puzzles™ literally take puzzles to another dimension. We loved watching the conversations that were stimulated by putting these puzzles together!



Faber -Castell® Art Supplies
Top Toy Award

Faber-Castell is renowned for its high quality, innovative products, commitment to tradition, and environmental awareness. One of the greatest gifts you can give is the ability to express yourself without limits. Faber-Castell® quality art pencils and products are a perfect gift for the adult in your life.

PARENTS



Spa Finder Card
Top Therapist Award

Give the caregiver in your life the opportunity to experience self-care. It will help them to de-stress and remind them they need to make time for themselves. Make sure to arrange childcare so they can actually use the gift card!



Relay™
Top Parent Award

Relay™ is a device with the power, sensors, and connectivity of a smart phone, all in a simple exterior a 5-year-old could operate. “Designing something better” usually means adding features and complexity, but Relay™ has done the opposite—by removing the screen, and constraining most interactions to a single button.



Queen for a Day by Maxine Rosaler
Top Book Award

Laugh, cry and shake your head at the way the main character’s life unfolds as she journeys through her son’s autism diagnosis and childhood. For any caregiver who has ever felt alone this book is a beautiful, funny affirmation that you are not alone.



Apples to Apples®
Mattel™

Top Game Award

Filled with surprises and outrageous answers! The judge plays a Green Apple card with a descriptive word on it. From the five red apple cards in your hand, play the one that makes the best combination with the Green Apple card. If the judge likes your combination the best, you keep the Green Apple card.



Headspace®
Top Toy Award

Specializing in meditation, Headspace® provides sessions of guided meditation to its registered users with the goal of mindfulness. Give the gift of mindfulness and meditation to the caregiver in your life. Headspace is self-paced and can help with stress management, sleep, self-regulation and more. •

To learn more or to order toys or gifts from the guide visit <http://autism-live.com/ToyGuide>



KEEPING

IT

FUN

CUTTING-EDGE SOCIAL SKILLS INSTRUCTION IN YOUNG CHILDREN WITH AUTISM

Early social development is connected to early language learning. We need to make sure that the young child with ASD is engaged in learning, and that teachers and parents become and remain the happy and fun conduit for learning.

BY ALAN SCHNEE, PH.D., BCBA-D

Anyone who reads the research related to language and social skills instruction for children with an autism spectrum disorder (ASD) will find a dizzying array of targets such as

learning to say “hello”, “listening and responding”, “initiating”, “teaching play skills”, “giving and accepting compliments”, saying “please and thank you”, “offering help”, etc.



THE FUN IN FUNDAMENTALS: Using games teaches children to listen to what we say. And by mixing things up a bit, it helps to keep children on their toes and prevent boredom.

While these skills might seem arbitrary, one thing that underlies a discussion of social skills and related deficits in children with ASD, is that social skills intervention usually involves teaching children to do things in language. This makes sense. Language deficits are a primary characteristic in children on the spectrum, and language itself is part of the human social experience. Thus, to a large extent, considerations for cutting edge social skills intervention are necessarily connected to language. To learn a language is to learn a *social* practice.

EARLY INTENSIVE INTERVENTION

Early intervention for children with ASD is most often organized around language learning. In Early Intensive Behavioral Intervention (EIBI), the sequence and domains under consideration are largely language-based. Children begin by learning the names of things, attributes, prepositions, pronouns, and verbs, often in discrete and contrived ways in order to establish foundational abilities. Later, these abilities and skills can be synthesized and systematically engineered toward broader and more natural applications.

There are several different stages in intervention. In the earliest of beginnings, one of the greatest obstacles to learning is the absence of shared attention and engagement with others.

When I first meet with parents whose young child was recently diagnosed, most of them suffer in saying the same thing: *"It is very difficult to engage my child."* *"I can't get my child to pay attention to me."* And, if parents are able to "connect," it is often through fleeting eye contact, which most parents will say is difficult to reliably elicit. Parents will do almost anything to get their children to meet their gaze. But standing on one's head is not necessary.

SETTING THE STAGE: STRATEGIES FOR EARLY ENGAGEMENT AND LEARNING

During a recent consultation with a 3.5-year-old boy who had already been involved in intervention for over a year, one thing seemed clear. He hated instruction. He was there because he had to be, not because he wanted to be. He avoided looking at his teachers and frequently ran away from them. It was not fun for anyone.

So, we backed everything up. No more naturalistic teaching, no more circle time or play groups, no more activities he actively tried to avoid, no more discrete trials, no more *anything* until we convinced him that things would be better.

At this stage, intervention is about getting children to pay attention to us well enough so that we can teach them efficiently and effectively. It requires that we identify the thing or things that that would catch a child's eye and light them up. Once those 'eye catchers' are identified, most, if not all children will meet us halfway. What we do is to hold a preferred item in our

hand and show it to the child. If it's the best item at that time, a child's excited eyes go to it immediately. We then track the item(s) to our eyes (between our eyes to be precise). As we track it up, the child's eyes come up to meet ours and the child receives the item. As eyes meet, children begin to also see our smiles and our excitement with them.

This basic 'social game', the terms of which are - 'you look at me and something terrific will happen' - is often a good starting point for building trust and engagement. It's simple for the child and easy to implement for parents and teachers. The 'rules of the game' also include our promise to pay attention to what the *child* wants and to assess what the child is willing to tolerate from us. We promise to not go beyond that. With those things in place, we find that we are soon able to insert a little something extra; a tickle, or a toss in the air, in addition to the child receiving the 'eye catcher'. As parents consider this earliest stage of intervention, it must be stressed that there is a profoundly important social dimension to the early work. Teaching in and of itself is a **social enterprise** in which there is an implicit contract.

"RELEVANCE:" A SPRINGBOARD TO TEACHING

As greater trust builds (children have come to trust that adults are sensitive to their unique tolerances and preferences) and enjoyment is established, it is often possible to introduce instruction. At this stage, information about *what* to teach is readily available in books and manuals, but one vital area of intervention does not receive much attention: strategies for establishing the relevance of others.

Once children begin to acquire early linguistic abilities, it is important to also consider what my colleague, Stein Lund, calls "Social Primacy" – that is, maintaining and establishing the relevance of other people. Children with ASD often miss this.

SIMPLE 'GAMES' TO TEACH RECEPTIVE LANGUAGE

"Selection-Based Imitation" (SBI), can be used as a vehicle for establishing social awareness, language skills and learning readiness skills. There are many possible iterations of this 'game', but to illustrate:

The parent (or teacher) places an array of pictures on a wall. A corresponding array of pictures is placed on a child's desk (or spread across the floor, it doesn't matter). In this exercise, there are a number of things that a parent or teacher can say:

- *"Find the ball" wherein the child finds ball in their array.*
- *A teacher can point to an item on the wall and ask, "What's this" or "What color is this?"*

Now, we change the 'game' a bit: We can point to something in our array and say:

- *"Find one like this" (which is the SBI piece).*

In this case, the child can be successful *only* by paying attention to the thing to which a teacher or parent points. The child is required to use the parent or teacher as the point of reference. If we place an additional array on a different wall and move from array to array, the child will have to track us as we move around the room!

Using these strategies (games) teaches children to attend to us; to watch for what we attend to; to consider our position in space, and to listen to what we say. And by mixing things up a bit, it helps to keep children on their toes and prevent boredom.

A NOTE ON SCREENS

Everyone is talking about apps and technology as the next frontier in autism intervention. I have found that over-reliance on the use of modern devices with touch screens in order to teach language and social skills tends to play into social disengagement, and can render parents, teachers and peers irrelevant. While screen-based learning has its place, parents should be mindful of this potential side effect and remember that **THEY**, not a screen, need to be the point of reference in learning.



WORD CHOICE

It is important that children with ASD learn to respond to contextual terms, such as this, that, here, there, him, her, she, he etc. When we say things like, "Put the block over there", or "Put that on his table", or "Get that and put it there", we not only expose the child to common language practices, but we also maintain the significance of "others" as they are the point of reference. The child has to attend to you and the context of the situation in order to know what to do.

SEQUENTIAL MATCHING

Once a child knows how to match, parents can leverage this basic skill by using a "sequential matching strategy" to foster social awareness.

In a common example, a child has a pile of things near them, which need to be matched to a corresponding array of pictures on the table in front of them. Parents or teachers can "sabotage" the child's ability to complete the task by removing some of the items, forcing the child to ask the adult for the matching item. This natural and fun social game can get children to learn to ask us for things.

It can be taken even further. Once a child asks for the item, we can direct the child to get it by pointing to its location:

- *"It's over there."*
- *"It's under that table."*

We can also use language and pointing to direct the child to another person:

- *"Alan has it."*
- *"Mommy has it."*
- *"She has it."*

We can even enlarge these possibilities:

- *"Alan has it"... but Alan's not in the room and the child has to go find Alan.*
The possibilities grow with one's imagination.

THE CHILD AS TEACHER

Later in intervention, as the child's linguistic abilities improve and they are able to use prepositional concepts, and/or color, shape and size concepts in rudimentary ways, we can contrive games in which development of social acuity is highlighted (as well as greater linguistic fluencies).

Putting your child in the role of teacher (and then playing along as a student who does not understand) is a fun way to encourage the development of social acuity.

For example, ask a child to tell you how to build a block structure, with a sample block structure in front of the child. Such a scenario might look like this:

- *Child: "Put the little triangle in front of the red block."*
- *Teacher: Places the triangle behind the red block.*
- *Child: "I said, place it in front of the red block."*
- *Teacher: Places it incorrectly again and asks "Here?"*
- *Child: "No, here" and shows the teacher where it goes.*

Here, the child has to pay careful attention to what you are doing, guide you and correct you along the way. In these kinds of games, it is a good idea to be as poor a direction follower as possible. The possibilities are limitless and fun, and this kind of feigned denseness can be used across many situations. Just remember, when trying these kinds of exercises: the child must be able to follow the direction "say" and echolalia can not be present because teaching the child to be the teacher is a difficult step before considering using this strategy for developing greater social acuity.

SUMMING IT ALL UP

Early social development is connected to early language learning. We need to make sure that the young child with ASD is engaged in learning, and that teachers and parents become *and remain* the happy and fun conduit for learning. The "contract" for learning comes with our promise to remain sensitive to the tolerances and enjoyments of children. The social dimensions of teaching are many and establishing the relevance of others is a domain which requires consideration when teaching children with ASD. •

ABOUT THE AUTHOR:

Alan Schnee, Ph.D., BCBA-D is a clinician, author and public speaker on effective autism intervention for young children. He has been involved in teaching children with ASD for almost 30 years. He is the director of Nexus Autism Intervention Services in Marlton, NJ. He studied under ABA pioneers at Princeton Child Development Institute, and with Dr. Bridget Taylor at Alpine Learning Group in Bergen County. For more, go to <https://www.nexusaia.com>

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BY RENEE DEASE

You will not meet someone more equipped to talk about Special Olympics and the importance of health for seniors than Maryann Gonzales.

Gonzales, a 46-year veteran of Special Olympics and member of the Florida Sports Hall of Fame and Special Olympics Florida Hall of Fame, is no stranger to success. She was introduced to Special Olympics at age nine and has not looked back. Since then, Gonzales has gone on to work for Special

Olympics Florida, officiate at multiple Special Olympics World Games, and advance a number of programming areas. In 2017, she undertook another important role – Special Olympics Health Messenger.

During her training, she decided she wanted to focus on the athletes who are older. Gonzales has started recruiting athletes within her program of Florida and is working on retaining older athletes already participating. The global numbers are striking as two of every three athletes right now are under 22 years old, but there is no age limit to Special Olympics participation.

STAYING ENGAGED: A CONVERSATION WITH MARYANN GONZALEZ

Maryann Gonzalez has been a Special Olympics athlete for more than 45 years. She has played 10 sports and officiated softball and volleyball in five Special Olympics World Games and four Special Olympics USA Games. Gonzalez was part of the first group of athletes to serve on the U.S. Leadership Council and first to sit on the North American Leader Council. She was inducted into Special Olympics Florida's Hall of Fame in 1999. Gonzales also graduated from college with an associate degree in computer technology. Learn a little more from Gonzales and her important work in an interview she recently had with Athlete Health Corner editor Renee Dease.

RD: What have you always liked best about Special Olympics?

MG: I like the joy that it brings to the athletes. And they can compete at whatever ability level they have. They can show you that on their best day they can achieve anything that is put in front of them.

RD: What do you do on a daily basis to stay fit?

MG: I exercise three to four times a week and I'm competing in two to three sports right now. I like going to the gym and I speed walk around the office with my co-workers to see who can get around the office the fastest. Also, I am getting older and I make sure I keep healthy. I got on the scale and didn't like what I saw. I lost 21 pounds by exercising more and eating healthier like taking in more proteins and less carbs. This makes me feel better and I can see the difference in my clothes' sizes. I have more energy and more motivation to keep going, and my final goal is 40 pounds by December. It's a realistic goal now; it's something I can accomplish. I weigh in once a week at the same time and on the same scale.

RD: What are your goals and plans in being a member of the Aging Athletes Task Force?

MG: In office meetings, I like to keep the task group informed about what Florida is doing. We are trying to engage more athletes that are older and keep them involved in either fitness or creating new sports programs that they are capable of doing. We moved track and field from May to November for cooler temperatures, and bocce from outside to inside to accommodate the aging population. For track and field, it is too early to tell, but bocce has had a big change. The numbers in the county went up alone as well as the state.

RD: Why is it important for Aging Athletes to continue to include fitness into their lifestyle?

MG: It will help them be healthier and keep them in Special Olympics.

RD: How did you feel when you found out you were selected as a Special Olympics Health Messenger?

letes who don't compete. The Florida fitness program is starting. It will show that they can stay engaged in other ways besides sports, come to a fitness class instead. Some athletes might lose confidence in their abilities. It's up to us to encourage them that you can do whatever you want to do, even if you need to



PLAYING THROUGH: (Opposite page) Maryann works with an athlete during a Health Messenger program. "I love sharing the message of how important good health and nutrition are to improving health for people with intellectual disabilities, including the senior population;" (Above) Maryann putts her ball onto the green. She has played 10 sports and officiated softball and volleyball in five Special Olympics World Games and four Special Olympics USA Games.

MG: I felt honored that people thought I could teach other athletes how to stay healthy. Having the class and interacting with everyone in Washington, D.C. gave me so many ideas about what to do when I went home.

RD: How would you approach Aging Athletes about re-entering Special Olympics?

MG: I would discuss all the new programs that they offer. I know a lot of ath-

letes who don't compete. You should give it a shot and, if you like it, that will keep you involved. Volunteering is also important. Older athletes would lose some friends because they don't get to see them anymore... Special Olympics gives you your physical ability and motivates you to continue to walk around and see your friends. •

ABOUT THE AUTHOR:

Renee Dease is Athlete Health Corner editor for Special Olympics.

A photograph of a middle-aged man with dark hair, wearing a red polo shirt and khaki pants, sitting in a wheelchair. He is in a living room with a leather sofa, a wall of framed photos, and a window with blinds in the background. The text "I AM A VETERAN AND THIS IS MY VICTORY." is overlaid in large white letters.

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MILITARY SECTION



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MILITARY LIFE

PLAN YOUR TRIP WITH SPACE-A TRAVEL

Service members and their families can use Space-Available flights – formally known as Military Airlift Command or MAC flights – to travel around the country and world at little to no cost. Though sometimes unpredictable, military flights are perfect for families with flexible plans and limited travel budgets. With the right planning and documentation, Space-A travel can be the best way to take a trip with your family.

SPACE-A TRAVEL BASICS

These flights are not commercial, but rather military flights with a mission. That means there are certain restrictions to travel, including:

- Only service members, retirees and their families are eligible. Only with certain qualifications are reservists, National Guardsmen and family members without an accompanying active-duty sponsor permitted.
- Flights are typically free of charge, but you should contact your closest Air Mobility Command, or AMC, passenger terminal or the terminal at the location you intend to depart from for specific information.
- Most terminals have a Facebook page where they post flight information, including their 72-hour flight schedule.

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- Category I: Emergency Leave Unfunded Travel.
- Category II: Accompanied Environmental and Morale

Leave, or EML.

- Category III: Ordinary Leave, Relatives, House Hunting Permissive Temporary Duty, Medal of Honor Holders and Foreign Military.
- Category IV: Unaccompanied EML.
- Category V: Permissive Temporary Duty (Non-House Hunting), Students, Dependents, Post Deployment/Mobilization Respite Absence and Others.
- Category VI: Retired, Dependents, Reserve, Reserve Officers' Training Corps, Nuclear Propulsion Officer Candidate Program and Civil Engineer Corps members.

PREPARE FOR YOUR SPACE-A FLIGHT

AMC has a travel page that includes the following important information about Space-A travel. You should review this travel page for up-to-date information, including what type of identification is required for you and your family, baggage allowance for checked and hand carried baggage, and prohibited items.

• *Travel instructions: travel eligibility; locations; required travel documents; registration, flight schedule and checking-in information.*

• *AMC Form 140, Space Available Travel Request (fill out a form online and email it to your desired AMC passenger terminal)*

• *Listing of Facebook pages for stateside and overseas locations.*

• *AMC passenger terminal contact information.*

• *Various travel information links.*

• *Legal information for Space-A travel.*

- *Operations security for social media and travelers.*



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– Military One Source

FINDING THE RIGHT OT FIT FOR YOUR CHILD AFTER PCS-ING

BY ROBIN ABBOTT, MS, OTR/L

Military families move quite a bit. The upheaval created by a PCS (permanent change of station) is stressful for most families to navigate, but for families of children with special needs, it can mean an interruption of services that can take months to overcome. As an occupational therapist, when I explain different types of OT available, I find that families are often left in the dark. Parents may think their child is receiving the appropriate therapy because they are getting occupational therapy (OT), but it may be in a setting that is not right for their child. In most situations, a child will have two types of OT available: school-based OT and clinic-based OT. It's important to know the difference.

School-based OT is offered as a result of the Individuals with Disabilities Educational Act, mandating that schools offer free and appropriate services to student who qualify for them. Because this type of OT is tied to the school setting, it is required to address concerns affecting a student's academic performance. That usually boils down to reading and writing, but could possibly include sensory and behavioral issues that affect a child's academic participation. Occupational therapists in schools might have caseloads of up to one hundred children or more, sometimes spread out over several schools. Your child may only be receiving 30 minutes of therapy per week, or possibly less, and that therapy might be in a group setting. It's a good idea to ask questions regarding how much therapy your child is receiving, and when, at their IEP meetings.

OT services can also be received in clinic-based therapy. This type of therapy must be prescribed by your child's doctor and you must have a referral from Tricare, if that is the insurance your child has. If your child is participating in outpatient, clinic-based services, you might want to consider whether the clinic is affiliated with a hospital or not. If your child has medically-complicated conditions, a hospital-based clinic may have more therapists with greater experience in specific medical diagnoses. If you would like your child's OT to address sensory and behavioral issues that affect your family, it might be helpful to tour a few clinics in the area before choosing one. Ideally, you are looking for one with a sensory-based therapy area that allows for lots of movement. Small rooms with desks, rooms that appear like school to a child, might not afford them many opportunities to address sensory and behavioral goals. Even if your child is working specifically on fine-motor coordination goals, those goals are often addressed with large motor movements and sensory equipment.

Most important, ask questions of the occupational therapist



THE RIGHT STUFF?: Parents may think their child is receiving the appropriate therapy because they are getting occupational therapy (OT), but it may be in a setting that is not right for their child.

to whom you are referred. Do they have experience with children like yours? What kind of progress can you expect to see and when? What is their approach and can they explain it in layman's terms, so that you can explain it to your spouse when they aren't able to make your child's appointments? All these factors are just part of the larger picture of decision-making that special needs military parents go through with every PCS.

The more quickly questions are answered to your satisfaction, the sooner your child can return to their regular routine and continue their progress.●

ABOUT THE AUTHOR:

Robin Abbott, MS, OTR/L is an occupational therapist with 12 years' experience working with families and children with autism, ADHD, SPD and Down Syndrome. Her practice is a theoretically-based, structured framework of auditory and vestibular activities to promote better sensory integration. She is currently works as a Rehab Liaison in Davenport, IA. She can be reached through her website, www.rabbottwriter.com.

Tell Me What You Really Think

Broden, as usual, taught me something that day. Sometimes, you just gotta say, "Screamin' Banshee" to get what you want.

It never fails. It doesn't matter how many times I tell myself that we will not procrastinate next year, we always do. I'm talking about Spirit Week. The week when the kiddos have a theme for every day of the week to show their school spirit. My oldest child, Hayden, really gets into it but likes to notify me of his vision a few days before. If I try to pry any intel out of him, I may be able to plan one or two days in advance, but that is usually as good as it gets in my house.

A few weeks ago, with Spirit Week on the horizon, I thought I was doing good. I knew one day involved a Spiderman costume with goggles. The online costume store was alerted and a package was on its way without the need for excessively priced shipping. Two days before the week of epic amusement, Hayden comes downstairs and tells me that Monday is pajama day and he would be wearing his polar bear pajama pants. The polar bear pajama pants that he owned were two sizes too small. The pajama pants looked like Spanx capris. Deliriously I said, "Hayden, you're not leaving the house in those. Actually, I don't know why you still have them."

On cue, the drama began, "Mom, I need to wear pajama pants to school Monday. It's my theme." As the mom, right on cue, I forgot that he gave me two days of notice and I began to solve the problem. I found a

store that sold polar bear pajama pants. It was located in a shopping area I have not been to yet and it was in an area of town I had not visited. With Mark and Hayden

already having plans the next day, I turned to Broden, "Broden, you and I are going to venture out to a new part of town tomorrow. It will be fun!" Broden had an unenthused look on his face. He knew what was really happening. Due to his big brother's inability to plan, he was not going to be able to relax. Broden would be an innocent victim of a plan to make Hayden's Spirit Week vision become a reality. Yes, I got that message from the look on his face.

The drive was pretty smooth for the first fifteen minutes and I could tell from Broden's facial expressions that he was starting to think so too. Our feelings changed dramatically once we veered off the highway towards an exit that included us in a traffic jam of overly excit-



As we nudged our way through two traffic lights while I was checking my phone navigation, I looked to the right and I gasped in disbelief. The Gap store is not in an open mall where we can just drive up to the store, get out, grab the pants and go. That would be too easy. I would have to navigate one of the largest shopping malls I had seen in a long time, with Broden in tow. I drove around and found a parking spot located in an area where I would have a better chance of not getting lost.

I got out and opened the door to Broden. The look on his face read, "Are you kidding me?" I told him, "I know, man. The mission is to get the pants and then we run out of there. I promise." He reluctantly slid out of the car and held on to my arm for comfort. He really wasn't sure what was waiting for him in that huge monstrosity of a complex, but he was willing to try.

Once we walked through the doors, the area was crawling with people, children screaming, heels clamoring on the hard floors, and strange scents billowing from the food court. I could sense what he was feeling and the farther we walked away from the front door, the harder he clasped my arm.

As I started to jog towards the Gap I said, "Broden, we're grabbing the pants, heading to the register, and then we're out of here." Broden looked forward with beady eyes and pursed his lips. After maneuvering through the kid's department, we found



PAYING ATTENTION: The gal at the register was unaware of my sense of urgency. She casually took the pants and asked, "Are you using a gift card?" No. "Are you using any reward points?" No. "Do you have a Gap card and, if you don't, do you want to apply for one? It's 10% off this purchase."

ed holiday shoppers. I wanted to roll down the window and scream, "Wait for the online sales! Amazon has next day shipping!"

the pants in the men's department and raced to the cash register. I quickly threw the pants on the counter, grabbed my wallet and had my credit card in hand. The gal at the register was quite unique, if I do say so myself. She was unaware of my sense of urgency and didn't seem to care that there was a line that was forming behind me with people who also wanted to purchase items.

She casually took the pants and softly said, "Are you using a gift card?" I quickly said no as I waved

my credit card in front of her face. She then asked, "Are you using any reward

points?" I say a little louder, "No ma'am, just want to buy the pants." Then she shifted her weight to her right hip and

asked nonchalantly, "Do you have a Gap card and, if you don't, do you want to apply for one? It's 10% off this purchase." As I leaned into the counter about to share a few choice words with her, Broden, with his piercing beady eyes, looked at the cashier and said, "S c r e a m i n' Banshee."

The look on her face was priceless. She had no idea what those words meant, but she

knew what he was thinking. She stopped talking, looked at me and quickly said,

"I found a store that sold polar bear pajama pants. I said to Broden, 'You and I are going to venture out to a new part of town tomorrow. It will be fun!' Broden had an unenthused look on his face. He knew what was really happening. Due to his brother's inability to plan, he was not going to be able to relax."

"Swipe your card please." I swiped, grabbed the bag, and we ran out the door and didn't look back. Once we got in the car, I looked in my review mirror at Broden. We took a deep simultaneous sigh of relief. We did it. We got the pants and Hayden was able to keep his theme for Spirit Week.

Broden, as usual, taught me something that day. Sometimes, you just gotta say, "Scream' Banshee" to get what you want. •

PUZZLES & CAMO

Shelly Huhtanen is an Army wife stationed at Fort Benning, GA who has a child with autism. She enjoys sharing her experiences of day-to-day life caring for her son with autism while serving as an Army spouse. She authored "*Giving a Voice to the Silent Many*" that encompasses many stories of raising a child with autism in the military. Shelly is passionate about autism advocacy for our military and works to bring awareness to our local legislators and command about providing better support for our military autism community, such as better health care and education.



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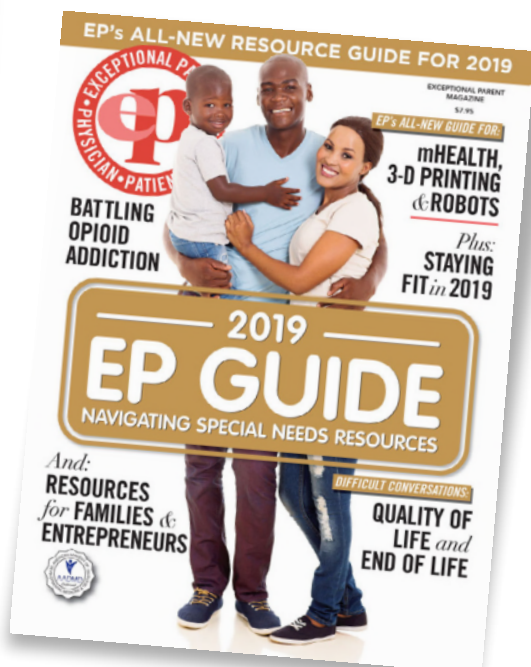
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