

EP's ALL-NEW RESOURCE GUIDE FOR 2019



EXCEPTIONAL PARENT
MAGAZINE

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EP's ALL-NEW GUIDE FOR:

**mHEALTH,
3-D PRINTING
& ROBOTS**

Plus:
**STAYING FIT
in 2019**

**BATTLING
OPIOID
ADDICTION**



2019
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

And:
**RESOURCES
for FAMILIES &
ENTREPRENEURS**

DIFFICULT CONVERSATIONS:

**QUALITY OF
LIFE and
END OF LIFE**



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*Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:882–887. DOI: <http://dx.doi.org/10.15585/mmwr.mm6732a3>

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EP is pleased to begin its 49th year of publication with the second annual edition of the *EP GUIDE: Navigating Special Needs Resources*. EP has refocused its efforts on its strengths: in-depth articles and sound guidance, covering such topics as education, entrepreneurship and employment, delivered by the most experienced and highly-regarded experts in the field of special needs. Please enjoy this innovative format and share your thoughts with us at vira@ep-magazine.com. *EP GUIDE: Navigating Special Needs Resources* begins on page 16.

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AND SHARE INFORMATION
AS TOOLS FOR POSITIVE
CHANGE FOR THE SPECIAL
NEEDS COMMUNITY.

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FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

2019
EP GUIDE
NAVIGATING SPECIAL
NEEDS RESOURCES

78 MILITARY LIFE 2019 RESOURCES FOR MILITARY FAMILIES TOUCHED BY SPECIAL NEEDS

By Angela Shaw

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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.





PEAK CUTENESS: Dogs have evolved specifically to rely on human care; “Around seven or eight weeks of age is exactly when they are most attractive to human beings.”

The One with the Waggly Tail

The lyrics to the hit song “The Doggie in the Window” commandeered you to sing along, and millions did. The song was cute because puppies are cute. And humans are captivated by “cute.”

So I’m in the car on the way to Birmingham for a presentation. The ride is about 150 miles and takes approximately two hours.

I’m lucky to find a radio station that plays vintage rock music. It’s the same station that inspired my September 2018 editorial on “Respect” when they played Aretha Franklin’s hit and announced her passing.

I’m listening to songs that I grew up with (which is the purpose of listening to vintage rock) and I’m singing along as if I’m a finalist on the TV show *The Voice*.

They are playing “Yakety Yak” by the Coasters and, after that, David Saville’s “Witch Doctor.” And I start thinking these were the stupidest songs imaginable. Despite those thoughts they continue to hurl more stupid songs at me. “The Purple People Eater,” and then “The Chipmunk

Song.” My threshold for these songs is reaching its peak when they really test my stamina and play, “Does Your Chewing Gum Lose Its Flavor on the Bedpost Overnight?” I’m about to switch to NPR when they take another shot over my bow with Chuck Berry’s “My Ding-a-Ling.”

Without ample time to recompose myself they push me to my limits with “Itsy Bitsy Teenie Weenie Yellow Polka Dot Bikini.” Finally, the announcer comes on and I take my first deep breath since “Yakety Yak.” He asks his radio audience if they have been enjoying these “novelty songs” – and, if anyone had a request, they should call in.

Writing in *That Old-time Rock & Roll*, Richard Aquila describes the novelty song. “A novelty song is a comical or nonsensical



song, performed principally for its comical effect. Novelty songs achieved great popularity during the 1920s and 1930s and had a resurgence of interest in the 1950s and 1960s.”

Novelty songs often are inspired by a holiday or fad such as a dance or TV program. They often use ridiculous lyrics, sounds or instrumentation. The novelty song “They’re Coming to Take Me Away, Ha-Haaa!” referred to someone having a nervous breakdown and being committed to a “funny farm.” Not exactly a sensitive and empathetic ballad to a psychiatric condition; and not exactly a song that would get any airtime if released today.

You don’t even have to listen to the songs themselves to know they are “novelty

songs." The titles alone announce themselves as belonging to that genre. "I Yust Go Nuts at Christmas," "Short Shorts," "The Little Nash Rambler," "Tie Me Kangaroo Down Sport," "Alley Oop," "Ahab The Arab," and "The Monster Mash" could only be "novelty songs".

As I'm pulling into the parking lot of the medical center at the University of Alabama, they finish me off with the hit song "The Doggie in the Window." Released in 1953 and sung by Patti Page, this song reached number

one on both the *Billboard* and *Cash Box* charts and sold over two million copies.

It suffered from terminal "cuteness." The lyrics commanded you to sing along, and millions did.

How much is that doggie in the window? (woof woof)

The one with the waggly tail

How much is that doggie in the window (woof woof)

I do hope that doggie's for sale

I don't want a bunny or a kitty

I don't want a parrot that talks

I don't want a bowl of little fishies

You can't take a goldfish for a walk.

I realized that I could have turned my car off before the end of the song, but I didn't. I heard the whole thing; and realized I was held captive by the "too cute" factor.

The song was cute because puppies are cute. And humans are captivated by "cute." Luckily for puppies that we find them cute.

There is actually an evolutionarily orchestration of when puppies reach "peak-cuteness."

New research into the foundations of human-dog bonding reveal that dogs reach maximum cuteness at about the time they get weaned. There is indeed a connection between pups' weaning age (the most vulnerable period during a dog's life) and their

attractiveness to humans. The research published in the journal *Anthrozoös* suggest that pups' attractiveness was lowest at birth, reached peak-cuteness at roughly 10 weeks of age, then gradually declined and

"For dogs, being able to connect with us, to find an emotional hook with us is what actually makes their lives possible," claims Dr. Wynne. "But having grabbed our interest, we continue to love them all their lives."

leveled off. Researcher Dr. Clive Wynne of Arizona State University's Canine Science Collaboratory reported, "Around seven or eight weeks of age, just as their mother is getting sick of them and is going to kick them out of the den and they are going to have to make their own way in

life, at that age, that is exactly when they are most attractive to human beings." He suggests that dogs have evolved specifically to rely on human care. "For them," Wynne submits, "it's the absolute bedrock of their existence... being able to connect with us, to find an emotional hook with us is what actually makes their lives possible. The eight-week point is just the point where the hook is biggest, the ability of the animal to grab our interest is strongest. But having grabbed our interest, we continue to love them all their lives."

Especially the ones with the waggly tails.

Like all parents, parents of children with special needs don't need six or eight weeks to get hooked; they are hooked, connected and transformed the second they see their babies, touch them and hold them. While they may not all be "cute" and may not have "waggly tails," they are loved all their lives... and beyond. •

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

Sweden Selected to Host the 2021 Special Olympics World Winter Games

Sweden has been granted the opportunity to host Special Olympics' flagship sporting event, the World Winter Games in 2021.

The Special Olympics World Games is one of the largest sporting events on the planet, and inspires, promotes and advances a world of full inclusion for people with intellectual disabilities. Taking place every two years and alternating between Summer and Winter Games, the World Games are broadcast globally in more than 150 countries attracting more than 2,500 journalists.



The 2021 Games are expected to host 2,000 athletes and Unified Sports Partners from 105 nations who will participate in nine various sport disciplines. Unified Sports is an inclusive sports program that combines an equal number of individuals with intellectual disabilities and individuals without intellectual disabilities. They will be joined by more than 3,000 volunteers as well as 5,000 family members.

A signature aspect of the Swedish bid was its focus on investment in public health for people with intellectual disabilities. Other features of the bid were a drive for more people with and without intellectual disabilities in organized sports; more people with intellectual disabilities active in sports at school; changing attitudes about people with intellectual disabilities; and an increased knowledge in society about people with intellectual disabilities and the way they are treated.

As Sweden celebrates the winning bid, the final countdown to the 2019 Special Olympics World Games has begun. The Games will take place in Abu Dhabi, United Arab Emirates, March 14 - 21, 2019. Visit www.specialolympics.org

WHAT'S HAPPENING

WORLD ECONOMIC FORUM ANNUAL MEETING 2019 TO HIGHLIGHT DISABILITY INCLUSION

The need to build a more inclusive society must include the estimated 1 billion people in the world living with a disability. This will be a key message at the World Economic Forum Annual Meeting 2019, January 22-25, in Davos-Klosters, Switzerland.

The meeting will bring together over 3,000 participants from government, international organizations, business, civil society, media, culture, as well as the foremost experts and young people from all over the world. Under the theme, *Globalization 4.0: Creating a Global Architecture in the Age of the Fourth Industrial Revolution*, participants will focus on identifying new ideas and solutions to ensure that any further global integration will be more inclusive and sustainable.

To highlight that inclusion must extend to those with disabilities and that people with disabilities have much to offer society and the economy, the Annual Meeting will host a major exhibition, ACCESS + ABILITY. Developed in collaboration with Cooper



DESIGNED FOR INCLUSION: A presentation at the 2016 Tokyo Forum; This year's annual meeting will host a major exhibition, ACCESS+ABILITY

Hewitt, Smithsonian Design Museum, it will feature designs made with and by people with disabilities and demonstrate that designing for inclusion spurs innovation and benefits everyone. Items include an eye-tracking device for hands-free communication, adaptive clothing and a Braille smartwatch.

Among disability advocates participating in the Annual Meeting are: Gina Badenoch, social entrepreneur; Susanne Bruyère, director, Institute on Employment and Disability, Cornell University; Sinéad Burke, writer and educator; Caroline Casey, inclu-

sivity activist; Yetnebersh Nigussie, lawyer and educator; Paul Polman, CEO, Unilever; Susannah Rodgers, paralympian athlete; and Thorkill Sonne, social entrepreneur.

"With people living longer and chronic health conditions increasing, most individuals will experience disability at some point during life. Caring for people with disabilities is in everyone's interest. Together, we must design a more inclusive world that takes care of everyone's current and future needs," said Nico Daswani, Head of Arts and Culture at the World Economic Forum.

ACCESS AND ABILITY : SESSIONS ON DISABILITY INCLUSION

TUESDAY, JANUARY 22

Betazone: Designing for Everyone

Stories of inclusive designs and best practices. With Sinéad Burke, writer; and Caroline Baumann, Director, Cooper Hewitt, Smithsonian Design Museum.

WEDNESDAY, JANUARY 23

Workshop: Making Disability

Inclusion Work Workshop with practical toolkit for making organizations more accessible. With Susan Bruyere, Cornell University.

THURSDAY, JANUARY 24

Panel Discussion: An Inclusive Future of Education

Dialogue on how to build

disability-inclusive school and education systems. With Yetnebersh Nigussie, lawyer and educator.

PRESS CONFERENCE

The #valuable Campaign Campaign aimed at committing 500 businesses to putting disability on the boardroom agenda. With Paul Polman, CEO, Unilever; and Caroline Casey, inclusivity activist.

PANEL DISCUSSION

The Business Case for Disability

Inclusion Setting an ambitious new standard for disability inclusion in 2019. With Paul Polman, CEO, Unilever.

OTHER HIGHLIGHTS

Sensory Dinner in the Dark A collective experience in total darkness, led by visually-impaired guides, which aims to change perceptions of the self and what people with different abilities can do. In collaboration with Sight of Emotion.

#valuable Campaign A worldwide call to action for business, to position disability on the business agenda and recognize the value and worth of the 1 billion people globally living with a disability. For more information, please visit www.weforum.org

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LJS Fac/X, a twenty-two year old company, has undergone its own evolution since the 1990s. Larry Smith began as an individual electrical contractor, founding the company as LJS Electric as his commercial clients grew his business. Larry saw the need to expand his capabilities, and, over the next two decades, he brought talented professionals together to complement each other's unique skill set. Together the staff of LJS Fac/X offers practical, hands-on experience in a broad array of specialties.

The staff forms two teams, each offering comprehensive expertise in one of the company's two main divisions of facility services. The "Electrical Team" and the "HVAC/Mechanical Team" can cope with any situation an client or homeowner might encounter.

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WHAT'S HAPPENING

ANNOUNCING THE 2019 AAPD PAUL G. HEARNE EMERGING LEADER AWARD RECIPIENTS

Through the AAPD Paul G. Hearne Emerging Leader Awards, the American Association of People with Disabilities (AAPD) recognizes outstanding emerging leaders with disabilities who exemplify leadership, advocacy, and dedication to the broader cross-disability community.

Two individuals each receive \$2,500 in recognition of their outstanding contributions and \$7,500 to further a new or existing initiative that increases the political and economic power of people with disabilities.

AAPD is proud to recognize Sarah Blahovec and Dustin Gibson as the recipients of the 2019 AAPD Paul G. Hearne Emerging Leader Awards.

Sarah Blahovec is a chronically ill disability advocate. Diagnosed with severe Crohn's Disease at age 15, Sarah has always had a passion for politics and focuses her advocacy on civic engagement and issues that intersect the chronic illness and disability communities. She graduated from American University in 2014 with a bachelor's degree in International Studies, and after struggling to find mentors with disabilities in her field, began blogging about disability rights for the Huffington Post. Sarah is currently the Disability Vote Organizer for the National Council on Independent Living, where she advocates for greater accessibility in elections; educates the disability community on voting rights and works to energize a disability voting bloc; and addresses barriers to running for office for people with disabilities. Sarah is also a founding board member, former Access and Inclusion chair, and current Communications chair of New Leaders Council of Virginia, which equips diverse Millennial leaders in Virginia with the skills to impact progressive change in their communities.

With the 2019 Paul G. Hearne Emerging Leader Award, Sarah is thrilled to establish the first campaign training curriculum for people with disabilities who want to run for elected office. While this online campaign training course will be open to all, it will specifically focus on bringing together trainers from marginalized communities and multi-marginalized people with disabilities who have run for office in the past, to teach essential skills on running for office from an intersectional perspective, and to intentionally uplift prospective disabled candidates of color, women, religious minorities, and/or members of the LGBTQIA+ community.

Dustin Gibson is a community builder who develops "heart-work" to expand the collective consciousness of marginalized communities and address the nexus between race, class, and disability. He works across classrooms, neighborhoods, kid jails, and adult prisons to support individuals in finding home and engage in creating a world without jails and prisons.

Dustin works beside community members and grassroots organizations to lead campaigns and build coalitions to eliminate police violence, address community needs, end the criminalization of students – specifically black, disabled students – and advocate for the implementation of policy and legislation to reduce harm.

He has worked with all three Centers for Independent Living in the Pittsburgh region and has held positions with national independent living organizations. He co-founded Disability Advocates for Rights and Transition, an organization led by disabled people

that works to end forced institutionalization of disabled people and assist them in navigating systems to live in the community of their choosing with the dignity of risk.

As a founding member of the Harriet Tubman Collective and co-creator of We Can't Breathe: The Deaf & Disabled Margin of Police Brutality Project, Dustin travels across the United States to build collective power within multiply-marginalized communities and construct alternatives to systems of policing and imprisonment.

With the 2019 Paul G. Hearne Emerging Leader Award, Dustin will work alongside youth who are or have been incarcerated, to build a critical disability lens, gain historical context to current systems, and provide resources to assist them in thinking through issues and strategizing points of advocacy to organize themselves.

The recipients of the 2019 AAPD Paul G. Hearne Emerging Leader Awards will be honored at the 2019 AAPD Leadership Awards Gala in Washington, DC on March 12, 2019. You can learn more about this year's award recipients on the AAPD website (www.aapd.com).

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ABOUT THE AAPD



The American Association of People with Disabilities (AAPD) is a convener, connector, and catalyst for change, increasing the political and economic power of people with disabilities. As a national cross-disability rights organization, AAPD advocates for full civil rights for the over 60 million Americans with disabilities by advancing equal opportunity, economic power, independent living, and political participation.



PROVEN LEADERS: Emerging Leader Award winners Sarah Blahovec and Dustin Gibson are "working on leading-edge issues that are lifting up the voices and advancing the rights and inclusion of multi-marginalized youth and adults with disabilities."

NEW PRODUCTS

NEW YEAR, NEW GEAR

CROCODILE ROCKER

The Crocodile Rocker is designed for children with balance disabilities and moving disabilities. It fits up to three children for a back and forward ride. It is intended to use to help children learn balance and play with others. It can hold 3 children, each weighing up to 110 pounds and can be used inside or outside. Ideal for ages 1-5. Made with high UV resistant colors to prevent fading.

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WEIGHTED BOWL

The Weighted Bowl is designed for individuals with arthritis, Parkinson's, multiple sclerosis, or other central nervous system disorders. It is helpful to other illnesses, injuries, or disorders that cause tremors in the upper body/to the hands. It is insulated to keep food warm/cold, a feature designed to help those who know it takes them longer to feed themselves. The weight is added internally to the base to lessen the effects of tremors of the hand commonly associated with having Parkinson's disease and other illnesses or injuries. Not for use in the microwave. Color: Blue. Capacity: 12 ounces.

ENABLING DEVICES

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Web: www.enablingdevices.com

THE BLACK BOOK OF COLORS

The Black Book of Colors is a color braille book designed for use by children who are blind or have low vision. The Braille book is designed to assist users in learning how to read the alphabet and numbers while using their fingertips. The descriptive, sensory text, which also incorporates white type and Braille, combined with an innovative design, makes this book a starting point for discussions on

difference, perspective, and experiencing and describing the world in new ways, topics that are relevant to readers. Suitable for ages 5 and up.

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ABLEDATA

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 30,000 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 and Rehabilitation Research (NIDRR) under contract number ED-OSE-13-C-0064. 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: www.abledata.com; email: abledata@neweditions.net; twitter: https://twitter.com/AT_Info; Facebook: <https://www.facebook.com/abledata>.

NEW PRODUCTS

ADAPTED BATTERY OPERATED SCISSORS

The Adapted Battery Operated Scissors are designed for individuals with fine motor disabilities or limited grasping ability. The switch-adapted scissors allow users to participate in art and other classroom or home activities. Connect a switch to activate and the scissors will easily cut through paper. The base includes suction feet to hold securely in place. Dimensions (base): 6 x 8 x 2 inches. Dimensions (scissors): 10

¼ x 5 inches. Operates with 4 AA batteries, not included. Switch not included.



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Oral Motor Tool for chewing; a Small Tin of Crazy Aaron's Thinking Putty to squeeze, twist, and pull; a Mini Water Wiggle for squishy tactile fun; and a Red Oggi Jr for fidgeting and sticking to windows.

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Exceptional Parent Magazine is proud to announce the launch of www.ep-magazine.com – our all new website which coincides with our expanding role as a leader in the field of special needs publishing and communications.

www.ep-magazine.com now features a bold new design and intuitive site-wide navigation system with improved menu functionality that directs you to the information most relevant to you. It is also fully responsive with mobile devices, making it easy to navigate on a wide range of web browsers and portable devices.

We've introduced a range of new content to the website, including *In This Issue* that highlights selected content from our latest issue, and

From Our Contributors, which features the most recent offerings from regulars such as Genetic Alliance and the AADMD.

Our eNewsletter is the latest innovation in our digital strategy, enabling you to sign up for updates right on the homepage, and access the articles that matter to you each and every week. We also plan to continue adding more video content and product information to provide you with all of the resources you need to care and plan for your loved one with special needs.

We're really proud of the new website and feel it will create the experience you're looking for when you pay us a visit. Check it out here: www.ep-magazine.com



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EP-MAGAZINE.COM: AN ALL-NEW DIGITAL HOME FOR THE SPECIAL NEEDS COMMUNITY

My Child Has a Disability... Do I Have To Worry About an Opioid Addiction Too?

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

“(In the United States), more people than ever are dying from opioid overdose; in 2016, over 42,000 people were killed by opioids. Across 52 areas in 45 states opioid overdoses increased by 30 percent from July 2016 through September 2017... Some opioids such as heroin, are illegal. However, many opioids are legal and are prescribed by health care providers to treat pain; these include oxycodone, hydrocodone, codeine and morphine... Use of these prescription drugs for short durations, as prescribed by a doctor I, is generally safe...”¹

“In 2016, 3.6 percent of adolescents age 12 to 17 reported misusing opioids over the past year... the CDC estimates that for every young adult overdose death, there are 119 emergency room visits and 22 treatment admissions... Signs of opioid misuse include: drowsiness, constipation, nausea, dizziness, vomiting, dry mouth, headaches, sweating and mood changes...”¹

“The estimated cost of the epidemic nationwide in 2016 alone was \$95.8 billion, and its estimated cost between 2001 and 2017 exceeded \$1 trillion from lost productivity and increased spending on health care, social services, education, and criminal justice.”²



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.

Living with a disability can have a serious impact on a person's well-being, especially when that disability is associated with chronic pain. **The challenges of living with daily pain contributes to substance abuse rates that are two to four times higher among individuals with disabilities than in the general population.**⁵ Every 25 minutes, an infant is born suffering from opioid withdrawal (a pre-birth consequence from mom), and an estimated 21,732 infants were born in 2012 with neonatal abstinence syndrome, a drug withdrawal syndrome.⁴

The risk factors for adolescent substance abuse are similar to the behavioral effects of learning disabilities: reduced self-esteem, academic difficulty, loneliness, depression and the desire for social acceptance. Thus, researchers theorize, learning disabilities may indirectly lead to substance abuse by generating the types of behavior that typically lead to substance abuse.⁵

Nevertheless, in the last decade there has been significant controversy about the appropriateness, efficacy, safety, and wisdom of treating chronic pain patients with opioids. Arguments against their use have included concerns about tolerance, dependence, addiction, persistent side effects, and interference with physical or psychosocial functioning. However, considerable experience and research suggests that in appropriately selected patients, opioids have a low morbidity, and a low addiction potential, and in addition to the primary analgesic action, can facilitate reduction in suffering, enhance functional activity level, and improve quality of life without significant risk of addictive behaviors.⁶

Although evidence is limited, the expert panel of the American Pain Society and the American Academy of Pain Medicine concluded that chronic opioid therapy can be an effective therapy for carefully selected and monitored patients with chronic noncancer pain. However, opioids are also associated with potentially serious harms, including opioid-related adverse effects and outcomes related to the abuse potential of opioids.⁷

Some patients are at risk.^{6,7}

SOME LESSONS IN ANATOMY AND PHYSIOLOGY

The brain is wired to encourage life-sustaining and healthy activities through the release of dopamine. Everyday rewards during adolescence—such as hanging out with friends, listening to music, playing sports, and all the other highly motivating experiences for teenagers—cause the release of this chemical in moderate amounts. This reinforces behaviors that contribute to learning, health, well-being, and the strengthening of social bonds.⁸

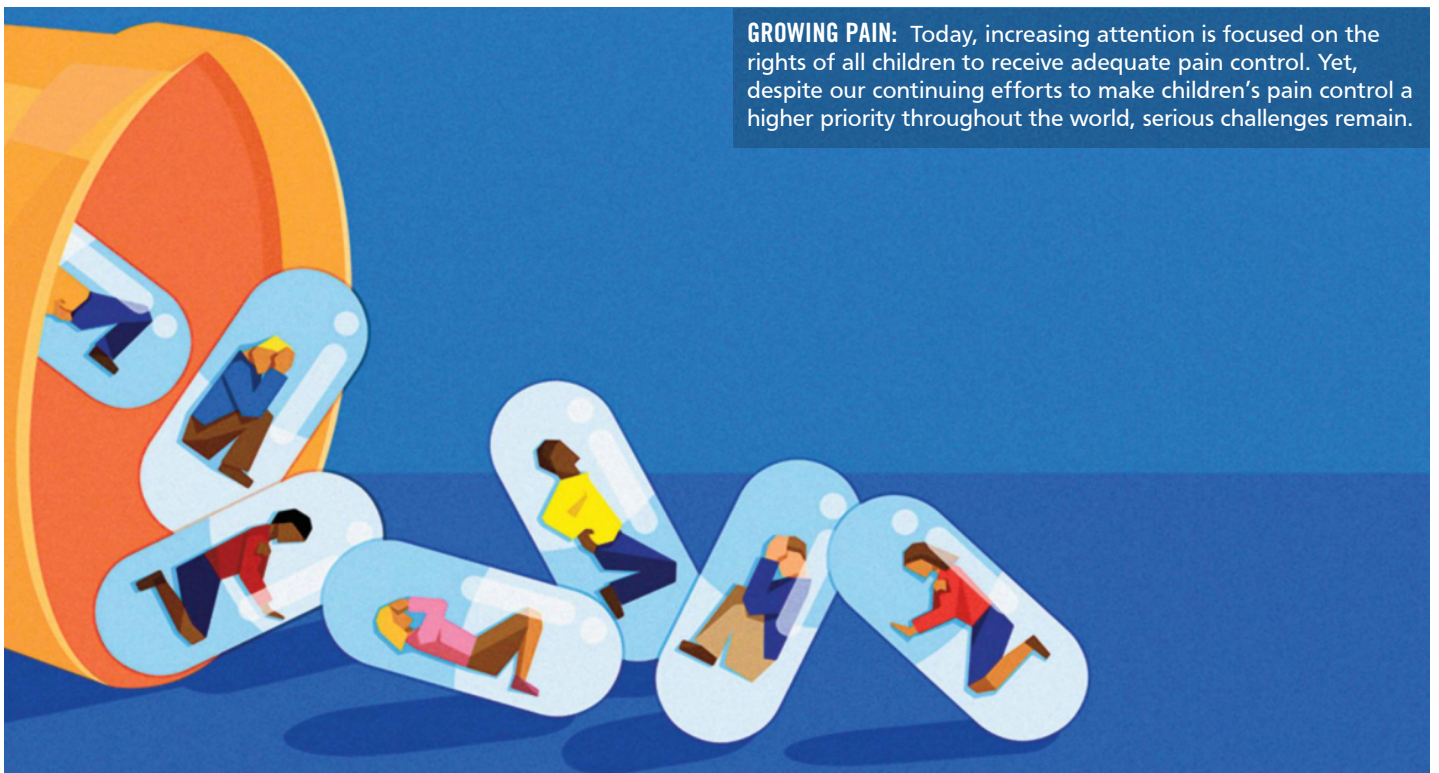
The “high” produced by drugs represents a flooding of the brain's reward circuits with much more dopamine than natural rewards generate. This creates an especially strong drive to repeat the experience. The immature brain, already struggling with balancing impulse and self-control, is more likely to take drugs again without adequately considering the consequences.⁹ If the experience is repeated, the brain reinforces the neural links between pleasure and drug-taking, making the association stronger and stronger. Soon, taking the drug may assume an importance in the adolescent's life out of proportion to other rewards.

“The development of addiction is like a vicious cycle: chronic drug use not only realigns a person's priorities but also may alter key brain areas necessary for judgment and self-control, further reducing the individual's ability to control or stop their drug use. This is why, despite popular belief, willpower alone is often insufficient to overcome an addiction. Drug use has compromised the very parts of the brain that make it possible to ‘say no.’”⁸

POTENTIAL SYMPTOMS IN SCHOOL-AGED CHILDREN

- *“Impaired verbal performance, reading, and arithmetic skills*
- *Poor mental and motor development*
- *Memory and perception problems*
- *Attention deficit hyperactivity disorder (ADHD)*
- *Developmental delays*
- *Speech problems, including challenges in producing speech*

GROWING PAIN: Today, increasing attention is focused on the rights of all children to receive adequate pain control. Yet, despite our continuing efforts to make children's pain control a higher priority throughout the world, serious challenges remain.



sounds correctly or fluently or difficulty with voice or resonance

- Language disorders, including trouble understanding others (receptive language) or sharing thoughts, ideas, and feelings (expressive language)
- Impaired self-regulation
- School absence, school failure, and other behavioral problems
- Depressed respiration or hypoxia
- Reduced decision-making abilities and behavior regulation
- Poor response to stressful situations
- Poorly developed sense of confidence or efficacy in task performance
- Depressive disorder
- Substance use disorder”¹⁰

REALITIES

Individuals with disabilities are a growing population that is confronted by multiple disadvantages from social and environmental determinants of health. “In particular, the 7 to 8 million people with an intellectual disability (ID) suffer disproportionately from substance (i.e. illicit drug) use problems, largely because of a lack of empirical evidence to inform (them, regarding) the availability of prevention and treatment efforts.”¹⁰ (Emphasis added) While the prevalence of alcohol and illicit drug use in this population is low, the risk of having a substance-related problem among ID users is comparatively high. Compared with substance abusers without ID, ID substance abusers are less likely to receive substance abuse treatment or remain in treatment.¹¹

A report from Canada provides further commentary on substance-related and addictive disorders (SRAD) among adults with and without intellectual and developmental disabilities. The prevalence of SRAD among adults with ID was considerably higher than for adults without ID in Ontario.¹²

“As a result of improved efficacy of treatments and care for life-threatening pediatric conditions, the survival of children with serious congenital or acquired diseases in developed countries has increased during the last decades. Yet, many of these children have not been cured (e.g. those with cystic fibrosis) or they have disabling sequelae of their disease (e.g. cerebral palsy and juvenile rheumatoid arthritis) or its treatment (e.g. retinopathy of prematurity). The incidences of some other conditions, such

as asthma and obesity, are rising. Therefore, the prevalence of chronic diseases in children and in young adults, which is a function of incidence and duration, has increased since the 1980s and will likely increase further.”¹³

“(In the past,) clinical decisions about whether children were experiencing pain and, if so, about the particular pain therapies required, were long based primarily on physicians’ personal beliefs rather than on scientific evidence. Regrettably, common misbeliefs – that children did not feel pain as intensely as adults and consequently did not require similar analgesics and pervasive fears – that children were at heightened risk for opioid addiction and should receive minimal analgesic doses, caused many children to suffer needlessly. (Note: *More than sixty years ago, one of us (HBW) was taught during his dental school training that the repeated movements and crying by pediatric patients during dental treatment were simply “childhood things” since the youngster really experienced little to no pain.*) Unprecedented scientific and clinical attention subsequently focused on the unique pain problems of infants, children and adolescents – revealing the adverse impact of untreated postoperative pain and inadequately treated procedural pain for children with cancer.

The ensuing publicity as people learned that minimal anesthesia and analgesia represented ‘the norm in pediatric postoperative management’, rather than the exception, sparked a revolution. Clinical practice started to change so that children began to receive more appropriate analgesics at adequate doses and regular dosing intervals. Treatment emphasis also shifted gradually from an almost exclusive disease-centered focus – detecting and treating the assumed source of tissue damage – to a more child-centered perspective – assessing the child to identify any environmental and psychological factors that contributed to pain, so as to target interventions accordingly.

Today, increasing attention is focused on the rights of all children to receive adequate pain control. Yet, despite our continuing efforts to make ‘children’s pain control’ a higher priority throughout the world, serious challenges remain. In particular, the management of childhood chronic pain is a continuing problem in many centers, creating ethical dilemmas from patient-centered, health care and societal perspectives.”¹⁴

SO, REGARDING YOUR CHILD WITH A DISABILITY, DO YOU HAVE TO WORRY ABOUT AN OPIOID ADDICTION TOO?

Unfortunately, like so many other parents raising their children at a time far different from that when they were raised, you have to be concerned with issues that seem far afield from the “usual” food, clothing, shelter and schooling issues. *But growing up, your child could lend you a hand with your computer complexities which he/she learned to fix before they could write a clear sentence.* •

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References

1. Department of Health and Human Services. Office of Adolescent Health Opioids and adolescents. Available from: <https://www.hhs.gov/ash/oah/adolescent-development/substance-use/drugs/opioids/index.html> Accessed November 21, 2018.
2. Normile B, Hanlon C, Eichner H. Antigoals Academy for State Policy. State strategies to meet the needs of young children and families affected by the opioid crisis. Available from: <https://nashp.org/wp-content/uploads/2018/09/Children-and-Opioid-Epidemic-1.pdf> Accessed November 21, 2018.
3. Wilson M. Able Well Organization. When addition, opioids, and disability meet. Available from: <https://ncdj.org/2018/03/when-addiction-opioids-and-disability-meet> Accessed November 22, 2018.
4. Ideas that Work. Intervention IDEAs for infants, toddlers, children, and youth impacted by OPIOID. Available from: <https://osepi-deasthatwork.org/sites/default/files/IDEASlssBrief-Opioids-508.pdf> Accessed November 20, 2018.
5. Daw J. Substance abuse linked to learning disabilities and behavioral disorders. Available from: <https://www.apa.org/monitor/jun01/disorders.aspx> Accessed November 21, 2018.
6. Aronoff GM. Opioids in chronic pain management: Is there a significant risk of addiction? *Current Review of Pain* 2000; 4(2):112-121.
7. Opioid treatment guideline for the use of chronic opioid therapy in chronic noncancer pain. *The Journal of Pain* 2009; 10(2):113-130.e22.
8. National Institute on Drug Abuse. Principles of adolescent substance use disorder treatment: A Research-Based Guide. Available from: <https://www.drugabuse.gov/publications/principles-adolescent-substance-use-disorder-treatment-research-based-guide/introduction> Accessed November 21, 2018.
9. Andersen SL, Teicher MH. Desperately driven and no brakes: Developmental stress exposure and subsequent risk for substance abuse. *Neuroscience & Biobehavioral Reviews* 2009;33(4):516-524.
10. Behnke M, Smith VC. Committee on Substance Abuse, & Committee on Fetus and Newborn. Prenatal substance abuse: Short- and long-term effects on the exposed fetus (Technical Report), 2013. Available from: <https://www.mofas.org/wp-content/uploads/2015/01/Prenatal-Substance-Abuse-Short-and-Long-term-Effects-on-the-ExposedFetus2.pdf> Accessed November 23, 2018.
11. Carroll Chapman SL, Wu LT. Substance abuse among individuals with intellectual disabilities. *Research Development in Disability* 2012;33(4):1147-56.
12. Lin E, Balogh R, McGarry, et al. Substance-related and addictive disorders among adults with intellectual and developmental disabilities (IDD): an Ontario population cohort study. *British Medical Journal* (open) 2016;6(9):e011638.
13. Van der Lee JH, Mokkink LB, Grootenhuys MA et al. Definitions and measurement of chronic health conditions in childhood: A systematic review. *Journal American Medical Association* 2007;297(24):2741-2751.
14. Ruskin DA. Caring for children with chronic pain: ethical considerations. *Pediatric Anesthesia* 2007; 17(6):505-508.



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2019
EP GUIDE
NAVIGATING SPECIAL
NEEDS RESOURCES



2019 Fitness Resources for People with Special Needs

The CDC says that obesity rates for adults with disabilities are approximately 57% higher than adults without disabilities. This is based on BMI (Body Mass Index) measurements. Does that get your attention? They also state that children with disabilities have obesity rates that are 38% higher than children without disabilities.

Obesity contributes to more health complications, which can mean a lower quality of life, and hospitalizations. With the changing health care system, this could cost more money. Prevention is always less costly than treatment, so staying active can save money.

It is important for all people to engage in physical activity, even if there are special needs. The physical activity should include both aerobic exercise for heart health, as well as strengthening exercise, to build muscle, keep bones healthy and boost metabolism. If a person's needs make exer-

cise challenging, it is still important to not be inactive. Physical activity has also been shown to improve mood, and decrease stress. Hopefully these resources can be used by everybody in the family to get moving.

The recommendation for all adults is the same; if any special needs limit the ability to get the recommended amount and/or intensity, do whatever is possible – aiming for the goals. Aerobic exercise is sustained activity, such



as walking, dancing, or cycling. And intensity matters! While you need to be able to keep the activity going continuously, if you are not pushing yourself into a zone that is stressing the body, you will not get the benefits. Think of a scale of 1 to 10, where 10 is an all-out sprint,

you want your aerobic exercise to be in a 4-6 / 10. If you are working at a 4/10, it is recommended that you get 2 hours and 30 minutes of working out per week. If you

push yourself to a 6/10 for your activity, you can get the recommended exercise in 1 hour and 15 minutes per week. Resistance activity is needed for strengthening. And it is recommended that this gets incorporated twice per week. This exercise needs to be performed at a higher intensity, at 7-9/10 on that scale. And bouts of work can be performed with periods of rest and recovery.

Here is an easy-to-follow guide for all adults to be active: <https://health.gov/paguidelines/2008/pdf/adultguide.pdf>

It is actually recommended that children and adolescents get 60 minutes of physical activity daily. This will promote healthy growth and bone health. On the other end of the spectrum, it is important that older adults add exercises that improve balance to their routines to ward off the risk of falls.

Getting children to be active can be encouraged by including friends or siblings. Find activities that are fun for your child. Some children may enjoy playing in the pool while others may like a playground better. Be sure to be active yourself, which will set a good example. Then include your children in your exercise routine!

When we think about getting exercise, we may think of going to a gym, or taking a fitness class. But there are many options out there, so it may take some time and effort to try a variety of activities to see what you and your children enjoy. There are activities that individuals can do alone for those of us who like to use workout time as a way to focus or clear the mind. There are activities that can be done together for family members who have special needs with those who do not, and then there are activities that people may enjoy doing among others with similar abilities. Do not limit yourself (or your family members) to only one type of workout. Look into all types. If you have children who do not have special needs playing team sports, look for local sports teams for your child with special needs. They can cheer each other on without competing with each other.

It can still be difficult to get started. First, you should make sure that your physician has cleared you for exercise. Then you may try to seek out a physical therapist for some

guidance. You do not need to have a PT by your side for exercise, but one can help you decide the best workouts for you, explore local options, and educate you on what to be cautious about with exercise. Physical therapists are experts in how the body moves, and you can find one who specializes in pediatrics or who specializes in the condition that causes the limitation. If you want help finding a physical therapist, go to the **American Physical Therapy Association** website at www.apta.org and choose “Find a PT” at the top of the page.

“Find activities that are fun for your child, like playing in the pool or at a playground. Be sure to be active yourself, which will set a good example. Then include your children in your exercise routine!”

The National Center on Health, Physical Activity, and Disability is a wonderful source for people with a disability to find resources regarding exercise. Per their site, NCHPAD seeks to help people with disability and other chronic health conditions achieve health benefits through increased participation in all types of physical and social activities, including fitness and aquatic activities, recreational and sports programs, adaptive equipment usage, and more. They offer a directory that provides links for programs available to people with disabilities by state, as well as organizations that can help people find local inclusive activities and/or adapted sports. There is a separate youth section for activities specifically geared toward children with disabilities. The NCHPAD also offers a directory of equipment companies that supply exercise, fitness, or sports equipment for people of all abilities. These are also organized by state. There is a directory of personal trainers who self-report expertise of working with the special needs population. Visit www.nchpad.org/Directories.

If you would like to find local individuals

who maintain active **American College of Sports Medicine (ACSM)** certification or registry status, you can follow this link: <https://certification2.acsm.org/profindex>

The US Department of Health and Human Services has the **President’s Council on Sports, Fitness, and Nutrition**, whose mission is to increase sports participation among youth of all backgrounds and abilities and to promote healthy and active lifestyles for all Americans. They started a program I Can Do It! (ICDI) which is a customizable and inclusive health promotion model aimed at transforming the lives of individuals with a disability. ICDI is centered on Mentor-Mentee relationships and weekly health-related goals. In ICDI programs around the country, ICDI Mentors (aged 16+) and ICDI Mentees (participants with a disability aged five+) meet weekly to engage in physical activity, learn and practice healthy eating behaviors, and set health-related goals. Click on www.hhs.gov/fitness/programs-and-awards/i-can-do-it/index.html. If you cannot find an I Can Do It! program in your area, there is information about how to start one.

Is your child receiving physical education at school? Federal law mandates that physical education be provided to students with disabilities and defines Physical Education as the development of:

- *physical and motor skills*
- *fundamental motor skills and patterns (throwing, catching, walking, running, etc.)*
- *skills in aquatics, dance, and individual and group games and sports (including intramural and lifetime sports)*

The APE (Adapted Physical Education) teacher is a direct service provider, not a related service provider, because physical education for children with disabilities is a federally mandated component of special education services [U.S.C.A. 1402 (25)]. This means that physical education needs to be provided to the student with a disability as part of the special education services that child and family receive. This is contrasted with physical therapy and occupational therapy, which are related services. These therapies are provided to the child with disabilities only if he/she needs them to benefit from instruction. If you want more information about getting your child adapted



physical education, further resources can be found at www.pecentral.org/adapted/adaptedmenu.html

The **Christopher and Dana Reeve Foundation** provides resources for people who are newly paralyzed, people who are living with paralysis, parents and caregivers. They offer a resource center that can help you find any activity you may be interested in trying: www.christopherreeve.org/living-with-paralysis/health/staying-active. There are videos to give easy tips about how to be healthier, and links to local organizations.

The **Arthritis Foundation** offers a six-week program called Walk With Ease. It is designed to teach you how to safely make physical activity a part of your daily activity. Walk with Ease aims to reduce pain and discomfort of arthritis, improve balance, increase strength, and increase walking pace. There is also a goal of building confidence and improving health. You can choose to follow the program in a self-guided fashion or a community-based format. www.arthritis.org/living-with-arthritis/tools-resources/walk-with-ease/about.php

The **Adaptive Sports Center** is in Colorado, and it is a full-fledged therapeutic recreation program that operates year-round with a variety of adaptive activities. They work with people of all abilities. Check them out: www.adaptivesports.org

No Barriers is a program that offer experiences to trial adapted outdoor adventures and listen to speakers who are working to advance the technology available for recreation. www.nobarriersusa.org

If you have limb loss, you can look to the **Amputee Coalition** for guidance on how to

stay active. www.amputee-coalition.org/limb-loss-resource-center

The **Arc** is an organization geared toward people with intellectual and developmental disabilities, and aims to support inclusion and participation in the community. www.thearc.org

Jared Ciner started **SPiRiT Fit and Health** in Maryland that is a certified personal trainer as well as a Disability Support Counselor. He suggests that the five top exercises for people in this population to perform regularly are:

1. *Planks to strengthen the core*
2. *High knees to strengthen the hips and the back*
3. *Arm circles to strengthen the upper back*
4. *Single leg stands to improve balance and reduce the risk for falls*
5. *Squats to strengthen the legs*

Another organization that we are familiar with for people with intellectual ability is the **Special Olympics**. The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities. This gives them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community. You can visit their website to find a local chapter and get involved in a variety of activities. www.specialolympics.org

There are activities for the visually impaired as well. With some research, people with impaired vision can participate in nearly every activity. Contacting the **United States Association for Blind Athletes** can get you started. www.usaba.org

Through the VisionAware website, you can learn more about rowing, martial arts, running, downhill skiing and cross-country skiing, sailing and boating, cycling and swimming. Whether you have long standing blindness, or vision loss associate with age, don't let that get in the way of your recreation and leisure activities. It is still important to stay active! Visit www.afb.org/info/living-with-vision-loss/visionaware/15

The government has started a program to improve the health of Americans, and this includes maximizing health, preventing chronic disease, improving social and environmental living conditions, and promoting full community participation, choice, health equity, and quality of life among individuals with disabilities of all ages. There are ten-year benchmarks, and the finding from 2010 led to new benchmarks for 2020. It is good to be aware of these types of programs because it can lead to new research or programs in your area. There may be grant money available for a fitness idea that you may have. There are resources that can be found at www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health •

THE FITNESS PRIORITY

My name is Kristin McNealus, DPT, MBA, and I received my Masters in Physical Therapy from Boston University and went on to earn my Doctorate in Physical Therapy from MGH Institute of Health Professions. I received my MBA from Pepperdine University in 2016. I started Every Body Fitness, an online fitness program for people with physical limitations to workout anywhere. We have a video-on-demand program that offers cardiovascular workouts, boot camp style strengthening workouts, balance classes, and adapted yoga programs. I started this because I know that it is important to get exercise, but there can be challenges getting out to some of the activities discussed in this article. I wanted to design an option with as few barriers as possible. This can be a primary workout program, or complement any other activities. You can check this program out at www.ebfitnesonline.com

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NAVIGATING LIFE
WITH A CHILD
WHO HAS
SPECIAL NEEDS

FINDING MORE JOY ON THE JOURNEY

BY MICHELE ROSNER

When you have a child with a disability, it's arguable that your life will have an unfair and unbalanced number of issues that cause bone-deep, lingering sorrow. This article is focused on helping you get organized, build your support team, make time for self-care, and seek professional therapy when necessary.

For more than sixteen years, our family has been navigating life with a child who has profound disabilities and complex medical challenges. I've learned firsthand that parenting a child with special needs is physically, mentally, emotionally and spiritually challenging. But, I've also discovered that hope and happiness *are* attainable at every step of the way.

I'm a realistic optimist, so I know that sadness and grief cannot always be avoided. In fact, when you have a child with a disability, it's arguable that your life will have an unfair and unbalanced number of issues that cause bone-deep, lingering sorrow. But, if you're like me, you don't want your life to be defined by chronic sorrow.



MEET THE ROSNERS: Our family of six includes Julia, our sixteen-year-old who has Aicardi syndrome. Her disabilities include intractable epilepsy, vision impairment, respiratory and GI issues, and significant developmental delays. While raising Julia is different than the journey we expected, my husband and I, as well as Julia's brothers and sister, have learned so many profound life lessons along the way. As we've navigated through the challenges, we've found some valuable resources that have provided insights, inspiration and hope.

This article explores strategies to move closer to the joy and further from the sadness and grief. It's focused on getting organized, building your support team, making time for self-care, and seeking professional therapy when necessary. I'm excited to share some of the strategies and resources my family and I have used to make our lives a little easier.

GETTING ORGANIZED

Having a child with special needs means that you often have unexpected challenges that need time, attention and energy to resolve. It can be easier to deal with those challenges if you've laid the foundation for the more manageable parts of your life to be running smoothly.

Here are four simple strategies that have worked for our family:

1. **Online Calendar:** We track all family appointments and activities, as well as the schedules for our daughter's private duty nurses, on Google Calendar.
2. **Family Command Center:** We have a huge bulletin board in our hallway where we keep a phone list, a supply list for monthly orders, invitations, and other items that we need frequent and easy access to.
3. **Go-Bag:** We keep a bag packed with everything we need for a day trip or doctor's appointment so we can just grab it on the way out the door. It includes the basics, such as diapers, wipes, and extra clothes. Beyond the basics, we make sure this bag includes those 'just in case' items like an extra g-tube extension.
4. **Medical Paperwork Binder:** For years, we kept a hodge-podge of files and piles to 'organize' the ever-growing mountain of medical paperwork. Now, we have a single binder that includes the most recent medical information. Every month, we archive the older information to a file drawer where we keep the information for long-term storage.

RESOURCES FOR GETTING ORGANIZED

- **Organizing Your Child's Special Needs: Tips & Tricks:** Blog post from Organize 365 which includes tips for organizing paperwork, medications/supplements, kids' schedules and parents' planners. <https://organize365.com/organizing-childs-special-needs-2/>
- **Get organized: Tips for parents of kids with special needs:** Blog post from SheKnows that focuses on tips for organizing your time. www.sheknows.com/parenting/articles/1006845/organizing-tips-for-parents-of-kids-with-special-needs

- **Organized Special Needs Paperwork:** Blog post that provides a step-by-step guide to creating a binder to organize special needs paperwork. www.simplyorganized.me/2012/10/organized-special-needs-paperwork.html
- **Special Needs Moms Organizing and Cleaning Support:** Facebook group that shares ideas and inspiration for organizing and cleaning projects. www.facebook.com/groups/specialneedsmomorganizingandcleaningsupport
- **Home Hospital NOT Hospital Home:** Facebook group focused on keeping your house looking like a home even when you have a lot of medical supplies and equipment. www.facebook.com/groups/506291616403397
- **Special Mom Advocate 'Printables':** For a small fee, you can download PDF 'printables' for organizing a binder for medical and IEP paperwork. www.specialmomadvocate.com/product-category/printable/
- **The Sensory Child Gets Organized:** This book teaches the parents of kids with sensory issues how to organize and empower their children for greater success at home, at school, and in life. www.amazon.com/Sensory-Child-Gets-Organized-Distracted/dp/1451664281/ref=sr_1_1?ie=UTF8&qid=1544985280&sr=81&keywords=the+sensory+child+gets+organized#customerReviews

BUILDING A SUPPORT NETWORK

Raising a child with special needs is nearly impossible to do it on your own. In fact, a huge part of empowering yourself is finding and accepting help from others. It has taken deliberate planning, creative problem-solving and a clear understanding of our current needs to build our family's support network. Here's a look at our team:

Family and friends: I've been a part of the special needs community for many years, and I've often seen families express frustration and feelings of isolation as they become more and more drawn into a world that their friends and family do not understand. Even worse, some feel like friends and family disappear just when they are needed the most.

While there are certainly circumstances where friends and family aren't willing or able to provide the support you need, sometimes they're just not sure how to

help. If you have the chance, try to let others be a part of your journey early on. That can help you build a support team that will be essential in the future.

If you have friends and family who ask how they can help, and you're struggling to figure out what kind of help to ask for, try this trick: Keep a running list of things you need. It could be a gallon of milk, picking up a prescription, taking the dog to the groomer, or getting your oil changed. Then, when someone offers to help, ask if they can take care of one or two tasks on your list.

Private Duty Nursing: If you have a child with significant medical needs, private duty nursing might be an option available to you, as it is for us. However, choosing to build a nursing team was not an easy decision for us. We value our privacy, and having a stranger in our home on a regular basis was something we thought about carefully. But, with four kids and two careers, we needed more support. Over the years, we've become more adept at hiring nurses, choosing only those who are great caregivers and meld well with our entire family. Now, it does not seem like we have strangers in our home; instead the nurses feel like extended family.

School: We've explored different schooling options for Julia over the years. At times, it's been a wonderful, collaborative relationship; sometimes it's been a challenge to get on the same page.

Since Julia has transitioned to high school, we've developed a homebound program that is a near perfect fit for her needs. She uses Skype to attend some classes from home, which we schedule around Julia's medical treatments and routines. She also participates in field trips and extracurricular activities when she can. This unique arrangement has fostered the development of friendships and inclusion; Julia has her own squad and is an integral part of the high school even if she's not physically in the building.

Medical Team: Julia's medical team includes more than ten specialists, which can be daunting to manage. Our local children's hospital provides a complex care team to help. That team includes a pediatrician who specializes in caring for medically complex kids, as well as a nurse case manager.

We've developed strong relationships with the specialists who care for Julia, building a foundation of trust between us and her doctors that helps us make solid decisions about Julia's care, both when she is healthy and when she's battling medical issues.

Co-Workers/Bosses: My husband and I both have employers that are extremely supportive of our need for flexibility. When Julia was born, we were both working for privately-owned companies that truly supported family values. However, that support and flexibility is a two-way street. We've both spent time working from Julia's hospital room or working extra hours when she's healthy and well. Whenever possible, we meet and exceed the expectations of our employers. That strategy has worked for us – we've both been able to stay and grow with the same companies we worked for when Julia was born.

RESOURCES FOR BUILDING A SUPPORT NETWORK

While your support network may look very different than ours, take some time to think about which of your family's needs are going unmet and brainstorm how you can add to your team to help fill those gaps.

Here are some resources that can help:

- **Help for Families with Special Needs: An Interview with Louise Bruce about Respite Care:** This blog post from Care.com share tips for finding caregivers who can help care for a child with special needs and ideas about when and how to take advantage of this respite care.
www.care.com/c/stories/6611/help-for-families-with-special-needs
- **6 Types of Support Groups for Parents of Special Needs Children:** A blog post from Verywell Family provides a guide to finding a support group that meets your needs.
www.verywellfamily.com/support-groups-for-parents-of-special-needs-children-4155146
- **How to Support Parents With Special Needs Kids'':** This blog post on A Fine Parent provides insights that can be shared with family and friends who want to help, but aren't sure what to say or do.
<https://afineparent.com/close-knit-family/special-needs-kids.html>
- **Private Duty Nursing: Providing Personal Care Outside the Hospital:** A blog post on Nurses.org that explains how private duty nursing works.
<https://nurse.org/articles/private-duty-nurse>
- **In-Home Pediatric Care: Children Need It and the Law Requires It:** This presentation from the American Academy of Pediatrics explains when private duty nursing is required by law.
www.aap.org/en-us/Documents/sohc_in_home_pediatric_care_law.pdf
- **Don't IEP Alone: A Day in Our Shoes:** This active Facebook group provides IEP support and resources from a special needs mom and advocate.
www.facebook.com/ADayInOurShoesIEP/
- **AAP Agenda for Children: Medical Home:** This overview from the American Academy of Pediatrics provides information about medical homes for children. This resource center provides additional tools, resources, and links to information that will assist families in successfully partnering with their child's medical home.
www.aap.org/en-us/about-the-aap/aap-facts/AAP-Agenda-for-Children-Strategic-Plan/pages/AAP-Agenda-for-Children-Strategic-Plan-Medical-Home.aspx
- **Working Moms of Special Needs Children: Tips for Balancing Life with a Special Needs Child:** This blog post from Balance Careers provides tips for achieving a work/life balance when you're the parent of a child with special needs.
www.thebalancecareers.com/working-moms-of-special-needs-children-3515737

TAKING CARE OF YOURSELF

Is there a voice in your head telling you that it's selfish to think of doing something for yourself when your child needs so much? I'm not surprised if you're already saying to yourself, "I hardly have time to do everything I need to do; there's no way I can find the time to do things I want to do." While there will be times when you have little or no time for yourself, that is not sustainable for long periods of time.

Over the years, I've learned how to make my own happiness a

priority. The better I care for myself, the more I have to give to my daughter and my other loved ones. Two of my self-care priorities include going for long walks while listening to podcasts and making healthy meals.

Your self-care priorities might be very different than mine, but you should have at least one or two ways that you consistently take care of yourself, even when you're busy, and *especially* in the midst of chaos and high stress.

The better you care for yourself, the more you have to give to your loved ones. You should have at least one or two ways that you consistently take care of yourself; Here are some resources for self-care:

- 55 Self-Care Strategies for Moms With Too Little Time: This great resource has ideas for how you can pamper yourself whether you have five minutes or a full day for self-care.

www.specialmomadvocate.com/self-care-moms

- 20 Things Every Parent of Kids with Special Needs Should Hear: This blog post from Abilities is a great reminder about how important it is to take care of yourself.

www.abilities.com/community/parents-20things.html

- Just for You: A Daily Self-Care Journal: This book has 365 days of fun and thought-provoking writing prompts developed specifically for caregivers.

<https://happyhealthycaregiver.com/product/journal>

- Tools for the Caregiver: A workbook for finding yourself through caregiving: This workbook is designed for those in a caregiving position who feel like they are losing track of their own needs and desires. It provides practical advice and journaling prompts to help you get back to yourself.

<http://strongvoicespublishing.com/product/tools-for-the-caregiver>

- Parents raising kids with special needs must manage their stress: This blog post from Expert Beacon offers practical strategies for dealing with stress.

<https://expertbeacon.com/parents-raising-kids-special-needs-must-manage-their-stress/>



JULIA'S JOURNEY: Julia was diagnosed with Aicardi syndrome. This rare disorder occurs almost exclusively in females and is characterized by the partial or complete absence of a key brain structure called the corpus callosum, the presence of retinal abnormalities, and seizures in the form of infantile spasms.

SEEKING PROFESSIONAL THERAPY

With some studies (<http://susanellisonbusch.com/chronic-sorrow-in-parenting-a-child-with-a-disability>) showing that up to 80 percent of parents who have a child with developmental disabilities suffer from chronic sorrow, it's not surprising that many parents who have a child with disabilities could benefit from professional therapy and counseling. However, reaching out for professional help can be intimidating. People often feel embarrassed to admit the need for help. That's changing, but not as much and as quickly as it should. Recognizing that you need help is brave and shows that you want to find better strategies to deal with your circumstances and emotions.

It can be challenging to find the right therapist for your specific needs and personality type. WebMd has a great article (www.webmd.com/mental-health/features/how-to-find-therapist#1) about how to find the right therapist for you.

Once you have a possible therapist in mind, here are some questions to ask them:

It can be challenging to find the right therapist for your specific needs. Some questions to ask a possible therapist:

1. Do you accept my insurance?
Can you help me navigate any necessary prior authorizations that might be needed?
2. My issue is dealing with the challenges of parenting a child with special needs. How do you think you could help me with that? Do you have any experience working with special needs parents?
3. What do you think is the goal of the therapy? How will we measure success?
4. What would I have to do to be ready for the first session?
5. Will I have homework between sessions?
6. What are your strengths as a therapist?
7. Do you tend to lead the session, or follow my lead?
8. If I wanted to bring someone else to a session, such as my spouse, would that be a problem?

RESOURCES FOR SEEKING PROFESSIONAL THERAPY

- **How to Find a Therapist:** This WebMD article provides an overview of the different types of professionals that can provide counseling as well as a practical guide for finding a therapist that fits your needs and personality. www.webmd.com/mental-health/features/how-to-find-therapist#1
- **Congratulations, We're Sorry: Finding Out That Your Baby Has Special Needs:** In this blog post, a licensed marriage and family therapist talks about the emotions many parents feel after learning about their child's diagnosis. www.therapywithcare.com/Article_SpecialNeedsChild.html

NAVIGATING THE JOURNEY TO JOY

One of the things I've struggled with over the years is the fact that my life is different... different than I expected and different than the lives of most people around me. But, with time, I've learned to embrace my life and recognize the unique gifts I have been given. Finding support from and for special needs parents has helped me navigate the challenges along the way. The following contain some resources that can help you on your journey to joy.

BLOGS

- **Bloom:** This blog is done by a children's rehab hospital in Toronto, with posts about once a week. It's a nice mix of posts about different kinds of therapy options for kids with special needs as well as parent perspectives on different challenges they face. <http://bloom-parentingkidswithdisabilities.blogspot.com>
- **Different Kind of Special:** This online community is focused on providing empowerment and positivity to families who have a child with special needs. You can subscribe (<https://mailchi.mp/9501aae0359a/joindifferentkindofspecial>) to a weekly newsletter for more insights and inspiration. www.differentkindofspecial.com

- **Firefly:** This blog sponsored by Leckey features frequent posts by special needs parents and healthcare professionals about the real-life stories, issues and experiences of day to day life. www.fireflyfriends.com/uk/blog
- **Friendship Circle:** A blog made possible by a non-profit organization in Michigan. Posts cover a wide variety of topics, including parenting, advocacy and education. www.friendshipcircle.org/blog

PODCASTS

- **Bringing Up Betty:** While this podcast has not released any new episodes recently, the twenty-two available episodes are well worth listening to. Host Sarah Evans interviews special needs moms and dads raising children with disabilities, differences, disease, delays and other challenges. <http://bringingupbetty.com/podcast-3>
- **Special Parents Confidential:** This podcast hosted by John Pellegrini takes a "we're all in this together" approach to looking at issues, finding successful tactics, and getting solid advice about the complex challenges of parenting special needs children. www.specialparentsconfidential.com/about-us/
- **Unexceptional Moms:** In this podcast, hosts Ellen Stumbo and Erin Loraine offer hope and encouragement for special needs parents. While there haven't been any new episodes since 2017, there are thirty episodes recorded. www.ellenstumbo.com/podcast

ABOUT THE AUTHOR:



Michele Rosner is the mother of four children, including a teenage daughter with multiple disabilities and complex medical challenges. Combining her love of writing with a desire to help others overcome adversity and find more joy on the journey of raising a child with disabilities, she launched Different Kind of Special (www.differentkindofspecial.com). This online community provides resources and support for families that have a child with special needs.



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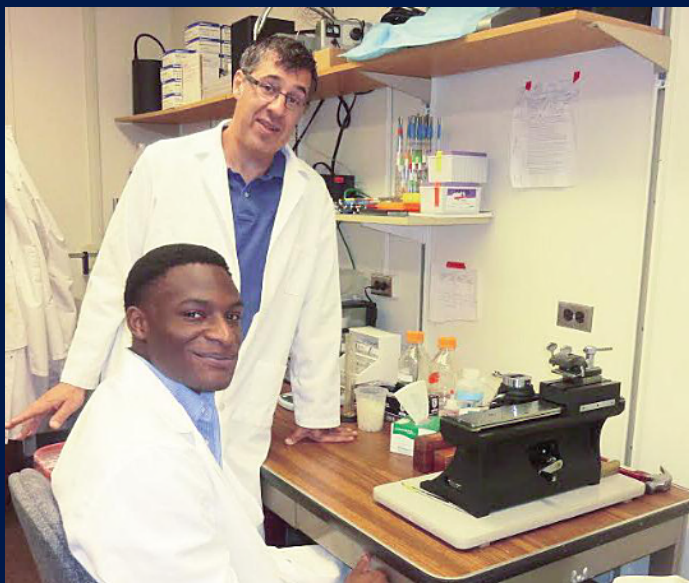




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HOW MHEALTH, 3-D PRINTING & ROBOTS WILL CHANGE THE WORLD FOR PEOPLE WITH SPECIAL NEEDS

BY DR. JOHN R. PATRICK



THE INCREDIBLE POWER OF SMARTPHONES, PLUS ADVANCES IN 3-D PRINTING AND ROBOTICS, WILL PROVIDE THOSE WITH SPECIAL NEEDS AND THEIR CAREGIVERS WITH NEW WAYS TO TRACK HEALTH INFORMATION, PRINT PROSTHETICS, GAIN ASSISTANCE FROM ROBOTS, AND HAVE ACCESS TO NEW AND WIDE RANGING ENABLING TECHNOLOGIES.

In 1976, Seymour Cray, the father of super-computing, introduced the most powerful computer in the world, the Cray-1. It was super in many respects. It cost \$5-\$10 million, weighed more than 5 tons, and used as much electricity as ten homes.¹ Super as it was, the Cray-1 had no app store, could not play a song, or even make a phone call. However, scientists and researchers embraced the Cray-1 because it enabled them to perform scientific simulations and explore data at a speed not previously possible.

Fast-forward four decades from the introduction of the Cray-1 to Apple and Android smartphones. We call them phones, but they are really computers; supercomputers 100+ times more powerful than the Cray-1. Hundreds of millions of people around the world carry them in their pocket or purse. The incredible power of the smartphones, plus advances in 3-D printing and robotics, will provide those with special needs and their caregivers with new ways to track health information, print prosthetics, gain assistance from robots, and have access to new and wide-ranging enabling technologies.

MHEALTH

Consumers and caregivers are taking a more active role in healthcare and taking advantage of new mobile health (mHealth) apps and devices. By measuring and tracking their health, consumers will have more data than ever before. Although some providers are not comfortable with consumer technology for self-diagnosis, the new technologies will lead to a new model of collaboration between patient and physician. Parents and caregivers will extend the use of mHealth to those with special needs.

People are finding tracking one's health is a good tool for improving one's health. More than half of Americans track weight, diet, or exercise.² Innovators are developing new mHealth apps and devices at a frenetic pace, and consumers have a healthy attitude about adopting them. According to industry estimates cited by the FDA, more than a billion smartphone users worldwide will be using a mobile healthcare application by 2018, including healthcare professionals, consumers, and patients.³ An explosion of development resulted in 325,000 mobile health apps available in 2017. Many of these are fitness related, but as consumers adopt mHealth devices, they will be using apps to perform tests at a much lower cost than traditional laboratories and in a convenient way, enabling them to send data to their doctor.

The term "regulation" is unfavorable to many technology innovators who fear government bureaucrats will inhibit getting new ideas to market. When it comes to healthcare, however, regulation is a different story. The FDA sees the widespread adoption and use of mobile technologies as creating new ways to improve health and the delivery of healthcare services. It's hard to come up with an exact number the FDA has approved but, according to Jonah Comstock, Editor in Chief, at MobiHealthNews, "What is clear is that there are a lot of FDA-cleared apps, easily hundreds, and that the number of apps going through the FDA goes up every year." The explosion of healthcare related apps and devices connected to smartphones is enabling a consumer-led revolution in healthcare.⁴

In the past, consumers had to make an appointment and drive to a doctor's office to get "checked". Now, consumers can check an increasing number of health indicators for themselves or for a person with special needs. Being able to monitor critical measurements on a regular basis can make all the difference in people's lives. The Internet has empowered consumers for more than 20 years. mHealth has provided even more empowerment to consumers in a short time through smartphones. The pace of mHealth adoption will accelerate; self-monitoring and self-diagnosis are here to stay. A new model of collaboration between patient and provider is emerging.

3-D PRINTING

The U.S. Centers for Disease Control and Prevention reported four in 10,000 children are born with some congenital hand loss. There is a need for 1,500 child hand prosthetics each year. A prosthetic can cost up to \$40,000, and insurance has usually not covered them. As children grow, they can have trouble adapting to a prosthetic. The need for pediatric prosthetics spawned a network of volunteer medical workers, engineers, designers, parents, and 3-D printing enthusiasts who have been designing, printing, and outfitting children with prosthetics.

Meredith Cohn at *The Baltimore Sun* wrote about how Albert Chi, a trauma surgeon at Johns Hopkins, was able to print a hand for a two-year-old.⁵ Chi said, "We thought the child was too young, but we weren't even able to finish strapping it on, and the kid was picking an object up." A network of thousands of volunteers and non-profit e-NABLE are using 3-D printing

technology to create free printed hands and arms for those in need. With free designs available online and the advent of sub-\$1,000 printers, families may be printing hands at home with free designs from e-NABLE's website. With prosthetics below \$20, it is practical to print new ones every few months as children grow. They can also pick their favorite color. Clinical trials are underway led by non-profit Limbitless Solutions to create 3-D printed arms. The organization is devoted to building a generation of innovators who use their skills and passion to improve the world around them, including creating arms for those in need.

Another powerful use of the technology is for printing models to aid in surgery. A case at Morgan Stanley Children's Hospital in New York represents a touching story which demonstrated the potential. A two-week-old baby suffering from a congenital heart defect was in urgent need of surgery. The baby's heart was riddled with holes and presented a highly complex surgical

challenge. Rather than stop the heart and examine its interior to determine a surgical strategy, as would have been the only option in the past, 3-D printing was used to create a model of the baby's heart using data from an MRI.⁷ The model served as a guide both for planning and during the surgery. Thanks to 3-D printing and the skill of a Columbia Presbyterian Hospital surgeon, the baby should lead a normal life. Thirty-five thousand babies are born each year with congenital heart defects. 3-D printing has the potential to improve the outcomes for those needing surgery.

3-D printing has already expanded to printing tissues of organs and bones. The promise of healthcare innovation using 3-D printing technology is extraordinary. A 60-year-old British man suffered from chondrosarcoma of the pelvis, a rare form of untreatable cancer. The only option was to replace the diseased half of his pelvis. Such surgery would have been unheard of in the recent past, but with the advent of 3-D scanners and printers, there was a

RECENT DEVELOPMENTS IN mHEALTH TECHNOLOGY

▷ **ALIVECOR HAS A HEART MONITOR** sensing device, called a Kardia, which attaches to the back of a smartphone or can be placed next to a smartphone. You put two fingers from each hand on the device sensors and the iPhone creates a 30-second EKG. You can save it, email it to your doctor, or click to have an AliveCor vetted cardiologist or technician provide an analysis for a small fee. The company also has a version of the Kardia with the sensing technology built into an Apple Watch band. In December 2018, Apple introduced an Apple Watch app which produces an EKG when the watch wearer holds his or her index finger against the watch crown for 30 seconds. Apple also received FDA clearance for an algorithm able to detect atrial fibrillation, an irregular and often rapid heart rate that can increase risk of stroke, heart failure and other heart-related complications. Alongside the EKG, the algorithm allows the Watch to screen users' heart rhythm in the background and send notification if it detects an irregular rhythm that appears to be atrial fibrillation.

▷ **HEALTHCARE PROVIDERS ARE BEGINNING TO** take advantage of the availability of consumer health data from mHealth devices and apps. Cedars-Sinai has integrated consumer data with the hospital's electronic health record (EHR) system for thousands of patients. Cardiac data will flow from

the Apple Watch or a Kardia sensor to the iPhone Apple Health database on an iPhone to the EHR database. Cardiologists will have access to vastly more data about a patient's heart than previously.

▷ **THE CELLSCOPE OTO TURNS A** smartphone into an ear-inspecting otoscope. A small attachment to a smartphone can capture a video of the eardrum. A companion app called Seymour analyzes the video and detects ear infections. A family member can email data from the Seymour app to a doctor to confirm diagnosis. Contrast this with making an appointment, driving across down, and sitting in the waiting room.



▷ **mHEALTH WILL PROVIDE GREAT HEALTHCARE** convenience for consumers. The convenience will eventually extend to blood tests. A team of engineers at Cornell University has developed The Smartphone Cholesterol Application for Rapid Diagnostics, or "smartCARD". The smartCARD accessory optically detects biomarkers in a drop of blood, sweat, or saliva. A consumer can extract a single drop of blood onto a strip. The smartphone camera attachment takes a photo of the strip and a smartphone app performs a colorimetric analysis displaying cholesterol level. The test takes about a minute.

chance of success. A United Kingdom implant maker used a 3-D scan and then printed a custom model of the half pelvis. The 3-D printing process used a laser to fuse multiple layers of titanium powder to create the new pelvis part. The part was then coated with a mineral receptive to the growth of new bone. The surgical team used a surgical robot to assist in the 12-hour procedure. The final step was to perform a hip replacement to fit into a socket of the new pelvis part.

British newspapers reported three years after the complex procedure, the man was able to walk with the help of a cane.⁸ A few years from now, the complex set of steps for 3-D printing of a pelvis or other human parts may seem primitive. More fully automated processes leading from diagnosis to treatment will seem commonplace.

A final example demonstrates the potential for young people. Peking University doctors implanted a 3-D printed vertebra successfully in a 12-year-old boy who had a malignant spinal cord tumor.⁹ A digital model was created from which the vertebra was printed.



Most 3-D printing uses polymers or metals but, in this case, the University used titanium powder, which is typically used for orthopedic implants. What was atypical was the implant did not require cement or screws because the implant was made to fit precisely. Normally, implants come in pre-determined sizes and may not fit exactly, hence requiring cement or screws. The 3-D printed implant included holes which allowed bone tissue to grow into the implant and hold it in place.

ROBOTS

Robots will play an increasingly important role in all aspects of healthcare in the years ahead. Westminster Technologies, Inc. in Cleveland, Ohio has developed a small child-like robot. The target market for the robots is K-12 schools. Some STEM programs (science technology engineering mathematics) have funding for the technology. Kids can learn how they work and develop programs the robot can execute. A simple example would be a program which

▷ **A SAN DIEGO STARTUP NAMED CUE** has developed a compact, consumer-oriented device which can detect five biological conditions at a molecular level including inflammation, vitamin D, fertility, influenza, and testosterone. The company is seeking FDA approval.

▷ **GLOOKO, A DIGITAL DIABETES CARE** company, has received FDA clearance for its Mobile Insulin Dosing System (MIDS). The app-driven tool recommends insulin dose adjustments using data collected directly from a patient's blood glucose meter. The MIDS module allows clinicians to create a customized treatment plan and send it to Type 2 diabetes patients directly through the company's unified mobile diabetes management app. Instead of relying on patients to input their own fasting blood glucose, however, the system pulls readings from the patient's blood glucose meter.

▷ **CAMBRIDGE, MA-BASED EMPATICA HAS DEVELOPED** a device that is worn on the wrist, called Embrace, which can continuously record physiological signals from multiple sensors and detect epileptic seizures. Embrace transmits data to a paired smartphone via a Bluetooth® connection, and from the smartphone to Empatica's secure servers which notifies caregivers. Although the FDA has approved the device, users will



have to secure a prescription from their neurologist to use the device's seizure-detecting features.



▷ **KINSA HAS A SMART STICK** Thermometer which is FDA-cleared for accuracy. The lightweight device requires no batteries and connects directly to your smartphone for an easy temperature read in less than ten seconds. The thin and flexible device plugs into the audio jack of an iPhone or Android smartphone.

Children can be intimidated by the temperature measurement process, but with the Kinsa thermometer, the process is more like a game. The smartphone retains a record of the temperature for one or more family members and can be annotated with other symptoms such as shivers or headache. A log over multiple days can be emailed to the doctor.

▷ **THE ENVIRONMENT OF A HOSPITAL** or doctor's office can also be intimidating to children. Pedia Pals has developed clinical furniture, such as a Dinosaur Exam Table to bridge the gap between children and medical professionals. Although not apps or devices, the company says their products "provide an entertaining and calming focus for children while improving diagnosis and treatment for these often frightened patients."

reads a text file. This may have applicability in home healthcare. A robot could remind a chronically ill patient when it is time to take a medication. For mentally ill patients or anyone with chronic illness, robots can become a trusted and helpful companion.

In theory, robots could take on a much greater role in home healthcare. They could help people recovering from a stroke to re-learn how to perform basic functions. Therapists and aides can perform the task, but such therapy can be expensive and not pleasant to administer. Robots, on the other hand, can work around the clock, and they never get bored with repetitive tasks. The question about robots is whether people will accept them and not be intimidated by them. A reason to be hopeful is that while the technology is gaining more and more capabilities, it is also becoming more human-like. Health attitudes will adapt, and robots will become allies in our healthcare.

Researchers at the Personal Robots Group at MIT's Media Lab have developed a robot with a baby face with a round head, small chin, and wide eyes that appears more capable of feeling than robots of other designs.¹⁰ The MIT Group found people prefer baby-faced robots for medical advice and for tasks that depend on emotion such as from a therapist. The research also showed child-faced robots are less likely to threaten the autonomy of elderly individuals. The Robot Group at MIT has built a robot named Nexi that exhibits many of the characteristics which may be critical to the long-term future of robots in healthcare. The MIT Media Lab's goal is to build socially engaging robots and interactive technologies to help people live healthier lives.¹¹

Dr. Adam Waytz, Assistant Professor at Northwestern University's Kellogg School of Management, and Dr. Michael Norton, Professor at Harvard Business School have developed a

list of five human-like characteristics they believe will be most important in the acceptance of robots. Faces and voices may be the most obvious. The ability to express empathy is a close third. More surprising but important characteristics Waytz and Norton believe will be important are the ability to provide mimicry and unpredictability.¹² The latter two characteristics pique the interest of humans and result in more acceptance and trust. The reason is these two characteristics are more like humans.

HEALTHCARE TECHNOLOGY IS EVOLVING VERY RAPIDLY. THE PROGRESS WE WILL SEE OVER THE NEXT YEARS WILL EXCEED THAT OF THE PAST 100 YEARS. THOSE WITH SPECIAL NEEDS WILL GAIN ACCESS TO TOOLS WHICH EMPOWER THEM TO IMPROVE THEIR HEALTH. SUMMARY

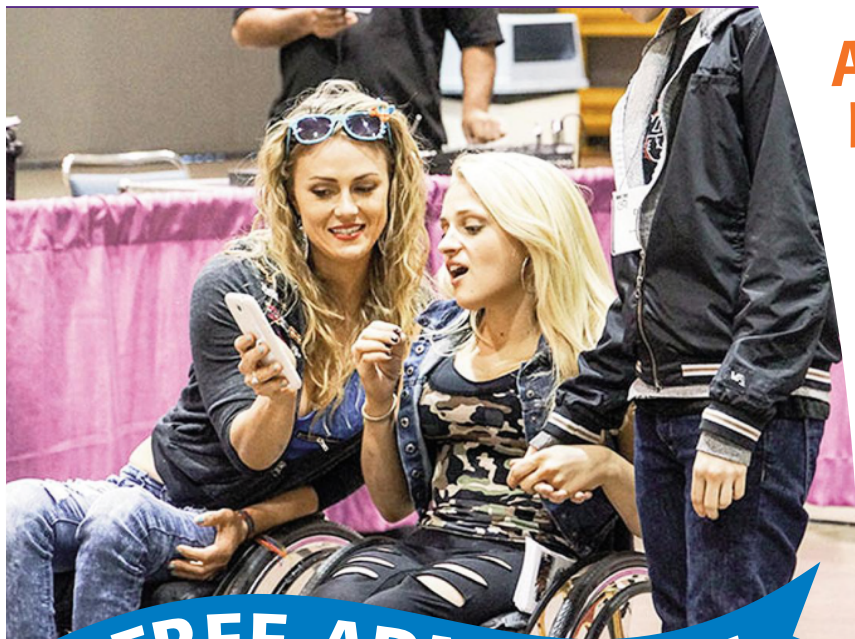
Healthcare technology is evolving very rapidly. I believe the progress we will see over the next years will exceed that of the past 100 years. The technology will improve information handling for patients, providers, payers, and policymakers. As was the focus of this article, consumers (patients) and those with special needs will gain access to tools which empower them to track their own health and thereby improve their health. In particular, mHealth, 3-D Printing, and robots will change the world for those with special needs. •

ABOUT THE AUTHOR:

Dr. John R. Patrick is president of Attitude LLC and former Vice President of Internet Technology at IBM. John has degrees in electrical engineering, management, law, and healthcare administration. He has more than four decades of experience in business and nine years serving on the board of a hospital. He is author of four books: *Health Attitude: Unraveling and Solving the Complexities of Healthcare*, *Net Attitude: What it is, How to Get it, and Why it is More Important Than Ever*, *Election Attitude - How Internet Voting Leads to a Stronger Democracy*, and *Home Attitude: Everything You Need To Know To Make Your Home Smart*. More information about Dr. Patrick is available at johnpatrick.com

References

1. Jas Lonquist, "The Cray-1 Supercomputer," Computer History Museum (2011), <https://www.computerhistory.org/revolution/supercomputers/10/7>
2. Susannah Fox and Maeve Duggan, "Tracking for Health," Pew Research Internet Project (2013), <http://www.pewinternet.org/2013/01/28/tracking-for-health/#fn-87-1>
3. "Mobile Medical Applications," U.S. Food and Drug Administration (2014), <http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ConnectedHealth/MobileMedicalApplications/ucm255978.htm>
4. Brian Dolan, "23 Notable FDA Clearances for Digital Health Apps, Devices So Far This Year," *mobilehealthnews* (2014), <http://mobilehealthnews.com/36795/23-notable-fda-clearances-for-digital-health-apps-devices-so-far-this-year/#more-36795>
5. Meredith Cohn, "Kids Outfitted with New Hands Made on 3-D Printers," *The Baltimore Sun* (2014), http://articles.baltimoresun.com/2014-09-28/health/bs-hs-printing-prosthetic-hands-20140923_1_prosthetics-printers-hand
6. "Empowering Children, Personalizing Bionics," *Limbitless Solutions* (2018), <https://limbitless-solutions.org/>
7. Brian Krassenstein, "3-D Printed Model of a 2-Week-Old Baby's Heart May Have Saved Its Life," *3D Printer & 3D Printing News* (2014), <http://3dprint.com/17443/3d-printed-heart-baby/>
8. "Medical Automation Newsletter," *Medical Automation: Health care for the future* (2014), <http://www.medicalautomation.org>
9. Jennifer Hicks, "Peking University Implants First 3D Printed Vertebra," *Forbes* (2014), <http://www.forbes.com/sites/jenniferhicks/2014/08/19/peking-university-implants-first-3d-printed-vertebra/>
10. Adam Waytz and Michael Norton, "How to Make Robots Seem Less Creepy," *The Wall Street Journal* (2014), <http://www.wsj.com/articles/how-to-make-robots-seem-less-creepy-1401473812>
11. "Medical Automation Newsletter"; "Building Socially Engaging Robots and Interactive Technologies to Help People Live Healthier Lives, Connect with Others, and Learn Better," MIT Media Lab (2018), <https://www.media.mit.edu/groups/personal-robots/updates/>
- 12 "How to Make Robots Seem Less Creepy".



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ASKING DIFFICULT QUESTIONS


A photograph of a woman with her hands clasped, looking at a child lying in a hospital bed. The child is wearing a white hospital gown. The background is a plain, light-colored wall.

BY CARA L. COLEMAN

QUALITY OF LIFE & END OF LIFE CONVERSATIONS

Parenting a child with special health-care needs and disabilities, as with any child, is filled with joys and challenges. It requires that we navigate across multiple systems of care, while ordering medications and supplies, providing medical care and balancing and making schedules all before noon each day. Superhuman status!

However, there are times in the journey when that superhuman strength may not feel sufficient in situations when tough questions must be asked, conversations raise stress levels, and none of us are quite sure what to say or do. Defining, discussing and striving for quality of life for children with special needs and disabilities begins when they are first born, and takes shape, twisting and turning, depending on where and with whom the discussion occurs. When children have serious, life-limiting illness, most of us think about quality of life and end of life, but struggle to discuss, plan and express our wishes. There are many resources available to help parents, children with serious, chron-



“LISTEN TO YOUR CHILD IN THE MYRIAD OF WAYS THAT YOU KNOW HOW, TRUST YOUR GUT, AND HAVE MANY CONVERSATIONS SO THAT YOUR CHILD AND FAMILY CAN FOCUS ON WHAT MATTERS AND ENJOY TIME TOGETHER.”

CARING AND PREPARING: The goal for pediatric palliative care is to allow a child to grow, develop and/or enjoy childhood in the face of serious illness. It focuses on the symptoms that inevitably arise from chronic, serious illness, such as pain, difficulty sleeping, fatigue, nausea, constipation, depression or stress, and seeks to relieve those symptoms so that a child can be a kid and a family can be a family.

ic and/or life-threatening medical conditions, family, friends and providers to ask difficult questions, embrace conversations, and plan for quality of life.

About 15 months before my daughter Justice Hope passed away, her father and I noticed changes and decline that were different than we had ever seen before. Our instincts kicked in and we began to talk. Many of the conversations we had were ones we had touched upon over the years to ensure Justice achieved “a life like yours,” but some were different; scary, sad and painful. Most pressing, however, was to get support for the symptoms that were taking over Justice’s life. Our experiences supporting Justice’s symptoms

so she had the strength to be a kid each day, and supporting Justice to have a “good death,” varied tremendously and were filled with both challenge and hope alike.

Prior to connecting you to information, tools and resources, I want to share what we found to be most important. Most parents have heard “you know your child best” and “trust your mom/dad gut.” Mom and dad gut are real, powerful and invaluable. Sometimes that is what gives us our superhuman status, and other times it is said and then immediately doubted – either by ourselves (with, for example, the self-doubt that can come when faced with difficult decisions) or by others (providers, family, friends) who may not know how to value, or even understand, shared decision-making and patient and family centered care. Listen to your child in the myriad of ways that **you** know how, trust your gut, and have many conversations so that your child and family can focus on what matters and enjoy time together.

WHAT IS THE DIFFERENCE BETWEEN PALLIATIVE AND HOSPICE CARE?

Getting to the difficult questions and conversations is not only challenging because of highly-charged emotions that may accompany untreated pain, symptom management, end of life and quality of life, but because of common misunderstanding of options, resources and supports.

WHAT IS PALLIATIVE CARE?

The goal for pediatric palliative care is to allow a child to grow, develop and/or enjoy childhood in the face of serious illness. It focuses on the symptoms that inevitably arise from chronic, serious illness, such as pain, difficulty sleeping, fatigue, nausea, constipation, depression or stress, and seeks to relieve those symptoms so that a child can be a kid and a family can be a family. This family-centered approach not only regards and cares for the child as a whole, but supports the well-being of the entire family as well. Palliative care is an added layer of support provided along side other medical “curative” care; a balance between curative medical treatments and comfort/ quality of life. Additionally, palliative care teams can often foster communication and coordination amongst multiple providers in a way that is can feel miraculous to all in an increasingly fragmented and overwhelmed system.

Here are some links to reading about palliative care and its benefits for the child and family:

<https://getpalliativecare.org/whatis/pediatric/>

<http://palliativedoctors.org/start/child>

Although this page is designed to outline what to expect at, and how to prepare for, a first palliative visit, it can be helpful in further understanding how palliative care might support the needs of a child:

<http://palliativedoctors.org/start/>

WHAT IS HOSPICE CARE?

Hospice care supports the needs of children when treatments to slow or stop an illness are hurting more than helping, or are no longer working. Hospice involves a shift in focus from cure to comfort and quality of life; when the balance of burden/ symptoms



WHAT REALLY MATTERS: Hospice is not about “giving up” but rather supports children and families to ensure that final days/months are good, lived well and focused on what matters to them. It may be important to note that if a child enters hospice and their illness improves, they can leave hospice care.

from treatment may outweigh the benefits. Hospice is not about “giving up” but rather supports children and families to ensure that final days/months are good, lived well and focused on what matters to them. It may be important to note that if a child enters hospice and their illness improves, they can leave hospice care.

To better understand what hospice is, what care it provides, and how to think of it in terms of your child’s care, visit:

<http://palliativedoctors.org/hospice/care>

This link provides a visual chart comparing the differences between palliative and hospice care in terms of services, location of care, team and other FAQs:

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3355>

If reading about and connecting to other people with similar experiences assists in understanding, thinking about, navigating this difficult journey or providing hope, here are links to stories from families around the country who have found support and relief in palliative and hospice care.

Stories for understanding and connection in palliative and hospice care:

<http://palliativedoctors.org/stories>

Being Mortal by Atul Gawande is a wonderful read mixing stories with evidence, history and thoughtful analysis and reflection. For information about the book, or to watch a Frontline series with key highlights from the book (click on the media tab) visit:

<http://atulgawande.com/book/being-mortal>

CONVERSATIONS

Unfortunately, there is no easy, single or definitive way to start having difficult conversations about quality of life and end of life wishes. How to start “the conversation” may depend on communication styles, the audience, or what you want to accomplish in the conversation. The conversation does not have to happen in one sitting and run through a checklist until all questions are answered and “the plan” is complete. The most important thing is to move from thinking about what matters and end of life wishes, to talking about them—and then continuing to talk often, with important people in the child’s life, and not just at the very end of life.

WITH YOUR CHILD

Most parents worry that having end of life conversations will only upset their children; hurting, rather than helping them as they struggle to face their illness. Thankfully, stories from families and research show us that this is not usually the case. As stated above, trust your mom/dad gut. You know your child better than anyone else.

Similarly, trust your child. It is likely that they are thinking about end of life and have thoughts about what matters. It is important to note that these statements are also true if your child is “non-verbal.” The methods of communication that your family and loved ones have developed with your child over the years can inform and guide identification of symptoms, whether those symptoms are relieved, what matters to your child/ quality of life and end of life discussions. Although the following tools may require adaptation, they can provide ideas, tips and help to begin conversations.

The Pediatric Starter Kit by the Conversation Project of the Institute for Healthcare Improvement offers very tangible, thoughtful and heartfelt ways (informed by and infused with real life experiences and insights from families) to begin to think about whether to have the conversation, how to organize thoughts and emotions to be able to start the conversation, and how to continue to have it with a seriously ill child. The Pediatric Starter kit is available in Chinese, English and Spanish.

<https://theconversationproject.org/starter-kits/#pediatric-starter-kit>

Available in both English and Spanish, this guide for talking to a child about their illness and treatment by the National Hospice and Palliative Care Organization focuses on hope, resilience and fostering positive feelings in children to help them cope with illness. The brochure includes age-appropriate tips for communication, as well as meaningful ways to build love, courage and strength in the face of tremendous challenge.

www.caringinfo.org/files/public/brochures/Talking_with_Your_Child_about_His_or_Her_Illness.pdf

Once parents have begun to have the conversation with a child, they may be in search of tools to help the child discover and express what matters to them in their own voice. Five Wishes can help children and families alike to think about, talk about and document thoughts, feeling and wishes about end of life. My Choices and My Wishes are developmentally appropriate guides for adolescents and young adults and younger children, respectively.

<https://fivewishes.org/five-wishes/individuals-and-families/children-and-adolescents>

WITH A CHILD'S PROVIDERS

Having discussions about the "quality of life" of a child with special needs and disabilities is quite common and often happens across many systems (health, education, social) and with all types of people and providers. Familiarity may help a family feel comfortable to bring up end of life wishes with a child's provider, but on the other hand, discussions about priorities, goals for care and quality of life may typically be led by others and thus feel overwhelming to initiate and lead on your own. It is normal to feel nervous, unsure and emotional.

This document provides a digestible list of 10 tips of how to organize thoughts, what to "report" or share during the visit, and how to develop questions for a doctor's appointment to discuss the child's serious medical condition. It also offers encouragement to ensure a family receives the information they seek and feel heard in the appointment:

www.caringinfo.org/files/public/brochures/Taking_With_Your_Child_s_Doctor.pdf

This toolkit reads almost like a map for how to think about, organize and walk through a conversation with a child's physician about end of life wishes. It is available in Chinese, English, French, Korean and Spanish:

<https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-TalkToYourDr-English.pdf>

ADVANCE DIRECTIVES

Another tool that may raise questions and foster conversations with a child and/or their providers are advance directives. Additionally, just as it is important to begin discussing end of life wishes, it is also important to document those wishes so they can be respected in times of crisis.

This link provides opportunities to read about types of directives, a glossary of terms, and a means to download advance directive specific to your state:

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>

WITH SIBLINGS, FAMILY AND FRIENDS

Once parents have had conversations with their child and their providers, it may be time to turn the conversations to the siblings, other family members and friends. Because palliative and hospice care teams include social workers, chaplains, counselors and other supportive staff, there are often a myriad of ways in which they can provide support (including with grief and loss) to the child, her/his siblings, and the whole family.

Siblings: The following resources from the American Academy of Pediatrics can assist, not only in having conversations with siblings of chronically ill children, but in fostering resilience, courage and hope that will assist with the well-being of that sibling and the entire family through tough times and beyond.

<https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Siblings-of-Children-with-Chronic-Illnesses.aspx>

<https://www.healthychildren.org/English/healthy-living/emotional-wellness/Building-Resilience/Pages/When-Things-Arent-Perfect-Caring-for-Yourself-Your-Children.aspx>

Family and friends: It is hard to know what to say and do, while a child is dying or once they have died. This brochure provides insights and guidance that is meaningful and actually rings true in both situations.

http://www.caringinfo.org/files/public/brochures/When_A_Child_Dies.pdf

HOW TO FIND PALLIATIVE AND HOSPICE CARE PROVIDERS

Perhaps the trusted physician with whom families initiate the conversation will connect the child to the appropriate palliative and hospice resources, but there are other resources available. •

If the family physician cannot connect the child to the appropriate resources, the following are directories for locating palliative and hospice providers:

<https://getpalliativecare.org/howtoget/find-a-palliative-care-team/>

<https://www.nhpco.org/resources/choosing-hospice>

ABOUT THE AUTHOR:

Cara L. Coleman is a wife, a mom, an attorney, a consultant with Family Voices National, a Family and Professional Partnership Specialist at the Institute for Patient and Family Centered Care, an Instructor of Pediatrics at VCU Medical School INOVA Campus and the author of *I am Justice*, *Hear Me Roar* about one of her daughters, Justice Hope, who passed away last year.

Families with special needs members often have unique circumstances that make having a 9-to-5 job nearly impossible. To make things more complicated, many families with special needs members also have additional expenses. Quite a conundrum, isn't it? When our personal journey started, we were told that the Applied



Behavior Analysis (ABA) therapy our daughter needed was going to require 30 to 40 hours of in-home parental supervised therapy and we needed to pay for a fair amount of it. This news created an urgent need get creative with how we could make a living and provide a life with possibilities for our daughter.

ENTREPRENEURSHIP RESOURCES FOR FAMILIES WITH SPECIAL NEEDS MEMBERS

BY JACKIE SCHWABE



This article provides resources on how to start a business as a family with special needs members, or for the family member with the special needs, as well as some tips for getting creative. Hopefully you are pleasantly surprised with the available resources as well as with the number of successful business run by family members with special needs.

HOW TO START A BUSINESS IN 9 STEPS

How do you start a business anyway? The good news is you start a business the same way, whether you do or do not have special needs. Depending on the resources you use, you will find a lot of blueprints for how to start a business. Here are the nine steps that I took to create my business:

1. Evaluate Your Skills and Constraints
2. Generate Ideas Based on Your Self-Evaluation
3. Do the Research
4. Get Some Input from Others
5. Finish the Legalities
6. Write Your Business Plan
7. Finance Your Business
8. Develop Your Product or Service
9. Build Your Team

Each of these steps are described in more detail later in the article. There were two considerations in my experience that seemed different between the average everyday joe trying to start a business and someone like you and me. The first consideration is we have different constraints; common constraints might be time, money, or space, but less common constraints might include intellectual or physical constraints of our family member or ourselves. The second consideration was where funding and or support for the family member with special needs could be obtained. In some cases, there are grants or other funding programs that are available to us that are not available to others.

Admittedly, after writing this article I found myself thinking that we are all more alike than we are different in the entrepreneur space. While there are still some unique challenges faced by our community, we can still use the resources available to everyone else and there are a few special ones set aside just for us. I hope you find inspiration in the resources provided and are able to find your creative entrepreneurial spirit.

EVALUATE YOUR SKILLS AND CONSTRAINTS

One of the first things to ponder when considering a new venture, is what are you good at and what do you enjoy doing. The Wisconsin Department of Vocational Rehabilitation (DVR) has toolkits that can assist you with doing some skills assessments. Just in case you think a skills assessment is a trite exercise in futility, let's look at an example of how it helped someone in real life.

A young man, one of my coworkers I worked with, has an autism diagnosis and was unable to read or write, but he loved to shred paper. (Sound familiar to anyone else with a loved one on the spectrum?) He said shredding paper calmed him down and made him happy.

His family worked with the Wisconsin DVR (http://bit.ly/WI_DVR) and DVR helped him get a commercial shredder and he started a business doing confidential paper shredding for banks and medical facilities. His marketing slogan was "Confidential Shredding Services. I can't read." Instead of looking at what he was not able to do, they looked at what he was able to do and what he loved.

QUICK REFERENCE : EVALUATE YOUR SKILLS AND CONSTRAINTS



WI DEPARTMENT OF VOCATIONAL REHABILITATION
<https://dwd.wisconsin.gov/dvr/>



DVR'S CUSTOM EMPLOYMENT TOOLKIT
https://dwd.wisconsin.gov/dvr/pdf_files/self_employment_customized_toolkit.pdf



DVR'S BUSINESS STARTUP TOOLKIT
https://dwd.wisconsin.gov/dvr/pdf_files/self_employment_toolkit.pdf



DVR'S INTEGRATED EMPLOYMENT TOOLKIT
<https://www.dhs.wisconsin.gov/familycare/mcos/integratedemply.pdf>



It's about not forgetting. Ever.

SOFTWARE APP FOR FAMILIES TO CONNECT, COORDINATE, AND COLLABORATE
<https://mindlight.io>



SUCCESSFUL BUSINESS BY THOSE WITH AN AUTISM DIAGNOSIS
<https://blog.theautismsite.greatertgood.com/business-owners>



DEVORA'S FRAMES
www.devorasdream.org



MORE SIMILARITIES THAN DIFFERENCES: You start a business the same way, whether you do or do not have special needs. While there are still some unique challenges faced by the special needs community, we can still use the resources available to everyone else and there are a few special ones set aside just for us.

Another consideration to ponder is what limitations do you or your family member have? For example, our family needed to have an adult home during ABA therapy. Therefore, a venture that involved daytime hours out of the house was a limitation. In our case, I started a business that created software for families to connect, care, and collaborate. I could build software anytime, so I was able to work within the time limits. You can learn more about the software here: <https://mindlight.io>.

The gentlemen above, the paper shredder, found that his limited ability to read was actually a marketing selling point. You can read about another young man that made a living from shredding paper and a few other success stories here: <http://bit.ly/PaperAutism>

Another family that was brought to my attention was Devora's family. Devora has mobility challenges. Devora also enjoys art. Together with her family and support teams they were able to find a way for her to create a product – Devora's Frames – and make a meaningful financial contribution to her family and community. Learn more about Devora at <http://bit.ly/FramesByDevora>.

GENERATE IDEAS BASED ON YOUR SELF EVALUATION

Once you know what you or your family member has for skills, what you or they enjoy, and what limitations you are trying to work within, you can use that information to generate business ideas. Devora's story is a great example of how this went well. Devora doesn't speak. Finding what she enjoyed took a little extra effort. However, her caregivers found that she smiles up a storm when she is doing art projects or watching others doing crafts. Her caregivers were able to figure out what she liked by observing her behaviors. Okay, so now what?

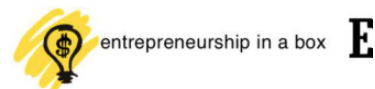
Devora may have liked arts and crafts, but she had limited mobility as well as a few other challenges. Her caregivers were able to figure out how to put mittens on her hands and the various supplies she needed near her so she could decorate picture frames. Once her skills, likes and dislikes, and limitations were identified, she became the artist for decorative picture frames. Now she sells the frames at craft fairs with her caregivers.

Perhaps you are a family member that is limited by your caregiving duties. You may not have physical limits, but you have limits on your time and your ability to work out of the home. Then ask yourself what can be done from home? What can you fix that drives you crazy? Can you apply your caregiving skills directly by getting certified somewhere like <https://www.caregiving.com> as a family caregiver that can help others? If you need some other ideas, here is a nice article on 40 business brainstorming ideas that might help get you started: <http://bit.ly/BrainstormBusiness>.

QUICK REFERENCE : GENERATE IDEAS



CERTIFIED CAREGIVING CONSULTANT
www.caregiving.com



BRAINSTORM BUSINESS IDEAS
www.entrepreneurshipinabox.com/6241/40-tips-to-brainstorm-business-ideas

DO THE RESEARCH AND GET INPUT FROM OTHERS

Before you jump in with both feet, you are going to want to do some due diligence. The best way to make sure you are chasing an idea that might be financially fruitful is to do a little market research. You are also going to need the market research data for your business plan anyway, so you might as well start now. If you end up requesting a loan or a grant, often you are required to provide a business plan with this information before they will consider your request.

Things to consider during your research are if anyone is already creating your product or doing the same service. If you find out they are, this isn't necessarily a bad thing. If someone else is doing it, then there is a market. If no one is doing it, is there a reason? You can also look at your potential competitors or partners to see what they are doing.

One of the best ways to do research is to ask the potential customers what they think of your business idea. You can ask them on social media about the idea, even if it isn't built yet. Ask your friends and family and caregivers. Ask anyone that might be in your target market. This is the best way to find out if what you are doing may not work. It is also the least expensive place to find out your idea will not work.

Even if you are unable to ask your potential customers their ideas, check out the Quick Reference: Do the Research and Get Feedback sidebar for a few other ideas to consider for doing market research.

FINISH THE LEGALITIES

If you find the idea has some potential, it is a good idea to get the legal aspects of starting a business out of the way. If you're helping a family member with special needs, consider contacting your local DVR or case manager to see how their benefits may or may not be impacted.

The intent of getting the legalities out of the way is to ensure a few things. You don't want to worry about someone stealing your idea, a partnership that goes badly, or getting sued. A few things to consider doing are setting up the business structure and name in

order to register your business. You should also consider getting a federal tax id, state tax id, any permits or licenses, trademarks, copyrights or patents, and a bank account.

These legal considerations apply if you are going to create a small business. You might only be considering a micro-enterprise. Most micro-enterprises are family-owned businesses employing one or two people. Most micro-enterprise owners are primarily interested in earning a living to support themselves and their families. The reason this is an important topic

QUICK REFERENCE : FINISH THE LEGALITIES

Entrepreneur

SELECT YOUR BUSINESS STRUCTURE

www.entrepreneur.com/article/38822



REGISTER YOUR BUSINESS FEDERAL TAX ID

www.irs.gov/businesses/small-businesses-self-employed/state-and-federal-online-business-registration



FEDERAL TAX ID

www.govdocfiling.com/tax-id-application



STATE AND FEDERAL TAX ID REFERENCE

www.sba.gov/business-guide/launch-your-business/get-federal-state-tax-id-numbers

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MICRO-ENTERPRISE

<https://en.wikipedia.org/wiki/Micro-enterprise>

QUICK REFERENCE : DO THE RESEARCH & GET FEEDBACK

Inc.

HOW TO DO MARKET RESEARCH INEXPENSIVELY

www.inc.com/christina-desmarais/how-to-conduct-budget-friendly-market-research.html

Entrepreneur

HOW TO DO MARKET RESEARCH

www.entrepreneur.com/article/217345

MARKET RESEARCH FOR BUSINESS PLANS

www.entrepreneur.com/article/241080

HOW TO GET FEEDBACK ON YOUR IDEAS

www.entrepreneur.com/article/243728

is that many governmental or DVR programs mention three types of employment: standard employment with supports, customized integrated employment, and micro-enterprises. If you are searching for grants or other funding to start a new enterprise, you might consider searching under micro-enterprises as well.

It is best to consult with a lawyer when you are just starting out so you can make sure you have covered everything you need. The lawyer can advise which of these items you do or do not need. If you need some insights into what questions to ask when looking for a small-business lawyer, here is a reference: <http://bit.ly/LawyerQuestions>

WRITE YOUR BUSINESS PLAN

While it may seem frustrating, and maybe fruitless, to write the business plan, it is a necessary part of the entrepreneurial process. While we were considering how to manage our finances with ABA thrown into the mix, we discarded what we thought was a great idea after taking the time to review the elements of a solid business plan.

There are eight essential elements to a business plan and the ones I include in my planning:

1. Title Page
2. Executive Summary
3. Business Description
4. Market Research
5. Competitive Analysis
6. Design and Development Plan
7. Operations and Management Plan
8. Financials

You can find out more details on how to write a business plan online at <http://bit.ly/BusPlanbyEntre> or <http://bit.ly/SBABusPlan>. While these are some of the standard templates that you will find in many places, if you are considering working with the DVR to assist your family member with special needs be sure to review their Custom Employment Toolkit at <http://bit.ly/CustomSelfEmploymentToolkit>. Their kit contains some great person-first business planning discussion points.

QUICK REFERENCE : WRITE YOUR BUSINESS PLAN

Entrepreneur

HOW TO WRITE A BUSINESS PLAN

www.entrepreneur.com/article/247575



SBA: HOW TO WRITE A BUSINESS PLAN

www.sba.gov/business-guide/plan-your-business/write-your-business-plan



DVR'S CUSTOM EMPLOYMENT TOOLKIT

https://dwd.wisconsin.gov/dvr/pdf_files/self_employment_customized_toolkit.pdf



SUCCESSFUL BUSINESSES BY FAMILIES WITH SPECIAL NEEDS

Creating and running a successful business with a special needs diagnosis of some kind isn't just an excessively optimistic fairytale told by a Pollyanna. A story posted on Reason to Bake in 2017 highlights just a few people with intellectual disabilities standing up and demanding to be counted as bread winners. There is Justin Rig French of Portland, Texas who owns Mr. Rigaroo's Shaved Ice. Beau's Coffee was started by Amy Write, who has two children with Down syndrome. Michael Williams of Canada was born with autism and he started "Conversation Starters" with the help of the Young Millionaires Program. Madeline Stuart, a model from Australia who has Down syndrome is taking the fashion world by storm. Blake Pyron of Saner, Texas is the proud owner of Blake's Snow Shack. Austin Underwood of Fort Worth, Texas is owner of Austin's Underdawgs. Jasmine Prices of Encinitas, California started a sewing business with the help of her mom. Read more at <http://bit.ly/YourMovement>

FINANCE YOUR BUSINESS

You have done all the work to figure out what you want to do, how to do it, and now you have to figure out how you can afford it. A few ideas are to tap into personal savings or ask family and friends to help you get started. You can also consider SBA-guaranteed loans from banks or credit unions or get financing from angel investors and venture capital firms. Some families do home equity loans or use credit cards to start. Grants at Grants.gov might be a good place to start or SBA's Women's Business Centers all around the country. Crowdfunding on sites like Kickstarter.com is also increasing in popularity.

If you are helping a special needs family member get financing, consider contacting the DVR and searching for grants for micro-enterprises. Other ideas for finding money to start your own business can be found here: <http://bit.ly/MoneyforBusiness>

DEVELOP YOUR PRODUCT OR SERVICE AND BUILD YOUR TEAM

Once you know you have a good idea and you have the money for the idea, now it is time to build your product or service and build your team. There are a number of resources out there on how to develop a product, but this resource breaks the process down into 7 simple steps: <http://bit.ly/7StepstoDevelopment>.

Having a product or service ready to sell is very exciting, but if you are trying to work around your family obligations, or you are assisting a special needs family member, it is important to consider who will be working in the business. You might expand your idea of a team and consider family members and maybe even caregivers as individuals that can assist on the team.

Last but not least, the reason I am writing this article is because I am passionate about everyone having the right to earn a living. I am a mother of four children, one with an autism diagnosis, who worked out of the home until my daughter was given her diagnosis. I had a very successful career making software applications in healthcare IT. Then, a whammy hit our family, I was forced into figuring out how to make a living and support my daughter's therapy requirements. For a moment, I thought my career was over. Once I got over myself, I was able to use my skills in software development and the limitation of working at home to help me craft the idea to create MindLight, a company that created a software application to help family members connect, coordinate, and collaborate with family, friends, and health care professionals regarding the health, safety, and education of their loved one.

It takes a village to raise a villager – but nowadays, the world is so virtual that I needed to find a way to build virtual villages. Parents like us, Amy Write, and many more mentioned in this article are finding ways to earn a living and care for their children. I hope you

are inspired to think creatively and join me and many others in the ranks of successful entrepreneurs. If you need a little more inspiration, check out the Quick Reference: Successful Businesses side bar. There are no less than 10 examples of success and even more resources to help you find what might work for you. •

ABOUT THE AUTHOR:

Jackie Schwabe is CEO of Mindlight, LLC. She is a Certified Caregiving Consultant and Certified Caregiving Educator. She received her BA in Management Computer Systems from the University of Wisconsin -Whitewater and her MBA in Technology Project Management from the University of Phoenix. She has been active in the area of healthcare integration, healthcare IT, telemedicine, product development, and product management for over 20 years. She has been a cross-sector, cross-discipline leadership practitioner her entire career. Jackie wakes up motivated to help others. Her mission, to provide the tools, opportunities, and connections people need to be their best self. A mother of four children – one with autism – she often says different is not less and communication happens in more ways than verbally. She co-founded MindLight, LLC as a way to technologically help caregivers.

QUICK REFERENCE : SUCCESSFUL BUSINESSES



REASON TO BAKE: SUCCESSES

http://reasontobake.com/The-Next-Movement-Special-Needs-Entrepreneurs-Build-Change-Making-Businesses_b_4.html



JUSTIN RIG FRENCH'S STORY

www.disabilityscoop.com/2016/06/21/teen-asd-face-family-business/22437/

AUSTIN'S UNDERDAWGS

www.disabilityscoop.com/2016/05/09/chef-down-syndrome-food-truck/22282/



BEAU'S COFFEE AND AMY WRITE

<https://portcitydaily.com/business/2016/01/26/beaus-coffee-breus-up-job-opportunities-for-adults-with-disabilities>



MICHAEL WILLIAM'S CONVERSATION STARTERS

www.cbc.ca/news/canada/prince-edward-island/pei-michael-williams-autism-business-1.3651592



YOUNG MILLIONAIRES PROGRAM

www.youngmillionairesprogram.ca/



SUPPORT DISABILITY IN BUSINESS

www.abilities.com/community/disability-entrepreneurs.html



ENTREPRENEURS WITH DISABILITIES UNITED

www.facebook.com/groups/479932335432977



PUSH LIVING: WHEELCHAIR ACCESSIBLE BUSINESS

www.pushliving.com/resources

THE ART OF AUTISM

ORGANIZATIONS SUPPORTING ENTREPRENEURS ON THE SPECTRUM

<https://the-art-of-autism.com/sponsors/directory-of-programsstudios/>



ENTREPRENEUR MAGAZINE: TOPIC - SPECIAL NEEDS

www.entrepreneur.com/topic/special-needs



SOAPERIOR ORGANIX: TEACHING E-COMMERCE SKILLS TO SONS ON SPECTRUM

<https://soaperiororganix.org/about/>



START A BUSINESS TO GET YOUR CHILD EXPERIENCE

www.metrokids.com/MetroKids/SpecialKids/Start-a-Business-to-Help-Your-Special-Needs-Child-Get-Work-Experience/

Creating & Organizing Disability Resources: ONE BITE AT A TIME

BY LAURA GEORGE

You are driving home from the hospital. Your loved one has just been given a diagnosis that involves the word disability. Your brain is overwhelmed with the resources needed, the information given and the wherewithal to sort it all out to make the future return to its normal daily hum.

That is easy to say and read, but I remember that is exactly how I felt when I was driving home from the hospital with my newly-paralyzed husband. I was overwhelmed, exhausted and confused as to which group to contact first. I was not sure if I even had accurate contact information. The hospital had given us at least four inches worth of material to read, most of which included fun things to do. We all like fun! But for me, it seemed that being able to incorporate the word fun into my daily vocabulary, as a newly-designated caregiver, would be far out on the horizon of life.

Where does one start? There's a joke that asks, "How does one eat an elephant?" The response is that it is eaten, "One bite at a time." That is how we are going to overcome this task: with the creation and organization of resources, one section at a time.

PUT TOGETHER BOOK

Within the first 24 hours, do only what is necessary to help your loved one with their new disability. It is important that both of you slow down, get some rest and have a few moments to clear your heads. Within the first 24 - 48 hours, put together an organizational binder. In this binder will be a location to tape all the doctor or medical

professional business cards that have been collected. Three holed pocket folders should also be added to hold important papers that have been collected through the diagnosis. Include a zippered pouch with tape, pens and pencils to tape in the cards, write and highlight notes. Also, include lined notebook paper to write down important information. Within the binder, sections will be created for prescriptions; medical supplies and equipment; nursing company, caregiving, nursing home and rehab contacts; financing; and a creative section. This completes the first bite in to the elephant. Yummy!

PRESCRIPTION

In the first week, while acclimating to your loved one's new disability, spend the time to become comfortable with how the day will now be processed. Identify all the medical supplies that require a prescription (hardware and software) to be used daily along with any additional necessary needs. Start identifying the suppliers, their insurance requirements, and how the product will be obtained. Include storage concerns such as shelf life, refrigeration, chemical, and amount. Consider if it is something that can be obtained at local grocery store, drug store, online, or via a resource that was provided by the medical professional working with your loved one. Some drug companies have financial assistance programs if the cost of the prescription is challenging. This section would be the second bite called prescriptions.

MEDICAL SUPPLIES/ EQUIPMENT

When moving from one topic (or bite) to the next, it is important to breathe and relax. There is no need to panic. Let us smile as we take another bite creating our third or medical supply section. Feeling overwhelmed and slightly panicked because the medical supply company is not delivering their supplies or working with

your insurance company means wisdom and creativity can now strike for the creation of your own resource library, as each company called can be listed along with their credentialing for being able to provide the items and services needed. Make sure that the acronym "DME" is listed in big letters at the top of the page with the definition of "durable medical equipment" underneath, to make it easier to find needed supplies and equipment. This becomes the third section in the book.

NURSING/REHAB/ CAREGIVING

Keep in mind that the medical professional, hospital or caregiving company who is becoming part of the support system, is also happy to receive additional calls asking for assistance. Nursing companies, personal care assistants, and in-home therapy assistants are great resources to get questions answered and more education on the topic. Unsure of how to find a good nurse, PCA or caregiver? Reach out to the hospitals, local physical and occupational medical licensing offices, or any national organization that provides education, information and questions to use in screening the prospective in-home assistance. Speak with everyone to get referrals and knowledge about the medical professionals to be employed. Remember to include yourself by arranging for respite coverage using the method above. Take a bite off the elephant's ear for putting together the fourth section!

FINANCES

Finances can always be a tough bite to swallow, yet when biting off the elephant's nose, it will be sweet. Hospitals, social security offices, financial institutions, and yes – even politicians – will all know of resources to help with the financial costs of paying for the equipment and supplies to help your loved one return to living independently. Automobile manufacturers even have dis-

count programs for adaptive equipment. To find those, put the words, "Disability Discount" and a car manufacturer into the search engine on the Internet and the direct link to the program should pop up. Another good financial resource is the county assessors' office for the possible Homestead Exemption you qualify for, by having a person in your home with a disability. (This is regardless of age and for retired military too!) Boy, that nose tasted good!

NATIONAL/LOCAL RESOURCES

In the sixth section, which might be started about three to four months after diagnosis, gather the specific disability and non-specific disability support organizations that can help with the child, adult or elder adult's disability. Some national organizations may also have centers on a statewide or even local level. For some types of disabilities, there may be more than one national version and it

would be recommended to call them all to see which can offer the best support. All of these can be contacted for assistance and help with finding reputable companies who can provide the medical supplies needed to assist with administering medication, toileting, breathing, doctors, financial assistance and more. Though some organizations are not disability-specific, they do easily address a wide variety of concerns, regardless of age and many times can answer questions that others may not know the answers to. Do not forget to contact the faith-based communities. Many of these also offer a wide range of support services and sometimes do not even have faith-based qualifications.

CREATIVE

All four feet have now been artistically eaten off. Your loved one with a disability is settling in and beginning to move forward in life.

ONE BITE AT A TIME : PRESCRIPTION + MEDICAL SUPPLIES/EQUIPMENT + NURSING HOME/REHAB RESOURCES

PRESCRIPTION



HEALTHFINDER.GOV PRESCRIPTION ASSISTANCE

Governmental website with a wide variety of assistance options
<https://healthfinder.gov/FindServices/SearchContext.aspx?topic=696>



PARTNERSHIP FOR PRESCRIPTION ASSISTANCE

Use for prescription financial assistance and clinic locations
www.pparx.org

MEDICAL SUPPLIES /EQUIPMENT



FRIENDS OF DISABLED ADULTS AND CHILDREN

Provides wide variety of equipment for people with disabilities, some refurbished
www.fodac.org



DISABLED DEALER

Magazine connecting sellers and buyers with accessible vehicles and mobility equipment
www.disableddealer.com



TRACH MOMMAS

Support for adults and parents of family or children with a tracheostomy
www.trachmommas.org

NURSING HOME /REHAB /CAREGIVING



Find lists of screening questions and resources addressing the topic
www.aarp.org/caregiving/home-care/info-2018/hiring-caregiver.html



AREA AGENCY ON AGING

Includes a list of screening questions
www.n4a.org



NATIONAL INSTITUTE ON AGING

Long term care, nursing homes, assisted living facilities including screening tips and financial assistance payment sources.
www.nia.nih.gov/health/topics/assisted-living-and-nursing-homes



NATIONAL FAMILY CAREGIVERS ASSOCIATION

Besides caregiver support services, organization offers resources for all ages, children to adult
www.caringcommunity.org/helpful-resources/models-research/national-family-caregivers-association-nfca



FAMILY CAREGIVER ALLIANCE

Offers caregiver support services and resources for adults and elderly adults
www.caregiver.org



PARENT TO PARENT

Provides emotional and informational support to families with children with disabilities. Aids in finding programs and services to help children in schools
www.p2pusa.org

Now is the time to start the last section in the binder that accommodates outside-the-box thinking. This is the section where adaptive clothing, legal assistance, accessible camps, education, barber shops, hotels, conferences, dentists, parks and more can be placed. In this section, legal resources can be added.

EMERGENCY PREPAREDNESS

This last section is very important; it is where all the friend, family and additional support contact information will go. Include the local fire department phone number and, depending

on the severity of the disability, feel free to reach out to them for an in-home visit to become familiar with your loved-one, their needs and medical equipment that may need to be taken in an emergency. Add your local health care liaison who can be found through the local health department. Make sure to contact with the county emergency management office to be placed onto the disaster notification list to keep everyone safe.

Most of the elephant should be eaten by now. The nose, ears, feet and tail have been chewed off! The sections in the binder are neat, full of resources and organized in a manner that is

ONE BITE AT A TIME : FINANCES + NATIONAL, MILITARY & FAITH BASED RESOURCES

FINANCES



USA.GOV: FINANCIAL ASSISTANCE AND SUPPORT SERVICES FOR PEOPLE WITH DISABILITIES

Large list with housing, transportation, insurance, bills offering resources for financial assistance

www.usa.gov/disability-financial-support



SALVATION ARMY

Provides resources and financial assistance

www.salvationarmy.org

NATIONAL RESOURCES



NATIONAL CENTER FOR INDEPENDENT LIVING

Help with finances, medical, housing, employment, advocacy and even more, regardless of age or background.

www.ncil.org



NATIONAL ORGANIZATION ON DISABILITIES

Promotes full and equal participation in life including employment

www.nod.org

MILITARY RESOURCES



DISABLED AMERICAN VETERANS

Provides a wide variety of resources, financial assistance and support services for the veteran

www.dav.org



FINANCIAL PLANNING FOR MILITARY FAMILIES WITH FAMILY MEMBERS WITH SPECIAL NEEDS

www.militaryonesource.mil/family-relationships/special-needs/support-for-families/financial-planning-and-assistance-for-families-with-special-needs

FAITH-BASED RESOURCES



ACCESSIBLE CHURCHES

Listing of churches that are accessible friendly

www.abilityministry.com/disability-ministry-locator



CATHOLIC CHARITIES USA

Variety of programs assisting with basic needs, as well as disasters

www.catholiccharitiesusa.org



CIVITAN INTERNATIONAL

Dedicated to helping children with developmental disabilities

www.civitan.org



HABITAT FOR HUMANITY INTERNATIONAL

Rehabilitated home purchase program with accessible home conversion

www.habitat.org



LUTHERAN SERVICES IN AMERICA

Wide range of services including housing, finances, employment, emergency and counseling programs

www.lutheranservices.org



YMCA & YWCA

Both have programs for low-income families for children and teens with disabilities

www.ymca.net • www.ywca.org

quickly and easily accessible. This binder is your spectacular library and is highly prized for its information. The feelings of fear, panic and lack of resources are no longer overwhelming. It is now a year later and many elephants have been eaten, one bite at a time.

What follows is a list of resources that most people have not heard of beyond the standard ones shared. My favorites have always been the uncommon, unheard of, and unique that making taking bites out of an elephant easy! •

ABOUT THE AUTHOR:

Laura George is the Emergency Management Disability Liaison, and sits on the National Center for Independent Living-Emergency Preparedness (NCIL-EP) Committee. She has spent the last 13 years volunteering her time, as well as consulting, sharing and presenting on the idea emergency design needs to include everyone and not just be taught to everyone. She has presented and sat on committees before local, county, state, regional/national organizations from a caregiver's point of view. She is an author, presenter and caregiver.

ONE BITE AT A TIME : CREATIVE + EMERGENCY PREPAREDNESS RESOURCES

CREATIVE



ADA.GOV: UNITED STATES DEPT. OF JUSTICE CIVIL RIGHTS DIVISION

Information on the Americans with Disabilities Act.
Very user-friendly and easy to navigate for information
www.ada.gov



FAMILY CAFÉ ANNUAL CONFERENCE

Attend the annual conference or visit their website and review
for resources and education
www.familycafe.net



COUNTY ASSESSOR'S OFFICE

Check for Homestead Exemption due to disability regardless
of age. Read carefully for qualifications



EDUCATION

Many colleges have Disability Departments that can offer
accessible classrooms and information on financing assistance
www.bestcollegesonline.com/blog/20-incredible-colleges-for-special-needs-students

EMERGENCY PREPAREDNESS



FEMA

FEMA

Preparing for Disaster for People With Disabilities
and Other Special Needs
www.fema.gov/media-library/assets/documents/897



Prepare. Plan. Stay Informed.

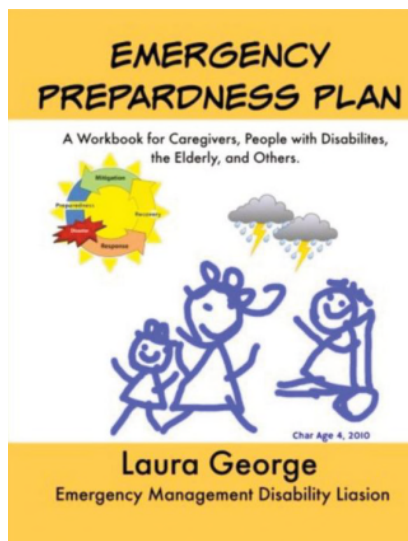
READY.GOV

www.ready.gov/individuals-access-functional-needs



U.S. DEPT OF HEALTH & HUMAN SERVICES CIVIL RIGHTS EMERGENCY PREPAREDNESS

Resources for Persons with Disabilities
www.hhs.gov/civil-rights/for-individuals/special-topics/emergency-preparedness/resources-persons-disabilities/index.html



"EMERGENCY PREPAREDNESS PLAN: A WORKBOOK FOR CAREGIVERS, PERSONS WITH DISABILITIES, THE ELDERLY AND OTHERS"

Written by Laura George, this workbook aids in the cre-
ation of an emergency preparedness plan for both the
caregiver and the person (regardless of age) with the dis-
ability. (Although available on Amazon now, an updated
version is expected out shortly.)

www.amazon.com/Emergency-Preparedness-Plan-Caregivers-Disabilities/dp/150774708X

2019
EP GUIDE
NAVIGATING SPECIAL
NEEDS RESOURCES

PLANNING FOR EMPLOYMENT FOR STUDENTS WITH SPECIAL NEEDS

BY ERNST VANBERGEIJK, PH.D., M.S.W.



“According to the U.S. Department of Labor, the unemployment rate nationally continued to be 3.7% in November. However, the unemployment picture for people with disabilities is far more complex.”

Parents of children with disabilities worry daily about a myriad of things that are immediate and pressing. It's hard to stop and think about the future, when you are worrying about how your child's play date went, or whether the school bus picked him or her up on time from school. Future employment seems so far away from the daily struggles we face.

Planning for employment may seem like a future luxury, but it is actually essential for the long-term success and survival of our children. Most people do not like to think about this topic. Why worry, anyway? The economy is strong and our unemployment rate is the best that it has been in over nearly 50 years. According to the U.S. Department of Labor, the unemployment rate nationally continued to be 3.7% in November. However, the unemployment picture for people with disabilities is far more complex.

The U.S. Department of Labor contends that the unemployment rate for people with disabilities is 9.2%. This unemployment rate is 2½ times greater than the general population. However, it does not tell the complete story. In order to be counted as unemployed, an individual has to engage in certain job-seeking behaviors within the last 30 days in order to be considered as looking for employment. The actual numbers are underreported. Many classes of individuals are not even considered to be a part of the employment numbers. Farm workers, military personnel, institutionalized and incarcerated individuals are not included in these figures. Two of the largest groups of persons with disabilities that are not counted in the unemployment rates are the self-employed and those individuals who have given up looking for work. People with disabilities are twice as likely to be self-employed as their non-disabled peers. According to the U.S. Department of Labor, 8 out of 10 persons with a disability have stopped looking for work.

Not only do people with disabilities face unemployment, but they also face under-employment and lower wages. The results vary widely depending upon the type of disability. One group that has a particularly difficult time with employment are transition-aged youth on the autism spectrum. Only 25% of individuals with ASD were employed (Holwerda, 2012, as cited in Walsh, 2014). In Barneveld's (2014) sample, 49% of 169 high-functioning individ-

uals on the autism spectrum had a paying job (as cited in Walsh, 2014). Shattuck and his team found over ½ of transition-aged youth on the autism spectrum were not employed 2 years following high school. Only about a third of their sample attended college and 55% had paid employment 6 years after high school. These rates are significantly lower when compared to non-disabled peers. Roux (2013) had similar findings. In this sample, not only did 53.4% of young adults on the autism spectrum ever work outside the home for pay, but they had the lowest employment rate among all disability groups. They also held jobs in a fewer number of occupational types and earned an average of \$8.10 an hour, which is a lower hourly rate than all other disabilities. As a part of the National Transition Longitudinal Study-2 (NTLS-2), the proportion of young adults with ASDs who were employed was comparable to young adults with deaf-blindness or multiple disabilities. Young adults with ASDs earned 86% as much money as young people with all other disabilities. Half of the young people with ASDs worked less than 20 hours per week, which was at a rate 4 times lower than other disabilities. In fact, as a group, their average number of hours worked per week was 23.3 hours. Young adults in other disability groups worked 35.8 hours per week, which was 36% greater than the ASD group. Finally, the proportion of young adults with ASDs who worked full-time was 1/3 of all other disabilities (Standifer, 2012).

“Whether a student participates in a degree-bearing program, a vocational training program, a college-based certificate program or even one-college course, that student stands a better chance of finding meaningful employment.”

WHAT IS A PARENT TO DO?

What works when it comes to helping transition-aged youth find and keep employment? Education matters. Whether a student participates in a degree-bearing program, a vocational training program, a college-based certificate program or even one-college course, that student stands a better chance of finding meaningful employment (Getzel & Wehman, 2005). Students with disabilities who earn a bachelor degree are hired at about the same rate as their non-disabled peers. The more education and training an individual receives, the higher his or her lifetime earnings (Julian, 2012). Now, not every student with a disability can earn a college degree. Many can, however, pursue post-secondary vocational training and college or community-based transition program certificates.

Under the Individuals with Disabilities Education Act (IDEA) and the Individuals with Disabilities Education Improvement Act (IDEIA), before the age of 14, parents in partnership with their local school district, can identify independent living and pre-employment skills goals, early, as a part of the Individual Education Plan (IEP) process. By the age of 14, a transition goal should be identi-



LEARNING AND EARNING: “Students with disabilities who earn a bachelor degree are hired at about the same rate as their non-disabled peers. The more education and training an individual receives, the higher his or her lifetime earnings. Not every student with a disability can earn a college degree, but many can pursue post-secondary vocational training and college or community-based transition program certificates.”

fied. The transition goal can be entering the world of work and independent living, or some form of post-secondary education, including pursuing a college degree. By age 16, a detailed transition plan should be developed to support those transition goals. Ideally, a student with a disability, should attempt to find a part-time job for pay. Students with ASDs who had paid employment during high school were more likely to be employed, post high school, than their friends who did not have paying jobs during high school (Chiang, Cheung, Li, & Tsai, 2013). It is important that parents, special educators, and professionals from state offices of vocational rehabilitative (VR) services work collaboratively while the student with a disability is still in high school. Students on the autism spectrum who received services from VR while they were still in high school were far more likely to be employed (Miligore, et al., 2012; Roux, 2018). However, only 48% of ASD youth received VR services (Miligore, et al., 2012). Post-secondary college services were the best predictor of better earning, but only 10% of the VR database received post-secondary college services.

HOW DOES A PARENT FIND POST-SECONDARY COLLEGE SERVICES?

There are a few resources available to locate these services. Those include:

1. *Think College!* <https://thinkcollege.net>
2. *Heath Center National Youth Transition Center:* www.heath.gwu.edu
3. *Comprehensive Transition & Post-secondary (CTP) programs:* <https://studentaid.ed.gov/sa/eligibility/intellectual-disabilities>
4. *Lesley University Threshold Program e-Book - Comprehensive Guide to Transition Programs* www.lesley.edu/six-qualities

This is just a starting point to help identify programs. A diligent internet search will yield more options.

Although much of the previously cited research focuses upon ASDs (a group of young people who have a particularly hard time finding gainful employment), much of what we have learned from transition aged youth with ASDs can be applied to students with intellectual and/or developmental disabilities (ID/DD). Pillay and Brownlow (2017) discovered 4 predictors of employment for the ASD population. The first is a supported work place, where the individual with a disability is supported by the employer and perhaps a job coach, vocational advisor, or mentor. Second, the level of ASD traits and behaviors predicted finding and keeping a job. The less severe the traits or behaviors, the more likely the individual is to be employed. Third, they uncovered that functional independence predicted employment. Functional independence skills can be learned while young and as a part of special education and the creation of the annual IEP. These skills can include: waking up on time using alarm clocks or smart phones; dressing appropriately for work; self-administering medication; doing laundry; independent travel on mass transit, financial literacy, etc. The final predictor of employment was family advocacy. This can take many forms, such as ensuring that certain independent living and employment skills goals are a part of the IEP; insisting that state offices of VR services professionals attend IEP meetings; and using the family's professional and personal social networks to help locate employment for their children with a disability. Remember 80% of jobs are not advertised in want ads or on job search sites. Rather, they are discovered through social networks. Do not hesitate to use these networks to find employment for your child.

DO POST-SECONDARY PROGRAMS HELP STUDENTS WITH DISABILITIES FIND EMPLOYMENT?

Wehman et al. (2013) randomly assigned students with ASDs to vocational training or the usual services they received from school districts and VR services. The results were surprising – 87.5% of the vocational training group were employed 6 months after the training, compared to only 6.25% of the control group which received the business-as-usual services from the local school district and VR services. Likewise, Moore and Schelling's (2015) research revealed that 9 out of 10 students with ID who graduated from a post-secondary program were employed within 2 years of the study, whereas only ½ of high school graduates with ID were employed. Furthermore, Diamant (2015) presented findings at a national conference that neither I.Q. or academic ability were better predictors of employment and independent living than the ability to successfully and consistently complete activities of daily living. Post-secondary vocational and transition programs can help students with disabilities not only learn employment skills, but also help them learn important activities of daily living skills that typically are not covered in traditional college curricula.

HOW DOES A PARENT ACCESS AND PAY FOR THESE SERVICES?

Planning for employment for a child with a disability takes long-term planning and study. Identifying and learning as much as possible about federal policies pertaining to children and youth with disabilities is paramount. The policies inform the parent

who is responsible for the provision of services, what the rules are, and who will pay for those services. The ABLE Act created tax-free savings plans for parents of children with disabilities that were modeled after the 529 College Savings plans and can be used to pay for a wide variety of support and transition services, including paying for college or community-based transition programs. Under IDEIA, IEP teams can fund transition plans that include community-based or college-based transition services, provided that the special education student has not graduated from high school or reached age 21. The Higher Education Opportunity Act, P.L.

110-315, established the Comprehensive Transition and Post-secondary (CTP) program model where students with intellectual disabilities (ID) and other significant cognitive disabilities could attend U.S. Department of Education-approved, college-based transition programs.

“Post-secondary vocational and transition programs can help students with disabilities learn important activities of daily living skills that typically are not covered in traditional college curricula.”

Threshold Program at Lesley University

College-Based Transition Program Cambridge, MA

The Threshold Program at Lesley University is a two-year, campus-based transition program for students with diverse learning differences. Our students gain career training, learn how to budget, pay bills, and use transportation. And best of all—they make friends for life.

lesley.edu/threshold-learning

Meet Dudley.

Since graduating in 2010, he's lived an independent life that's full of purpose. He credits this to the support he gained in the Threshold Program. “Some of the things I'm really excited about when I wake up in the morning are starting a new day at work or getting together with friends,” says Dudley.



The significance of this law is that it allowed students with ID to receive federal student aid in the form of grants, even though they are not enrolled in a degree-bearing program, full time. The Workforce Innovation Opportunity Act (WIOA) (H.R.803) has been hailed as the most significant piece of disability civil rights legislation since the passage of the Americans with Disability Act (ADA). This law is a game changer for transition aged youth because it expands the federal age range from 14-21 to 14-24 years of age, thereby extending the time period during which services can be rendered. Further, it requires state offices of Vocational Rehabilitative services to allocate 15% of their budgets to provide services for transition-aged youth. The law also expanded the kinds of services that now can be funded. Previously, the provision of pre-employment training services could not be paid for using VR funds. Now, such services are covered.

Finally, for families where one of the parents is either an active duty service member or retired military, they may transfer their unused educational benefits to their dependents to pay for college or vocational training, including transition programs under Post 9/11 Veterans Educational Assistance Improvements Act of 2008 (P.L. 110-252) and Post 9/11 Veterans Educational Assistance Improvements Act of 2010 (P.L. 111-377), more commonly known as the New G.I. Bill and the New G.I. Bill 2.0. The Yellow Ribbon program under these two laws helps families pay for the difference in costs between public and private college-based programs. •

For more in depth reading on the subjects contained in this article please see the references and resources below.

ABOUT THE AUTHOR:

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References and Resources

- 20 Code of Federal Regulations (CFR) Parts, 676, 677, and 678. Department of Labor. Employment and Training Administration.
- 34 CFR Parts 300 and 301 Assistance to States for the Education of Children with Disabilities and Preschool Grants for Children with Disabilities; Final Rule
- 34 Code of Federal Regulations (CFR) Parts 361 and 463. Department of Education. Workforce Innovation and Opportunity, Joint Rule for Unified and Combined State Plans, Performance Accountability, the One-Stop System Joint Provisions; Final Rule
- 34 CFR Parts 361, 363, and 397
RIN 1820-AB70
[Docket ID ED-2015-OSERS-0001]
State Vocational Rehabilitation Services program;
State Supported Employment Services program; Limitations on Use of Subminimum Wage
<https://s5.amazonaws.com/public-inspection.federalregister.gov/2015-05538.pdf>
- Brown, K.R. (2017). Accommodations and Support Services for Students with Autism Spectrum Disorder (ASD): A National Survey of Disability Resource Providers. *Journal of Education and Disability*, 30 (2): 141-156
- Carter, E.W., Austin, D., and Trainor, A.A. (2012). Predictors of Post-school Employment Outcomes for Young Adults with Severe Disabilities. *Journal of Disability Policy Studies*. 23 (1):50-63.
- Chiang, H.M., Cheung, Y.K., Li, H. and Tsai, L.Y. (2013). Factors Associate with Participation in Employment for High School Leavers with Autism. *Journal of Autism and Developmental Disorders*. 43:1852-1842.
- Diamant, M. (2015). As More with Autism Reach Adulthood Clues to success Emerge; Disability Scoop. Retrieved from: <http://disabilityscoop.com/2015/5/14/as-autism-adulthood-clues/20299>
- FinAid (2016). The history of Federal Student Aid. Retrieved from <http://www.finaid.org/educators/historyrpt.html> October 10, 2016
- Getzel, E. and Wehman, P. (2005). *Going to College: Expanding Opportunities for People with Disabilities*. Paul H. Brookes Publishing; Baltimore, MD.
- Higher Education Opportunities Act of 2008. (P.L. 110 -315).
- History & Regulations –IN.gov. Legislative History of the American State-Federal Vocational Rehabilitative (VR) Program. Retrieved from: https://www.in.gov/fssa/files/History_and_Regulations.pdf. October 17, 2017.
- Individuals with Disabilities Education Act (1997). U.S.C. 20. Part A & Part B. §1400, §1401, §1412, §1414, and §1415.
- Julian, T. (October 2012). Work-Life Earnings by Field of Degree and Occupation for People With a Bachelor's Degree: 2011 American Community Survey Briefs
- Migliore, A., Timmons, J., Butterworth, J., & Lugas, J. (2012). Predictors of employment and postsecondary education of youth with autism. *Rehabilitation Counseling Bulletin*, 55(3), 176-184. doi: 10.1177/0034355212438943
- Moore, E.J. and Schelling, A. (2015). Postsecondary inclusion for individuals with intellectual disabilities and its effects on employment. *Journal of Intellectual Disabilities*. DOI: 1744629514564448
- National Skills Coalition. Federal Policy. The Workforce Innovation and Opportunity Act. Retrieved from: <http://www.nationalskillscoalition.org/federal-policy/workforce-investment-act>. September 28, 2016.
- Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., Zanjirian, A. (2017). Predictors of employment status among adults with Autism Spectrum Disorder. *Work*. 56(2):345-355. doi: 10.3233/WOR-172492.
- O'Leary, Christopher J., and Randall W. Eberts. 2008. "The Wagner-Peyser Act and U.S. Employment Service: Seventy-Five Years of Matching Job Seekers and Employers." Report prepared for Center for Employment Security Education and Research (SESER); National Association of State Workforce Agencies (NASWA). <http://research.upjohn.org/reports/29>
- Pillay, Y. and Brownlow, C. (2017). Predictors of Successful Employment Outcomes for Adolescents with Autism Spectrum Disorders: A Systematic Literature Review. *Journal of Autism and Developmental Disorders*. 41(1):1-11.
- Post 9/11 Veterans Educational Assistance Improvements Act of 2008 (P.L. 110-252).
- Post 9/11 Veterans Educational Assistance Improvements Act of 2010 (P.L. 111-377).
- Roux, A.M., Rast, J.E. & Shattuck, P.T. (2018). State-Level Variation in Vocational Rehabilitation Service Use and Related Outcomes Among Transition-Age Youth on the Autism Spectrum. *Journal of Autism Developmental Disorders*. pp.1-13. <https://doi.org/10.1007/s10803-018-3793-5>
- Roux, A.M., Shattuck, P.T., Cooper, B.P., Anderson, K.A., and Narendorf, S.C. (2013). Postsecondary Employment Experiences Among Young Adults With an Autism Spectrum Disorder *Journal of the American Academy of Child & Adolescent Psychiatry*. 52 (9): 931-939.
- Shattuck, P.T., Narendorf, S.C., Cooper, B., Sterzing, P.R., Wagner, M. and Lounds Taylor, J. (2012). Postsecondary Education and Employment Among Youth with an Autism Spectrum Disorder. *Pediatrics*, 129:1042-1049. doi:10.1542/peds.2011-2864
- Standifer, S. (2012). Fact Sheet on Autism Employment. Autism Works. The National Conference on Autism Employment. Retrieved from <http://autismhandbook.org/images/5/5d/AutismFactSheet2011.pdf>. October 15, 2017.
- The Workforce Innovation and Opportunity Act (WIOA) (H.R. 803).
- U.S. Department of Labor Bureau of Labor Statistics (2018a). Economic New Release. <https://www.bls.gov>
- U.S. Department of Labor Bureau of Labor Statistics (2017a). Current Employment Statistics (CES). How Does the CES define employment? Retrieved from <https://www.bls.gov/web/empst/cesfaq.htm> October 9, 2017.
- U.S. Department of Labor Bureau of Labor Statistics. (21 June, 2017b). Economic News Release. Persons with a Disability: Labor Force Characteristics Summary - 2016. Retrieved from: <https://www.bls.gov/news.release/disabl.nr0.htm>. October 9, 2017.
- U.S. Department of Labor Bureau of Labor Statistics (2018b). Economic New Release. Table A-6. Employment status of the civilian population by sex, age, and disability status, not seasonally adjusted. (September, 7, 2018).
- U.S. Department of Labor Bureau of Labor Statistics (2018c). Persons with a Disability: Labor Force Characteristics - 2017.
- U.S. Department of Labor Bureau of Labor Statistics (2018d). Economic New Release. Table A-6. Employment status of the civilian population by sex, age, and disability status, not seasonally adjusted. (November, 7, 2018).
- U.S. Department of Labor. (2016). The Workforce Innovation and Opportunity Act. Retrieved from: <https://www.doleta.gov/wioa/> September 28, 2016.
- U.S. Department of Labor Bureau of Labor Statistics (2015). Labor Force Statistics from the Current Population Survey. Who Is Counted as Employed? Retrieved from: <https://www.bls.gov/cps/faq.htm#Ques4>. October 9, 2017.
- VanBergeijk, E.O., and Cavanagh, P.K. (2012 May/June). Federal Student Aid for students with Intellectual Disabilities: A well-kept secret? *Parenting Special Needs Magazine*, pp.64-65 <http://www.mydigitalpublication.com/publication/?i=111307&l=&m=&p=8&id=5779>
- Walsh, L., Lydon, S., and Healy, O. (2014). Employment and Vocational Skills Among Individuals with Autism Spectrum Disorder: Predictors, Impact, and Interventions Review of the *Journal of Autism and Developmental Disorders*, 1: 266-275.
- Wehman, P. H. (2001). *Life beyond the classroom: Transition strategies for young people with disabilities*. (3rd ed.). Paul H. Brookes Publishing; Baltimore, MD.
- Wehman P.H. et al. (2013). Competitive employment for youth with Autism Spectrum Disorders: Early results from a randomized clinical trial. *Journal of Autism and Developmental Disorders*, DOI 10.1007/s10803-013-1892-

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

*This article explores caregiving for person/s with neurodegenerative disease/s (PWND).
 The focus is on the family caregiver's experience before, during, and after the caregiving journey ends.*

CAREGIVING FOR PERSONS WITH NEURODEGENERATIVE DISEASES

BY ANDREW KOCH

DEFINING NEURODEGENERATIVE DISEASES

Neurodegeneration refers to the altering, minimization, destruction of, or unspecified degradation of **neurons**. Typically, paths of neurodegeneration occur in either the brain, brainstem, and/or in the peripheral nervous system. Depending on which types of neurons are affected by disease process, the corresponding function is impaired. Neurodegenerative diseases (NDs) can be broken into two rough categories: dementia and motor neuron diseases (MNDs). The diagnosis of any disease is based primarily on symptoms. So, ask, *“What were the first symptoms?”* Diseases affecting the mind are most likely labeled **dementia**. Common areas altered are: cognition, emotional expression, orientation with time and place, and personality. Whereas, disease influencing movement and the body are often labeled as motor neuron diseases.

There is often overlap between symptoms and both the mind and body are impacted by the disease process. Uncertainty, fear, survival mode, confusion, anger, sadness, are few of the cyclical emotions a person with NDs may experience on a daily basis. Whether it is the chronic memory loss of dementia, or the gradual loss of mobility within a motor neuron disease, two things are true: the disease is shaped by the person and the disease shapes the person. Each person is unique, gifted, and blessed with specific talents, abilities, interests, memories, and mementos. Each disease has its specific strains, progression, and finality.

At the intersection of who a person is and the diagnosis they receive, is a **brilliant sanity**. This brilliant sanity is an opportunity to find the shimmering spark of humanity discovered at the core of every being. Brilliant sanity is the choice to honor, accept, make friends with, and fully embrace the person you love regardless of diagnosis. Brilliant sanity is **being with** non-movement, loss, grief, confusion, hallucinations, and word salads with openness, curiosity, and compassion.

In this article we will make use of two theoretical frameworks. The first is the Transpersonal framework that validates and integrates a person's phenomenological, religious, existential, spiritual,

and transpersonal experiences and identities, as well as other and altered states of consciousness, such as a psychosis or disease and drug-induced states. This holistic approach makes space for the one being cared for to express themselves authentically and finds value in the brilliant sanity of the “downward staircase” of a progressive disease. Each hallucination can be treated with an attitude of receptivity and interest. Instead of labeling repetitive or unintelligible speech as “disruptive” or a “behavior,” reframe this as a healthy attempt to communicate a core need. The person who is often “medicated” by anti-psychotics may be approached with humility, gentleness, and a desire to uplift and understand, rather than suppression and rejection. **Reality orientation** is the forceful effort by caregivers to orient someone with a non-ordinary state of consciousness to time and place, whereas **reality validation** is going with their flow and joining them with a **willing suspension of disbelief**. The consistent trial and error of reality orientation is exhausting and, quite frankly, invalidating to the lived, embodied experience of another. The transpersonal perspective evaluates and infuses personalized care that honors the intrapsychic, interpersonal, cultural, and collective experiences of personhood and fiercely advocates for them when oppression is ideological, institutional, interpersonal, or internalized.

The second theoretical framework is The Caregiving Years Model (CYM) developed by Denise Brown in 1997 as a direct response to the question, “What would happen when we listened to the family caregiver?” (Brown 2008). After years of intentional effort and dedication, six stages were formed that bookmarked each chapter of the caregiver's journey when supporting a loved one. The six stages are **Expectant, Freshman, Entrenched, Pragmatic, Transitioning, and Godspeed**. For simplicity, let's combine Expectant and Freshman into **Before Caregiving Begins**, Entrenched and Pragmatic into **During Caregiving**, and Transitioning and Godspeed into **After Caregiving Ends**.

BEFORE CAREGIVING BEGINS

Expectant: Stepping into Uncertainty By Asking Questions

Let's assume your loved one has not yet received a diagnosis. Let's go back before the symptoms started. *What systems of support do you have? What is your current relationship with this loved one? Does your loved one have a healthcare and financial power of attorney (POA)? Who are your loved one's current healthcare providers?* A series of questions begins, stepping into uncertainty by asking tough questions now ensures we gain vital information that prepares us for the future of caregiving. *How do you want to live? If you lose your body, how do you want to be moved? If you lose your mind, what will remind you of your true self? What music makes your heart sing?* The caregiver becomes the detective, discovering all the essential knowledge of the person they love and support. The caregiver honors themselves and commits to self-care now, not later, and reflects upon the answers to the questions to provide guidance when the road becomes rocky. Be bold. Be brave.

Freshman: Brace for Impact by Finding Answers

Life is different now. The onset could be unexpected, sudden or subtle. Regardless of when and how you found out about the symptoms or diagnosis, life is different now. The time for hypotheticals is over and it is now time to become involved more deeply with your loved one's life. You are going to continue to ask questions, in fact you will become quite the sleuth as you begin to find out solutions that work for you and your loved one. *What do I know about this disease? How am I going to cope with the stress? How will I keep track of everything? What community services can assist me?* By finding and utilizing national family caregiver training programs, local non-profit-led, and online education will help you

brace for the impact of hands-on caregiving.

As your new role comes into fruition, the budding experience of the person with a diagnosis can be traumatic and, for the entire family, life changing. Consider the triathlete who learns they can no longer bike, run, or swim alone. Empathize with the former teacher, librarian, or electrician who can no longer trust their brain to accurately translate reality to them. The freshman stage is brutal. Normal responses include denial, aggression, avoidance, depression, and a hesitance to welcome the changes. These normal responses keep us from feeling the pain in the short term, but longer term leads to burnout and staying in the hurt. Denial is especially insidious in the early stages when a diagnosis is not clear. Depending on the nature of how a disease progresses, the caregiver or loved one may find themselves in the land denial often that rises, plateaus, and falls.

Your mission, should you accept it, is to adapt, improvise, and overcome, to find out what works and what doesn't, to find humor and play in profound and mundane moments. From the long-distance caregiver ordering meals and a weekly shopping list from 3,000 miles away, to helping clean both their parent and child's poopy Picasso finger paintings off the walls, life is different now for the caregiver. Create a journal for yourself and one for your loved one. There is an important adage, "If it wasn't documented, it didn't happen." The journal will help keep you sane and be a powerful testimony to the nitpicky bunch who will invalidate your good work as a family caregiver (there are many). Your ability to play and experiment will become crucial as the progressive nature of the disease consistently challenges the status quo and your relationship with your loved one.



Entrenched: Frustration and Burnout

“The more limited one’s capabilities for contact, the more one’s experience of self and of the environment becomes fragmentary, disorganized, and subject to resistance.” (James, 1993). When are you celebrating your good work? From whom are you receiving support? What has changed since diagnosis? Where do you go to recharge your batteries? How do you stay current with the changing care needs? More questions, some new with each new month, some old. Maybe you’ve mastered the art of handwashing, scheduling, or bed-baths. Maybe you were thrust into a fulltime job of caring for your loved one, having to give up your career in the process. Millions of maybes later, here you are, in the trenches, mud on your feet, grit in your teeth, a smile, a soft heart, and a strong back.

All your hard work and effort is an investment. Keep going. You are doing great! At this stage, your voice becomes loud and clear as you begin to identify *what’s mine*, that is, my baggage and agenda and *what’s theirs*, your loved one’s baggage and agenda. Frustration and burnout are common and occur no matter how resilient or level-headed you may have been before caregiving began. Things are different, remember? Keep journaling, honoring your limits, and create a system that works for you. Truly invest in finding a support system. Let yourself say no. Stay in contact with your true self and watch the evolution of willpower.

Pragmatic: Harmony and Synergy

You have set healthy boundaries, you know what doesn’t work and have a gut sense of what does, even if your loved one can no longer speak for himself or herself. Your loved one is different

now too. At this stage in the journey, your goal is to become familiar with the beauty of change and the intimate relationship, the special bond you share with the person you are caring for. Both of you have swallowed your pride, you move together in stride. There may have been falls, sometimes three in one week, but falls are no longer the trigger for distressful panic. A fall now causes a vigilant, thoughtful reaction, rather than a frantic response. Take time now, to slow down and reflect on the moments of chaos and stress and how you adapted, improvised, and overcame each of those challenges. Just as you received support when you were neck-deep, so too you continue to rely on others. You fill your cup and it runs over. You already know you will be spending a great deal of time with your loved one. ***How will you find time for shared activities that you both enjoy? When you have your regularly scheduled breaks (and you deserve and need them), what will you do?*** The sky is the limit, and your local communities often have resources to help you thrive. Explore offerings from local senior services, colleges, and libraries. Share your heartache and your insights in a forum or on social media; express yourself.

Being pragmatic means using both technology and the resources available to you to move from surviving into thriving. Despite obstacles, there are always ways to adapt to the changing needs of a loved one. Installing do-it-yourself lifts, ramps, and elevators takes courage and faith. Yet, the resulting independence can turn five years of agony and degeneration into five years of play, exploration, experiments, projects, and proactive adaptation. Throw out the throw rugs, get used to the naked body, and laugh every chance you can. This is hard work. You are not alone!



AFTER CAREGIVING ENDS

Transitioning: The End Is the Beginning

You have come a long way. The journey has tested your wit, strength, and your flexibility. You have scars, some may be visible, but most are hidden. You have carried the burden and now you sense the end is coming near. *What do you struggle with? How do you feel about the good work you have done? When was the last time you read the hero's tale told by your journals and busy schedule?* You have done so much for your loved one. Reflect on what you have done. Allow yourself to scream and shout, eat the ice cream, cry inconsolably, grieve, mourn, and honor your loved one. The final moments are not like the rest of the journey. A slowing down occurs. In the end, we see the person as a precious gem in the rugged shell of a diseased body. We find beauty in frailty, we cherish gentleness. We choose brilliant sanity.

The end marks the beginning. We can soften or harden ourselves. If we harden ourselves, we become brittle. Remain soft. Allow forgiveness and welcome your changing emotions. Each emotion is a messenger that gifts you with a potent truth about the internal experience. Trust your emotions, ride their wave for ninety seconds. See if they still have their grip, if so, ride another wave. Eventually, you will have learned to surf. No matter how high the waters rise you will not drown. Trust yourself, trust the process, seek out hospice when it is time. Keep asking the tough questions. *What is a good death? How can I live now, without regrets? When can I create memories? What do I need to ask before it's too late?*

Godspeed: Dare to Live

At the end of our loved one's life, a new journey begins. Life beyond caregiving. It doesn't end at the moment of death, it continues. The form changes, our function changes. We shift from doing into being. Now we are sorer, wiser, and absent our loved one. They live with us in our muscles, in our heart, in our minds. Ponder and contemplate your role as a caregiver and ask, *who have I become? How will I follow my dreams?* The lessons you learned are valuable. When will you share your story? Dare to live.

ABOUT THE AUTHOR:



He talks a lot and smiles often. He listens deeply. He prefers he/him/his, and you can call him Andrew. Andrew Koch has been caregiving professionally for eight years and cares for his uncles and one of his grandmas, long-distance from Boulder, Colorado where he is a Registered Psychotherapist and Owner of Contemplative Caregiver. He pursues a Master of Arts in Clinical Mental Health specializing in Mindfulness-Based Transpersonal Counseling. As a freshman family caregiver, Andrew is asking questions and finding answers within, cultivating loving-kindness for himself so that he may support those he cares for, spread compassion to the healthcare system and be the change that he wants to see in the world.

References

- Brown, D. M. (2009). The caregiving years: Six stages to a meaningful journey. Tad Pub.
Brown, D. M. (2015). The caregiving years tip sheets. Tad Pub.
Kepner, James. (1993). Mobilization and Body Process (pp. 120 -128). In Body Process: Working with the Body in Psychotherapy. SF: Jossey - Bass.

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HOW SELF-ADVOCATES AND FAMILIES CAN DEAL WITH HEALTH DISPARITIES AFFECTING PEOPLE WITH DISABILITIES

BY LAUREN AGORATUS, M.A.

Families of children with special needs may not realize that there are disparities in health care, which include differences in access to health care, health care quality, and exposure to harmful conditions that impact health such as environmental factors and living conditions (*see information on social determinants of health at www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health and www.cdc.gov/socialdeterminants.) Access to quality healthcare can be unfairly limited based on age, gender, race/ethnicity, socio-economic status, and even disability.*

Because people of color and those with lower incomes are more likely to have disabilities, this lack of access to quality, culturally-appropriate healthcare is likely to result in poorer health outcomes, including increased morbidity and mortality among

people with disabilities. In fact, according to the National Alliance on Mental Illness, people with mental health conditions die on average 25 years earlier than their peers.¹ Despite these challenges, there are actions that parents and self-advocates can take to mitigate the potential for these negative health outcomes for their children with all kinds of disabilities.

WHEN DO DISPARITIES OCCUR?

There are many variables affecting health care access for people with disabilities. This can range from basic accessibility to differences in medical interventions.

ACCESSIBILITY

The first hurdle may be something as simple as getting into the doctor's office. Even when the outside of the facility is accessible, some of the inside features of the office may not be. For example, examination tables and diagnostic equipment may not be accessible to individuals with disabilities. Many people found that once Medicaid went to managed care, even in-network doctors often did not have accessible facilities.

TREATMENT

There may be a difference in the treatment of a secondary condition for a person with a disability. Some parents are still asked if they want sterilization procedures for their teen with special needs. One mother was asked if she wanted to give antibiotics to her toddler (who happened to have



Down syndrome) with pneumonia, a completely treatable condition. Families of typically developing children are not asked questions about whether or not they want their child to have potentially life-saving antibiotics when they have pneumonia!

ORGAN TRANSPLANTS

Disability is often seen by transplant specialists as contraindicated for organ transplants. The decision should be made based on the individual's medical condition and overall health, not if they have a disability, which would not affect or be affected by a transplant. There are two excellent resources addressing this issue. The Boggs Center has a booklet on preparing people with disabilities for transplant at <http://rwjms.umdj.edu/boggscenter/news/documents/TransplantPampletFINAL6-11.pdf>.

In addition the Autistic Self Advocacy Network (ASAN) has a report regarding transplant discrimination, particularly for those with intellectual/developmental disabilities, at https://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf. Some states have since developed legislation to address this discrimination. ASAN also has a toolkit on transplants and disability including information on rights, guidance for clinicians, and tips for advocates at <https://autisticadvocacy.org/policy/toolkits/organs/>.

EMERGENCY PREPAREDNESS

It was demonstrated during both 9/11 and Hurricane Katrina that some people with disabilities were not being rescued. Many of them were either saved by friends, or their friends remained by their side waiting for rescue and perished with them. Some of the Centers for Independent Living now have initiatives on emergency preparedness and people with disabilities found at www.ncil.org. Family Voices also has a tip sheet on emergency preparedness for children with special health care needs at <http://familyvoices.org/wp-content/uploads/2018/06/EmergencyPreparednessResources.pdf>.

UNDERSERVED POPULATIONS

There are differences in several key areas which affect health outcomes. In addition to disability, certain racial/ethnic groups may lack any, or appropriate, health insurance, resulting in a later diagnosis. Besides making the condition harder to treat later, this adversely affects early intervention for children with disabilities, resulting in poorer outcomes. For example, African-American and Hispanic children with autism are diagnosed later.² The CDC (Centers for Disease Control and Prevention) recently recognized individuals with intellectual and developmental disabilities as a specific population subject to health disparities based on disability.³ The Arc National has a policy statement which includes "Integrating health disparities based on disabilities on the same basis as racial and ethnic disparities in research and program development."⁴ The Arc has also developed HealthMeet initiatives to address health disparities with information for families, providers, and self-advocates found at <https://www.thearc.org/healthmeet/whats-new>. It is also true that prevention/wellness initiatives help people with mental health issues as well as physical health issues.

The National Association of City and County Health Officials



EYE TO EYE: Examination tables and diagnostic equipment are often not accessible to individuals with disabilities. Some progress is being made.

(NACCHO) considers health care access for people with disabilities to be a public health issue and has developed a "Health and Disability" initiative found at <https://www.naccho.org/programs/community-health/disability>. NACCHO also offers a free online course for professionals regarding the inclusion of people with disabilities in public health programs at <https://www.pathlms.com/naccho/courses/5037>. For more information on NACCHO activities on including people with disabilities in public health, see <https://www.eparent.com/healthcare-2/including-people-disabilities-communities-public-health-initiatives-eliminate-health-disparities/>.

ADDRESSING HEALTH DISPARITIES FOR PEOPLE WITH DISABILITIES

According to the CDC, people with "any kind of disability experience three times the risk of heart disease, diabetes, stroke, and cancer as compared to the general population."⁵ Wellness and prevention is a key area for individuals with disabilities. Too often, medical visits solely address the main condition without consideration of general wellness such as lab tests for high cholesterol, diabetes, etc. The American Association on Health and Disability (AAHD) has a Health Promotion Resource Center which includes information on smoking cessation, physical activity, quality of life, emergency preparedness, and disability specific information at <https://www.aaahd.us/resource-center/>.

If families or self-advocates think there has been health care discrimination based on disability, they can contact their state office on Protection & Advocacy at <https://acli.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems> or file a complaint with the Office of Civil Rights at www.hhs.gov/ocr/complaints/index.html.

For additional information about health equity for children with special healthcare needs, check out the Catalyst Center resources at <http://cahpp.org/resources/?place=project&keyword=health-equity&sort=date-desc>.

For resources to enhance the capacity of diverse parents of CSHCN to advocate for quality healthcare services, check out resources from Family Voices and the National Center for Family Professional Partnerships at <http://familyvoices.org/ncfpp/resources-ncfpp/?sq=&f%5B%5D=best-practices>.

There are many issues affecting fair health care use for people with disabilities including physical access, stigma and stereotypes, and lack of preparation. For more information on health disparities and people with disabilities, see the blog from the SPAN Parent Advocacy Network, "Unfair Access to Healthcare Affects Our Families," at www.spanadvocacy.org/content/unfair-access-healthcare-affects-our-families-lauren-agoratus

Parents of children with special health care needs and self-advocates can lessen these barriers by knowing their rights, and being aware of wellness and prevention resources, which will improve health outcomes across their child's life span. •

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References

1. <https://www.nami.org/Learn-More/Mental-Health-By-the-Numbers>
2. <https://www.cdc.gov/ncbddd/autism/addm-community-report/differences-in-children.html>
3. <https://www.cdc.gov/ncbddd/disabilityandhealth/features/unrecognizedpopulation.html>
4. <https://www.thearc.org/document.doc?id=3729>
5. <http://www.cdc.gov/vitalsigns/pdf/2014-05-vitalsigns.pdf>

COME ONE, COME ALL : RESOURCES FOR DEALING WITH HEALTHCARE DISPARITIES

GENERAL



AMERICAN ASSOCIATION ON HEALTH AND DISABILITY
Health Promotion Resource Center
www.aahd.us/resource-center



THE ARC: HEALTHMEET
www.thearc.org/healthmeet/whats-new



CATALYST CENTER
Inequities in Coverage and Financing of Care for Children with Special Health Care Needs
<http://cahpp.org/resources/?place=project&keyword=health-equity&sort=date-desc>



NATIONAL ASSOCIATION OF CITY AND COUNTY HEALTH OFFICIALS (NACCHO)
Health & Disability
www.naccho.org/programs/community-health/disability
Health & Disability 101: Online provider course for inclusion in public health
www.pathlms.com/naccho/courses/5037



SPAN PARENT ADVOCACY NETWORK
"Unfair Access to Healthcare Affects Our Families" blog
www.spanadvocacy.org/content/unfair-access-healthcare-affects-our-families-lauren-agoratus

DISCRIMINATION



PROTECTION & ADVOCACY
<https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>



OFFICE OF CIVIL RIGHTS
www.hhs.gov/ocr/complaints/index.html

EMERGENCY PREPAREDNESS



NCIL
Centers for Independent Living: Lists all centers nationally
www.ncil.org



FAMILY VOICES
Emergency Preparedness for CYSCN (Children/Youth with Special Health Care Needs)
<http://familyvoices.org/wp-content/uploads/2018/06/EmergencyPreparednessResources.pdf>
See also: Best Practices in Cultural Competency
<http://familyvoices.org/ncfpp/resources-ncfpp/?sq=&f%5B%5D=best-practices>

TRANSPLANTS



AUTISTIC SELF ADVOCACY NETWORK (ASAN)
Organ Transplantation and People with IDD: report
https://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf
Organ Transplantation and People with Disabilities: Toolkit
<https://autisticadvocacy.org/policy/toolkits/organs>



BOGGS CENTER
Transplants for Children with Disabilities
<http://rwjms.umdnj.edu/boggscenter/news/documents/TransplantPampletFINAL6-11.pdf>

IN THE AUTISM WORLD, WHY ARE WE AFRAID OF SEX?

BY MICHAEL JOHN CARLEY

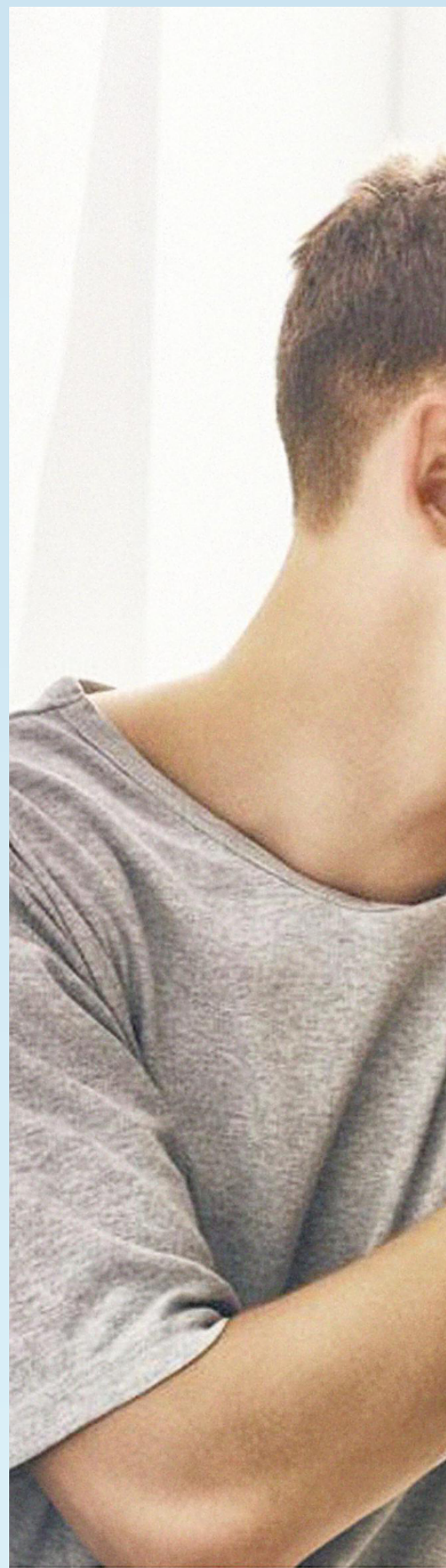
[Editor's Note: This article is loosely adapted from a four part series Carley wrote for Sinkhole Literary Magazine. For access to the entire series, please contact the author through his website.]

In 2003, I founded the Global and Regional Asperger Syndrome Partnership (GRASP), the largest membership organization in the world for adults on the autism spectrum. During my ten-year term as its first executive director, I couldn't help noticing that many members were terrified of sex. Despite remarkable progress in many areas for the autism community, adults on the spectrum still experienced noticeably high levels of guilt, fear, and shame when it came to even the idea of sexual activity. The rest of the world was starting to develop healthier attitudes about sex during this same decade, but almost none of that wonderful, reassuring, neurotypical world knowledge was reaching people with non-apparent disabilities.¹

Additionally, many other spectrumites shied away from sex due either to rectifi-

able sensory issues and/or often-rectifiable social anxiety – yet I found no sensory or anxiety-reducing activities attempting to address their challenges. Entire sexual lives were being sacrificed because people were too embarrassed to ask for help, too lazy to provide the context needed to teach people about sex, or were secretly relieved that their children would be spared the “dangers” of a sexual existence. Even masturbation – “sex with one’s self” – is an avoided topic. This cluster of forces continues to keep many of our folks unnecessarily celibate, even self-celibate.

This widespread, fear-based abstinence has appealed to our caregivers. Looking at all the available sexuality curriculums for individuals on the autism spectrum, the instruction experienced by most of our population (if we get any at all, as most of it is written for parents) is so overloaded²





SHEDDING STIGMAS: “I couldn’t help but notice that, despite remarkable progress in many areas for the autism community, adults on the spectrum still experienced noticeably high levels of guilt, fear, and shame when it came to even the idea of sexual activity.”

with relationship concerns, puberty instruction, or fear-based disclaimers regarding health and legal concerns... that it becomes impossible for us spectrum literal-thinkers to believe that sex is a good thing. As sex educator Al Vernacchio has made clear, we teach our kids (spectrum or not) that we do not want them to have great sex.³ We want people to know how babies are made, how to avoid becoming victims of crime, and (if lucky) what will happen to our bodies at age 13 or so, but we seem morally opposed to training kids to (eventually) become confident lovers who experience fabulous orgasms.

That said, the scare tactics in our segregated universe have a legitimate, social origin.

(Maybe) Why We're So Scared

Individuals with *all* disabilities have a medieval, awful, and trauma-filled history with sexual assault⁴ in schools, institutions, on the streets as homeless adults, or in the supposed safety of family life; a terrifying legacy⁵ that carries an infinitely higher degree of danger than what neurotypicals experience—especially for young women. Often, the abuse is hidden, and so the vast extent to which the problem exists goes mostly unacknowledged, even to this day.

In the early 1970s, a young journalist named Geraldo Rivera made his name by uncovering widespread mistreatment and neglect⁶ at a then-respected New York institution for the developmentally disabled. The name of the institute, Willowbrook, has since become a word in our collective lexicon that resonates as a nightmare. But starting with the discovery of horrors like those at Willowbrook, society began examining other institutions (schools, even families), uncovering vast abuse in the process. We then set out to correct the problem,⁷ and though the issue hasn't been eradicated,⁸ we've made great strides.

Yet, as with so many other things, we jumped over the emotionally-healthy middle ground and landed in the opposite extreme.

Nowadays, too many authors and clinicians in the autism world regard themselves as “sexpositive” even as they conclude every sentence about how wonderful sex can be with a giant “BUT!” We are too afraid to admit without disclaimer that sex is not about horrors. We can't state the truth that, to most, sex is about pleasure.

My intention here is not to trivialize the dangers, like sexual assault, that sex educators warn us spectrumites about. Instead, I want the conversation to be framed differently. Bear with me...

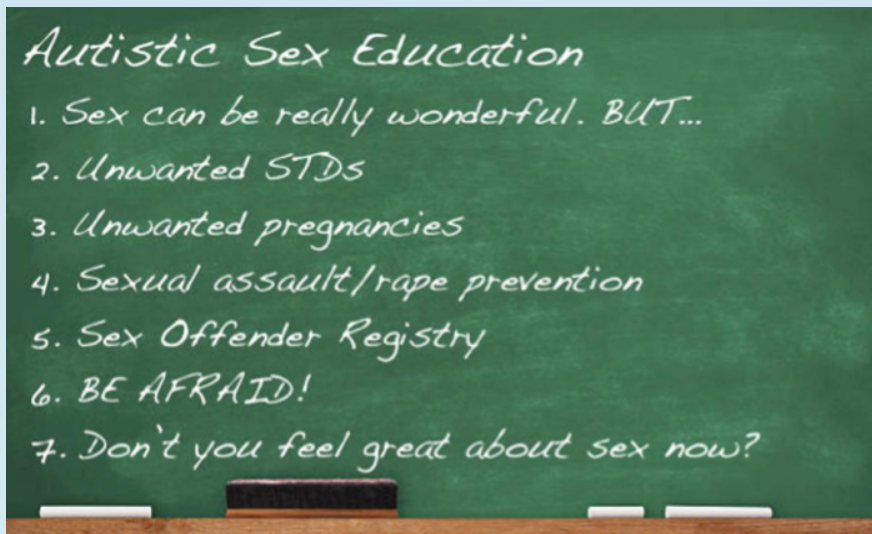
1. What if the imperative subjects of unwanted pregnancies, safe sex practices, and Sexually Transmitted Diseases (STDs) were categorized under the auspices of “Health” instead of “Sex”?
2. What if avoiding sexual assault, stalking charges, or the Sex Offender Registry, were listed under “The Law”? How would we spectrum-folk, as precision-based learners, regard the word “sexuality” then?
3. What if (for everyone) we stopped teaching sex within the context of developing relationships? I propose that this confuses us due to the infinitely more complicated subject of friendships and/or relationships—and nobody needs an existing relationship

to become sexually aroused.

There is so much potential happiness therein, and yet with the exception of death, nothing seems to scare our society more than sex. All because we have to frame the subject amidst the aforementioned horrors.

Another part of the problem is religious influence.⁹ While the ethical examination of sexual behavior may appeal to many, alongside the promise (that most major religions subscribe to) that monogamy works for everyone, I believe religious scripture is the basis for much of our ridiculous attitudes towards women, and it is the basis for pretty much all of our bigotry towards the LGBTQ community.

Another part of the problem is that parents, even the supposed-



FIGHTING FEARS: “My intention here is not to trivialize the dangers, like sexual assault, that sex educators warn us spectrumites about. Instead, I want the conversation to be framed differently.”

ly “cool” ones, overestimate their value as teachers. While well-intended, and maybe a good starter course, parental instruction herein needs context in order to become a helpful part of their child's education. And that context is this: Every generation is convinced it reinvented sexuality (myself included, folks). The child's generation will define their sexual existence, not their parents'.

Because of our educators' terror on our behalf – that we not succumb to the aforementioned horror stories – we spectrum-folk are also not being given confirmation of how pleasurable sex can be, how healthy sex is for the physical body, how no one has low self-esteem when experiencing an orgasm, or how many options individuals really have (as opposed to the limited options we are informed of). Even the most non-verbal of us will know what turns us on and what doesn't – regardless of whether or not we'll ever have sex with another person. And if raised in a heterosexual environment, very often – whether the caregivers are bigots or not – the option (and subsequent permission) that you might be different is almost never presented to you. Others who are quite verbal are usually given the standard “you'll figure it out” cop-out when, of course, “figuring it out” is a known diagnostic challenge for us.

Everyone needs instruction – even in the basics. And in our society, we often don't get it.¹⁰ Many schools out there know they should teach their more-challenged spectrum students what mas-

turbation is and when and where it's appropriate. But these schools won't go near the topic.¹¹ Today, in the one of the most prosperous nations on earth, we ruin lives in the name of the highly elusive concept of "safety." Helen Keller, of all people, teaches us that:

Security is a superstition. It does not exist in nature.

Life is either a daring adventure, or nothing.

Our instructors instead try to spin the seemingly mandatory, fear-based instruction as being simultaneously full of positive attitudes. But the result is a spectrum adult that is scared and confused, not positive. We need instruction that is healthy and positive,¹² clear and with context, and open to all possibilities.

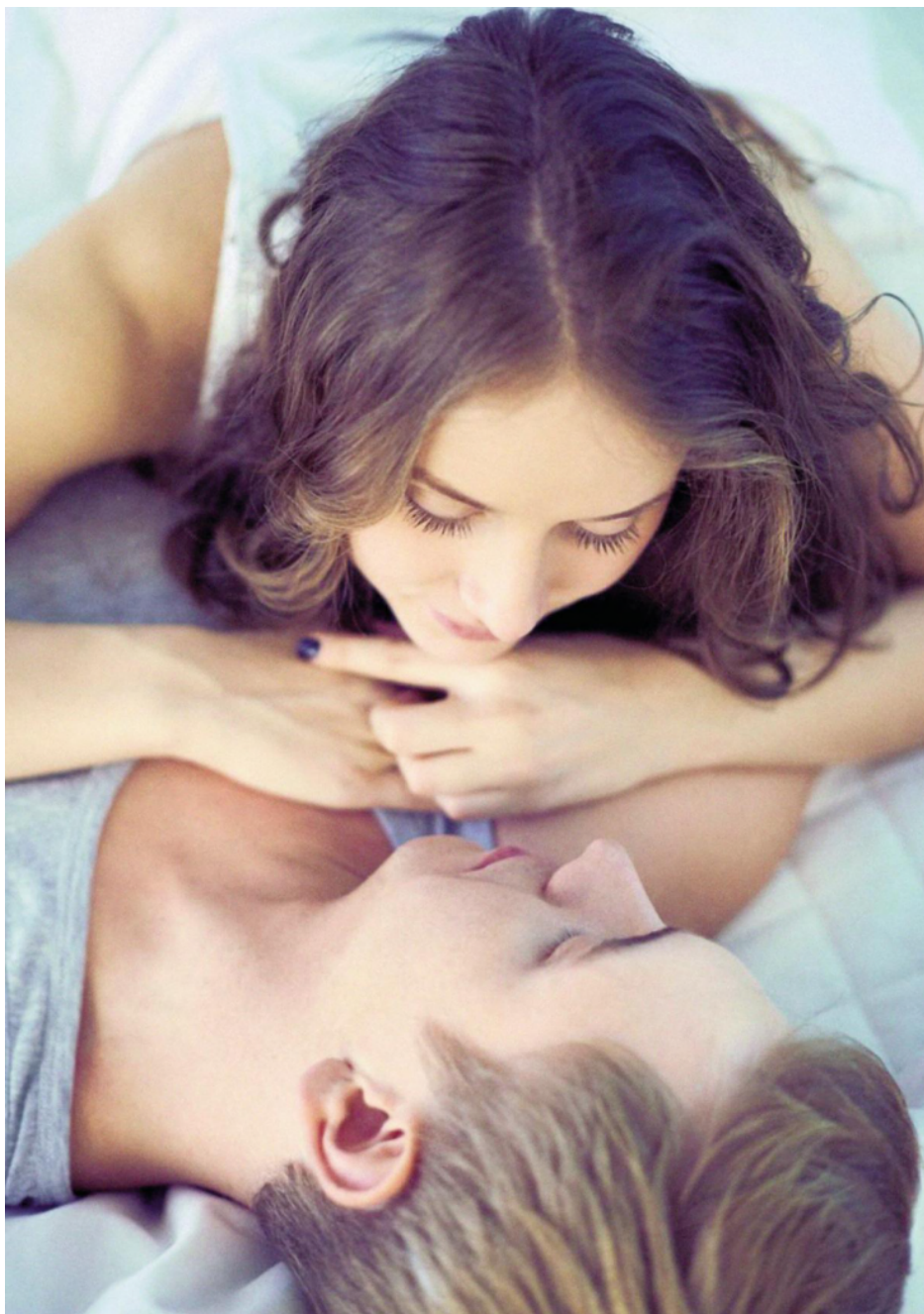
Sex is Not "Complicated:" It's Awesome

Look, being people on the spectrum, we are not a population with the best chance of obtaining the great, mountain-moving, reciprocal love affair, nor do we have the same shot at career fame that neurotypicals have. Sex might be the best thing we have... if we're allowed, and if we allow ourselves. If reciprocal relationships are truly beyond us, then why not make masturbation a more important declaration of self-love?

I can't tell you how many times I've run into a clinical professional or a self-contained classroom teacher who's worked with significantly-challenged spectrumites, and who has a story about that non-verbal male who one day "whipped it out" and began masturbating in a supposedly-inappropriate setting. The clinicians all tell this first-person narrative the same way – by bravely admitting how freaked out they were about how to stop it.

And yet no one tries to imagine what's going on in the mind of the spectrumite. He's just discovered the greatest thing since sliced bread, and you're telling him it's wrong to do it?

Even today, some still think it is okay to bypass instruction on such challenged folk as to the changes their body will undergo during puberty. However, though our minds are different, our bodies usually grow at the same rate as everyone else. Neglecting such instruction may lead to future problems that are very hard to reverse; or as I like to say, "If you think



BREAKING THROUGH: "Our barriers to promoting healthy attitudes stem not from logic, but from unconscious, semi-conscious, or conscious moral objections – often-flawed value systems that have been embedded in us whether we wanted them or not."

you've seen behavioral problems, and you don't tell them what's going to happen to their body during puberty? You ain't seen behavioral problems yet."

Our barriers to promoting healthy attitudes stem not from logic, but from unconscious, semi-conscious, or conscious moral objections – often-flawed value systems that have been embedded in us whether we wanted them or not. And the analytical truth is that they have no place influencing what at root, is a discussion about biology.

The Autism World is NOT "Sexpositive." Here's Why...

In 2004, one year into my tenure at GRASP, I got the first of what would become several similar phone calls. The mother of an adult spectrum male called to ask if I could refer her to any "disability-friendly escorts" for her Asperger son. She felt that her child, who reportedly had never encountered reciprocated sexual activity, needed the confidence of experience in order to develop and go forward as a sexual



CLOSING THE GAP: “While not sexpositive, the autism world isn’t “sexnegative.” It wants to move forward, and it does move forward, but at such a slow pace that the discrepancy is beyond noticeable and the knowledge gap grows steadily between us and the neurotypical world.”

being. The only alternative was to wait even more years (her son was already in his 30s) until he (hopefully) gained the social skills that might bring about that beautiful combination of attraction, confidence, and informed consent. She knew that banking on the latter combo, i.e. waiting *more* years, was a risky gamble, if not a sadly dubious assumption.

I wondered how I felt about this, and shared the conversation with my wife Kathryn. I shared how I felt as a fellow spectrumite, as an executive director, and simply as a person wondering how much cognitive groundwork was necessary in order for a somewhat-challenged person to process such an experience. I concluded not only that I had no right to judge him, or his mother, but also that if the sex worker (the justifiably/politically correct term for “escort/hooker/prostitute”) was the only experience he would ever have, that yes, I’ll say it...this was far better than no sex at all.

Kathryn’s conclusion was slightly different.

“So, you’d throw away your career to become a pimp?”

She was right, and I obeyed; but the quandary only intensified. As the epiphany of adult diagnosis continued to explode until 2010, I not only got more calls like these from parents, I also started receiving confidential communiques from adult film actors, and sex workers, who *themselves were getting diagnoses of Asperger’s syndrome*. From my standpoint, I had quite the elephant in the bathtub – as the clinical world grappled with spectrumites’ relationship to porn, the idea that the actors we watched were often us was really not on anyone’s radar but mine.

What to do with such knowledge? I sought advice from a few colleagues, trying to open this can of worms as gently as I could. But the autism world didn’t just say, “Maybe not now.” The autism world made it clear, *“Michael John, we love you. But on this one? Shut the \$#! up.”*

So while I continued to support these adults as I would any GRASP members, I did not write about the subject. Many of them wanted out of their professions. But equally vexing was that many others didn’t. They liked sex, and whether they wanted primary romantic partners or not, they were sure they stunk at relationships anyway – so why not? The diagnosis, as with all of us, felt like a positive validation for why they were who they were, and why their lives were as they were.

The Sex Offender Registry

While the topic deserves more time than I will give herein, the sickening over-use of the Sex Offender Registry¹³ (SOR), if not an overall Draconian criminal justice system,¹⁴ has also been a very visible, “sex negative” influence on my years at GRASP. Too often, people with autism are railroaded into signing confessions (regarding many crimes) they did not have to sign, or did not understand, because their spectrum trauma only wanted the detective or District Attorney to stop yelling at them. Teenagers have had their lives ruined for consensual acts.¹⁵ Other spectrum individuals, who had committed legitimately illegal offenses, such as downloading and viewing the wrong kind of porn¹⁶ – including that which involved children – should have incurred lighter sentences with an educational component if the offenses were as non-violent as they often were. But no, in a scene that spoke so much about who Americans are as a people,¹⁷ the powers that be insisted that they be allowed to destroy the lives of these young people forever¹⁸ through hard time and the SOR. We are so sick that we cannot see anything wrong with sending someone away for years of hard time because they viewed the wrong kind of porn online...even though we know it means that they will be raped repeatedly once incarcerated.¹⁹ One could argue that this counter-productive²⁰ era has inflicted a

collective trauma on all of us in the autism world, and not just on the individuals whose lives were destroyed. In our consciousness, the prevention of falling into the clutches of a corrupt, and Kafkaesque criminal justice system...easily supersedes healthy sexuality.

The Autism Community Pretends to Move Forward...

Well, maybe that subtitle isn't entirely fair...While not sex-positive, the autism world isn't "sexnegative." It wants to move forward, and it does move forward, but at such a slow pace that the discrepancy is beyond noticeable and the knowledge gap grows steadily between us and the neurotypical world. As the new millennium dawned, non-spectrum communities were beginning to tune into Dan Savage and Esther Perel, yet we were still having issues with allowing moderately-impacted spectrumfolk to pursue sexual lives. And later, in the middle of the last decade, as porn and its performers were becoming legitimized in mainstream culture (or at least less and less stigmatized), the very existence of an LGBTQ influence on the spectrum was becoming acknowledged not through invitation, but through much kicking and screaming. Today, no one provides the context that watching porn needs – in order to avoid the minefields that porn presents to an uneducated viewer. Yet far too few of us provide an alternative, and so porn has become the de facto sex ed.²¹

Lastly, spectrumites these days are finally being encouraged to feel sexual, and to think of themselves as sexual beings. But this is still allowed in the context of the sexual void. Look at the speaking circuit: The spectrum sex speakers that we are comfortable promoting actually *haven't experienced much sex* – it's like the employment book written by the person who never held a job for much time (lots of "don't"s, but very few "do"s). We are showing our pain, sometimes bravely, and that moves folks. We cater to the neurotypical world's desire for warm and fuzzy wholesomeness, using words like "naughty;" the sexual zoo exhibit that allows for subliminal pity, therein pleasing and reassuring its audience, because God forbid any of us should realize that we deserve pleasure,²² that there is nothing noble in rejecting it, that it is so easily accessible, and that it carries significant benefits to both our physical and mental well being.

More Lies That People WITHOUT Autism Live By

The subject of sex is unique for the autism universe not because healthy sexuality is something we fail to successfully implement. It's unique because herein, the neurotypical world fails too. The large discrepancy between what we get to learn and what the neurotypical world gets to learn is the basis for this article. But the situation is remarkable because neurotypicals don't have it that good either—we're bad at teaching sex to everyone.

Despite our economic advantages as Americans, sex has always been a topic we've struggled with. While we may never reach the emotional health of the Dutch²³ (where it is no coincidence that an extremely low rate of teen pregnancy reflects programs providing free birth control, with no parental approval needed, to students 13 and older), or the French (attitude, attitude, attitude) on the subject of sex, we struggle far more than our relative privilege warrants. Herein, the struggles of people with disabilities are mere extensions of a larger, American problem.

Not to try to be too comedic, but part of our problem might have to do with having gotten off to a bad start. Four hundred years ago, remember, our first settlers had left a sexually-repressive England for the very reason that, for them...*it wasn't sexually repressive enough*. They were called "Puritans," who believed in Puritanism; a way of life that journalist, H. L. Mencken referred to as "The haunting fear that someone, somewhere, may be happy."

Thereafter we somewhat mirrored our European lookalikes, including up to the industrial revolution wherein the pressure for couples to marry²⁴ both emerged and gained the stronghold it still maintains today. However, fidelity (99% for men) back then was not a staple of the marriage contract. Males were allowed to roam freely so long as the heterosexuals did not encroach upon "good" women whose reputations often dictated whether they lived or died. LGBTQ folks made arrangements in dangerous secrecy, and straight women, unlike their straight male counterparts, faced social and financial ruin for sexual contact outside the marriage.

Later, starting in the post-World War I era, we first saw pressure for true monogamy amongst *both* heterosexual partners. It began as a backlash against widespread outbreaks of venereal disease, and after World War II became more of a cultural preference rather than strategic element of disease control. And after the pill's emergence in the 1960s, thus freeing sex from the fear of reproduction, pretty much all marginalized and unmarginalized groups began their real pushes down the path towards sexual transparency.

There've been thousands of contradictions along the way, some of which today act as elephants in the bathtub (if a spectrum person may be allowed a euphemism). For example, we argue incessantly about how sexual education should occur in the schools.²⁵ But doesn't our very (worthy) desire for a diversified society herein bite us on the rear end? When we accept people of differing faiths and cultures into public education, we are therein allowing the conservative factions of almost every major religion—most of whom preach against pre-marital sex (especially for women)—to thrive and spread their fear-based instruction in our schools. This is another reason why school classes reframed as "Health," "Violence Prevention," "What the Law Tells Us," or "Self-Esteem 101" might win more approval from (if not sneak by) the conservative crowd.

A Book's Complicated Journey

When I left GRASP I did do something. I wrote a book called *The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!* But the book had a more complicated journey than I expected.

In 2014, I signed a two-book deal with one of the three autism trade publishing companies (hereafter referred to as "Publisher A"). One of the two books, the one I would write last, would be the "big, fat sex book" I'd been dying to write since early in my GRASP tenure. My commissioning editor was a young, LGBTQ woman, and she and I really saw eye-to-eye on what the book should look like. But halfway through the writing of the book, as the first book (on unemployment) came out successfully, she left for a job at another publishing house. So as I enjoyed the honeymoon period from the first book in my two-book deal, I also started to put the finishing touches on the sex book, including the soliciting of testimonial quotes from better brains than mine in the autism field. I got lucky. I got raves by authors like *Far From the Tree's* Andrew Solomon, and

Uniquely Human's Barry Prizant; clinicians and autism world luminaries like Sue Marenco, Fred Volkmar, and Linda Walder Fiddle; and in the foreword, well-known disabilities and sex expert, Dr. Michelle Ballan, called my *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!* both “the most LGBTQ-friendly book of its kind,” and “Carley’s most passionate book yet.” Life was good!

Problem was... my cool, younger editor had been replaced. As soon as a draft of the sex book was seen in early 2016, Publisher A dropped the book within 36 hours. No “Hey Michael, can we talk?” Just an unceremonious email saying “We’re dropping you.” I’d known the owner for a decade, we hadn’t had any arguments, and we’d just published a highly successful unemployment book together, AND she had competed with Penguin for my very first book in 2006! When I initiated a conversation that asked “Are you kidding?”, they lied about context, and in a derogatory fashion utilized the words, “anything goes” to negatively describe my book.

But then, the owner of one of the other two autism trade companies, call them “Publisher B,” a main rival of Publisher A, called me up. “*Michael, your book has a found a home,*” and they quickly sent a contract. After I reviewed the contract, signed and send it back for their signature... crickets. Six weeks later, after many emails and follow up calls to “where are you?”, the owner of Publisher B called with his tail between his legs to tell me he couldn’t do it. He wouldn’t say why, but a spy told me that the authors of Publisher B’s old and existing sex books (for trade books rarely go out of print) had raised a large protest – How could Publisher B publish a book (mine) that so directly contradicted much of what they said in theirs?

What was so different about my book? Well, the views expressed in this article certainly ran counter to the prior literature. But my book also had several, very specific, “how-to” chapters (which, I will argue, we spectrumites are desperate for). These occupied most of the 72 sexually explicit illustrations. The characters drawn (by a wonderful Indonesian artist who had to keep his identity—both sexual and personal—anonymous) also included individuals of different skin colors, ages, and body types.

To be fair about the three autism trade companies (that I’m herein inferring as prudish) in the years 1998-2004, it was they that published all of the ground-breaking material that lifted autism literature out of the stone age. But since then, they’ve regurgitated the same info in book after book, and two of the three owners have since passed away. Nowadays, the ground-breaking books like *Far from the Tree*, *Uniquely Human*, *Neurotribes*, and *In a Different Key* all come from the mainstream publishing world.

Long story short, my book’s publication has merely been delayed, and has a happy ending forthcoming, but the point being is that the powers that be in the autism trade publishing world – being reflective of the greater autism world – are socially conservative, and not “sexpositive.”

Conclusion

Our feelings are complex, yes, and the spectrum provides few absolutes for us to theoretically rely on. Whereas some of us require more closeness in a relationship, others require more distance and boundaries. But in other disabilities—physical disabilities—lie perhaps paradoxes that better test our assumptions.

What of the person who has no ability to control or utilize their hands, and yet their clitoris and penis work fine? In order to gain release by masturbating, they need help from another person. Are we so morally opposed as to object to someone, perhaps paid, who acts as their masturbator? What of the physically disabled couple who reside in an assisted-living or supportive housing facility, and who have decided they want to have sex together, yet they don’t have the physical means to join their genitalia? What if they need a third person to make it happen, to literally push the two bodies together? Are we to fire the orderly who facilitates this for them?

And what of the woman with massive mental health issues who has been deemed by the courts as too challenged to be able to provide informed consent? Is everyone she consensually sleeps with then subject to being arrested on charges of rape?

Luckily, we are not a culture that is *completely* bereft of critical thinking. While minors will always need to be protected from predatory grownups, movies like *The Diary of a Teenage Girl*, and *Call Me By My Name* (both admittedly, which are set in the era in which I came of age) challenge the inflexibility of modern times.

Finally, very few people (spectrum or no) are having too much sex. The vast majority of us are not having enough, and the opportunity for a magnificent, erotic life passes us by.

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 now at home with Sinkhole. Dozens of past “Autism Without Fear” columns can be found at <http://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.

References

1. https://broadly.vice.com/en_us/article/pg79xm/this-is-what-sex-ed-for-the-intellectually-disabled-looks-like
2. https://www.autismspeaks.org/docs/family_services_docs/parentworkbook.pdf
3. <https://www.nytimes.com/2011/11/20/magazine/teaching-good-sex.html>
4. <https://disabilityjustice.org/sexual-abuse/>
5. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC181173/>
6. <https://www.youtube.com/watch?v=IWDt5IE8RP1>
7. <https://www.npr.org/2018/01/16/577063976/its-an-easy-crime-to-get-away-with-but-prosecutors-are-trying-to-change-that>
8. <https://www.npr.org/series/575502633/abused-and-betrayed>
9. http://www.slate.com/blogs/xx_factor/2013/05/06/elizabeth_smart_abstinence_only_sex_education_hurts_victims_of_rape_and.html
10. <https://www.thestranger.com/features/feature/2015/04/15/22062331/i-sat-in-on-my-sons-sex-ed-class-and-i-was-shocked-by-what-i-heard>
11. <http://journals.sagepub.com/doi/abs/10.1177/1365460712439655>
12. https://www.huffingtonpost.com/lea-grover/this-is-what-sex-positive-parenting-really-looks-like_b_5516707.html
13. <https://www.cbsnews.com/news/indiana-teen-zach-anderson-labeled-sex-offender-after-sex-girl-lied-about-age/>
14. <http://www.abc.net.au/news/2014-10-22/barns-its-time-to-rethink-sex-offender-registers/5832176>
15. <https://www.npr.org/templates/story/story.php?storyId=10972703>
16. <https://www.themarshallproject.org/2017/05/31/downloading-a-nightmare>
17. <https://www.aclu-nj.org/theissues/criminaljustice/whysexoffenderlawsdomoreha/>
18. <https://www.vox.com/2016/7/5/11883784/sex-offender-registry>
19. <https://www.nytimes.com/2015/04/18/opinion/why-we-let-prison-rape-go-on.html>
20. <http://time.com/3486493/preventing-child-sex-abuse-stephen-collins/>
21. [https://www.nytimes.com/2016/03/20/opinion/sunday/when-did-porn-become-sex-ed.html?referer =](https://www.nytimes.com/2016/03/20/opinion/sunday/when-did-porn-become-sex-ed.html?referer=)
22. <https://ideas.ted.com/why-pleasure-is-important/>
23. <https://www.nytimes.com/2011/07/24/opinion/sunday/24schalet.html>
24. <https://www.livescience.com/37777-history-of-marriage.html>
25. <https://splinternews.com/what-schools-are-teaching-teens-about-sex-will-horrify-1793851150>

#BeUnderstood

Ad
Council

**SOME PARENTS THINK THEIR KIDS AREN'T LISTENING.
SOME KIDS GET DISTRACTED BY ALL THEY HEAR.**

Learning and attention issues can look different to parents and kids. That's why there's Understood, a free online resource with answers, advice and tools to help your child thrive. Go from misunderstanding to [understood.org](https://www.understood.org).

Understood

for learning & attention issues

Brought to you by 15 nonprofit partners

ORGANIZATIONS AND INFORMATION IN SUPPORT OF CHILDREN WITH SPECIAL NEEDS

BY ANGELA SHAW

In order to provide a comprehensive list of supports to meet the needs of today's family, resources for children and adults with special needs are encompassed within the following guide.

ATTENTION DEFICIT



CHILDREN AND ADULTS WITH ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (CHADD): Founded in 1987 in response to the frustration and sense of isolation that was being experienced by parents and their children, due to the fact that there were few resources and little understanding of about the disability at that time. Today CHADD has grown to become the leading non-profit national organization for children and adults with ADHD.

Provided within the website are links, tips and resources, and an opportunity to subscribe to a free newsletter. In addition to free resources provided within the website, various paid membership is available. CHADD has three current goals and priorities objectives to including serving as:

1. A clearinghouse for evidence-based information on ADHD.
2. A local face-to-face family support group for families and individuals affected by ADHD.
3. An advocate for appropriate public policies and public recognition in response to needs faced by families and individuals with ADHD

www.chadd.org

AUTISM



THE AUTISM INTERNET MODULES (AIM): One of many online resources available to family members, educators, or any individual who works with or lives with someone with autism. AIM

provides no-cost instructional modules to include evidence-based practices for home, school, community, and work place. Modules are simple to navigate and make it easy for the busy parent to learn at their own pace. This site features tools to ensure that families and service providers are equipped to effectively care for, support, educate, employ, or work with individuals on the autism spectrum from early childhood to young adulthood.

Provided within the site is an online video-based learning solution that offers families with practical information, real-life examples, and skills to utilize in care and support of loved ones with ASD from early childhood through young adulthood. Click on ASD Strategies in Action to discover how to get started in a course tailored to your specific needs based upon the individual with ASD and your role as a caregiver. Navigate the Explore tab to discover:

- *New Courses*
- *Video Gallery*
- *Continuing Education*
- *For Families*
- *Resources*

www.autisminternetmodules.org

CEREBRAL PALSY



CP DAILY LIVING: Inspired by one family's struggle to find resources information about the day-to-day details involved in raising a child with cerebral palsy. The goal of this site is to help make the journey easier by helping parents and caregivers navigate the challenges of CP through sharing of information and experiences about a range of topics to include treatment modalities, negotiation of air travel, emotional perspectives, education/preschool, sleeping, eating, and growing up. Tabs include:

- *What is Cerebral Palsy*
- *Newly Diagnosed*
- *CP News & Books*
- *Daily Living*
- *Adaptive Needs*
- *Support & Planning*
- *Associated Disorders/Difficulties*
- *Inspiration*
- *Supporting the CP Community & More*
- *Patient-Professional Communications*

Each of these tabs provides a comprehensive list of content that provides guidance to parents and families within a range of topics to include inspiration, practical day-to-day guidance, parent organizations listed by state, research and news, and so much more. This is a great resource to share with educators, as well as extended family members.

cpdailyliving.com

DEAF / HARD OF HEARING



CALIFORNIA STATE UNIVERSITY, NORTHRIDGE DEAF EDUCATION & FAMILIES PROJECT (CSUN DEAF PROJECT):

Consists of faculty and staff associated with the Family Focus Resource Center at CSUN, in addition to faculty in the Deaf Education Program in the Department of Special Education. Resources to support the family, as well as a newsletter is available. Within the family project at CSUN, the goal is to empower parents of children who are deaf to get educated, get together, and learn to communicate. In addition to a news and events within the home page, a comprehensive collection of links for parents and families is provided. Some unique links for families in the home page include:

- *Resources tab: The Lending Library. It is noted that the Lending Library is for families with deaf or hard-of-hearing children. Families may borrow any items for a specified period of time. The contact for Lending Library is deafproject@sun.edu or 818-677-6854.*
- *Parent Links tab: Portal that serves to connect parents of children who are deaf or hard of hearing (DHH) to other parents in similar circumstance.*
- *Newsletter: Sign up for the newsletter available through this website.*

www.csun.edu/deafproject



HANDS & VOICES (H&V): A parent-driven, non-profit organization in support of families of children who are deaf or hard of hearing. All approaches and experiences with deafness or hearing loss are included, from American Sign Language to cochlear implants. Local chapters comprised mainly of parents along with professionals are available and can be contacted via the website. Additionally, resources such as links and handbooks are available within this site. Topics ranging from education, the law, perspectives from families and individuals who are deaf or hard of hearing, and much more is available on the website.

www.handsandvoices.org

DOWN SYNDROME



DOWN SYNDROME ADVANCEMENT COALITION (DSAC) OF ARKANSAS: Founded in 2016 by Brittany Boccher, an Air Force spouse. Under the *Resources* tab, there are links to local and

national links, as well as events within the state of Arkansas. Education, advocacy, awareness, and outreach are foundational aspects of this organization. The coalition goals reflective of these four cornerstones are shared within the Mission and Vision link provided within the home page to include:

- *Educate: Inform families about the resources and benefits designed for individuals with Down syndrome.*
- *Advocate: On behalf of individuals with Down syndrome on the issues of wellness, education, and employment.*
- *Awareness: Promote awareness and understanding about Down syndrome and make the community aware of the ABILITIES of individuals with Down syndrome.*
- *Outreach: Connect families by bridging the communication gap between our community and the public and private agencies that serve us so we can work together, better.*

www.csun.edu/deafproject



NATIONAL DOWN SYNDROME SOCIETY (NDSS): A non-profit organization committed to their vision of "...a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities." There are a number of programs and resources available within the website, to provide across-the-lifespan guidance, support and information. Additionally, there local support groups, social media, and newsletter links to support families. Tabs to navigate and discover include:

- *Work*
- *Involve*
- *Advocate*
- *Engage*

www.csun.edu/deafproject

DYSLEXIA



THE INTERNATIONAL DYSLEXIA ASSOCIATE (IDA): The oldest organization dedicated to the study and treatment of dyslexia. IDA is rooted to Dr. Samuel T. Orton's pioneering studies in the 1920s, relative to the field of reading research and multisensory teaching. Formalized organization of the Orton Society began after Dr. Orton's death, through his wife and colleague June Orton, in 1949. Orton's important pioneering work would continue through teacher training and published instructional materials. The Orton Society would eventually become today's International Dyslexia Association that abides by their mission: "To create a future for all individuals who struggle with dyslexia and other related reading differences so that they may have richer, more robust lives and access to the tools and resources they need."

Families and professionals are provided access to handbooks, fact sheets, conferences, and workshops. Under the *Families* tab, discover the helpful *IDA Dyslexia Handbook: What Every Family Should Know*. Numerous fact sheets and resources are provided within this website.



OVER AND ABOVE: Military families are charged with balancing the challenges of the military lifestyle and responsibilities, in addition to the regular day-to-day, year-to-year, and decade-to-decade family and life experiences that civilian families face.

Additionally, check out the Youth Art Gallery under the *Families* tab to learn how IDA highlights the artistic talents of students with dyslexia and other related learning disabilities during Annual Conferences and throughout the year. A resource guide for parents of children with learning disabilities is not complete without the information from the IDA.

<https://dyslexiaida.org>



THE YALE CENTER FOR DYSLEXIA AND CREATIVITY

(YCDC): Provides a comprehensive wealth of information for parents and educators. YCDC was founded by world-renowned physician-scientist and leaders in the field of dyslexia research and diagnosis, Drs. Sally and Bennett Shaywitz. It provides avenues to support understanding of dyslexia for the parent, teacher, and child. The mission of YCDC is to increase awareness of dyslexia and its true nature, specifically to illuminate the creative and intellectual strengths of those with dyslexia, as well as disseminate the latest scientific research and practical resources. Transformation of the treatment of all dyslexic children and adults is of critical importance, based upon the mission provided. If you are interested in learning about dyslexia, this website will provide you an abundance of information. Under the *Resources* tab information is shared within the categories of:

- Accommodations
 - Parents
 - Dyslexic Kids & Adults
 - Educators
- www.dyslexia.yale.edu

LEARNING DISABILITIES



LD ONLINE: Noted to be an educator’s guide to learning disabilities and ADHD, but lends a comprehensive hand to support parents, as well. The site features LD Basics and ADHD Basics, LD Topics, Home-to-School Connection, Resources, and more. LD OnLine describes their organization as one that seeks to help children and adults reach their full potential by providing accurate and up-to-date information and advice. LD OnLine is a national educational service of WETA-TV (the PBS station in Washington, D.C.). The Home-to-School link within the site provides a great start point for parents and educators. LD OnLine’s pursuit of building a strong bridge between families and educators categories provides links and resources in support of proactive and solution-focused IEP teams:

- *Top Subjects*
 - *Top Articles*
 - *Multimedia*
 - *Resources*
 - *Recommended Links*
 - *In the Forums*
- www.ldonline.org

MENTAL HEALTH & LEARNING DISORDERS



THE CHILD MIND INSTITUTE: An independent, national non-profit organization. This organization is dedicated to transforming the lives of children and families struggling with mental health and

learning disorders. The Child Mind Institute shares, “We share all of our resources freely and do not accept any funding from the pharmaceutical industry.” Child Mind Institute shares their three commitments, relative to creating a brighter future for children to include:

- *Best, most effective treatments when and where needed most.*
- *Advancement of the science of the developing brain to improve diagnosis and treatment.*
- *Provision of useful, accurate information that empowers families and communities to get the help they need.*

Navigate the *Topics from A-Z* tab to discover what is available to families relative to issues ranging from ADHD, anxiety, learning, medication and more. Guides are available for families to include a range of subjects within this section. The *For Families* tab includes insights and advice regarding common concerns that families face, including subjects ranging from parenting guides containing information about selective mutism and ADHD medications, as well as a special section relative to the unique challenges that military families face – including a collection of articles, strategies, and expert advice on how to know when children are not responding in a healthy way to stressors in the family. Check the sub-tabs under *More on Military Families* within the Military Family page to provide a quick and more focused glance of available topics:

- *Latest*
- *Autism Spectrum Disorder*
- *Mental Health*
- *Suicide and Self-Harm*
- *Trauma and Grief*
- *Trauma and Stress Related Disorders*
- *Parenting Challenges*
- *Special Needs*
- *Stress and Resilience*
- *Teenagers*
- *Responding to Traumatic Events*

childmind.org

LEARNING DISABILITIES



CENTER FOR PARENT INFORMATION AND RESOURCES:

A broad-reaching support for families and professionals. Serving as a central resource of information and products to the community of Parent Training Information (PTI) Centers, as well as the Community Parent Resource Centers (CPRCs), military families can discover a wealth of information to support them with a range of resources and information with nearly 100 PTIs and CPRCs in the U.S. and Territories. Direct services are available for children and youth with disabilities, as well as families, professionals, and other organizations that support them to include a range of activities such as:

- *Working with families caring for children and youth with disabilities from birth to 26 years of age.*
- *Helping parents to effectively participate in their child's education and development.*
- *Partnering with professionals and policy makers to improve outcomes for all children with disabilities.*

Visit the website and learn about their parent support websites to include links to:

- *Branch Military Parent Technical Assistant Center (MPTAC) – building the capacity of parent centers to provide effective services to military parents of children with disabilities in military families.*
- *Native American Parent Technical Assistant Center (NA PTAC) – building the capacity to provide services to Native American parents of children with disabilities, as well as youth with disabilities, in an effective and culturally-responsive manner.*
- *Center for Parent Information and Resources (CPIR) – Funded through the Office of Special Education Programs (OSEP) at the U.S. Department of Education, supports the Parent Center network and the role that Parent Centers play in educating parents and improving outcomes for children with disabilities.*

www.parentcenterhub.org



SHIELD HEALTHCARE: A medical supply company accredited in 2007 by the Community Health Accreditation Partner's (CHAP) Board of Review. Shield HealthCare provides a comprehensive website to consumers and the caregiving community, to include families and providers. Originally established in 1957 as a specialty pharmacy, the company provides products and services for the home healthcare market. Beyond their product line, families can discover a broad array of resource to support them under the Community tab, as they seek to understand and navigate a diagnosis or specialized strategy to include blogs, webinars, and newsletters. Check under the *Services* tab and learn about how the insurance billing services, relative to TRICARE, may benefit you and your family. Peruse the website and the labeled tabs to discover the community of support available for individuals with special needs and their caregivers within the digital pages.

www.shieldhealthcare.com



SMART KIDS WITH LEARNING DISABILITIES: Offers a comprehensive website and blog, as well as a free e-newsletter, articles and regional programs. Their mission is to educate, guide and inspire parents of children with learning disabilities or ADHD. The organization, founded by Jane B. Ross, M.S., a former publishing executive and consultant, was inspired by her determination to help other parents who find themselves parenting a child with learning disabilities. The aim is to help parents realize their children's significant gifts and talents. In addition to getting informed through their free e-newsletter, another way to stay informed and get involved is to send a question to Ask the Experts, which will be answered by a member of the Smart Kids Professional Advisory Board. For residents of Connecticut, check out the website to discover local chapters that have started and discover the opportunities available in the vicinity.

www.smartkidswithld.org



SPECIAL NEEDS RESOURCE PROJECT (SNRP): Helps parents of children with chronic health issues, disabilities and special needs get a jump-start in search of helpful information and resources, unique to their needs. The site includes a military section, resource links, newsletters, and much more. Navigation under the Military tab provides information to include:

- *Introduction: Special Needs and the Military Family*
 - *DEERS & ID Cards*
 - *TriCare Introduction*
 - *Early Intervention*
 - *Individual Case Management*
 - *Exceptional Family Member Program (EFMP)*
 - *TriCare Extended Care Health Option (ECHO)*
 - *Community Contacts Letters of Medical Sufficiency*
 - *Dependency Determination*
 - *TriCare Program Options*
 - *Housing Options*
 - *Family Support Services*
- www.snrproject.com



UNDERSTOOD FOR LEARNING & ATTENTION ISSUES: For families who are parenting children, ages 3-20, who are struggling with learning and attention issues. The website was founded by 15 non-profit organizations, under the operation and management of the National Center for Learning Disabilities. This site provides for a broad perspective, which one single organization may not be capable of providing on its own. The sponsoring organizations include:

- *Benetech*
- *Center for Applied Special Technology (CAST)*
- *Children's Health Counsel (CHC)*
- *Child Mind Institute*
- *Common Sense Media*
- *Emily Hall Tremaine Foundation*
- *Eye to Eye*
- *Great!Schools*
- *Learning Disabilities Association of America (LDA)*
- *National Center for Learning Disabilities (NCLD)*
- *New Profit*
- *Oak Foundation*
- *Poses Family Foundation (PFF)*
- *Reading Rockets*
- *Peter and Elizabeth C. Tower Foundation*

The goal of Understood is to help the millions of parents whose children, ages 3-20, are struggling with learning and attention issues. They strive to empower parents to understand their children's issues and relate to their experiences. With this knowledge, Understood looks toward providing parents the tools "to make effective choices that propel their children from simply coping to truly thriving." The tabs available provide for a wide variety of topics for parents and families to become empowered in their quest for knowledge and understanding, in order to put them on a direct path to support them in feeling more confident and capable, as well as less frustrated and alone. Support tabs include:

- *Learning & Attention Issues*
- *School & Learning*
- *Friends & Feelings*
- *You & Your Family*
- *Community & Events*
- *Your Parent Toolkit*

www.understood.org

SENSORY & MOVEMENT



FUN AND FUNCTION: A retail-based company specializing in sensory needs. The company found its roots and purpose in finding kid-friendly sensory tools that fit their family's needs. They share their purpose as one that is guided by their values of making kid-friendly, affordable, and making a real developmental and therapeutic difference in the lives of children. In addition to providing a marketplace for therapeutic and fun toys and tools, Fun and Function offers a free newsletter that provides information to educators and families to include sensory activities, guidance on subjects ranging from how to reduce sensory meltdowns, vacation friendly sensory tools, and much more. Additionally, they provide a quick link to resources on their home page to include such links as:

- *Self-Regulation Tools*
- *Tips from Pediatric Therapists*
- *School Tools*
- *Blog*
- *Sensory Activity Guide*
- *Checklist for Therapist Recommendations*

www.funandfunction.com

SPEECH/LANGUAGE IMPAIRMENT



THE NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD): Part of the National Institutes of Health (NIH). The organization conducts and supports research in the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language. Under the *Health Info* tab, there is a wealth of information and links to include:

- *Hearing, Ear Infections and Deafness*
- *Balance*
- *Voice, Speech, and Language*
- *Taste and Smell*
- *Información en español*
- *Statistics*
- *Health Resources*
- *Clinical Studies*

Click on the Free Publications link to discover an array publications covering the following topics, plus many more areas pertaining to deafness and other communication disorders:

- *ASD: Communication Problems in Children*
- *Specific Language Impairment in Children*
- *Speech and Language Developmental Milestones*
- *Stuttering*

www.nidcd.nih.gov



SUPER DUPER PUBLICATIONS: A retail-based company specializing in speech/language materials and curriculum. Although

retail in nature, it also provides a *FREE Stuff* tab that contains free online, informational newsletters for teachers and parents. Due to the unique and wide-ranging needs of students with communication disorders, which inhibit so many aspects of living life, this recommended site will provide a perspective to parents that is often not readily available to those outside of the very specialized field of the speech/language pathologist. Free flyers for parents and teachers include:

- *How to use picture books to develop language skills, build social-emotional competence, and improve a child's ability to listen*
- *Identifying signs of disorders in language, speech sound, stuttering, voice quality, and hearing*
- *Special education disability categories*
- *Understanding dyslexia*
- *Preparing a child with special needs for the holiday season.*

www.superduperinc.com

VISUAL IMPAIRMENT, INCLUDING BLINDNESS



PATHS TO LITERACY FOR STUDENTS WHO ARE BLIND OR VISUALLY IMPAIRED: A resource, resulting from a joint project between Perkins School for the Blind and Texas School for the Blind and Visually Impaired (TSBVI)—combines resources and

expertise to support educators and families in their quest to provide literacy experiences for children who are blind or visually impaired. Helpful and informative links within this website are blogs, strategies, resources, events and webinars. A Path to Literacy Newsletter is available. Readers can browse by topic to discover areas of need to include:

- *Auditory Strategies*
- *Cortical Visual Impairment (CVI)*
- *Dual Media*
- *English Language Learners*
- *Learning Media Assessment*
- *Multiple Disabilities*
- *Braille*
- *Deafblind*
- *Emergent Literacy*
- *General Literacy*
- *Math Literacy*

www.pathstoliteracy.org

ABOUT THE AUTHOR:



Angela Shaw is a special educator who synthesizes her diverse education and experience to collaborate with families and staff, in order to promote success and encourage the students in her care to be life-long learners. Her publishing focus is on special education topics. Shaw's son-in-law is an active duty U.S. Coast Guard. Shaw and her husband spend much of their free time adventuring to various PCS locations and enjoying every possible minute with their son-in-law, daughter, and baby grandson.



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FIND information, CONNECT with others & SHARE ideas.

Disability.gov





LET ME WIN

BY MEAGHAN MCHUGH, MPH, PHD

Ask an individual with intellectual disabilities (ID), who is also a Special Olympics athlete, to finish the statement, “Let me win”, you will undoubtedly hear the reply, “...but if I cannot win, let me be brave in the attempt.” This oath speaks to the strength and competitive spirit of the 5 million Special Olympics athletes all over the world. Unfortunately, some of our athletes’ battle more than just an opponent,

many individuals with ID suffer from undetected health concerns and inadequate access to health services. Barriers to access to care include limited numbers of health care providers willing and able to provide care, as well as health facilities and health information that have not taken into consideration the needs of individuals with ID. This is where Healthy Athletes comes in.



SCREEN STARS: (Opposite page) An athlete attends a Fit Feet Healthy Athletes Screening at the 2017 World Winter Games. (Above, left to right) Special Olympics Southern California basketball player Timothy Riemann gets a hearing examination at Healthy Hearing; Michelle Falcon, a swimmer from Mexico, has her vision examined at Opening Eyes.

SPECIAL OLYMPICS HEALTHY ATHLETES PROGRAM

Since 1997, Healthy Athletes has offered more than 2.1 million person-centered health screenings in over 135 countries around the world. The program is dedicated to providing appropriate health services and health education to Special Olympics athletes while changing the way health systems interact with people with ID. The overall goal of Special Olympics Health, made possible by the Golisano Foundation, is to reach a 'tipping point' so that all indi-

viduals with ID have access to quality health services and programs. Specifically, Special Olympics seeks to increase access to health care for 11 million people with ID by 2020 ("11 by 20"). Special Olympics has several strategies to reach this goal, one of them is Healthy Athletes.

UNDETECTED HEALTH CONCERNS

Individuals with ID are often at greater risk for chronic health issues such as diabetes.^{1,2} Through Healthy Athletes, health professionals are trained to work with ath-

letes, to use effective communication techniques, and to create a more welcoming space for patients with ID. During the Special Olympics USA Games in Seattle, Washington (July 2018), 1,762 athletes received at least one health screening with most athletes receiving 4 of the 7 screenings offered (Healthy Athletes conducted 7,125 health screenings in total). The screenings uncovered some concerning statistics, including that 42% of the participating adults with ID screened for height and weight (BMI) were found to be obese.³

HEALTHY ATHLETES IS COMPRISED OF 8 DISCIPLINES THAT FOCUS ON A DIFFERENT ASPECT OF AN ATHLETE'S HEALTH

Fit Feet: A program to help alleviate treatable and preventable conditions by evaluating problems of the feet, ankles and lower extremity biomechanics.

FUNfitness: A physical therapy event that examines for flexibility of hamstring, calf, shoulder rotator and hip flexor muscles; functional strength of the abdominal and lower extremity muscles, and for balance.

Health Promotion: (BMI, Blood Pressure, Bone Density, Healthy Habits, and Tobacco Avoidance): This discipline uses interactive educational tools and displays, motivational literature and demonstrations to raise the awareness of Special Olympics athletes about the need to improve and maintain an enhanced level of wellness and self-care.

Healthy Hearing: Provides free hearing screenings and other medical services, including ear wax removal, swim molds, hearing aid maintenance and minor repairs.

Opening Eyes: Provides free eye assessments, prescription eyewear, sunglasses and sports goggles through a 12-station vision evaluation.

Special Smiles: Provides comprehensive oral health care information, dental screenings and instructions on correct brushing and flossing techniques.

Strong Minds: Offers interactive learning activities focused on developing adaptive coping skills to help athletes develop active strategies for maintaining emotional wellness under stress, such as thinking positive thoughts, releasing stress and connecting with others.

MedFest: Provides a physical exam that all athletes need prior to participating in Special Olympics sports. Screenings assess blood pressure, temperature, pulse, height, weight, body mass index, vision, hearing, medical history, potential medication side effects and general physical health.



PHYSICAL ACTIVITY MY GOAL: Become a better athlete and healthier by enjoying physical activity outside of my sports practice.

GETTING STARTED

- List the reasons you want to get active
- Write down active things you like to do
- Pick something you will want to stick with
- Find some buddies to exercise with
- Schedule regular time to do it
- Start slowly, start small

PHYSICAL ACTIVITY IS ANYTHING YOU DO THAT MAKES YOU MOVE. IT'S EASY TO FIT PHYSICAL ACTIVITY INTO YOUR EVERYDAY

What do you like to do to be more active?

LIMIT YOUR SITTING AND SCREEN TIME

How: more, all less, everyday!

BEING MORE ACTIVE MAKES US HEALTHIER

- Improves sleep
- Lowers blood pressure
- Reduces anxiety
- Improves mood
- Strengthens bones
- Helps manage weight
- Increases energy
- Reduces brain power
- Helps manage weight
- Increases energy

PICK ACTIVITIES THAT IMPROVE YOUR...

Strength
Flexibility
Endurance
Balance

Remember to stay hydrated when you exercise.

FRUITS AND VEGETABLES MY GOAL: Eat at least 5 fruits and vegetables every day.

FRUITS AND VEGETABLES ARE IMPORTANT BECAUSE...

- They give your body important vitamins, minerals and energy needed for good health.
- Provide energy for your sport
- They are colorful and taste good
- You can grow at school, home or in your community

TIP: Fresh, local and in season fruits and vegetables are the best!

IT'S EASY EVERY DAY

- Make half my plate fruits and vegetables
- Include fruit at breakfast
- Include a salad for lunch and dinner
- Eat a rainbow of colors
- Add vegetable to soups, broth and sandwiches and other foods
- Plant a vegetable or fruit garden at home or in your community

IT'S EASY AT SPORTS TIME

- Bring cut-up vegetables or fruit or a quick healthy snack to your practice
- For crunchy foods, try apple slices, small carrots, celery sticks, or snap peas
- Don't forget to bring fruits and vegetables to eat when traveling to your competitions

TRACK YOUR DAILY 5 FRUITS AND VEGETABLES IN YOUR FIT 5 TRACKING TOOL

LIVE AND LEARN: Athletes learn about incorporating physical activity into their lives, how to power their bodies with fruits and vegetables and how to stay safe from the sun at Health Promotion.

In the general population, it is estimated that about 35% of adults are obese.³ In addition, about 15% reported blood pressure rates that suggested hypertension with 18% of athletes arriving to compete with untreated tooth decay.

In addition to receiving high quality health screenings from trained professionals, Healthy Athletes offers individuals with ID appropriate health education. For example, within the Special Smiles venue, athletes are provided information on how to effectively brush and floss their teeth. They also have an opportunity to practice on models provided onsite. Within the Health Promotion venue, athletes have an opportunity choose to change one unhealthy behavior to a healthier one – such as eating five fruits and vegetables each day. Athletes are encouraged to choose from a variety of healthy behaviors, and they leave the venue with a card reminding them of their healthy choice.

During the health screenings within Healthy Athletes, it is not uncommon for medical professionals to find undetected and often preventable health concerns. For example, during the USA games, an athlete experienced mouth pain during the flight to Seattle. Upon arriving at the games, he was given antibiotics for an abscessed tooth (an abscessed tooth is a pocket of pus that can form in parts of the tooth due to a bacterial infection). Left untreated, an abscessed tooth can become serious and potentially life threatening. The athlete was screened at Healthy Athletes and, due to a partnership between Special Olympics and the Pacific Dental Foundation, the adult with ID received on-site dental care.

EMPOWERMENT

One of the most powerful aspects of the Healthy Athlete program is that during the screenings, individuals with ID have an opportunity (and a responsibility) to teach health professionals how to effectively work with adults with ID. This offers a chance for athletes to be teachers, to mentor the professionals, and to help shape the health message. For example, Special Olympics athletes have taught us to ask medical professionals to think about using simpler language and to slow the pace at which they speak. Athletes have an intellectual disability of varying degrees,

SUN SAFETY MY GOAL: Be Safe in the Sun

SUN SAFETY IS IMPORTANT

Because it protects us from...

- Skin Damage
- Skin Cancer
- Heat Stroke
- Heat Exhaustion

SUNLIGHT IS

The main source of **VITAMIN D**

BUT ALSO

The main cause of **SKIN CANCER**

- Our bodies need Vitamin D. We produce it mainly from sunlight. How much sun we need varies.
- Enjoying the sun safely and avoiding burners should help you get a good balance.
- Too much UV from the sun or tanning beds raises the risk of skin cancer.

USE A LAYERED APPROACH FOR SUN PROTECTION

- Sunscreen must be re-applied every 2 hours after swimming, sweating or towel drying.
- Wear a hat, sunglasses and protective clothing to shield skin and eyes.
- Use broad spectrum sunscreen with at least SPF 15 to protect exposed skin.
- Seek shade, especially during midday hours.

THINGS TO LOOK FOR IN A SUNSCREEN

WATER RESISTANT

Water resistant for at least 40 minutes of water and sweat. Water resistant for at least 80 minutes of water and sweat.

SPF 15 OR HIGHER

Broad spectrum

ENJOY THE OUTDOORS

Being physically active outside is healthy and can help prevent conditions like obesity. But it's important to be sun smart when playing and working outdoors.

but they are not all necessarily hard of hearing – speaking louder won't make them understand better. Athletes have taught us that they prefer to know what is going to happen during the health screening, so professionals are asked to describe what they will be doing and perhaps the next one or two steps that will follow. One of the clearest and most consistent messages athletes have taught us is not to speak down to them but to get to know them, smile and make the experience fun!

Special Olympics is open to individuals with ID of all ages starting in the early years (Young Athletes) and extending well into adulthood (78+ years young). The Healthy Athletes program is just one program offered by Special Olympics to support individuals with ID so they might be “brave in their attempt”. To find out more about how you can become involved in Special Olympics Healthy Athletes program, visit www.specialolympics.org/programs •

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References

- Balogh et al. Disparities in Diabetes Prevalence and Preventable Hospitalizations in People with Intellectual and Developmental Disability: A Population-Based Study. *Diabetic Medicine*. 32: 235-242. 201
- Bregholdt R, Eising S, Nerup J, Pociot F. Increased Prevalence of Down Syndrome in Individuals with Type 1 Diabetes in Denmark: A Nationwide Population-Based Study. *Diabetologia*. 49:1179. 2006
- Flegal, K. M., Carroll, M. D., Kit, B. K., & Ogden, C. L. (2012). Prevalence of obesity and trends in the distribution of body mass index among US adults, 1999-2010. *Jama*, 307(5), 491-497.



FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION



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78 2019 RESOURCES FOR MILITARY FAMILIES TOUCHED BY SPECIAL NEEDS

By Angela Shaw





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2019 RESOURCES FOR MILITARY FAMILIES TOUCHED BY SPECIAL NEEDS

BY ANGELA SHAW

Military service men and women have an ultimate responsibility of protecting and serving the people within our nation. Military-connected parents carry a dual responsibility of caring for their family—and our nation's populace. Military families are charged with balancing the challenges of the military lifestyle and responsibilities, in addition to the regular day-to-day, year-to-year, and decade-to-decade family and life experiences that civilian families face. Safeguarding the children of our military service members is one important way we, as citizens, can demonstrate gratitude, respect and honor to those who serve.

The foundation of military life is one of perseverance, adventure, and service to country. When families have a child with special needs, many typical activities of family life take on added complexity requiring a creative and flexible mindset. Our service men and women, along with their families, are up to the challenges of change and thinking out of the box—as they receive new orders that move them to new and different regions, hundreds and even thousands of miles from the support and love of their extended family, friends, and hometowns.

In addition to frequent relocations and international moves, service members and their families experience wartime deployment and its consequences, as well as numerous separations other than war. Nevertheless, military families touched by special needs, may discover that the journey of support, when meeting the challenges of their child's special need, can be fraught with hurdles and seeming roadblocks never before imagined. Whether the family is brand-new to a child's diagnosis or is a time-wizened veteran, raising a child with special needs, without doubt, adds an extra layer of challenge for military families.



insight needed, as arrival at a new duty station yields changes in conditions, availability of services and support personnel. As you march purposefully through this journey, remember these proactive and collaborative tips:

- *Share your child's history and ideas with the support team.*
- *Build positive relationships along the way*
- *Listen with an open mind to new ideas.*
- *Ask questions.*

Partnership between parents and those within the intertwined fields of medicine and education are essential components of a comprehensive system of support. Villaging up to support the military-connected child with special needs, encourages a comprehensive and open communication system that yields opportunities to proactively blend the expertise and experience of the healthcare and/or education professionals with the resourceful and unique voice of the parent. This powerful combination is just the spark to ignite and unite the creative juices of the professional and the parental caregiving team, in order to create an appropriately ambitious program that meets the unique needs of the child.

Educating oneself about a child's unique need is vital to bridging the gap between parent and professional. Discovering as much as possible about how to support a child with special needs, as well as keeping one's self strong and positive will go a long way toward increasing productivity, quality of life, and endeavoring upon a growth mindset. Remain calm and solution-focused through the processes of collaboration and initial phases of discovery. Oftentimes, best decisions develop when stepping back and mentally considering all options, in order to gain the perspective needed to plan constructively in a

cooperative approach. A proactive beginning can be established through recommendations, summarized below, shared by special needs mom and blogger Alethea Mshar, relative to six ways to cope with a difficult diagnosis for your child (2017):

1. *The diagnosis does not change who your child is. Rather this information*

can serve to empower the family through a deeper understanding and discovery of therapies or strategies specific to the child's needs.

2. *Seek out a community of people to meet your needs.*

3. *Confide in a friend who has enough distance from the situation that their grief will not distract them from providing you the encouragement and strength you need to cope with a diagnosis that you are struggling to accept.*

4. *Allow yourself to grieve. Accept and acknowledge your strong emotions. Realize that it is normal to go through, and even cycle back through the stages of grief, to include sadness, anger, denial and bargaining before accepting the reality of the news.*

5. *Get organized or make plans. Moving forward, restore your sense of power in a chaotic situation, in order to help you process and make sense of things.*

6. *Ask questions. Getting information from reliable sources can foster a sense of power through gaining knowledge and understanding.*

“AS MILITARY PARENTS WIND THEIR WAY THROUGH THE EMOTIONAL UPS-&-DOWNS OF RAISING A CHILD WITH SPECIAL NEEDS, REMEMBERING THAT THEY ARE THEIR CHILD’S MOST PRIZED ADVOCATE IS CRITICAL.”

As military parents wind their way through the emotional ups-and-downs of raising a child with special needs, remembering that they are their child's most prized advocate is critical. Therefore, staying the course by caring for themselves along with their child is essential. Enhancing knowledge about their child's unique needs and about the resources and tools necessary to support their child are the pathway that will serve to build parental resilience. Balance is an essential component in that journey.

As the family moves and grows, a practical solution is building a network of support along the way through creating a digital or hard copy notebook containing organizations, people, and notations of what has worked along the way. Creating this historical binder will provide the

Many children with special needs depend on a highly structured routine. According to the DoDEA (All About DoDEA Educational Partnership), military-connected children move up to three times more often than their civilian cousins do. In fact, on average, they

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move six to nine times between kindergarten and high school (DoDEA), causing their schedule to be interrupted much more often by major change of family relocation than children with special needs who are not military-connected. Fortunately, Military installations can support parents with the technical realities of the move. Military-specific websites provide a robust assortment of supports to assist with connecting to school liaisons at the new destination, as well as opportunities to review initiatives created to support our military-connected children with special needs. It is essential to plan ahead, in order to mitigate your child's anxiety and support them and

provide a smooth transition to their new community. Following some of these steps will pave a smoother road on this journey:

With your child:

- *Talk positively about the changes ahead.*
- *Keep a calendar tailored to your child's unique need. Track the days and weeks together, as the change approaches.*
- *Share photographs and digital images of the new location.*
- *Together create a list and itinerary of ten places to explore when you arrive.*

With professionals:

- *Within an appropriate time line, let your child's teachers,*

ROBUST RESOURCES: A SNAPSHOT

Military-connected families have a robust range of resources available to them within their branch of service. These summaries contain an examination of three military-specific resources designed to support the military family touched by special needs as they maneuver through the perpetual shifts characteristic to military life.

dodea

DEPARTMENT OF DEFENSE EDUCATION ACTIVITY

DEPARTMENT OF DEFENSE EDUCATIONAL ACTIVITY

The DoDEA is charged with providing high-quality education for military-connected children domestically and overseas. Explore this website at www.dodea.edu where their mission of educating, engaging and empowering military-connected students to succeed in a dynamic world is shared. One of only two federally-operated school systems, the DoDEA is responsible for ensuring that all school-aged children of military families receive quality education through coordinating and managing pre-kindergarten through 12th grade education programs on behalf of the Department of Defense (DoD). The DoDEA is globally positioned with 164 accredited schools in 8 districts located in 11 foreign countries, 7 states, Guam and Puerto Rico. DoDEA's schools are divided into three geographic areas to include Europe, the Pacific, and the Americas. All DoDEA schools are currently noted to be 100% accredited and in good standing with their regional accrediting agency.

Connecting to the website will provide access to resources and information to a wide variety of audiences, to include military parents and students, as

well as military or Department of Defense (DoD) parents and students. In addition to the basics of school enrollment, school calendars, immunization requirements, transportation, student meals, curriculum and graduation requirements, parents can learn about a variety of other education-based services to include:

- *Special education, which includes early intervention, education and related services, as well as DoDEA overseas-related services through development of intervention services.*
- *Interstate Compact on Educational Opportunity for Military Children, which addresses key educational transitions issues encountered by military families of enrollment, placement, attendance, eligibility, and graduation.*
- *Communications such as parent guides, press releases, and multimedia clips.*



THE EXCEPTIONAL FAMILY MEMBER PROGRAM

The EFMP takes on the task of helping families navigate the medical and educational system, in order to ensure peace of mind about the family mem-

ber's care (Military OneSource, 11/28/2018). It is mandatory within the Army, Navy, Marines, or Air Force, that a dependent with special needs, whether a spouse or a child, be enrolled in the Exceptional Family Program. Each military service branch, within the Department of Defense, has EFMP resources to connect with, in order to ensure that service members are assigned to duty stations where their military-connected family member can be addressed, particularly relative to specialists that may not be available in all duty stations (NMFA, 12/11/2018). Critical aspects of assignment coordination are provided by EFMP, in order to support the military family in maneuvering the military medical system, as well as provide guidance with specific aspects of the special education system. A quick overview of coordination services provided by EFMP includes (Military One Source, 11/28/2018):

- *Identification and enrollment of family members with special medical or educational needs.*
- *Discovery of services available at the present or future duty station.*
- *Support with information, referrals and non-clinical case management to access services.*

Three avenues of entrance are available to get started on the road toward peace of mind and quality of life that

physicians, therapists and other care-giving professionals that work with your child know that you are moving.

- Request copies of all evaluations, assessments, reports, IEPs and related school documents.
- Send copies of all records to your child's new school.
- Connect with new teachers, case carrier and/or related service providers, in order to begin proactively building a collaborating partnership within your child's learning community.
- Request copies of any medical records needed for the transition.
- Request referrals to physicians in your new location.

- Do NOT pack medical or educational records. Keep all records with you throughout the move.

In addition to our nation's special education law entitled *The Individuals with Disabilities Education Act (IDEA)*, military-connected families have a robust range of resources available to them within their branch of service. Discover some of these opportunities through the quick snapshot presented below. These summaries contain an examination of three military-specific resources designed to support the military family touched by special needs as they maneuver through the perpetual shifts characteristic to military life.

EFMP will afford the personal home-front of each military family (Military One Source, 11/28/2018):

- Communicate with local installation's Military and Family Support Center.
- Obtain paperwork from the EFMP medical point of contact at the local military treatment facility.
- Contact Military OneSource and ask for a referral to a special needs consultant.

According to Military OneSource (11/21/2018), Special Needs Consultations can provide guidance across a multitude of circumstances with licensed consultants at the helm. EFMP Resources, Option and Consultations (ROC), provides enhanced support for families with special needs and connect the military-connected family with a wide variety of subject matter expertise in education, the military health care system, TRICARE coverage, state and federal programs and more (Military OneSource, 11/21/2018).



SCHOOL LIAISON PROGRAM

School Liaison Program coordinates and assists military parents of school-aged children with educational opportunities and information to succeed in an academic environment. School Liaison Officers (SLO) represent, inform and assist Commands, coordinates with local school systems and forges partner-

ship between the military and schools (DODEA, 8/09/18). According to the U.S. Department of Defense Educational Activity (DODEA), the goals of this program and the SLOs are to (8/09/18):

- Identify barriers to academic success and develop solutions.
- Promote parental involvement and educate local communities and schools regarding the needs of military children.
- Develop and coordinate partnerships in education.
- Provide parents with the tools they need to overcome obstacles to education that stem from the military lifestyle.

Liaison Directories are available within each branch of the military. The DoDEA (8/09/18) provides an overview of the School Liaison Program and a downloadable guide specific to that branch at

www.dodea.edu/Partnership/schoolLiaisonOfficers.cfm

ARMY: Each installation has an active School Liaison Officer program. The Army SLO serves active Army service members, National Guard/Army Reserve/Accessions Commands and geographically dispersed families within a one-hour distance of their installation.

MARINE CORPS: School Liaisons (SLs) support transitioning families in obtaining educational information and assistance from local school districts. The role of the USMC SL is noted to be very comprehensive and adapted to the needs of the community at each installation.

NAVY: A K-12 support to military families through Child and Youth Education Services at all major Navy installations is being implemented for the families of service men and women.

AIR FORCE: Within the Air Force, each base has a point-of-contact (POC) for local military child education matters. This POC advocates for the educational needs of military children, assists Airmen and families with information and referrals regarding local school districts and other education options to include home schooling, private schools, charter schools, and cyber schools. Additionally, a communication link with inbound or outbound family members for educational issues is ensured.

COAST GUARD: Family Resource Specialists (FRS) and/or Child Development Service Specialists (CDSS) are available at each Health, Safety & Work-Life – Regional Practice to assist Coast Guard service members and their families with school-related issues.

Parents are a vital member of their child's IEP team and other professionals that support their child with special needs. Parents have expert knowledge and understanding of their child that can have a positive impact to solution-focused teams. Connecting with military resources, reaching out to helpful supports, and increasing knowledge about a child's special needs, go a long way toward increasing positive outcomes before, during, and after the transition.

A COMPILATION OF WEB-BASED RESOURCES TO EMPOWER AND EDUCATE THE MILITARY FAMILY TOUCHED BY SPECIAL NEEDS

In order to provide a comprehensive list of supports to meet the needs of today's military family, resources for children and adults with special needs are encompassed within the following guide. Further, military and civilian supports and resources are included, due to the duality of the military family and the varying needs of children with a profile unique to each child and their family.



AUTISM CARE TODAY (ACT): A national non-profit organization. ACT strives to provide necessary services so that each child with autism can reach his or her highest potential. Their mission is to raise awareness and provision of financial assistance to help defray out-of-pocket costs for families who cannot afford the autism treatments and other quality of life services their children require. Within the website, a list of resources is provided, as well as a blog to support military families who have children on the autism spectrum.

www.acttodayformilitaryfamilies.org



AMERICAN MILITARY FAMILIES AUTISM SUPPORT

(AMFAS): An award-winning Facebook page in support of military families, by military families. The page was founded in 2008. The mission of AMFAS is to provide news, information, community and support to military families that are dealing with autism spectrum disorder.

www.facebook.com/militaryautism



THE ARMED SERVICES YMCA (ASYMCA): A military non-profit designed to strengthen our military family providing programs and services to the service men and women of all five branches of the service: Army, Marine Corps, Navy, Air Force, and Coast Guard. The organization is a national member association of the YMCA of the USA and is exclusively focused on military families. ASYMCA operates more than 200 program centers across the nation. They work in coordination with the Department of Defense and installation commands, in order to identify gaps in programs and services. Additionally, ASYMCA has strong partnerships and works collaboratively with other

non-profits such as the YMCA, Operation Homefront, and the USO. ASYMCA provides support of military families through programs focused in three areas:

- Youth Development
- Healthy Living
- Social Responsibility

Navigate the *What We Do* tab to discover the powerful range of programs provided by ASYMCA to include honoring and recognizing heroes to providing camping opportunities to encourage healthy living as part of their core mission of strengthening our military family—and provide recreational and bonding opportunities for military-connected children and their families who have experienced multiple deployments. The wide array of programs offered also include child care, preschool, and no-cost, after-school programs tailored to the unique needs of military children. Operation Holiday Joy is an ASYMCA program that provides toys or food baskets at holiday time. Operation Ride Home is another holiday support provided to active duty junior-enlisted military and their families. The program provides financial assistance, in order to help families travel from their current duty station, back home around the country for the holidays. Discover the details of these programs and more at the ASYMCA website.

www.asymca.org



BLUE STAR FAMILIES: Offers a wide variety of programs to enhance military family life. The organization was founded in 2009 by military spouses. Blue Star Families' purpose is to empower military families to thrive by connecting them with their civilian neighbors, in order to create strong communities of support. A wide variety of programs are available within the digital pages of this website to include programs that enhance family life. Click the tab *For Mil Families* and discover a comprehensive array of opportunities to include family events supported through Blue Star Parks, Blue Star Museums, Blue Star Books, and Blue Star Theaters. Additionally, caregiving support, volunteer opportunities, and community connections are available for the military-connected family. Wellness support crosses the lifecycle of military service from enlistment to retirement and into Veteran status. Caregiving resources are geared to support of those giving care to their veteran or their service

member. Blue Star Families invites you to download the Connected Caregiver's Tool kit to increase your knowledge and awareness of issues surrounding caregiving and learn about resources to meet the challenges.

www.bluestarfam.org



ELIZABETH DOLE FOUNDATION: Founded by Senator Elizabeth Dole in 2012 to support military caregivers. Dole witnessed the hardship of caregivers, while she was caring for her husband, Bob Dole, during an extended stay at Walter Reed Hospital. The foundation's website shares their mission: "Strengthen and empower America's military caregivers and their families by raising public awareness, driving research, championing policy, and leading collaborations that make a significant impact on their lives."

Within this website, discover a link to HiddenHeros.org, which is a major campaign of the Elizabeth Dole Foundation to bring attention to untold stories of military caregivers and seeks solutions to the challenges and long-term needs. Within the link to HiddenHeros.org, you will discover stories of military caregivers, a directory of resources, and an online support group that offers a positive place for military caregivers of all eras.

www.elizabethdolefoundation.org



FULL CIRCLE HOME: A not-for-profit organization that connects deployed service members with their loved ones across the country and on bases around the world. Full Circle Home helps service members to send their holiday gifts and loves notes to their Heros at Home. The organization relates that this connection provides encouragement and support for both those at home and those overseas, because the whole family is affected by a deployment. Under *Troop Sign-Up* tab there is a reminder to those who will be deployed in 2019 to have chaplain, FRO, FRG or Ombudsman make contact WELL BEFORE deployment.

www.fullcirclehome.org



HEARTS OF VALOR: Hearts of Valor is a non-profit organization with a mission to honor the service and sacrifice of the people who care for our nation's wounded, ill or injured warriors through a community of support, based upon a foundation of empathy and mutual understanding. Member benefits include:

- **Retreats:** Hosted in cities around the United States, the retreats provide an opportunity to come together and gain

additional tools for successful care-giving, at no cost.

- **Support Groups:** Peer-facilitated by volunteer caregivers. The goal of each group is to improve the lives of the individuals who are caring for wounded warriors.
- **Online Forums:** Virtual communities that provide online discussion forums that are private and protected. Members can ask questions, share struggles, successes and encourage each other.
- **Facebook:** www.facebook.com/heartsofvalor is a place where current events, contests and success stories can be accessed.
- **Newsletters:** Electronic newsletter is sent out monthly and contain new caregiver information, upcoming events, contests, and success stories.

Under the *Forums* tab, you can apply for membership or sign into your existing account. Discover qualifying criteria for membership at the website under the *Member Benefits* tab or locate a local support group under the *Support Groups* tab.

www.heartsofvalor.org



THE MILITARY CHILD EDUCATION COALITION: Shares their mission: "To ensure inclusive, quality educational opportunities for all military and veteran-connected children affected by mobility, transition, and family separation." Within this website, military-connected families can access an array of resources specific to:

- *College, Workforce, and Life Readiness*
- *Exceptional Needs*
- *Policies and Initiatives*
- *Transition*
- *Publications*

A link to the Military Child Education Coalition store is available for families to shop online for a multitude of products to support them in their endeavor to provide quality education programs. Topics range from military culture resources to exceptional needs resources.

www.militarychild.org



NATIONAL MILITARY FAMILY ASSOCIATION (NMFA): Shares within their mission statement that they are the "go to" source for Administration Officials, Members of Congress, and key decision makers when they want to understand the issues facing military families. NMFA reports that they have "boots on the ground" with military families and understand better than anyone that "military families serve, too." In addition to a varying amount of military family specific topics, the tab *Info + Resources* provides a nice overview of the Exceptional Family Member Program (EFMP), which serves the essential function of coordinating the assignment process to ensure families



OVER AND ABOVE: Military families are charged with balancing the challenges of the military lifestyle and responsibilities, in addition to the regular day-to-day, year-to-year, and decade-to-decade family and life experiences that civilian families face.

touched by special needs are sent to locations that provide access to adequate medical or educational resources. Additionally, a link of the Interstate Compact on Educational Opportunities for Military Children is available within this website. Of further note is the link *Kids + Operation Purple* that provides an overview of programs available to military families and kids to include:

- **Operation Purple Camp:** A free week of summer camp where kids can connect with other kids like them.
- **Family Retreats:** Opportunities to spend quality time reconnecting with family after deployment, separation or during a time of transition.
- **Healing adventures:** A free three-day experience that offers rediscovery of family-fun and togetherness after an injury.
- **Buddy camp:** An opportunity to share one-on-one bonding and resiliency-strengthening camp for children ages 5-8 and their adult “buddy.”

www.militaryfamily.org



MILITARY INTERSTATE CHILDREN'S COMPACT COMMISSION (MIC3):

Eases the educational challenges that military children encounter, and supports uniform treatment as they transfer between public schools in member states. The Compact was developed in 2006 and has been adopted by all 50 states, the District of Columbia and the Department of Defense Education Activity. The mission includ-

ed in the website states, “Through the Interstate Compact, MIC3 addresses key educational transition issues encountered by children of military families.” The vision expressed is, “Successful Educational Transitions.” The values represented by the MIC3 website include:

- *Doing the right thing for children*
- *Resolving issues fairly*
- *Transparency in all we do*
- *Respect for all*
- *Commitment to make a difference*

In addition to newsletters and articles highlighting the compact, under the *News & Media* tab, parents can find information relative to their state and a Guide for Parents and Schools, under the *Parent* tab. A parent flow chart to support contact with School Liaison Officers (SLO), MIC3 State Commissioner, and MIC3 National Office, is offered under the *Parent* tab. Under the *Resources* tab, State Statutes, Compact rules, including a section on special education services, useful links, and publications can be accessed.

www.mic3.net



OUR MILITARY KIDS:

A nonprofit organization that endeavors to support military connected children to cope with stress and anxiety. This organization is for families of deployed National Guard and Reserve service members, as well as children of wounded veterans from all services branches. Roam the site to discover how to apply for a grant up to \$500 to sup-

port children while their parent is recovering or serving overseas. This program is for children and youth at least 5 years old, but no older than 18/19 years. Children will become ineligible once they have graduated from high school. Explore the flyer and Frequently Asked questions document, within the website, to discover how parents can apply for a grant for such extra-curricular activities as sports or fine arts, in order to nurture a sense of self-confidence and positivity, during a time of intense stress and anxiety. Additionally, click the Resources tab to discover an array of links to support military families, ranging from insurance and health care to shopping and discounts.

<https://ourmilitarykids.org>



MILITARY ONESOURCE: Shares their mission to connect you to your best MilLife. Within the comprehensive site, the military-connected family has access to an array of topics. Particularly relevant to parents who are raising children with special needs is the category of *Family & Relationships*, which includes topics of *Special Needs and Parenting & Children*. For military families searching for a great resource to support navigation through a wide range of military-focused topics, Military OneSource provides portal to Service-specific news, resources and social media.

www.militaryonesource.mil

MILITARY SPOUSE

MILITARY SPOUSE: A digital magazine featuring a masthead with the statement, “Simplify your crazy, wonderful military life.” In addition to the free digital magazine *Military Spouse*, there is a bounty of information available the military-connected family under tabs to include areas of:

- Life
- Employment
- Education
- Deals
- Moving
- Book Club
- Money & More

militaryspouse.com



NATIONAL RESOURCE DIRECTION: A resource website that connects wounded warriors, Service Members, Veterans, their families and caregivers to programs and services that support them. Access to services and resources is available at the national, state, and local levels to support recovery, rehabilitation and community reintegration. An array of resource categories can be linked to within this website across a range to include American Red Cross to Family and Caregiver Support.

nrd.gov



OPERATION AUTISM: A Resource Guide for Military Families reports that it directly supports U.S. military families touched by autism and autism spectrum disorders. Introduction to autism, a guide for life journey with autism, and a ready reference for available resources, services, and support are featured within the website. The sponsorship and maintenance of the website is through Organization for Autism Research (OA), and funding support of the American Legion Child Welfare Foundation. The shared intent of OAR includes:

- *Provision of military families touched by autism with access to quality evidence-based information about ASD.*
- *Identification of sources of treatment and support on and off base.*
- *Offering of tips for dealing with some of the unique challenges military life poses for military dependent children with autism and their families.*
- *Informing parents about their child’s educational rights and offering of some practical strategies for success in the classroom.*

www.operationautismonline.org



OPERATION HOME FRONT: A national nonprofit organization with a mission to build strong, stable, and secure military families so they can thrive—not simply struggle to get by—in the communities they have worked so hard to protect. Operation Home Front provides programs that offer:

- *Relief: Through Critical Financial Assistance and transitional housing programs.*
- *Resiliency: Through permanent housing and caregiver support services.*
- *Recurring Family Support: Through programs and services throughout the year that help military families overcome short-term bumps in the road.*

www.operationhomefront.org



PARTNERSHIP FOR ACTION, VOICES FOR EMPOWERMENT (PAVE): Provides partnership for military parents of children or young adults with a disability or special healthcare need. In addition to the various links to resources, articles, and newsletters, programs of PAVE are introduced to include Specialized Training of Military Parents (STOMP). STOMP provides in-person workshops and one-hour webinars throughout the US and overseas for military families and military personnel.

wapave.org

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STOMP: SPECIALIZED TRAINING OF MILITARY PARENTS:

A Facebook community that connects military families, resources, and events. Noted on the *About* page is the mission statement: “STOMP, a parent-directed project, exists to empower military parents, individuals with disabilities, and service providers with knowledge, skills, and resources so that they might access services to create a collaborative environment for family and professional partnerships without regard to geographic location.”

facebook.com/STOMPproject



TRICARE: The official website of the Defense Health Agency (DHA), a component of the Military Health System. In addition to providing an overview of TRICARE plans, costs, and benefits, guidance about Special Needs is available under the *What's Covered* tab. There you can download a fact sheet Extended Care Health Options (ECHO), which provides services for active duty family members with special needs. Navigate the *Plans & Eligibility* tab to learn about which TRICARE plan fits you and your family's needs.

www.tricare.mil



ZERO TO THREE : Supports military families in an endeavor to increase awareness and collaboration throughout the military community in support of parents and professionals, to increase effectiveness in the care of very young children and their families. Within the website, families and professionals have access to an array of information to include a series to build the resilience of young children and their families through the specialized lens of the military family. In addition to developmental topics of ages and stages, within the military pages, Zero to Three provides topics relative to Early Intervention. The “Over There” Activity Book provides a support for young children for parent or caregiver to download and create to reassure when a parent is on deployment. Additionally, information about a new app launched in September 2018, is available on the website to support connection between military-connected babies, toddlers and their parents when their parents work takes them away.

The mission statement of Zero to Three encompasses a broad goal and, therefore, drives a comprehensive wealth of information across the website within the military domain, as well as the realm of the general public. Links to the broad range of topics listed below can be accessed on the home page:

- *Early Development & Well Being*
- *Early Learning*
- *Parenting*
- *Policy & Advocacy*

Their mission is to ensure that all babies and toddlers have a strong start in life. They envision a society that has the knowledge and will to support all infants and toddlers in reaching their full potential. They note that during the first three years of life, emotionally nourishing relationships lay the foundation for lifelong health and well-being. By supporting the caring adults who touch the lives of infants and toddlers, they hope to maximize the long-term impact in ensuring all infants and toddlers have a bright future.

www.zerotothree.org

ABOUT THE AUTHOR:



Angela Shaw is a special educator who synthesizes her diverse education and experience to collaborate with families and staff, in order to promote success and encourage the students in her care to be life-long learners. Her publishing focus is on special education topics. Shaw's son-in-law is an active duty U.S. Coast Guard. Shaw and her husband spend much of their free time adventuring to various PCS locations and enjoying every possible minute with their son-in-law, daughter, and baby grandson.

References

- Military OneSource. (Nov. 21, 2018) Specialty Consultations: Special Needs. Special Needs Consultations. Retrieved 11 December 2018 from <https://www.militaryonesource.mil/confidential-help/specialty-consultations/special-needs/special-needs-consultations>
- Military OneSource. (Nov. 28, 2018) Family & Relationships: Special Needs. The Exceptional Family Member Program: For Families with Special Needs. Retrieved 11 December 2018 from <https://www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member/the-exceptional-family-member-program-for-families-with-special-needs>
- Mshar, A., (1/09/2017). 6 ways to cope with a difficult diagnosis for your child. (Grow Community with Shield HealthCare). Retrieved December 04 2018 from www.shieldhealthcare.com.
- National Military Family Association (NMFA): Info + Resources. EFMP + Special Needs. Retrieved 11 December 2018 from <http://www.militaryfamily.org/info-resources/efmp-special-needs.html>
- U.S. Department of Defense Education Activity (DoDEA) (retrieved 12/9/2018 from <https://www.dodea.edu>). All about DoDEA educational partnership.
- U.S. Department of Defense Education Activity (DoDEA) (retrieved 12/9/2018 from <https://www.dodea.edu>). School liaison officers. Last modified: 8/09/18.

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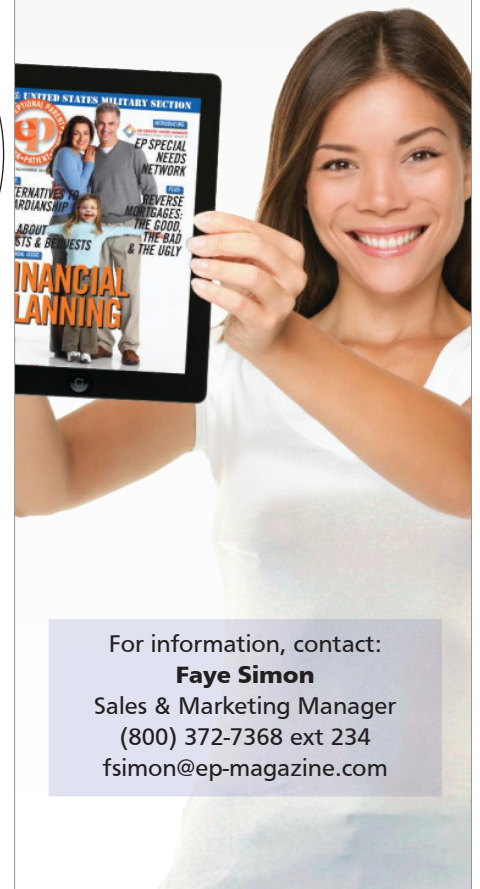


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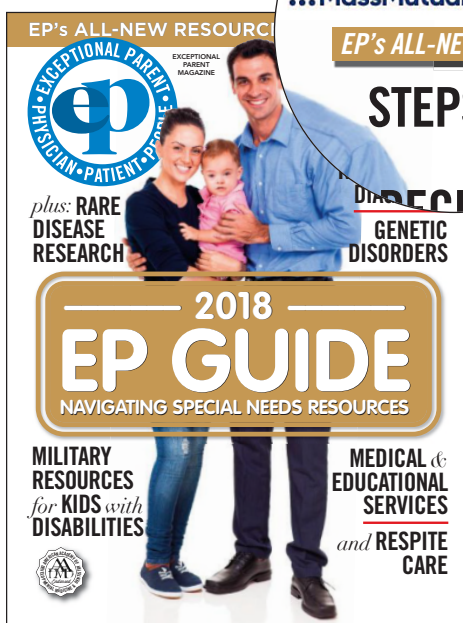


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