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EXCEPTIONAL PARENT
MAGAZINE
SEPTEMBER 2024
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AN AUTISTIC FATHER'S STORY:

NAVIGATING THE GOLDEN YEARS

PLUS:

FUTURES PLANNING *for* LOVED ONES

INSIDE:

YOUR RIGHT TO A SUPPORT PERSON *in the* DOCTOR'S OFFICE

AS A SENIOR NEEDING LONG TERM CARE:

CAN I PROVIDE *for a* FAMILY MEMBER WITH A DISABILITY?

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Each issue includes a special Military Section that addresses the unique challenges of military families caring for a family member with a disability.

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Taking Care

Along with the aging of the US population, the need for caregivers is growing.

According to the CDC, the need for caregivers is growing along with the aging of the US population. This important topic is covered in EP's Annual Eldercare Issue. We explore several facets of this serious challenge in this edition.

In the article "The Importance of Self-Care When Caring for Someone with Dementia," Macie P. Smith, Ed.D defines compassion fatigue as "a health condition that is characterized by deep mental, physical, and emotional exhaustion, and a pronounced change in the helper's ability to feel empathy for others." She suggests ways for caregivers to overcome this obstacle and ensure that they get much-needed breaks and respite.

> EP's Annual Eldercare Issue explores the challenges Americans face with caregiving and the aging population.

Elder law attorney Shana Siegel, Esq. contributed our cover story, "As a Senior Needing Long Term Care, Can I Provide for a Family Member with a Disability?" In it, she outlines viable strategies for providing for loved ones with disabilities, even as an older adult who may need to access long term care for themselves.

In "Navigating the Golden Years: An Autistic Father's Story," Marta Chmielowicz introduces Jeff Rickel, who was diagnosed with autism and ADHD later in life. He copes with these challenges while caring for his 28-year-old son Jonathan, who has co-occurring autism and Down syndrome. In addition, articles about futures planning and options for senior care are helpful resources.

This issue also features articles on the right of an individual with a disability to have a support person in hospitals or doctor's offices, what to do when diagnosed with ADHD, and the usefulness of labels for self-advocacy, accommodations and treatment.

All of your comments, suggestions, and questions about *EP Magazine* are welcome. We appreciate your feedback, which helps us maintain the relevance of our magazine.

Feel free to get in touch with me at **epmagazinevp@gmail.com** or **fsimon@epmagazine.com**. Follow us on **facebook.com/exceptionalparentmag**, Instagram **@epmzine** and **twitter.com/epmzine** and share our posts. It's easy to subscribe and get "EP for Free" – just visit our homepage at **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. Faye has been interviewed about *EP Magazine* and IES Brain Research Foundation multiple times including on: Mrs. D's Corner, SFN Dad to Dad Podcast, Oscar Mike Radio, Wreaths Across America Radio, Shana Siegel's Aging Answers, and Able Today Show.

Information and Support for the Special Needs Community

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WHAT'S HAPPENING

COLIN FARRELL LAUNCHES FOUNDATION IN HONOR OF SON WITH RARE NEUROGENETIC DISORDER

Actor Colin Farrell recently disclosed that his son, James, has Angelman syndrome. He has since launched the Colin Farrell Foundation with the goal of finding a cure for the rare disorder.

Colin Farrell is speaking about his son with Angelman syndrome publicly for the first time. Farrell announced that he is starting a foundation to support people with intellectual disabilities.

Farrell's 20-year-old son James has Angelman syndrome, a rare neurogenetic disorder. Diagnosed as a child, James is nonverbal and receives live-in care, according to Farrell, who discussed his son's condition in a new interview with *People* magazine.

"I want the world to be kind to James," the actor told the magazine. "I want the world to treat him with kindness and respect."

The Oscar-nominated actor, 48, has launched the Colin Farrell Foundation, which is "committed to transforming the lives of individuals and families living with intellectual disability through education, awareness, advocacy, and innovative programs," according to its website. He will serve as president of the organization.

FIRM FOUNDATION: Colin Farrell has revealed he's launching a foundation to help support adult children with intellectual disabilities such as his son, James.

> *"All the safeguards that are put in place, special ed classes, that all goes away, so you're left with a young adult who should be an integrated part of our modern society but more often than not is left behind."*

According to the Mayo Clinic, Angelman syndrome is a rare condition that causes "delayed development, problems with speech and balance, mental disability, and, sometimes, seizures." Symptoms include intellectual disability, little or no speech and difficulty walking, the clinic notes. Currently there is no cure for the condition.

"Once your child turns 21, they're kind of on their own," Farrell said. "All the safeguards that are put in place, special ed classes, that all goes away, so you're left with a young adult who should be an integrated part of our modern society and more often than not is left behind."

The new foundation aims to help other families like theirs through advocacy, education and innovative programs. Farrell said he was also inspired by fears about whether his son will have the support he needs as he grows older, especially if something happens to him or James' mother, model Kim Bordenave.

He said he believes that if his son could communicate verbally about their new public effort, "he would say, 'Dad, what are you talking about? Why are you even asking me? It's a no-brainer.'"

"So that's why we're doing it," Farrell said. "This is all because of James – it's all in his honor."

Farrell said watching his son accomplish milestones throughout his life has provided him with perspective and left him "proud."

"He works harder than I've ever had to work on myself," Farrell said. "If anything, he also gifts me with the ability to look at the human being and the human body and life as a marvel because I see how much he struggles with things that I would never have give a seconds thought to – that I would just, like many of us, take for granted."

Discussing his decision to go public about the condition, Colin added: "It was at the Special Olympics in Shanghai in 2007 that I decided, after consulting with James' mother, that I wanted to talk publicly about the pride and joy I had in our son. He has enriched my life, but I don't want to minimise the trials that so many families go through; the fear, consternation, frustration, and pain. When you're the parent of a child with special needs, it's important to feel that you're not alone."

Farrell said that he hopes to open a camp one day through his foundation. He knows that it's been a privilege to provide quality care for his son and wants the same for other families in similar circumstances.

"He has a good life, James. He's a happy young man, I'm glad to say," he said.

Learn more at **www.colinfarrellfoundation.org**

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WHAT'S HAPPENING

HEALTHY AGING MONTH IS A TIME TO CELEBRATE LIFE AND THE POSITIVE ASPECTS OF GROWING OLDER

Healthy Aging Month is observed during the month of September. This observance raises awareness on the physical and mental health of older adults and serves as a reminder that as we age, our minds and bodies change. It is important to maintain a healthy lifestyle to help deal with those changes and to help prevent some common age-related health problems.

As we age, we become aware that our physical and mental health, as well as dietary and social needs, change over time. However, that doesn't mean you've lost control. You can take charge of your well-being, by taking steps to age with a healthy body and a healthy mind.

CHECK YOURSELF: Regular checkups help health professionals catch chronic diseases early and can help reduce risk factors for disease, such as high blood pressure and cholesterol levels.

You can take a proactive approach to aging by adopting healthy habits and behaviors, managing existing health conditions, and staying connected to your community. Consider practicing the tips below to help you stay active and independent as you age.

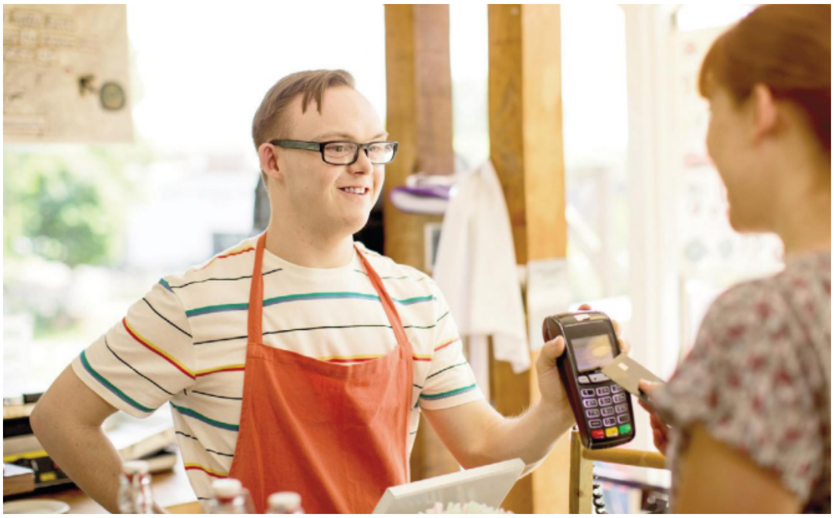
- **Eat and Drink Healthy.** Dietary needs may change as you age. A healthy eating plan includes nutritious foods that are low in cholesterol, fat, and artificial ingredients. You should also drink plenty of liquids, especially water, to stay hydrated. Eat nutrient dense foods like fruits, vegetables, whole grains, lean meats, and low-fat dairy products.
- **Move More, Sit Less.** Staying active can help you prevent, delay, and manage chronic diseases, improve balance and stamina, reduce the risk of falling, and improve brain health. Aim for moderate physical activity, like walking, at least 150 minutes a week (22-30 minutes a day) and muscle strengthening activities, like carrying groceries, at least 2 days a week. Always consult with your doctor before starting a new exercise regimen.
- **Get Regular Checkups.** It is vital to go to the doctor for regular health screenings for healthy aging. Regular checkups help doctors catch chronic diseases early and can help patients reduce risk factors for disease, such as high blood pressure and cholesterol levels. In some cases, regular checkups have been linked to improved quality of life and feelings of wellness.
- **Be Aware of Changes in Brain Health.** Everyone's brain changes as they age, but dementia is not a normal part of aging. There are a variety of healthy behaviors that can be done to reduce age-related cognitive decline or manage dementia. Engaging in social and intellectually stimulating activities, getting enough sleep, and not smoking are a few actions you can take. See your doctor if you have questions about memory or brain health.

For additional resources and information on healthy aging, please visit the National Institute on Aging, Healthy Aging website at **www.nia.nih.gov/health/healthy-aging**

WHAT'S HAPPENING

FEDERAL REPORT ILLUMINATES NEED FOR DISABILITY INCLUSION, MORE ACCESS IN CLINICAL TRIALS

The National Council on Disability (NCD) has released a timely report on exclusionary practices that prevent people with disabilities from participating in clinical trials.



TRIAL AND ERROR: People with Down syndrome have a 90% lifetime risk of developing Alzheimer's disease or a similar form of dementia, yet they are not included in clinical trials for treatment of the disease.

The Implicit and Explicit Exclusion of People with Disabilities in Clinical Trials discusses how healthcare practitioners' internal biases and federal policies contribute to the participation rates, and how the disparity affects people with disabilities and the efficacy of clinical trials. See the report at **www.ncd.gov/report/the-implicit-and-explicit-exclusion-of-people-with-disabilities-in-clinical-trials**

Federal agencies have made efforts to address exclusionary practices pertaining to people with disabilities, including the U.S. Department of Health and Human Services' explicit requirements of clinical trials inclusion in the amended Section 504 regulations. However, much work remains to ensure that people with disabilities are meaningfully included in clinical trials.

"A significant step forward was made last September when the NIH finally recognized individuals with disabilities as a health disparities population," said NCD Chair Claudia Gordon.

"Building upon this progress, our report underscores the alarming reality that people with disabilities are systematically excluded from crucial clinical trials," said Gordon. "To effectively address health disparities, HHS must prioritize this issue as a connected policy matter across the entire department."

"The fact that 90 percent of people with Down syndrome will develop Alzheimer's during their lifetimes and yet none of them have ever been included in a clinical trial for Alzheimer's treatments is a poignant example of the cost of exclusion," said NCD Vice Chair Emily Voorde. "How can this population benefit from these potentially life-changing treatments if they're excluded from the trials? And how can anyone know what these therapeutics' efficacy and safety is on this population – and one of the populations most affected? Exclusion exacts too high a price."

This report offers recommendations for federal agencies, Congress, and healthcare practitioners focused on improving the participation rate of people with disabilities in clinical trials.

Read this and all of NCD's reports at **NCD.gov**

TESTING, TESTING : EXPANDING CLINICAL TRIALS

NCD's key findings include:

- Multiple efforts in recent years have been made to enhance diversity in clinical trials; however, disability is not included as a dimension of diversity in such efforts.
- The inclusion and exclusion criteria embedded in clinical trial criteria can create barriers for people with disabilities – often without scientific justification.
- Clinical trials for Alzheimer's therapeutics have excluded people with Down syndrome, even though 90 percent of people with Down syndrome will develop Alzheimer's by the age of 55.

NCD's key recommendations include:

- FDA and HHS should develop guidance on eligibility parameters for investigators, similar to FDA's "Informed Consent: Guidance for IRBs, Clinical Investigators, and Sponsors."
- NCD recommends FDA should promulgate regulations that incorporate the "Informed Consent: Guidance for IRBs, Clinical Investigators, and Sponsors," making the guidance legally enforceable.
- Clinical trial study teams should incorporate overt explanations and justifications of the availability of reasonable accommodations in informed consent documents.

ABOUT THE NATIONAL COUNCIL ON DISABILITY:

The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting Americans with disabilities. NCD is comprised of a team of fifteen Presidential appointees, an Executive Director appointed by the Chairman, and twelve, full-time professional staff. On their website the NCD has publications and policy briefs that provide recommendations to the Administration, Congress, and executive branch agencies on the broad spectrum of issues that affect people with disabilities. Visit **www.ncd.gov**

WHAT'S HAPPENING

BIDEN ADMINISTRATION TOUTS BILLIONS IN SAVINGS AS IT DEBUTS MEDICARE DRUG DISCOUNTS

The Biden administration has announced that drug price negotiations will knock hundreds of dollars – in some cases thousands – off the list prices of 10 of Medicare's most popular and costliest drugs.

PRICE CHECK: Medicare negotiated discounts on 10 drugs prescribed to treat blood clots, cancer, heart disease, and diabetes.

The discounts, agreed to after months of negotiations with drug manufacturers, range between 38% and 79% on the medication's list price, which is the cost of medication before discounts or rebates are applied – not the price people actually pay for prescriptions.

Medicare spent $50 billion covering the drugs last year and taxpayers are expected to save $6 billion on the new prices, which do not go into effect until 2026. Older adults could save as much as $1.5 billion in total on their medications in out-of-pocket costs. Administration officials released few details about how they arrived at those calculations.

The newly negotiated prices will impact the price of drugs used by millions of older Americans to help manage diabetes, blood cancers and prevent heart failure or blood clots. The drugs include the blood thinners Xarelto and Eliquis and diabetes drugs Jardiance and Januvia.

Under President Joe Biden's 2022 climate and health legislation called the Inflation Reduction Act, Medicare was empowered to negotiate prices with pharmaceutical companies on a limited number of medications. Another 30 drugs will be selected over the next two years for negotiated prices that will be rolled out in 2027 and 2028.

The prices won't take effect until 2026, but the measure is a landmark for Medicare. The federal government has never been able to directly haggle with drugmakers over the prices of their prescription drugs.

"For years, millions of Americans were forced to choose between paying for medications or putting food on the table, while Big Pharma blocked Medicare from being able to negotiate prices on behalf of seniors and people with disabilities," President Joe Biden said in a statement. "But we fought back – and won."

The drug deals will become a focal point for Vice President Kamala Harris' presidential campaign, especially since she cast the tiebreaking vote to pass the law. Powerful drug companies unsuccessfully tried to file lawsuits to stop the negotiations, which became law in 2022, when a Democratic-controlled Congress passed the Inflation Reduction Act (IRA), overhauling several Medicare prescription drug regulations. But executives of those companies have also hinted in recent weeks during earnings calls that they don't expect the negotiations to impact their bottom line.

Pharmaceutical officials blasted the news from the White House, saying it will spread health care costs to taxpayers in other ways, including their Medicare premiums.

"The administration is using the IRA's price-setting scheme to drive political headlines, but patients will be disappointed when they find out what it means for them," Steve Ubl, the president of the Pharmaceutical Research and Manufacturers of America (PhRMA).

Next year, the Department of Health and Human Services can select another 15 drugs for price negotiations.•

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Letter of Intent: A Free Virtual Workshop

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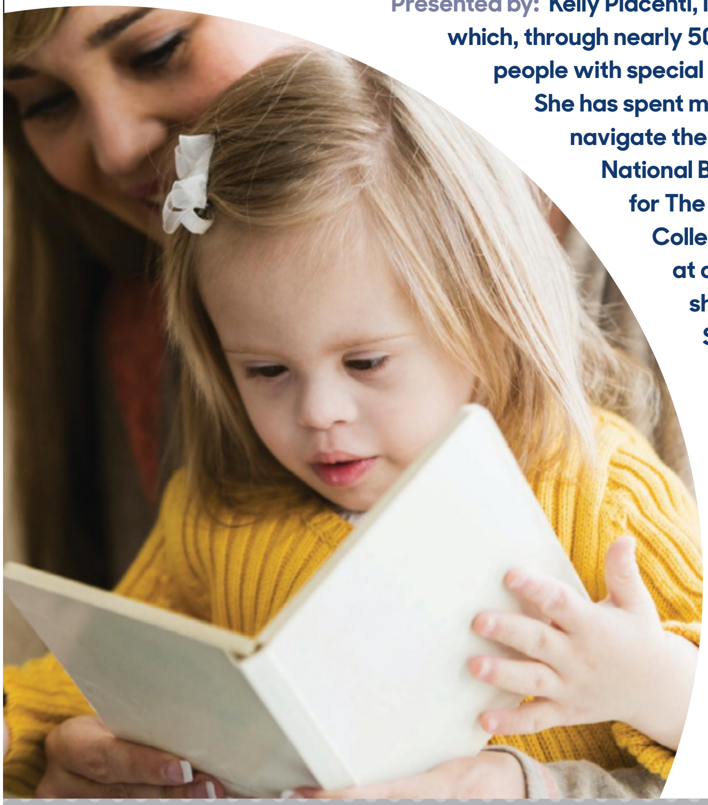
RSVP by October 20th to Faye Simon, Editor In Chief • epmagazinevp@gmail.com (the webinar link will be emailed to you before October 23rd)



Presented by: **Kelly Placenti, MA, CHSNC® is the Head of MassMutual's Special*Care* Program which, through nearly 500 Special*Care* Planners, helps families and caregivers of people with special needs provide a secure financial future for their loved ones. She has spent more than 20 years helping those with special needs dependents navigate the legal and financial complexities they face. Kelly serves on the National Board of Directors for United Cerebral Palsy, the Advisory Board for The Academy of Special Needs Planners, as well as The American College Center for Special Needs. Kelly has been a featured speaker at dozens of special needs conferences, a guest on national radio shows, and a guest author in numerous industry publications. She also was the mother of a child with special needs for 19 years and has been named "Working Mother of the Year" by *Working Mother Magazine.***

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*The presentation will run approximately **45 minutes**, with plenty of time afterwards to answer your questions.*

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FUTURES PLANNING

IS A MUST FOR PARENTS OF CHILDREN OF ALL AGES WITH SPECIAL NEEDS

BY LARRY LANDAUER

It's a subject few parents really want to talk about: What will happen to my child with special needs when I pass away or am unable to provide daily care?

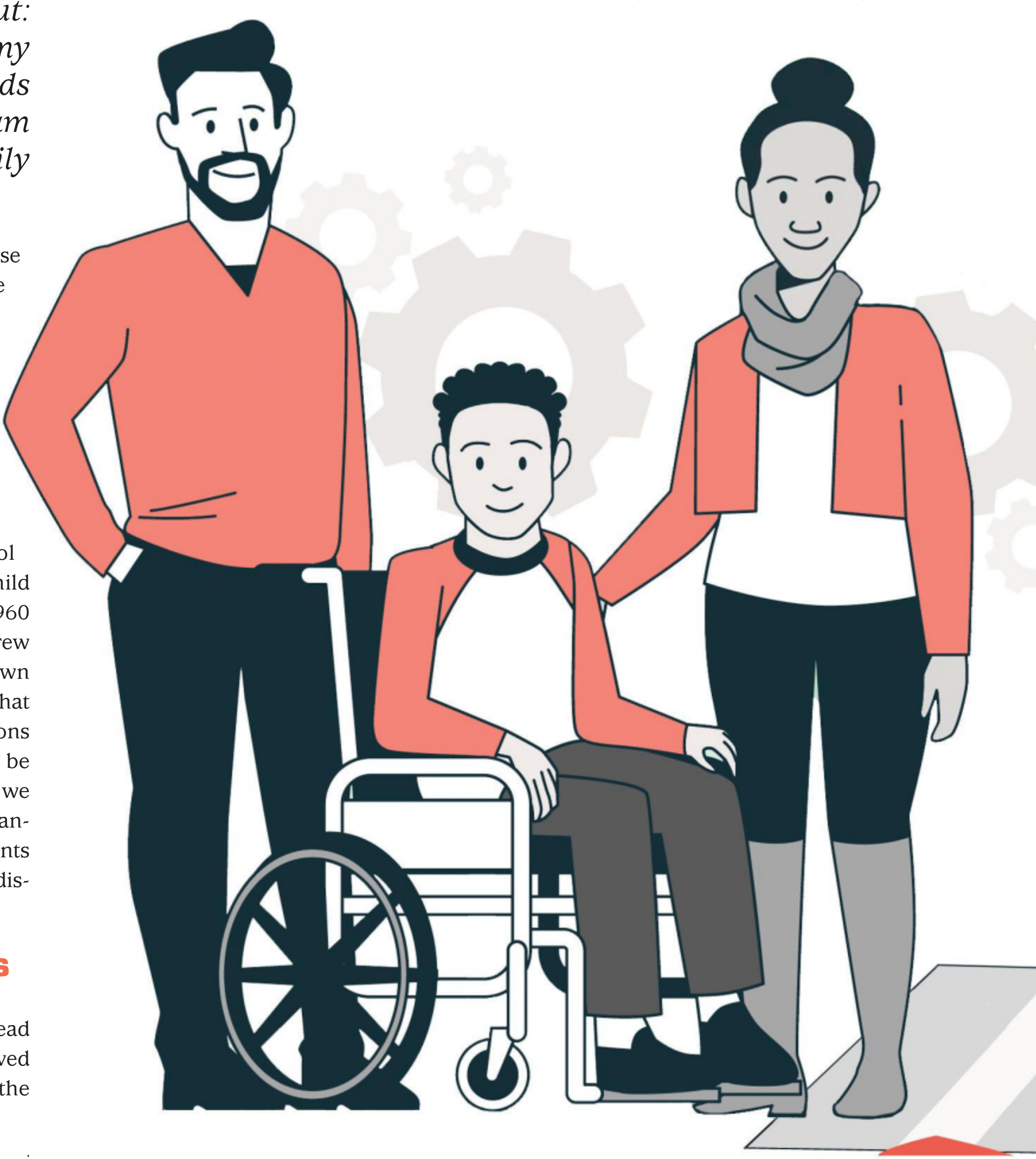
While it is sadly the case that many people with disabilities still have a much shorter life expectancy than those without disabilities, better medical care, access to care, and understanding of various disabilities has greatly increased life spans.

For example, according to the U.S. Centers for Disease Control (CDC),[1] the life expectancy of a child born with Down syndrome in 1960 was just about 10 years old, and grew to about 47 by 2007. The Global Down Syndrome Foundation[2] estimates that now the average life span of persons with Down syndrome in the U.S. to be 60 years. This is wonderful news we should all celebrate. It also makes planning for the future a must for parents of children or adult children with disabilities.

WHAT IS FUTURES PLANNING?

Futures planning is thinking ahead and planning for the future of a loved one with disabilities. It is discussing the many options there are to help ensure that the individual with disabilities' life, health, work and educational needs are supported after the primary caregivers are no longer available or able to assist.

Throughout the world, family members



are the mainstay of the circle of support for people with disabilities. For example, of the more than 26,000 individuals Regional Center of Orange County serves, more than 22,000 reside in the family home. Over half of those we serve are adults, so it's not just children living at home.

Though a variety of residential options are available for adults with disabilities, many prefer to live with family, and many parents prefer to be their loved ones' primary caregivers. Futures planning is important to consider, because as parents become older, many are likely to become less able to meet their children or adult children's daily needs.

SOME KEY ISSUES TO CONSIDER

A well-crafted futures plan takes into account various situations, for example; who will step up in the parent's absence to provide day-to-day care? Sometimes this will be a sibling or extended family member, or it could be a trusted, pre-identified professional service provider.

In addition to specifying where the person with disabilities will live and who will take over as primary caregiver, a good futures plan aims to help the person develop the skills for independence that is needed, as the parent is less able to handle tasks such as: grocery shopping, meal preparation and laundry.

Financial arrangements are also important to consider. For parents with the means, working with an estate planning attorney to set up a special needs trust can be an effective way to provide for a more comfortable and secure future for their child. However, all U.S. families have access to tax-advantaged ABLE (Achieving a Better Life Experience) accounts[3] that currently (in 2024) allow families to set aside up to $18,000 a year for qualified disability expenses, which include things like housing, education and transportation.

WHY IT'S IMPORTANT TO PLAN AHEAD

Reliable routines are very important to many people with disabilities. When an elderly caregiving parent becomes incapacitated and unable to provide daily care, the disruption is much more challenging, as the person with disabilities must also cope with emotional concerns for the parent's well-being.

If the person with disabilities is equipped with independent living skills, comfortable with their caregiver, and understands the plans that will go into effect, the situation will be less overwhelming. Talking about the plan with each other can help reduce some stress around this topic. Discussions about details can be reassuring, even though it's not a topic most people enjoy discussing.

Planning ahead gives parents peace of mind, knowing their loved one's needs will continue to be met, even after they are gone. •

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3. Tax-advantaged ABLE (Achieving a Better Life Experience) accounts https://www.irs.gov/government-entities/federal-state-local-governments/able-accounts-tax-benefit-for-people-with-disabilities

ABOUT THE AUTHOR:

Larry Landauer is Executive Director for Regional Center of Orange County, the private, nonprofit organization contracted by the State of California to coordinate lifelong services and supports for more than 26,000 Orange County residents with developmental disabilities and their families. The Regional Center is the first stop for those seeking to obtain local services and supports to help them live safely and with dignity in the community. Developmental disabilities include intellectual disabilities, autism, epilepsy and cerebral palsy. Learn more at **www.rcocdd.com**

AS A SENIOR NEEDING LONG TERM CARE, CAN I PROVIDE FOR A FAMILY MEMBER WITH A DISABILITY?

EMBRACING THE FUTURE: It can be reassuring that providing for disabled loved ones is a viable strategy for older adults facing long term care needs.

BY SHANA SIEGEL

Martha had been a big saver for her whole life. While many of her retired friends went on extravagant vacations, she stayed home. She helped her daughter care for her grandson David, who has autism.

Martha focused on saving because she felt that David would probably be unable to support himself throughout adulthood, and she wanted to be able to leave a nice nest egg for his future. Then Martha had a stroke and needed a daily home health aide. Not only was it hard to adjust to needing assistance, but she was afraid that her plans to provide for David's future were in jeopardy.

However, after visiting an elder law attorney, Martha learned that she could ensure that funds were seta aside for David, while not jeopardizing her own care needs,

Medicaid planning is a crucial process for older adults who want to ensure they can access long-term care while preserving as much of their estate as possible. Unfortunately, many Medicaid strategies require seniors to plan five years ahead of applying for Medicaid. However, transferring assets to disabled family members can be done at any point. This can be an effective way to protect assets from Medicaid spend-down requirements, while ensuring that loved ones are cared for. However, this strategy requires careful planning and adherence to legal guidelines to avoid potential pitfalls.

UNDERSTANDING MEDICAID ELIGIBILITY

Medicaid is a joint federal and state program designed to assist individuals with limited income and resources to cover the cost of medical care, including long-term care. Eligibility for Medicaid varies by state, but generally, individuals must meet specific income and asset limits. For seniors needing long-term care, Medicaid can cover costs that Medicare does not, such as nursing home care as well as, home and community-based services. To qualify for Medicaid, applicants must often "spend down" their assets to meet eligibility requirements. This is where Medicaid planning comes into play.

> "There are many factors to consider, including how much to set aside, and when and how to make transfers, in coordinating Medicaid planning with disability planning."

ASSET TRANSFER STRATEGY

One common strategy in Medicaid planning is to transfer assets to family members. Medicaid generally imposes penalties for asset transfers made for less than fair market value within five years of applying for Medicaid, but there is a policy exception for transfers to children of the Medicaid applicant who are disabled or disabled individuals under the age of 65.[1] Assets can be transferred to family members who are disabled and qualify as "disabled" under Medicaid rules. This includes individuals who receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), or who are otherwise determined to be disabled according to medical and legal standards.

OUTRIGHT OR IN TRUST

Transfers can be made to the disabled individual directly, but this may be inadvisable for several reasons. If the disabled family member is receiving means-tested benefits, then the gift must be in trust to avoid impacting the recipient's benefits. Sometimes a trust is necessary to manage the funds. If the individual has a preexisting first party special needs trust, then the gift can be made to that trust. Otherwise, the donor like Martha would establish a special kind of trust called a sole benefit trust.

SOLE BENEFIT TRUST

A sole benefit trust is one that is solely for the benefit of the disabled individual. Medicaid rules provide that the sole benefit test can be met either by 1) providing for actuarily sound disbursements, i.e. requiring that the trust assets are disbursed over the life expectancy of the beneficiary, or 2) including a payback provision to ensure that the Medicaid agency can be reimbursed for any services provided from the trust assets remaining at the disabled individual's death. For Martha, a sole benefit trust meets all her needs. She can make sure that David is provided for, using her savings as she always wanted. She intends that the trust would be depleted for whatever David needs, and if there happens to be something left at the end of his life, she does not mind that it will go the state.

OTHER OPTIONS

Some older adults may not have the same view. They may, for instance, be concerned about their home staying in the family. In that case, an outright transfer may make more sense, since there is no payback requirement.[2] In other cases, we find adult children who do not have a formal disability finding, but live with their parents. In that case, it may be worth considering if the child might qualify under a different exception, the caretaker child, in order to allow transfer of the home to the child. This policy exception applies to transfer of the home without penalty to a child who has resided there and provided care to the parent for a period of two years.[3]

CONCLUSION

In coordinating Medicaid planning with disability planning, there are many factors to consider including how much to set aside, and when and how to make transfers. It can be reassuring that providing for disabled loved ones is a viable strategy for older adults facing long term care needs. Seniors like Martha do not have to choose between their health care needs and supporting their family members with a disability. •

References

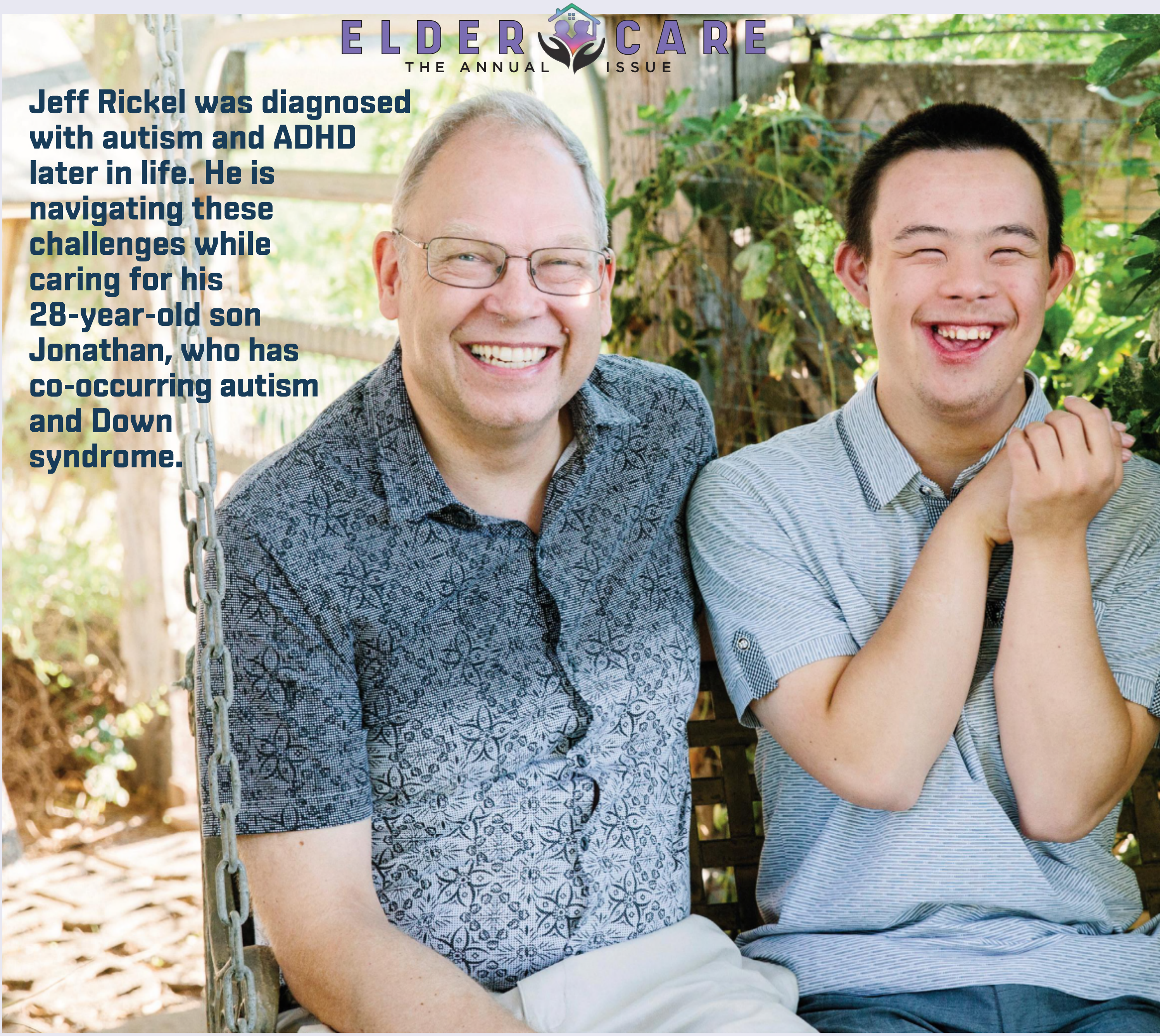
1. It is not uncommon for Medicaid caseworkers to believe that the exception only applies to children of the applicant but 42 U.S.C. § 1396p(c)(2)(B) clearly states that any disabled individual under age 65 is included, so Martha can create trust for her grandson.

2. Of course, if the home is ever sold it could impact certain public benefits for the disabled family member.

3. There are a number of detailed requirements for this exception so an elder law attorney should be consulted.

ABOUT THE AUTHOR:

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



Jeff Rickel was diagnosed with autism and ADHD later in life. He is navigating these challenges while caring for his 28-year-old son Jonathan, who has co-occurring autism and Down syndrome.

NAVIGATING THE GOLDEN YEARS

AN AUTISTIC FATHER'S STORY

Autism Speaks' Jeff Rickel opens up about the realities of aging on the spectrum.

BY MARTA CHMIELOWICZ

PHOTOS PROVIDED BY JEFF RICKEL

TAKING THE LONG VIEW:
Jeff Rickel and son Jonathan at home; One issue that is always at the top of autistic adults and caregivers' minds is future planning. Families and caregivers must consider long-term plans for housing, healthcare and financial stability to ensure the wellbeing of their loved ones as they age.

A growing population of autistic people are reaching their senior years and finding themselves in uncharted territory. As the autistic population ages, they often encounter issues such as increased social isolation, difficulty accessing quality healthcare, and lack of appropriate supports and services.

Additionally, concerns about future planning, such as securing stable housing and long-term care become more pressing, particularly for those who lack a strong family support system.

Jeff Rickel, a database manager at Autism Speaks, was diagnosed with autism and ADHD later in life. He is navigating these challenges while caring for his 28-year-old son Jonathan, who has co-occurring autism and Down syndrome.[1] With each passing year, Jeff confronts new obstacles, from managing Jonathan's growing health needs to grappling with the inevitable changes that come with aging. Yet through it all, Jeff draws strength from his faith and from Jonathan's resilience.

FINDING SELF-ACCEPTANCE IN A DIAGNOSIS

Many older adults grew up in a time where autism was less understood, leading to countless individuals navigating life undiagnosed. As awareness of autism grows, an increasing number of adults are receiving a diagnosis later in life.[2]

Some adults may not receive a diagnosis because they don't realize their behaviors are linked to autism, have learned to mask their autistic traits, or find the process of getting an autism diagnosis expensive or inaccessible. While many undiagnosed adults live happy lives, others struggle to feel accepted or fulfilled in their lives.

> **Some adults may not receive a diagnosis because they don't realize their behaviors are linked to autism or they find the process of getting an autism diagnosis expensive or inaccessible.**

This was the case for Jeff before he got his autism diagnosis. Throughout his life, Jeff struggled with depression, decision making, impulsivity, and feelings of worthlessness. When his mental health deteriorated to the point where he considered suicide, Jeff knew that it was time for a change.

"I was messing up all the time, being impulsive, and making the wrong decisions. I would beat myself up every time I made a mistake. Honestly, I thought the whole reason I existed on earth was to mess up my life and the lives of people around me. I didn't think there was anything in me that was any good or of any value," he says.

Discovering his faith played a crucial role in his journey toward fulfillment and self-acceptance, gradually allowing him to see the positive impact of autism in his life. In his church, Jeff found a community of supportive people who accepted him despite his differences. Attending regularly helped him learn to socialize and make friends, many of whom have been a source of strength and support for Jeff, Jonathan and his wife Esther, ever since.

Later, getting an official diagnosis offered clarity, helping Jeff understand his behaviors and lifelong challenges.

"For a long time, I felt like the incredible Hulk, like I had to keep this monster inside and never let it come out. Getting an autism diagnosis helped me understand what was going on and what areas of my life I had to be careful of. Eventually, I realized that there are parts of autism that are good. I started seeing myself as a human being with both strengths and barriers. I realized I can accomplish things and that I'm a worthwhile person. Now, I wouldn't trade my life for anything."

Understanding his autism helped Jeff learn to advocate for his needs, as he navigates his life. "Don't be worried about the negative stigma associated with an autism diagnosis. It's something you need to be aware of," he explains. "When you go somewhere, you need to be able to say, 'I'm autistic, please bear with me.' Most people are very willing to accommodate."

GETTING AN AUTISM DIAGNOSIS AS AN ADULT

The only way to know for sure if you are autistic is to get a formal diagnosis. The gold standard is to obtain a diagnosis from a psychologist, psychiatrist or similarly trained clinician who specializes in autism spectrum disorder (ASD). You may want to start by making an appointment with your primary care physician.

You can also check with a respected autism center in your area, like those in Autism Speaks Autism Care Network,[3] or check with your insurance provider.

WHAT IS THE PROCESS FOR GETTING AN ADULT AUTISM DIAGNOSIS?

There is not one autism test for adults. Instead, an autism evaluation typically consists of multiple appointments with a clinician. The process involves talking with the clinician, doing some cognitive activity-based tests, and filling out a couple of questionnaires.

Getting a diagnosis as an adult can be more challenging than getting one as a child. Oftentimes, healthcare professionals ask adults seeking a diagnosis or their loved ones questions about their early development, which some people may not have answers to.

A history of other diagnoses may also complicate getting an autism diagnosis. You should expect your doctor will want to rule out other conditions that commonly co-occur with autism, such as ADHD, anxiety and depression.

PUTTING HEALTH AND WELLBEING FIRST

Accessing quality healthcare is another major hurdle for aging autistic adults. Many healthcare providers lack the specialized training needed to effectively support autistic patients, which can lead to inadequate treatment. Sensory sensitivities and communication differences may not be accommodated in all medical settings, causing significant stress and anxiety and often leading people with autism to avoid seeking medical care altogether.

"In general, research shows that autistic adults' lifespans are somewhere between 15 to 20 years shorter than the neurotypical population," says Dean Hartley, senior director of genetic discovery and translational science at Autism Speaks. "Two contributing factors are inequity in healthcare and high rates of co-occurring conditions. Most adults who have autism either have never been diagnosed or have been misdiagnosed. They have difficulties making an appointment and finding autism-friendly providers who can accommodate their sensory sensitivities. As a result, they often avoid the healthcare system. In the long term, that means that they have more health issues, often preventable conditions like: diabetes, obesity and cardiovascular issues."

Research shows that autistic adults face a higher risk of physical and mental health challenges. A 2020 study[4] showed that older adults with autism are 19 times more likely to have epilepsy, 6 times more likely to have Parkinson's disease, 25 times more likely to have schizophrenia, 11 times more likely to have suicidal thoughts or self-harm behaviors, and 22 times more likely to have ADHD. Because most autism research has been focused on children, researchers know little about how physical and mental health issues unfold over an autistic person's lifetime and how aging complicates their healthcare needs.

Jeff has experienced some of these challenges firsthand, noting changes in his health as he ages. He has had to adopt new strategies to manage increased impulsivity, memory loss, and difficulty with executive function and multitasking.

"I've had to start focusing on one task at a time and organize my time better," says Jeff. "I've learned that this is a normal part of aging. You have to learn to cope and adapt to the aging process. You're not as strong, you're not as fast, your body is going to hurt, so you need to be more careful. You need to understand your limitations and accept that things that were a little bit of a problem before, might become a bigger problem, and the things that you

SELF-ASSURED: Jeff and his wife Esther share an embrace with Jonathan; Prioritizing self-care is essential for maintaining good mental health, as Jeff's role as a caregiver has become increasingly demanding due to Jonathan's evolving needs.

didn't think were a problem can become one."

Finding quality healthcare has also had its challenges. Jeff recalls struggling to learn proper dental care techniques, and only finding a dentist who could help him after years of damaging his gums.

"I find that I have to be more open with the doctors about my autism. In mental health, if you look around, you can find people that deal with autism. It's just a matter of finding the right provider. For physical healthcare, it's more difficult, but I look for people who can set me at ease and communicate well. You don't want someone who will rush you through the process."

Jeff has had similar difficulties finding providers for Jonathan, that were covered by his insurance.

"We had significant problems with Jonathan's healthcare before he went on Medicare," explains Jeff. "Because of his special needs, we used to have problems finding doctors in network who could treat him, and there were often problems with insurance. Resolving this required strong advocacy and several appeals within the healthcare system, even up to state level."

For aging autistic caregivers, prioritizing self-care is essential for maintaining good mental health.

For aging autistic caregivers like Jeff, prioritizing self-care is essential for maintaining good mental health. Jeff's role as a caregiver has become increasingly demanding due to Jonathan's evolving care needs. Jonathan's back injury forced Jeff to make significant lifestyle adjustments for Jonathan's wellbeing, such as using a wheelchair for longer distances and providing close supervision to his son.

Jeff views his role as Jonathan's caregiver, as both an honor and a responsibility, but he also recognizes the toll it takes on him and the need for rest.

"I feel like I've been entrusted with the greatest treasure in the world," Jeff says. "I am honored that God chose my wife Esther and me as parents to Jonathan, and I want to live up to that trust. But the caregiver fatigue is there. Learning how to take care of myself, to find hobbies that I enjoy, while still taking care of the family has been essential. When I do that, there's more to give others in the long run. The best gift Esther and I can give to Jonathan is to be strong, loving, healthy parents."

CONTINUING TO THRIVE : AUTISM AT AN ADVANCED AGE

AUTISM SPEAKS

To learn more about getting an autism diagnosis as an adult, download the Autism Speaks Adult Autism Diagnosis Tool Kit

https://www.autismspeaks.org/tool-kit/adult-autism-diagnosis-tool-kit

or contact the Autism Response Team (ART) at 1-888-288-4762

or help@autismspeaks.org

988 SUICIDE & CRISIS LIFELINE

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https://988lifeline.org

PLANNING FOR THE FUTURE

One issue that is always at the top of autistic adults' and caregivers' minds is future planning. Families and caregivers must consider long-term plans for housing, healthcare and financial stability to ensure the wellbeing of their loved ones as they age.

Legal and financial planning, such as establishing trusts, conservatorships and guardianships, can provide security and support for the autistic person as they age. It is crucial that caregivers involve the person with autism in these decisions, respecting their autonomy and preferences for their future.

As Jeff and Esther age, planning for Jonathan's future has become increasingly urgent. Jonathan's back injury has complicated their original plans, making it harder for him to achieve the level of independence they had hoped for. While they have already set up a conservatorship for Jonathan, they are working to identify additional conservators who can guide Jonathan's financial decisions. Jeff is also focused on setting up a special needs trust to ensure that Jonathan will be cared for after they are gone.[5]

Another key aspect of their planning involves building a strong network of people in their community who will look out for Jonathan. Loss of parents and other caretakers can be devastating for an autistic person's emotional and practical support system. Jeff is determined to make sure this doesn't happen to Jonathan.

"We want to make sure his life doesn't fall apart after we're gone," he says. "Our church has been very active with him, but we had to stop coming because of his back injury and COVID. I need to get him back into that, because he needs other people in his life. We are considering moving closer to family, and have thought about places like retirement communities, where he can continue to live with us and inherit the house afterwards. It's important for me to get a group of people around him who will look out for him."

With the right support systems, thoughtful preparation and a strong community, autistic adults and their caregivers can navigate the complexities of aging, and continue to thrive. •

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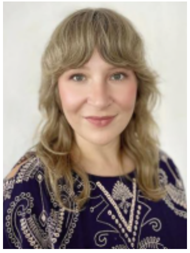

Marta Chmielowicz leads science communications at Autism Speaks, working to advance the mission of the organization to create an inclusive world for all individuals with autism throughout their lifespan.


From Red Hawk
to Project Manager
Ariana Leyton-White
Class of 2022

COMPASSION FATIGUE IS CHARACTERIZED BY DEEP MENTAL, PHYSICAL, AND EMOTIONAL EXHAUSTION, AND A PRONOUNCED CHANGE IN THE ABILITY TO FEEL EMPATHY FOR OTHERS.

THE IMPORTANCE OF SELF-CARE

WHEN CARING FOR SOMEONE WITH DEMENTIA

BY MACIE P. SMITH, ED.D

With the growing aging population, many will be faced with the real possibility of caring for an elderly loved one in the future, if they are not already doing so.

Currently, there are more than 53 million caregivers in America (www.cdc.gov/aging/publications/features/supporting-caregivers.htm), with more than11 million caregivers caring for someone with Alzheimer's or a related dementia, and providing more than 18 billion hours of unpaid care (www.alz.org/alzheimers-dementia/facts-figures). Caring for someone with dementia presents very unique and difficult challenges. Their loved on could experience: the loss of cognition, memory, judgement, recall, communication, and the ability to carry out basic activities of daily living. This is why it's very important for dementia caregivers to receive the support they need to reduce their risk of developing chronic illness that could impede their ability to care for their elderly family member.

Often people who are caregiving don't even identify as a caregiver. In many communities, families take care of their own. If momma gets sick or needs to go to the doctor, someone in the family takes her or makes sure she gets there. This person does not necessarily consider him/herself a caregiver, but rather feels that this is his/her responsibility. If you accept responsibility for providing any level of supervision; hands on care; transportation; and/or medication assistance for a loved one, you are a family caregiver. Studies support that most family caregivers experience high levels of stress (www.aarp.org/caregiving/health/info-2023/report-caregiver-mental-health.html). However, many enjoy caring for their loved ones and wouldn't have it any other way.

It is possible that the demand for Long Term Services and Supports (LTSS) is going to surpass the number of support services available. That means that the brunt of the responsibility for providing care will rest on the family members.

As a caregiver, you may have become worn out by giving your all to others, day in and day out, and perhaps there is very limited, if any, support left for you. When this happens, you are increasing your risk of developing compassion fatigue. Compassion fatigue, also known as secondary traumatic stress or vicarious trauma, is a health condition that is characterized by deep mental, physical, and emotional exhaustion, and a pronounced change in the helper's ability to feel empathy for others. Compassion fatigue can prove to be very dangerous if not addressed as early as possible.

SIGNS OF COMPASSION FATIGUE

Below are the most common emotions/symptoms that may be included compassion fatigue:

- *Anger*
- *Grief*
- *Sadness*
- *Loneliness*
- *Guilt*
- *Resentment*
- *Feeling Helpless*
- *Feeling Hopeless*
- *Feeling overwhelmed*
- *Feeling Exhausted*
- *Feeling detached or numb*

A few signs in addition to the above that compassion fatigue may be occurring are:

- *Reduced empathy or sensitivity*
- *Difficulty sleeping*
- *Blaming*
- *Pessimism*
- *Insulting others*
- *Defensiveness*
- *Irritability*
- *Headaches*

If you are experiencing or displaying any of these feelings or actions, and they begin to impede your ability to enjoy activities and/or complete tasks, such as going to dinner with friends; exercising daily; shopping; going to work, etc., you may be experiencing compassion fatigue. Once you notice the signs, you'll need to address them immediately.

TIME OUT: You might consider taking time off from caring for your loved one so that you can get a much-needed break and respite. Your mind, body, and spirit are screaming for it.

You might consider taking time off from work *(and yes caring for a loved one is work),* or hiring a caregiver to watch over your loved one so that you can get the much-needed break and respite. Your mind, body, and spirit are screaming for it. You might consider joining a support group. Join a group of people that has been through what you are going through and is able to offer you tangible support and strategies.

One of the things that helped me when I was emotionally exhausted after working ten years with the aging and disabled population was taking true time far away from work and from anything that reminded me of work. I began to schedule vacation time, even if I did not leave my house. The mindfulness I was able to experience during my away time was priceless. Whatever you do, DO NOT IGNORE your body's messages. It is a necessity to respond, as no one else is responsible for you but you!

One support that is available is the respite program at the Area Agency on Aging. Each county in the U.S. has a Area Agency on Aging that helps families with respite, education, meals on wheels and so much more. This program may offer supportive services, such as Respite vouchers, so family caregivers can pay for care. When it comes to respite care, it can be provided in your home, or you might consider visiting an assisted living in your area to inquire about doing out-of-home respite at that facility. This will give you an added layer of the type of respite and rest you need and deserve.

For support groups, the Alzheimer's Association and Leeza's Care Connection have been extremely helpful to my clients, as they offer in-person and virtual support groups for different types of caregivers, such as African American caregivers; LGBTQIA+ caregivers, spousal caregivers, male caregivers, millennial caregivers, etc. Simply tap into your county by going to **www.alz.org** for more information. You can access the virtual support groups at Leeza's Care Connection by going to **www.leezascareconnection.org** •

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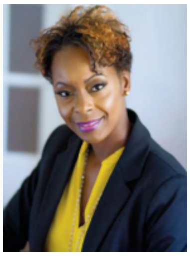

Dr. Macie P. Smith is a Licensed Gerontology Social Worker and an award-winning Alzheimer's and Dementia educator and author with more than 24 years of experience. She provides support for those living with Alzheimer's, dementia, cognitive impairment, intellectual and developmental disabilities, traumatic brain injury (TBI) and chronic traumatic encephalopathy (CTE) and their families. Dr. Smith is the owner and operator of DTC Group, a Geriatric Care Management organization, and the author of two best sellers *A Dementia Caregiver's Guide to Care* and *A Dementia Caregiver Called to Action.* Dr. Smith has also been a featured panelist at the White House.

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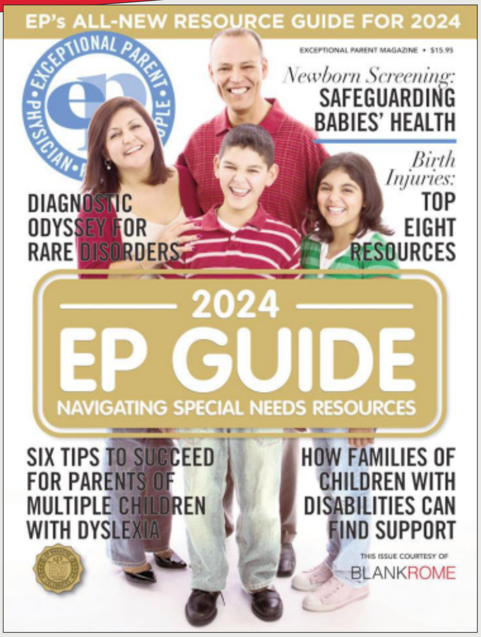

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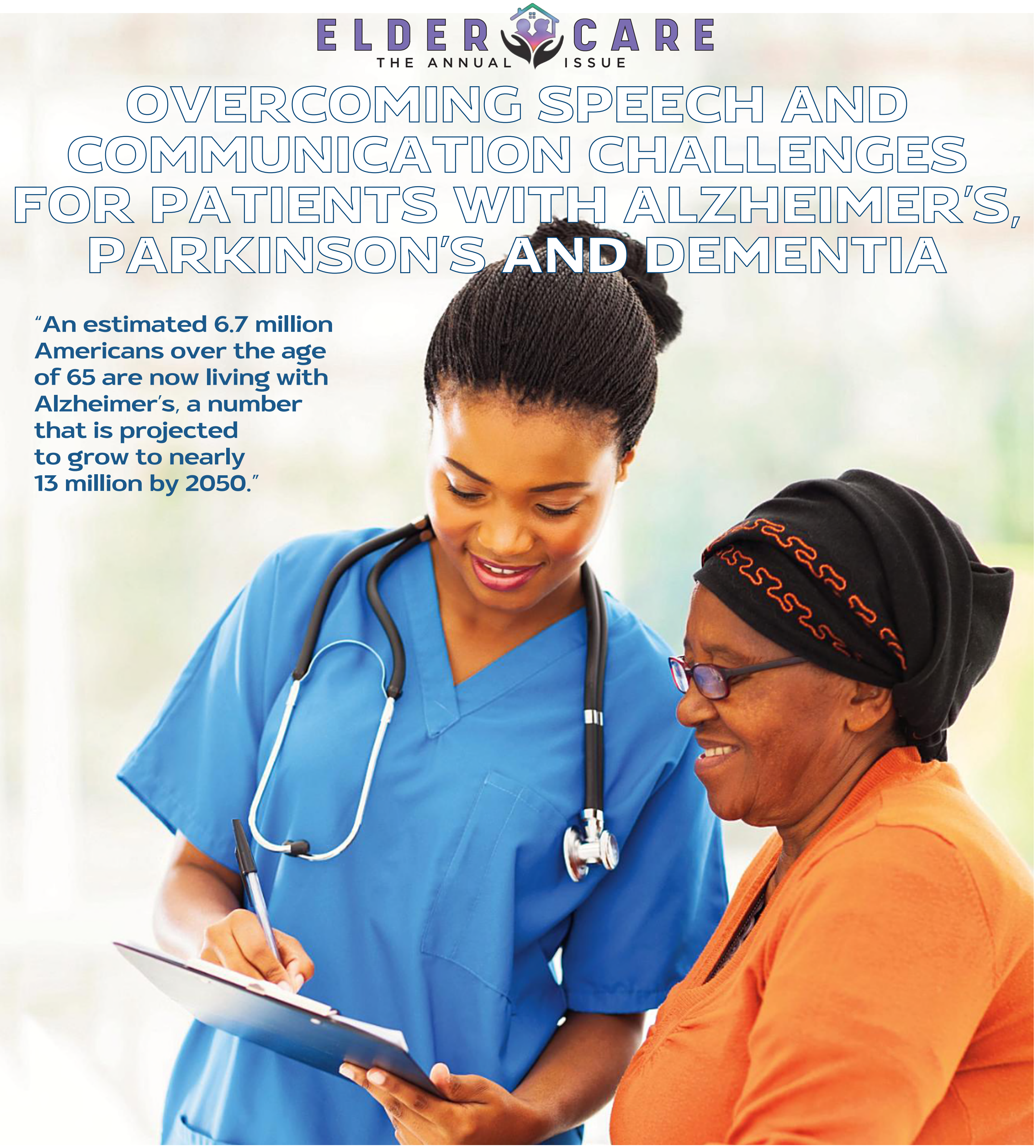
OVERCOMING SPEECH AND COMMUNICATION CHALLENGES FOR PATIENTS WITH ALZHEIMER'S, PARKINSON'S AND DEMENTIA



"An estimated 6.7 million Americans over the age of 65 are now living with Alzheimer's, a number that is projected to grow to nearly 13 million by 2050."

BY AVIVIT BEN-AHARON, M.S.ED., M.A. CCC SLP

As we age, our bodies change in a wide variety of ways, some of which are unexpected. While people have come to expect physical challenges that accompany the aging process – such as eyesight or hearing changes – they may be surprised by changes that diminish a person's ability to speak and express oneself. When speech and language skills decline, especially with the onset of Alzheimer's Disease (AD), Parkinson's and dementia, one's independence and quality of life often dissipates.

Early diagnosis, and intervention with speech therapy, and the opportunity for people to access care "online" or "virtually" from licensed Speech-Language Pathologists (SLPs) may help to delay the onset or progression of issues which impact self-expression. With speech therapists available nationwide, virtual speech therapy offers increased access to personalized care and a specialized therapy plan that is tailored to each individual for more focused therapy sessions, and possibly faster results in a shorter time frame.

A key goal of an intervention plan is to maintain current cognitive function, as much as possible. This involves developing coping skills that enable individuals to manage their decline, as effectively as possible, and address memory loss or other cognitive deficits.

Speech and language therapy means not only working on speech-related issues, but also stimulating the brain so that language skills, including memory, also improve. This enhances a person's quality of life, interpersonal and familial relationships, and the impact of worsening symptoms.

ASSESSING SPEECH AND LANGUAGE SKILLS : A CLOSER LOOK AT COMMUNICATIONS CHALLENGES

ALZHEIMER'S DISEASE (AD)

For the 55+ million people worldwide who are living with AD or another form of dementia, communication is challenging because the individuals have trouble remembering.[1] According to the National Institute on Aging, AD causes some people to get confused about language, struggle to find words or forget what they want to say.[2] For example, the person might forget or no longer understand English, if it was learned as a second language, and prefer to use only the first language learned, such as Spanish. Other issues include:

- *Finding the right word or losing his or her train of thought when speaking*
- *Understanding what words mean*
- *Paying attention during long conversations*
- *Remembering the steps in common activities – cooking,[3] paying bills, or getting dressed*
- *Dealing with background noises from the radio, TV, or conversations*
- *Becoming very sensitive to touch and to the tone and loudness of voices*

These individuals may show signs[4] of memory loss, challenges in planning or solving problems, confusion with time or place and trouble understanding visual images and spatial relations. All of these symptoms can lead to social isolation and diminished quality of life.

To help make communication easier, experts offer these tips:

- *Make eye contact and call the person by name.*
- *Be aware of your tone, how loud your voice is, how you look at the person, and your body language.*
- *Encourage a two-way conversation, for as long as possible.*
- *Use other methods besides speaking, such as gentle touching.*
- *Try distracting the person if communication creates problems.*

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PARKINSON'S

The Parkinson's Foundation advises that most people with the disease experience a soft voice volume, that may be difficult to hear. Loss of automatic facial expression can be misinterpreted as boredom, anger or sadness.[5]

Mood changes in Parkinson's, such as: apathy, depression or anxiety can also affect communication, as speech may become fast or slow, rushed, mumbled or slurred. Some people notice a stutter, or difficulty starting to speak, and their voices can become quieter, breathy, hoarse, or change in pitch.

The following tips can ease communications:

- *Try to have conversations one-on-one or in small groups.*
- *Reduce or remove distractions, like TV, radio or music, when conversing.*
- *Be close to each other when you talk, so it is easier to hear. Avoid yelling from another room in the house! Encourage the individual to take a deep breath before beginning to speak, to enhance his or her vocal loudness.*
- *Give him/her time to respond or participate in conversation.*
- *Do not make assumptions about how your loved one is feeling based on facial expressions.*

5. www.parkinson.org/sites/default/files/documents/addressing-communication-challenges.pdf.

ADOPTING THE USE OF TECHNOLOGY

According to Pew Research Center, the adoption of technology by Americans in the oldest age group has grown "markedly" over the past decade: 61% of those 65+ own a smartphone and 45% reported using social media.[6] As the elderly become more comfortable with using new technology, it becomes easier for them to receive virtual care.

Dementia and gait impairments often coexist in older adults and patients with neurodegenerative diseases, such as AD and Parkinson's.[7] Since mobility issues often restrict someone's ability to travel to clinics or treatment facilities, the availability of online speech therapy is key to accessing timely, ongoing care.

This option can relieve some of the burdens and stress for family members and caregivers. It improves quality of life for those who prefer the familiar surroundings of home, instead of traveling to brick and mortar offices. There is the benefit of scheduling flexibil-

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6 www.pewresearch.org/fact-tank/2022/01/13/share-of-those-65-and-older-who-are-tech-users-has-grown-in-the-past-decade/

7. www.ncbi.nlm.nih.gov/pmc/articles/PMC4119872/

ity, since often, SLPs working virtually offer wide availability, including evenings and weekends. Convenient access to care accommodates busy schedules, that may be strained by ongoing appointments with doctors or other treatment regimens.

ADDRESSING ISSUES OF ISOLATION AND LONELINESS

Virtual speech therapy also helps to address challenges of isolation and loneliness, key Social Determinants of Health (SDoH) that accompany these conditions.

- **Help Recovering Lost Memories:** SLPs can work with patients to retrieve memories, helping people learn ways to recall daily tasks or more deep-seated memories. When patients can remember specifics, it helps them process thoughts and communicate better.
- **Increase Social Interaction:** It's not uncommon to see these individuals withdraw from friends, family, and regular social activities, when they develop communication issues. The onset of depression and loneliness can lead to more rapid deterioration. As people rebuild their ability to recall information and communicate clearly, they feel more confident, and are more likely to interact with others, and reconnect with friends and loved ones.
- **Changes in Behavior:** When it's tough to communicate, anyone might act out. When people with Parkinson's, Alzheimer's and dementia struggle to form thoughts and communicate, it can lead to poor behavior. Speech therapy helps patients feel heard, communicate more effectively, and abandon poor behavior that they may have used to get attention.

> "A key goal of an intervention plan is to maintain current cognitive function, as much as possible. This involves developing coping skills that enable individuals to manage their decline, as effectively as possible, and address memory loss or other cognitive deficits."

Research from the Alzheimer's Association shows the number of people being diagnosed continues to go up, as the baby boomer population ages.[8,9] It's estimated that 6.7 million Americans over the age of 65 are now living with Alzheimer's, a number that is projected to grow to nearly 13 million by 2050. The U.S. will face an unprecedented wave of dementia and cognitive decline, and it is more important than ever that individuals have access to virtual care nationwide.•

ABOUT THE AUTHOR:

Avivit Ben-Aharon, MS ED., MA CCC SLP is the Founder and Clinical Director at Great Speech, Inc, a virtual speech therapy company founded in 2014. She is recognized as a trail blazer for nationwide virtual access to speech therapy. It allows anyone to receive expert services to improve their communication, regardless of location or scheduling limitations. Her work has been featured on Forbes, Good Morning America, US News and World Report, Miami Herald and more. She holds an undergraduate and a Master of Arts degree in Speech-Language Pathology from The City University of New York. She earned a Master of Science in Special Education and Teaching from Hunter College. For more information: **www.greatspeech.com**.

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

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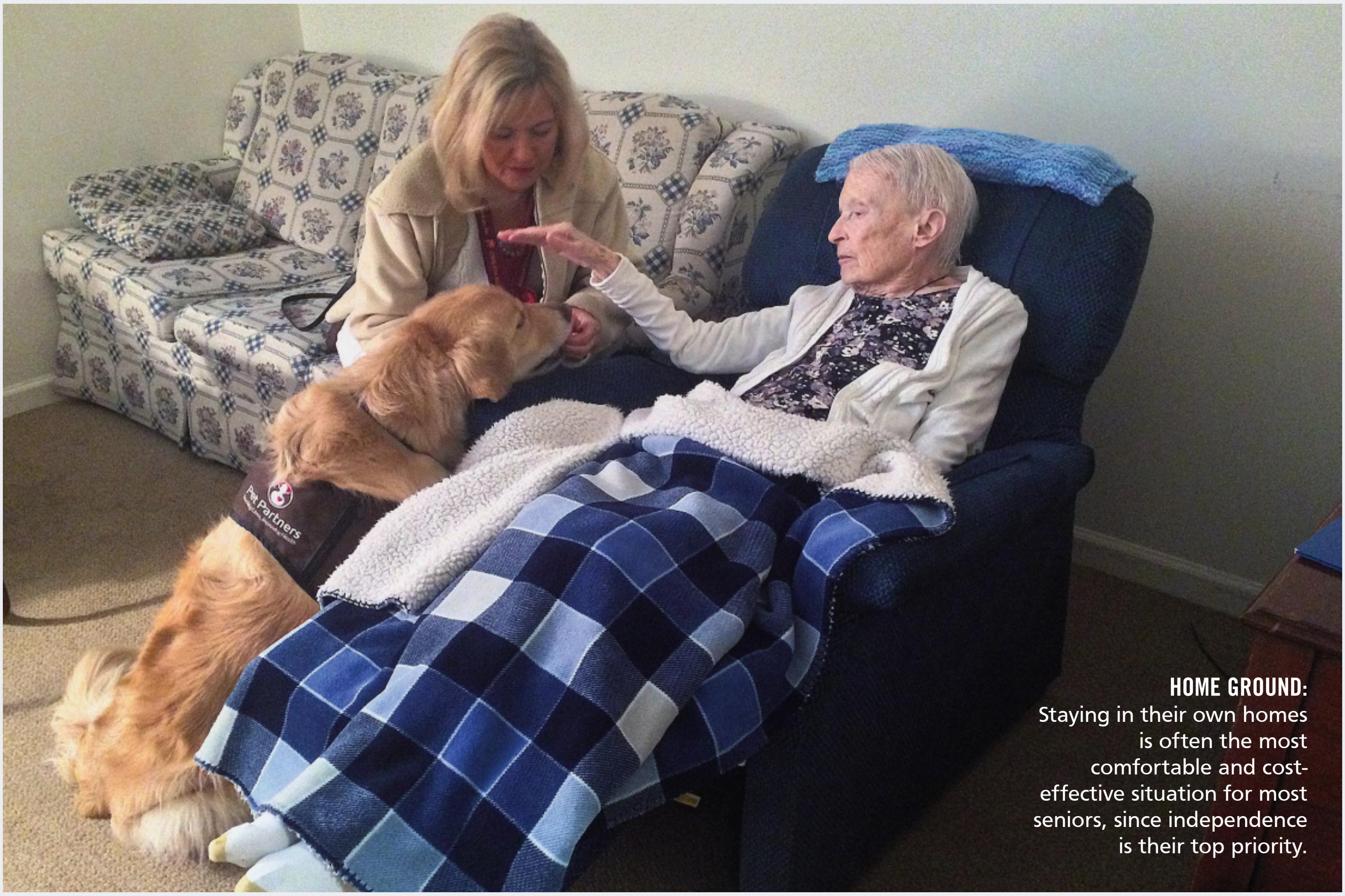
8. www.cbsnews.com/philadelphia/news/alzheimers-disease-numbers-increasing-as-baby-boomers-age-study
9. www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf

NAVIGATING CARE OPTIONS FOR SENIOR LOVED ONES



HOME GROUND: Staying in their own homes is often the most comfortable and cost-effective situation for most seniors, since independence is their top priority.

CONTRIBUTED BY ASSISTED LIVING SERVICES, INC.

Americans are living longer and healthier thanks to medical advances and lifestyle changes. In fact, the number of Americans ages 100 and older is projected to quadruple over the next three decades, from an estimated 101,000 in 2024 to about 422,000 in 2054, according to projections from the U.S. Census Bureau.

"Navigating the complex maze and ever-changing options of senior care can certainly become an overwhelming experience," said Mario D'Aquila, MBA and COO of family-owned Assisted Living Services, Inc

D'Aquila emphasizes that independence is the top priority for most seniors, and staying in their own homes is often the most comfortable and cost-effective situation. However, he offers the following comprehensive comparison of the various types of senior care and what he sees as the advantages and disadvantages of each:

PHOTO PROVIDED BY ASSISTED LIVING SERVICES, INC.

HOME AND BEYOND : COMPARING THE VARIOUS TYPES OF SENIOR CARE

Mario D'Aquila's comparison of the various types of senior care and the advantages and disadvantages of each.

NON-MEDICAL IN-HOME CARE

Allows a person to "age in place with family, offering privacy and comfort. Seniors enjoy independence and control in scheduling and routine, with one-on-one personal care and safety monitoring. Caregivers assist with all activities of daily living (ADL's) like: meal preparation, feeding, light house cleaning, laundry, transferring, toileting, incontinence care, transportation, socialization and companionship. Caregivers can be available from 1 hour to 24 hours per day. Some home care agencies participate in the Medicaid waiver programs to offset the cost. Disadvantages with this type of care could include a feeling of intrusiveness by other family members and continued upkeep of the home.

SKILLED HOME HEALTHCARE (MEDICAL)

Provides certified medical practitioners, such as an M.D. or R.N., to administer medical services like: injections, wound care, physical therapy and occupational therapy, among others. Skilled home health care is often temporary and is often used after a senior is discharged from a hospital or medical rehabilitation center.

ASSISTED LIVING COMMUNITIES

Are ideal for seniors who also need support with ADL's, but still want to maintain a level of independence. Besides providing a wide array of services, including: dining, housekeeping, transportation, social activities, and personal care, these communities also offer specialized services, like memory care for residents with dementia. These are often large facilities with a variety of living options, including private apartments with licensed nursing staff available for additional healthcare needs. As such, they are regulated by the state Department of Public Health. The primary disadvantages to this model are: separation from a senior's home and family can cause emotional distress, and additional services are often an added cost. When funds are depleted, there may be no or little State funding available.

CONTINUING CARE RETIREMENT COMMUNITIES

Offer a one-stop facility with healthcare support, along with planned on-site activities. The drawback is that a senior must pay a substantial one-time buy-in, plus a monthly community cost and additional fees, depending on the particular level of care needed.

LONG-TERM AND SHORT-TERM CARE FACILITIES

Address chronic illness and are designed for short or long-term care or medical rehabilitation in a sterile, hospital-like environment. They provide intensive rehabilitation with Physical Therapy, Occupational Therapy and Speech Therapy, preparing a senior for a return to their home environment.

INDEPENDENT LIVING COMMUNITIES

Are designed for seniors who do not require assistance with ADLs, but want to live in a community that offers convenience, social opportunities, and a maintenance-free lifestyle. They vary in size, ranging from apartment complexes to large campuses, but do not provide medical or personal care, nor are they regulated as healthcare facilities.

RESIDENTIAL CARE HOMES

Are suitable for individuals who need some assistance with daily activities, such as bathing, dressing, and medication management. However, they do not provide extensive medical or nursing care. In Connecticut, RCHs are licensed and regulated by the Department of Public Health, ensuring compliance with specific standards for care, staffing, and facility operations.

HOSPICE CARE

A service for people with serious illnesses who choose not to get or continue treatment to cure or control their illness. Hospice aims to provide comfort and peace to help improve quality of life for the person nearing death. It also helps family members cope with their loved one's illness, and supports the family after the person dies, through bereavement care. Medicare reimburses for hospice services when a physician determines that a patient has a life-expectancy of 6 months or less. Hospice can be at home or in a facility. •

ABOUT ASSISTED LIVING SERVICES, INC.:

Assisted Living
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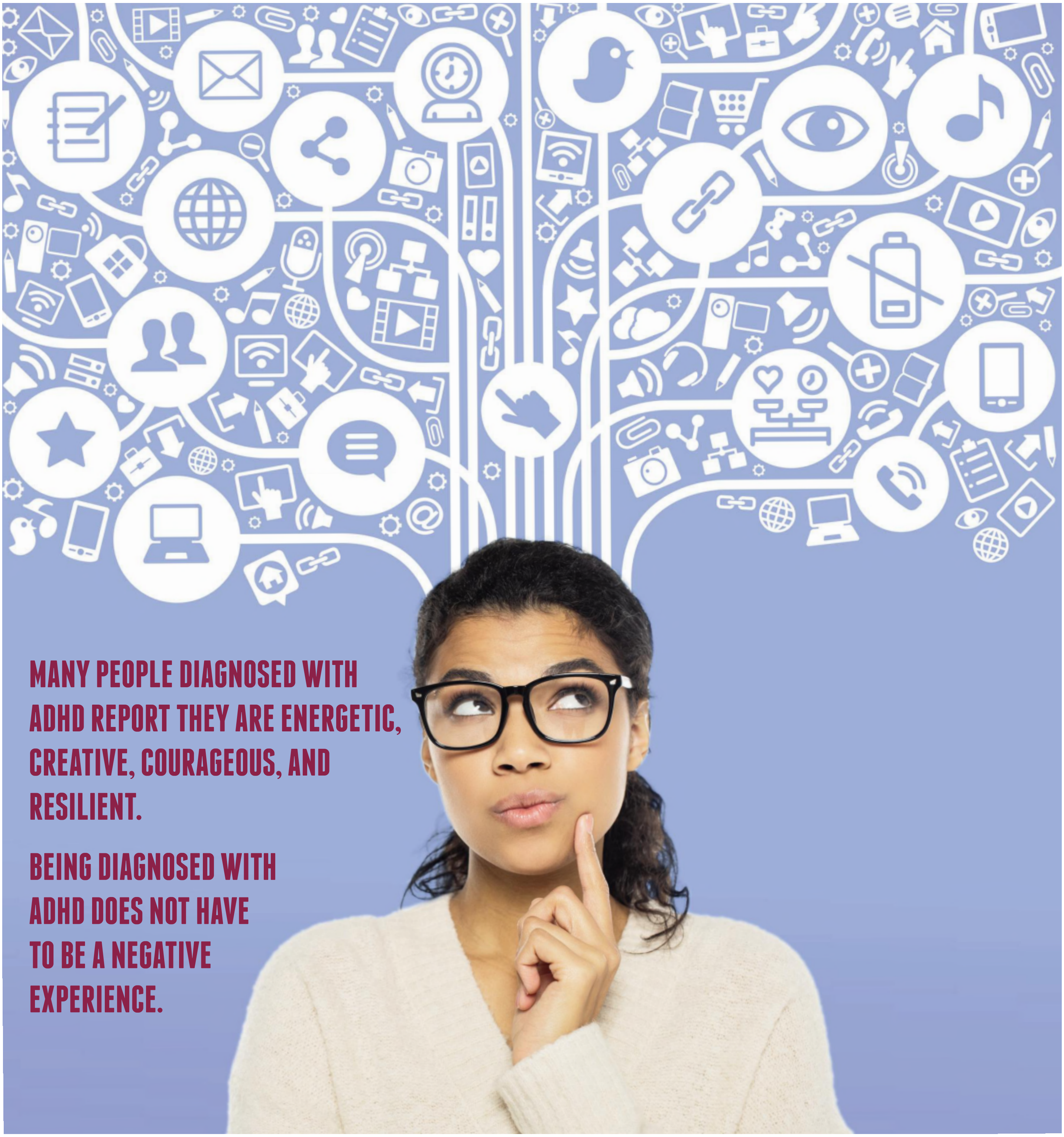
Since 1996, award-winning home care agency Assisted Living Services, Inc. (ALS) in Cheshire, Putnam and Westport has provided quality care to residents across Connecticut. Its unique CarePlus program blends personal care by over 700 employees and caregivers with technological safety and monitoring devices from sister company Assisted Living Technologies, Inc. Visit **www.assistedlivingct.com**



MANY PEOPLE DIAGNOSED WITH ADHD REPORT THEY ARE ENERGETIC, CREATIVE, COURAGEOUS, AND RESILIENT.

BEING DIAGNOSED WITH ADHD DOES NOT HAVE TO BE A NEGATIVE EXPERIENCE.

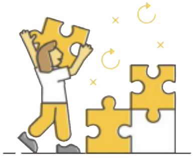
WHAT TO DO WHEN YOU'VE BEEN DIAGNOSED WITH ADHD

BY JOHN WILLSON, MS, LRT/CTRS

*If you've recently learned that you have ADHD, you're not alone. ADHD is among the most commonly diagnosed mental conditions, affecting 8.7 million adults and an estimated 6 million kids aged 3 to 17 years, according to the Centers for Disease Control and Prevention (CDC) (***www.cdc.gov/adhd/data***).*

SOARING BEYOND EXPECTATIONS : THRIVING AFTER AN ADHD DIAGNOSIS

Discovering you have ADHD is not the end; it's the beginning of a new chapter in your life. Here are some things you can do to not only cope, but thrive if you have been diagnosed with ADHD:

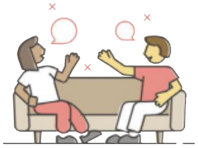


1. EMBRACE THE JOURNEY

Being diagnosed with ADHD does not have to be a negative experience. Many people diagnosed with ADHD report they are energetic, creative, courageous, and resilient, according to a study titled "The positive aspects of attention deficit hyperactivity disorder: a qualitative investigation of successful adults with ADHD" (**https://link.springer.com/article/10.1007/s12402-018-0277-6**). Embrace the journey with an open heart and a willingness to understand yourself better.

2. EDUCATE AND UNDERSTAND

Learn more about ADHD by researching the characteristics, symptoms, and challenges associated with it in articles such as this one from The National Institute for Mental Health (**www.nimh.nih.gov/health/publications/attention-deficit-hyperactivity-disorder-in-children-and-teens-what-you-need-to-know**). This knowledge can help you better navigate your experience, and communicate effectively with others. It is also important to understand that ADHD can look different in each individual and can change as you get older. ADHD "typically does not get worse with age if a person is aware of their symptoms and knows how to manage them," according to *Medical News Today* (**www.medicalnewstoday.com/articles/adhd-getting-worse-with-age**). Knowledge is key.



3. BUILD A SUPPORT SYSTEM

Connect with a community that understands your experience, by joining support groups where you can share insights, ask questions, and learn from others who have faced similar challenges. A good place to start is through affiliates of CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder, a nonprofit organization serving people affected by ADHD (**https://chadd.org/affiliate-locator**). You should also consider discussing your ADHD diagnosis with your friends, family, colleagues, and teachers. Doing so can foster understanding and create a supportive environment. You may even learn that one of them has ADHD as well!

4. SEEK PROFESSIONAL GUIDANCE

Schedule a follow-up appointment with the healthcare professional who diagnosed you. Discuss treatment options such as: medication, therapy, or a combination of both (**www.cdc.gov/adhd/treatment/?CDC**). While medications such as Adderall are commonly used to treat ADHD, they don't work for everyone. It is important to find out what treatment plan works best for you. Be sure to meet with your designated healthcare professional regularly, especially when you're first starting treatment.

5. GET OUTSIDE

We believe that spending time outdoors has direct mental and physical benefits for all individuals, but especially for those diagnosed with ADHD. Whether you're hiking, biking, or just chilling in green spaces, these outdoor activities get your body moving, promote better attention and help your brain regulate those ADHD-related neurotransmitters (**https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1448497**). Next time you're feeling restless or overwhelmed, consider heading outdoors for a natural boost that goes beyond just a breath of fresh air.

We believe that individuals with ADHD possess incredible strengths, creativity, and resilience. It's not about overcoming ADHD; it's about leveraging your unique qualities to soar beyond expectations.•

ABOUT THE AUTHOR:

John Willson, MS, LRT/CTRS*, is Executive Director for SOAR, the world's premier adventure program serving youth with ADHD (Attention Deficit Hyperactivity Disorder) and LD (Learning Disabilities). SOAR's outdoor adventure-based programs provide academic instruction, experiential education, and life skills development for youth and young adults ages 8-25. SOAR stands for Success-Oriented, Achievements Realized. With a passion for fostering resilience and nurturing strengths in neurodiverse communities, John is a respected advocate among those who serve individuals with learning differences and attention challenges.

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GETTING RESULTS: It is mutually beneficial for the hospital and the patient to have the support person there, because the outcomes are better.

PEOPLE WITH DISABILITIES CAN HAVE A SUPPORT PERSON WITH THEM IN HOSPITALS AND DOCTOR'S OFFICES

BY LAUREN AGORATUS, M.A.

The mother who was undergoing cancer treatment couldn't be in the hospital with her daughter with disabilities during hospitalization for the first time in her life.

The daughter is medically fragile and also has autism. The father called the mom and said that the nurse was kicking him out because visiting hours were over. She told him, "Hold on, in the left pocket of your folder of her medical records is a memo from the State Department of Health which allows a patient with a disability to have a support person with them at any time. You are not a visitor."

NOW PEOPLE WITH DISABILITIES CAN HAVE A "SUPPORT PERSON" WITH THEM AT ANY TIME IF NEEDED.

During the COVID pandemic, initially hospitals and doctors' offices were only allowing the patient in. This meant that people with disabilities were on their own, even if they were unable to communicate with medical professionals. Disability advocates pushed back and now people with disabilities can have a "support person" with them at all times, if needed.

It is important for families and friends not to just say they are the parent or caregiver, but rather a "support person" for the individual with a disability. **You are not a "visitor." You are a support person.**

In the story above, the patient was refusing medications because she knew what she was supposed to take, and the doctors kept changing her meds in the hospital. She was not cooperating with labs and bloodwork because she was tactile defensive (hypersensitivity to touch). This young adult with autism was also refusing to hold still for any testing like EKGs or CT scans due to anxiety, rendering testing useless.

The next day, the father showed the security guards the same memo, and although it took 45 minutes to clear him, he was allowed in earlier than visiting hours to support his daughter. Once there, he explained the medication changes to her, and she took her meds. He asked for Emla (numbing) cream, and she did her bloodwork.

I'LL BE THERE : RESOURCES FOR SUPPORT PERSONS

DISABILITY RIGHTS NJ

www.drnj-covid.org/critical-issues/hospital-visitation-policies

U.S. DEPT. OF HEALTH AND HUMAN SERVICES

Civil Rights for People with Disabilities

www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/disabilty-faqs/index.html

OFFICE OF CIVIL RIGHTS

Complaints

www.hhs.gov/ocr/complaints/index.html

He kept her calm during medical testing, so they were able to find the cause of her severe illness (which was life-threatening sepsis).

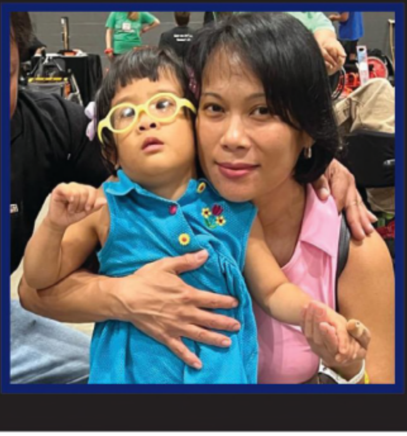
It is mutually beneficial for the hospital/doctor and the patient/family to have the support person there, because the outcomes are better.

Disability Rights NJ has a section on their website devoted to this issue *(see Resources)*. The U.S. Department of Health and Human Services reaffirmed the rights of people with disabilities under Section 504 of the ADA (Americans with Disabilities Act) and Section 1557 of the ACA (Affordable Care Act). This was true even during the public health emergency during the pandemic. It may be helpful for families to keep a copy of the webpage or link in case it is needed. If families or self-advocates are having problems allowing a support person into a medical facility, they can file a complaint with the HHS Office for Civil Rights. Fortunately for this patient, her mother was a healthcare advocate and knew her rights. But if it happened to this family, it must be happening to other families, including families who are unaware of their rights in these challenging situations.

Self-advocates and their families need to know that there are disability protections in place, established by laws including the ADA and ACA, so that they can have a support person accompany them during medical treatment.•

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 2 academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was named a Hero Advocate by Exceptional Parent Magazine (**www.epmagazine.com Archives June 2022**).



DO WE NEED LABELS?

BY PAMELA AASEN AND PAULA AASEN-HAINES

Our opinions are formed throughout our lives and by our experiences. We believe having the confidence to explore, face challenges and take risks comes from having a strong sense of who you are. We feel that when we are taught to be ashamed of the labels that exist to help us and provide equity, we are possibly losing out on tools to help us experience success and meet our potential.

Life is full of labels. We are identical twins, that was our first label. Many of our shared beliefs on the use of labels and our opinions on the need for acceptance come from our early experiences. When you are an identical twin, there is really no way to avoid that label and all that comes with it. For example: twins should dress alike, or twins should express their individuality and dress differently, twinny names are cute or twinny names are weird; twins should be separated to develop their own identity, or they should be together because they are twins. Everyone has an opinion on it. It affected us differently, depending on the situation. At times we embraced it and at times we withdrew. What was clear to us was, even though at school they chose to separate us repeatedly, when we had the choice to do what we wanted outside of school, we chose to do the same activities.

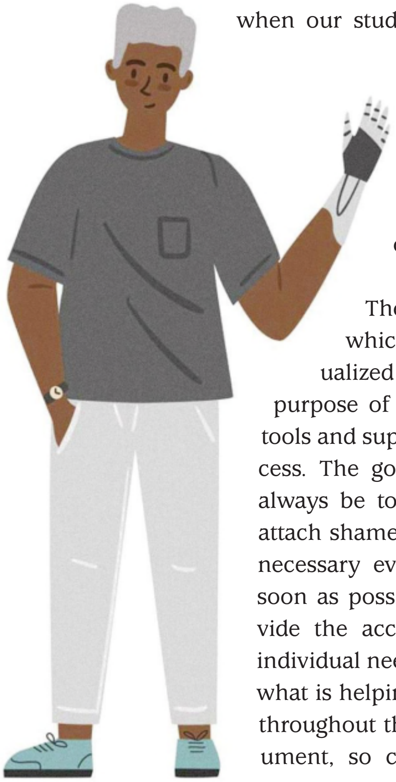
We often wondered why we were never asked what we wanted. When we finally got to make our own decisions when we graduated from high school, we chose to go to university together, live together, study together, and eventually even get our first teaching jobs together at the same school. The key for us was, if you are making a decision about us, ask us. We have carried this belief to our professional careers in the field of special education and for our children. Ask your student/child about his/her needs. It does not mean that the professional opinion is not valid or that parental input is not needed. It is simply that we need to involve the individual who will be affected the most by any decision that is made on their behalf.

PROUD TO SHARE: If we were more accepting of labels, there would be no need for shame.

This is where the need for a label comes in. To understand what you need, you first must understand and embrace the part of you that is different and what that means for your life. That requires a label, a name. It is hard to understand something that does not have a name. We need to ask ourselves what help comes from not providing that information or even waiting until the child is older. To be proud of who you are you need to have acceptance about everything about you. Certainly, age and ability to understand must be taken into consideration, but early knowledge and involvement leads to better understanding. We also must take into consideration communication skills, cognitive ability, level of maturity, and severity of the diagnosis, but like everything, it is individually based, and those decisions can be made based on the individual. It is also essential to keep in mind that we generally underestimate what our children can handle.

Avoiding a label or hiding a diagnosis in the medical field could have disastrous consequences. Why do we not look at it the same way in the field of education? It is certainly not life and death, but not incorporating the label essentially attaches shame. If you are hiding something, the inference is that there is something wrong with you. If we were more open and accepting of the labels, there would be no need for shame. We want our children to go out into the world believing they are fine just the way they are, as there are very few of us that do not have academic needs, different learning styles, mental health issues, or other challenges.

In addition to attitudes about labels there are attitudes about having an Individualized Education Plan (IEP). This is something that often has negative connotations for parents in the school system. The name has been changed in some areas like New Brunswick, Canada, to attempt to remove the stigma that has developed. We have tried to teach our students/children that having an IEP is a good thing. They are lucky they will be getting the support they need to level the playing field. When we shift our own attitudes and look at it as a positive instead of a negative, it will affect how our students/children approach it. Furthermore, when our students/children have input to that IEP, they gain ownership and a sense of their importance in the process. Follow the simple premise, "if you want to know how to help, ask me", applies to everyone. It also can save a lot of time.



Labels are necessary for the IEP. The label provides the justification, which was identified through individualized testing and individual needs. The purpose of this document is to provide the tools and support, necessary to meet with success. The goal of having an IEP should not always be to eventually remove the IEP. We attach shame again when we approach it as a necessary evil that needs to be removed as soon as possible. The ultimate goal is to provide the accommodations and support that individual needs to meet with success. If that is what is helping, we should want it to continue throughout the school years. It is a living document, so changes can be made as needs change. The key is for the child/student to gain an understanding of those shifts during school and throughout life.

EMBRACING LABELS : ADVOCACY & UNDERSTANDING

SPAN PARENT ADVOCACY NETWORK

https://spanadvocacy.org

ADVOCACY STORIES FOR YOUTH BY YOUTH

www.youtube.com/playlist?list=PLGXju3IK5UOUBG3sB6nMkAQyLreaw7CRI

NATIONAL MENTORING RESOURCE CENTER

https://nationalmentoringresourcecenter.org

NATIONAL YOUTH ADVOCATE PROGRAM

www.nyap.org

INDIVIDUALIZED EDUCATION PROGRAMS

https://kidshealth.org/en/parents/iep.html

Everyone has their own level of comfortability with sharing. We are not suggesting that all of us have to put everything out there for the world to see. Some may prefer to keep the circle small, while others may be more comfortable adding their voice to the broader advocacy world. The goal is simply to feel comfortable and confident to advocate for yourself or your child, when the situation calls for it. Once the individuals understand why they are struggling and know there are supports to help, they can be on the road to acceptance, advocacy, and the understanding that learning differences, difficulties, and deficits are not uncommon.

Our hope is that we can shift our thinking so we can all lose the shame, speak up, embrace our labels, accept our differences, and most of all encourage each other along the way. •

ABOUT THE AUTHORS:

Pamela Aasen currently lives with her family in New Jersey and was a Special Education Teacher for 25 years. She is the parent of two adult sons with Usher syndrome and was the Early Hearing Detection and Intervention (EHDI) Mentoring and Family Engagement Project Director for the SPAN Parent Advocacy Network from 2018 to December 2023.

Paula Aasen-Haines lives with her family in New Brunswick, Canada. She is the parent of 3 adult children and recently retired after 34 years as a Special Education teacher. For many years she was the Department Head of Education Support Services at Hampton High School and then Kennebecasis Valley High School. She is also a Board Certified Behavior Analyst (BCBA).

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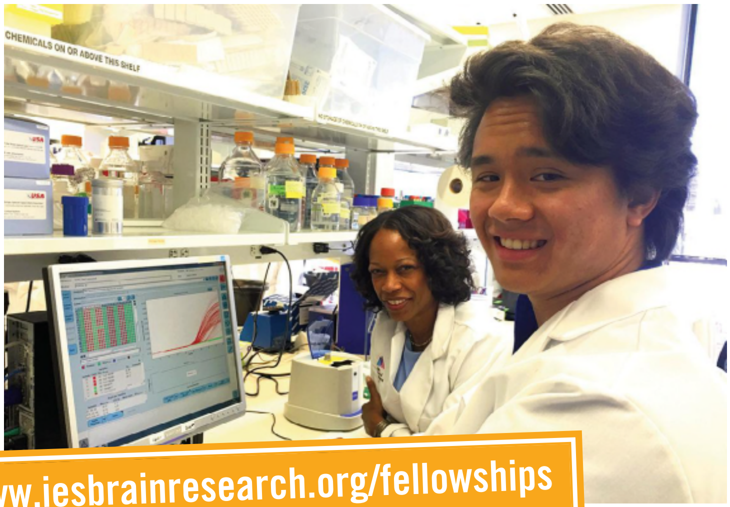
The inspiration for our Foundation, Eric Simon
would have been 100,
as well as his wife and Foundation co-namesake, Irene.
2024 is also the 20th anniversary of Irene and Eric Simon
Brain Research Foundation being announced.



See selected 2024 Summer Fellows: www.iesbrainresearch.org/fellowships

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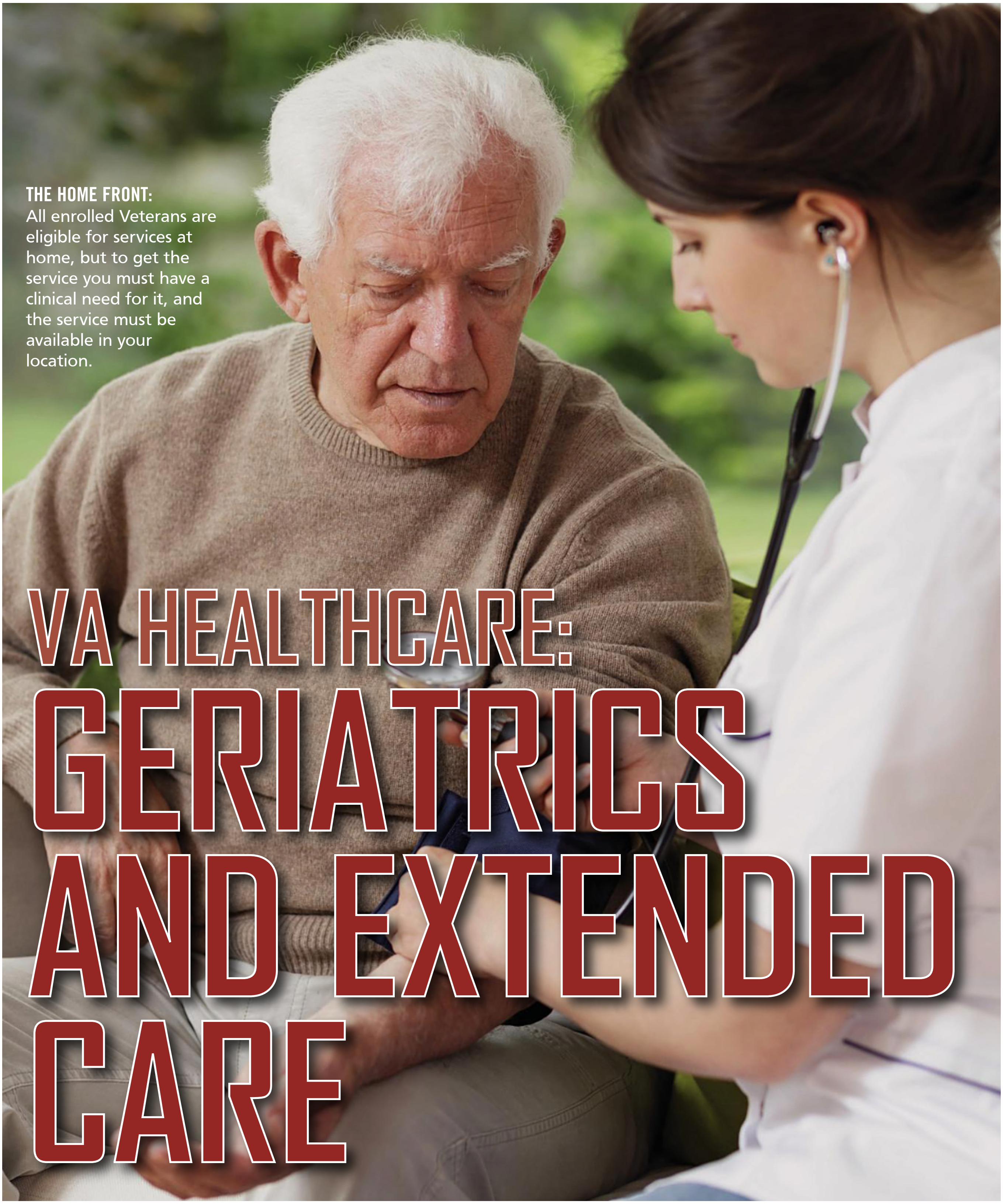


THE HOME FRONT: All enrolled Veterans are eligible for services at home, but to get the service you must have a clinical need for it, and the service must be available in your location.

VA HEALTHCARE: GERIATRICS AND EXTENDED CARE

The shared purpose of all Geriatric and Extended Care programs is to prevent or lessen the burden of disability on older, frail, chronically ill patients and their families/caregivers, and to maximize each patient's functional independence.

VA LONG TERM CARE SERVICES

Services at Home and in the Community are part of the VA Medical Benefits Package. All enrolled Veterans are eligible for these services. However, to get the service you must have a clinical need for it, and the service must be available in your location. Services in the VA Standard Benefits Package include:

- *Geriatric Evaluation to assess your care needs and to create a care plan*
- *Adult Day Health Care*
- *Homemaker and Home Health Aide Care*
- *Respite Care*
- *Skilled Home Health Care*

To learn more, visit the Veterans Health Administration at www.va.gov/GERIATRICS/pages/Home_and_Community_Based_Services.asp.

Residential Settings and Nursing Homes have different eligibility requirements for each setting. The VA does not pay for room and board in residential settings such as Assisted Living or Adult Family Homes; to learn more, visit www.va.gov/GERIATRICS/pages/Nursing_Home_and_Residential_Services.asp. However, you may receive some Services at Home and in the Community while you are living in a residential setting. The VA also provides Community Living Center (VA Nursing Home) or community nursing home care IF you meet certain eligibility criteria involving your service-connected status, level of disability, and income.

Factors that Affect Your Costs for VA Services: When you enroll in VA health care, your VA service-connected disability status and income will be reviewed to determine if you will be charged a copay. Long term care copays are not charged until the 22nd day of care. Copays are NOT charged for Hospice Care provided in any setting. However, the VA is required by law to bill any health insurance you may have (except Medicare) for treatment of conditions that are not service connected. Payments received from your insurance company may reduce the copays that VA bills to you.

HOW DO I APPLY FOR LONG TERM CARE SERVICES IN VA?

Standard Medical Benefits: Veterans must be enrolled in VA health care before applying for VA long term care services, which means you have applied for VA health care benefits and receive care through a VA facility on a regular basis.

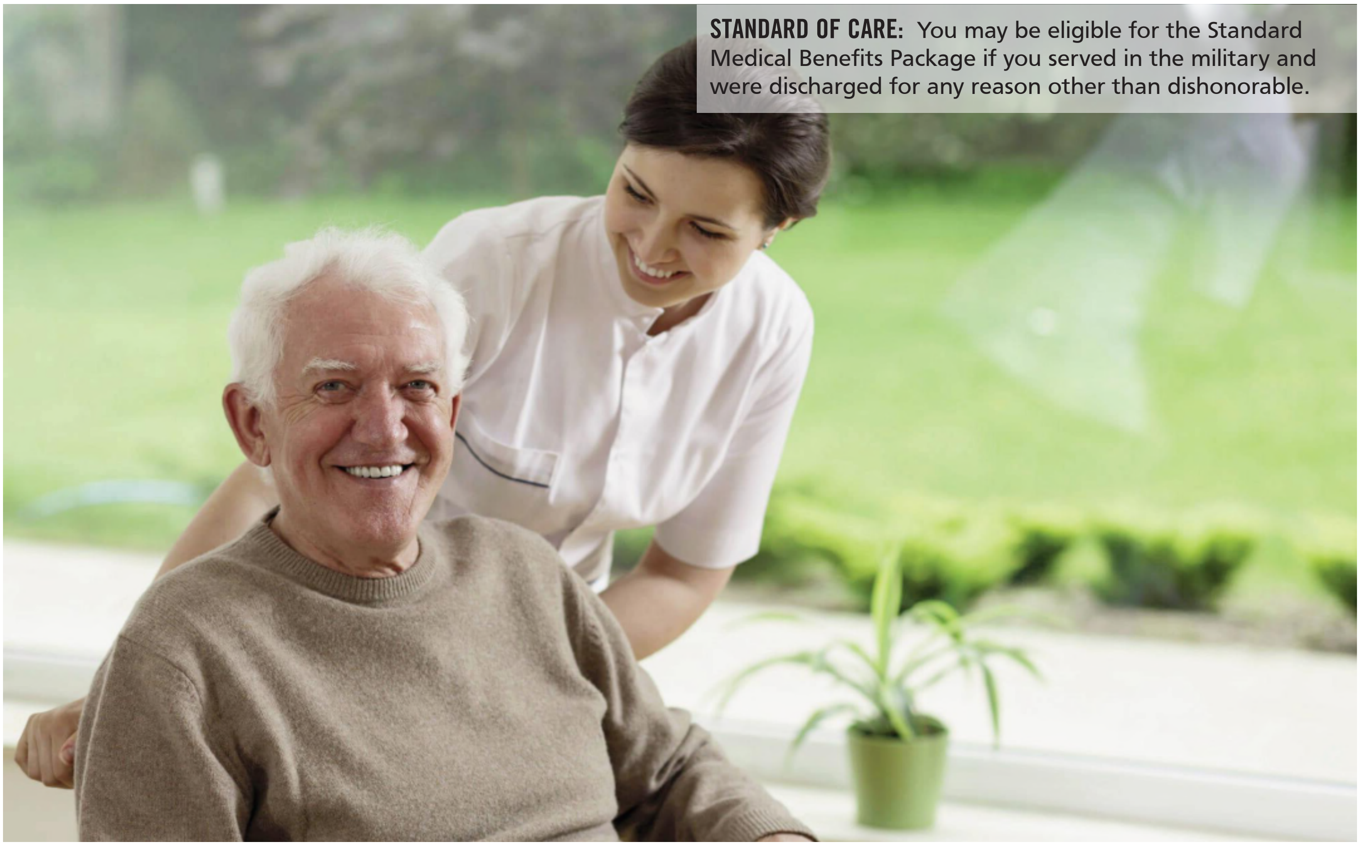
Receiving financial compensation for a VA disability does NOT automatically enroll you in VA health care.

You may be eligible for VA health care services (known as the Standard Medical Benefits Package) if you served in the military and were discharged for any reason other than dishonorable.

Detailed eligibility information can be found on the main VA Health Benefits website.

To Enroll in Health Care Services: Visit your local VA medical center's New Patient Registration office at www.va.gov/directory/guide/allstate.asp to complete and submit the VA Application for Health Benefits (www.va.gov/GERIATRICS/docs/VA_Form_10-10EZ.pdf), or Enroll online using the Online Application for Health Benefits at www.1010ez.med.va.gov/sec/vha/1010ez/

– U.S. Department of Veterans Affairs



STANDARD OF CARE: You may be eligible for the Standard Medical Benefits Package if you served in the military and were discharged for any reason other than dishonorable.

REMEMBER ★ HONOR ★ TEACH

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

Use this link:

https://wreathsacrossamerica.org/epmagazine

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

The Irene & Eric Simon (IES) Brain Research Foundation is a volunteer-run nonprofit whose mission is to help advance research toward treatments and cures for brain diseases and conditions. The Irene & Eric Simon (IES) Brain Research Foundation Summer Fellowship Program in Neuroscience attracts bright, motivated students to neuroscience. These remarkable students are mentored for the summer by brilliant neuroscientists heading top-notch labs. The Foundation will have given 116 summer fellowships as of Summer 2024.

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

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

TO DONATE TO ONE OF MANY LOCATIONS:

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4. If a participating cemetery you would like to support is not listed, scroll to the bottom of the list and select "choose another cemetery to support." You will enter that cemetery name, and your donation will count towards our goal.

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1. Select "Volunteer."
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3. Complete Registration.

Thank you for supporting IES Brain Research Foundation and Wreaths Across America!

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REMEMBER HONOR TEACH
WREATHS across AMERICA

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BOOK EXCERPT 23RD OF A SERIES ★ U.S. MILITARY

THE RESILIENT WARRIOR

ANNUAL PHYSICALS

BY MICHAEL A. "BING" CROSBY

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 twenty third in a series that EP Magazine has featured over the last several months.*

Make it a regular habit to receive your annual physicals and make sure it becomes a part of your newly designed lifestyle.

Annual physicals have been a part of my "Warrior Routine" that commenced in flight school in 1984, and have continued to this day. It was a requirement if you wanted to strap on a jet and fly, so, you had no choice back then.

But as I grew older, it was clear the benefit of having a productive relationship with those that are trained to provide your medical care was important. It is my belief that "Your health is your responsibility." You cannot expect others to be charged with your care.

The need for constant exercise has been forgotten by most of our society, hence the rise in obesity, cardiac issues, and cancer. For many years, the demands of work seemed to get in the way of a simple walk or 30 minutes of weightlifting, but as we grow older, it is even more important.•

AIMING HIGH: Mike “Bing” Crosby, a graduate of the US Navy Fighter Weapons School “TOPGUN” and prostate cancer awareness advocate, is dedicated to the need to educate all men of the importance of annual screening for prostate cancer; If found early, it has a 99 percent chance of cure, but if left to advance to a later stage, those chances reduce to less than 30 percent.

ABOUT THE AUTHORS:

Michael “Bing” Crosby is a 1983 graduate of the United States Naval Academy and earned a Master of Science from the University of Southern California in Los Angeles in 1991. He is also a graduate of the US Navy Fighter Weapons School “TOPGUN” and Allied Air Forces Central Europe “Tactical Leadership Program” in Jever, Germany. Mr. Crosby has logged over 3,000 hours in multiple tactical jet aircraft, including, the F-14, F/A-18, B-1B, Mirage 2000, Tornado GR1, Harrier, and the F-16N. CDR Crosby was diagnosed in 2015 with Prostate Cancer at the Phoenix VA, but chose a course of treatment outside the VA. In 2016, because of the diagnosis of prostate cancer and finding out firsthand the lack of education or awareness around the disease in the VA, CDR Crosby founded Veterans Prostate Cancer Awareness Inc., a 501c3 nonprofit focused on providing educational resources to Veterans and Active-Duty Military. Since discovering his own prostate cancer and learning that prostate is the number one cancer diagnosis in the VA it has become clear that Veterans and men in general are not paying attention to this disease. The simple mission of raising awareness has led to our newly launched website **https://www.vpca.vet** and a growing awareness within the VA of the need to educate all men of the importance of annual screening for prostate cancer. If found early, it has a 99 percent chance of cure but if left to advance to a later stage, those chances reduce to less than 30 percent.

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.

Act of Kindness

It's amazing how one small act of kindness can make such a big difference in someone's world.

July is typically one of my favorite months of the year. For the last thirteen years, my parents have visited our home for a few days before packing up and caravanning to the beach for the week. I have a special relationship with the beach, the calmness of the waves, the warm sun on my skin and the feel of the sand under my feet. It's rare that I miss a sunrise while I drink my morning coffee that week, and the only time I'm inside is to eat a meal or get Broden ready for his time in the waves.

With Broden's rigid behavior, our lives revolve around routine and the schedule that we create with Broden, each morning. At the beach, Broden knows that he would eat breakfast, go to the beach, eat lunch and rest, go to the beach again, shower, play, eat dinner, then get ready for bed. This was his set schedule every day until we packed up and drove home. Once we made the drive back to the house, a schedule was built on what his week would look like that included time at his ABA clinic Monday through Friday.

After a few days back into our schedule with Broden going to clinic in the morning and getting picked up in the afternoon, I started to feel like we were back into our rhythm. Mark headed back to work. My parents and my aunt were still visiting and staying in a cozy cabin, located on a pond about a mile away from our house. A few days into our weekly routine, I drove into the clinic parking lot to drop off Broden. Something didn't feel right. All the staff were standing around in the parking lot outside, and seemed to be receiving guidance from one of the supervisors. I got out of the car while I kept the car running to see what was happening, "The first floor of the clinic has flooded. We think the cleaning crew left the water on last night. We're not sure what we're going to do."

COAST IS CLEAR: Broden in Myrtle Beach, SC; "At the beach, Broden knows that he would eat breakfast, go to the beach, eat lunch and rest, go to the beach again, shower, play, eat dinner, then get ready for bed.'"

I told them I would stand by the car to wait for instructions. A few minutes later, Broden's RBT walked to the car and told me that since the older children were on the second floor, Broden would still have services. We were concerned about his rigid behavior, because the stairwell that he likes to use was damaged and the gym was inaccessible due to the flood. I was reluctant to leave him, but I knew that if Broden got back in the car after heading to clinic and not being able to stay, he would have a difficult time adjusting to the change. I told her to call me if she felt Broden was becoming too overwhelmed due to this unforeseen circumstance. After Broden walked into the clinic, I jumped in the car and headed to my parent's cabin to spend time with them. Once I parked and opened the door to the screened in porch, the clinic called, "Shelly, we need you to pick up Broden. The water damage is more extensive than we thought. We are going to shut down the clinic for the rest of the week, and we plan to temporarily provide services next door in the basement of the church.

I walked into the cabin, "I must go get Broden. There was a flood, and services aren't available." My parents looked confused, "You just dropped him off and you have to drive back and get him?" I nodded and ran out the door, jumped in my car

PHOTO PROVIDED BY SHELLY HUHTANEN

and drove to the clinic. The side door was propped open, so I walked inside. There was significant water damage, and it was evident that the floors would need to be replaced. Broden's RBT led him downstairs as I stood by the door, “Broden we're going to go to the cabin to see Nana and Papaw, ok?” My hope was that his short visit to the clinic would suffice, and we could visit my parents for a little bit, head back to the house for lunch and continue our day.

After fifteen minutes at the cabin, Broden was asking me if he could go back to school, “Go to car? School?” I repeated several times, “Broden, the school is closed. You're going to be with me for the rest of the week.” Broden became physically upset and ran outside to sit in a chair on the front porch. A few minutes later, Broden started to scream and then started to hit himself. At that moment, I knew we needed to get home and address the behavior. After hours of screaming, he finally calmed down.

The next week, services resumed in the basement of the church. Again, for Broden the change was too much, and as a team, we decided to keep Broden home for two weeks while the clinic's flooring was being replaced. Mark and I created a calendar for Broden to ensure there was structure. Each day included car rides and trips in between breakfast, lunch, and dinner. Something as simple as taking him to refill a medical prescription at Walgreens means something to Broden, so errands such as these are included on his calendar.

This morning after breakfast, Broden climbed the stairs back up to his room to play. A few minutes later Mark followed him upstairs to get ready for work. While I was shoving a bagel in the toaster for my breakfast, I hear Broden starting to scream, then I heard Mark run into his bedroom, “Broden, please stop hitting yourself. What is wrong? What do you want?” I ran upstairs into the room, “What's going on?” Mark looked exasperated, “I don't know! I started to get my uniform on and Broden started screaming and hitting himself.” I turned to Broden, “What do you want? You had breakfast.” Broden started to tense up and scratch his hands. He then said, “Hamburger and french fries.” That didn't sound right to me because he just had breakfast. I told Mark to get ready for work and waved him on, signaling to him that I had it. He looked frustrated and guilty as he walked back into the bedroom to finish putting his uniform on. A few minutes later he walked back in the hall, “I'm going to call into work and tell them I need to be home with you. I hate to leave you like this.” As I walked down the stairs with Broden I said, “That's ridiculous. Go to work. I know what I'm doing.”

> “With some patience, a few car rides and trips to Target, we'll get through”

Once Broden and I were downstairs, I grabbed a piece of paper and wrote, “Hamburger and french fries on one side of the paper and go for a car ride on the other side.” I then showed him the paper, “Show me which one you want.” Broden looked at both sides of the paper and yelled, “Target! Go to car!” As Broden was communicating what he wanted to me, Mark was walking into the kitchen, “He wants to go to Target?” As I walked out the door I said, “Yea, we're going to Target.”

Once we jumped in the car and backed out of the garage with yacht rock blaring through the speakers, the Broden I know was back. He bounced to the Eagles as I drove through the Target parking lot. Once I slowed down to park, he started to look around his seat and looked confused. Once I came to a stop I asked, “Broden what are you looking for?” He looked up, “Candy?” Broden had a half-eaten bag of gummies in the car the night before and I ate them thinking he didn't want the rest of them. I couldn't have been more wrong. Broden purposefully ate only half of the bag, because he was saving the other half for later.

Once I told him that I ate the rest of his candy, he looked up at me with a look of disgust. I quickly responded, “Do you want to go inside Target and buy some gummies?” Keeping his look of disgust on his face, he responded, “Yea.”

In the rain, we ran into Target to the candy aisle so he could pick out two bags of gummies. Once we were at the self-check-out, I told Broden to scan each of the items. One of them wouldn't scan, and the screen directed us to stay while an employee came to us. Quickly, an employee walked over, “Did something not scan?” As I moved around the area trying to keep Broden from bumping into other patrons, I explained to the employee that the candy was $3.49 and it needed to be scanned in properly. He couldn't get it to scan, so he started to manually put in a code. He looked up at Broden and smiled as Broden danced around the check-out counter. Eventually, he looked up at me and said, “You're ready to put your card in and pay.” Once everything was paid for, I grabbed the bags of candy and swiped the receipt out of the machine. As I glanced down, I noticed that the employee had only charge me $1 for Broden's bag of candy. I walked over while holding the bottom of Broden's shirt to keep tabs on him, “You only charged me $1 for the candy.” He looked over at Broden and them looked at me again with a smile, “You're good.”

As Broden dragged me out of Target back out into the rain, I started to cry. It's amazing how one small act of kindness can make such a big difference in someone's world. These two weeks have been rough, but with some patience, a few car rides and trips to Target, we'll get through. •

OUR JOURNEY IN CAMO

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

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SHE WANTS TO HANG OUT WITH FRIENDS OUTSIDE OF SCHOOL.

Help her plan to resist peer pressure.

Fifty-three percent of people ages 12 to 17 got prescription pain relievers from a friend or relative. Talk to your children about having an "exit plan" if they are offered prescription pain relievers that don't belong to them. Having a plan to avoid drug misuse can help children make better choices. For tips on how—and when—to begin the conversation, visit:

www.underagedrinking.samhsa.gov

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