

PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
MAGAZINE
NOVEMBER 2024
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INSIDE:

**ABLE
ACCOUNTS
and
SPECIAL
NEEDS TRUSTS**

PLUS:

**PEOPLE WITH
DISABILITIES
SHOULD BE
ABLE to
GET MARRIED!**

MASSMUTUAL SPECIALCARE:

**CONSIDERATIONS
for SUCCESSOR
CAREGIVING**

ALSO • LIVING WITH DIABETES:

“LIVABETES”

FINANCIAL PLANNING ISSUE:

BENEFITS FOR MILITARY FAMILIES WITH SPECIAL NEEDS





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ON OUR COVER
Families raising children with disabilities face a variety of challenges and complexities in financial planning. Developing the right strategies now can ensure that loved ones have the assistance they will need in every aspect of their life. EP's Annual Financial Planning Issue offers practical advice and valuable resources to help overcome these challenges. *Coverage begins on page 15.*

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Planning for Success

Developing the right strategies now can ensure that loved ones have the assistance they need in every aspect of their life.

Financial planning is difficult for everyone, but families raising children with disabilities face unique challenges that demand strategies to address a variety of complexities. EP Magazine's Annual Financial Planning Issue features several helpful articles that shed light on the planning process.



Features this month include articles on attaining the proper supports and services for a student who may be struggling academically, as well as a suggested approach to parenting a child with autism from a young man who lives with autism.

Comments, suggestions, and questions are always welcome. If you are not receiving the monthly newsletter nor email from news@epmagazine.com, email me at

Veterans Day is celebrated in November, and our cover story, "Benefits for Military Families with Special Needs," summarizes federal and state programs committed to providing additional assistance for families with special needs children of any age.

As the sponsor of our November issue, MassMutual Special-Care contributes an article by program Head Kelly Piacenti, CHSNC® entitled "Considerations for Successor Caregiving," with the goal of ensuring loved ones have the assistance they need in every aspect of their life.

In her article "Planning for the Future with an ABLE Account, Special Needs Trust or Both," certified elderlaw attorney Shana Siegel, Esq. explains that ABLE Accounts were originally developed as an easier, more affordable alternative to special needs trusts, but that they are, in fact, complementary tools.

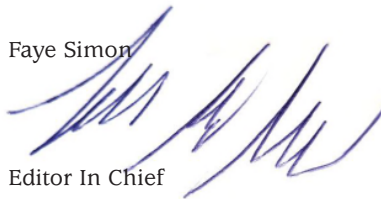
When medical expenses become too high for families to handle, starting a fundraising campaign can be a way to embrace the help that is available, both financially and emotionally, as your community rallies around your cause. Emily Progin details how to approach medical fundraising without jeopardizing your eligibility for asset-based assistance and state benefits.

Families raising children with disabilities face challenges in financial planning that demand strategies to address a variety of complexities.

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Faye Simon

Editor In Chief



THE EDITOR IN CHIEF'S DESK

Faye Simon is a certified pre-K-8 teacher with a wide range of educational experience. She has worked in deaf/blind and infant stimulation programs, taught K-2 in public schools, and was a Head Teacher and Parent Coordinator for Head Start. She is Founder and President of the volunteer-run IES Brain Research Foundation. Faye has been interviewed about EP Magazine and IES Brain Research Foundation multiple times including on: Mrs. D's Corner, SFN Dad to Dad Podcast, Oscar Mike Radio, Wreaths Across America Radio, Shana Siegel's Aging Answers, and Able Today Show.



Information and Support for the Special Needs Community

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WHAT'S HAPPENING

FRIENDLIER SKIES FOR EVERYONE: AIRPORTS ARE MAKING TRAVEL EASIER FOR PEOPLE WITH AUTISM

For people with disabilities, part of living a full life in their community includes being able to travel to faraway locations for both work and pleasure.

People with intellectual and developmental disabilities (IDD) are entitled to this piece of community participation—just like anyone else—and should be able to navigate air transit comfortably to experience the same opportunities as every other traveler.

People with autism and other IDDs often experience barriers to participating in air travel. Airports and airplanes can be overwhelming and full of unexpected and overstimulating variables, such as bright lights, noises, TSA security screening, and crowds. Too often, there is a lack of understanding among airport and airline staff—leading to confusion on how to handle accommodations or unexpected behaviors when a flier is overwhelmed or nervous about navigating the air travel process.

Combined, these barriers lead to hesitation and fear, inhibiting participation in air travel. As a result, people can miss out on new experiences and connecting with family members and friends that live far away.

The Arc's Wings for All program gives families and aviation professionals the confidence to take to the skies with ease by providing an airport "rehearsal," as well as a presentation on the air-



COME FLY WITH ME: A young traveler is greeted by a TSA worker during a Wings for All event while his parents look on.

craft features and in-flight safety protocols. Chapters of The Arc, local partners, and airport/airline/TSA personnel work collaboratively to design and carry out each Wings event.

Wings for All alleviates some of the stress that people with autism and other IDDs and their families experience when traveling by air by providing families with the opportunity to experience and learn about how their loved ones will react to different stimuli in the airport.

Wings for All gives airport, airline, TSA professionals, and other personnel the opportunity to observe, interact, and deliver their services in a structured learning environment—improving their disability competency and processes for accommodating all passengers who fly. Here are a few Participant Activities that occur during a Wings for All event:

- Check-in to receive boarding passes
- Pass through the TSA security checkpoint
- Wait in the boarding area
- Board an aircraft (that does not take off)

This special project, made possible by community partnerships and concerned local people, has made a real and lasting difference in the lives of so many people who are now confident to travel by air. Wings for All was created by Charles River Center, an affiliated chapter of The Arc, in collaboration with the Massachusetts Port Authority.

FRIENDLY SKIES : UPCOMING WINGS FOR ALL EVENTS

Wings for All holds dozens of Wings events each year. Check back often to see when new locations/dates are announced near you. Upcoming Events:

November 9: Dulles International Airport (IAD)

Registration Form: <https://secure.qgiv.com/for/wingsforall/event/wingsforall>


November 9: Dane County Regional Airport (MSN)

Registration Form: <https://fs30.formsite.com/wingsforautism/tjzbwtsw7d/index>

November 9: Dane County Regional Airport (MSN)

Registration Form: <https://fs30.formsite.com/wingsforautism/tjzbwtsw7d/index>

Don't see your city? Sign up to be on our alert list to receive an email notification when we come to an airport in your area! If you are looking for events, please visit this page: https://fs30.formsite.com/wingsforautism/sxgfcenf2/index?_gl=1*121bnt0*_ga*



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WHAT'S HAPPENING

DISABILITY RIGHTS GROUP CALLS FOR EXPANSION OF MEDICARE'S HOME HEALTHCARE COVERAGE

The Disability Rights Education and Defense Fund (DREDF) applauds Vice President Harris for recognizing the critical need to expand Medicare's home healthcare coverage and echoes the Center for Medicare Advocacy's strong support her proposed enhancement of Medicare coverage along with a call to better enforce existing Medicare home care benefits.

DREDF stresses that building on Medicare's currently limited coverage of home health and rehabilitation will strengthen our entire healthcare system as well as people with disabilities and families with longer-term care needs.

Right now, according to an AARP Public Policy Institute analysis, the median annual cost of care for most long-term services and supports exceeds both the median assets and household income of older adults. For disabled people and older adults, access to reliable, affordable home care is essential—not optional.

While Medicare traditionally does not cover long-term care, it does provide for short-term home health services and rehabilitation. However, current payment and administrative rules incentivize agencies to prioritize high-cost, short-term medical services over the kind of longer-term, less expensive home-based care that will allow people to safely and appropriately stay in their homes. This leaves too many without essential supports, forcing people into institutional care or left to navigate care needs alone – often with devastating consequences.

In addition, the proposal would expand Medicare to cover vision and hearing, and end a practice known as “estate recovery” when Medicaid recoups the costs of home care from the sale of decedents' homes and estates. “We have a unique opportunity,” said Silvia Yee, DREDF Policy Director, “to not only expand Medicare's coverage of home care but to build a system where every person who qualifies gets the long-term care they need and deserve – without gaps.”



BRINGING IT HOME: If enacted, this would be the first major expansion of Medicare since the Medicare Modernization Act of 2003 that added a prescription drug benefit to the program.

DREDF supports the Harris campaign in bringing this issue to the forefront. DREDF is ready to assist in designing policies that reflect the lived realities of people with disabilities, older adults, and their families.



SPECIAL THANKS TO



Special Fathers Network is a mentoring program for fathers raising children with special needs.

For more information please go to:
www.21stCenturyDads.org

Help 21CD gather research on families raising children with special needs by having them complete the **SFN Early Intervention Parent Survey**.



As a special thank you for completing the SFN EI Parent survey, 21CD will send you a complementary Great Dad Coin.



AFFORDABLE HOME CARE : WHAT CAN BE DONE NOW

1. Ensure home health workers deliver services Medicare already covers, preventing premature discontinuation of care.
2. Expand Medicare home care to cover long-term needs, so people aren't forced into nursing homes just because they need help at home.
3. Involve the disability community, advocate expertise, and other key stakeholders such as paid and unpaid care providers in planning new Medicare benefits, to create a range of home health policies that actually meet the real needs of people with disabilities and older adults.

WHAT'S HAPPENING

MISS DELAWARE TEEN USA VISITS CAPITOL HILL TO ADVOCATE FOR INDEPENDENT WORKERS

Miss Delaware Teen USA Kayla Kosmalski has served as an inspiration for young girls and women as a pageant winner advocating for others with Down Syndrome, and is now using her voice to share the benefits of direct selling with legislators.

At just 18, Kayla has become a successful independent entrepreneur with leading health and wellness company Plexus Worldwide, following in her mother's footsteps who also found success with the company while balancing her role as a mother to Kayla. Kayla recently went to Washington DC for the Direct Selling Association's annual Day on Capitol Hill, to meet with lawmakers, share her experiences as a businesswoman, and advocate for laws that benefit entrepreneurs like herself.

As a brand ambassador for Plexus Worldwide, Amy and Kayla Kosmalski built a successful independent health and wellness business based in their hometown of Middletown, Delaware. On September 25, 2024, Amy and Kayla traveled to Capitol Hill to meet with members of Congress representing Middletown about important issues affecting independent contractors.

When direct sellers meet face-to-face with their elected officials, members of Congress hear first-hand from their entrepreneur constituents about successes and challenges, including how their businesses are directly impacted by legislation and regulatory actions. The annual Direct Selling Day on Capitol Hill provides a national stage for independent workers to advocate for themselves with lawmakers.

"Kayla recently went to Washington to share her experiences as a businesswoman and to advocate for laws that benefit entrepreneurs like herself."

Kayla, an 18 year old high school graduate, is a remarkable individual with a 3.7 GPA and a passion for making a difference. She has excelled in various activities, from varsity cheerleading and competitive cheerleading to varsity swimming and theater.

Kayla's dedication led her to be selected as a Gold Cheerleader to represent Middletown High School at the prestigious DFRC Blue-Gold All-Star Game. Additionally, she has actively contributed to the 321foundation and made a significant impact as an advocate for individuals with Down syndrome, successfully lobbying for the passage of laws such as Kayla's Law, which empowers Americans with disabilities to achieve financial independence.

Beyond her advocacy work, Kayla has also pursued her interests in modeling and acting, and will soon be featured in the upcoming film *I Win*. Her achievements and determination have made her the first person with Down syndrome to represent Delaware as Miss Teen USA, a truly inspiring accomplishment.



DIRECT APPEAL: Plexus Ambassadors Amy and Kayla from Delaware (third from the left, top row and third from the left, bottom row) met with members of Congress on Capitol Hill to educate and advocate for independent business owners.

Direct Selling Day on Capitol Hill was hosted by the Direct Selling Association (DSA), the national trade association for direct selling companies, of which Plexus is a proud member. Plexus, one of the largest direct-selling health and wellness companies in the world, is supported by hundreds of thousands of independent business owners worldwide.

ABOUT PLEXUS WORLDWIDE:



Plexus Worldwide, LLC, is a leading health and wellness company featuring products that enable people to improve their lives and well-being. With hundreds of thousands of independent business owners ("Brand Ambassadors") worldwide, Plexus is among the top 30 largest direct sales companies globally, according to Direct Selling News. Plexus products and opportunities help individuals meet their health and financial goals. For more information about the company, visit www.plexusworldwide.com

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Nassan's Place can't stop the diagnosis, but we can help the families affected by it!



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www.nassansplace.org

WHAT'S HAPPENING

NIH DESIGNATES PEOPLE WITH DISABILITIES AS A POPULATION WITH HEALTH DISPARITIES

New designation, research program and update to NIH mission are actions to ensure inclusion of people with disabilities.

A new National Institutes of Health program will support studies to understand how ableism – discrimination and social prejudice against people with disabilities – contributes to health disparities. The effort, funded by NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Eye Institute, and Office of Behavioral and Social Sciences Research, will also support research on how to counter the negative health effects of ableism.

Eliseo J. Pérez-Stable, M.D., director of the National Institute on Minority Health and Health Disparities (NIMHD), designated people with disabilities as a population with health disparities for research supported by the National Institutes of Health. "This designation recognizes the importance and need for research advances to improve our understanding of the complexities leading to disparate health outcomes and multilevel interventions," said Dr. Pérez-Stable. "Toward this effort, NIMHD and other NIH institutes launched a new research program to better understand the health disparities faced by people with disabilities who are also part of other populations designated as having health disparities."

People with disabilities often experience inaccessible medical offices and equipment, biased medical decision-making, limited services, less aggressive treatment, and refusal of certain types of care. The new NIH program will fund 10 projects, totaling nearly \$30 million over 5 years, to examine the potential impact of ableism on pregnancy, childbirth, and postpartum outcomes among Medicaid patients with intellectual and developmental disabilities (IDDs), to help people with low vision access services and navigate barriers in the health care system, and to develop interventions to identify and overcome ableist beliefs and practices among caregivers, educators, and healthcare providers who care for children who are blind or visually impaired.



BETTER HEALTH FOR ALL: This designation marks an important step in advancing health equity for people with disabilities.

Other projects will seek to identify and reduce the effects of diagnostic overshadowing – the attribution of symptoms to disability rather than to a new medical condition, to investigate how ableism affects health outcomes in people with mobility disabilities, and to develop an online education program for obstetricians to help them avoid ableism and meet the health care needs of disabled pregnant people. "To the disability community, we hear you and thank you for sharing your lived experiences with NIH," said Acting NIH Director Lawrence A. Tabak, D.D.S., Ph.D. "This designation marks an important step in an agency-wide effort to advance health equity for people with disabilities which also includes updating the NIH mission statement to accurately reflect our goal of turning

scientific discoveries into better health for all, including people with disabilities." •

ing scientific discoveries into better health for all, including people with disabilities." •



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Shana concentrates her practice in the following areas:

- Special Needs Planning
- Guardianship
- Public Benefits
- Estate Planning
- Long Term Care Planning
- Trust and Estate Administration



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WHAT'S NEW ALL IN FOR FALL



HEDGEHOG'S FIRST AUTUMN

Practice sensory skills, hand-eye coordination and math skills by playing the Hedgehog Game. It's hedgehog's first autumn and he needs you help to gather all his tips. This innovative board game features a duel mode, where 1, 2 or 4 children race simultaneously to get their hedgehog all his wooden tips on the board by rolling dice and practicing their arithmetic. Whoever fills the holes first – or whoever pulls out all of the tips on the hedgehogs first – wins. Children can use

one or two dice to increase the fun and difficulty of this multiplayer game. This fun, fast-paced game can aid children's color perception, math skills and fine motor skills. Ideal for providing an early start on your child's STEM development, exercising his concentration and hands-on abilities. Perfect for home, school and travel.

FICCURYS
www.ficcurys.com

GLOVE PILOT

Make sure your hands are warm on chilly days! Getting winter gloves on when you have hands that don't do what you want can be tricky. The Glove Pilot helps you to guide your hands into your gloves. The glove pilot sits inside your gloves and the channels help to get your fingers into the fingers of your gloves. These glove pilots are also great for children – set them up the night before ready for the school

run on frosty mornings. Put wet gloves on the glove pilot and hang them up to dry so they are ready for the next day.

ACTIVE HANDS
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ADAPTIVE WINTER COAT

Designed with the needs of wheelchair users in mind, this coat has a long zip on the front that can be fully opened and a velcro closure on the back. The sleeves also feature wind catchers to keep the wearer warm and cozy. It comes in a variety of standard colors and fleece linings, providing options for the perfect combination for your style. Say goodbye to the hassle of lifting your arms to put on a coat, and hello to the ultimate winter wardrobe essential.


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PEOPLE WITH DISABILITIES SHOULD BE ABLE TO GET MARRIED!

BY LAUREN AGORATUS, M.A.

TO HAVE AND TO HOLD:
Garry Wickham and
Patrice Jetter during
their commitment
ceremony in August
2023; People with
disabilities should not
have to fall into
poverty if they
choose to
marry.

When individuals with disabilities marry, they could lose important benefits that helps keep them independent.

A CIVIL RIGHTS ISSUE

When one or both people in a couple have a disability, there is a marriage penalty if they wed. Benefits like Supplemental Security Income (SSI), Survivor's Benefits, or DAC (Disabled Adult Child) that are through Social Security, can be affected. They could even lose healthcare coverage through Medicare and Medicaid.

Living with a disability can be expensive and not everything is covered. Many people with disabilities need home or vehicle modifications, which may not be covered. Besides premiums, copays, and deductibles, people with disabilities need access to prescriptions, personal care assistance, and some need DME (durable medical equipment) like: wheelchairs, shower benches or chairs, walk-

ers, braces, or commodes. Some of these may not be covered. 26% of people with disabilities live in poverty.¹ It is even higher for people with disabilities of color: 40% of African Americans with disability live in poverty.²

WHO IS PENALIZED?

People with disabilities, particularly those who marry another person with a disability, experience the greatest penalties. For example, if they live together while married, they lose 25% of their benefits.³ If they live together not married, not only will they lose their benefits, it might be considered giving the appearance of being spouses, which is considered withholding, and benefits could be cut, as well.

HOW THIS IS BEING ADDRESSED

Raising awareness of this issue is crucial. Disability self-advocates gathered in Washington DC in September 2023 with DREDF (Disability Rights Education and Defense Fund). They set up a stage in the National Mall in front of the Capital and recited commitment vows. DREDF also created a marriage equality toolkit (see Resources). Recently, an award-winning documentary addressed marriage inequity for people with disabilities. The couple, Patrice Jetter and Garry Wickham of New Jersey, held a commitment ceremony as they are unable to marry or live as a couple together. (To read a May 2024 article by Patrice published in EP Magazine, visit <https://reader.mediawiremobile.com/epmagazine/issues/208928/viewer?page=34>) There are several proposed laws to address these concerns, most notably the Marriage Equality for Disabled Adults Act.

Self-advocates and their families can follow the steps outlined in the toolkit and contact their legislators. People with disabilities should not have to choose between paying for their basic needs, or losing their benefits, and potentially falling into poverty if they marry. •

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Lauren Agoratus, M.A. is the NJ Coordinator for Family Voices, NJ Regional Coordinator for the Family-to-Family Health Information Center, and Product Development Coordinator for RAISE (Resources for Advocacy, Independence, Self-Determination, and Employment). She also serves as NJ representative for the Caregiver Community Action Network as a volunteer. Nationally, Lauren has served on the Center for Dignity in Healthcare for People with Disabilities transplant committee (antidiscrimination), Center for Health Care Strategies

Medicaid Workgroup on Family Engagement, Family Advisor for Children & Youth with Special Health Care Needs National Research Network, National Quality Forum-Pediatric Measures Steering Committee, and Population Health for Children with Medical Complexity Project-UCLA. She has written blogs and articles nationally, including publications in 2 academic journals (<https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+1>). Lauren was named a Hero Advocate by Exceptional Parent Magazine (www.epmagazine.com Archives June 2022).

I DO : COMBATting MARRIAGE INEQUITY



NATIONAL PUBLIC RADIO

Report: Couples say they can't get married because of this government program's outdated rules

www.npr.org/2024/06/18/g-s1-4991/social-security-ssi-marriage-penalty

Podcast: Millions of disabled Americans could lose federal benefits if they get married

www.npr.org/2022/02/13/1080464176/disabled-americans-cant-marry-able-bodied-partners-without-losing-federal-benefits



PATRICE: THE MOVIE

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Marriage Equity Toolkit

<https://dredf.org/marriage-equality-toolkit>



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Marriage Equality for Disabled Adults Act

www.congress.gov/bill/118th-congress/house-bill/6640



CENTER FOR DISABILITY RIGHTS

Blog: Marriage Equality

<https://cdnys.org/blog/disability-dialogue/the-disability-dialogue-marriage-equality>



HOW I OBTAINED BERNADETTE

EP Magazine, May 2024

<https://reader.mediawiremobile.com/epmagazine/issues/208928/viewer?page=34>

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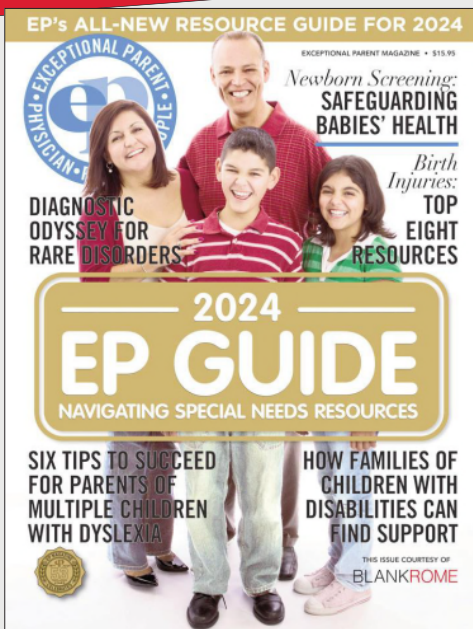
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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

PLANNING FOR THE FUTURE WITH AN ABLE ACCOUNT, SPECIAL NEEDS TRUST OR BOTH

BY SHANA SIEGEL

WILLING AND ABLE:
You can provide your loved one with more financial stability while safeguarding their eligibility for essential benefits by understanding how certain financial tools complement each other.

ABLE Accounts were originally developed as an easier, more affordable alternative to special needs trusts, but many families will find that they are complementary tools.

UNDERSTANDING ABLE ACCOUNTS

ABLE stands for Achieving a Better Life Experience. Established under the ABLE Act of 2014, these accounts are similar to a 529 college savings plan in that they allow loved ones to make contributions which grow tax-free. As long as the funds are used for qualified expenses, including: education, housing, transportation, and healthcare, the withdrawals are also tax-free. Another major

benefit of ABLE accounts is that, like special needs trusts, the funds are available to enhance the life of the beneficiary without jeopardizing their eligibility for government benefits like Supplemental Security Income (SSI) or Medicaid as long as the account stays below a threshold of \$100,000 for SSI purposes. The threshold for Medicaid eligibility purposes is higher, but varies by state.

Another important advantage of an ABLÉ Account is that individuals can manage their accounts whereas a disabled beneficiary cannot be trustee of their own special needs trust. An ABLÉ account can be opened without the need of an attorney and are relatively easy to operate. ABLÉ accounts are especially useful for individuals who have modest savings, or receive an inheritance or settlement that is not large enough to make a special needs trust practical.

However, because annual contributions are capped at the federal annual gift tax exemption amount (18,000 in 2024) and the account cannot exceed \$100,000 to remain exempt for SSI purposes, these accounts are often not the only planning tool for many families.

LIMITATIONS TO ABLÉ ACCOUNTS

ABLÉ accounts are most appropriate for modest contributions. This is not just because of the annual funding limitation and SSI threshold, but also because the accounts are subject to a payback requirement at the death of the beneficiary. If a parent or other third party wants to set aside funds or make a gift for the benefit of a disabled individual, those funds can be placed into a third-party supplemental benefits trust and be used for the benefit of the individual during their lifetime. After their passing, those funds can be designated to pass to another individual, trust or charity. However, funds in an ABLÉ account are subject to state payback requirements if the beneficiary received Medicaid benefits.

Another issue with ABLÉ accounts is that they are only available to individuals who were deemed disabled prior to age 26. However, beginning in 2026, individuals who were determined to be disabled prior to age 46 will be eligible.

BEST USES OF ABLÉ ACCOUNTS

An ABLÉ account can hold not just gifts from others, but also funds of the beneficiary, including earnings. This makes them a particularly useful tool for an individual who may work a limited amount or who may be receiving public benefits with an asset threshold. A disabled individual can make contributions to their ABLÉ account to remain under the asset limit for SSI or Medicaid (subject to the annual contribution limit). This can be a great way to allow the individual to save for a larger purchase, such as a car. The ability of the individual to manage the account can make these accounts great tools for independence, regardless of whether the individual is beneficiary of a trust as well.

ABLÉ accounts may often be complementary to a trust, since there may be more flexibility in withdrawals from ABLÉ accounts than from trusts. Depending on the terms of the trust, and the benefits the beneficiary is on, a trust may have strict limits on the use of trust distributions. For example, first party special needs trusts, i.e. those funded with the assets of the disabled individual, require the funds to be used for the sole benefit of the beneficiary. An ABLÉ Account can be used for a fairly broad array of qualified expenses which are not strictly tied to disability-related needs of the individual. For instance, rent is a qualified expense.

Moreover, there is an important policy exception that allows payments to be made from an ABLÉ account for housing without causing an impact on public benefits that the same payment from a trust would cause. When an individual on SSI or Medicaid

receives housing from someone else, or does not pay fair market value for their shelter costs, this is treated as unearned income, called "in-kind support and maintenance" or ISM. Receiving ISM will result in the beneficiary's SSI benefit being reduced. It also can be counted as income for Medicaid purposes. If ABLÉ account monies are used to pay for housing costs, there is no reduction in public benefits. Therefore, I often advise clients to fund an ABLÉ account for this express purpose in addition to funding a third-party special needs trust.

COORDINATING TOOLS

By using both an ABLÉ account and a special needs trust, you can create a more robust and flexible financial safety net. While the ABLÉ account allows for annual contributions and flexibility in distributions, the special needs trust can hold larger assets without jeopardizing mean-tested benefits. A third-party trust can also allow for passing the assets to other beneficiaries after the disabled individual's death.

It is always advisable to work with an attorney who specializes in special needs planning, not just in helping you design a special needs trust, but in helping you know how to use an ABLÉ account to complement the trust, as follows:

- 1. Determine Contribution Strategies:** *Decide how much you will contribute to each account. Balancing contributions ensures you maximize the benefits of both accounts, and don't subject funds to payback, unnecessarily.*
- 2. Set Clear Spending Guidelines:** *Outline which expenses will be covered by the ABLÉ account, and which will be paid from the special needs trust. Having this clarity prevents confusion and ensures that funds are used effectively.*
- 3. Regularly Review and Adjust:** *As your child ages and their needs change, regularly review your financial strategy. Adjust contributions, spending guidelines, and trust provisions to reflect any shifts in circumstances or regulations. You may be able to make a distribution from a SNT (Special Needs Trust) to an ABLÉ account in order to take advantage of the benefits outlined above, such as paying for housing costs without reduction in benefits.*

CONCLUSION

Coordinating an ABLÉ account with a special needs trust can create a powerful strategy for ensuring your child's financial future. By understanding how these tools complement each other, you can provide your loved one with more financial stability while safeguarding their eligibility for essential benefits. •

ABOUT THE AUTHOR:



Shana Siegel concentrates her practice on representing seniors, individuals with disabilities, and their families with life care planning, public benefits, trust and estate planning and administration, resident rights, health care decisionmaking, guardianships and long-term care advocacy. Shana has been certified by the National Elder Law Foundation (NELF) and is recognized as a member of the Counsel of Advanced Practitioners. Prior to joining Norris McLaughlin, P.A., Shana was with WanderPolo & Siegel for over 10 years. She is a past president of the New Jersey Chapter of the National Academy of Elder Law Attorneys (NAELA). Additionally, she has been an officer for the New Jersey State Bar Elder & Disability Law Section.



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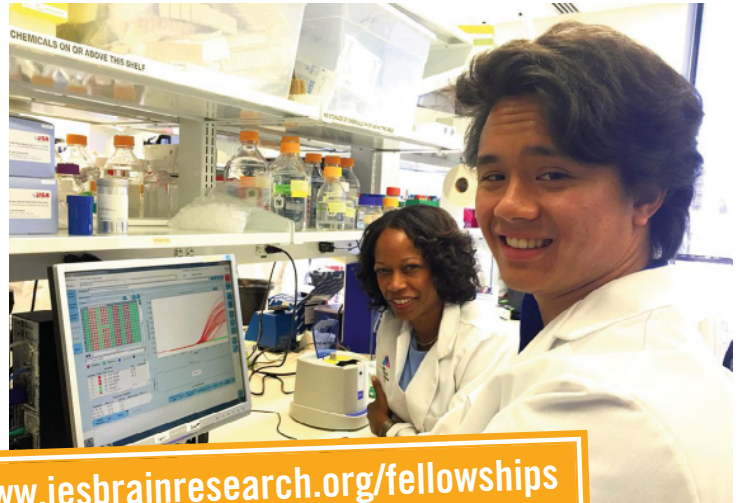
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WHAT YOU NEED TO KNOW ABOUT MEDICAL FUNDRAISING



BY EMILY PROGIN

Anyone with a close connection to an individual with a disability knows that insurance doesn't cover every cost for what they need to heal, live, and thrive. When you've fought as many battles as you can with the insurance system, or when your household needs change, you may consider medical fundraising. There are a few key things you should know.

In this article, are answers to a few of the most commonly asked questions about medical fundraising. You'll learn how fundraising can help, how to choose the right platform, the potential impact on taxes and benefits, how to fundraise effectively, and more.

WHAT CAN I GAIN FROM A MEDICAL FUNDRAISING CAMPAIGN?

Many individuals and families have a hard time asking for help, even when they need it most. Starting a fundraising campaign can be a way to embrace the help that is available, both financially and emotionally, as your community rallies around your cause.



HAPPY TO HELP:

Make it easy for donors to see and feel their impact by providing updates, photos, videos. They love to feel that they are making an impact and are directly tied to a cause they care about.

You can fundraise for one significant or one-off expense, or smaller year-round expenses.

In addition to financial support, fundraising can make you feel more connected to your community. It may give you a reason to communicate updates about a loved one with disabilities more frequently, so your community can understand the full impact of their support.

Q AND A : WHICH EXPENSES FUNDRAISERS COVER

Q. What do families typically fundraise for?

A. Individuals and families impacted by disabilities fundraise for a wide range of expenses. Here are a few common examples comprising a small sample of the expenses that families fundraise for when insurance doesn't cover the cost.

- *Surgical procedures*
- *Medications*
- *Unexpected hospitalizations*
- *Physical, vocational, educational, or occupational rehabilitation*
- *Caregiving*
- *Medical travel and temporary lodging*
- *Durable medical equipment*
- *Mobility devices such as: braces, walkers, canes, power chairs, or wheelchairs (plus replacements and repairs)*
- *Home modifications for accessibility*
- *A wheelchair accessible vehicle*
- *Service animals and service animal training*

WHAT IF OUR INSURANCE ALREADY PROVIDES STRONG COVERAGE?

Fundraising isn't a necessity for every family. However, it can help improve the quality of life and provide long-term peace of mind for many.

HOW SHOULD I CHOOSE A FUNDRAISING PLATFORM?

Ask the following question before you choose a fundraising platform: "Will fundraising jeopardize our asset-based benefits?"

Fundraising CAN jeopardize your eligibility for asset-based assistance and state benefits if the funds are considered personal income or assets. This is a complicated part of medical fundraising that truly doesn't get enough coverage or attention.

Even if you're fundraising for a legitimate medical expense, if donations go to your bank account, they may be considered personal income or assets to you.

As a result, you may have to pay taxes on those funds and they may cause you to exceed your income or assets limits for asset-based programs, such as Medicaid or SSDI.

If the funds go into your bank account, they may be considered personal income or assets. As a result, they may cause you to lose eligibility for certain benefits, even if you are using the funds for medical and related expenses.

However, if you fundraise through a nonprofit platform such as Help Hope Live, the nonprofit will hold the funds and directly pay medical and related bills. Those funds won't go to your bank account directly.

As a result, funds raised through that kind of nonprofit fundraising platform typically will not jeopardize any eligibility for state-based or asset-based benefits.

You should always talk to a local office that specializes in your program or benefits before you start a fundraising campaign.

HOW CAN I HELP SUPPORTERS FEEL CONFIDENT ABOUT DONATING?

Communication is a key part of effective fundraising. To increase the confidence donors will feel, here are a few tips:

1. *Write your family's "story" for the fundraising page in a way that is easy to understand. Imagine that you are talking to someone with no prior knowledge of a certain diagnosis or disability, and no personal connection to your family. That will*

Q AND A : FINDING THE TIME AND ENERGY

Q. Fundraising seems like a lot of work – what if I don't have the time and energy?

A. One of the biggest barriers to medical fundraising success is lack of time. Fundraising can be like a part-time or even full-time job that requires energy, focus, creativity, communication, and planning. If you feel overwhelmed as you think about taking on this kind of challenge, there are a few things you can do:

1. *Take it at your own pace. If planning a fundraiser is too much work, focus on what you CAN do, such as sending out a group email to past donors, or updating social media accounts weekly with updates and a link to the donation page.*
2. *See if your medical fundraising platform offers one-on-one help. Some platforms even offer services such as personalized flyers, social media help, and press outreach on your behalf. Talking to a real person about your fundraising efforts and needs can make a big difference. So consider choosing a platform that can offer that kind of backup when you need it.*
3. *Find a fundraising champion. One of the most valuable tools in your toolkit for a medical fundraising campaign is appointing a motivated friend or volunteer who can take the lead on planning, organizing, and sharing updates. Asking for help can be hard! Keep in mind that people typically want to help when someone they care about is experiencing a challenge. But they often don't know how. Think about your community and see who might be willing to pledge their time and talent to help with your fundraising efforts.*

make it easier for potential donors to understand your need and story, so they feel confident about why their donation matters.

2. *Choose a fundraising platform that offers medical verification. Donors will feel more confident that there is no scam or fraud risk when they donate.*
3. *Share updates frequently, and say thanks! Donors love to feel that they are making an impact and are directly tied to a cause they care about. Make it easy for them to see and feel their impact by providing updates, photos, videos, and other content, especially if you reach a fundraising goal. Celebrate every bit of progress, and express gratitude often!*

HOW SHOULD I CHOOSE A FUNDRAISING GOAL?

This is a tough question! One of the best pieces of advice about choosing a goal is this: people are most likely to donate when a campaign is making strong progress towards a goal, or even when a campaign has already exceeded its goal.

Even if it realistically represents your need, a staggeringly high fundraising goal such as \$500,000 can make donors feel like their donation won't make any impact.

Set smaller "micro-goals" that will help you check off or fund one need at a time. Make these micro-goals easy to reach and realistic for your community.

Every time you reach a micro-goal, celebrate it. Always remember that supporters LOVE to be acknowledged and thanked!

WHAT ARE SOME CREATIVE WAYS TO FUNDRAISE?

There are so many different ways to fundraise! You can plan traditional in-person events, such as a golf tournament or 5K, or focus on online and social media fundraising, or both. There are literally hundreds of other options! Here are just a few ideas:

- *Start a social media account dedicated exclusively to sharing fundraising campaign progress and updates. A new account can help you branch into a new audience of people who may not know you and your family personally. Just remember to point your personal account audience to the new account, so they can follow along. Update your followers as often as you can.*
- *Keep your eyes peeled for fundraisers that do well in your area. Successful fundraisers tend to be unique to each community. In one town, a yoga-thon may be a hit, and in the next town, an annual gala may be the most loved fundraiser of the year. Take notes about what you see. Attend fundraisers in-person or virtually, when you can, to get a sense of what engages your community the most.*
- *Hold a silent auction with handmade items donated by friends and family. You can add services from local businesses or individuals with unique talents. It can be anything from a gutter cleaning to a closet decluttering session, to a resume workshop.*
- *Partner up with a local school or organization that holds charity fundraisers. See if you can be part of an existing annual fundraising event. Keep in mind, you will need to be fundraising with a nonprofit to qualify as a "charity" for annual local charity events.*
- *Reach out to the local press to get your fundraisers listed in their community calendars or featured in the news.*
- *Hold a creative virtual event, such as a movie night, costume party, family fun night, cooking class, tea party, or dance marathon.*

HERE'S A RECAP ABOUT MEDICAL FUNDRAISING:

- *You can fundraise for one big cost or lots of smaller costs.*
- *If possible, choose a platform that offers tax deductibility for donors, medical verification, and maximum protection for your asset-based or state-based benefits. Always talk to a local office that specializes in your program or benefits before you start a fundraising campaign.*
- *Choose an achievable micro-goal instead of a large goal.*
- *Take it at your own pace and tailor your fundraising plans to your community.*
- *If you can, find a fundraising champion who can help you plan and execute your campaign.*

Fundraising can be emotionally and financially beneficial. It's worth taking the time to weigh your options and decide if it might be a way to access more equipment, services, or hope as you support someone you love with a disability. •

ABOUT THE AUTHOR:

Emily Progin is the Content Manager for the national nonprofit Help Hope Live (www.helphopelive.org). As the primary author for Help Hope Live's "Latest" blog, she has more than a decade of experience covering health care topics and answering questions about medical fundraising for individuals and families living with a disability, transplant need, or chronic illness.



Considerations for Successor Caregiving

BY KELLY PIACENTI, CHSNC®

Who will continue caring after my loved one with special needs when I am no longer able to?

This is a critical question many caregivers caring for a loved one with special needs will need to anticipate and plan for. The role of a successor caregiver is vital. Planning and considerations can be put into place in advance to help make the transition to the successor caregiver successful.

Person-centered life care planning with integrated legal and financial planning

Following a person-centered life care planning process keeps the person with special needs as the primary focus and develops a life care plan that helps enable that person to obtain the best quality of life possible. A life care plan is a coordinated and integrated program of social, medical, financial, and legal strategies for people with disabilities and their families. A life care plan con-



ily as well as the responsibilities of the individual with special needs. It is imperative for successor caregivers to have all the available information and resources in place to assist them. In addition to administering funds out of a special needs trust or ABLE account for the individual with special needs you may want to consider additional trusts.

Additional trusts as discussed in the August 2019 article “Special Needs Estate Planning – Seven Overlooked Challenges”¹ of the Journal of Financial Service Professionals include a caregiver trust, legacy trust and spendthrift trust which can provide additional assistance and flexibility for the successor caregiver. Please visit <https://mydigitalpublication.com/publication/?i=610649>

- **A caregiver trust** can be set up to alleviate some of the financial aspects of providing care by the caregiver and cover some items a special needs trust might not be able to.
- **A legacy trust is an irrevocable trust which allows you to remove assets from your primary estate into the trust, which acts like a secondary estate.**
- **A spendthrift trust** allows for a beneficiary to receive funds incrementally (this would not necessarily be a good option for an individual on resource tested government benefits).

THE PRIMARY FOCUS: “A life care plan should integrate estate, legal and financial planning with government benefits, assuring the vision and quality of life you have in mind for your loved one with special needs.”

tinually changes to adapt to the needs of the individual throughout his or her life and is integrated with the broader family planning. A life care plan should integrate estate, legal and financial planning with government benefits, assuring the vision and quality of life you have in mind for your loved one with special needs.

Next phase of successor caregiver

You may have established a life care plan, but additional and important consideration will also be your vision for successor caregivers. Caregiving can be stressful, often taking a toll emotionally as well as economically. Many successor caregivers will have to balance the needs of their fam-

Creating a letter of intent

Creating a letter of intent document is also a good way to capture your desires and concerns, as well as caregiving instructions to future caregivers, guardians, trustees, and advocates of the individual with special needs. Although not a legally binding document, the letter of intent will allow future caregivers to more quickly learn how to deliver the very best care. MassMutual’s SpecialCare program can provide a template of the letter of intent for you to customize for your unique situation.

Family meetings and communication

Having conversations and meetings regularly can help to identify needs, plans and openness of potential successor caregivers.

1. Focus on Estate Planning & Financial Planning, Special Needs Estate Planning – Seven Overlooked Challenges, Journal of Financial Service Professionals, August 2019, Harry L. Ehrenberg, CLU, accessed at: https://mydigitalpublication.com/publication/?i=610649&article_id=3454341&view=articleBrowser&ver=html5

Keep in mind that dynamics may change over time as caregivers age and siblings grow up, therefore it is important to continue a fluid conversation with all individuals involved. Make sure everyone is aware there is a plan in place, and they know where to find the information (legal documents, letter of intent, etc.).

Remember the goal is to achieve and sustain the best quality of life for your loved one with special needs and ensure they have the assistance they need in every aspect of their life. •

– Note: This article was republished from EP Magazine April 2023

MassMutual SpecialCare™

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The Special Care Planner title is used by MassMutual financial professionals who have received advanced training and information in estate and tax planning concepts, special needs trusts, government programs, and the emotional dynamics of working with people with disabilities and other special needs and their families.

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ABOUT THE AUTHOR:



Kelly Piacenti is Head of MassMutual’s SpecialCare program with nearly 500 Special Care Planners. She oversees partnerships with some of the largest national special needs non-profit organizations and serves on the National Board of Directors for United Cerebral

Palsy. She also serves on the Advisory Board for The Academy of Special Needs Planners, as well as The American College Center for Special Needs Planning. Kelly often lectures at industry conferences and is published and quoted in numerous industry publications for the special needs community. She has four children and was the mother of a son with special needs for 19 years.

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THE KEY TO BEING A STRONGER CAREGIVER

Caregiving is not just a labor of love. It is real, demanding work. We often acknowledge the important work of professional caregivers in settings like daycares and nursing homes. But family caregivers, espe-



cially those supporting autistic loved ones, face unique challenges that frequently go unnoticed. These dedicated individuals often carry their burdens quietly without the recognition and support they deserve.

BY MARTA CHMIELOWICZ

COAST IS CLEAR:

Mona DiPasquale (right), art director at Autism Speaks, and her son Jack, an autistic teenager, have fun at the beach; Placing your loved ones' needs above your own can cost you your physical and mental health.



“It can be difficult for others to understand the responsibility that comes with being a caregiver to an autistic child or sibling,” says Lindsay Naeder, vice president of services and supports at Autism Speaks and caregiver to her autistic brother. “As a caregiver, many times the emotional, physical and mental well-being of others rests on your shoulders. Caregivers become experts in looking at everything from their autistic loved one’s point of view, to be able to adapt and plan for whatever may be needed.”

To provide effective care, it’s important for caregivers to remember to also prioritize their own well-being. Without intentional self-care, the demands and pressures of caregiving can become overwhelming, sometimes leading to burnout.

PRIORITIZE YOUR OWN NEEDS

In certain situations, caregivers may find themselves placing their loved ones’ needs above their own, but this can come at the cost of their own physical and mental health. We see this happen when access to resources or support from sources outside the family are inadequate or hard to find.

“There is no shame in taking time for yourself and prioritizing time to meet your own needs,” says Lindsay. “Being a caregiver is a huge part of our identity, but by finding time for self-care, you will build the resilience and confidence needed to care for others. Don’t look at it as being selfish, or that you are putting your needs ahead of your loved ones. Reframe that thought to, you are reinforcing your ability to put your best foot forward for them.”

In the busy routine of caregiving, it’s important to set aside time each day to focus on yourself, whether in the morning or at night. This could involve journaling, meditating or simply enjoying a cup of tea. The goal is to carve out moments that allow you to recharge.

EMBRACE TIME APART

Stepping away from your routine can feel like stepping away from your child or loved one, and this can be difficult, especially when they have significant support needs. However, taking breaks is crucial, not only for your benefit, but for theirs as well.

“Don’t hesitate to take a break,” advises Lindsay. “Arranging for alternate care so that you both can have some time apart is crucial. Even if it’s just a short walk, these moments can be incredibly restorative. Encouraging your autistic loved one to engage in activities they enjoy during this time, can enrich their experience and help alleviate any guilt about stepping away. Time apart is essential for both of you, leading to renewed energy when you reconnect.”

Enrolling your loved one in daily programs or activities can be

helpful. It can free up time for self-care and completing daily tasks without interruption. These programs can also enrich your loved one’s life, giving them an opportunity to become more independent, meet new people and broaden their experiences.

The Autism Speaks Resource Guide (www.autismspeaks.org/resource-guide) can help you find autism-friendly recreational or respite options in your area.

BUILD A SUPPORT NETWORK

Caring for a person with autism often means navigating a world that doesn’t understand their unique needs. This can feel isolating, especially when everyday activities, from grocery shopping trips to family gatherings, turn into complex logistical challenges that feel impossible to take on.

Caregivers may find themselves increasingly isolated, particularly when they feel that few people around them understand their circumstances. “It can be challenging to participate in spontaneous events or community activities,” says Lindsay. “Caregivers may often opt out of these gatherings to focus on their autistic loved

ones, leading to feelings of isolation, particularly when those loved ones are unable to live independently. The weight of this responsibility is immense, especially without a support system.”

Many caregivers feel a responsibility to manage everything on their own, but this can lead to burnout. Instead, it’s helpful to lean on the people around you and ask for help. Whether it is a partner, family member or trusted friend, delegating smaller tasks like running errands or preparing meals can help lessen the load and reduce stress.

Connecting with others who understand what you are going through is also essential. Consider joining local support groups or online communities where you can share your experiences, seek advice or simply vent. These connections can provide a sense of belonging when you’re feeling overwhelmed or alone.

By prioritizing self-care and building community, you can replenish the energy needed to continue supporting your loved one. When caregivers thrive, so do their families. •

ABOUT THE AUTHOR:



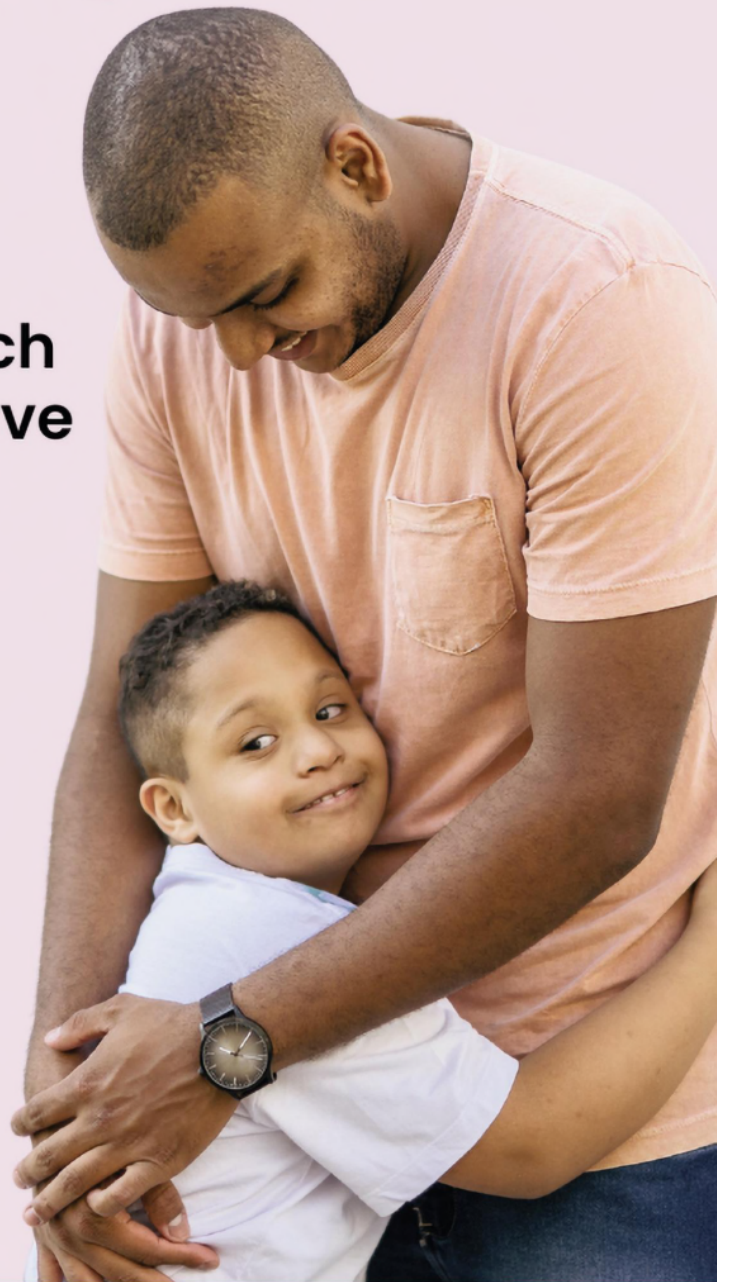
Marta Chmielowicz leads science communications at Autism Speaks, working to advance the mission of the organization to create an inclusive world for all individuals with autism throughout their lifespan.




TIME TO RECHARGE: It’s important for caregivers to prioritize their own well-being in order to provide effective care. The demands and pressures of caregiving can become overwhelming without intentional self-care, sometimes leading to burnout.

November is National Family Caregivers Month

Caregivers do so much for others. They deserve to prioritize their own well-being, too.



FIND MENTAL HEALTH RESOURCES:
[MHANATIONAL.ORG/CAREGIVERS](https://mhanational.org/caregivers)



“NEARLY 1 IN 5 STUDENTS HAVE A LEARNING DISABILITY AT SOME POINT IN THEIR LIFE, AND THE NUMBER WHO QUALIFY FOR SPECIAL EDUCATION SERVICES HAS GROWN RAPIDLY OVER THE PAST DECADE.”

A FAMILY’S JOURNEY TO GETTING THE SUPPORT THEIR SON NEEDED

BY CHRIS ROE

When a parent sees signs that their child is struggling, it can be distressing, as it was for Jessica, who noticed that her young son was having challenges that other children his age didn’t seem to have.



“I have always been fascinated by behavior, and then was gifted a beautiful little boy who had some significant behavior challenges.”

Before having a formal diagnosis, Jessica¹ suspected her son had sensory issues, possibly Autism, and anxiety that could interfere with his ability to succeed in school. Like many parents, Jessica worried about her son's future.

Jessica is a special education teacher, which helped her navigate the complexities of obtaining the support her son needed. Like many parents, she found the process of obtaining that support to be stressful and complicated.

Given their concerns, she and her husband decided to homeschool their son. In Grade 2, they enrolled him in a private school that agreed to offer some accommodations to address his challenges. They decided to switch to public school in Grade 3, and successfully obtained a 504 Plan that included a range of accommodations he needed.

According to Jessica, “When we were moving into public school, I told the principal, ‘Here's the child that I'm bringing you. Here's the history and a list of accommodations we were using in private school last year.’ I brought her a very clear and compelling history that documented a disability with evidence-based accommodations. I knew how the system worked, and I knew what was needed.”

However, they encountered pushback from her son's school about his accommodations and decided on online homeschooling. Soon after, they realized he needed to be with his peers and decided to re-enroll in public school, where their son is currently attending middle school.

Their journey yielded some important lessons about the process of obtaining support, how to collaborate with their school, and how to advocate for their son.

GETTING YOUR CHILD THE SUPPORT THEY NEED

Getting answers about *why* a child is struggling can be scary for parents. Once a parent has more information about *what is happening*, their attention turns to figuring out how they can support their child in reaching their full potential.

Parents have the right to have their child evaluated by their local public school and, if it is determined that the child has a disability,

to obtain the necessary support. When families are informed and collaboratively partner with their school to secure needed support and monitor the progress, it can be a game changer for students.

Nearly 1 in 5 students are identified as having a learning disability at some point in their life. According to the most recent data from the US Department of Education, the number of students who qualify for special education services or accommodations has grown rapidly over the past decade, even after a drop-off in numbers during COVID.²

There are two main federal laws that ensure students can access a free and appropriate public education (FAPE): the Individuals with Disabilities in Education Act (IDEA) and the Rehabilitation Act of 1973 (Section 504). While there is some overlap between these two major laws, IDEA focuses on the educational needs for children from birth to 21 years of age with documented disabilities. Section 504 of the Rehabilitation Act is a civil rights law that focuses on individuals with disabilities who may need support to equitably participate in major life activities, including schooling. Parents may be familiar with the Americans with Disabilities Act (ADA), which provides individuals with disabilities protections from discrimination, but is not regarded as an on-ramp to obtain needed services.

If a parent suspects their child is struggling academically or having difficulty participating in the classroom due to a physical, behavioral or social challenge, they should request that their school conduct an evaluation to determine if their child qualifies for services or other supports beyond those offered by the school to all students. While this is a fundamental right for parents at public school, private schools are not obligated to conduct evaluations, nor provide any needed services. In some cases like Jessica's, private schools may decide to offer services to students with disabilities.

Evaluations can range from a comprehensive evaluation across a range of cognitive and physical domains, to more narrowly tailored ones that may evaluate only one or two suspected areas of disability. It is best to ask for a more comprehensive evaluation to identify any disability that may impact access to education.

STEPS TO SUCCESS: If a parent suspects their child is struggling academically, they should request that their school conduct an evaluation to determine if their child qualifies for services or other supports.

1. Jessica is a pseudonym used to protect her and her son's identity.

2. National Center for Education Statistics. (2024). Students With Disabilities. Condition of Education. U.S. Department of Education, Institute of Education Sciences. Retrieved Oct. 25, 2024, from <https://nces.ed.gov/programs/coel/indicator/cgg>.

To activate the students' legal rights and initiate the process, it is imperative that parents *request in writing* that the school conduct an evaluation that addresses their suspected areas of concern. Otherwise, schools may delay taking action. Some schools may want to wait to see how interventions such as Response to Intervention (RTI) or Multi-Tiered Support Services (MTSS) play out before conducting an evaluation. Parents should understand that even if the school tells them they need to wait to see the results of RTI or MTSS before they conduct an evaluation, schools are obligated under law to begin the process if the parent requests one.

Once the school responds to your request, it may take several weeks to initiate and complete the evaluation. Even though the parent or guardian's right to an evaluation is covered under federal IDEA and Section 504 laws, states have latitude regarding evaluation procedures (i.e., how long schools have to complete the evaluation), so you need to research your state's educational code. Parents should track the progress of their child's evaluation and not be afraid to ask questions of the school's evaluation team or other independent experts, in order to understand the process (i.e., what will be evaluated, by whom, and how) and the results. Parent observations and data should be included as part of the evaluation.

When the evaluation is complete, the school should schedule a meeting with the parents to review the results. At this meeting, the team identifies whether your child qualifies for necessary services and supports under either IDEA, requiring the development of an Individualized Education Program (IEP), or under Section 504 of the Rehabilitation Act (e.g., a 504 Plan).

What happens if parents disagree with the evaluation results or the school's decision not to provide services? Under IDEA, parents have the right to request an Independent Educational Evaluation (IEE) from another expert, at the school's expense. If the school agrees, the findings must be considered. However, they are not required to agree with them. If the parent and school still can't agree, parents can appeal the results through the formal dispute resolution process outlined in IDEA and Section 504.

DIFFERENCE BETWEEN IEPs AND 504 PLANS

One major difference between an IEP and a 504 Plan relates to how a student qualifies for services. There is a higher bar to qualify for an IEP than a 504 plan. To qualify for an IEP, a student must meet detailed eligibility criteria spelled out by the state under one of 13 federally recognized conditions.³ The team will also need to demonstrate that the disability is interfering with the student's ability to progress in school.

If your child doesn't meet these criteria, but still needs additional help, then the school may offer a 504 Plan. Some families may choose to opt for a 504 Plan despite eligibility for an IEP. If your student has a 504 Plan, they are not considered to be a special education student.

A 504 Plan generally includes specific accommodations that will allow the student to access their education, such as: extra time for classwork or the use of aids or special technology. In most cases, 504 Plans do not include services like speech or occupational therapy, or modifications to the curriculum.

While both IEPs and 504 plans are legally binding agreements between the school and parents or legal guardian, an IEP includes much greater detail about a student's challenges and current performance.

3. The full list of federally recognized disabilities under IDEA includes Autism, Deaf or Hard of Hearing, Deaf-Blindness, Developmental Delay, Emotional Disturbance, Intellectual Disabilities, Multiple Disabilities, Orthopedic Impairment, Other Health Impairment, Specific Learning Disability, Speech or Language Impairment, Traumatic Brain Injury and Visual Impairment

An IEP will spell out goals for improvement, specialized instruction needed, the precise types and amount of specialized support services a student will receive, and where and how they will receive services.

It will specify whether the student will be placed in a general education classroom with their peers, in a specially designed classroom that serves only special education students, or some combination of these settings. School districts are required to provide a continuum of learning environments, depending on the level of support the child needs.

It is important to remember that IDEA requires a student be placed in their Least Restrictive Environment (LRE), meaning a classroom setting that allows integration with peers who do not have disabilities, to the greatest extent possible. If parents disagree with the school about the student's placement, they have the right to appeal the decision. IDEA includes robust mechanisms that spell out how teams can resolve disputes, including filing a formal complaint, going to mediation and seeking a due process hearing.

Another key difference is that IDEA requires that parents are equal, meaningful partners in their child's educational program, and participate fully in the process of developing their child's IEP.

504 plans are often developed by school personnel. Parents and guardians can be involved in their development, but schools are not required to take their input into consideration,

| COMPARING IEPs AND 504 PLANS | | |
|--|--|--|
| | 504 Plans | Individualized Educational Plans (IEP) |
| What is the authorizing law? | Section 504 of The Rehabilitation Act of 1973 | IDEA – Individuals with Disabilities Education Act |
| How does a child qualify? | Must have a diagnosed or suspected disability that affects access to general school curriculum | Must have a documented disability that requires specialized instruction and related services in order to learn in school |
| What does it offer? | Accommodations | Specialized instruction, services, and accommodations |
| Does it include goals and objectives? | Not required | Required |
| Is it legally binding? | Yes | Yes |
| Is it considered Special Education? | No | Yes |

nor to put the plan in writing. If there are disagreements, though, parents have rights and mechanisms to settle disputes through a hearing process that may include mediation. Like IDEA, mediation cannot be used to delay a hearing, if requested.

Both IEPs and 504 plans should be reviewed periodically, and updated to address any gaps or changes in the child's progress. With IEPs, the IEP team (including parents) must meet annually, to review and make any needed changes to the plan, but can meet more frequently, if needed. On the other hand, 504 regulations do not address how often 504 plans must be reviewed, but parents should not be afraid to request to meet for changes.

SUPPORTS THAT A STUDENT CAN GET IF THEY HAVE A DISABILITY

Services such as occupational therapy, physical therapy, speech therapy or counseling may be provided in a one-on-one setting or small group, by a licensed professional. If a student qualifies for specialized service, it will likely be through an IEP. Some 504 plans may include services.

Modifications are changes made to the school's general curriculum or instructional model that addresses the needs of a student due to their disability. If your student needs modifications to progress in their education, it likely means that he or she needs an IEP that includes changes in detail.

Accommodations are changes that can be made in the school setting that allow your student to access their education without requiring the school to make significant changes to the curriculum or instruction. Some common examples include: special seating, assistive technology,⁴ and extra time to complete classwork or tests. Both IEPs and 504 plans may include accommodations that a school will provide.

4. Some examples of assistive technology tools and devices include speech-to-text, text-to-speech, timers, visual and graphic organizers, keyboards and touchscreens.

TIPS FOR PARENTS

- Develop a positive relationship with your child's teachers, support team and school leaders. Understand their roles and authority regarding special education.
- Communicate directly with your child's teachers and specialists if concerns arise. If necessary, ask to convene their academic and support team to problem-solve.
- Always put requests for evaluations, support, and your concerns in writing. Be as objective as possible.
- Be sure to collect your own data on your child's progress, and identify any new issues that arise, or changes you see in support needs.
- When things aren't working as you expect, ask for changes to your child's IEP or 504 plan.
- If you are unable to resolve issues at the classroom or team level, don't be afraid to enlist outside support, or go up the chain of command to resolve the issue, including utilizing dispute resolution options.



OUTSIDE OPINION: "Ask questions if you are not sure what to do, and seek out the assistance of professionals, including experts on disabilities and education advocates."

For Jessica's son, they were able to get a number of accommodations as part of their 504 Plan, including: weekly check-ins, shortened assignments, alternative assignments, assessments to increase engagement, frequent movement breaks, check-ins with a learning coach, and preferential seating. These accommodations allowed him to be educated alongside his peers in the general education classroom.

Students with disabilities may be able to obtain support from private schools, but private schools are not obligated to provide support to students with disabilities, unless they receive federal funding.

"When we got to middle school, we saw things change in terms of his needs," Jessica recalled. She said the school pushed back when it came to implementing his 504 Plan. She noted, "It's so stressful on the parent side of navigating and managing the team." She decided to seek help. "I found an advocate to work with me, and built a solid 504 team. I gathered the data from the past year to present at the meeting, so it was harder for them to push back."

SUMMARY

Jessica and her family's journey led to valuable insights to support her son and successfully work with the school. Her advice to other parents is to ask questions if you are not sure what to do, and to seek out the assistance of professionals, including experts on disabilities and education advocates. Her experiences demonstrate that a team with a strong student focus, two-way communication, and collaboration can overcome challenges and make all the difference for a student with disabilities. •

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ABOUT THE AUTHOR:

Chris Roe lives in New Orleans, LA where he and his husband are raising two boys with neurological and learning disabilities. He serves as Director of State Policy for the Council of Parent Attorneys and Advocates, where he helps members advocate for policies that support students with disabilities at the state and local levels. He is currently working on a project to assist parents in understanding 504 Plans. Roe has served as co-chair of New Orleans Public Schools' Special Education Advisory Council and co-founded Sunshine Parents, a group that educates and empowers families of students with disabilities. For more information about COPAA's project regarding 504 Plans, see Section 504 of Rehabilitation Act of 1973 - Council of Parent Attorneys and Advocates, Inc.

PART I OF II

ARM IN ARM:

Guy Gordon educates the kids with whom he works about his condition, proudly wearing his continuous glucose monitor and mentoring kids with TD1 as well as those who are at risk for becoming a pre- or full-type 2 diabetic.



LIVABETES

BY LAURIE GORDON

My husband, Guy, is a type 1 diabetic (TD1). He wasn't always. It just happened on April 24th 2012. Here is our story and why we don't call it diabetes. We call it "livabetes."

A LOW

Guy looked possessed as he stumbled into the bedroom. His eyes were glazed and sweat poured down his face dripping onto his shirt, which I quickly realized was already saturated. It had come over him in a matter of minutes, just since he'd gone to brush his teeth. He was confused and disoriented. As had happened several times before, during our past three years dealing with TD1, he

became angry when I tried to help him. I'd learned that during a bad diabetic low it wasn't Guy who was angry, it was the mayhem of the malady that had taken control of his body and his rational thinking.

"Think quickly, do something!" I thought, as my mind raced. You're never prepared for this because it's as unpredictable as a wild animal. I needed help. I'd started weightlifting so that I could lift his torso enough when he fell onto the floor, to pour apple juice

into his mouth and administer the emergency shot of glucagon. But this was a bad one, and I had no choice. I needed help. My then 10-year-old daughter was well aware of our rare, yet serious confrontations with a severe low.

My husband's gut reaction deep from within was "Not the child... keep her away from this horror." But in his state, he couldn't vocalize it. Even if he could have, I wouldn't have listened. I couldn't. I had to get him carbs before he passed out. He tried to push me away, staring at our daughter and shaking his head. Perspiration poured from his temples as tears streamed from my eyes. He was a different person now.

Our daughter had witnessed two bad lows before. One time he'd thrown a water bottle, and the other time, thankfully, we'd heard a thud in the hallway and found him on the floor. She'd had to stay with him while I got the shot and the juice, and had helped me prop him up to administer them.

This time, it was too far gone. She and her friend who was sleeping over called 911.

BATTLING A MONSTER

A severe diabetic low can be horrific. For the diabetic, it's a living nightmare, a state of blur where you're suddenly out of control and battling a monster that's trying to control your body and mind. For the caregiver, it's equally terrifying, as you see someone you love transform so rapidly and so completely into someone they are not.

Severe diabetic lows are rare, but real. Two years ago, Guy finally agreed to wear a continuous glucose monitor which sends a piercing beeping signal to his phone, as well as mine and my daughter's, to alert a high or low number. When this happens, we immediately call him.

My husband was diagnosed with TD1, out of the blue. After having an insatiable thirst, needing to urinate constantly, and then discovering he'd lost 9 pounds in four days, he arrived home on a Tuesday evening the color of dusty ash. He'd seen an intern covering for his regular doctor a few days prior, who'd said his blood sugar "was a little high," and sent him off with a bottle of Metformin and a glucose monitor.

On that nearly deadly April evening, we took his sugar and the machine said "Hi," which prompted me – while he trained a client in our home gym – to immediately search Google for what that meant. Google didn't mess around with its answers. All were in caps or bold and some in red, and each urged to get to the emergency room a.s.a.p. The client left and my husband procrastinated as long as he could, until I finally got him into the car. We arrived to learn his number was well over 600. If he'd had dinner that night, the number would have risen to the point of a diabetic coma and probably death.

That weekend, he was suddenly a type 1 diabetic and was dependent on insulin to survive. Our lives would change dramatically and I quickly learned that though there are so many support groups out there for all kinds of illnesses, other than some blogs, those didn't seem to exist for spouses of a TD1. You just had to figure it out yourself. We couldn't count on most family or friends to "get it," because they didn't see what goes on behind the scenes or understand why, for instance, my husband can't have a traditional holiday meal. Finger pricking to draw blood and test his sugar, along with long acting and short acting insulin shots and carb counting became part of our daily routine.

At first, Guy was really down about his diagnosis and subsequent lifestyle change. Who would have thought that a former nationally-ranked marathon runner would have to test his blood 10 times a day or give himself shots to survive? TD1 doesn't discriminate. You can be the best athlete in the world and it can strike. Olympic swimmer Gary Hall Jr., US gymnast Carlotte Drury, Kansas City Chiefs tight end Noah Gray, Australian pro basketball player Lara McSpadden, two-time Paralympic tandem cycling medalist Pamela Fernandes, and Canadian pro hockey player Max Domi, who released a book about balancing blood sugar management and hockey, are just a few examples.

Fortunately, we're both optimists, and since his diagnosis, Guy has come to find the silver lining in what some consider a perpetual

"Since his diagnosis, Guy has come to find the silver lining in what some consider a perpetual cloud of living with TD1."

cloud of living with TD1. He directs an agency called Back on Track. He motivates and counsels kids and teens going through all sorts of varying life challenges in the context of health and fitness. He educates them about his disease, showing them what it's like to give himself a shot of insulin.

He has worked with a number of kids with TD1 as well as obese kids who are at risk for becoming pre- or full-type 2 diabetic.

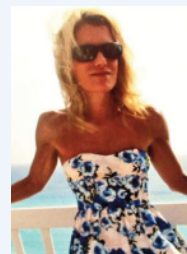
Now, instead of diabetes, my husband calls it "livabetes." It may be an inconvenience at times, but he uses it to educate the kids with whom he works. He now wears his continuous glucose monitor proudly, and gives a thumbs up when he encounters someone else wearing the same white circle on their arm.

TD 1 VS TD 2 (EMEDICINEHEALTH.COM)

Type 1 diabetes is an autoimmune condition where the body's immune system attacks the pancreas, preventing it from producing insulin. The cause is a gray area, but studies show that it can pop up months or, in Guy's case, years after having a very high fever when for some reason the body attacks and destroys pancreas function. Type 2 diabetes is a hormonal condition where the body doesn't respond properly to insulin, or the pancreas doesn't produce enough insulin. People with type 1 diabetes need insulin medicine because their bodies can't make it. People with type 2 diabetes can manage their condition with diet and exercise, and some may need insulin when their pancreas stops making it. •

Part two of this two-part series will be entitled "When You Have To Become an Expert in Something You've Never Been Trained to Do."

ABOUT THE AUTHOR:



Laurie Gordon is the owner/director of Motivation Ink Services, a publicist and writing agency based in Sussex County, New Jersey. She has written for numerous magazines, newspapers and websites. She has done a host of public relations work for varying businesses, individuals and nonprofits. After she wrote a story about a devastating storm that hit New Jersey, she was contacted by and featured live on The Weather Channel. Laurie is a former US Olympic Marathon Trials qualifier who was sponsored by Nike and whose women's team won the team division at the prestigious Boston Marathon. She works with women and teens as a personal trainer. Laurie volunteers coaching children through The Bears Youth Running Program. MotivationInkServices@gmail.com



REMEMBER ★ HONOR ★ TEACH



Help Wreaths Across America Remember, Honor, and Teach on December 14, 2024 at 12:00 pm (*Wreath Placement Beginning at 8:00 am*) by sponsoring a wreath, volunteering, or inviting friends to help.

Use this link:

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and \$5 from each Wreath Sponsored through this page
will benefit IES Brain Research Foundation.

The Irene & Eric Simon (IES) Brain Research Foundation is a volunteer-run nonprofit whose mission is to help advance research toward treatments and cures for brain diseases and conditions. The Irene & Eric Simon (IES) Brain Research Foundation Summer Fellowship Program in Neuroscience attracts bright, motivated students to neuroscience.

These remarkable students are mentored for the summer by brilliant neuroscientists heading top-notch labs. The Foundation will have given 116 summer fellowships as of Summer 2024.

Many fellows have gone on for PhDs or MD/PhDs in neuroscience, have published papers and even won awards. The goal is for the student fellows to add to the work of the senior scientists towards treatments and cures for Alzheimer's, Traumatic Brain Injury, autism, MS, brain cancer, PTSD, stroke, addiction, MS, depression, Parkinson's, ALS, pain, epilepsy and other brain diseases and conditions. The Summer Fellowship Program is funded strictly by events like the Endorphin Golf Outing & Dinner being held on June 3rd 2024, and donations often made in memory or in honor of loved ones.

REMEMBER THE FALLEN HONOR THOSE WHO SERVE TEACH OUR CHILDREN THE VALUE OF FREEDOM

TO DONATE TO ONE OF MANY LOCATIONS:

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2. Select a location to volunteer. If the cemetery is not listed, select "Lookup by Cemetery Name" OR "Lookup by City or Postal Code."
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Thank you for supporting IES Brain Research Foundation and Wreaths Across America!



EP MAGAZINE



**THE IRENE AND ERIC SIMON
BRAIN RESEARCH FOUNDATION**

PARENTING SOMEONE WITH AUTISM: THE RIGHT APPROACH

BY KADIN MCELWAIN

Picture this: You're a new parent of a child, and you notice that they're having trouble with social interactions. You go to the doctor, and you find out that your child has autism.

You're shocked and the doctor doesn't offer any reassurance about the child's capabilities. In fact, your entire family tells you that your child won't be able to live a normal life because of what they know about autism. But you are persistent. You are determined to prove the naysayers wrong and show your child that he is okay as is, and that having autism doesn't define his capabilities.

You put in lots of work to ensure your child is treated like everyone else while still getting the resources he needs to thrive socially. You have your child enrolled in occupational therapy, physical therapy, ABA therapy, and almost every resource under the sun. When teachers try to say your child can't do it, you tell them off immediately. You know what your child is capable of. When your child gets into trouble, as all kids do, you don't treat them any different than a neurotypical child regarding discipline. You put your foot down and make them take accountability.

Then it comes time for college. Your child is nervous, as many students are when they're about to start college. But it's different for those who are neurodivergent. Their routines get thrown off when they first start college, and they may not know if they'll like it or not. This is exactly what's going through your child's mind. But you assure him that you'll always be there for him if he needs anything, and that it'll be a new adventure. With those words of encouragement, your child starts loving college and makes a few friends.

Then, your child decides to start advocating for those on the spectrum. He knows what it feels like to be misunderstood and have only his parents to turn to. So, he wants to ensure that no one on the spectrum ever feels alone again. You greatly support your child's ambitions and even book a few speaking engagements for him. But little did you know, you were about to get more than you bargained for.



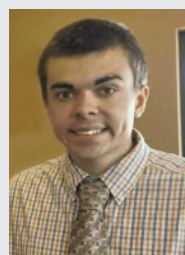
NEW ADVENTURES: "Your child is nervous about starting college, but you assure him that you'll always be there for him if he needs anything, and that it'll be a new adventure."

You start receiving compliments from total strangers all over the world, telling you how much your child inspires them. From there, his story starts receiving more and more attention. Blogs start covering your child left and right, podcasts and media platforms start interviewing your child, parents of children with autism start reaching out to your child for advice, and an autism magazine even does a feature on your child. (It wasn't on the cover, but it's still an honor to get an article.) Meanwhile, you sit and watch the success that you and your child were able to make together. You smile with pride, knowing that you were able to prove the naysayers wrong. That's what makes this all worth it in the end.

This is my story. This is the parenting style my parents used with me. They treated me like everyone else, and fought hard for me, even when I didn't deserve it. If more parents use this approach when raising someone on the spectrum, then more

neurodivergent people will have success in the world. •

ABOUT THE AUTHOR:



Kadin McElwain is an autistic college student, writer, and activist based in Painesville, Ohio. During his life, his capabilities were questioned due to who he was. But thanks to supportive of parents, he proved the naysayers wrong.



National Veterans and Military Families Month – Fact Sheet

Every November, the Defense Department and the military community celebrate military families and transitioning veterans during National Veterans and Military Families month.

Join the celebration:

- Free cooking book for families
- Fun giveaways for service providers
- Resources to support your well-being

<https://www.militaryonesource.mil/media/toolkits/service-provider/national-veterans-military-families-month>



U.S. Department of Defense

Helpful Resources Throughout November

Helpful resources

In November, the Defense Department and Military OneSource are showcasing resources at the ready for military families and transitioning veterans on our National Veterans and Military Families Month webpage: <https://www.militaryonesource.mil/parenting/family-life/military-family-appreciation/>. Our resources include topics on parenting, adoption and foster care, relationships, families with special needs, surviving family members, financial support and spouse employment. Look for special podcast episodes, a video featuring Sesame Street resources for military families and much more.

We'll also be highlighting resources on our Military OneSource and Spouse Education and Career Opportunities social channels. Follow along and share posts you think will be fun or helpful for families in your community.

Giveaways for military families

We'll be offering a free cooking book to military families to nurture family connections. Find stories and tips for planning nutritious meals, even with busy schedules. The book is available to military service members and their immediate family members, as well as to veterans within 365 days of their post-separation date.

Service providers, Military OneSource also has freebies to support the wonderful work you do! Order Military OneSource 6-in-1 pens, football stress balls, popper fidget wrist strap keychains and sticker sheets. Distribute these fun giveaways at installation events throughout November.

Support whenever it's needed

Military OneSource consultants are available 24/7 all year long. DOD wants to ensure military families have the support they need to enhance their well-being. See all the ways we support military families at <https://www.militaryonesource.mil/parenting/family-life/military-family-appreciation/>.

Taking Care of Our
Military Families

MILITARY
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FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION



VETERANS DAY

HONORING ALL WHO SERVED

MILITARY LIFE

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MILITARY LIFE

BENEFITS FOR FAMILIES WITH SPECIAL NEEDS



There are federal and state programs committed to providing additional assistance for families with special needs. As a military family, you also can count on the support of the Exceptional Family Member Program (www.militaryonesource.mil/special-needs/efmp) and Military OneSource special needs consultants (www.militaryonesource.mil/benefits/special-needs-consultations).

Whether you're looking for employment or already have a job, know that your rights are protected. There are several laws to protect adults with a disability in the workforce, including the Americans With Disabilities Act. Learn about the benefits available to you and use them to take good care of your family.

SUPPLEMENTAL SECURITY INCOME

Supplemental Security Income (www.ssa.gov/ssi) is a federal program that helps to covers the basic needs for people with disabilities who have little or no income. SSI provides cash payments that can be used for food, medical and dental care, home improvements and other personal needs. To qualify, you or your family member must meet certain requirements:

- *Income and other financial resources can't exceed the limits set for your state. However, as a military family, combat pay, hostile fire pay and imminent danger pay don't count towards the limits. Check with your local Social Security office (<https://secure.ssa.gov/ICON/main.jsp>) to learn more.*
- *You must have medical evidence of a severe physical or mental impairment that limits your family member's ability to function for a continuous period of at least 12 months.*
- *If the parent is a member of the U.S. military and stationed overseas, children under 18 with special needs can receive benefits while overseas (www.ssa.gov/ssi/spotlights/spot-military-overseas.htm).*

Check your family member's eligibility by completing the SSA Benefit Eligibility Screening Tool (www.ssa.gov/prepare/check-eligibility-for-benefits) and learn everything you need to know before applying.

TITLE V PROGRAMS

In every state, you'll find services for children under 18 with special health care needs, which are funded by Title V of the Social Security Act. Eligibility is determined by age, medical criteria and income. Title V programs assist with:

- *Delivery of health services: Organization and delivery of health care services that meet the emotional, social and developmental needs of children.*
- *Development of health care plan: Integration of families into all aspects of developing and updating the health care plan.*
- *Support for families: Assistance in finding alternatives and choices that meet the needs of your family.*
- *Facilitation of professional collaboration: Assisting in the planning, implementing and evaluating programs and related policies.*

State maternal and child health agencies maintain a toll-free hotline for information about Title V programs and providers. Check here to locate your local Title V program (<https://mchb.tvisdata.hrsa.gov/>) or call the national Title V toll-free number at 800-311-2229.

THE FAIR HOUSING ACT AND OTHER HOUSING PROGRAMS

If you or someone in your family has disability-related needs, your home may need specific modifications such as a wheelchair ramp or wider doorways to make it accessible for daily living.

The Fair Housing Act (www.hud.gov/program_offices/fair_housing_equal_op) protects your family with disability-related needs from discrimination when renting or buying property. Under this law, property owners are required to make reasonable accommodations for disabilities, as well as allowing residents to make their own modifications.

If you live in privatized housing on a military installation, your property managers are required – at no cost to you – to make reasonable accommodations that abide by the Americans with Disabilities Act (www.ada.gov/law-and-regs/ada).

Families with medical needs have the right to accessible housing. EFMP Family Support providers can help you navigate the housing process by connecting you to the installation housing office and the medical treatment facility to address your family's housing needs. Visit MilitaryINSTALLATIONS (<https://installations.militaryonesource.mil/search?program-service=16/view-by=ALL>) to find contact information.

MEDICAID BENEFITS FOR INDIVIDUALS WITH DISABILITIES

Medicaid (www.medicaid.gov) is a federal program that covers basic health and long-term care services. This benefit is available for military family members with special medical or educational needs that require medical attention beyond what is available through TRICARE.

The Children's Health Insurance Program provides health coverage to eligible children through both Medicaid and separate CHIP programs. Eligible children are in families with

incomes too high to qualify for Medicaid but too low to afford private coverage (www.medicaid.gov/chip/index.html).

Every state has its own Medicaid program with income restrictions and criteria for eligibility. Visit www.medicaid.gov/state-overviews/state-profiles/index.html for information about your state's Medicaid program. You can also find more information through the Military OneSource eLearning module on government assistance (https://millifelearning.militaryonesource.mil/course/efmp_elearning_gap).

MEDICARE

Medicare could also help provide health care coverage and save you money in the process. Children and adult children with disabilities may be eligible for services. Learn more at www.medicare.gov. You can also contact your installation's Exceptional Family Member Program office or a Military OneSource special needs consultant.

ADDITIONAL GOVERNMENT PROGRAMS

The Supplemental Nutrition Assistance Program provides food benefits to families to supplement their grocery budget so they can afford the nutritious food essential to health and well-being. The Women, Infants and Children program aims to safeguard women, infants and children by providing information on healthy eating and nutritious foods to supplement their diets.

Learn more about these benefits at <https://www.USA.gov>, an official government website search engine that links to government agencies, programs and services. For information about WIC benefits while living overseas, go to DOD – WIC Overseas Program (www.fns.usda.gov/wic/applicant-participant/dod-overseas). •

– Military OneSource

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THE RESILIENT WARRIOR

AFTERWORD

BY SARAH PLUMMER TAYLOR, MSW

*I would like to thank Nick Benas and Richard “Buzz” Bryan (and their contributors) for allowing EP Magazine to share chapters from their book, **The Resilient Warrior**, with our readers for the past 24 months. For all of you who have been reading their chapters in our Military Section, I felt Sarah Plummer’s Afterword would be a great way to end this series in our magazine.*

– With gratitude, Faye Simon, Editor In Chief

From meditation to marksmanship and bubble baths to basketball, research and anecdotes, guidance from subject matter experts and laypeople, the authors of this book have covered the spectrum of resilience advice.

In reading this compilation of works by my fellow veterans, I loved seeing that, in one way or another, they’ve all authentically elucidated the three empirically validated pillars of resilience: self-care, social support, and spiritual practices. There are, of course, many different forms of practice within each category, meaning there’s room to personalize and customize what works for you based on your personality, resources, and interest. Moreover, there are many places where the key pillars overlap with one another. For instance, social support and spiritual practices often overlap when we are doing service work in the community with members of our place of worship.

But when life gets complicated, simplifying is often incredibly helpful. Having been in the trenches myself, I know that simplicity has been empowering in my most difficult times. I loved serving in the military, and it was a time full of intense challenges and choices. In a beautiful variety of ways, this

book lays out some options for choices to make about our personal wellness path. That’s what I so appreciate about it.

Thus, my encouragement to you would be “*simplify to amplify*.” At first, choose just one or two things from this book to either re-engage in or start anew. Keep in mind that although there is a military veteran focus in *The Resilient Warrior*, wellness and resilience is relevant for us all. Transitions are pretty universally some of the trickiest times in our lives. In their journey from military life to civilian life, veterans can experience a loss of identity, loss of community, and loss of a sense of purpose. That space between point A and point B is often a scary one for most of us, a kind of a space where we’re swinging between trapezes, having just let go of one without having yet grabbed the other.

Even when transition is something we see as a positive change, change is still change, and change is hard for most of us. Couple that with a worldwide pandemic and competing priorities, and we can all become vulnerable to burn out. We need something more than “self-care isn’t selfish” sayings to help you stay the course.

Certainly, you have already cultivated resilience in some regard through your experiences in the military and beyond. My hope is that this book offered you a reminder (or some new ideas) for how to navigate these stressful times and keep doing

the work you feel called to do, all while living the life you deem most valuable, efficiently and effectively. Now more than ever, in these unusual times, we need to be creative as veterans, as we find ourselves in a community or at a workplace where we may be one of only a few who have served in the military, or in a new home where we may feel disconnected. Resilience will help us bridge the gap as we enhance our understanding of how important connection to self and with others is.

Resilience helps us strive even more to make it happen in whatever ways we can, and we become better able to think more clearly so that we feel fresh and available to our work and families. There's this old saying that if the only tool you have is a hammer, everything looks like a nail. The "just keep going" tool isn't enough. You can make it through life that way, but you're not going to: feel anywhere near your best, be your best with your friends and family, nor perform your best at work. We simply have to figure out new ways to connect to our sense of self, connect with others, and connect with our sense of purpose.

Today, and beyond, I encourage you to spend some time building out your toolkit, so you have a range of responses at your disposal, and you have more tools in your toolkit. Simplify to amplify! Just pick one or two things to focus on changing. If you try to change a dozen things, you'll likely reinforce the misbelief that "nothing works." Explore mindfulness apps or online classes, reach out to a friend who you know is into this stuff, spend more time reading books about resilience, than scrolling social media. Mindfulness and resilience-building is exactly about increasing our range of responses, bulletproofing our psyche, and building our skillsets. Resilience is not about having one perfect plan to handle every situation. It's about being adaptive, responsive, able to pivot, empowering you to be flexible, dynamic and creative.

Veterans: we are assets! Let's take care of ourselves like we really believe that, and bring our strength fully into the world. I want to live in a world with more resilient veterans. Don't you?! Please, I urge you, choose to take care of yourself enough that you are able to bring your gifts forward. The truth is, we've all faced battles in combat, or divorce, illness, loss, violence, sorrows, and setbacks. But we are resilient. We have choice. From choice, we have hope.

Ask yourself, where you grow stronger, one choice at a time. We served, we will continue to serve, and we are the change we seek. We can do this! I sincerely wish you the very best along your resilience journey, and am grateful to have been a part of it in any way at all. •



THE CHANGE WE SEEK: Sarah Plummer Taylor and her family at home; "I urge you to take care of yourself enough that you are able to bring your gifts forward. The truth is, we've all faced battles in combat, or divorce, illness, loss, violence, sorrows, and setbacks. But we are resilient."

ABOUT THE AUTHORS:



Sarah Plummer Taylor is an established leader in the field of resilience building and holistic wellness. She teaches veterans, busy professionals, students, and entrepreneurs how to find clarity and build stronger, healthier lives. A U.S. Marine veteran who deployed twice to Iraq, Sarah is the author of *Just Roll With It: 7 Battle Tested Truths for Creating a Resilient Life*. She is also the founder of SEMPER Sarah®, a national wellness practice. Sarah lives in North Carolina with her husband, their two daughters, and dog.



Nick Benas grew up in Guilford, Connecticut. The author of *Mental Health Emergencies*, *Warrior Wisdom*, *Tactical Mobility*, and co-author of *The Warrior's Book of Virtues*, Benas is a former United States Marine Sergeant and Iraqi Combat Veteran with a background in Martial Arts (2nd Dan Black Belt in Tae Kwon-Do and Green Belt Instructor in Marine Corps Martial Arts Program). Nick attended Southern Connecticut State University for his undergraduate degree in Sociology and his M.S. in Public Policy. He has been featured for his business success and entrepreneurship by more than 50 major media outlets, including *Entrepreneur Magazine*, *Men's Health*, ABC, FOX, ESPN, and CNBC.



Richard "Buzz" Bryan is currently the Outreach Coordinator for the West Palm Beach VA medical center. The co-author of *The Warrior's Book of Virtues*, Buzz previously served as the OEF/OIF Transition Patient Advocate (TPA) for the Veterans Integrated Service Network (VISN4) based in Pittsburgh, PA for ten years, working specifically with Iraq and Afghanistan veterans. Buzz was a member of the Navy/Marine Corps team and retired from the United States Navy in July 2011

after 22 years of honorable service as a Fleet Marine Force Senior Chief Hospital Corpsman.



Teaching the Teacher

Time and time again, I notice that my students teach me more than I teach them. There are more ways than one to solve a problem.

One of the classes that I teach at USC is University 101. This course involves teaching skills that encourage first year students to thrive in a university setting. For this population, this is the first time they are away from home. They aren't being told when to study, when to go to bed, or when to eat. For this course to be effective, there is limited time lecturing, and more time encouraging students to talk to one another to share their experiences and how they are managing life away from home. I have a teaching cohort for this course, and we spend a lot of time asking questions to connect with students and to encourage them to connect with others. One skill I've worked hard to encourage in students is creative problem solving. To many, they may see only one way to solve a problem, and this can cause stress and anxiety. If we learn to take our blinders off, which create unnecessary boundaries to possible solutions, a new set of options can be seen.

Last semester, I had a student who was a frequent visitor before class. He would wander in around 10-15 minutes before class started. I realized that he just wanted to talk and, most of the time, I just listened. One day, he came into the class and said, "I'm failing one of my classes. I don't think I'm going to make it through. I don't know what to do." I looked over at him and said, "I'm going to ask you an honest question. Do you want to come back to USC next year?" At first, he was offended by my question. Giving me a dirty look, he snapped, "Of course I want to come back next year! I want it more than anything!" I smiled, "Ok, if you want it bad enough, then there is always another way to get to where you want to go. We just need to look outside the box and look at other options. They may not be ideal options, but there is another way."



We spent about 10 minutes that morning brainstorming ways that he could make up a few credits so he could raise his GPA and head into his second year at USC. I remember telling him, "There are three ways to get there. You've got to do the work, but there's a way." I remember him looking back at me, realizing that it was on him to deliver. I made a point to not give him any advice on the best path to take. He needed to decide which path to take and do the work. A few weeks before Fall semester started, I received a text from this student, "I just want you to know that I chose one of the options we

IMPERFECT PATH: Broden and his dad Mark relax in the backyard; "There are more ways than one to solve a problem. It may not be an ideal path, but it's a path that eventually leads to the goal you're seeking."

talked about last semester, and I am returning as a sophomore at USC.” After a huge sigh of relief, I texted him back congratulating him on a huge achievement. He was presented with a difficult problem, and he figured out how to solve it.

A few days later after receiving that text from my student, I was sitting on the sink sulking over how Broden has continued to rely on me for showering. We have been working on this for years, at a snail’s pace. Some mornings are better than others, but when I feel I’m burning at both ends, I break down and do all the work. Broden is smart and knows I’ll bathe him myself without him having to do the work, if I’m running late. It takes twice as long to prompt him to do it himself. If he had his way, he would have me do all the work every morning. That way, he would just have to stand there in the shower. I thought, “I just told my student last semester, that there is always another

way. Why am I not taking my own advice?” I sat on the sink and started to ask myself where the barriers were. One of them is putting his head under the water long enough to rinse the soap out of his hair. He will put his head in the water for about 10 seconds, pull it out, and then wait for me to prompt him to do it again. He’ll stand under the shower until I break down and prompt him, because he knows we’re running late in the morning.

“We just need to look outside the box, remind ourselves what we truly want to accomplish, and then do the work.”

This is a never-ending cycle that we go through. What is another way? I kept repeating to myself, “Look outside the box. It won’t be perfect, but there could be another way.” Finally, I walked over to the shower, took the shower head off the wall and put it in his hand, “Broden, you’re in control. Put the water where you need it to get the soap out of your hair.” I started hand over hand and over a few days, I started giving him gestural prompts, so he could move the shower head where he wanted it. I real-

ized this was not an ideal option for teaching him to shower independently with the shower head in the wall, but at this point, I needed to keep an open mind. What is my goal? I want Broden to eventually realize that he can be in control of what happens in the shower. He doesn’t need me.

Time and time again, I notice that my students teach me more than I teach them. There are more ways than one to solve a problem. It may not be an ideal path, but it’s a path that eventually leads to the goal you’re seeking. We just need to look outside the box, remind ourselves what we truly want to accomplish, and then do the work. •

OUR JOURNEY IN CAMO

Shelly Huhtanen is an Army wife stationed at Fort Jackson, SC. She enjoys sharing her experiences of her day-to-day life caring for her son with autism. Shelly authored *Giving a Voice to the Silent Many* that encompasses many stories of raising a child with autism in the military. She also teaches Public Communication at the University of South Carolina and has contributed to *EP Magazine* for over 10 years.



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