

PLUS: UNITED STATES MILITARY SECTION

EXCEPTIONAL PARENT
MAGAZINE
NOVEMBER 2023
\$14.95



FINANCIAL PLANNING ISSUE:

**ESTATE PLANNING *for*
COLLEGE STUDENTS WITH
SPECIAL NEEDS**

PLUS:

**OVERCOMING
ANALYSIS
PARALYSIS**

AND:

**3 OPTIONS *for* MORE
FINANCIAL SECURITY**

DEPENDENTS WITH DISABILITIES:

**DISCUSSING
FUTURE NEEDS**

ALSO • SPECIAL NEEDS TRUSTS:

**SECURING YOUR
CHILD'S FUTURE**





Exceptional parents deserve exceptional financial advice

Only a **Chartered Special Needs Consultant® (ChSNC®)** has the know-how to meet the unique financial and life planning challenges faced by children with special needs and their caregivers.

Caring for a child with special needs means looking at finances differently. You need a partner who understands how to prepare you not just for your own future, but for your loved ones as well.

A ChSNC® designation from The American College of Financial Services means knowing how to navigate all of life's challenges—governmental support, long-term caregiving, estate planning, disability advocacy, and more.

Visit **TheAmericanCollege.edu/ChSNC** or call an Admissions Advisor at **866-749-5609**

ChSNC®
CHARTERED SPECIAL
NEEDS CONSULTANT



THE
**AMERICAN
COLLEGE**
OF FINANCIAL SERVICES®

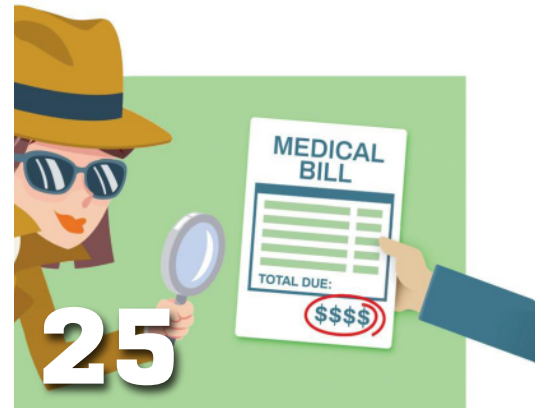
CONTENTS

NOVEMBER 2023 VOLUME 53 ISSUE 11



**FINANCIAL
PLANNING**
THE ANNUAL ISSUE

15



25

FINANCIAL PLANNING

12 EMPOWERING FINANCIAL PLANNING AND INDEPENDENCE THROUGH ABLE ACCOUNTS: HOW THE NATIONAL ABLE PROGRAM TRANSFORMS LIVES

By ABLE Today

COVER STORY

15 DISCUSS THE FUTURE NEEDS OF DEPENDENTS WITH SPECIAL NEEDS: TOPIC SUGGESTIONS FOR PLANNING MEETING WITH FAMILY/FRIENDS

Courtesy of Massachusetts Mutual Life Insurance Company (MassMutual) SpecialCare

18 THREE OPTIONS TO GIVE YOUR CHILD WITH ADDITIONAL NEEDS MORE FINANCIAL SECURITY

By Graham Caldwell

22 OVERCOMING ANALYSIS PARALYSIS AND PLANNING FOR YOUR CHILD'S FUTURE

By Corey Briskey, MPH

25 OVERWHELMED WITH MEDICAL BILLS? IT HELPS TO THINK LIKE A DETECTIVE

By Jennifer McLelland

28 QUESTIONS ABOUT YOUR LOVED ONE'S FUTURE HOUSING

By Pam Blanton

32 FINANCIAL PLANNING ACROSS THE SPECTRUM

By Marta Chmielowicz

35 ESTATE PLANNING FOR COLLEGE STUDENTS WITH SPECIAL NEEDS

By Mitch Mitchell

38 SECURING YOUR CHILD'S FUTURE: THE IMPORTANCE OF SPECIAL NEEDS TRUSTS

By Bianca Farr



28



32

FEATURES

40 INDIVIDUALS WITH MEDICAL COMPLEXITY MAY EXPERIENCE MEDICAL TRAUMA

By Lauren Agoratus, M.A.

ON OUR COVER

You, your family, and your team of professionals should work collectively to help develop a life care plan that best suits the needs of your loved one with a disability – now and far into the future. Coverage begins on page 12.



35

CONTENTS

NOVEMBER 2023 VOLUME 53 ISSUE 11

DEPARTMENTS

- 4 THE EDITOR IN CHIEF'S DESK**
A SENSE OF PURPOSE
By Faye Simon
- 5 WHAT'S HAPPENING**
- 10 WHAT'S NEW**
- 52 PRODUCTS & SERVICES**



MILITARY SECTION

- 44 MILITARY LIFE**
DEPRESSION: THE STRUGGLE IS REAL
By Margie Harding
- 46 BOOK EXCERPT 12TH OF A SERIES**
THE RESILIENT WARRIOR
By Nick Benas and Buzz Bryan
- 50 OUR JOURNEY IN CAMO**
THE EXTRAORDINARY AND UNUSUAL
By Shelly Huhtanen

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

MILITARY LIFE
44 **DEPRESSION: THE STRUGGLE IS REAL**
By Margie Harding

BOOK EXCERPT 12TH OF A SERIES
46 **THE RESILIENT WARRIOR**
By Nick Benas and Buzz Bryan

OUR JOURNEY IN CAMO
50 **THE EXTRAORDINARY AND UNUSUAL**
By Shelly Huhtanen

ARMY
NAVY
AIR FORCE
MARINES

EP FOR FREE!

INFORMATION, INSPIRING STORIES, AND RESOURCES ON DISABILITIES AND SPECIAL HEALTH NEEDS FROM INFANCY TO ELDERLY INCLUDING A SPECIAL MILITARY SECTION.

Visit www.epmagazine.com to subscribe to the free eMagazine or for the print magazine (\$199 per year)

To purchase single issues (if available) contact fsimon@epmagazine.com



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

GET SOCIAL WITH EP MAGAZINE

Stay current with Exceptional Parent Magazine. New issue updates, exclusive article excerpts, and inspiring and helpful content for the special needs community.

FOLLOW US TODAY • SHARE OUR POSTS • RETWEET

FACEBOOK



facebook.com/
exceptionalparentmag

FOLLOW EP ON TWITTER



[NEW TWITTER ADDRESS]
twitter.com/epmzine

INSTAGRAM



instagram.com/epmzine



**SUBSCRIBE FOR FREE
AT EPMAGAZINE.COM**



A Sense of Purpose

For parents with a child with a disability, special plans may be necessary to achieve independence within the community.

As many of EP Magazine's readers know, planning for the future of a loved one with special needs is a daunting task. A multifaceted approach that factors in social, legal, medical and financial necessities can take years of careful considerations to develop. As Bianca Farr notes in her article "Securing Your Child's Future: The Importance of Special Needs Trusts," "A parent's wish is that their child grows to be an independent, productive member of their community. For parents with a child with a disability, a different approach may be necessary to achieve independence and inclusion within



"A life plan will enable your child to live their best life and to consider what will give them a sense of purpose and meaning."

the community." Hers is just one in a wide selection of articles that can help parents ensure a more secure future for their child in our Annual Financial Planning Issue.

Our cover story, submitted by MassMutual Specialcare, recommends that caregivers host a meeting with their family and/or friends to discuss the future medical, educational, and housing needs of their dependent with special needs. They suggest a range of topics for discussion to help develop a life care plan that best suits the needs of a person with a disability. In "Financial Planning Across the Spectrum," Marta Chmielowicz of Autism Speaks focuses on planning concepts as they relate to the care of autistic loved ones. Partners4Housing founder Pam Blanton tackles tough questions like "What does my family member need to live outside our family home?," "Who will they live with?," and "How will we afford it?" in her article "Questions about Your Loved One's Future Housing."

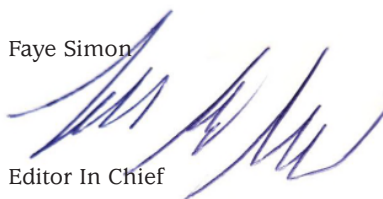
In "Three Options To Give Your Child With Additional Needs More Financial Security," Graham Caldwell writes "A life

plan will enable your child to live their best life. Time has been taken to plan and prioritize what's important for them, to consider what will give them a happy life, what will give them a sense of purpose and meaning, what will give them pride and self-respect, and what will give them a greater feeling of being independent, autonomous people."

In addition, we highlight related topics like ABLE accounts, special needs trusts, estate planning for college students, and dealing with overwhelming medical bills.

Follow us on [facebook.com/exceptionalparentmag](https://www.facebook.com/exceptionalparentmag), Instagram [@epmzine](https://www.instagram.com/epmzine) and [twitter.com/epmzine](https://www.twitter.com/epmzine) and share our posts. Our mission is that everyone interested will know they can read the valuable information for FREE! It's easy to subscribe and receive "EP for Free" – just visit www.epmagazine.com and click EP for Free Sign Up!

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. As EP's Editor In Chief, Faye sources and edits articles, creates partnerships with businesses and not-for-profit organizations, and develops relationships with EP's writers, corporate partners, readers and staff.



Information and Support for the Special Needs Community

VOLUME 53 ISSUE 11
ESTABLISHED 1971

Publisher
Len Harac
lharac@epmagazine.com

Editor In Chief
Faye Simon
fsimon@epmagazine.com

Art Direction & Design
Leverett Cooper
lev@foxprintdesign.com

Subscriber Services
1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012
www.epmagazine.com

Customer Service/New Orders
Faye Simon fsimon@epmagazine.com
(973) 726-6218

Publishing & Editorial Office
1360 Clifton Avenue, Ste. 327
Clifton, NJ 07012



Exceptional Parent (ISSN 0046-9157) is published monthly 12 times per year including the special January EP Guide - Navigating Special Needs Resources by Exceptional Parent Magazine, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 Internet address: www.epmagazine.com. All rights reserved. Copyright ©2023 by Exceptional Parent Magazine. Exceptional Parent™ is a registered trademark of Exceptional Parent Magazine. Postmaster: Please send address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Any applicable periodical postage paid at Clifton, NJ and additional mailing offices (USPS 557-810). Basic annual subscription for EP Digital is free. Limited edition print subscription \$199.00. Subscriber Service: Direct all inquiries & address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 08758. Customer Service/New Orders: E-mail: fsimon@epmagazine.com or call (973) 726-6218. Back issues incur a charge of \$17 each with shipping, (January issue \$20 when requested) and depend upon availability. Call (973) 726-6218. Agreement #1420542



WHAT'S HAPPENING

NEW PLAYSTATION CONTROLLER TO MAKE GAMING MORE ACCESSIBLE FOR PEOPLE WITH DISABILITIES

One of the most popular video game systems is unveiling a new controller designed to be more accessible for people with disabilities

Sony said it will make its Access controller available for PlayStation starting Dec. 6. The circular controller, which has been in the works for five years, features buttons that can be rearranged with various caps to allow users to select the shape and texture that suits them. It also includes a control stick that can be adjusted to the desired length for comfort.

"Introducing the Access controller, a versatile controller kit that can be customized to meet players' diverse needs, designed in close collaboration with the accessibility community to help players with disabilities play more comfortably for longer," PlayStation announced.

Users can configure button and stick settings to meet their needs and the Access controller can be used alone or connected with other controllers and accessories.

The accessible controller can be placed on a flat surface like a wheelchair tray and is intended to "help gamers with disabilities play more comfortably and for longer periods," Hideaki Nishino, senior vice president of platform experience at Sony Interactive Entertainment, indicated in a blog post. "Our goal was to create an innovative design that's adaptable to the needs of a wide array of players."

The Access controller, which will be available globally on Dec. 6 and costs \$90 in the U.S., features swappable buttons and sticks that allow players to arrange the controller to best suit their individual needs.

The circular device is surrounded by buttons and an extending joystick, and other accessories can be added on in separate ports. According to CNet, it was designed for those with various gaming needs and includes interchangeable magnetic buttons, a box that can be opened with one hand and the ability to combine controllers.

"As someone who's disabled, you're given tons of accessible equipment that feels medical; it feels like something that's from the hospital," accessibility consultant Cesar Flores told the outlet. "If you look closely on each of those buttons, there's tiny X's, squares, triangles – that's so special. That's the difference right there, because that really makes it so I feel like I'm just going to game."

Sony Interactive Entertainment's senior technical program manager Alvin Daniel added that accessibility with a controller is important if games and consoles are accessible as well. "Our PlayStation Studios have done an amazing job with each

title and really pushing the boundaries as far as accessible gaming," he said. "The critical link in that chain is the controller."

Nishino said that the company tried out half a dozen concepts and worked with accessibility experts and testers with disabilities to identify the best option. Even the controller's packaging is designed to be accessible, using loops to allow customers to unpack the item with just one hand.

In addition to the Access controller itself, Sony said that Logitech G will offer an accessory kit beginning in January that will allow for even more customization.

The PlayStation Access controller was first revealed at CES, an annual consumer technology trade show in Las Vegas, earlier this year, but it was still in development at that time. Sony rival Microsoft has offered an Adaptive Controller for Xbox since 2018.

Sony is accepting pre-orders for the new Access controller, which runs \$89.99.



TAKING CONTROL: The Access controller can be customized to meet diverse needs and was designed in close collaboration with the accessibility community.



KayserBetten—A Name You Can Trust
Since 1978



A complete line of beds with innovative designs and unique features.

See the difference!

1-800-574-7880

www.KayserBettenUS.com

WHAT'S HAPPENING

A THIRD OF SCHOOLS NATIONWIDE DON'T HAVE A NURSE. HERE'S WHY THAT'S A PROBLEM.

BY COLLEEN DEGUZMAN

Jodi Bobbitt, the school nurse at William Ramsay Elementary in Alexandria, Virginia, is always ready to see children with a wide range of injuries and illnesses. One day during the first week of school, the parade started before the first bell when a little girl walked in with red, irritated eyes.

Then it got busy. A student fell from the monkey bars and another tripped while playing tag. Two kids hit each other's heads with lunchboxes and needed ice packs. A young boy had a stomachache. Bobbitt also saw her regular kiddos: one who has special needs and uses a wheelchair and another who has diabetes and gets his blood sugar checked daily before lunch.

"Every day, I'm seeing more and more [youngsters]," Bobbitt, who is a certified nurse practitioner, said with a smile. "I saw more today than yesterday, so we just have to wait and see what the year has in store."

As the only school nurse at this suburban Washington, D.C., elementary school, Bobbitt's responsibilities extend beyond treating scraped knees and sniffles for the school's 600 pupils. At her under-the-sea-themed clinic, she administers medications, teaches kids about health care, and conducts routine health screenings. As the school nurse, she also serves as a public health point person – tracking student vaccinations, linking parents to local health care resources, and communicating sometimes difficult messages to them, such as warnings about sexually transmitted diseases and signs of depression.

It's a full plate, but Bobbitt considers herself lucky. In a previous school nursing job, she split her time between two buildings within the same school district – some years three. What hasn't changed is that



STRETCHED THIN: Jodi Bobbitt is the only school nurse at William Ramsay Elementary in Alexandria, Virginia. In a previous school nursing job, she split her time between two school buildings – some years three. Now she has only one campus to care for.

school nurses play a critical role in keeping students healthy and ready to learn, but it's an often-unrecognized field for which schools struggle to attract and retain employees.

More than a third of schools nationwide don't have a full-time nurse on-site, according to a 2021 survey by the National Association of School Nurses. The schools that don't have a dedicated nurse either share one with other campuses, or don't have one at all. Meanwhile, the nation is facing high rates of chronic illnesses among K-12 students, such as diabetes and asthma, along with an unprecedented mental health crisis among youth, and school nurses are at the front lines – often, alone.

School nurses' roles were further complicated by covid-19. Since the pandemic took hold, they've been tasked with tracking cases and tracing exposures. An "extreme load of work was put on school nurses' shoulders during the pandemic," said Kate King, president of the NASN.

They got caught in the middle between anti-maskers and maskers and anti-vaccine and pro-vaccine parents, and were the

point of contact whenever students had to quarantine. "School nurses are used to interacting with parents who are angry," said King, but because of the pandemic "that anger just got to levels we had never seen before."

In general, kids' attendance and learning can suffer when students don't have access to a school nurse. "You're going to see more absences," she said, citing a study from the *Journal of School Nursing* that found students with illnesses or injuries were sent home 18% of the time when evaluated by an unlicensed school employee while only 5% went home after being seen by a school nurse.

Teachers and administrators are shouldering some of the burden by learning how to handle injuries and illnesses themselves, but "it doesn't take the place of having a school nurse who can respond immediately," King said.

Though there is no federal law requiring schools to have nurses on staff, the Centers for Disease Control and Prevention recommends at least one full-time nurse for every 750 students enrolled – but most

states are missing the mark by miles. School nurses in California have one of the heaviest workloads in the country with a student-to-school-nurse ratio of 2,410 students for every nurse, according to the Public Policy Institute of California.

According to research organization Child Trends, California, along with 34 other states and the District of Columbia, requires schools to employ school nurses. Of those, 12 set required nurse-to-student ratios. Seven states encourage schools to have nurses on staff. Eight states don't have mandates on the books.

Still, schools were scrambling over the summer to hire nurses.

Jessica Sawko, director of education for Children Now, a California-based nonprofit organization, said schools struggle not only to retain nurses but also encourage aspiring nurses to consider working in schools. Districts can't compete with the salaries and benefits hospitals offer. The national median salary for school nurses is nearly \$55,000 a year, but a registered nurse could make nearly \$30,000 more annually working at a hospital.



SURVIVING SHORTAGES: Robin Wallin, director of school health services for Alexandria City Public Schools, says an aging cohort of school nurses has contributed to the nationwide shortage. As nurses retire, she says, "we need to start to replenish our cohorts."

In some states, school nurses need special certification in addition to their nursing degrees.

The lack of school nurses is a byproduct of a larger issue: the nation's overall nursing shortage. Health organizations in general – even those that offer healthy salaries – are facing difficulties hiring and keeping nurses. Around 40% of nurses who participated in a 2023 survey by McKinsey & Co. said they were considering leaving their position.

As a nurse for junior high students, King said she is keenly aware that school nurses sometimes serve as students' only contact with a health care professional, especially at her campus.

World Language Middle School in Columbus, Ohio, where King works, has a diverse student body and takes in many students who are new to the country. "So that requires school nurses like myself to have a very broad range of knowledge of diseases and symptoms," she said.

Robin Wallin, director of school health services for Alexandria City Public Schools, said that another layer of this issue is that school nursing "is an aging cohort." The district has at least one school nurse in each of its 18 campuses – but this year it was a challenge to fill every spot. Many school nurses are aging out, starting to retire, she said. "We need to start to replenish our cohorts."

Bobbitt said the nursing students who shadow her almost never imagine themselves working in a school. "They want to work in the ER, they want to work in the hospital, they want to work in the NICU, or somewhere where they can have that adrenaline," Bobbitt said. "This is a little different," she said, adding that it is fast paced in its own way.

Robin Cogan is a clinical coordinator at Rutgers University's School Nurse Specialty Program in New Jersey, and she said one of the biggest learning curves for nurses who opt to work in school settings is that they are "often an independent practitioner," which involves juggling a lot of responsibilities.

Meanwhile, Bobbitt, working in her brightly colored clinic, stays focused on her daily mission: to address the students' needs as quickly as possible. "We don't want them to miss very much school or much class work," Bobbitt said. "That's our goal, right?"

ABOUT THE AUTHOR:

Colleen DeGuzman, Peggy Girshman Fellow, is based in Austin, Texas, and reports on a broad range of public health topics. Previously, she was a reporter for the Austin American-Statesman. She also was a reporting fellow for The Texas Tribune and reporter for The Monitor newspaper in McAllen, Texas. She has had internships at NBC's "Weekend Today" and Ashoka's Washington bureau, and is an NPR Next Generation Radio mentee.

Colvent Group

Property Management & Vehicle Solutions



Colvent Group Inc. provides property services for fiduciaries. We specialize in nationwide property management, vehicle purchasing and insurance procurement.

Our services span all 50 states. We have forged partnerships with local, licensed, insured contractors and dealers to ensure that vehicles and homes are purchased, repaired and maintained with excellence. Our standard in applying root-cause problem-solving techniques is the cornerstone of our company as we ensure that home, vehicle and client requirements are well defined.

HomeWize
A Colvent Group Service

- ✓ ADA Compliance
- ✓ Construction Services
- ✓ Plumbing, HVAC, Electrical
- ✓ 24/7 Emergency Call Center

CleaView
A Colvent Group Service

- ✓ Annual Inspections
- ✓ Full Property Inspections
- ✓ 3-year Property Valuations
- ✓ Pre-Purchase Home Due Diligence

Colvent Group Vehicle Services

- ✓ Purchasing Solutions
- ✓ Leinholder Compliance
- ✓ Insurance Premium Foresight
- ✓ Nationwide Insurance Underwriting

Connect with us



866.833.7811

homes@colventgroup.com

www.colventgroup.com

WHAT'S HAPPENING

NEARLY 4 IN 10 TODDLERS DIAGNOSED WITH AUTISM NO LONGER HAVE IT BY AGE 6

A recent study in *JAMA Pediatrics* finds that some toddlers diagnosed with autism may outgrow the condition by age six.

This is reassuring news given the startling number of kids currently on the spectrum.

Autism spectrum disorder is characterized by varying degrees of difficulty with social communication and social interactions, repetitive behaviors, and sensory symptoms. It is four times more common in boys than girls.

The prevalence of autism continues to rise and more efforts are being made to diagnose kids early so they can get prompt treatment.

Researchers at Boston Children's Hospital wanted to know how many toddlers continue to meet the criteria for autism as they get older. They looked at 213 children who had been diagnosed with autism at 1 to 3 years of age and reevaluated them at 5 to 7 years of age after receiving some form of intervention.

All of the children in the study received interventions based on the diagnosis. The most common intervention used was applied behavior analysis, which is a therapy that focuses on increasing helpful behaviors and decreasing unhelpful ones. Applied behavior analysis can teach people to improve skills in areas like communication, attention, focus, and socializing.

They found that by around age 6, more than a third, almost 40%, of the children no longer met the criteria for autism.

"I think what this shows is the importance of continuing to get developmental follow-up for all children with a young diagnosis of ASD [autism spectrum disorder]," said lead study author Dr. Elizabeth Harstad, a developmental pediatrician at Boston Children's. "I don't want these findings to imply that losing the diagnosis is the best outcome. Children can have a range of wonderful outcomes whether or not they have the diagnosis."



THE LONG VIEW: The study authors noted the importance of continuing to assess autism throughout a diagnosed child's development.

The findings were published this month in *JAMA Pediatrics*. The study included 213 children who were diagnosed with autism spectrum disorder (ASD) when they were between the ages of 1 and 3 years old. On average, the children were diagnosed around 2½ years old, and 83% of those in

"Our research shows how important it is that we monitor kids over time, because some children may really have changes in their social communication and behavioral function."

the study were boys.

The kids who outgrew their diagnosis were more likely to be girls or at baseline, to have better communication, self-care, and decision-making skills. But the researchers stress that it's important for children with autism to have ongoing assessments throughout their development because the diagnosis may evolve over time and their treatment needs to evolve with them.

"It is possible that children who no longer have autism at age 6 may have responded better to treatment than children whose autism persisted," study co-author William Barbaresi, MD, chief of developmental medicine at Boston Children's Hospital, said in a statement. "The findings of the study should cause a very frank reconsideration of the need for far more research to understand if current treatment for autism is working, or if major new efforts to develop treatment approaches are needed."

The findings in this latest study show that parents of children diagnosed with ASD need to remain open-minded, said Dr. Harstad.

"It is important to recognize that diagnoses can evolve as a child develops," she said in a statement. "Our research shows how important it is that we monitor kids over time, because some children may really have changes in their social communication and behavioral function. This underscores the need for continuous assessments and adaptable intervention strategies." •

Are You Ready to...

- Increase your income?
- Explore your work options?
- Keep your Medicaid/Medicare while you work?
- Gain greater personal fulfillment through work?

Social Security's Ticket to Work program and Work Incentives can help you find meaningful work. If you're age 18 through 64 and you receive Social Security disability benefits, you can take advantage of these free services.



**Choose a Ticket to Work employment services provider.
Work with your provider to plan a better future.**

Are You Ready to Choose Work?

Information/Resources

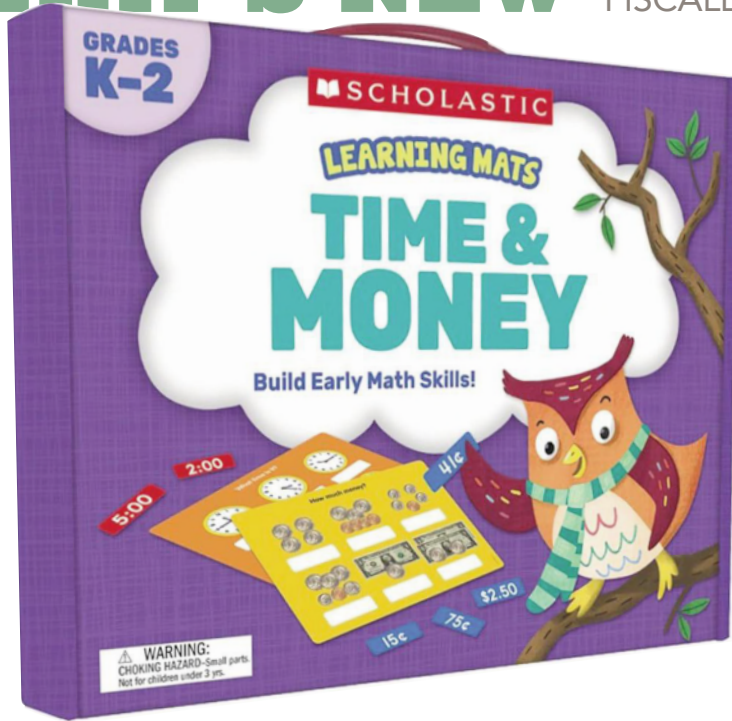
Call 1-866-968-7842 or
1-866-833-2967 (TTY)

Visit www.socialsecurity.gov/work
www.facebook.com/choosework



TICKET
to **Work**

WHAT'S NEW FISCALLY FUN



TIME AND MONEY LEARNING MATS

Time & Money Learning Mats are a new fun way to lead children on the road to literacy. Colorful mats and word tiles make learning and practicing telling time and counting money fun – this kit helps children practice these key skills. Start building a foundation for academic success. Each mat features six analog clock images on one side and six groups of currency images on the other; students find the corresponding digital time tiles

and numerical money tiles representing the images shown. Children can learn to tell time in hours, half-hours, quarter-hours, and to the nearest 5 minutes using analog clocks. They will identify the values of coins and bills, find the value of different money combinations and add simple money amounts.

concepts
SCHOOL SPECIALTY
www.schoolspecialty.com

WISE OWL TEACHING BANK

Children will learn money management skills with the Wise Owl Teaching Bank. Children can insert coins into three different compartments, labeled “save,” “spend,” and “share.” There is also a random option – just insert the coin in the top slot and let the owl decide! Early money management skills take on a fun interactive element thanks to this cute owl. The compartments’ clear plastic construc-



tion makes it easy to keep track of progress towards savings goals, identify when one area is out of balance with the others, or remove “spend” or “share” money once kids meet their goals. When it's not teaching valuable money skills, this unique bank also makes an adorable decor item in kids’ bedrooms or playrooms.

RAINBOW RESOURCE CENTER
www.rainbowresource.com



HAPE CHECKOUT REGISTER

Thanks to this Wooden Cash Register Pretend Playset, your child can start learning about the value of money early on. This 37 piece wood toy set comes with a pretend cash register, as well as code scanner and card reader. With included play money, coins, and credit cards, your child can open their own pretend store and role play. Not only does the checkout register provide little ones with creative role-playing fun, but it also helps foster communication and math skills important to your child’s development.

MAZIPLY
www.maziply.com



POWER PEN: MONEY

Here’s a super-fun way to build money skills – with instant reinforcement! Kids just touch an answer with the special pen, and the pen tells them if they’re right or wrong. Practice and reinforce important math skills. Identify coins and bills, and find the same amount in different denominations. Count to find what amount is shown and compare different amounts of money. Power Pen sold separately.

LAKESHORE LEARNING
www.lakeshorelearning.com

EP FOR FREE!

**RECEIVE A
FREE SUBSCRIPTION
TO THE DIGITAL VERSION OF
EXCEPTIONAL PARENT
MAGAZINE**

Simply visit us at
www.epmagazine.com
and click
"EP FOR FREE"
you will receive an email each month
when the magazine is published
as well as a free newsletter.

Both will come from
news@EPmagazine.com

Print subscriptions: \$199 a year;
Available at www.epmagazine.com
Questions: epmagazinevp@gmail.com

Empowering the
Special Needs
Community
since 1971



Subscribe Today at www.epmagazine.com

EP's ALL-NEW RESOURCE GUIDE FOR 2023

EXCEPTIONAL PARENT MAGAZINE • \$15.95
Early Intervention:
**STANDARDS
FOR EARLY
CARE**
Plus:
ESTATE
AND CARE
PLANNING

**2023
EP GUIDE**
NAVIGATING SPECIAL NEEDS RESOURCES

AI Solutions:
WHAT STUDENTS WITH
DISABILITIES NEED TO
SUCCEED IN COLLEGE

Special Olympics:
NAVIGATING YOUR
CHILD'S INTELLECTUAL
DISABILITY DIAGNOSIS

THIS ISSUE COURTESY OF
BLANKROME

52

AN AMAZING ADVERTISING OPPORTUNITY

With a dedicated readership and a rapidly expanding audience, more and more advertisers are taking advantage of the unique opportunities that Exceptional Parent can offer. Whether it's a full or half page ad in our print and digital magazine editions, or a dynamic banner ad on our www.epmagazine.com website, there has never been a better value enabling your products or services to capture a large and motivated readerhip. Discounts and special offers are available for cross-platform insertions.

We are now offering many additional opportunities for lasting partnerships that can affordably and effectively communicate your brand's message.

For more advertising opportunities, email us at
fsimon@epmagazine.com



EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

EMPOWERING FINANCIAL PLANNING & INDEPENDENCE THROUGH ABLE ACCOUNTS

HOW THE NATIONAL ABLE PROGRAM TRANSFORMS LIVES

BY ABLE TODAY

ABLE today's mission is to advance financial empowerment for people with disabilities by increasing the awareness of ABLE accounts.

The National ABLE Program continues to be a transformative force for individuals living with disabilities across the United States, which allows individuals to save money while helping them to protect benefits like Medicaid and SSI.

ABLE accounts offer eligible individuals with disabilities, a financial solution and sense of financial freedom to save, invest and spend resources in their accounts for disability-related expenses – all while maintaining important benefits like Medicaid and Supplemental Security Income (SSI). In this article, we will provide additional background on the National ABLE Program: how to use an ABLE account for short-term spending and long-term savings, as well as how to partner with ABLE today to access additional ABLE educational opportunities.

UNDERSTANDING THE NATIONAL ABLE PROGRAM

The Stephen Beck Jr., *Achieving a Better Life Experience (ABLE) Act*, was a legislative concept that took four U.S. Congresses and almost a decade to enact into federal law. The primary purpose is to enable individuals with disabilities to save and invest funds without jeopardizing their eligibility for critical government benefits, such as, Medicaid and SSI. These tax-advantaged savings accounts are designed to cover expenses that enhance the quality of life for people with disabilities.

HOW TO USE AN ABLE ACCOUNT FOR SHORT TERM SPENDING

Qualified Disability Expenses (QDEs) are the cornerstone of the ABLE program. These expenses include a wide array of costs directly related to the disability of the account holder, such as housing, education, transportation, employment training, assistive technology, personal support services, and health and wellness. The flexibility of QDEs allows account holders to significantly improve their overall well-being.

HOW TO USE AN ABLE ACCOUNT FOR LONG TERM SAVINGS

The National ABLE Program is modelled after the traditional 529 College/University Savings Program. Thus, in addition to saving for QDEs, individuals with disabilities are also able to invest their savings for the long-term, in their ABLE account, just like in a 529 account. Earnings on ABLE accounts grow free of federal income taxes, so long as account proceeds are used to purchase Qualified Disability Expenses. Many state ABLE programs also offer a state income tax deduction or credit for contributions to ABLE accounts.

ABLE ACCOUNT HOLDERS : SUCCESS STORIES

To illustrate the profound impact of the National ABLE Program, here are some possible scenarios.

MARIA'S PURSUIT OF EDUCATION

Maria, a young woman with Down syndrome, dreams of pursuing a college education. With her ABLE account, she can save for tuition, textbooks, and other education-related expenses. This enables her to fulfill her academic aspirations while preserving her eligibility for Medicaid, which covers her essential healthcare needs.

JAKE'S QUEST FOR INDEPENDENCE

Jake is a wheelchair-bound professional who wishes to modify his living space to accommodate his mobility needs. Using his ABLE account, he can invest in home modifications like ramps and accessible bathrooms. These expenses directly contribute to his independence and quality of life while ensuring he continues to receive SSI.

SOPHIE'S JOURNEY TO WORK

Sophie has cerebral palsy and is passionate about working in a field she's truly passionate about. Her ABLE account allows her to cover transportation costs, personal support services, and job-related expenses, empowering her to maintain steady employment without risking her government assistance.

DAVID'S PURSUIT OF HEALTH

David, a man with a visual impairment, requires specialized medical equipment and services. His ABLE account enables him to pay for adaptive technology and support services, improving his daily life, while Medicaid continues to cover his essential healthcare needs.

ABLE accounts offer eligible individuals with disabilities, a financial solution and sense of financial independence. •

ABOUT ABLE TODAY



ABLE today is committed to sharing information on ABLE accounts directly to the disability community. ABLE today partners with disability organizations, government agencies, employers and other key stakeholders to share free resources and provide in-person / virtual educational webinars on ABLE. You can learn more ABLE today, please visit www.abletoday.org. To partner together on hosting an ABLE presentation for your organization or group, please email sara@abletoday.org.



BanTec SANITIZING

EXPOSURE RESPONSE

BANTEC SANITIZING IS YOUR ALLY IN THE FIGHT AGAINST COVID-19

With efficient and affordable solutions for cleaning and safely sanitizing residential, school and business settings, BanTec Sanitizing can help you prepare for living, learning and working in a safe and healthy environment.

COMMERCIAL AND RESIDENTIAL CLEANING PRODUCTS & SERVICES



HOME



SCHOOL



OFFICE

EXCLUSIVE OFFER

BANTEC DISINFECTING KIT

Easy for anyone to use in multiple environments to protect themselves by disinfecting touch surfaces they encounter throughout the day. Perfect for use between cleanings. Featuring Enviro-Pro® products which meet the EPA's criteria for use against the novel coronavirus. Each kit contains:

- 3 gallons CleanSmart Enviro-Pro
- 1 1/8 oz. dispensing pump
- 1 1/8 oz. dispensing pump
- 2 each 32-oz. Enviro-Pro labeled spray bottles
- 2 each spray bottles triggers
- 1 box of disposable gloves
- 1 pack of 12 machine washable microfiber cloths
- 2 each disposable, non-medical face masks
- 1 pack disposable dusting sheets
- Directions, tips and more.



www.bantec.store/products/bantec-disinfecting-kit



INDUSTRY INNOVATOR

BANTEC AUTONOMOUS SOLUTIONS

BanTec Sanitizing has expanded its variety of products and services to help facility managers, safety professionals, and maintenance personnel to include autonomous health monitoring, sanitizing and teaching self-driving humanoid robots. Systems such as the Cruzr Health Monitor, below, can improve workplace safety and present helpful information.

Autonomous Mobile Solution

- Navigates autonomously
- No manual repositioning needed
- Up to 8 hours autonomy (6 hours to recharge)
- Automatic docking and recharging

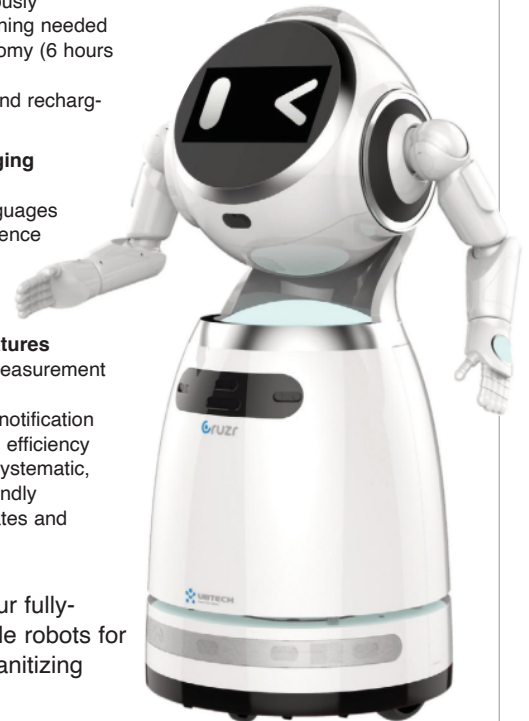
Interactive and Engaging Humanoid Robot

- Speaks multiple languages
- Detects human presence
- Deploys information (text, pictures, videos and more)

Health Monitoring Features

- Body temperature measurement and notification
- Mask detection and notification
- Increases workplace efficiency
- Engaging, reliable, systematic, tireless and user-friendly
- Reduces infection rates and associated costs

Learn more about our fully-programmable mobile robots for health monitoring, sanitizing and education:



<https://bantec.store/products/cruzr-health-monitor>



A DIVISION OF
BANTEC

www.bantec.store



ENDLESS POSSIBILITIES

Montclair State University's nationally recognized programs deliver superior student outcomes. Our welcoming and inclusive community empowers students from all backgrounds to realize their most ambitious dreams.

Learn more at montclair.edu/exceptional.

NEW JERSEY'S
PREMIER
PUBLIC SERVICE
UNIVERSITY



MONTCLAIR STATE
UNIVERSITY



Discuss The Future Needs Of Dependents With Special Needs

TOPIC SUGGESTIONS FOR PLANNING MEETING WITH FAMILY/FRIENDS

COURTESY OF MASSACHUSETTS MUTUAL LIFE INSURANCE COMPANY (MASSMUTUAL) SPECIALCARE

Just as caring for a dependent with special needs is a family affair, so is the related planning.

It is recommended that caregivers host a meeting with family/friends to discuss the future medical, educational, and housing needs of their dependent with special needs. Share information about you and your dependent's vision of the future and discuss any concerns and options for future care.

A person-centered life care planning process focuses on the

development of a Life Care Plan that will enable the person with a disability to obtain the best quality of life possible. You, your loved one with special needs, if applicable, and your team of professionals should work collectively to help develop a life care plan that best suits the needs of a person with a disability – now and far into the future.

PLANNING MEETING WITH FAMILY/FRIENDS : TOPIC SUGGESTIONS FOR FUTURE NEEDS DISCUSSIONS

You, your loved one with special needs, if applicable, and your team of professionals should work collectively to help develop a life care plan that best suits the needs of a person with a disability. Here are some recommended topics of discussion.



LETTER OF INTENT (LOI)

(Recommended to be completed prior to meeting)

- Explain what a Letter of Intent is. A Letter of Intent can be used as part of a special needs estate planning process. Although it is not legally binding, this document provides direction for the person(s) who will care for the dependent with special needs in the future. It should detail medical history, daily care needs, housing and services, as well as specific wishes and expectations as they relate to the dependent's future. It is a working document for the future caregiver(s) to follow that is updated regularly.
- Discuss the process of your Letter of Intent (written or video format) with your family/friends/professionals and make any necessary updates and changes (the LOI is a work in progress, it is never fully done and needs to be updated as situations change)
- Advise your family/friends/professionals where your Letter of Intent is located, should it need to be accessed.



GOVERNMENT BENEFITS

- Inform your family/friends what government benefits your loved one with special needs is receiving, if applicable.
- Government benefits may help to provide for the needs of a loved one with special needs in the form of medical treatments and supplies, equipment, financial assistance and more. Some supports they may be entitled to, while others they may have to apply and qualify for. Here are some examples, however, benefits vary by state and jurisdiction.

Entitlement Benefits	Public Assistance
<i>Social Security Retirement Income</i>	<i>Supplemental Security Income (SSI)</i>
<i>Social Security Disability Insurance (SSDI)</i>	<i>Medicaid</i>
<i>Family benefits</i>	<i>Public Supports</i>
<i>Spouse and Survivor Benefits</i>	<i>Supplemental Nutrition Assistance Program (SNAP)</i>
<i>Children's Disability Benefit</i>	<i>Temporary Assistance for Needy Families (TANF)</i>
<i>Medicare</i>	<i>Children's Health Insurance Program (CHIP)</i>

For more information, visit www.ssa.gov

- Communicate the importance of not having any assets in your dependent's name over the \$2,000 limit, in most states, for them to continue qualifying for SSI and Medicaid, if applicable. Examples of such assets include:
 - ▷ *Cash, art, jewelry, etc. worth more than \$2,000*
 - ▷ *Inheritance and inherited assets*
 - ▷ *Insurance benefits*



BENEFICIARY DESIGNATIONS

- Recommend everyone review their beneficiary, transfer on death (TOD), paid on death (POD) designations on their accounts, such as life insurance policies, bank accounts, and align with all legal documents (wills, trusts, etc.) to ensure money is not left directly to the dependent with special needs or it could disqualify their eligibility for government benefits.
- There are distinct ways to leave money to individuals with special needs so that their government benefits are not lost, such as through a Special Needs Trust or ABLE Account.



SPECIAL NEEDS TRUSTS BENEFITS

- If you have a Special Needs Trust already established or plan on setting one up, explain to your family that money can still be left to an individual with special needs by listing your dependent's special needs trust as the beneficiary.
- Explain what a special needs trust is in general and how it can benefit your loved one with special needs:

A special needs trust may offer a means of protecting a dependent with special needs' eligibility for government benefits, while addressing their ongoing care and needs.

In general, a trust is an arrangement by which property is held by one party (the trustee) to benefit someone else (the beneficiary). Different types of trusts suit different needs and may have different tax implications. There are two main types of special needs trusts: first party and third party depending upon the source of the funds.

A trust created to benefit a person with special needs can:

- ▷ *receive assets, such as an inheritance, a court settlement, an insurance claim payment, gifts of money, or life insurance proceeds,*
- ▷ *protect current or future government benefits, and*
- ▷ *pay for medical care, special equipment, education, entertainment, transportation, and more.*
- Consult an attorney who has experience with special needs planning. A financial professional with experience in working with special needs families can help with funding options for special needs trusts.



ABLE ACCOUNTS

If your loved one with special needs has an ABL account already, share this information with your family/friends and explain what an ABL Account is.

What Is An Able Account?

ABLE (Achieving a Better Life Experience) accounts allows eligible individuals with special needs who have a disability that manifested itself before the age of 26 to open tax-advantaged savings accounts. Only one ABL Account can be opened per eligible individual. The account can be established by the eligible dependent with special needs, or their parent, legal guardian, or agent acting pursuant to a power of attorney. ABL accounts are developed and managed on a state level. Most states allow deposits from out of state residents so even if your state does not have the program you may still be able to sign up for another state's account.

The funds can come from either the individual with special needs or any third person (including family, friends, co-workers, Special Needs Trust, or Pooled Trust).

Income earned by the ABL account is not taxed. Contributions must be made with post-taxed dollars and is not tax deductible for federal taxes, however, some states may allow for state income tax deductions for contributions made to an ABL account.

Funds in a 529 college savings plan can be moved into an ABL account without incurring

tax or penalties if both accounts have the same beneficiary or a qualifying member of the beneficiary's family. The rollover amount must be within the annual ABL contribution limit (\$17,000 in 2023) and must occur by December 31, 2025. There are direct rollovers where the two programs transfer assets directly from one to the other. And there are indirect rollovers in which the account owner of the 529 plan would take possession of funds before they are transferred. The transfer must occur within 60 days of withdrawal.

Money from the individual with a disability's special needs trust may also be moved into their ABL account with no tax consequences, again, while staying within the annual ABL contribution limit.

The funds can be used for a range of expenses related to the disability of the dependent, such as education, housing, transportation, health, prevention and wellness, financial management, administrative services, legal fees, personal support services, employment training, etc. In most states, upon death of the dependent with special needs or termination of the account, there is a Medicaid pay-back provision in most states regardless of who deposited the funds. Some states are doing away with the Medicaid pay-back provision.

Annual Contributions

A total of \$17,000 for 2023, plus an addi-

tional \$13,590 can be contributed from the earnings of the beneficiary.

If the ABL account owner is employed and does not participate in their employer's defined contribution plan (such as a 401(k) plan, profit-sharing plan, 403(b) plan, or 457(b) plan), they may make an additional annual contribution up to the lesser of:

1. *The ABL account owner's compensation from their employer for the tax year*
OR
2. *The United States poverty line amount in 2023 of \$15,630 in Hawaii, \$16,990 in Alaska, or \$13,590 in all other U.S. states*

Total Account Limit Maximum

The maximum accumulation amount in the ABL account is subject to the individual state's limit, based on the state's cap for the traditional 529 Plans. The amount can range from \$235,000 to \$550,000 for 2023.

For ABL account owner's receiving Supplemental Security Income (SSI), if the account combined with their other resources exceeds \$100,000 there will be a suspension of their SSI until all their resources no longer exceed the \$100,000 limit. However, there is no effect on benefits under the Medicaid program, even if a beneficiary's SSI is suspended because the account exceeds the \$100,000 limit.

For the most current information and states that offer an ABL Account, visit www.ablenrc.org



YOUR TEAM OF PROFESSIONALS

It's important to pull together a support team of professionals that can help guide caregivers through the variety of options available to plan for the future care of dependents with special needs.

The composition of the team may vary depending on your unique situation, but it should include you and your loved one with special needs, if applicable, working collaboratively with professionals

who have experience in working with special needs families, such as:

- *Special needs financial professional*
- *Special needs attorney, and*
- *Perhaps a health professional and a school guidance counselor, among others.*

Advise your family who will be on your "Team" to assist you with executing your plan for your loved one's future.



SpecialCare is a program created by MassMutual that provides access to information, specialists and financial solutions to people with disabilities and their families. For more information about Massachusetts Mutual Life Insurance Company (MassMutual) and its SpecialCare program, please visit www.massmutual.com/specialcare.

The information provided is not written or intended as specific tax or legal advice. MassMutual, its subsidiaries, employees, and representatives are not authorized to give tax or legal advice. Individuals are encouraged to seek advice from their own tax or legal counsel. Individuals involved in the estate planning process should work with an estate planning team, including their own personal legal or tax counsel.

3 OPTIONS

TO GIVE YOUR CHILD WITH ADDITIONAL NEEDS MORE FINANCIAL SECURITY

BY GRAHAM CALDOW

The problems you currently face with how to give your child with additional needs more financial security are those we also faced as a family. We developed a way to make a life plan for our daughter and our life plan will work for you too.

We created the Red Giraffe Route Map by dividing the main aspects of her life into four categories which we liken to train lines: the Daily Living line, the Relationships line, the Purpose line and the Finance line.

Everyone needs money for their long-term security, but our young adults may rely more heavily on others to help plan and manage this security. Financial security underpins their long-term future, and for this reason, careful planning of the Financial line is imperative.

Disclaimer: Everything that follows is for educational purposes only. It is not intended to be financial advice and should not be used as such.

You should seek professional advice from someone suitably qualified, who can tailor advice specifically to your circumstances.

The central concern of the Financial line is how your child's finances will be organized. It all starts with deciding who controls their finances. Everyone wants to leave their children financially secure but the question is, how? At one end of the continuum is a guardianship, where their finances are fully controlled by someone else. At the other end is complete autonomy where they control all their own finances. In between, are numerous other permutations. Each has advantages and disadvantages. We must decide the best way to offer our children financial security when we are not around to support them. For this, we need a vision of how their financial affairs will be organized.





1. GUARDIANSHIPS

Guardianships give complete control of their finances to someone else. There are many advantages, and for some, this is the best option, not only to protect your child financially, but also to look out for their best interests, both physically and emotionally.

If your child is to live the life they want (and you want them to have), they must have financial security. Ideally, they should have as much financial autonomy as possible, because this encourages greater independence. But if you are leaving them money through inheritance, you have a right to expect it will be used wisely. Our children are disproportionately poorer compared to other groups in society; so, ensuring a sound financial future is imperative. Regardless of the exact solution or combination of financial

options you elect to use, we need to organize their financial affairs to give them as much security as possible, for when we are not around to support them.

Vision on the Financial line requires us to answer a key question: does my child need a guardianship to protect them? Often this is a matter of personal choice, but we should always allow them as much autonomy as possible. Not being financially literate is not, I believe, a reason to stop them from having control over their finances – many people aren't that financially literate, and yet they manage to get by. However, that's not to say you shouldn't use the tools available to protect major assets or inheritances they might receive.



2. TRUSTS

Next to guardianships on the Financial line and close in terms of control, are Trusts. You may use something like a special needs trust to hold assets, which means finding a balance between the finances your child controls and those controlled by the trustees.

Assets put in a trust do not belong to your child. This has important implications when applying for government support, as the asset is not considered theirs and it cannot be regarded as money they have available. This is important if applying for means-tested benefits or other forms of financially assessed support, where having too much money available can prevent a successful application for government support. This is often the main reason why parents set up trusts for their children.

There are also other benefits to a trust. It can offer a degree of protection for your child, as well as financial security. For example, if you leave the house in which they live to a trust, they will always

have a place to live, but that house is not considered 'theirs'. This means that even if they are not good at managing their own money, they cannot get into debt to the point where their home is taken into foreclosure. They can't be defrauded out of it. If they became romantically involved and the relationship ends, a partner could not claim half the asset, because your child does not own it.

Setting up a trust is not as difficult as people imagine. Trusts for the most part follow the same basic pattern. There is a 'settlor' (the person who starts the trust), a 'beneficiary' (the person who gets money and assets from the trust), and a number of 'trustees' (people who run and administer the trust, and the legal owners of the assets held in the trust). Most trusts have at least two people as trustees, most likely starting with you. They can be set up by a lawyer or financial adviser, who will talk you through the process in more detail.

From my experience, setting up a trust is a great deal easier to do than deciding who future trustees might be. You could use professional people as future trustees, but this will come at a cost. Lawyers and accountants charge for their time, and over the years these costs can mount up. However, this option will ensure that the trust is likely to be well-managed and meet its legal and regulatory obligations.

If you choose nonprofessionals, there are certain things you should consider:

- *Are the possible trustees young enough to be around for your child well into the future?*
- *Are they good money managers themselves?*
- *Are they willing and capable of handling the responsibility?*
- *Are they good administrators? Being good with money is not the same as doing the necessary paperwork each year after the trust becomes active.*

I would advise against any automatic assumption in favour of choosing family members as trustees. They may not be impartial, and may not always follow your instructions as closely as paid professionals or slightly more distanced non-professionals might. Whoever is in control of their finances needs to know your intentions, so they can facilitate the financing of it.



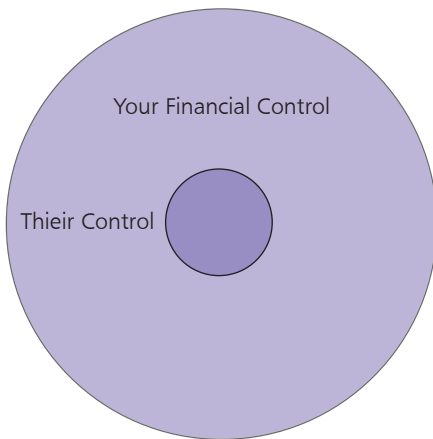


3. PASSING OVER GREATER CONTROL TO YOUR CHILD

At the other end of the continuum is the option of letting your child have complete control over their finances. This can be a worrying prospect for any parent, but do remember that our children are frequently more capable than we imagine, and safety nets and plans can be put in place to help. Fixed expenses can often be managed by your child when you establish a workable system to control them, and many young adults are capable of working within clearly defined rules, if the purpose and rationale are explained to them in advance.

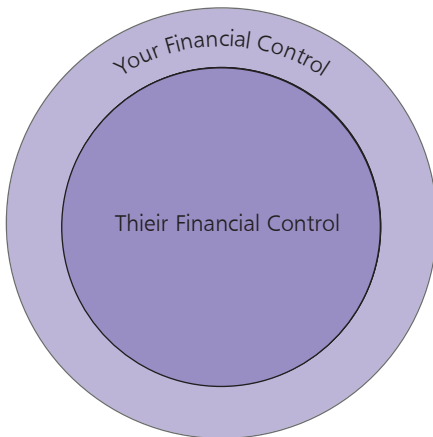
While this is a huge milestone in the maturity of your child, this handover also signifies more. It is the start of you separating your finances from theirs.

When they are a child, their finances could be visually represented like this:



You have control over their financial affairs. You control income and manage all expenses like: housing, utility bills, clothing, food, and leisure. They have a small amount of control within this, possibly with only their pocket money to spend.

As they get older, they may take on a greater degree of financial control. This might look something like this:



Here they have taken over most aspects of their finances, from paying for housing to utility costs, from clothing to leisure spending, and all else in between. They are by far the biggest financial player, but you may still have control, perhaps via a trust and the assets you have put in the trust. Your protective ring encloses their circle of control, however large it might be.

The size of the circle in the middle may vary from person to person. For example, a trust might pay their utility bills and housing costs, while they control all other aspects of their spending. The logic behind this could be to ensure they always have a home with the heating and lights on. The inner circle may be significantly smaller if their ability to manage their finances is more restricted. But it should always be as large as can be safely managed. When you are considering options, you want to ask how large that inner circle can safely be made. How much financial independence should we give them while, at the same time, maintaining their financial security?

“A life plan will enable your child to live their best life – to prioritise what’s important for them, to consider what will give them a happy life, a sense of purpose and meaning, pride and self-respect, and a greater feeling of being independent, autonomous people.”

The Financial line is slightly different from the other lines, because so much of it is within your direct control. The more deeply you plan and organise, the greater the beneficial effect. The thing that sometimes stops people thinking

about this, however, is that it relies on us thinking about our mortality. We need to make decisions about how their finances will work long after we have died, and we also need to make plans for our own finances in our will. This can be difficult.

A life plan will enable your child to live their best life. Time has been taken to plan and prioritise what’s important for them, to consider what will give them a happy life, what will give them a sense of purpose and meaning, what will give them pride and self-respect, and what will give them a greater feeling of being independent, autonomous people. •

ABOUT THE AUTHOR:



Graham Caldwell’s mission is to help parents of children and young adults with additional needs answer the question: “What’s next for my child?” As the parent of a young adult with additional needs himself, his ultimate goal is to ensure they are financially secure and live with dignity. Through his new book *What’s Possible?*, Graham is dedicated to helping other parents and guardians support their own young adults with additional needs through bespoke life plans, covering topics such as finances, building a community, developing independence skills and living with purpose. This is an adapted extract from *What’s Possible? Plan a Better Future for Your Child with Additional Needs*.

www.amazon.com/Whats-Possible-better-future-additional/dp/BOCJLMV4B2



**“Working
lets me...**

**keep
contributing.”**



**earn
a living.”**



**be there for
the team.”**

**provide
for my family.”**

Working Works.

America works best when *all* Americans can work. Ensuring workers can stay on the job or return to work following an injury or illness is essential to America's economy.

WhatCanYouDoCampaign.org



OFFICE OF DISABILITY EMPLOYMENT POLICY
UNITED STATES DEPARTMENT OF LABOR

**What can
YOU do?**
THE CAMPAIGN FOR
DISABILITY EMPLOYMENT



OVERCOMING ANALYSIS PARALYSIS AND PLANNING FOR YOUR CHILD'S FUTURE

BY COREY BRISKEY, MPH

BEING A CAREGIVER TO A CHILD WITH A DISABILITY LEAVES YOU WITH A LOT OF WORRIES ABOUT YOUR CHILD'S CURRENT HEALTH AND WELL-BEING, AS WELL AS FEARS FOR THE FUTURE.

The problem is many caregivers are already too overwhelmed with managing their child's daily life to take the time to explore future scenarios and plan for those. As a mother to a seven-year-old with disabilities, I know that feeling all too well.

As caregivers we take on so many roles, including therapist, doctor, advocate, and let's not forget... parent. Also taking on the role of financial planner can be daunting and easy to put off. Like me, you might be tempted to wait to see how things look a few years down the road, so you can plan based on what developmental and health level your child is at. But also like me, you might be paralyzed by the mountain of information you need to learn, and the hefty decisions you will need to make, in order to properly support your child's future.

But it's important to educate yourself about the options you have to make for your child, and start putting a plan in place. You never know what the future will hold.

Starting now will help alleviate stress levels that you may not realize are weighing you down, like a homework assignment you've put off, but will eventually have to complete. You are not alone in this feeling. I want to validate your experience and let you know, even just taking one step towards planning and educating yourself will help to propel you forward. Here are three actions you can take to start the process:

- 1. Schedule it on your calendar:** *Scheduling yourself a one-hour block during the day will give you a concrete time to address planning, which will relieve the pressure of knowing you have to do something, but don't know when.*
- 2. Start small:** *Don't tackle the whole task at once. Give yourself time to look through resources and educate yourself, without overwhelming yourself. Small bits of information are easier to digest and remember, than large chunks.*
- 3. Talk to someone knowledgeable:** *Find a forum or a fellow parent that has been through the process. You might even want to consult a professional. Most disability attorneys will be able to explain the basics and start you on the right path. Once you talk to a person that is very knowledgeable, you will feel more at ease. You will be able to better understand the decisions you will have to make, and the small next steps in the planning process. Don't let the unknown get in the way of taking action.*

To get you started on your path to educating yourself and for planning your child's future, here's a checklist and resources you can access now, to help jumpstart the process. Just remember, small steps can get you all the way there. You got this!

ABOUT THE AUTHOR:



Corey Briskey, MPH is a mom of two wonderful children, one of which is medically complex and has disabilities. Corey is a writer, blogger, and a neurodiversity-affirming advocate for children with disabilities and their families. Corey has written a memoir, not yet published, centered around raising a child with disabilities, among the crushing pressures of society. She has a Master's degree in public health from the University of Buffalo and a bachelor's degree in psychology from The College at Brockport. You can follow Corey on Instagram (@corey-briskey) or view her website and subscribe to her blog at coreybriskey.com

JUMPSTART THE PROCESS : CHECKLISTS & RESOURCES

NEMOURS
KidsHealth
KIDSHEALTH

Checklist

<https://kidshealth.org/en/parents/needs-planning.html>

 **ABLE today.**

ABLE TODAY

ABLE Account Information

www.abletoday.org/overview

 **The Arc**

THE ARC

In-depth Planning Handbook

<https://futureplanning.thearc.org>

 **SNA**
SPECIAL NEEDS ALLIANCE

SPECIAL NEEDS ALLIANCE

Special Needs Trust

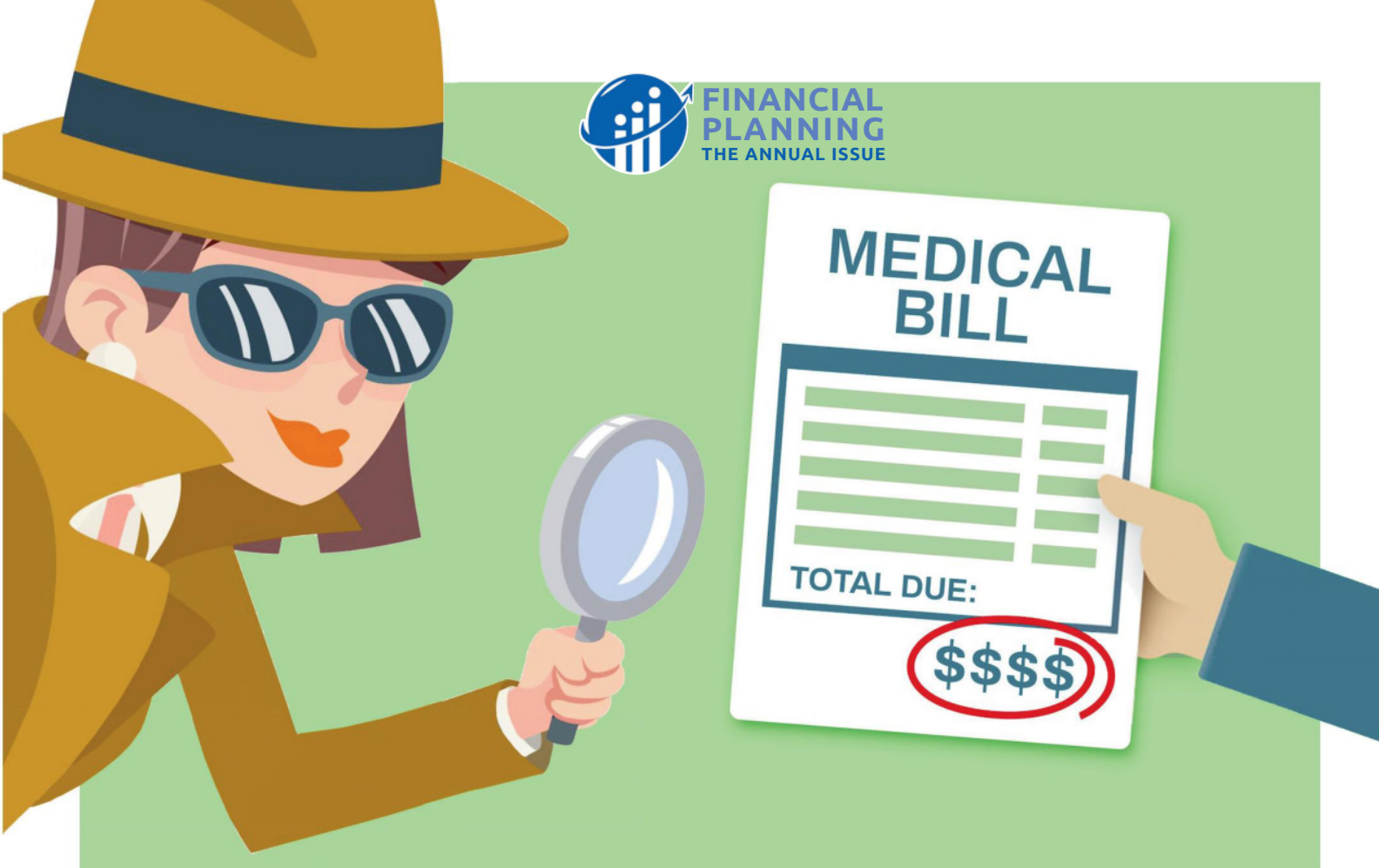
www.specialneedsalliance.org/the-voice/your-special-needs-trust-snt-defined-2

ABLE account vs Special Needs Trust - How to choose

www.specialneedsalliance.org/blog/able-accounts-and-snts-how-to-choose

Finding a Financial Planner

www.specialneedsalliance.org



OVERWHELMED WITH MEDICAL BILLS? IT HELPS TO THINK LIKE A DETECTIVE

BY JENNIFER MCLELLAND

As a parent of a child with medically complex conditions, I'm good at handling health emergencies. My child is tracheostomy dependent, which means that several times a day, his breathing tube gets blocked and I have to act quickly to clear it. When my son's ventilator alarm sounds, I know how to troubleshoot and figure out what went wrong, so he can keep breathing. Handling medical emergencies isn't hard for me anymore, it's just a part of life.

But handling all of the paperwork that the medical emergencies create? That's an entirely different skillset. Unlike with medical emergencies, parents get no training on how to deal with health care approval paperwork and bills. They must figure it out on their own. This used to be a huge source of stress for me, until I changed my mindset. Now, I'm no longer a frustrated mom sorting through bills and insurance denials – I'm a health care detective and I'm solving health care billing mysteries.

In my first career, I was a police officer. Being a mom to a med-

ically fragile child is actually very similar. There are moments of life-threatening danger where I have to act quickly and decisively, followed by hours of paperwork. Being good at emergencies keeps my son alive. Being good at paperwork means my son gets the care he needs and the bills get paid. Some bills do end up being my responsibility, but understanding the terms and the rules of his three health insurance programs: Medi-Cal (California's version of Medicaid), California Children's Services and our private insurance) means that I don't panic when I get a stray bill for more than my car is worth.

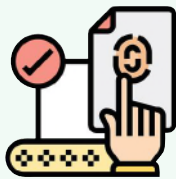
JUST THE FACTS : FIVE STEPS FOR TACKLING MEDICAL PAPERWORK LIKE A DETECTIVE

Thinking of myself as a health care detective who is solving a mystery, makes a frustrating process feel a little bit more interesting. You have to figure out the motive, gather the evidence, interrogate the suspects, and put together a case. Every health care paperwork problem is slightly different, so any advice on how to solve these problems has to be broad. But if you can think like a detective, you too can solve medical billing mysteries. Here are my five steps for tackling medical paperwork like a detective:



1. MOTIVE MATTERS

To figure out how to fix a medical bill, you have to figure out why the bill exists. Providers are trying to get paid for the care they've already provided — that's their motive. Insurance companies and Medi-Cal (California's version of Medicaid) managed care plans have conflicted motives. At first glance, it might seem like they're trying not to pay claims to save themselves money. But on an individual case level, it's more likely they're not paying the claim because the paperwork isn't quite right. Never attribute to malice what can be adequately explained by bureaucracy. The people denying the claim don't personally profit off of not paying your claim, they often just need someone to send them information that they don't have yet.



2. GATHER AND EXAMINE THE EVIDENCE

This means sitting down at the kitchen table and spreading out all the paperwork you can find, related to the bill. When you receive a health care bill, you can match the information on the bill to the claim that was (hopefully) filed with your insurance company. If you're being asked to pay, it's a bill. If the insurance company is being asked to pay, it's a claim. If a claim wasn't filed it can be an easy fix, just call the number on the bill and make sure the agency sending the bill has your correct insurance information. If you have private insurance, every claim that is filed generates an explanation of benefits (a document that explains what insurance is going to cover). You can usually access this through your insurance company's online portal, or you can choose to have them mailed to you. If you have Medi-Cal, you'll receive a different document called a notice of action for any claim that is denied, but you generally won't receive anything if the claim is paid.

As you scour the evidence, keep in mind, if you have private insurance, you are generally responsible for copays, deductibles and coinsurance for covered, in-network services. Every policy is different, so you'll need to look at the rules for your specific policy. The explanation of benefits paperwork will tell you why you are being asked to pay. If you're confused by their reasons, you can call and ask for more details. If you understand their reasons but you still disagree, you can file an appeal.



3. INTERROGATE THE SUSPECTS

Once you've examined the evidence, you'll probably have an idea of why the bill hasn't been paid, but you'll need to confirm your theory. In order to solve the mystery, you're going to have to interrogate the suspects and try to get a confession. There are a lot of suspects: Separate bills can come from hospitals, doctors and laboratories for things that happened at the same visit. In California, the bills could legally be the responsibility of private insurance, Medi-Cal or California Children's Services. They're all going to blame the problem on each other. Use this to your advantage. For example, if you suspect the insurance company ignored a fax sent over by the doctor's office, instead of accusing them of doing this, use your best customer service voice to ask if they can check to make sure the doctor's office actually sent the fax. In the end, all you need the insurance company to do is admit that they got the fax, by giving them the option of blaming someone else for the mistake, and you get the problem solved.



4. MAKE YOUR CASE

To resolve your claim, you have to put all the information together and make your case. The provider may have submitted their claim wrong or sent it to the wrong agency. Children with medically complex conditions frequently have multiple agencies covering their care — private insurance, Medi-Cal, California Children's Services and Regional Centers are all potentially responsible for a bill in California. Sometimes the problem is that the agencies were billed in the wrong order. For example, if Medi-Cal is the secondary insurance, then private insurance needs to either pay or deny the claim first. Sometimes the problem is that two agencies — commonly here: Medi-Cal and California Children's Services — each say that the other agency is responsible for the bill. Once you've figured out where the claim went wrong, you can usually find a way to fix it either by making some phone calls or filing an appeal. The appeal can be intimidating — but when you're a health care detective you're not intimidated by paperwork.



5. CALL FOR BACKUP

Knowing when to call for backup is critical. If you can't figure out a health care billing problem on your own, there are agencies that can help. Case management services are available through private insurance, Medi-Cal and California Children's Service, in California. Think of case management services as a private detective that you're hiring to do some of the legwork in your investigation. The Department of Managed Health Care Services regulates private health insurance companies and provides resources to help you understand the appeals process.

The Health Consumer Alliance operates a hotline that can provide direct assistance with health insurance appeals and grievances.

Children and youth with special health care needs don't always qualify for Medi-Cal insurance, but if they do, there are special protections. Children with intellectual disabilities or medically intensive care needs can qualify for Medi-Cal through waiver programs, even if their family income is over the established limit. If you go to a provider who accepts Medi-Cal, they are legally required to accept what Medi-Cal pays them as payment in full, even if they're not in-network with your Medi-Cal Managed Care Organization. That means they're not legally allowed to bill the patient for anything. (If a provider does not accept Medi-Cal payments at all, this rule doesn't apply). If you have a problem with a Medi-Cal provider that you can't resolve, the Medi-Cal Managed Care Ombudsman can help.

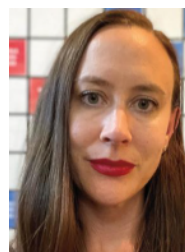
My hope is that these steps will help all the harried caregivers out there struggling with medical paperwork. Admittedly, I still get a knot of fear in my stomach when I open bill-sized envelopes from medical providers, even though I know we have good insurance coverage. But once I sit down at the table with my trusty yellow highlighter, I know I have the tools to figure out the problem. These same detective skills can work in advance of a bill too — you can troubleshoot prior authorizations and pharmacy approvals using the same set of steps, you just have to do it before the bill arrives instead of after.

Exciting, right? Who knows, maybe medical billing detectives could be the next crossover primetime show. Instead of handsome doctors performing surgery, it would show overworked moms sitting at the kitchen table, on hold with insurance companies, and billing department employees, faxing prior authorization forms. I doubt anyone else would watch it — but I would. •

This article was produced in collaboration with the California Health Report; Check in your state for corresponding organizations .

Agency or Service	Availability
Medi-Cal (CA's version of Medicaid)	Different names in other states
California Children's Services	Doesn't exist in other states
Dept. of Managed Health Care	Every state has an equivalent
Regional DD Center	Each state has their own
Health Consumer Alliance	Each state has their own
Managed Care Ombudsman	Some states have this, most don't

ABOUT THE AUTHOR:



Jennifer McLelland has a bachelor's degree in public policy and management from the University of Southern California and a master's degree in criminology from California State University, Fresno. She worked for the Fresno Police Department in patrol for eight years. She is currently a stay-at-home mother and paid caregiver through the In-Home Supportive Services program. She is active in advocating for disability rights and home- and community-based services.



Abilities EXPO

Serving the Community
Since 1979

Access Your World

Find out how at Abilities Expo.

Knock these off your bucket list:

- Test drive the latest product & tech
- Consult experts from the disability community
- Push your limits with adaptive activities
- Network with your Expo family
- Get the answers you need

Ft. Lauderdale October 13-15, 2023 **Dallas** Dec. 1-3, 2023 **Los Angeles** March 15-17, 2024 **New York Metro** May 3-5, 2024

Chicago June 21-23, 2024 **Houston** August 2-4, 2024 **Phoenix** September 6-8, 2024



Abilities.com

Get registered and join us!

FREE
ADMISSION



@AbilitiesExpo



@AbilitiesExpo



@abilities_expo

“One solution that works beautifully for many families is a model called Shared Living. In this person-centered model, people with disabilities choose to live together, sharing the cost of housing and support services.”



QUESTIONS ABOUT YOUR LOVED ONE'S FUTURE HOUSING

BY PAM BLANTON



GOOD CHEERS: IDD residents Samantha Y., Erica A. and Clarise G. enjoy sharing time in the kitchen with their live-in caregiver.



During my 30 years working in the field of special needs housing, I've met so many moms, dads, siblings and other family members who worry about the future. Many of them believe the only real option is for their loved one to live at home, forever.

Living outside the family home poses many unknowns, including these three big questions:

- *What does my family member need to live outside our family home?*
- *Who will they live with?*
- *How will we afford it?*

These questions can be daunting. While it might be tough to think about now, it's important to plan for that day when your loved one may want to move out, or when you are no longer able to support your loved one at home. Many families find peace in exploring what supported housing might look like for their loved one, especially if they are not in a huge hurry or experiencing a crisis.

One solution that works beautifully for many families, and helps answer these three important questions, is a model called Shared Living. In this person-centered model, people with disabilities choose to live together, sharing the cost of housing and support services.

PUTTING THE PIECES TOGETHER

Unlike other housing models, the Shared Living model is completely family driven. Compatible individuals and their families work together to develop caregiver agreements and job descriptions. They decide whether to rent or buy. They develop household budgets and guidelines for the home. They hire caregivers, develop family commitment agreements, and decide how to provide coverage during the caregiver's days off or in emergencies.

Putting all the pieces together can feel like a jigsaw puzzle. Below are some things you can start doing now to be ready for whatever the future holds.

AVOID THIS COMMON "IN-KIND" MISTAKE TO MAXIMIZE YOUR LOVED ONE'S SSI

The federal Supplemental Security Income (SSI) program (www.ssa.gov/benefits/ssi) pays benefits to adults and children with

disabilities, who have limited income and resources. Once an individual turns 18, this benefit is based on the individual's income, not the family's income. The 2023 maximum benefit for an adult with disabilities is \$914. Medicaid comes automatically with SSI, and Medicaid also funds state services.

The amount the individual receives depends on the individual's income; both earned income and "in-kind" income. SSI defines in-kind income as: "food, shelter, or both that you get for free or for less than its fair market value." If your loved one is living in your family home and not paying rent, the SSI benefit will be reduced by one-third.

The good news? Completing a simple rental agreement and submitting it to SSI will help ensure your loved one receives the full benefit amount.

BE PREPARED FOR THE STATE ASSESSMENT FOR MEDICAID WAIVER SERVICES

It's important to be prepared for your loved one's state Medicaid assessment, because this is how most state services are funded. Your local Arc (<https://thearc.org/find-a-chapter>) or other advocacy organization may be able to help you prepare. Understanding what will be considered during the assessment will help you present the right information to maximize your loved one's services from the state. Doing this while your loved one is living at home establishes the need for the services your loved one will need to thrive outside your family home.

GET ON THE WAITLIST FOR A SECTION 8 HOUSING VOUCHER

HUD's Housing Choice Voucher Program (Section 8) (www.hud.gov/topics/housing_choice_voucher_program_section_8) provides a valuable housing subsidy that makes rent more affordable. This is an important piece of the puzzle, if you are looking at a shared living solution. Section 8 waitlists are long, and it can take years to receive a voucher.

My advice is to start early, even if you and your loved one are not ready to make a move yet. Start by paying attention to waitlist openings in your area and apply as soon as they open. You can sign up on Affordablehousing.com to be notified when your local housing authority opens their waitlist.

To be eligible for a preference for Section 8, rent should be at least 50% of the monthly income.

DON'T FORGET TO APPLY FOR SNAP

Supplemental Nutrition Assistance Program (SNAP) benefits can help with food costs. Use this SNAP state directory (www.fns.usda.gov/snap/state-directory) to connect with the program in your state. Once your loved one is 18 and paying rent, they are considered the head of their own household. This is important to remember as your loved one transitions to adulthood, and you begin applying for benefits for them as an adult.

START SEARCHING FOR COMPATIBLE FAMILIES AND POTENTIAL ROOMMATES

Most young people, regardless of ability or special needs, have roommates when they move out of their family home. By sharing the cost of housing and services with compatible roommates, a Shared Living solution for your loved one will be more affordable. Roommates with common interests and lifestyles also offer friendship, which can prevent loneliness and isolation. You might start by looking at friends your loved one may know in community programs, school or work.

BEGINNING THE TRANSITION TOWARD INDEPENDENCE

While taking care of the details of applying for benefits, getting your finances in order and searching for roommates, don't lose sight of the big picture. The reason you are going through all of this is to help your loved one launch into a meaningful, more independent life.

Remember, housing isn't just about bricks and mortar. Encourage your loved one to get involved in meaningful community activities before moving out. Help your loved one think about volunteer opportunities or find community groups to join. Guide your loved one on using public transportation to get around town. Make time to explore the community and help your loved one find ways to engage. When it's time for your loved one to move into the new Shared Living home, you will all feel that much more confident. •

ABOUT THE AUTHOR:



Pam founded Partners4Housing to empower families of people with IDD to create Shared Living solutions. An acknowledged expert in the field of special needs housing, Pam was a 2007 "Friends of Housing" Award Honoree. As housing coordinator in Seattle, she helped more than 450 people with IDD move into housing over a 5-year period. Her in-depth working knowledge helps people navigate SSI, SSDI, State Residential Support, Medicaid-funded personal care services, supported employment income, and Section 8 housing subsidies.

To learn more about housing options, benefits, and finding compatible roommates, our Benefits and Housing Review is a great first step!



DYSLEXIA

fluency builders®

Results in Weeks... Not Years

www.earlyliteracysolutions.com

800.982.1290

Build wealth through Real Estate

Let us show
you in three
easy steps how
you can change
your life.

Unlike other investments, Real Estate is also a 'lifestyle asset'. That means setting yourself up for the future by generating wealth now, while creating family memories along the way.

visit oxygenmortgage.net or scan here



OXYGEN
Mortgage

Oxygen Mortgage LLC NMLS#2247462 Illinois Residential
Mortgage Licensee. AL,AZ,CO,IL,GA,FL,SC,NC,TN



An Equal Housing Lender

From helping choose the location, getting a mortgage and finding the best real estate agent, to managing the short term rental once you own it, let **Oxygen Mortgage** show you how you can build wealth from real estate, right now.

Call or text now to explore the possibilities
+1-720-308-0055

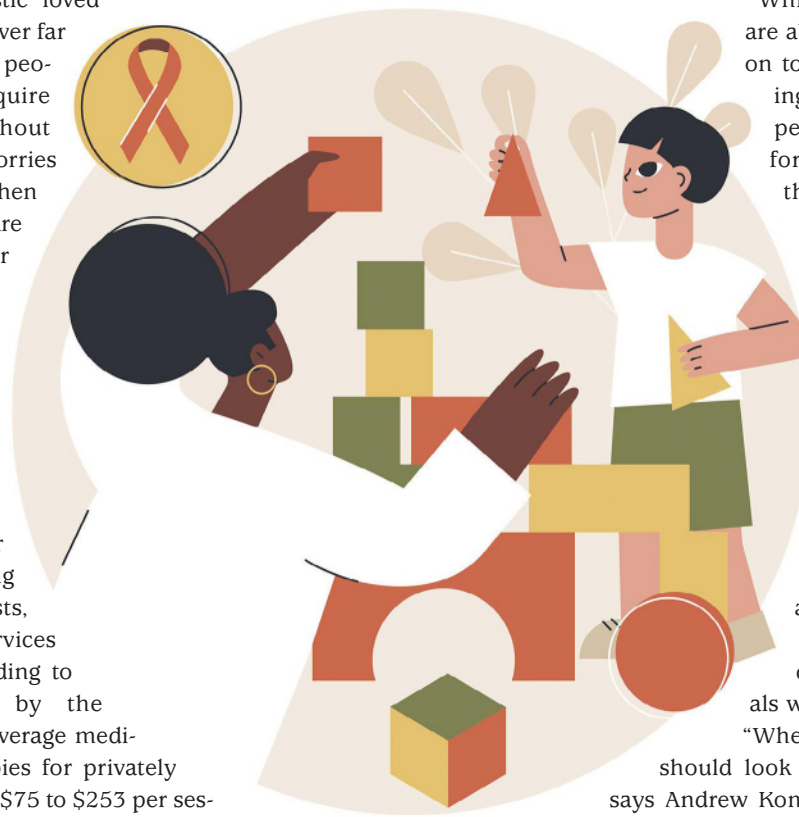
FINANCIAL PLANNING ACROSS THE SPECTRUM

BY MARTA CHMIELOWICZ

“When I’m gone, what will happen to my child?”

For families with autistic loved ones, this thought is never far from their mind. Many people with autism require ongoing support throughout their lives, bringing up worries about what will happen when their parents or caregivers are no longer able to provide for them. Developing a long-term financial plan is critical to making sure autistic individuals receive the care they need, no matter the circumstances.

People with autism often have a variety of expenses required to meet their unique needs, including additional healthcare costs, insurance costs, special services and loss of income. According to Autism Speaks’ Autism by the Numbers dashboard,¹ the average median cost of common therapies for privately insured people ranges from \$75 to \$253 per session, while emergency care typically costs nearly \$1,400 per visit (see Table 1).



While some autistic individuals are able to attend college and/or go on to full time employment allowing them to be financially independent, many require other forms of financial support throughout their lives, both from government benefits and from private sources like family income.

Fortunately for families worried about their child’s financial future, there are a variety of agencies and programs designed to support autistic people and others, who are facing hard times and need financial support.² Some of these are available to all who meet financial criteria, while others are specifically designed to support individuals with disabilities.

“When it comes to benefits, you should look at what is available to you,” says Andrew Komarow, autistic certified financial planner. “Take advantage of every opportunity, every benefit, anything that you are eligible for. I find a lot of people are either afraid of doing so, or feel that somebody else might better need it, but these resources are there for everyone to use.”

Below, you will find an overview of benefits and programs that could provide financial relief for your family. We encourage you to explore all of these different funding sources to determine what your family may qualify for. For more detailed information, download the Autism Speaks Financial Planning Tool Kit at autismspeaks.org/financial-planning-tool-kit.

For personalized assistance, contact the Autism Speaks Autism Response Team in English (888-288-4762 or help@autismspeaks.org) and Spanish (888-772-9050 or ayuda@autismspeaks.org).

Table 1. Autism by the Numbers: Cost of Healthcare

Service category	Average median cost	Highest charge
Adaptive Behavior	\$82.25	\$780.60
Developmental Screening	\$165.95	\$933.81
Emergency Department	\$1,397.22	\$9,588.91
Physical Therapy	\$74.99	\$512.36
Psychiatry	\$253.40	\$2,544.90
Speech/Language	\$174.80	\$1,692.68
Therapeutic Behavioral	\$175.44	\$1,006.76

Curious about the cost of services in your state? Go to autismspeaks.org/ABN

BENEFITS AND PROGRAMS THAT COULD PROVIDE FINANCIAL RELIEF FOR YOUR FAMILY

We encourage you to explore all of these different funding sources to determine what your family may qualify for. For more detailed information, download the Autism Speaks Financial Planning Tool Kit at autismspeaks.org/financial-planning-tool-kit.

STATE AND FEDERAL DISABILITY BENEFITS



MEDICAID

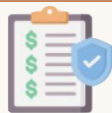
Medicaid is a program that is funded in part by both the federal and state government. Medicaid pays for a wide array of services for people with disabilities, and provides government-funded health insurance for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports. An individual can qualify for Medicaid based on both income and disability. Eligibility rules vary widely across states.



MEDICAID HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVERS

In the past, Medicaid funding was limited to those who live in certain types of facilities. But now, through the use of Medicaid HCBS waivers, people with autism and other disabilities can use these funds more flexibly.³ The program enables states to serve people who wouldn't normally be eligible for Medicaid, or provide services that aren't offered as part of the regular Medicaid benefit package in that state.

A Medicaid waiver is designed to provide support, services and care, allowing an individual to remain at home or in the community, rather than in an institution, nursing home or hospital. The benefits provided by these waiver programs vary by state. Generally, they provide coverage for medical treatments, respite care, transportation, in-home support and more. In some states, children do not need to meet eligibility criteria for Medicaid in order to qualify for a waiver. However, just like insurance laws, waiver criteria and availability vary from state to state.



SUPPLEMENTAL SECURITY INCOME (SSI)

Supplemental Security Income is a monthly government payment through Social Security, which is designed to support people who are aged 65 and older, as well as, blind or disabled. Individuals with autism may be eligible to receive SSI to help support them financially. Qualification for SSI depends on household income and resources. Information on this and other programs can be found at www.ssa.gov.



SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

Social Security Disability Insurance provides income supplements to people who are restricted in their ability to be employed, because of a disability. The SSDI program pays benefits to adults who have a disability that began before they became adults. SSDI is payable to adult children of parents who are receiving Social Security retirement or disability benefits, or who have died and worked enough prior to their deaths to qualify for Social Security benefits. The Social Security Administration considers this a "child's" benefit, because it is paid on a parent's Social Security earnings record. These benefits continue as long as your child meets the definition of disabled.

One important difference between SSI and SSDI is that SSDI payments are uniform in all states. SSI is different in each state, as sometimes the state supplements the federal payments.



OTHER ENTITLEMENTS

Once you or your child is eligible for payments through SSI, you may also be able to access additional supports. In many cases, eligibility for SSI automatically qualifies you for other low-income assistance programs in your state. These can include, but are not limited to:

- *Supplemental Nutrition Assistance Program (SNAP)*
- *Energy cost savings through the Low-Income Home Energy Assistance Program (LIHEAP)*
- *Childcare subsidies through Temporary Assistance for Needy Families (TANF)*
- *Head Start (school readiness programs for young children)*
- *Housing assistance (contact your local public housing authority—often low-income housing will prioritize services for individuals who are disabled or are receiving SSI)*
- *Work Incentives Planning and Assistance (service to help you plan benefits in a way that enables you to work)*



ABLE ACCOUNTS

A new type of savings option was made available for families of individuals with disabilities through the Achieving a Better Life Experience (ABLE) Act of 2014.⁴ The ABLE Act, passed after years of advocacy from Autism Speaks, authorized the establishment of private tax-advantaged savings accounts that can help you save for long-term expenses, without sacrificing eligibility for public benefits, such as Medicaid and SSI.⁵

These accounts are modeled after the current 529 education savings plans that help families save for future college costs. Once an account is established for a beneficiary, account contributions will accumulate tax deferred, and any earnings will be tax free at the federal level, if the money is used for qualified expenses.

COMMUNITY AND STATE FINANCIAL RESOURCES



COMMUNITY ACTION AGENCIES

A great place to start, if you are in need of financial help, is your local Community Action Agency.⁶ Nearly every community in the U.S. has a Community Action Agency. These are non-profit organizations which receive state and federal funding. They administer many assistance programs for low-income residents, including rental assistance, energy assistance, food and nutrition programs, case management, education and literacy programs, and emergency assistance. Your local Community Action Agency will be able to connect you with various programs and sources of financial assistance that are available in your area.



FAMILY GRANT OPPORTUNITIES

Autism Speaks maintains a Resource Library for families, which contains a list of Family Grant Opportunities.⁷ Each of these grants are designed to help parents pay for a variety of needs related to autism treatment and care. You can visit autismspeaks.org/family-grant-opportunities for each listing to learn more about how to apply.

There also may be local grant opportunities listed in our online Resource Guide.⁸ Go to autismspeaks.org/resource-guide, then select your state and look under the category "Advocacy, Financial and Legal Resources" to find any available grant programs.

TIPS TO CREATE AND MANAGE YOUR BUDGET



- Involve the entire family: *Agree on a budget up front and meet regularly to check your progress.*
- Stay disciplined: *Try to make managing your budget a part of your daily routine.*
- Choose your timing wisely. *Start your new budget at a time when it will be easy to follow and stick with the plan (i.e., start at the beginning of the year, as opposed to right before the holidays).*
 - Find a budgeting system that fits your needs (i.e., budgeting software).
 - Categorize your expenses, distinguish between expenses that are "wants" (i.e., designer shoes) and expenses that are "needs" (i.e., groceries).
 - Build rewards into your budget (i.e., eat out every other week).
 - Build an emergency fund: *Accumulate 3 to 6 months of fixed expenses as an emergency reserve. This will make it easier to address life's inevitable surprises or emergencies and allow you to stay on track with your budget without having to utilize your credit cards.*

References

1. <https://nationalautismdatacenter.org/costs-of-common-services/>
2. <https://hcup-us.ahrq.gov/reports/statbriefs/sb268-ED-Costs-2017.jsp>
3. <https://www.autismspeaks.org/financial-autism-support#able>
4. <https://www.autismspeaks.org/blog/home-and-community-based-services-hcbs-waivers>
5. <https://www.autismspeaks.org/news/10-things-know-about-able-act>
6. <https://www.autismspeaks.org/advocacy-news/update-able-accounts>
7. <https://communityactionpartnership.com/>
8. <https://www.autismspeaks.org/family-grant-opportunities>
9. <https://www.autismspeaks.org/resource-guide>

Read more in the Autism Speaks Financial Planning Tool Kit at autismspeaks.org/financial-planning-tool-kit. •

ABOUT THE AUTHOR:

Marta Chmielowicz is the Content Manager of Mission Delivery at Autism Speaks, where she leads science communications to advance the mission of Autism Speaks to create an inclusive world for all individuals with autism throughout their lifespan.



ESTATE PLANNING FOR COLLEGE STUDENTS WITH SPECIAL NEEDS 101

BY MITCH MITCHELL

Estate planning is an indispensable way to prepare for the uncertain future, and the value of this planning amplifies when you have a college student with special needs.

As parents, we juggle a lot already: medical appointments, educational accommodations, and daily life management. Given these responsibilities, it's even more crucial to ensure that our children are financially and medically secure for the future, especially when

they step into adulthood and independence.

This article includes considerations parents of college students with special needs must weigh, when planning an estate. These considerations are vital to your child's welfare and can provide a safeguard for those unpredictable moments.

WHY ESTATE PLANNING IS UNIQUELY IMPORTANT FOR COLLEGE STUDENTS WITH SPECIAL NEEDS

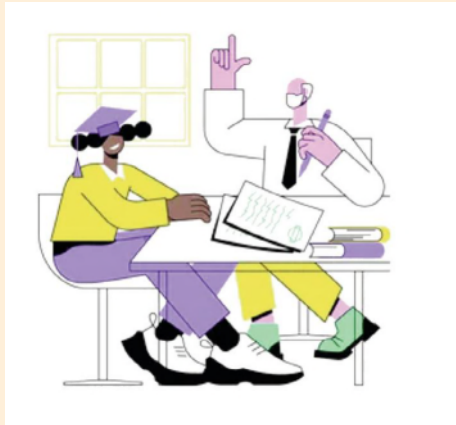
From the moment your child turns 18 and enters college, they're exposed to new challenges and responsibilities. In addition to the usual adulthood responsibilities, like managing finances or making medical decisions, students with special needs often need to coordinate accommodations and supportive services. Estate planning can alleviate much of the anxiety surrounding these concerns.

It's important to note here that a parent cannot create an estate plan for their special needs child. Instead, it is the parent's job to ensure their child has a plan in place. There are min-

imum capacities required for a child to create an estate plan. If a child's needs are great enough that they lack capacity to create an estate plan, having a court appointed conservatorship may be required.

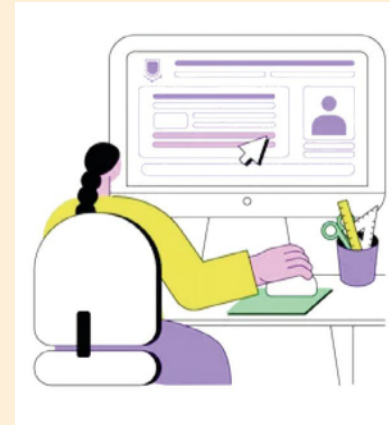
When a child with special needs turns 18, parents lose many of their legal rights to intervene in medical or financial matters. A well-structured Estate Plan empowers you to continue advocating for your child when they most need it. Special Needs Trusts or ABLE Accounts can ensure that your child's government benefits are not compromised, while powers of attorney can secure your ability to make timely medical and financial decisions on their behalf.

HIGHER LEARNING : CREATING A WELL-STRUCTURED ESTATE PLAN



DOCUMENTS EVERY COLLEGE STUDENT WITH SPECIAL NEEDS SHOULD HAVE

- 1. Special Needs Trust or ABLE Account:** Special Needs Trusts and ABLE Accounts protect your child's assets without jeopardizing eligibility for government benefits like Medicaid or Supplemental Security Income. Consult an experienced estate planning attorney familiar with special needs planning to determine the best choice for your family.
- 2. Healthcare Power of Attorney (POA) or Living Will:** This grants you the legal authority to make medical decisions for your child, a must-have given the unpredictable nature of health emergencies.
- 3. Durable Power of Attorney (POA):** Besides healthcare, you may need to manage financial accounts or tuition payments for your child. A Durable POA can enable you to act on their behalf in a variety of financial contexts. It's also important to ensure your child's school has a copy on file to avoid administrative delays, if you need to act for your child.
- 4. HIPAA Authorization:** Necessary for you to have legal access to your child's medical records and communicate directly with healthcare providers.
- 5. Letter of Intent:** Though not a legal document, this letter can guide future caregivers, trustees, or guardians in understanding your child's needs and preferences.



ADDITIONAL CONCERNS

- 1. FERPA Waiver:** The Family Educational Rights and Privacy Act (FERPA) waiver allows you to access your child's educational records, invaluable during emergencies.
- 2. Advance Directives:** These legal documents allow your child to express their preferences for end-of-life care, which is particularly important if verbal communication is a challenge for them.
- 3. Conservatorship or Guardianship:** In some cases, especially where intellectual or developmental challenges are present, you may need to consider establishing conservatorship or guardianship to retain legal authority over decision-making.

THE LAST LESSON: TEACHING ADULTHOOD

Explaining the importance of estate planning to your college-going child is invaluable. It demonstrates the essence of responsibility and the need to prepare for life's unpredictabilities. For a young adult with special needs, this is not just a life lesson – it's a lifeline. •

ABOUT THE AUTHOR:



Mitch Mitchell is Products Counsel of Estate Planning at Trust & Will, where he acts as an integral part of the company's internal legal team. As an experienced estate planning and probate attorney, Mitch brings over a decade of knowledge and real-life experience to Trust & Will's service offerings. Before joining Trust & Will, Mitch was a lawyer in private practice, where he helped individuals prepare their estate plans and helped families navigate probate after the loss of a loved one. He is a Baylor University School of Law graduate, where he earned a JD. Mitch lives in Houston with his wife and three young children.



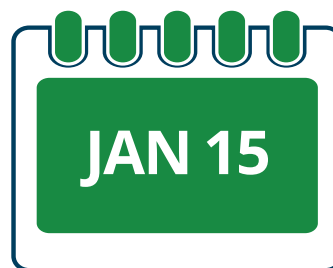
Get Health Insurance

Put your health and well-being first with Marketplace health insurance. You can compare plans and find out what your costs will be before you enroll. You may qualify for savings, even if you haven't before! Learn more at [HealthCare.gov](https://www.healthcare.gov).

OPEN ENROLLMENT RUNS



TO



You have the right to get your information in an accessible format, like large print, braille, or audio.

You also have the right to file a complaint if you feel you've been discriminated against.

Visit [CMS.gov/About-CMS/Agency-Information/Aboutwebsite/CMSNondiscriminationNotice](https://www.cms.gov/About-CMS/Agency-Information/Aboutwebsite/CMSNondiscriminationNotice)

or call 1-800-318-2596. TTY users can call 1-855-889-4325.

Health Insurance Marketplace

CMS Product No. 11920
September 2023

This product was produced at U.S. taxpayer expense.
Health Insurance Marketplace® is a registered service mark of
the U.S. Department of Health & Human Services.



[HealthCare.gov](https://www.healthcare.gov)

SECURING YOUR CHILD'S FUTURE: THE IMPORTANCE OF SPECIAL NEEDS TRUSTS

BY BIANCA FARR

A parent's wish is that their child grows to be an independent, productive member of their community. For parents with a child with a disability, a different approach may be necessary to achieve independence and inclusion within the community.

“What will happen when I’m gone?” This is the universal question that parents and family members ask when planning for their child’s future – and especially when planning for the future of a child with a disability. Will their loved one be taken care of? Can their child receive an inheritance or life insur-

ance proceeds – and what will happen to those funds, if they do? How do families ensure that their child keeps their public benefits (Medicaid, Social Security, SNAP benefits, housing)? Will their loved one have a good quality of life? No one can predict the future, but proper planning can offer families some hope and security.

RECIPE FOR SUCCESS: A special needs trust is an important financial tool that may provide peace of mind that your child’s future is secure and that they will be well taken care of long after you are gone.



A special needs trust is one financial planning tool available to help parents plan for the future of their child with a disability. A special needs trust is established for the benefit of the individual with the disability, and allows individuals to receive funds without being disqualified from receiving public benefits. The individual can use the funds in the trust for their supplemental needs, such as: clothing, dental care, medical

expenses, travel, entertainment, and personal needs. Some expenses cannot be paid for using funds in the trust, such as: rent or mortgage payments, basic utilities, and groceries. Cash cannot be provided to the beneficiary, nor can the beneficiary be repaid. Those expenses and scenarios could negatively impact public benefits.

There are two types of special needs trusts:

TRUST IN THE FUTURE : TWO TYPES OF AN IMPORTANT FINANCIAL TOOL



FIRST-PARTY TRUSTS

- Are established by the individual with their own assets – or established by a parent, grandparent, guardian, or court for the benefit of the individual with a disability.
- Are irrevocable.
- Require Medicaid Payback.
- Funded typically from back pay from Social Security, unplanned inheritance, and a settlement from a lawsuit.

Here is an example of a first-party trust. At the age of 15, Emily was injured in a car accident that left her paralyzed from the waist down. Tragically, her mother perished in the accident. With funds from the personal injury settlement, Emily's father established a first-party trust which ensures the protection of Emily's public benefits. She can access the funds for her supplemental needs like going to the movies with friends, taking a summer vacation, and shopping for new clothes.



THIRD-PARTY TRUSTS

- Are established by the donor, rather than the individual with a disability.
- Are funded by the donor's assets, life insurance policies, personal funds, or wills and estates.
- Can be revocable or irrevocable.
- Do not require a Medicaid Payback.
- If the beneficiary passes away, any remaining funds in the trust will be re-distributed per the donor's wishes.

The following scenario is an example where a third-party trust is a good choice. Johnny was born prematurely at 32 weeks. He was diagnosed with Down Syndrome and other medical conditions. He is now 10 years old and thriving, but still has several hurdles to overcome on his way to independence. The possibility that he may require lifetime support is a real and pressing concern. His family began talking about what they could do now to prepare for Johnny's future. For Johnny's family, a third-party trust may be a great option. His parents and/or other family members can leave an inheritance or monetary gifts to Johnny, that would not impact his public benefits.

To assist families with understanding and setting up trusts, more than 100 pooled trust organizations exist across the United States. Pooled trust organizations may be specific to certain states, or regions, or may serve the entire nation. For example, Midwest Special Needs Trust (MSNT) is a pooled trust, nonprofit organization that offers each of these trust types (first, third, and inactive) and serves the Midwest region.

A pooled trust organization maintains separate accounts for each beneficiary, but the assets are pooled for investment and management purposes. The pooled trust organization serves as trustee of the trust, but co-trustees can be designated to represent the beneficiary's interests.

For families unsure of what route to take in their financial planning, an inactive special needs trust is an option. This type of trust may be established with as little as \$200 and assumes that additional funds will be deposited later. It provides families with the time to plan for their child's future. There are no fees for this type of trust while it is inactive.

When using a pooled trust organization, a percentage of funds from each closed trust will be donated to that organization's charitable fund. The charitable fund distributes funds back into the community to help other individuals with disabilities.

A special needs trust may help answer the question, "What will happen to my child when I'm gone?" This important financial tool may provide peace of mind that your child's future is secure and that they will be well taken care of long after you are gone. With careful planning and foresight, parents can help ensure that their loved one has the financial resources needed to live a comfortable and full life. •

ABOUT THE AUTHOR:



Bianca Farr, MSW, LCSW, serves as executive director of Midwest Special Needs Trust. Since graduating from the University of Missouri with a BA in Psychology and a Master's in Social Work, she has devoted her career to enhancing the quality of life for people of all abilities. Her experience includes over 22 years in state government as a mental health professional working with individuals/families with disabilities and policy development for behavioral health programs. Before MSNT, she served as the director of Employment Services for the Missouri Department of Mental Health, Division of Behavioral Health. In this role, she promoted the importance of supported employment and financial well-being of individuals with mental health and/or substance use disorders.

INDIVIDUALS WITH MEDICAL COMPLEXITY MAY EXPERIENCE MEDICAL TRAUMA

BY LAUREN AGORATUS, M.A.

Many children¹ and adults with complex medical needs, and their families, may have long lasting emotional effects from medical interventions.

MEDICAL INTERVENTION AND TRAUMA

Children, and adults, who have been involved with multiple medical procedures may experience this as trauma. For example, just being in ICU (Intensive Care Unit) is a risk factor^{2,3} for up to 20% of patients. Some procedures may be painful or prolonged. It was found that some adults⁴ and children on ventilators suffered from PTSD (post traumatic stress disorder), which is usually associated with warfare, assault, or natural disasters. 1 of 3 patients on ventilators suffered from PTSD.⁵ Studies have shown that journaling is ineffective at preventing PTSD.⁶ This is of particular importance due to the COVID pandemic and the use of ventilators. Being hooked up to medical equipment such as I-J's, med-comps, PICC lines, broviacs, etc. can be stressful, as can procedures such as apheresis or temporary dialysis or transfusions. Some patients are put on TPN (Total Parenteral Nutrition) or feeding tubes for weeks or months. Regardless of the cause, it is clear that equipment, procedures, and ICU stays can be traumatic for some patients.

PREPARING PATIENTS AHEAD OF TIME

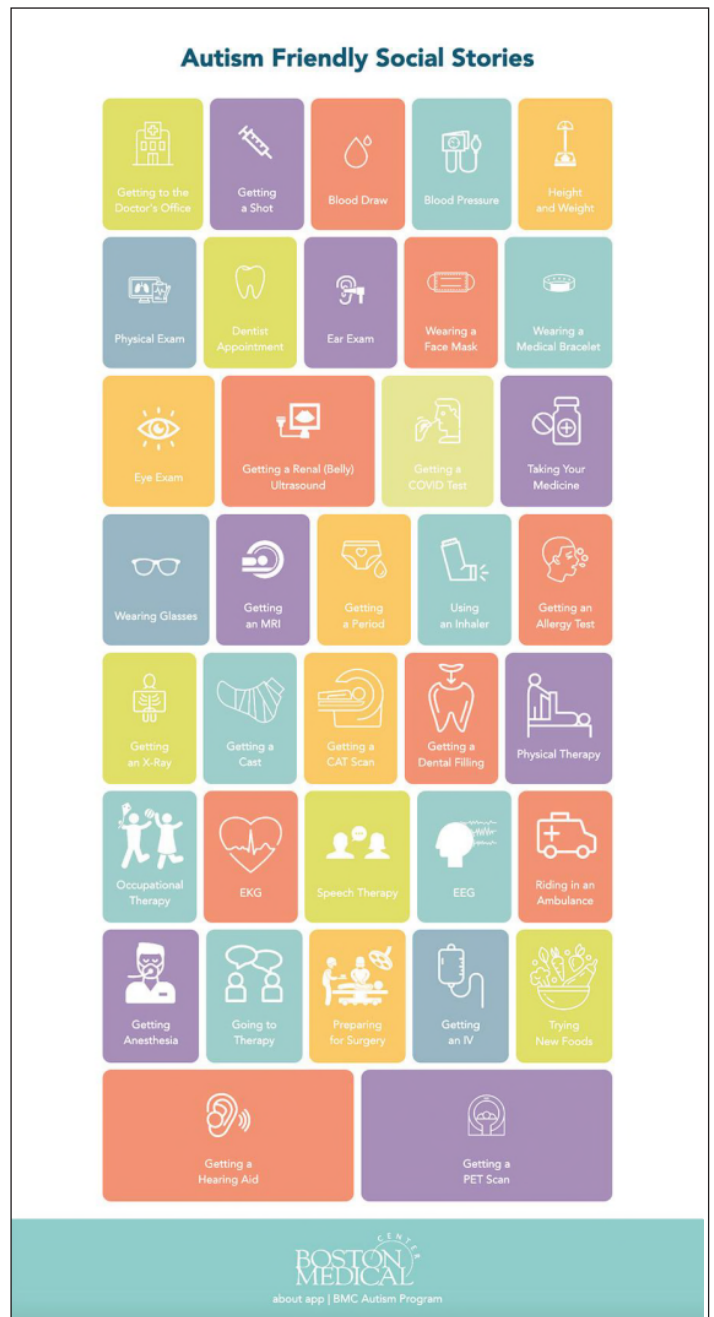
Many times, just letting the person know what to expect ahead of time helps. For individuals with developmental disabilities, social stories may be helpful. Boston Medical Center's "Autism Friendly Social Stories" includes: getting a shot, using an inhaler, etc. Rady's Children's Hospital Social Stories include EEGs, angiograms, etc (see graphic, right). There are even "toy" medical devices for patients to see and understand what will happen (see Resources). Many children's hospitals have Child Life specialists who help calm the child using dolls, calming images, soundscapes etc.

WHAT WORKS

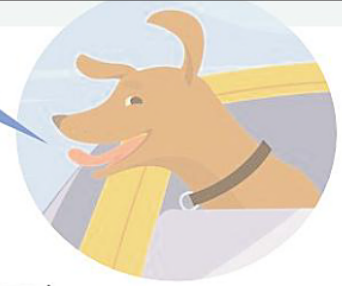
In addition to preparation and support from Child Life, there are other resources available from various pediatric and other organizations. The National Child Traumatic Stress Network's resources on medical trauma include: a toolkit for providers, and factsheets on self-care, and how families can help children after they have been in the hospital.

Children's Hospital of Philadelphia has assessment tools, as well as intervention strategies for pediatric traumatic stress due to medical trauma. The National Institutes of Health has information on bio-psycho-social processes. This means that biological events, such as: hyperarousal due to constant stress, psychological factors like the use of cognitive behavioral therapy, and social factors

including environment (e.g. school absence), all play a role and must be addressed. Currently no models consider all three areas to maximize effective interventions. In addition, preventing PTSD and other sustained stress reactions, must be considered to eliminate or minimize medical trauma. It was noted that earlier intervention (i.e. timeliness), resulted in better outcomes. Families can contact their local NAMI (National Alliance on Mental Illness) if they need help finding mental health professionals (www.nami.org).



Tell your story like Angel did by filling in the blanks below.



The reason I went to the hospital was because _____.
(reason)

When I think about what happened to me now, I feel _____.
(how you feel when you think about it)

Some of the things that remind me of what happened to me are _____ and _____.
(something that reminds you of what happened)

_____. If I think about what happened and get upset, one way I can calm down is by _____.
(something else that reminds you of what happened)

_____. I could also talk to _____ about how I feel. The next time _____.
(something you can do to calm down) (name of person)

I get upset about what happened, I plan to: _____.
(your plan)

AFTER THE FACT: The NCTSN's Pediatric Medical Traumatic Stress Toolkit for Health Care Providers provides information and worksheets to children who have experienced medical trauma.

Patients with medical complexity undergo a variety of tests, medical interventions, and hospitalizations, which can result in medical trauma. Healthcare practitioners, mental health providers, and families can collaborate to mitigate the effects of medical trauma in medically complex individuals, and improve resilience.

References

1. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4319666/>
2. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4346029/>
3. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5747308/>
4. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2982948/>
5. https://www.hopkinsmedicine.org/news/media/releases/ptsd_symptoms_common_among_icu_survivors
6. <https://jamanetwork.com/journals/jama/fullarticle/2738291>

ABOUT THE AUTHOR:



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 two 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.

IMPROVING RESILIENCE : MITIGATING THE EFFECTS OF MEDICAL TRAUMA



BOSTON MEDICAL

Autism Friendly Social Stories
<https://bmcautismfriendly.github.io/socialstories>



RADY'S CHILDREN'S HOSPITAL

Healthcare Social Stories
www.rchsd.org/programs-services/autism-discovery-institute/hospital-visit-tips/social-stories



THE BUTTERFLY PIG

Toy Medical Devices Designed to Empower Children
<https://thrbutterflypig.com>



NATIONAL CHILD TRAUMATIC STRESS NETWORK

Medical Trauma
www.nctsn.org/what-is-child-trauma/trauma-types/medical-trauma



CHILDREN'S HOSPITAL OF PHILADELPHIA

Pediatric Traumatic Stress
www.chop.edu/conditions-diseases/pediatric-traumatic-stress



NATIONAL INSTITUTES OF HEALTH

Posttraumatic stress following acute medical trauma in children
www.ncbi.nlm.nih.gov/pmc/articles/PMC4319666

Veterans,
when you're struggling,
soon becomes
later becomes
someday becomes
...when?

Don't wait. Reach out.

Whatever you're going through,
you don't have to do it alone.

Find resources at [VA.GOV/REACH](https://www.va.gov/reach)



VA



U.S. Department
of Veterans Affairs



FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

MILITARY LIFE

44 **DEPRESSION: THE STRUGGLE IS REAL**

By Margie Harding

BOOK EXCERPT 12TH OF A SERIES

46 **THE RESILIENT WARRIOR**

By Nick Benas and Buzz Bryan

OUR JOURNEY IN CAMO

50 **THE EXTRAORDINARY AND UNUSUAL**

By Shelly Huhtanen



MILITARY LIFE



A FRESH START: Depression affects everyone it touches, but there is hope. When outside factors improve or circumstances change, along with medications and counseling, normalcy can once again reign.

DEPRESSION

THE STRUGGLE IS REAL

BY MARGIE HARDING

As the wife of a Vietnam veteran, I've witnessed the dark moods of PTSD and depression, which made him angry or jumpy without warning, causing him to lash out at the children or me. I've seen him get lost in his thoughts, warning those who recognized it, to just leave him be. I didn't understand what it was back then; I suspect neither did he.

He often talked about the treatment he received after he got back from Vietnam, even while in the hospital recovering from bullet wounds. He, along with other returning veterans after that war, were treated badly, like they were criminals or horrid people who deserved nothing more than disdain and disrespect. It didn't seem to matter that these men and women were not only fighting for their country, but for the very people who had the right to protest the war and treated them vilely.

The saying "sticks and stones may break my bones, but words will never harm me" is wrong. Words can create scars worse than any physical beating. Physical injuries heal and eventually the pain subsides, even if you can still see the out-

ward scars. Words rip a person to pieces on the inside, breaking the spirit, leaving scars that sometimes never heal.

WHAT IS DEPRESSION?

It wasn't until my husband was diagnosed with PTSD that we recognized the connection to depression. PTSD can singularly cause intense and disturbing thoughts relating to the trauma a person has endured. The war was long over for my husband. But memories not only remained, they sometimes haunted him with tormenting flashbacks, and were reminders that turned up in dreams, compounding already tense emotions, and inciting fear and anger.

Depression can cause significant physical problems accentuating the mental state. Feelings of worthlessness and hopelessness can cause fatigue, irritability, unexplained physical pain, sleep problems and even thoughts of suicide or thoughts of harming another. This can be difficult to understand for both the patient and family.

When adding these elements together, then adding a disability component, the problem is greatly enhanced. Because of the war, my husband now had a disability. It wasn't until years later, after working with a psychologist and getting the right medication, that we were finally able to live a much more serene life, despite knowing the Camp Lejeune contaminated water reports, potentially added new problems to the litany of medical issues he is facing. All of this causes him anxious moments and mental distress.

CAREGIVERS NEED "CARE" TOO

As a society, we need to accept depression as a disease. Additionally, just as my children and I were directly affected by my husband's condition, it's a factor that rings true with other families. Dr. Zaki explains, "When a family member is depressed, everyone dealing and living with the patient gets affected. It affects the relationships and reflects on everyone."

Caregivers need to give love, offer advice (especially as a parent) and support loved ones as much as possible. But there is the need to take personal care, just from a good health perspective, especially for those who tend to the needs of a child (or spouse) with special needs.

Taking the time to include activities and habits to help deal with and navigate the emotional stress, illnesses that compound problems, unhappiness, and the "trapped and lost feelings" are paramount.

"The war was long over for my husband. But memories not only remained, they sometimes haunted him with tormenting flashbacks, and were reminders that turned up in dreams, compounding already tense emotions, and inciting fear and anger."

Mr. Hudson believes, "self-care is foundational." He begins encouraging this from the first session. He explains, it directly correlates with symptoms decreasing. Patients struggle with finding any pleasure in living. This struggle is transferred to self-care, making any positive action "challenging, overwhelming, undesirable and even exhausting for someone already fatigued."

Self-care methods include doing something you enjoy, like quilting, reading, playing music or taking time for another kind of hobby. Write about what is happening in your life; either in a personal journal, or create a blog and dialogue with others in similar situations. There are many ideas available. It's vital, that as care-giver, you take the time to take care of you, as well!

Depression steals natural abilities from its victims, and affects everyone it touches. Family structure is disintegrating, lifestyles changing, while communities are becoming more isolated. Anxiety, depression and other psychological diseases have found fertile places to grow. But there is hope. When outside factors improve or circumstances change, along with medications and counseling, normalcy can once again reign. •

References

- Alison Brunier and Carla Drysdale, Communication Officers World Health Organization. "Wake-up Call To All Countries To Step Up Mental Health Services And Support" March 2022. <https://www.who.int/news/item/02-03-2022-covid-19-pandemic-triggers-25-increase-in-prevalence-of-anxiety-and-depression-worldwide>
- American Academy of Pediatrics Staff. "Depression in Children and Teens" Last Updated 9/12/2022. <https://www.healthychildren.org/English/health-issues/conditions/emotional-problems/Pages/childhood-depression-what-parents-can-do-to-help.aspx> Source Adapted from Depression in Children and Adolescents: Types and Signs (American Academy of Pediatrics Copyright © 2021)
- CDC Staff. "Data and Statistics on Children's Mental Health" Last Reviewed: March 8, 2023 <https://www.cdc.gov/childrensmentalhealth/data.html> Source: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention
- CDC/DHDS Staff. "The Mental Health of People with Disabilities" Last reviewed: 30 November 2020. <https://www.cdc.gov/ncbddd/disabilityandhealth/features/mental-health-for-all.html> Content source: National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention
- Hollins, Sheila (UK) and Allen, Eimear (UK) "Depression In People With Intellectual Disabilities" Updated in 2020. <http://www.intellectualdisability.info/mental-health/articles/depression-in-people-with-intellectual-disabilities>
- Recovery Ranch TN Staff "When Disability Leads To Depression" 1 April 2022 <https://www.recoveryranch.com/addiction-blog/when-disability-leads-to-depression/>
- UCL Staff. "People with disabilities more likely to be depressed, anxious and lonely during pandemic" 21 April 2021 <https://www.ucl.ac.uk/news/2021/apr/people-disabilities-more-likely-be-depressed-anxious-and-lonely-during-pandemic>
- Personal Email Interview, Dr. Wafik Zaki, MD, Family Medicine, 836 S 5th Ave, Denton, MD 21629; 1 August 2023; (410) 479-1388
- Personal Email Interview, Brad Hudson, Licensed Marriage and Family Therapist, Gillette WY; 7 July 2023; (307)-209-4649

ABOUT THE AUTHOR:



Margie Harding is a wife to Charles, mother to five adult children, grandmother to 17 grandchildren, and a loyal friend and writer. She has an AA degree in Early Elementary Education and, while not currently enrolled in any formal school environment, is a perpetual student in a variety of different subjects! She enjoys quilting, reading, and learning new things. Her passion is creative writing, particularly in special needs, but also in the Christian genre. She dabbles in other genres, as well. Find her on the web at www.margieharding.com and at LinkedIn at <https://www.linkedin.com/in/margie-harding-6212a859>

THE RESILIENT WARRIOR

SHAVING COMFORT & HYGIENE

BY JOE WADANOLI

*Book Editor's Note: Featuring self-help, mental health, and mind and body tactics from a variety of sources – veterans, former and active U.S. Marines, Navy, Army Rangers, Green Berets, family members and caretakers – **The Resilient Warrior** is collaborative collection providing needed wisdom for complete well-being for all of us. The first step to thriving is surviving, and the first step to surviving is knowing how to get what you need, when you need it. The following excerpt of this essential self-help guide to living a healthy, resilient, fulfilled and better life is the twelfth in a series that EP Magazine has featured over the last several months.*

Practicing good hygiene is a rewarding, mindful practice that will also help reduce stress and anxiety.

To some people, shaving is no big deal. They wake up, splash some water on their face; a bit of shave cream and zip-zam-zoom, see ya later! For many others, however, shaving is an intimidating, uncomfortable, downright painful task! Razor nicks, razor bumps, burn, rash, ingrown hairs...the list goes on. All of these are nasty things, and when not meticulously kept clean, can cause infection. Here are some tactics you can implement into your shave routine that will not only keep you looking and feeling good, but also protect your overall health.

Skin preparation. The base to a good shave is preparing the skin, and this is as simple as washing your face! Use warm water with a washcloth and some mild soap. Lightly scrub your face. This will loosen and remove any dead skin, dirt and oil that may be present. This works best while taking a warm shower. Another way to maximize your skin comfort and protection is to apply pre-shave. Pre-shave oil can be purchased in different fragrances and essential oils to suit anybody's senses. You also can easily make it yourself by mixing the following in a small container:

- 3 shot glass castor oil
- 1 shot glass of olive oil
- 11 drops lavender essential oil (or any skin safe essential oil),
- 5 drops Vitamin E oil

To use, add a dime-sized amount of oil into your hand and rub your palms together. Massage it into the desired area. The oil will further the softening of hair and add a layer of lubrication to the skin for your blade to glide smoothly across.

Cutting edge razors: Chances are, you have seen the prices of razors! With an understanding of budget in mind, the adage “You get what you pay for” still reigns supreme. But that does not mean buying a \$50+ razor will get you the best shave of your life. The professional opinion is that any double or triple bladed major manufacturer disposable razor will do fine. With that said, you do want to have the *sharpest* razor you can have. The sharper the blade, the easier it cuts the hair, ultimately giving you the most comfort. When you feel the razor pulling, it's time to replace the blade. The size of the area that you shave, coupled with the coarseness of your hair will determine your own blade's life. For some of us, that means a new blade every shave, but the average rule of thumb is 2 to 3 uses. To help prolong the life of your razor, rinse it clean and shake it dry before storing in a dry place.

Shave with the grain. Run your hand down your face. Feels smooth, right? Now run your hand up your face. Kind of like sandpaper, huh? That sandpaper feel is “against the grain”. Avoid shaving this direction, it will cut the hair too short and as it grows back it can become ingrown and provide an open vector for bacteria to get inside the pore. This is most prone to be on the neck, but can occur anywhere on the body.

Shaving cream: the main purpose of shaving cream is to lubricate the skin for the razor to glide with ease. Find one that has aloe or tea tree oil added, or else try substituting your shave cream with Shea butter, coconut oil, or aloe lotion. It will work just as well (if not better) than the regular stuff. Make sure you rinse off the razor well between strokes! Start with a quarter to half-dollar sized amount of shave cream, gel or lotion in your palm using your palm as a cup. Then, with the back of your other hand's fingers, apply it to the skin in a circular motion. This will aid in standing the hairs up for a



A CUT ABOVE: “Make your shave become a favorite part of your routine. Shaving can be a rewarding, mindful practice that will also help reduce stress and anxiety;” Joe Wadanoli is a Master Barber and owner of Joe & Co. Barbershop in Madison, CT.

clean cut. You should have a thin layer of lather on your skin, not a full Santa beard of cream—a little goes a long way! Rinse the blade under warm water while tapping the razor head in the sink to knock out any hair caught between the blades. Never wipe the hair out of the razor with your finger. You will cut your

After-shave: Traditional aftershaves contain alcohol. Unfortunately, alcohol dries your skin out, which is counterproductive for our purpose. Tea tree oil will help with soreness and redness, and protect from infection, because tea tree oil contains anti-inflammatory and antimicrobial properties, which make it a perfect post shave option to penetrate the newly open pores and raw skin.

Bumps and acne: If you are prone to

razor bumps, press a cold wet washcloth on the bumps after shaving or whenever you feel the need. The cold water will help shrink the bumps down and sooth any discomfort related. Always keep the affected area moisturized. Lots of us also suffer from pimples. A great way to combat acne is to dab a cotton ball with some apple cider vinegar. The acids in the vinegar will neutralize fungus and bacteria found in acne. It will also help with acne scarring. Apply it to the area morning and night. Fresh aloe applied to the area has been known to soothe painful acne and help with scarring as well. There are aloe gels and lotions you can purchase, or better yet, buy an aloe plant. Just cut inch sized ends off the plant and use the fresh aloe from inside. Just do not forget to water the plant!

U.S. MILITARY ★

R and R: Shaving is a violent act we put our skin through. That is why in between shaves, it is vital to nourish your skin with hydration, not only from drinking plenty of water, but by applying a moisturizing cream to your skin. Some jobs require a clean shave. If you can get away with it, shave every 2 to 3 days. This will give your skin time to rejuvenate itself. There are certain waivers that can be obtained if your shaving-related skin problems become a doctor-treated medical issue.

ABOUT THE AUTHORS:

Joe Wadanoli is a Master Barber and a former member of the United States Coast Guard Auxiliary. He is the owner of Joe & Co. Barbershop in Madison, CT. For more information, visit www.joecobarbers.com



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.

If only one thing sticks with you from my advice, let it be this. Do not rush, take your time, smell the fragrances. Make your shave become a favorite part of your routine. Shaving can be a rewarding, mindful practice that will also help reduce stress and anxiety. A good shave will leave you feeling invigorated. Shaving is profoundly good for the mind, body, and soul. •



"My victory is removing 'can't' from my vocabulary." Alex was hit by an IED in Afghanistan. He lost both legs, his left hand and has a traumatic brain injury. With support from DAV, Alex is taking on mountains. DAV helps veterans of all generations get the benefits they've earned—helping more than a million veterans each year. Support more victories for veterans®. Go to DAV.org.





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**
ONESOURCE

The Extraordinary and Unusual

Broden was experiencing change. Change is inevitable, but in Broden's world it's still a tough pill to swallow.

Last week, after relaxing on my couch after dinner, I decided to head into the kitchen and grab something sweet to eat. The pantry door was open. The silverware drawer was open and the cupboard door, where we store the plates and bowls, was open. My kitchen looked like it had been raided by bandits, "What in the world? Broden's been in the kitchen." Mark got off the couch, walked over and closed the pantry door while I was straightening up the kitchen. There were three spoons placed in a line along the edge of the sink. I examined the spoons like a detective in a Sherlock Holmes movie, "Looks like he grabbed the frosting out of the fridge and used three different spoons to eat the frosting". Mark opened the fridge door and looked inside, "We are probably the only ones in the neighborhood who have four con-

tainers of Pillsbury frosting in their fridge right now. All four of them are the same flavor of frosting and are all 75% full." I reorganized the fridge and lined the frosting containers along the side of the top shelf, knowing that Broden would be looking for those again the next day.



back, "Is he in the bathroom? Didn't he go to the bathroom before bed? Is he playing in the sink?" Under Mark's breath I heard, "Are you kidding me?" He ripped the comforter off his body and jumped out of bed, "Broden, go to bed. Stop playing in the sink. It's time

That night, "Huhtanen Land" continued to shift into a more unusual sense of reality after Broden's bedtime ritual. About 20 minutes after putting Broden to bed, we heard the pitter patter of feet. Mark and I lifted our heads and rolled over to look at each other. Mark whispered, "Do you hear that?" The sound of water running in the bathroom echoed through the hallway. I whispered

for bed. Shut the door." Broden yelled back, "Door!" I heard the door shut. Mark came back into the room and cracked the door so we could monitor the hallway. I crammed ear plugs in my ears, so I could try to sleep and pretend that I had no idea what was going on outside of the bedroom. I selfishly thought, "Mark's got it. I'm out."

The next morning at 5 am, Mark and I slid out of bed and opened our bedroom door into the hallway. A pile of Broden's



BROTHERS IN ARMS: Hayden and Broden on the front porch. Hayden was able to come home from college for Fall Break.

blankets had been stacked on top of the dehumidifier near his door. Mark and I stood there staring at the bazaar spectacle. I turned and squinted in the direction of Mark, "Have you ever seen him do this before?" Mark slowly squatted down and picked up about five blankets, "Nope. This is some freaky stuff right here." We slowly walked into Broden's room, not quite sure what we were going to see. We looked down on the floor and Broden had lined up his "Troll" slippers and shoved his sequined slippers inside them. Both of us turned to examine Broden. He was passed out on the bed, wrapped in the remaining blankets. His body was in a diagonal position and one blanket was wrapped around one arm, almost like a snake squeezing the air out of its next victim, "He must be exhausted. He had quite a night." Once we were downstairs, we shuffled our feet to the kitchen to make our coffee. I looked around to see if Broden had been there the night before, for one last spoonful of frosting. Due to all the cupboards and drawers still being closed, I assumed he stayed upstairs. At this point, after seeing the pile of blankets stacked on the dehumidifier, anything was possible.

It was 7:20 am and I had delayed the infamous shower ritual long enough. I walked upstairs and stuck my head in his room. He was slowly rolling around in his bed with one blanket still snug around one of his arms, "Good morning, Broden. It's time for your shower." Broden slowly rolled his head towards me and struggled to open his eyes." Yea, it was going to be one of those mornings. I played with his hair and rubbed his back, as he rolled around some more. Finally, he sat up, "Ok buddy. It's time. We're going to be late for clinic." Broden stood up with his eyes half closed, "Broden, get your robe and walk into the bathroom." He slowly moved over to his robe and pulled it off the hook on his closet door. His robe dragged on the floor as he walked into the bathroom. My standards for the shower slowly diminished that morning. The goal was for him to do as much as possible independently, and if I needed to

do some hand over hand guidance, I was prepared to provide it quickly. He was tired. I was tired and the goal was to get out of the house at a decent time.

Once Broden was downstairs eating, I gulped the rest of my morning coffee down and finished packing his lunch. Broden grabbed his drink cup and headed to the car. On the drive, I tried to find all his favorites on Sirius XM. We played

"Broden's RBT told me 'You're right. Broden has been doing some interesting new things, but we think we know what it is. We have started the changes to his behavior plan.' After he notified me of those changes, it was so clear to me now. Broden was experiencing change."

some Little River Band, Queen, and Boston. In our house, good music always seems to make things a little more manageable. We finally pulled into the parking lot at The Unumb Center. We were a few minutes late, but Nick was there waiting for us at the door. He headed over to the car door where Broden was sitting, "How are you doing?" I kept my hand on the door handle before letting Broden out, "Nick, I honestly do not know how today is going to go." I proceeded to give him the update on the last 24 hours. Nick looked perplexed, but said he would talk to the other Registered Behavior Technicians (RBTs) who work with him, and Amanda, his Program Manager, so they could keep an eye on him.

A few hours later, I got a text from Amanda. She was tracking what happened at home and agreed that there had been a shift in Broden.

That afternoon, when I picked him up, Cameron, an RBT who has worked with him for quite some time, was working with him that afternoon. After helping me put Broden in the car and telling him goodbye, we had a nice chat, "You're right. Broden has been doing some interesting new things, but we think we know what it is. We have started the changes to his behavior plan that we discussed a few weeks ago." After Cameron notified me of those changes, it was so clear to me now. Broden was experiencing change. Change is inevitable, but in Broden's world it's still a tough pill to swallow.

I thanked her for the update and told her I would continue to keep the team in the loop. After Mark got home from work, I told him what I had learned. He agreed. It had to be the change in his program. The plan was to push through to see if the behavior would subside. If not, we would go back to the clinic and ask for them to slow down a bit on the program changes. At least we had a plan forward.

The other day, Mark grabbed the mail and brought it in the house. He laid it on the counter and told me that the results of my mammogram had arrived. I walked over to the kitchen and opened the envelop. Mark looked over at me and saw me smile and chuckle, "What's so funny? What does it say?" I looked up at him, "It says my mammogram was 'normal.' I couldn't tell you the last time I had connected myself to that term." Mark smiled and nodded his head, "You're right, but we'll take it in this circumstance." •

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.

PRODUCTS AND SERVICES

ADAPTIVE/SPECIAL NEEDS BEDS

KAYSERBETTEN-US

P: 800-574-7880

E: ruthann@kayserbettenus.com

W: www.kayserbettenus.com

Tall Rail and Home Care beds with unique designs to meet safety and medical needs.



CLEANING/SANITIZING SOLUTIONS

BANTEC SANITIZING

www.bantec.store

Easy to use disinfecting products and safe, environmentally friendly hygiene strategies that are efficient and cost effective.

FINANCIAL PLANNING/ESTATE PLANNING/INSURANCE

MASS MUTUAL SPECIALCARE

www.massmutual.com/specialcare

Financial planning products and services by a company that cares.

THE AMERICAN COLLEGE OF FINANCIAL SERVICES

www.theamericancollege.edu

A private college focused on professional training for financial practitioners

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

www.iesbrainresearch.org

Helping to further research and find answers to addiction, pain and other brain diseases and disorders.



ADVERTISE IN EP MAGAZINE

Exceptional Parent Magazine, a print and digital publication for over 50 years, provides information on disabilities and special health care needs and is available for free (EP for Free) at www.epmagazine.com

EP provides informative articles, resources and inspirational stories for children and adults with disabilities and special healthcare needs. The information covers all ages from infancy to elderly. EP Magazine also includes a military section dedicated to the unique challenges of military families caring for loved ones with disabilities, including returning veterans.

EP Magazine has a varied and constantly growing readership of individuals, families, caregivers, education and medical professionals. Our partnership with various organizations and universities greatly increases our exposure nationwide.

We offer digital and print advertising opportunities for companies whose PR plan includes corporate warmth and/or companies with products & services they would like to advertise to our readers. Custom advertising packages can be created to meet your needs.

Contact Faye at epmagazinevp@gmail.com

COMING NEXT MONTH IN EP:

FAMILY AND COMMUNITY THE ANNUAL ISSUE



TO LEARN MORE ABOUT ADVERTISING OPPORTUNITIES

CALL 973-726-6218
OR EMAIL [EPMAGAZINEVP@GMAIL.COM](mailto:epmagazinevp@gmail.com)





i talk
they hear you®

IT CAN BE HARD TO GET HIS ATTENTION.

While you're dropping off your child, discuss a plan to help him avoid alcohol and other drugs.

Talk with your children about what to do if they are faced with a decision about alcohol and other drugs, such as texting a code word to a family member. Practice the exit plan in a safe environment. For tips on how—and when—to begin the conversation, visit:

www.underagedrinking.samhsa.gov



SAMHSA
Substance Abuse and Mental Health
Services Administration

SMA-18-5086FLY



Special needs require *Special Care.*

When you're ready, we're here to help. MassMutual's *Special Care* program provides access to information, specialists and financial products and services to help families facing the financial responsibilities of raising a child with a disability or other special needs. To learn more about how a financial professional can help your family, visit [MassMutual.com/SpecialCare](https://www.massmutual.com/SpecialCare)

Insurance. Retirement. Investments.

 **MassMutual**

SpecialCare
a special needs program developed by MassMutual

Massachusetts Mutual Life Insurance Company (MassMutual), Springfield, MA 01111-0001. Insurance products issued by MassMutual, Springfield, MA 01111, and its subsidiaries, C.M. Life Insurance Co. and MML Bay State Life Insurance Co., Enfield, CT 06082. Securities offered through MML Investors Services, LLC, Member SIPC and a MassMutual subsidiary. CRN202012-222355