PLUS: **UNITED STATES MILITARY SECTION**

EXCEPTIONAL PARENT
MAGAZINE
OCTOBER 2019
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EXCLUSIVE TO EP:

WORK *& the* ROAD TO INDEPENDENCE

IN THIS ISSUE:

HOW TO MAXIMIZE EARNINGS & SAVINGS

EMPLOYMENT & TRANSITION

ALSO INSIDE:

TRANSITION PLANNING *for* THE DEAF STUDENT

PLUS • AADMD:

WILL MY TEENAGER WITH A DISABILITY FIND WORK?

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

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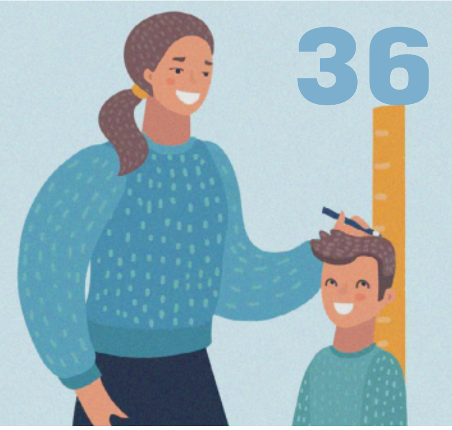

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ON OUR COVER

Whether you are just starting the transition planning process or looking for details on benefits eligibilty, *EP Magazine*'s Annual Emploment and Transition Issue is a comprehensive source designed to support families' varied needs. Explore relevant articles and current resources that will help youth meet their goals for life as they head toward adulthood. *Coverage begins on page 14.*

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Information and Support for the Special Needs Community

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

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

ANCORA IMPARO RICK RADER, MD ▪ EDITOR-IN-CHIEF

On Being Touched by a Rhino

It is sad that humans often need a first-hand experience with someone with a disability to "get it." But perhaps that is what it takes. And if so, that provides the justification to aspire to an "inclusive society," one that exists so that "getting it" becomes natural, desirable and commonplace.

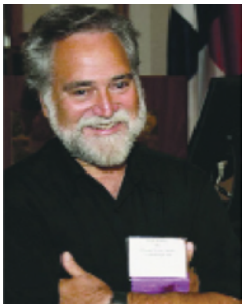
The estimated number of animal species on our planet falls somewhere in the vast range of three to 30 million.

For my money, the one animal that is the most formidable, intimidating and imposing is the rhinoceros. No other animal appears to be a direct left over from the dinosaurs. They weigh over 2,000 pounds, have thick and protective skin, and have one or two horns. The front horn on the black and white rhinos can grow to 20 to 51 inches while the rear horn can grow to about 20 inches. To say they know how to use them is an understatement. They can reach speeds of over 30 mph. The largest rhino species is the white rhino, it grows to 13 feet and weighs around 5,000 (think of an SUV).

They are indeed formidable, intimidating and imposing. They are also endangered.

There is a mythology about the powers inherent in their horns. The rhinos are killed and their horns are sold to dealers who grind the horns into powder for "magic medicinals." It is estimated that there were 500,000 rhinos across Africa and Asia at the beginning of the 20th century. Today there are 29,000 rhinos in the wild. Some of the species of the rhino are headed for extinction. In Kenya's Ol Pejeta Rhino Sanctuary, Najin and Fatu are only two northern white rhinos left in the world, and since they are both females, despite efforts at artificially inseminating them with southern white rhino sperm, they will probably be lost forever.

Richard Vigne, Managing Director of the Ol Pejeta Rhino Sanctuary shared, "Ol Pejeta is saddened that we are now down to the last two northern white rhinos on the planet, a testament to the profligate way the human race continues to interact with the natural world around us. However, we are also immensely proud to be part of the groundbreaking work which is now being deployed to rescue this species. We hope it signals the start of an era where humans finally start to understand that proper stewardship of the environment is not a luxury but a necessity."



HORN OF AFRICA: While I jumped at the chance to touch Barracka I was a little skeptical. He was after all a black rhino and, despite his docile history, the large posted warning signs attesting to the unpredictability of animals served as a reminder that this was not a Disney animatronic display.

PHOTO PROVIDED BY RICK RADER, MD

In my role as a member of the Global Medical Advisory Committee at Special Olympics International, I recently attended our annual meeting in Nairobi. Following the meeting I, along with several of my colleagues, took advantage of going on a safari tour to several bush campsites. Part of this "trip of a lifetime" was to actually see Africa's "Big Five." We were fortunate to see lions, elephants, rhinos, cape buffalos and the elusive leopards. The operative word is "see" them, from the safety of being in a Land Cruiser and under the guidance of our tracker and driver. Seeing them can be both life changing and life lifting. What was especially impressive was watching vast herds of wildebeests crossing the river in an expansive migration. Sitting in the open Land Cruiser it was obvious that in a different setting we (you and I) are incredibly insignificant; this was both humbling and soothing.

No one expects to touch a rhino any more than one would expect to touch an electric fence. Touching both would be fool hearty and suicidal. But I did and I doubt I will ever be the same.

The Ol Pejeta Rhino Sanctuary in Kenya is dedicated to protecting the dwindling number of rhinos. It provides a safe haven to over 100 rhinos in an area that offers them the opportunity to behave and live as free roaming rhinos. The sanctuary is not to be confused with a zoo, or game park (a la Florida); it is a true sanctuary that offers protection from poachers. It guarantees a natural life where the rhinos are exposed to the same conditions they have lived in for centuries.

> "Our guide gave me a handful of grass and prompted me to approach him, stand in front of him and offer the grass. While Barracka was eating from one hand I stoked his head and horn with my free hand. While I can say that I touched a rhino, the reality is that I was touched by a rhino."

It is also the home to Barracka, the black rhino that tolerated my touch.

In Ol Pejeta Barracka is a celebrity. He is 24 years old and has been at the sanctuary for the last 12 years. He is perhaps the only rhino in the world that can be touched by a human.

Barracka is blind.

Barracka lost his right eye in a fight with another rhino. Having one eye in a species that normally has limited vision is a hindrance for survival. Barracka's loss of vision in one eye was noticed by the park rangers and he was brought to the sanctuary to insure his survival. Out in the bush he would not have survived. In the sanctuary Barracka acted and conducted himself like any other rhino until he lost the vision in his other eye due to cataracts. The vets tried to restore his vision with cataract surgery on several occasions but were unsuccessful.

It was when Barracka became totally blind that his life changed. He is now required to live in a smaller secure environment where his food was readily available. He also became docile and allowed the rangers to approach him, touch him and feed him his favorite grass.

Our guide asked me if I would like to touch him. While I jumped at the chance I was a little skeptical. Barracka was after all a black rhino and, despite his docile history, the large posted warning signs attesting to the unpredictability of animals served as a reminder that this was not a Disney animatronic display.

Our guide gave me a handful of grass and prompted me to approach him, stand in front of him and offer the grass. While Barracka was eating from one hand I stoked his head and horn with my free hand. While I can say that I touched a rhino, the reality is that I was touched by a rhino.

While it was a great opportunity I realized that it was his acquired disability that allowed me to touch him. It provided me with the realization how life changing a disability can be. And while the ability to touch Barracka has been afforded to hundreds (perhaps thousands) of visitors, and in turn educated them on the plight of this endangered species, and even inspired them to become advocates, it is unfortunate that it required a disabling condition to mediate it.

It is sad that humans often need a first-hand experience with someone with a disability to "get it." But perhaps that is what it takes. And if so, that provides the justification to aspire to an "inclusive society," one that exists so that "getting it" becomes natural, desirable and commonplace.

It is noteworthy that Barracka in Swahili means "blessing." He deserves the name.•

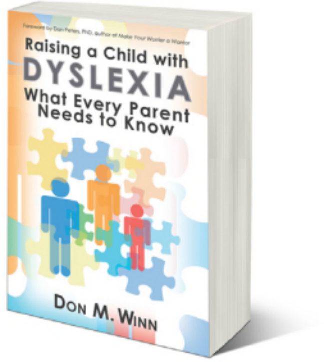
ANCORA IMPARO

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

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

NEW BOOK ON RAISING A CHILD WITH DYSLEXIA

Dyslexia and ADHD challenges can make children feel inadequate, misunderstood, and frustrated both in and out of the classroom. However, teaching children to cope effectively with these challenges will create inner strength and benefits that will empower dyslexic children for their entire lives.



Title: **Raising a Child with Dyslexia: What Every Parent Needs to Know**

Author: **Don M. Winn**

Publisher: **Cardboard Box Adventures**
Publication Date**: September 11, 2019**
Paperback: **262 pages**
ISBN-13: **978-1937615567**
Available at amazon, barnes and noble, www.cba-books.com/nonfiction.html

Author Don M. Winn explores how learning difficulties affect kids in a number of ways and illustrates how those who care for them can better understand their challenges and cultivate learning and emotional growth. Winn writes from his personal experience as a lifelong dyslexic reader and writer.

Raising a Child with Dyslexia explores: how parents can help their child at home; how grandparents can take part in helping their grandchildren at home; tips on working with your child's school to create an optimal learning environment; symptoms that warrant the diagnosis of a professional; how to offer a safe space for children with dyslexia to learn and grow; specific techniques in helping a child deal with the difficult emotional fallout of dyslexia.

The book includes questions for discussion that parents can use to help their child sort out how they feel about dyslexia and themselves.•

EP MAGAZINE WELCOMES NEW EDITORIAL ADVISORY BOARD MEMBERS

EP Magazine (Exceptional Parent) recently welcomed two distinguished individuals to its Editorial Advisory Board. They are Amged M. Soliman, Esq. and Tera Roberts.

Amged M. Soliman, Esq., is a member of the Maryland State Bar and has spent several years practicing disability rights law. He has lectured on the subjects of disability rights law and administrative law at various conferences and classrooms nationally. Much of Mr. Soliman's work over the years has revolved around examining issues of accessibility for people with intellectual and developmental disabilities, including with respect to medical and dental care, among others. He currently serves as an Attorney-Advisor at the National Council on Disability, an independent federal government agency, and has previously held positions at Franklin & Prokopik and the Law Office of Adele L. Abrams P.C.


Soliman

Tera Roberts, MPA will assume the position of CEO/Executive Director of Orange Grove in November 2019 and looks forward to leading this great agency into continued success. She has worked at Orange Grove for the past 24 years and has served as the Director of Adult Services for the past 17 years. Orange Grove serves approximately 1,000 people with disabilities annually, with approximately 750 having intellectual and/or developmental disabilities. Orange Grove employs 900 full-time staff and is governed by a 24-person Board of Directors.


Roberts

Tera previously worked at several state and non-profit agencies and served as CEO & Founder for four years of The Youth Advantage, providing after-school care for at-risk youth. She has developed numerous programs and departments, with the primary goal of enriching the lives of people in need and people with disabilities. As a lifelong resident of Ringgold, Georgia, one of her most rewarding experiences has been expanding Orange Grove's services into North Georgia. Orange Grove opened their office in Ringgold in 2012 and currently supports more than 100 people in three North Georgia locations. Tera is a member of the Chattanooga Women's Leadership Institute and the Ruritan Club. She graduated from the University of Georgia as a Presidential Scholar. After earning her Bachelors of Social Work, she obtained her Master's in Public Administration from The University of Tennessee at Chattanooga.

NATIONAL COUNCIL ON DISABILITY EXAMINES ORGAN TRANSPLANT DISCRIMINATION

The National Council on Disability (NCD) very recently released the first of five reports in a bioethics and disability series and calls on the U.S. Department of Health and Human Services Office for Civil Rights and the U.S. Department of Justice to issue critical federal guidance on organ transplant discrimination.

This first report titled, Organ Transplant Discrimination Against People with Disabilities, provides an overview of the ways people with disabilities are discriminated against in the organ transplant and procurement processes; an analysis of the protections provided; and the reasons underlying continued discrimination.

"We live in a world where organ denials are based on disability, rather than suitability," said NCD Chairman Neil Romano. "Receiving an organ to save your life should never be jeopardized because of fears, myths, and stereotypes about disability. Especially not with so many federal laws making that practice illegal."

Although federal and state laws ban organ transplant discrimination, people with disabilities are often denied equal access to organ transplants because of discriminatory assumptions that the lives of people with disabilities are of poorer quality than those of people without disabilities, and due to misperceptions about the ability of people with disabilities to comply with post-operative care.

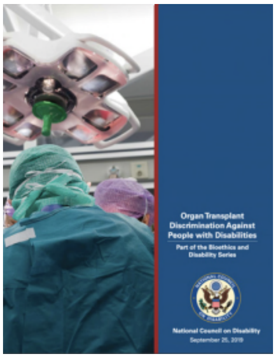
"We call on HHS OCR to demonstrate leadership by issuing critical guidance in this area. It simply cannot wait," said Romano.

Key findings from the report include:

- If a person has a disability that is unrelated to the reason a person needs an organ transplant, the disability will generally have little or no impact on the likelihood of the transplant being successful. If a person with a disability receives adequate support, the person's disability should also have very limited impact on the ability to adhere to a post-transplant care regimen.
- Disability-related policies vary greatly across organ transplant centers and across categories of disability. Many centers may have a current or past policy that treats HIV or AIDS, psychiatric disabilities, or intellectual and developmental disabilities

(I/DD) as relative or absolute contraindications to transplant.

- The Americans with Disabilities Act and Section 504 of the Rehabilitation Act prohibit organ transplant centers from discriminating on the basis of disability.
- Nine states have laws banning organ transplant discrimination.
- The federally-run system overseen by HHS is called the Organ Procurement and Transplantation Network (OPTN), and it is run by the United Network for Organ Sharing (UNOS) as the sole contractor. UNOS/OPTN has proposed organ procurement policies that pose serious risk to people with disabilities. Existing policies and practices fail to protect people with disabilities from being pressured to donate organs, and some recent OPTN proposals would weaken the few protections that currently exist.



Organ Transplant Discrimination Against People with Disabilities
Part of the Bioethics and Disability Series
National Council on Disability
September 25, 2019

Key recommendations from the report include:

- *The Department of Justice (DOJ), in conjunction with the Department of Health and Human Services (HHS), should release guidance and provide technical assistance clarifying that Titles II and III of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 apply to organ transplant centers and hospitals. This guidance and technical assistance should:*
- *Detail the obligations of organ transplant centers and hospitals to avoid discriminating on the basis of disability in the organ transplant process and advise organ transplant centers how to ensure their evaluation of candidates complies with federal law.*
- *Emphasize that UNOS/OPTN should ensure that its policies are consistently applied in a manner that avoids discrimination.*
- *Explicitly state that making assumptions regarding the post-transplant quality of life for people with disabilities violates federal law.*

ABOUT THE NATIONAL COUNCIL ON DISABILITY

First established as an advisory Council within the Department of Education in 1978, NCD became an independent federal agency in 1984. In 1986, NCD recommended enactment of an Americans with Disabilities Act (ADA), and drafted the first version of the bill which was introduced in the House and Senate in 1988. Since enactment of the ADA in 1990, NCD has continued to play a leading role in crafting disability policy, and advising the President, Congress and other federal agencies on disability policies, programs, and practices.

- *Make clear that the ADA and Section 504 apply throughout the organ transplant process, including informal eligibility determinations, such that disability should only be taken into account to the extent that it can be clearly shown to be likely to impair successful transplantation.*
- *Encourage priority review of any cases brought challenging discrimination on the basis of disability in the organ transplant context in acknowledgment of the time-sensitive nature of a transplant denial.*
- *UNOS/OPTN should ensure that individuals and families are able to make informed decisions about the withdrawal of life-sustaining treatment prior to and independent from any contacts from organ procurement organizations.*

NCD's bioethics and disability report series focuses on how historical and current devaluation of the lives of people with disabilities by the medical community, researchers, and health economists perpetuates unequal access to medical care, including life-saving care. NCD has released/will release its reports in the series on the following schedule:

- September 25: Organ Transplant Discrimination Against People with Disabilities
- October 9: The Danger of Assisted Suicide Laws
- October 23: Genetic Testing and the Rush to Perfection
- November 6: Quality-Adjusted Life Years and the Devaluation of Life with a Disability
- November 20: Medical Futility and Disability Bias

OCTOBER IS LEARNING DISABILITY MONTH

Did you know that 2.3 million students are diagnosed with specific learning disabilities (SLD) and receive services under IDEA (Individuals with Disabilities Act)? This represents 35% of all students receiving special education services, according to the Learning Disabilities Association of America.

Children with learning disabilities begin school excited to learn. If your child is having difficulty in school, he/she may learn differently from other kids. For many kids, these disorders go undetected despite their ongoing struggles with school work and the behavior issues that often accompany these disorders. Parents are often the first to notice that "something doesn't seem right." But sometimes knowing what to do and where to find help can be confusing.

A learning disability is not a problem with intelligence or motivation. Kids with learning disabilities are just as smart as

WIRED DIFFERENTLY : TYPES OF LEARNING DISABILITIES

If you suspect that your child is having trouble with learning in general, there is help available.

DYSLEXIA: Dyslexia is perhaps the best-known learning disability. Children with this disorder may have difficulty with spelling, vocabulary, or comprehension. They may be slow readers, struggle learning left from right, or have organizational problems with both written and spoken language.

DYSGRAPHIA: Dysgraphia affects a child's ability to perform handwriting and other fine motor skills. People with dysgraphia might have problems with inconsistent spacing, difficulty composing writing, poor spelling, illegible handwriting, poor spatial planning on paper, and thinking and writing at the same time.

ADHD: ADHD is one of the most common neurodevelopmental disorders of childhood. It is usually first diagnosed in childhood and often lasts into adulthood. A child has difficulty controlling focus, impulse, energy levels, or some mix of the three.

DYSCALCULIA: A child with this condition may have an effect on one's ability to develop math skills, understand numbers, and learn math-based facts. It can be difficult for individuals with dyscalculia to comprehend math symbols, organize or memorize numbers, tell time, and count.

everyone else. Their brains are simply wired differently affecting how they receive and process information.

If you think your child might have a learning disability, don't despair! There are many steps you can take to ensure that your child gets evaluated appropriately.

WHAT TO DO IF YOU SUSPECT YOUR CHILD HAS A LEARNING DISABILITY

If you suspect that your child is having trouble learning to read, or trouble with learning in general, there is help available. For parents of school-age children, the first source of help should be the public school serving your area. Contact your child's school principal, express your concerns, and ask to have your child evaluated. The school system is required by federal and state law to evaluate your child at no cost to you or your family. The results of the evaluation will show whether or not your child has a problem with reading or learning and, if so, the nature of the problem.

Once your child has received a diagnosis, your school psychologist should be able to recommend and help you set up services or accommodations for your kid. Depending on the specific learning disability, your child may qualify for special education services under the federal Individuals with Disabilities Education Act (IDEA) or accommodations through Section 504 of the Rehabilitation Act.

Keep in mind, you are your child's best advocate. So read books and articles on your child's specific learning disability and learn how you and your school can help. Talk to your kid's teacher about additional ways the teacher can assist your child. Most teachers are eager to help. Although, depending on the student-teacher ratio and the school's resources, it's sometimes challenging for teachers to do as much as they'd like. There are likely other kids in their classroom with special needs as well. If you feel your child isn't getting the help he or she needs, talk to the school administrator. •

[Article contributed by Octopus Watch Motion Edition, the first icon-based watch that empowers kids by teaching good habits and the concept of time, while also encouraging them to stay active with its new fitness tracker. For more information, visit https://www.heyjoy.io *]*

AUDITORY MEMORY AND PROCESSING DISABILITIES: Kids with this condition may have difficulty recognizing the differences between sounds, understanding the order of sounds, recognizing where sounds have come from, or separating sounds from background noise.

VISUAL PERCEPTUAL/VISUAL MOTOR DEFICIT: These are disorders that can result in missing subtle differences in shapes or printed letters, losing place frequently, struggles with cutting, holding pencil too tightly, or poor eye/hand coordination. Visual Processing Disorders can cause people to struggle with seeing differences between similar letters, number, objects, colors, shapes and patterns.

NEW PRODUCTS FINE MOTOR SKILL FUN

HI HO CHERRY-O

This adapted version of the classic counting game Hi Ho Cherry-O will delight children of all ages and abilities. This game encourages the development of cognitive skills and interaction. The set includes a game board equipped with two switch plates and two external jacks to accommodate external switches. Push the red switch plate to pick a cherry off the tree and hear a tone. Push the blue switch and a cherry goes back on the tree and a different tone sounds. Users can activate the spinner by pressing its rim or using a switch. The set also includes the original Hi Ho Cherry-O game without the spinner. Game Board Size: 10 inches x 8½ inches x 7 inches. Spinner Size: 8½ inches in diameter. Game Board Requires 4 AA Batteries and Spinner Requires 2 AA Batteries. Weight: 2¾ pounds. Not for children under 3 years.

ENABLING DEVICES
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WOODEN LATCHES BOARD

The Wooden Latches Board is an educational activity play board to help children build dexterity as they figure out how the six different latches work. The play board helps to build fine and gross motor skills while learning colors, numbers, animals and more. Children can undo a lock or latch, swing open the numbered door, and count on finding fun when the picture beneath is revealed on this wooden play board. This smooth-sanded, solid-wood board features surprises behind the opening doors and windows. Suitable for ages 3 years and up.

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Email: Owners@MelissaAndDoug.com

ALL THAT GLITTERS

All That Glitters is a multi-dome activity center that keeps playtime interesting for hours. This activity center encourages reaching, increases tactile awareness, encourages swiping, and increases auditory development. The gentlest pressure to any corner of the activity center rewards the user with lights, vibration, music, flying beads and glitter. This is a dynamic experience that simultaneously awakens the user's visual, auditory, and tactile senses. Size: 11 inches x 11 inches x 6 inches. Weight: 3½ pounds. Requires 4 C battery.

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ABLEDATA

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 30,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for these pages by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by New Editions Consulting, Inc., is funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under contract number ED-OSE-13-C-0064.
For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: ABLEDATA, 103 W. Broad Street, Suite 400, Falls Church, VA 22046; phone: 1-800-227-0216; TTY – 703-992-8313; website: www.abledata.com; email: abledata@neweditions.net; twitter: https://twitter.com/AT_Info; Facebook: https://www.facebook.com/abledata.

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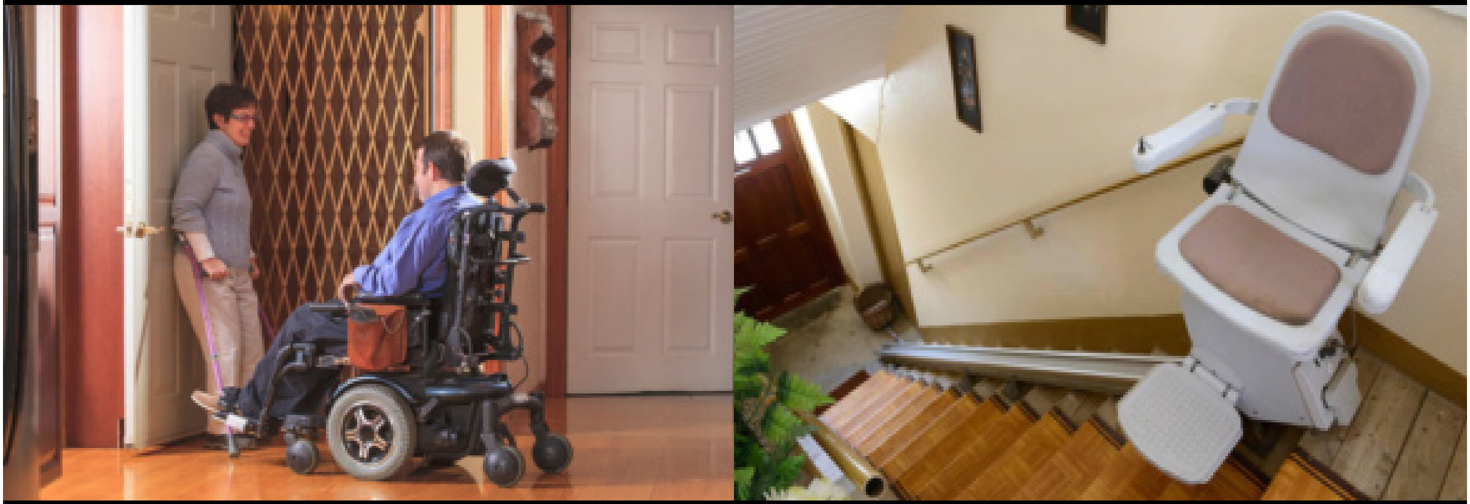

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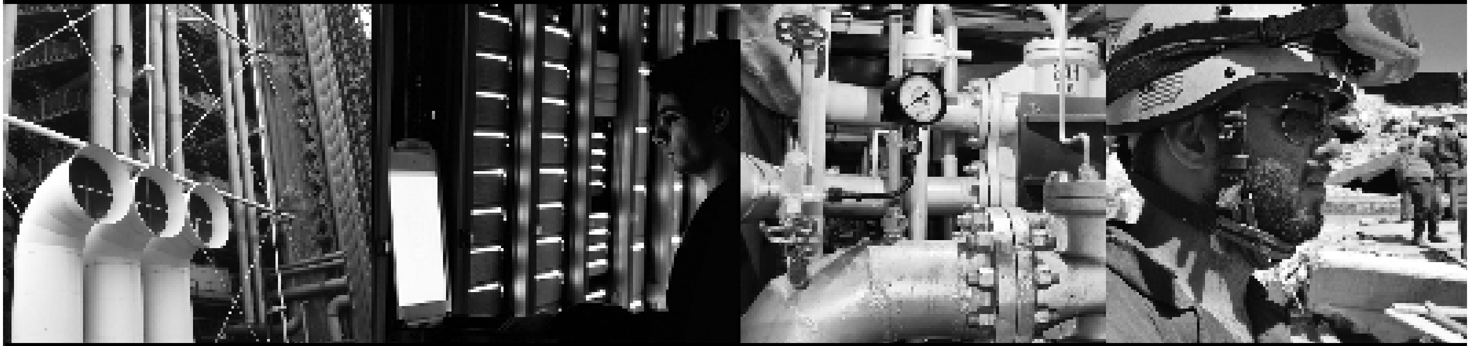

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COMPETENT ■ PROFESSIONAL ■ COMPASSIONATE

Employment and Transition

My teenager has a disability - will he/she find employment after high school or college?

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

“In 2018, the employment-population ratio – the proportion of the population that is employed – was 19.1 percent among those with a disability, the U.S. Bureau of Labor Statistics reported today. In contrast, the employment-population ratio for those without a disability was 65.9 percent.” [1]

DO PEOPLE WITH DISABILITIES EARN EQUAL PAY?

> *“Today, a record 9 million people with a disability work. While these workers, age 16 and older, are spread throughout the labor force, workers with a disability tend to concentrate in certain jobs depending on their age and particular disability.”* [2]

The U.S. Census Bureau reported for the year 2017, that overall, workers with a disability earn less than workers who do not have a disability. As a group, full-time, year-round workers with a disability earn 87 cents for every dollar earned by those with no disability. However, among people working similar jobs and schedules, the median earnings for workers with a disability are either very close to, or not different from, earnings for workers with no disability. In fact, accounting for the differential mix of occupations between these workers with or without a disability reduces the overall disparity in median earnings by about half. [2,3]

A few occupations stand out as exceptions, with notable differences in median earnings between the two groups. These occupations typically have much higher median earnings for people both with a disability and with no disability. These include:

- *Chief executives*
- *Lawyers*
- *Marketing and sales managers*
- *Financial analysts.*

However, the median earnings for physicians and surgeons, who rank at the top of the earnings list, are no different between those with a disability and those without.

OCCUPATION

The most common occupations for people with a disability are janitors and building cleaners, where about 300,000 workers with disabilities find employment. They make up 11 percent of workers in this occupation. Other large occupations for workers with disabilities are:

- *Drivers/sales workers/truck drivers*
- *Cashiers*
- *Retail salespersons*
- *Laborers and freight, stock and material movers.* (See chart 1)

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

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

Workers with disabilities increase with age

Workers with a disability make up just 6 percent of working adults, but this figure rises with age. About 4 percent of workers under age 45, 7 percent of workers ages 45-59, and 13 percent of workers age 60 and older have a disability.

Top-ranked occupations for younger workers (ages 16 to 44) with a disability are:

- Cashiers
- Laborers/freight/ stock/material movers-hand
- Janitors and building cleaners
- Customer service representatives
- Cooks
- Retail salespersons
- Stock clerks/order fillers
- Waiters/waitresses. [2,3]

BY TYPE OF DISABILITY

Ambulatory, hearing and cognitive disabilities are the most common difficulties among workers with a disability, which may have an impact on the type of jobs they can get. For younger workers with a disability, cognitive difficulty is the most common, while ambulatory and hearing difficulties are more common among older workers. In fact, about half of working-age adults with a disability reported they had a health condition that was an impediment for the kinds of work they could perform or the number of hours they could work. This varies by disability type. People with a hearing disability are more likely to work than people with other disability types. [2,3]

Highest and lowest employment rates for workers with disabilities by state (2016)

There is a wide range of employment rates for workers with disabilities in the individual states; ranging from 25.4% in West Virginia to 57.1% in Wyoming. [4]

1. Wyoming	57.1%	46. South Carolina	28.7%
2. South Dakota	51.7	47. Alabama	27.9
3. North Dakota	48.8	48. Mississippi	27.5
4. Nebraska	48.6	49. Kentucky	27.4
5. Minnesota	47.5	50. West Virginia	25.4

AMERICANS WITH DISABILITIES ACT OF 1990 (ADA)

If your teenager is seeking a job or is new to the workforce, as a parent you should become familiar with ADA, a federal civil rights law designed to prevent discrimination and enable individuals with disabilities to participate fully in all aspects of society. One fundamental principle of the ADA is that individuals with disabilities who want to work and are qualified to work must have equal opportunity to work.

To be protected, your teenager must be a qualified individual with a disability. This means that he/she must have a disability as defined by the ADA. Under the ADA, you have a disability if you have a physical or mental impairment that substantially limits a major life activity such as hearing, seeing, speaking, thinking, walking, breathing, or performing manual tasks. Your teenager also must be able to do the desired job he/she wants or was hired to do, with or without reason-

WORK TO DO: Ambulatory, hearing and cognitive disabilities are the most common difficulties among workers with a disability. For younger workers with a disability, cognitive difficulty is the most common, while ambulatory and hearing difficulties are more common among older workers.

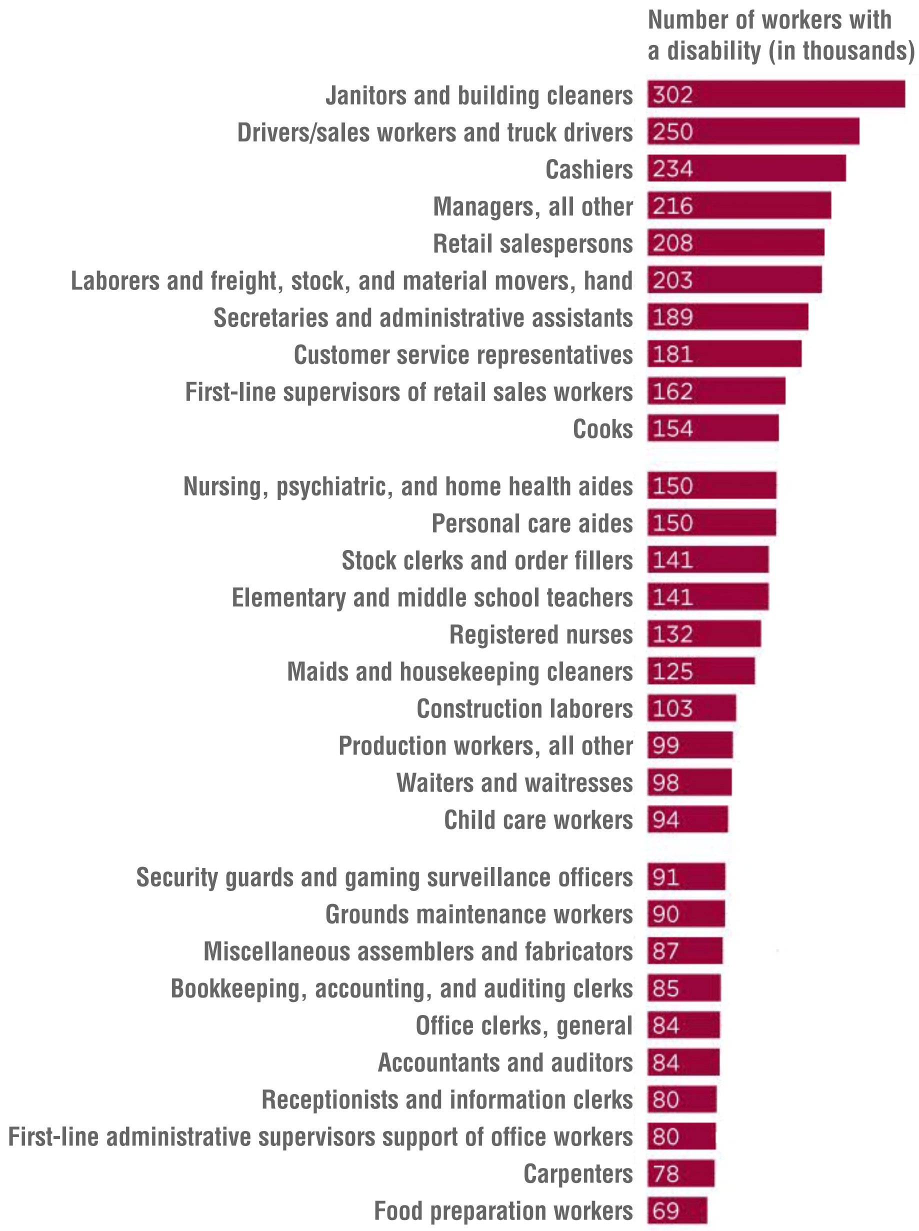
able accommodation. A reasonable accommodation is any change or adjustment to a job, the work environment, or the way things usually are done that would allow your teenager to apply for a job, perform job functions, or enjoy equal access to benefits available to other individuals in the workplace.

You or teenager simply must let the employer know that the youngster needs an adjustment or change because of the disability. There are no special forms or use of technical language to do this. For example, if a wheelchair is needed and it does not fit under your desk at work, all that is needed is to inform the supervisor. This is a request for a reasonable accommodation. A doctor's note requesting time off due to a disability or stating that your teenager can work with certain restrictions is also a request for a reasonable accommodation. *(See reference 5 for more details in the Guide for People with Disabilities Seeking Employment)*

PREPARING YOUR TEENAGER WITH A DISABILITY FOR EMPLOYMENT

> *"One of the most important parts of transition planning is ensuring that a youth with disabilities should learn to advocate for themselves and the supports they need. Youths need to understand their rights. As they transition into employment or postsecondary education, they will need to be able to communicate their needs and may need to help identify where they can receive those supports…"* [6]

Chart 1. *Workers With Disabilities by Occupation* [2]



Source: U.S. Census Bureau, 2017 American Community Survey, 1-Year Estimates.

The Individual Disability Education Act (IDEA) includes requirements for special education and related services for children and youth until the age of 21. Recognizing the importance of maintaining a continuum of services beyond high school and into adulthood, federal disability legislation requires the inclusion of transition planning in each child's Individualized Education Plan (IEP). By the time a student reaches the age of 16 (if not before), the IEP must include measurable postsecondary goals and identify appropriate transition services.[6]

Parents "know their children," but so do their health practitioners and service personnel. The need is for input from concerned individuals who realistically can assist and guide your teenager who is transitioning from the difficulties of the teen years to the early stages of adulthood and employment. Now add the complexities of disabilities! •

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HEARTSIGHT CHRISTINA LLANES MABALOT

GETTING TO WORK: "I advise persons with disabilities transitioning to employment to develop their passion for bringing in some form of income. When, and if possible, creating work or starting a small business can be a winning option."

Gainful Employment

My rejection led to an epiphany! I would build a school, practice my brand of selecting the best teaching methods suitable to each learner, open the school doors to the marginalized, and turn my dream to reality!

Gainful employment is the prize one gets for working through the grueling years of education – or so I thought. Earning a master's degree in education was a milestone for me, but after receiving a stack of rejection letters from schools I had applied to, I seemed to have reached a dead end. I put everything on the line, my years, blood, sweat, tears, and my future, only to be a bum with a post-graduate degree.

Back then, in the Philippines, employment doors would be shut to persons with disabilities as society perceived them unproductive. This cultural barrier was aggravated by the rising rate of unemployment at that time, which meant that persons with a disability were much less likely to be employed. Also, employment options for people with visual impairment were stereotyped; they were either masseurs/masseuses, musicians, or social workers. I loved music, but it didn't like me. My hands were too puny for me to be a masseuse, and I did not have any social work background. Educated and successful visually-impaired professionals were more of an exception than the rule, and some with post-graduate education were even forced to go out to the streets to beg for their survival.

Transitioning from being a student to being a productive adult in the community entails navigating through the longest rite of passage. This process begins with stripping one's self of all pride, confidence, previously established identity, and options. There wasn't a learning institution I could work for that I had not targeted for application. I considered going back to school to pursue social work, but realized that would not assure me of a job. At most, going back to school would make me a… professional student.

I desperately searched for clues that could lead to employment. I replayed my job interviews mentally and discerned that my philosophy of education played a significant part in my rejection. I believed in learner-centered education and would practice the method that works best for a child, and this didn't go well with schools, because they specialized in specific ways of teaching. I wasn't ready to compromise my conviction just to get employed.

"I wanted a way to plant the seed of the desire to learn in every young heart, even if I had to do it alone!" I reasoned.

The light bulb came on. My rejection led to an epiphany! I would build a school, practice my brand of selecting the best teaching methods suitable to each learner, open the school doors to the marginalized, and turn my dream to reality!

I rounded up the people who believed in my vision. We founded the "Tuklasan" (Filipino word for discovery) Center for Children Foundation, a non-profit organization that aimed to bring out the best in every child. Reflecting on the hardships I went through as a visually-impaired individual, I was dedicated to turn the tables and empower children by providing more accessible education in a nurturing environment. I struck an exchange deal with my father; I'd use the ground floor of our house for my school if I covered the cost for remodeling and repair. For 12 years, Tuklasan Center for Children Foundation provided pre-school education to students with and without disabilities and those who were economically marginalized. Realizing the difficulty of transitioning, I made sure to facilitate and follow through with the children moving up to elementary schools.

> "I felt fulfilled doing significant and sustainable work for the differently-abled community. I loved my work and would have done the job even if I didn't get paid, that is, if I didn't have bills to pay."

I became an entrepreneur, investing my time, treasure, and talents in work I was called to do, and earned a decent livelihood from it. Frequent transitioning through the different phases of my life also seasoned me to be adaptable and to flourish in diverse social and cultural climates.

Relocating to my husband's home city where we decided to raise our family, I then had the privilege of building a unique educational component in a regular school. It was the perfect setting for inclusion. We accommodated students with visual and hearing impairments and integrated them into the school. Simultaneously, I set up a livelihood program for visually-impaired masseurs to deliver services to reputable hotels. Later, I partnered with a company for medical transcription to include visually-impaired trainees. I felt fulfilled doing significant and sustainable work for the differently-abled community. I loved my work and would have done the job even if I didn't get paid, that is, if I didn't have bills to pay.

In today's volatile marketplace, landing a job may be difficult, especially for those with special needs. Compelled to earn a living, persons with disabilities often find themselves constricted into roles that are out of line with their abilities, interests, and talents. St. Thomas Aquinas said, "There can be no joy in living without joy in work." I believe that a job is doing something that you get paid for, but work is doing something that you live for. I advise persons with disabilities transitioning to employment to develop their passion for bringing in some form of income. When, and if possible, creating work or starting a small business can be a winning option.

The success story of a father and son million-dollar business, John's Crazy Socks, testifies to this principle. John's Crazy Socks, named after its co-founder, John Lee Cronin, a young man with Down syndrome, was born out of John's love for crazy and unique socks. John didn't like the options that were available to him in his last year of high school, so he thought that the best way to find a job he would love was to create one. Today, John's Crazy Socks hires people with various abilities and gives five percent of earnings to the Special Olympics while spreading happiness. Check their website at www.johnscrazysocks.com

CURRENT EMPLOYMENT

When my family migrated to America, I realized that I could not pick up from where I left off in my entrepreneurial track record. I have had to work in corporate America, which isn't a bad thing because I landed in a good company. The company I work for is one of the largest and most reliable networks in the wireless industry; it is also the best equal opportunity employer in mainstream America. Its values include diversity and inclusion, ideals which I uphold. My next goal is to link my current job with my purpose, one of which is to make the world of people with special needs better through what I do. I want to be the face of equal opportunity for the company I serve. After all, I am a woman, member of a minority group, and a person with special needs. Let me put a cherry on top of that cake; I'm approaching the age of senior citizenship. I'll soon be representing four sectors and would be a perfect example of equal opportunity and diversity.•

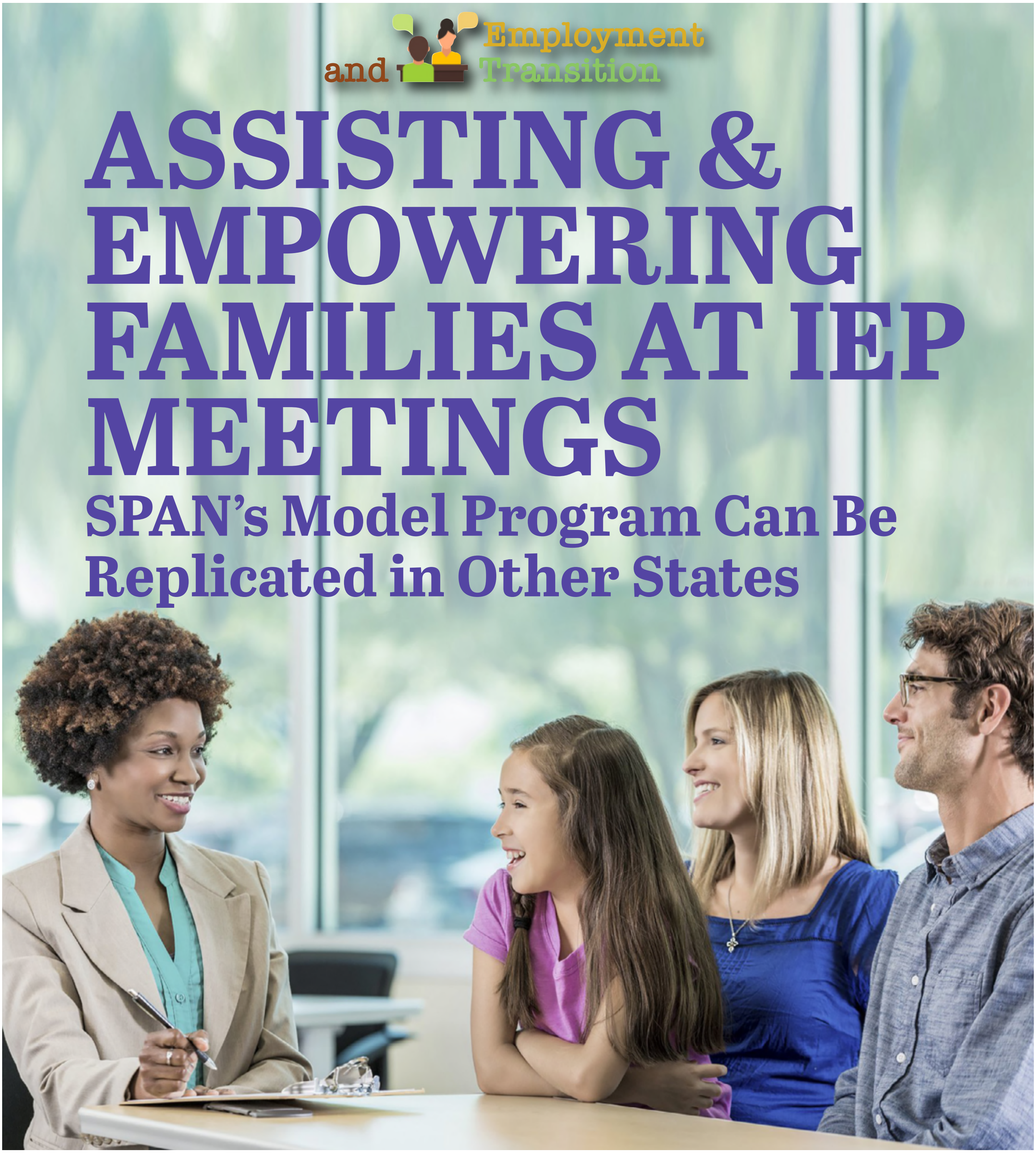
HEARTSIGHT

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

Employment and Transition

ASSISTING & EMPOWERING FAMILIES AT IEP MEETINGS

SPAN's Model Program Can Be Replicated in Other States



BY LAUREN AGORATUS, M.A.

Many families may feel unprepared to attend their IEP meeting and want someone to attend with them for guidance. SPAN Parent Advocacy Network, which is New Jersey's Parent Training and Information (PTI) Center, has a new project called SEVA that stands for Special Education Volunteer Advocates.

SEVA means "selfless service" in Sanskrit and is the core of SPAN's Special Education Volunteer Advocate program. SEVAs are trained by SPAN to help families prepare for, participate effectively in, and follow up from, IEP meetings where families are seeking more inclusive services and/or effective transition to adult life plans. SEVAs are not providing legal advice but serve as peer mentors, letting families know their rights and the responsibilities of the school district and helping them learn and exercise effective family-professional partnership and communication skills. SEVAs help families understand their choices, give the families options, and respect their decisions. SEVA Training has been provided to parents, self-advocates, siblings and youth participants.

> *"I was so grateful when you called and told me about your project. It was like a prayer answered. I never imagined that I would have to fight so hard for my son to be included in the general education classroom…"*
>
> – Parent seeking inclusion

> *"My most valuable take-away was to be open, to listen with my heart and be able to offer to support to families."*
>
> – SEVA trainee

Basics: How it Works

After training, a SEVA is matched with a family. SPAN has focused on either LRE (least restrictive environment) or transition to adult life issues. The SEVA gets basic information on the family from the intake line. Then there is an initial meeting to determine the goals of the family and student. The SEVA will attend the IEP meeting with the parent. Finally, there is an exit meeting in which the family decides on ongoing goals and is empowered to reach them in the future. The SEVA can participate in group or individual technical assistance calls to help them assist the family. SEVAs are reimbursed for all 3 family meetings. Of course, if a parent needs additional assistance later, they can always contact the SPAN warmline.

HOW SEVA HELPS

SEVA enhances the capacity of SPAN Resource Parents to serve as volunteer supports for families in preparing for and at IEP meetings focused on inclusion and effective transition to adult life. The program increases the number of under-served families who can be provided with in-person support. SEVA builds the knowledge and skills of families and youth, particularly those facing the greatest challenges, to advocate on their own behalf to secure effective inclusion and transition to adult life

Funding the Project

Many other PTIs may have received requests to attend IEP meetings with parents but lack adequate funding to provide this service. In addition, some of the Disability Rights or Protection and Advocacy organizations in the states receive calls that don't warrant legal representation but could be handled by the PTI. Also, there are Councils on Developmental Disabilities in each state, which may have mini-grants to organizations helping those with developmental disabilities. SPAN was able to get this funding from the NJ Council on Developmental Disabilities and referrals from Disability Rights NJ.

Opportunities for other PTIs, DD Councils and Disability Rights

SPAN has already been asked how this program can be replicated in other states to help families of students with disabilities. SPAN has presented at both the National Disability Rights Network annual conference in Baltimore, MD (June 2019) as well as the National Councils on Developmental Disabilities in New Orleans, LA (July 2019). Future learning opportunities will be SPAN presentations at the upcoming National Parent Center Conference (September 2020) and the Association of University Centers on Disabilities Conference (TBA 2020). For a more detailed overview of the SEVA project, see Resources.

Project Impact

Evaluations are given to the SEVAs on the quality of training. In addition, after the family meetings, parents will also receive a brief evaluation of the services they received. To date, responses have been overwhelmingly positive.

Attending IEP meetings has allowed the PTI to expand their services to parents. Families are benefitting from guidance and learning how to advocate for their child.•

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the parent of a child with multiple disabilities. She serves as the Coordinator for Family Voices-NJ and as the central/southern coordinator in her state's Family-to-Family Health Information Center, both housed at the SPAN Parent Advocacy Network (SPAN) at www.spanadvocacy.org

SELFLESS SERVICE : IEP RESOURCES

PARENT CENTERS - HELP FOR FAMILIES AND STUDENTS

www.parentcenterhub.org/find-your-center

NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES

https://nacdd.org/councils

NATIONAL DISABILITY RIGHTS NETWORK

www.ndrn.org/about/ndrn-member-agencies

SPAN PARENT ADVOCACY NETWORK - SEVA

https://spanadvocacy.org/programs/seva

COVER STORY

Employment and Transition

Support, in and of itself, is not unnecessary. However, it should lead to a destination beyond itself. It should lead to the creation of a life of independence. Benefit checks should be replaced by earnings and public healthcare should be replaced with employer-based healthcare.

The Road to Independence is Paved with Work

BY GREG MAKELY

For those who experience disability, often the arduous journey begins with a cultivated dependence upon parents, school officials, and public benefits: Supplemental Security Income (SSI) and Medicaid or Social Security Disability Insurance (SSDI) and Medicare. There is an expectation set that things will always be done "for", and not "by" them, and that alternative means support must always remain available.

So, instead of making the normal transition from childhood dependence to adulthood independence that people without disabilities make, adults with disabilities are largely held in check. If there is no expectation for independence, there is no need for the means to create it; namely, work. So, instead of putting serious effort into creating career paths, parents and school officials often concentrate on the acquisition of benefits and day programming. Support, in and of itself, is not unnecessary. However, it should lead to a destination beyond itself. It should lead to the creation of a life of independence. Benefit checks should be replaced by earnings and public healthcare should be replaced with employer-based healthcare. The Social Security Administration (SSA) understands this.

In 1999, SSA began to take steps to move a tenth of the 1 % of those on the disability rolls off, by incentivizing work, through the Ticket to Work Program legislation enacted. They had already installed Work Incentives, years prior, but those were being largely unused, due in part to local offices being too busy with the administration of retirement benefits to dedicate time to properly promote and implement available Work Incentive protections on an individual basis. In the passage of this legislation, the Benefits Planning & Outreach program was created, which granted money to agencies outside the Administration, to assist SSI and SSDI beneficiaries with learning about and applying for Work Incentives in order to protect cash and healthcare benefits while pursuing work efforts. Today, the program which has now evolved into the Work Incentives Planning and Assistance program, retains the same purpose, the incentivization of work efforts with the promise of benefit protections. The Family Resource Network has been a provider of this programming, since its inception, in 2001, under the name NJ Work Incentives Network Support program (NJWINS).

"Program participants are taught that they must develop a work record they can use to both retain employment and to create their next career step."

During the provision of Work Incentives Planning Services, The Family Resource Network recognized the need to provide services that would not only incentivize work for beneficiaries but also assist them with finding, keeping and augmenting work efforts. To this end, The Family Resource Network created the Getting to Work program, with three years of grant funding from the Kessler Foundation, one year of federal funding from the SSA Ticket program and by becoming a vendor of NJ Division of Vocational Rehabilitation Services, the NJ Commission for the Blind and Visually Impaired, and the NJ Division of Developmental Disabilities referral.

FINDING THE RIGHT FIT: The Getting to Work program emphasizes a person-centered, individualized and customized approach that begins with discovering who a person is and what he/she dreams of doing. In that discovery process, a dream can be sized to fit into a realistic job goal. The goal is always both job retention and career development.

The Getting to Work program emphasizes a person-centered, individualized and customized approach that begins with discovering who a person is and what he/she dreams of doing. In that discovery process, a dream can be sized to fit into a realistic job goal. For example, if a person wants to be a doctor, but lacks that aptitude, exploration begins to identify an alternative job goal that also fits into a medical setting. Perhaps, that means placement on a hospital janitorial staff. Perhaps, the desire to become a professional baseball player is resized to placement on the groundskeeping staff at a local triple A ballpark. The goal is always both job retention and career development.

Program participants are taught to understand that the acquisition of a job is only the starting point, that they must develop a work record they can use to both retain employment and to create their next career step.

Since it is easier to teach these this kind of thinking at an early age than to have to reshape entrenched thinking in adulthood, The Family Resource Network created transition to work programming for both high school students and college undergraduates who experience blindness, with a program called Employment Development Guidance and Engagement (EDGE). The EDGE program touches all aspects of life that require independence, with classes and activities geared to teach student the means to independence, and parents, the means to supporting independence by allowing their children to venture beyond parental advocacy and achievement to self-advocacy, achievement of independent living skills and employment. A valued part of this transition programming is the use of

ABOUT THE FAMILY RESOURCE NETWORK (FRN):

The Family Resource Network

Providing families with access, answers and action

The Family Resource Network (FRN) is a comprehensive, family-focused organization designed to meet the growing need for community-based programs and services for individuals and their families with continuing needs. For almost 50 years, FRN has assisted thousands of New Jersey families with a variety of disabilities and chronic conditions connect with resources and support services they need to live full and happy lives. FRN's network agencies are: Autism Family Services of NJ, Caregivers of NJ, and Epilepsy Services of NJ.

FRN Employment Services provides person-centered employment support services to people with disabilities who would like to prepare for, find and retain competitive employment. Programs include: New Jersey Work Incentives Network Support (NJWINS); Getting to Work (GTW); and Employment, Development, Guidance & Employment (EDGE) 1.0 & 2.0. Services are referred to by one of the following agencies: NJ Commission for the Blind and Visually Impaired, NJ Division of Developmental Disabilities, NJ Division of Vocational Rehabilitation Services.

For more information, visit www.familyresourcenetwork.org or call 800-376-2345.

mentors who, themselves, have achieved professional success, while experiencing the same disability.

As Getting to Work and EDGE programming is successful and work efforts grow, participants can loop back around to NJWINS to address the next topic: asset development. NJWINS does so by helping them widen the door to benefit maintenance, with programs such as NJ Workability Medicaid (also created from the 1999 Ticket to Work legislation) and NJABLE, which will allow them to earn and save more; possibly enough money to eventually afford to become homeowners. This, in turn, addresses the largest advocacy issue for people with disabilities. Those who don't pay property tax tend to have no voice in municipal undertakings. Home ownership, therefore, is critical to lobbying for the accessibility, transportation and expanded scholastic offerings that make career establishment possible.

> **"Home ownership is critical to lobbying for the accessibility, transportation and expanded scholastic offerings that make career establishment possible."**

Federal and state government have been partnering with agencies such as The Family Resource Network to dispel the myth that careers and independence are not possible for people with disabilities by providing the innovative benefit and employment support necessary to bridge that fictitious gap and pave the road to the land of self-sufficiency and full potential.•

ABOUT THE AUTHOR:

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Employment and Transition

How IRWE (Ur-wee) ABLE to earn more and still PASS the eligibility criteria for disability benefits?

BY ALEXANDRA BAIG, MBA, CFP

In this article, we are going to show you how to use Impairment Related Work Expenses (IRWE), Plans to Achieve Self-Support (PASS) and Achieving a Better Life Experience (ABLE) accounts to maximize the amount you can earn from working and the amount you can save and accumulate without affecting your SSI or SSDI benefits.

"How much can I earn and not lose my Social Security Benefits?" I get this question a lot from my clients with disabilities who want to go to work or increase their work hours, but do not want to jeopardize their cash benefits. The question is analogous to asking a dietician, "How much can I eat and still lose weight?" The answer to both questions is: "It depends."

In the latter case, it depends on how tall you are, how old you are, how high your metabolism is and how active you are. In the former case, it depends on which Social Security benefit you are getting and which Work Incentives you can use to reduce the income and resources (assets) that Social Security counts.

If you have a disability and work, the income you receive from work affects different benefits differently. For example, once you earn more than $85 (or $65 if you have any unearned income), your income from work reduces your Supplemental Security Income (SSI) by 50 cents for every dollar you earn. That $85 represents a small Work Incentive called the Earned Income Exclusion. But if you are under 22 years old and a full-time student, then you qualify for a much larger Work Incentive called the Student Earned Income Exclusion, which is $1,870/month up to $7,550/year. So, all else equal, if you are 22 or over or not a student, you may start losing 50 cents on the dollar once you earn your 86th dollar in the month. But if you are 21 and in full-time school, you can earn more than $1,700 more and still keep your full SSI. It depends.

With Social Security Disability Insurance (SSDI), you will continue to receive your full SSDI benefit until you begin earning consistently at or above the level Social Security has determined

IT ADDS UP: People with disabilities sometimes have particular expenses related to their disability, including physician and therapist visits, prescription drugs, over-the-counter medications, assistive technology, service animals, adapted vehicles, prostheses and similar expenses.

to indicate Substantial Gainful Activity. That level is $1,220 for 2019 if you are not blind and $2,040. Social Security has a series of steps to let you try out whether you can work steadily to earn at SGA-level. During some of the steps, you may be able to earn above the SGA level and still keep your full benefit. Once you've completed all the steps, your entire benefit goes away if you are still working at SGA level. That said, there are some things you can do to reduce the amount of income Social Security counts and applies towards that SGA threshold. So, it depends.

In this article, we are going to show you how to use Impairment Related Work Expenses (IRWE), Plans to Achieve Self-Support (PASS) and Achieving a Better Life Experience (ABLE) accounts to maximize the amount you can earn from working and the amount you can save and accumulate without affecting your SSI or SSDI benefits. IRWE and PASS are relevant to maintaining both SSI and SSDI as well as Medicaid to the extent that one's Medicaid eligibility is linked to one's SSI eligibility. ABLE is relevant to keeping SSI and Medicaid.

People with disabilities sometimes have particular expenses related to their disability. Such expenses might include the deductibles and co-pays on physician and therapist visits for treatment or maintenance, the co-pays on prescription drugs, the cost of over-the-counter medications, the cost of assistive technology, the cost of purchasing, training and maintaining a service animal, the cost of purchasing an adapted vehicle, the costs of buying and maintaining prostheses and similar expenses. If these expenses are for an item or service that is 1) required by the person's disability, 2) paid for out-of-pocket; i.e., not covered by any of the person's insurance and 3) necessary for the person to work, that item or service may be considered an Impairment Related Work Expense or IRWE. It is not necessary that the item or service be required ONLY for work. It may also be necessary for daily life.

> "If I do not have a disability and I opt to take an Uber rather than the public fixed-route bus, that is a convenience. But if I do have a disability that limits my mobility and the bus is not accessible for me, then the Uber fare becomes IRWE."

Some expenses incurred by people without disabilities for convenience may be incurred as a necessity for people with disabilities and thus may be considered IRWE. For example, if I do not have a disability and I opt to take an Uber rather than the public fixed-route bus, that is a convenience. But if I do have a disability that limits my mobility and the bus is not accessible for me, then the Uber fare becomes IRWE. If I do not have a disability but find noise-cancelling headphones help me concentrate in my open-plan office, that is just a preference. If I have a disability that impacts my focus and attention, then those noise-cancelling headphones may be an IRWE.

Social Security needs to approve each IRWE on claimant-by-claimant basis because what is IRWE for you may not be IRWE for me, depending on the characteristics and severity of our disabling conditions, the type of insurance coverage we have, the nature of our work and other distinctions. You are most likely to get your IRWE approved if you make a clear connection between the expense and your disability—either the disability under which you qualified for benefits or another condition diagnosed by a medical professional that also impacts your capacity to work. You must also explain clearly how you would not be able to work without the item or service. Finally, you must provide to the Social Security Administration a cost figure that is reasonable. Recurring monthly expenses will be approved for monthly deduction as long as the person is working, and the item or service remains required. One-time expenses are generally approved for deduction in the month paid; however, for large ticket items, the expense may be pro-rated for deduction over 12 months or over the terms of the payment plan, if any.

IRWE can have a significant impact on how much a person can earn and still maintain benefits. If I receive the full SSI benefit of $771/month (2019) and start a job in which I make $885/month, my SSI will decrease by $400 after taking into account the earned income exclusion. I will still be better off by working, because I will have $885 + $331 = $1,216 vs. the $771 I had on SSI alone. But, if I have IRWE of $500/month, then my SSI will decrease by only $150/month and I will have $885 + $621 = $1,506. If I receive SSDI of $2,000 and take a job in which I earn $1,500/month and I am not blind, I lose my entire SSDI check, and I actually end up worse off by working. But If I have $500 of IRWE, then my countable income is only $1,000 and, thus, below the SGA level and I keep my entire SSDI check. Now, I have $3,500/month in income.

"If you are a person with a disability, you can create a Plan to Achieve Self-Support and the income set aside to fulfill the plan will not be counted for purposes of SSI eligibility."

As a worker or a prospective worker with disability, you might realize that you need additional education or industry-specific training to start or advance a career. Perhaps you want to work in bookkeeping, horticulture, hospitality, interior design, IT, health care, music or manufacturing and realize that you will have a stronger resume with a certificate? Perhaps you want to complete your bachelors or master's degree in your previous or even new field. Perhaps your academic skills are sufficient, but you need to learn a new software system or otherwise upgrade your computer skills. Or perhaps you need to purchase additional assistive technology to move forward and upward with work. Perhaps you have decided your best route to work is as an entrepreneur. You have a good idea for a small business, but you need to buy equipment, set up a website and pay for a marketing coach. All of these scenarios pose a challenge because it might be hard to set aside income to pay the required expenses.

A Plan to Achieve Self-Support or PASS can address these challenges. If you are a person with a disability, you can create a PASS and the income set aside to fulfill the plan will not be counted for purposes of SSI eligibility. In addition, income set aside and left to accumulate for plan expense not yet incurred will not be counted as a resource for purposes of SSI eligibility. Your PASS must provide a road map to a specific work goal that will, once achieved, reduce your reliance on your SSI and SSDI cash benefits. The plan must have specific steps and a specific time frame. Each item and step required to fulfill the plan must have a definite and reasonable cost assigned to it. Here's an example. Suppose I currently work at the dollar store at the minimum wage of $8.25/hour. My goal is to work as a Heating, Ventilation, Air Conditioning or Refrigeration (HVAC) service technician, where my wages will start at $16.50/hour. To pursue this course, I need to obtain an HVAC service technician certification, which requires 33 credit hours at my local community college. Tuition is $140/credit hour, so my program will cost $4,620. Textbooks and course materials will cost $200. I detail this clearly in my PASS in writing, using form SSA-545-BK. I submit my PASS and it is approved by Social Security.

I work 30 hours per week at the dollar store, earning a gross monthly wage of $990/month. After my $85 earned income reduction, I have $905 remaining. My countable income is half of that or $453, which then reduces my monthly SSI benefit from $771 to $771 - $453 = $318. After creating my PASS, I begin to save $300/month towards my work goal. Contributions to my PASS are deducted from my countable income. Now, my reduction is only $153, so I receive $771 - $153 = $618/month of SSI.

Suppose, instead, that I worked before developing my disability. Now, I receive $1,000 in SSDI. Since SSDI is unearned income, which reduces my potential SSI dollar for dollar, I am not eligible to receive any SSI at all because my SSDI exceeds the maximum SSI payment. Prior to my disability, I worked as a sports instructor at the YMCA. My disability precludes the physicality of that kind of job, but my overall health has improved such that I can return to work. I want to retrain as an ophthalmic technician. The position requires an Associates of Science degree and 64 credits for a total cost of $8,960. Textbooks and course materials are another $200. As an ophthalmic technician, I would earn $40,000/year, well above the $1,220/month threshold of substantial gainful activity. I would go off my SSDI benefits with those earnings. I detail this clearly in my PASS in writing, using form SSA-545-BK. I submit my PASS and it is approved by Social Security.

Prior to creating my PASS, I was not eligible for SSI; however, now, I decide to set aside $400/month from my SSDI. My countable income is thus reduced from $1,000 – 20 (unearned income exclusion) = $960 to $560. I am now eligible for $771 – 560 = $211 in SSI. It is important to note that in both this and the prior example, money that I accumulate for the purpose of fulfilling my PASS does not count as a resource for SSI eligibility. The money set aside for my PASS must be clearly separated from my other funds.

The question of countable resources, as noted above, used to be more significant for SSI eligibility. SSI recipients remain limited to $2,000 of countable resources held in their own names. However, the relatively new Achieving a Better Life Experience (ABLE) accounts now provide a welcome exception to this rule. ABLE accounts may be opened by any person whose disability began before age 26 and who meets the Social Security definition of having a disability, whether or not they are receiving cash benefit. The person with a disability, who is the owner of the account, as well as any other party, can contribute up to $15,000 to the ABLE. If the person with a disability works, s/he can contribute up to an additional $12,000 from work earnings. Funds in the account grow tax deferred and the growth is not taxed if the funds are removed for Qualified Disability Expenses, a very broad definition. Funds can be invested and withdrawn easily, and the accounts have low management and investment fees.

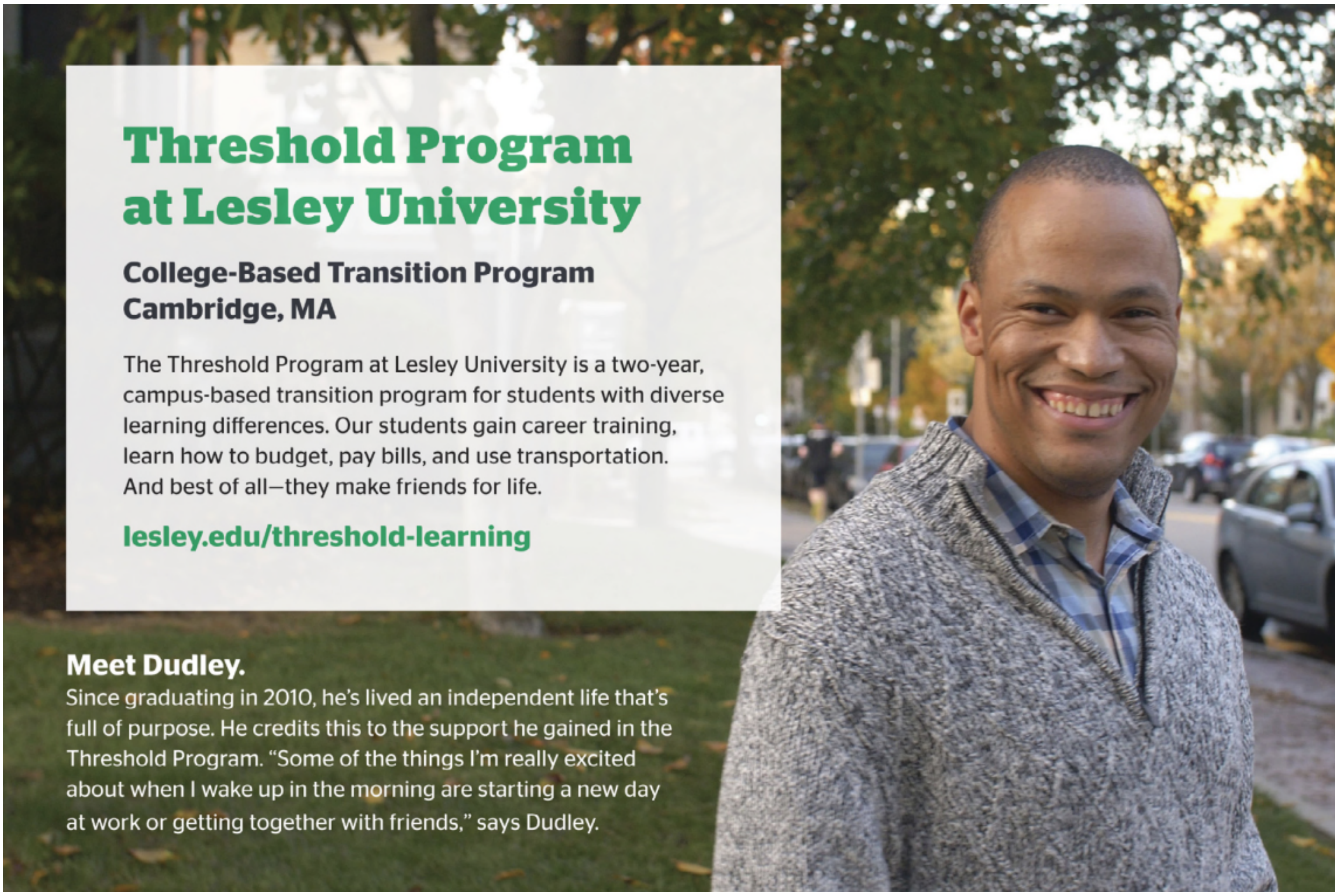
> "Using IRWE and PASS will allow you to earn more while still keeping your SSI and/or SSDI cash benefits. ABLE will allow you to save more while still keeping your SSI and Medicaid benefits."

The most important characteristic of these accounts, though, is that the balance will be disregarded by Social Security until it reaches $100,000. At that point, the person's SSI eligibility will be suspended but not revoked. If the account balance dips below $100,000, eligibility will resume. A person's Medicaid eligibility will remain until the account reaches $400,000. The accounts do have a payback feature in which funds remaining in the account at the owner's death may be claimed first by Medicaid; however, given the modest contribution levels and the newness of the accounts, this will not be a concern for some time to come.

Increasing your weekly exercise and swapping out the white flour and processed sugar in your diet for whole grains and fruit will probably allow you to eat more while still meeting your weight loss goals. Using IRWE and PASS will allow you to earn more while still keeping your SSI and/or SSDI cash benefits. ABLE will allow you to save more while still keeping your SSI and Medicaid benefits. As a person with a disability, you may face bigger hurdles to employment than the general population. Use IRWE, PASS and ABLE are flexible tools to help you meet the challenge.•

ABOUT THE AUTHOR:

Alexandra Baig has an MBA from the University of Michigan and her CERTIFIED FINANCIAL PLANNER™ designation, and is a member of the Academy of Special Needs Planners. Alexandra's first career was as a stock market analyst in Hong Kong and China. A search for a more meaningful life's work took her to L'Arche, an international, interfaith network of communities where people with and without intellectual and developmental disabilities share life. Her work at L'Arche introduced Alexandra to the financial planning challenges of people with physical, intellectual, developmental and behavioral disabilities and their families. In particular, she is well-versed in the government benefits available to people with special needs and the rules governing them. Her goal is to help people with disabilities and their families make the most of public and private money to live the life they chose.



TRANSITION PLANNING FOR THE DEAF STUDENT

J. FREEMAN KING, ED.D.

Transition planning is the process deaf students navigate as they move from a high school setting to further education, employment, and/or independent living. Quality transition planning is proactive and coordinated as it enables students and their parents to prepare for life after high school.

An effective transition program provides students with the tools and the confidence needed to assume responsibility for their educational, social, and employment decisions. Transition planning is essential for deaf students, who experience unique educational and life challenges as a result of their hearing loss, such as communication barriers, lack of effective accommodations, and intentional and unintentional discrimination.

There are several important transition questions that must be addressed by both the student and the parent:

- *What kinds of extracurricular experiences will provide the student opportunities to learn social and problem-solving skills?*
- *What kind of classes will prepare the student for postsecondary programs and/or employment?*
- *Should the student be employed while in high school?*
- *Will the student participate in general education classes or need more intense training to achieve postsecondary goals?*
- *What types of accommodations are needed in various employment opportunities?*

Transition planning is a team process that engages the student, their teachers, their parents, and other service providers. It is complex and presents a different scenario for each student. An effective transition plan is initiated as early as middle school and is articulated in an individual transition plan that works in concert with the student's individualized education plan (IEP). The transition team plans a course of action that includes the following:

- *Conducting appropriate assessments that identify the deaf student's strengths, needs, likes, and dislikes in areas such as academics, career, employment, and extracurricular/social activities.*
- *Identifying postsecondary goals that encompass employment, education/training, and/or independent living.*
- *Creating a course plan of action for classes needed to meet postsecondary and annual goals.*
- *Agreeing on annual high school goals that support the postsecondary goals, including opportunities to promote self-determination and self-advocacy skills.*

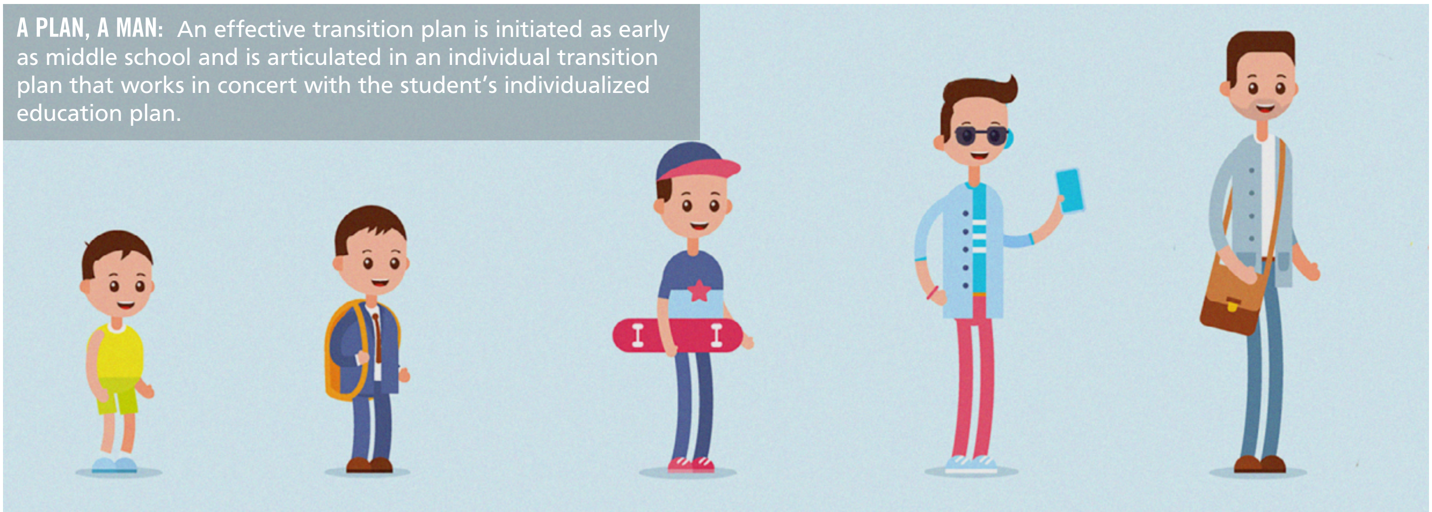
The design of the actual transition plan will pay particular attention to the following:

- *The plan should be student-focused.*
- *The plan should ensure that the student is involved and his/her contributions are incorporated.*
- *Parents should be actively involved in the transition plan as well as its process.*
- *The plan will utilize appropriate transition assessments that are normed on the deaf student and should be utilized to gather valuable information.*
- *The transition plan should include regular checks with the student about barriers encountered and accommodations used.*
- *The transition plan will include annual reviews and revisions; it should be flexible.*

It is imperative that the student be involved in the transition planning and process. When a student is involved in the identification and decision making of an activity, goal, or plan, he/she will have a greater stake in the outcome. For deaf students, whose ready access to incidental learning is limited, student involvement in transition planning is critical. Students need to learn what their strengths and needs are, understand how their hearing loss and/other disabilities might impact them in different settings, and explore what they want to do after they complete their high school education. Their opinions need to be taken into consideration to keep transition goals on target.

Though it is important that the student participates in the process and the implementation of transition skills, the role of the parents and other family members in transition planning should not be underestimated. The parents can contribute information that the school does not have about the student's life and support systems outside of school. When the parents and other members of the family understand the transition plan and its importance to the deaf student's success, they are more likely to be committed and contribute to the plan.

It is also important that the student and parents are aware that the federal government requires that schools address transition planning for deaf students starting at age 16. This requirement is part of the Individuals with Disabilities Education Act (IDEA), which also mandates that the student be invited to his/her annual transition planning meetings. There are other federal laws, often termed



A PLAN, A MAN: An effective transition plan is initiated as early as middle school and is articulated in an individual transition plan that works in concert with the student's individualized education plan.

Accessibility Laws, of which the student and the parent need to be aware when addressing the transition plan: Section 504 of the Rehabilitation Act of 1973; the Individual with Disabilities Education Act of 1975; and the Americans with Disabilities Act of 1990.

Section 504 of the Rehabilitation Act of 1973: This was the first civil rights disability law to be enacted in the United States. It prohibits discrimination of qualified individuals with disabilities by entities that receive federal financial assistance.

Individuals with Disabilities Education Act of 1975 (IDEA): This law insures that every child with a disability has access to a free and appropriate public education. This federal law governs all aspects of special education services to eligible children from birth to high school graduation or age 21.

Americans with Disabilities Act of 1990 (ADA): This is a federal civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including employment, education, transportation, and all public and private places that are open to the general public, regardless of whether or not they receive federal financial assistance.

It is imperative that the parent and the deaf student both feel they are empowered by the law to assure that the student's transition program/plan is appropriate and effective.

ABOUT THE AUTHOR:

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DO I LOOK FAT IN THIS DIAGNOSIS?

Due to our autism challenges, some of us are unaware of the stigma.

We may not notice society's condemnation of our extra pounds in similar fashion to how we often avoid the nonsense of gender expectation.

But even if nonverbal, we still need to be coerced into healthier habits, as our bodies develop the same as others, even if our minds don't.

BY MICHAEL JOHN CARLEY

As a collective, it would seem that people with autism have higher prevalence rates for obesity and being overweight. Is that true?

Though it's currently early fall, the subject makes me think of many Januaries, when after an over-abundance of holiday food/under-abundance of exercise, we tend to see added skin in the mirror, or feel relatively ill. For a few, the food hangover even feels like a spiritual hole; a void where our workout regimens or dietary discipline once lived.

I myself didn't exercise for two weeks one December, ate terribly, and as a result, felt awful after the winter break.

Over the past four years, Disability Scoop[1] has written about obesity's effect on spectrum children, as has Spectrum News[2] and WebMD.[3] The journal *Pediatrics* covered the topic in a 2015 study[4] (that found 33% of spectrum kids to be overweight, and 18% to be obese); and a year earlier, the National Institute of Health (NIH) had looked into multiple, international studies[5] that found roughly the same findings as the Pediatrics study. Additionally, NIH cited that *all* children's obesity rates have tripled over the last 20 years.

Now, the absence of adults in these studies is somewhat infuriating. But the data wouldn't differ that much if they studied our grownups because the social origins of obesity are primarily the same: a bad diet, lack of exercise, side effects of medications, sensory issues with food texture (we tend to love soft, mushy, fast food, and we can be picky about the good stuff), sleep issues, and an all-around pragmatic questioning of, if not the depression-induced, *"Why should I care how long I live when I don't like my life?"* at least the culturally-induced, *"Why should I care if I'm fat? Isn't it what's inside that counts?"*

Well, yes and yes (it *is* what's inside that counts). Yes, in the literal sense because if you eat crap, and the crap goes inside you, then you will feel like crap.

But yes, also on a figurative level, because privileged societies are notoriously bigoted when it comes to body types. We still watch Bravo shows, and read fashion magazines that demonize the "unskinny." We are fooled into thinking that "plus-sized" (I hate that term) models are accepted in the fashion world when they are not – they are tolerated (I hate that word). My 28 years in New York, a very body-conscious town, certainly showed me how cruel folks can be to those whose forms deviate from whatever the "shape du jour" is for that afternoon. And yet oddly enough, in progressive NY, L.A.,… etc., and in *direct contrast* to other forms of bigotry, body-shaming is more prevalent in more educated and wealthier communities. Usually, these tribes are the incubators for social progress; but in this one issue of body pluralism, big cities are surprisingly backwards.

We still, as a culture, haven't separated "health" from appearance. Ok, the super models aren't as deathbed anorexic as they once were, but we are still idealizing an image that is not usually healthy, and we are still labeling overweight (as opposed to obese) people unfairly as "unhealthy." Though no data exists, I would wager that the average "overweight" person has more energy, capacity for focus, and sex drive than the average skinny person – as many skinny folks are malnourished.

Even obese people (as defined by the CDC[6]) shouldn't be pigeon-holed, pitied, or judged into a negative light because they could be, yes, as lazy or suicidal as all get-out. But they could also be working their tails off to rectify things and adopt healthier habits. And we will not be able to decipher whether or not they are trying hard simply by their appearance.

Obesity will never be healthy. And the national epidemic that we now have – spectrum or not – is scary, and says nothing good about Americans as a people. But we too often assume character deficits are the cause of the obesity. Again, there could be medications that cause the problems, an inability to exercise caused by another disability or injury… etc.

Needless to say, there is also a major role here played by income. Lower-income folks do not have the money to afford the more expensive, organic versions of their daily foods; nor do they have the money for gym memberships, or the wherewithal to not be so overwhelmed that they can't find room in their day to exercise. And as our (already out of control) income discrepancy is expected to keep widening… it's not getting better.

Lower-income folks do not have the money to afford the more expensive, organic versions of their daily foods; nor do they have the money for gym memberships, or the wherewithal to not be so overwhelmed that they can't find room in their day to exercise.

It starts early, with arguably more inflexibility coming from spectrum kids about what they are willing to eat. The afore-mentioned sensory issues, in addition to taste, plays a huge role, as that a mushy food satisfies perhaps sensitive gums and teeth, as well as contains that pleasing taste; the broth of minimal nutrients mixed with teasing salts and sugars. And if there are other issues going on, then emotional dysregulation will intimidate parents from making the same necessary corrections to their child's diet as the parents of neurotypical children face.

Furthermore … it's no secret that I'm a big advocate for spectrum kids not being shut out of competitive sports.[7] But in my school consulting I have spent years and years having the same conversation with parents of overweight kids:

"He can't play anything. Look at how obese he is!"

"The risks of concussions are more real than anyone tells you. But football is also the only arena where a body type like your son's will be heralded, and celebrated – Not demonized. Wouldn't it be nice for him to feel great about his body, just for once?" (and for God's sake, isn't that the only nice thing we can say about football these days?)

Readers of my column also know that too often, I find my hometown of Green Bay, Wisconsin to be a surprisingly backwards incubator for bigotry and corruption themselves. But go figger: Green Bay has actually created an atmosphere wherein the negative stigma for larger body types… barely exists. Granted, they are proportionately "bigger" here in Wisconsin than in New York City, making for more of a majority viewpoint. And this phenomenon also doesn't negate the fact that the entire Midwest has a major health problem with obesity (and depression, and economic ineptitude, and racism, and poor education, and homophobia…). But the culture here celebrates the extra pounds, "owns" them – few would dare to body shame someone in Green Bay, and it is a surprisingly cool element about this place. This aura of protection for those at risk of ridicule couldn't really be characterized as a "movement," given that it is so unconscious. But there's still tremendous civil rights value to unconscious movements.

Also, our cultural perceptions change. In the late 1980s and 1990s, when thin was in, fashion models with near-fatal eating disorders were the pinnacle of sexuality, whereas today, celebrities like Jennifer Lopez and Kim Kardashian have gone to surgical lengths to make their butts bigger.

And what do we really know about food? In a span of 10 years, I've gone from drinking skim milk, to soy milk, to rice milk, to almond milk, and now coconut milk. We used to think pasta was the healthiest thing in the world, and that red meat was terrible. We used to think sugar only affected our teeth, and yet books like, *The Case Against Sugar*[8] now paint the dangers of this additive (and they make a convincing case) *as equal to cigarette smoke.* Reality TV shows about people losing tremendous amounts of weight? Sorry … the producers snuck them pills to cause drastic short-term weight-loss, and contestants immediately gained the weight back once the show was over.[9] Oh, and guess what… Calorie-counting? Turns out the whole calorie counting thing was a myth (weight loss is now all about processed food vs. real food).[10]

WHAT LIES BENEATH: Many people who are categorized as overweight are emotionally healthy about their bodies. The acceptance of fat, and the loving of fat (since it is a part of our body)… that's a good start. After that can come the courage it takes to want to be happy.

Due to our autism challenges, some of us are unaware of the stigma. We may not notice society's condemnation of our extra pounds in similar fashion to how we often avoid the nonsense of gender expectation. But even if nonverbal, we still need to be coerced into healthier habits, as our bodies develop the same as others, even if our minds don't. Unfortunately, parents often feel too overwhelmed to deal with the negative fallback ("meltdowns") of such a transition. But these parents need to understand that in addition to their children being in better moods because they feel better, that their efforts could result in restoring many extra years of their child's life. A failure to address this, dare I say it, in addition to being a sign that the parents need help, might also be a sign that they believe their child's life has less value than theirs.

And on the other end of the spectrum, those of us who have the cognitive or functional ability to decipher what others think of us… these spectrum brothers and sisters would do well to separate health, from body appearance; *and* to separate cultural pressure (which changes day by day) versus true biology. By all means, provide constructive criticism to those who have no desire to exercise or eat well. Tell them to love their autism (and yes, their fat – for even the skinniest need it to survive). Yet also tell them to kick depression's butt.

But to judge supposedly obese or overweight people by what they look like – in addition to the potential bigotry – invalidates not only their true health, but also the fact that, again, they may be doing everything they can to get healthier. Furthermore, why would obese people continue to try and get healthy, if supposedly healthy people won't give them a chance? If that's how healthy people behave, then who wants to be like healthy people?

When does the conversation about what's "emotionally healthy" finally get a word in?

My penance for my bad habits over that holiday break was to do "the Insanity workout" for the third time. Not the smartest workout for someone my age, no, but I didn't do such a difficult regimen because there's a roll where two of my abs used to be. It's because I've been healthy enough to know what being healthy feels like. It greatly affects my capacity for confidence and self-esteem. When it's there, it's awesome. And I wanted that back at its fullest. Knowing what this emotional health feels like also makes it easier for me to obtain it again. For others, it's like trying to describe a color they've never seen. If they have never truly loved themselves, what frame of reference do we think they have… to understand what loving yourself even means?

You math brains out there that are bored by all this self-esteem stuff? Think of it this way: if I exercise 30 minutes a day, 6 days per week, in the hopes of living 10 years more than someone who doesn't exercise, then I will have exercised for 156 hours (or 6.5 days) per year. If I do that over the course of 30 years then I will have exercised for 195 days, a little over half a year, to live those 10 extra years.

Many people who are categorized as overweight are emotionally healthy about their bodies. Many supermodels are not. And Father Time is going to get us all to a physically hideous place someday anyway. The acceptance of fat, and the loving of fat (since it is a part of our body)… that's a good start. After that can come the courage it takes to want to be happy.

And this is where those seemingly perfect folks at the gym are unfortunately right. We *do* have to strive to feel good. Because aside from consciously accepting a much shorter, or a sadder life on earth for ourselves? We really have no other option.•

ABOUT THE AUTHOR:

Michael John Carley is the Founder of GRASP, a school consultant, and the author of ***Asperger's From the Inside-Out***[11] (Penguin/Perigee 2008), ***Unemployed on the Autism Spectrum,***[12] (Jessica Kingsley Publishers 2016), the upcoming ***Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum…and Beyond!,*** and the column, "Autism Without Fear," which for four years ran with the Huffington Post but is soon to move to Neurodiversity Press. Dozens of past "Autism Without Fear" columns can be found by going to www.michaeljohncarley.com/index.php/articles.htm | And for more information on Michael John, or to subscribe to his updates, you can go to www.michaeljohncarley.com

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***EP MAGAZINE:* THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS**

DENO'S STORY

SPREADING THE WORD ON GROWTH AND ENDOCRINE DISORDERS

BY MARY ANDREWS.

I remember walking into the shoe store and the look of shock on the salesman's face. My son wore his shoes out before he grew out of them, again. At that time, a specific manufacturer guaranteed a new pair of shoes if they wore out before the child grew out of them. It would have been nice if there were a manufacturer of boys clothing that did the same!

My son, Deno, did not outgrow his clothing or shoes for several years. Any hand-me-downs from relatives with younger children were always too big on him. I did have concerns about his growth but was told that he will grow in his own time and not to worry.

Deno's baby sister, Dianne, was born exactly two years after her brother. My first clue and concern about his growth was when Dianne, almost one year old at the time, began walking. She did not appear that much smaller than Deno. Compared to cousins his age he appeared to be at least two years younger. But at each doctors visit I continued to express my concerns. His measurements were not plotted on a growth chart therefore his growth failure was not documented.

At the end of the second year, Deno had in fact grown almost three inches. He was nearly 5'5". Then I was told that it was Deno's decision if he wanted to go on for one more year… That was difficult for me. The question was asked. I was to my son's back, as not to give him any signs. His response caused tears in my eyes as I heard him say, "Hey Doc, what's one more year for the rest of my life?"

Several attempts were made to convince the doctor that something was wrong. Now at the age of four and his baby sister two, they stood the same height. Everyone complimented me on the cute pair of "twins" I had. It was almost embarrassing to tell them he was two years older for they would gasp in front of Deno and comment how small he was. It took two more years before I was finally referred to a pediatric endocrinologist. I couldn't even pronounce this specialty doctor let alone know how to spell it! At that time Dianne stood over three inches taller than Deno.

VISIT TO THE PEDIATRIC ENDOCRINOLOGIST

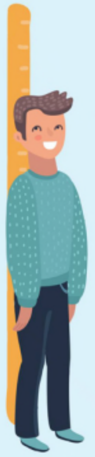
Our first visit to the pediatric endocrinologist was overwhelming, for the doctor was using terminology I had never heard before. I had no background in medicine in any way and I was so confused when he was talking about the pituitary gland, the tests they needed to perform, the percentiles on the growth chart and much more. Plus, it is so disheartening to know that something was evidently wrong, for he was not even on the growth chart. One of the first tests they wanted to perform was a "bone age" and it was not until I found out it was a simple x-ray of the hand and wrist did I become a little more relaxed. The first blood draw scared me more than Deno for it is so hard to see your child go through these types of tests.

Being I am going back many years ago, the tests performed and the results took much longer than today's visits for growth failure. Now, at the age of almost seven, some results showed Deno as thyroid deficient. He was started on thyroid medication immediately and did start to grow slightly, but then we found out that his growth was not substantial enough and there had to be another underlying condition for his lack of growth. So back we went for more tests.

At the conclusion of the next visit to the endocrinologist I was in tears. Thyroid deficiency was something I could understand and after a few trips to the library (pre-internet years) I was feeling more comfortable with his diagnosis of thyroid deficiency. Now, realizing there was more going on, the terminology thrown at me was more frightening than I could ever imagine. They wanted to test Deno for Growth Hormone Deficiency (GHD). What in the world was Growth Hormone? What was this stimulation test they were talking about?

I ran back to the library. I tried desperately to find information on GHD and could find nothing. I called a friend who had access to a medical library and she was able to get some articles for me. I was not able to get through one paragraph and understand what they were talking about. All the medical terminology was impossible to comprehend. I had no one to talk to, no one that understood my concerns and I felt so alone in the world. What was wrong with my son? Why did this have to happen to him? What could I do to better understand this whole process of growth failure? Did I do something wrong that caused this?

Total shock, you can even call it near heart failure, when I was told that I was going to be trained to give the growth hormone "injections." No way. I was not going to stick a needle in my kid three times a week!



The stimulation test took several hours. The test measures Deno's output of Growth Hormone to determine if he has sufficient growth hormone in his system to grow normally. Unfortunately, Deno's level of Growth Hormone was extremely low. Now they had their diagnosis and we finally knew why Deno wasn't growing.

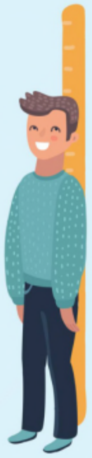
Hypopituitary Dwarfism was his diagnosis. You can imagine my terrified look at the doctors when they gave me the medical diagnosis. He was not a dwarf. Yes, he was small, but he did not have the characteristics of a dwarf, so why were they calling his disorder Hypopituitary Dwarfism? That's what it is called was the answer I was given. So now back to the library to understand as much as I could. But do you think I found anything on Hypopituitary Dwarfism? You guessed it… literally nothing! Back to my friend for more articles from the medical library.

On the next visit back to the pediatric endocrinologist, after diagnosis, they told me Deno would qualify for Growth Hormone therapy. I guess I was excited, for there was something they could do for him, but I was told that there are no guarantees that he will grow. They told me they were ordering the drug (GH) and that I should return when it arrives and they will teach me how to administer the drug. That made no sense to me so I asked what educational process I needed to administer GH. I assumed it was a pill. Total shock, you can even call it near heart failure, when I was advised that I was going to be trained to give the GH "injections". No way. I was not going to stick a needle in my kid three times a week! I left a nervous wreck. I did not know what to do. There had to be a solution but the doctor's office told me that it would be impossible for me to return three times per week for someone there to give the injection.

The wheels were turning, almost worn out, as I tried to assess the whole situation. I had some great neighbors that were both nurses and I knew I could count on them to help me. I decided not to worry any longer for I would figure it out every other day.

Nervous as ever I went to the appointment I was dreading all along. When I arrived, they brought the GH into the room with other vials, syringes, alcohol swabs, and some written direction. The nurse told me she would have me prepare an injection with sterilized water and she would teach me how to give the injection. I told her to just show me and I could do it. I tried to act very confident so she would believe me. Some how, I'll never know how, she believed me and simply showed me how to do it. Little did I know until many, many years later that I was her first parent of a child to take GH and she admitted she should have never let me leave without the training.

I took the bundle of GH and all that went with the injection process and went home. That night was to be the first injection. Deno did not seem to be bothered and was preparing for it like a champ. After everything was on the kitchen counter and ready to mix, I called my neighbor and asked her to come over and help me. She came right over but told me that I had to do this on my own for she would not always be available when I needed her. I was not happy and called the other neighbor. I guess to no surprise I got the same response. Now I wish I had paid better attention to the directions the nurse showed me. She did give me her home phone number in case I had any questions but I was too embarrassed to call her. My husband was in the kitchen with me when I sat to read the directions again. I mixed the vial with the sterile water and prepared the syringe. Mind you this was back in late 1978 and the syringe was much, much larger than what they use today. Instead of a sub Q injection (under the skin) it used to be muscular injections, deep into the muscle.



Deno was measured with a stadiometer. I waited patiently in the exam room. When they came back in the room the doctor told me that Deno had grown almost 1 inch. After several years he was growing!

I called Deno and he stood there in front of me like a champ. I knew this type of injection was not easy and I knew it had to hurt, but he was a trooper. We were told to rotate injections between thighs and arms and Deno wanted the first to be in his arm. I was trembling. My hand was shaking so bad I did not know how I would accomplish this injection. All I wanted to do was burst into tears but I didn't want my son to see me so scared. I tried hard to remember some comments by the nurse regarding the "art" of giving injections. If this was art, I knew that ability in me was nowhere to be found! I did remember the words "pinch the skin and jab quickly". So I did. I jabbed so quickly that the needle went in and came right back out. Deno looked up at me with such a sweet innocent smile and said, "See, it wasn't that bad." I ran into the bathroom. I did not want Deno to see me crying. I was still shaking and so nervous. What was I supposed to do now that I messed up so severely?

Let me explain a little about Jim, my husband, for he enters the situation now with much enthusiasm. Jim is a hard worker, a great husband and a great father. His life is always wrapped around his family. Due to his many hours of work each day I was more involved in the day-to-day decisions of the children and was more involved in the education process of Deno's growth disorder. Even though we would discuss what I had learned, or the news from our latest visit to the endocrinologist, he always stood behind the decisions I made for Deno and supported all the decisions—except one. Injections! Not taking them, but giving them. I asked Jim to consider doing this for me. His quick, thoughtless response was, "Fathers work to support their families and Mothers learn to give injections when needed." That was the worst comment he could have made to me at that time. He was, plain and simple, more scared than I was but didn't want to admit it.

So while I'm still crying in the bathroom, Jim enters. He looks at me with a challenging face. He tells me to "grow up" and get out there and complete the injection. I explained to Deno that the injection did not go right and the precious kid was so willing to do it again! I only wish I was as willing as he was. I prepared another syringe and to make a long story short I finally did it. It was devastating for me and what made me feel even worse was that Deno took it all better than I did.

That whole first three months were brutal. I could not get over all the anxiety every time I had to give an injection. We had a follow-up appointment three months after our first injection and I kept thinking that I cannot possibly continue like this for several years. But our next visit to the endocrinologist proved to be a major turning point in not only my attitude toward injections, but the future of my son.

Deno was measured with a stadiometer. This is an accurate measuring device used by growth specialists. I waited patiently in the exam room while they measured him. It seemed like an eternity. When they came back in the room the doctor told me that Deno had grown almost 1 inch. I cannot tell you what that meant for me and even more for Deno. After several years he was growing! I asked them to measure him one more time to make sure, but they told me they checked it three times and it was true. The smile on Deno's face was worth a million dollars to me. He so desperately wanted to grow and it was finally happening.

Our children's growth is a blessing. We take advantage of so much that sometimes we do not realize the important of so many things around us. Deno's childhood was not considered normal. We did everything we could to make it as normal as ever, but you would be surprised how cruel children and adults alike can be. I've learned more than I ever expected from Deno and credit my accomplishments from the learning curve I experienced during his growing years.

Imagine going to the grocery store, or any other store, and trying to ignore people for you knew what would happen if you didn't. One time I was at the grocery store with Deno. I always let my kids pick out their cereal for the week. Deno stood next to me in the aisle filled with cereals stacked up very high on the shelf. As he stared at the variety, he then looked at me and said, "I really don't know which one I would prefer this week." Standing the size of a four year old, but actually seven at the time, and with a great vocabulary for a youngster, this mother next to him immediately took a double take at Deno and said to me, "Boy is he smart!" I simple looked at her, said, "I know" and took Deno's hand and went around to the next aisle. Deno and I were both laughing and Deno said, "Thanks, Mom." Realistically we both knew that if I told that other mother that he was seven years old the next comment out of her mouth would have been how small he was. We experienced that so much that it was easier for us to walk away.

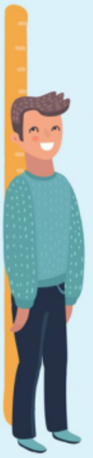
A MEASURE OF HAPPINESS: Deno *(right)* and sister Dianne; "Our children's growth is a blessing. Deno's childhood was not considered normal. I've learned more than I ever expected from Deno and credit my accomplishments from the learning curve I experienced during his growing years."

School was difficult, and as we all know kids can be verbally abusive. We had good days and we had bad days. It was like a double education in learning how to handle so many difficult situations. I spent each new year explaining to his teachers about his growth disorder and how difficult it was to treat him by his age and not his size. Of course, until reality hit me hard, I was guilty of doing that myself.

KINDERGARTEN

I remember Deno's first day in kindergarten. There was a separate entrance for the kindergarteners. We both so proudly walked up to the door together and when the teacher greeted us at the door she immediately put her hand on my shoulder and explained to me that pre-school was across the street and I was in the wrong location. I guess I wasn't ready for that and immediately, with attitude, told her he was five. Her answer was, "You're kidding!"

I was spoiling Deno and did not realize it. I quickly realized that Deno was extremely smart and now using his short stature for his benefit. Was he in for a surprise when he got home from school that day!



Deno became the class toy. He was like the baby in the group and all the other kids would help him with his coat, lift him up to the drinking fountain, reach up in his locker for him and more. Deno kind of thought this was cute for everyone was paying attention to him.

It would not be until almost two years later that all the testing would begin, to determine why Deno wasn't growing, so the first and second grade years remained very difficult for him. It was fun getting attention in kindergarten, but other situations now were not so enlightening. On the playground he could not keep up with the other kids so they most often ignored him and didn't allow him to participate. These were days he would come home crying because no one would play with him.

I was spoiling Deno and did not realize it. My family saw it and often made mention of the fact that I must learn to let him do things on his own. I did not appreciate their input for I felt they did not realize what Deno was going through and had no compassion for his daily problems. During the course of several years, situations would arise that made me see the light. I was spoiling him and allowing him to get away with much, and turning the tables was not an easy task.

One of these altering situations was when I was approached by one of his teachers while I was volunteering time at the school. She very sympathetically kept telling me that she felt sorry for Deno and me. I knew she was going to talk about his stature but I was going to force her to say it. Instead she commented on his hands. That confused me for I did not know what she was talking about. She kept telling me, "You know," but I had no idea. Finally, she told me that each and every day when she collects homework Deno only turns in half of his homework. When questioned why, Deno would look sadly down at his hands and respond, "My little hands got so tired that I could only finish half of my homework." And she believed him! I had to laugh at her for she actually thought that the size of his hands for his age could prevent Deno from completing all of his homework. I quickly realized that Deno was extremely smart and now using his short stature for his benefit. Was he in for a surprise when he got home from school that day! The one comment back from Deno is one I need to share with you. He told me, "If they were dumb enough to fall for it, I was smart enough to pull it off!"

Gymnastics was probably one of the most difficult times for Deno. One day when he came home crying and explained to me what happened in gym class that day, I lost my cool and took Deno and went immediately back to the school. Unfortunate for the gym teacher, for he was still in the building. That day the students were crossing the stall bars and Deno, in front of the whole class, was told to go sit in the corner that he was too small to do that. Not only did he insult him, but punished him for being small by sending him to the corner. I explained to the teacher what he had done, though he

PHOTO COURTESY MARY ANDREWS

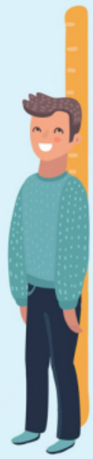
never saw it that way. I told him Deno just wanted to be like the other kids and do what they do, even though it may be more difficult for him. No child's feet touch the ground, crossing the stall bars so why should this be any different for Deno. The challenge was completed the next day. Even though Deno did not make it all the way across, he was proud to show his classmates that he can do things they do.

CATCHING UP SOMEWHAT

The years went by. Deno continued to grow. I know he was catching up somewhat, but the process seemed slow. Deno's attitude was very positive for he knew he was still growing. Our beginning years on growth hormone were from the National Pituitary Agency. The hormone was extracted from cadavers and purified. Because there was such a limited supply, only the worst case scenarios were approved for therapy. Deno's original diagnosis was never to see four feet tall, based upon his rate of growth and amount of growth hormone his body was producing. We were one of the approved cases but that did not mean that shortages wouldn't stop our supply every now and then. I remember the first three to four months we had to go without growth hormone. It is so devastating to see your child finally growing well only to be cut off and see no growth for a few months. We found some European sources for growth hormone and, on several occasions, we purchased the hormone from overseas so we did not have to stop. This was costly and you had to pay cash up front. But we did what we had to do.

There was talk about synthetic growth hormone in the future. This would enable any child in need to have the drug. I heard about "Genentech", the pioneers in Research and tried to keep abreast of what was going on. In the meantime, Deno continued to grow but was also entering puberty. Little did I know, at the time, what an important role puberty played in his growing years. It was like the educational process would never end.

On our next visit to the endocrinologist I was thrown for a loop. He explained to me that Deno was well into puberty and that his bones would fuse in the very near future. At the time Deno stood 4' 11" tall. He spoke about discontinuing his growth hormone treatment for they felt he had little growth left. I cannot tell you how heartbreaking this news was to Deno and me. I was on the verge of tears and rage combined. We'd had come so far. He was 11 inches taller than they ever expected but I could not imagine him only being 4' 11" for the rest of his life. My anger and gut instinct took over immediately. I asked where I could go and what I could do to help my son growth taller. There were no answers. I asked again and again and was told that I was being unrealistic and I had to face the fact that Deno had reached his adult height and I had to learn to live with those results. I just wouldn't accept their words and I became further agitated. The second endocrinologist on Deno's case entered when he heard our argument. He confirmed that there was nothing more we could do. I stood up, blocked the doorway, and told them they were not leaving the room until they could tell me where to go or what to do.



To delay his puberty Deno was given a drug to suppress sex hormones. This required daily injections, but if this could delay his bones from fusing, we could ultimately get another year or two of growth.

I was told I was unrealistic and could not accept the inevitable. These words meant nothing to me. All I wanted to hear was what I could do for my child. And after 20 minutes, which sparked my anger even more, I was told to call this endocrinologist from another state, which may have a program starting to delay puberty and continue growth hormone. I could not believe what I was hearing. I had an alternative. Yet they were willing to let me walk away without ever mentioning this possibility. I was outraged at this point.

DELAYING PUBERTY

I called this new endocrinologist immediately upon arriving at home. I left a message and was surprised when I received a call back within an hour. My anger was my new force of action. The endocrinologists told me that Deno appeared to be very qualified for this new research. He also stated that the protocol was not set as yet but we had very little time to waste. We made plans to fly out a few days later to meet with this doctor and discuss Deno's participation.

The doctor had reviewed Deno's file and determined that he would qualify. I was also told that Deno needed to switch to the new synthetic growth hormone, which had not been approved as yet by the FDA, but was part of the study protocol. I had been trying my hardest to keep up with Genentech's research and asked the doctor for his opinion as well. When he told me he would put his child on it, that he felt it was a safe product, I decided to move ahead. I believe Deno was one of the first, if not the first, to participate in this research study.

To delay his puberty Deno was given a drug to suppress sex hormones, trying to delay his puberty, which would delay his bones from fusing. This required a daily injection and a daily injection of growth hormone. If this could delay his bones from fusing, we could ultimately get another year or two of growth. No one had any idea of how these results would turn out. Sometimes I would lay in bed at night asking myself what I was doing. Was it the right thing? Will this work for him? Yet, as some time passed, I noticed that Deno's underarm hair was diminishing, his darkened shadow of a mustache was now lighter and it appeared that some of the hair on his legs was not as coarse as before. Could this be working? Could we get another inch or two for Deno?

We made about three visits the first year, traveling to Virginia from Chicago. It appeared the therapy was working but you never knew from day-to-day when things would change. Deno grew about another 2.5 inches since we delayed puberty. This was great news as Deno now stood over five feet. I prayed this would continue for him and maybe get another two inches in the following year.

At the end of the second year, Deno had in fact grown almost three inches. He was nearly 5'5". Then I was told that it was

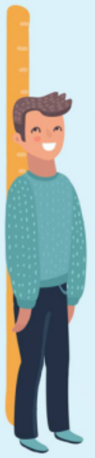
Deno's decision if he wanted to go on for one more year. I believe the protocol was for two years, but they were willing to extend it further. I had no say so in this. That was difficult for me. The question was asked. I was to my son's back, as not to give him any signs. His response caused tears in my eyes as I heard him say, "Hey Doc, what's one more year for the rest of my life?" At the end of the third year, Deno stood 5'6 ¾ ". We say 5' 7" when anyone asks, a far cry from 4' 11".

Was the battle worth it? You bet it was.

In between these growing years I was fortunate to meet some other families of children with growth disorders. By most part it was my doctor introducing me to someone or giving someone my name and number.

End result of meeting others lead to the formation of The MAGIC Foundation (Major Aspects of Growth in Children). We all suffered the lack of networking with others, educational materials regarding our children's disorders, and just knowing there were others out there like us. Even though I was a stay-at-home mom, I was enthused about starting a foundation that could provide others what so many of us missed out on. The corporate and business worlds were new to me, especially when I needed to fill out the forms for tax-exemption. I thought learning about growth disorders was a tough job. The IRS met their match when I walked into their office for help. They tried desperately to laugh me right back out the door, but I would not accept that offer. In less than 6 months MAGIC was a tax-exempt, non-profit corporation and ready to provide support.

> In April 1999, Deno married his high school sweetheart, Allison. All the years of injections, doctors appointments, worry, and anticipation were going through my head as I watched him as happy as ever.



WE WERE OFFICIAL

I knew nothing about support groups, tax forms, registration forms, state forms and so on, that were all an integral part of running a foundation. I had no idea how to run computers, set up databases, spreadsheets, financial records, etc. I can honestly say I was scared but I wanted to do this for others so badly that I kept telling myself, "If someone else can do it so can I." I set up an office in one of my bedrooms. My husband provided funds for a computer and a toll-free number. Our first brochure on Growth Hormone Deficiency made us feel so "official". We may have only had 15 families in our database, but we were official. How we would grow was a concern to me but quickly it began to happen. Over the years we grew to thousands in our database, covered eight to 10 different types of growth disorders, had a national networking system in place and had some money in the bank to expand our support services.

The next few years brought about much more normalcy than our family was used to. No more doctors visits, no more injections, no more wondering about growth. I was busy with MAGIC, but how different to listen to others going through similar situations and being able to tell them that I understood and it would be okay.

In April, 1999, I sat in church, with tears of joy, as I watched Deno marry his high school sweetheart, Allison. All the years of injections, doctors appointments, worry, anticipation and more were going through my head as I watched him as happy as ever. I knew I had taken the right steps to give his life some normalcy and happiness.

It was three years later that the tears of happiness struck again. Deno called and told us they were coming over to BBQ and not to prepare anything. His wife's parents came over as well and I cannot tell you the joy that hit us all when they announced we were going to be grandparents. Our precious Sophia was born in March of 2001, a perfectly happy and healthy baby. And, in July of 2006, our second grandchild, James, from Deno and Allison was born.

Let's backtrack several years from 2006 for the story was not totally complete. After Deno completed his growth hormone therapy, we did begin to see changes in him during the next couple of years. He started to gain weight and sleeping many more hours than usual. He appeared to be lethargic at times. I was following many articles about adult GHD and all the research they were conducting. I continued my aggressive attempts for Deno to read up on adult GHD, but he was not interested. After about 30 pounds of weight gain, sleeping about 12-14 hours a day and feeling very sluggish, he finally told me he was going back to the endocrinologist to find out about this adult GHD. He was retested and his growth hormone levels were extremely low. He began adult replacement therapy soon after and the changes were amazing! Needless to say, MAGIC now added adult GHD to our support services as we realized how many adults affected had no where to go as well.

Deno has provided much support to many of our families in MAGIC. He participates in our Annual National Convention each year and works with the children and parents. He has become a mentor for many of the kids.

I often wonder what my life would be like today if Deno were not affected with GHD. I was this typical stay-at-home mother and how life takes its course is quite interesting. I am looking forward to retirement in a few more years and wonder if I can actually walk away from these many years of "growth." I will try, but I do not see myself staying too far away. In fact, I can see the staff at MAGIC telling me to go home when I plan to visit (probably every day)! •

ABOUT THE AUTHOR:

Mary Andrews is the parent of a son, Deno, now an adult, who was diagnosed with Growth Hormone Deficiency (GHD) when he was a child. Due to her son's growth failure and difficult problems with information many years ago, Mary co-founded the MAGIC Foundation, based in Warrenville, IL, which is today the largest non-profit for children with growth and endocrine disorders. The organization is more concerned about spreading the word on growth, as growth failure is a major sign of overall health in children. Visit: www.magicfoundation.org

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BOOK EXCERPT

> **"She taught me so much, and not in that stupid, goofy way that people like to say. She really did help me learn about life. For one thing, she brought me to this great profession that I love. I get to meet so many awesome people because of her."**

After Elizabeth's Passing

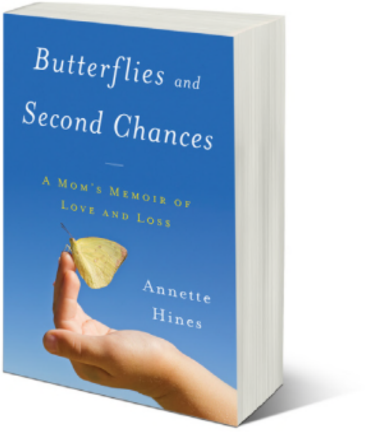
BY ANNETTE HINES

My daughter Elizabeth was the love of my life.

I know most people say their husband or their wife is the love of their life. But for me, I know it was her. Elizabeth just totally got me, and I got her. We spent a lot of time alone together, she and I. She was a good daughter. Even though she was so disabled, she was incredibly powerful in her way, and so good to me—and good for me.

She taught me so much, and not in that stupid, goofy way that people like to say. She really did help me learn about life. For one thing, she brought me to this great profession that I love. I get to meet so many awesome people because of her.

After Elizabeth passed, after the parade of people in our house, suddenly everybody was gone. The house was empty. A crew came and took away all her medical equipment. They removed her hospital bed, her medicines, everything. It was weird. Then I had to go to the funeral home and pick out a casket. I couldn't even think. I don't really remember much about it. It felt so surreal: what am I doing here, picking out a coffin, what am I even supposed to be asking for?



Title: **Butterflies and Second Chances: A Mom's Memoir of Love and Loss**

Author: **Annette Hines**

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All in all, it felt like the longest week of my life. We buried her on Friday, four days after she passed. It was raining outside, and I remember waking up that morning and thinking that I just wanted it to rain forever. I never wanted the sun to shine again. It felt right somehow, appropriate, that it was so cold out. It was the kind of November cold that just sits in your bones and makes you hurt, you know?

When we buried her, I thought I was ready. I was so full of myself thinking about how smart I was that I had made all these preparations and how I was going to be ready when the time came. I wasn't ready. I'm still not ready.

In the months after Elizabeth died, in fact for a whole year after, I was like a dead person, just walking around like a zombie. I still did my job; I connected with people. But it was all a charade. I struggled every morning just to get out of bed and go to work. I remember spending a lot of time that winter lying on my bed, doing nothing, just staring at the ceiling. Mark, my husband, took up the slack in terms of keeping the household running, getting Caroline, my other daughter, back and forth from school, calling in laundry service, having meals delivered. He was amazing. Me, I just couldn't get up. It was like my arms and legs and head were all so heavy, weighing me down. It took so much energy just to lift myself up out of bed, get my clothes on, and get out the door.

People had stopped visiting. For them, it was all over. For me, it was still such a difficult time. I couldn't think. Grief is funny that way, how it hits you. It's not always about the crying. It's not like you're in the same excruciating pain and agony that you were. But the grief is still there, it's deep, and it impacts you in other ways: it interferes with your memory, your ability to think and process information.

Grief comes like the ocean: it crashes over you like waves, then retreats for a little while, then comes back again. In the same way that the waves reshape the shoreline, my grief would slowly reshape my life. It's a very gradual transition, just like with the seascape, but very powerful. It is the process of becoming something else.

At some point, almost a year after Elizabeth's death, I was able to get my footing again. The sand had come back and the tide had gone out. The waves weren't as strong. Whereas earlier, I felt like I was drowning, now the ocean was calm and I could catch my breath. I started to think clearly again, and to try to rediscover who I was in life and why I was doing what I was doing.

But then I started to question everything about myself. If I wasn't

IMAGE COURTESY ERIN MACDONALD-BIRNBAUM

PRECIOUS MOMENTS: Sister Caroline with Elizabeth. "If I wasn't Elizabeth's mom anymore, who was I? The relationship had defined me for so long, almost my entire life. My whole identity as an adult was being Elizabeth's mother. Without it, I was lost."

Elizabeth's mom anymore, who was I? The relationship had defined me for so long, almost my entire life. I had her right after I graduated from law school. It had been school, school, school, school, school, married, baby. My whole identity as an adult was being Elizabeth's mother. Without it, I was lost. I started to perform a kind of inventory of self. Yes, I was an attorney, but did I still want to do that kind of work? Did I want to get another job instead? Did I want to shut my practice down?

I was also a wife. Did I want to stay married to Mark? I loved him, but part of me wanted to just sell everything, shed all the trapping of my previous life, and move away with Caroline. I know how harsh that sounds, and I'm certainly glad I didn't do that, didn't act on those impulses. But at the time, I just didn't have anything left. As devoted as Mark had been to me, I didn't think I had it in me to love him the way he loved me. I was struggling just to love Caroline. It's awful, but it's the truth. I was struggling to feel anything at that time.

My family—my mom, my sister—were there for me during this time, but they also kept a distance. Everyone did. I get it now: it's just too painful. As much as people say they want to help, the reality of losing a child is just so devastating and traumatic that it's too much to engage with. It's a psychological hurdle and most people can't make that leap. Unless they've been there themselves. I had known several people in my life who'd lost their children before me. I had been to their funerals. The beautiful thing is that every single one of those moms came to Elizabeth's wake and funeral. They all showed up for me, because they knew. They'd been through it too. But they were the exception. The natural instinct is to turn away, and that's what a lot of people did.

I was surprised at the number of friends, or people I had considered friends, who didn't reach out after Elizabeth passed. They were there for me during her active dying phase. And then right after, people came for a while to pay their respects. But then it was all over so quickly. Everybody just went on with their lives. I couldn't understand it. Was I also supposed to move on so quickly? How do people do that? I couldn't wrap my head around living without Elizabeth in my world.

When we had a luncheon at a local restaurant on the Friday morning after she died, the place was packed with friends. But strangely, I don't remember who exactly was there. Many of them didn't stay in my world for long after that. There were lots of cards and gifts. People sent these strange things to put out in my yard, ornaments to hang on the trees, little poems and angels and wind chimes.

I smiled and thanked everyone who gave me those gifts, but I didn't want them. I put them all in a box, and they're still sitting in that box. I haven't opened it since, but maybe one day, it will be time for me to pull them out. Back then, I wasn't ready. I did what I had to do to put up a brave face and keep up with appearances. But it would still be many years until true healing came.

PHOTO COURTESY LIONCREST PUBLISHING

It wasn't until the spring of 2015, the second spring after Elizabeth passed, that I started to come alive again. What changed? The turning point was when I attended a grief group—put on by Children's Hospital and the Dana Farber Cancer Institute—for parents who had lost their children through illness. The team at Children's had been trying to check in with me, calling and emailing, for a full year. But I just wasn't ready to talk or engage. I never answered, but to their credit, they kept trying. Then, one day, they sent me a note about the grief group.

Something about this invite struck a chord with me. I had almost tried something similar in the past, a group that the hospice had sent me to. But when I had gotten there, I couldn't do it. I had stopped and turned around—partly because I was terrified, but also because I realized I didn't want to hear about kids who had died from suicides and car accidents and the like. Those are terrible tragedies, of course, and I feel for the families, but I don't totally relate. They are a different kind of loss. It took me a while to figure this out: all loss is not the same.

Healing doesn't come in a linear fashion. Rather, it shows up in patches, like puffs of smoke. You catch a piece of it and start to feel whole again, but then it evaporates. There are starts and stops.

Also, at that point I was still just pissed off. Back then, the hospice group had given me a little pamphlet to read, and it was just crap. I wasn't in the right state of mind to hear that kind of stuff. And there was a certain value in my feeling pissed-off. It made me happy in a way. It was a step in the right direction. At least when I was pissed off, I wasn't numb. But when the invitation to the new grief group arrived, it was the right circumstances and the right time. Don't get me wrong: I was still pissed, and I was definitely the angriest person in the group. I had the roughest edges. But the fact that the other parents had experienced the same kind of loss as me made a big difference. Those parents really touched me.

Not only that, but I got to reunite with some of the amazing hospital personnel who I had lost touch with: my social worker and my nurse practitioner. It felt good. Everyone else who had been part of my world—the network who used to help me take care of Elizabeth—was now gone, all the teachers, all the nurses. I had no more Perkins people, no more healthcare people. Everything was just over. Done. So to see the social worker and nurse practitioner felt like a glass of water in the desert. They were almost the only ones left who were still part of my connection with Elizabeth.

But of course, there was also Mark. He came with me to the grief group and was able to listen, but it was also the first time he was able to talk and be heard. Because he was the newcomer to our situation and the Best Supporting Actor, he never felt like he was able to claim the tragedy for himself. Finally, he was about to talk about it in that group, a full year and a half after Elizabeth died.

I never knew how he felt. Shame on me: I never asked him how he was doing. And even in that group, he talked maybe 20% of the time that I talked. But I got to have a little window into how he felt, and particularly how hard it had been for him to see me so hurt and crushed by life. That group was so good for him; he got so much out of it. They were able to tell him things that I hadn't been able to say, like just what a wonderful person he was.

The grief group changed me too. It was amazing in so many ways. We had different readings every week, and not all of them were slam-dunks but they were always thought provoking. We also each got a little bottle, and would add a new layer of colored sand each week, whatever color we chose. We did that for three months, and at the end we all had these beautiful bottles: a collage of colorful sand in different layers and different colors.

The layers were not all the same depth and they were a little intermingled. But the whole project connected with me, like I was developing my own new shoreline. As art, it was imperfect, and always changing. Some weeks the sand would be black, some weeks pink or gray or brown or white. But I always felt like it represented what I was going through during this process of creating my new seascape.

It wasn't just about survival. It was a process of transformation. Through it all, I became something different and awesome. I still have the bottle to this day. It sits on top of my piano. Mark did one, too, and his sits next to mine.

It may have taken me a while to get in the groove of the grief group, but once I did, it was just what I needed, to let it all go and talk freely. It couldn't have happened earlier, until all the right pieces were in place. But now I had this group that I could really relate to, this tragic club of parents who had lost their children to disease. What an odd kind of community: it's a group you never expect to be a part of, and you certainly never want to join—but there it is. Thank God that they were there for me, that they understood and wanted to listen. I didn't have that anywhere else. Healing doesn't come in a linear fashion. Rather, it shows up in patches, like puffs of smoke. You catch a piece of it and start to feel whole again, but then it evaporates. There are starts and stops. But like the ocean, eventually the angry waves subside.

It marked the beginning of true healing for me. Finally, it was my time. I was ready for it, and I came out of the experience that spring with a renewed passion for my life.•

[Excerpt contributed by the author.]

ABOUT THE AUTHOR:

Annette Hines, Esq. is the author of Butterflies and Second Chances: A Mom's Memoir of Love and Loss. She is a powerhouse advocate for the special needs community. Not only has she founded the Special Needs Law Group of Massachusetts, PC, specializing in special needs estate panning, where special needs families compromise 80 percent of the firm's clients, Hines brings personal experience with special needs to her practice, as the mother of two daughters, one of whom passed away from Mitochondrial disease in November 2013. This deep understanding of special needs fuels her passion for quality special needs planning and drives her dedication to the practice. For more information, please visit, https://specialneedscompanies.com/ and connect with her on Facebook, @SpecialNeedsLawGroup.

Achieving Your Best ON THE FIELD AND OFF

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SPECIAL OLYMPICS

EP MAGAZINE JOINS SPECIAL OLYMPICS IN CELEBRATING NATIONAL DOWN SYNDROME AWARENESS MONTH WITH THESE REMARKABLE ATHLETES.

DOWN SYNDROME AWARENESS MONTH

People with intellectual disabilities (ID) are accomplishing more than anyone ever thought possible, as Special Olympics athletes prove every day around the world.

PHOTO PROVIDED BY STEPHANIE CORKETT / SPECIAL OLYMPICS

TEEING IT UP: *(Above left)* Amy concentrates on her golf swing; she loves to golf and crowds always cheer her on as she plays. *(Above right)* Amy and last year's Phoenix Open champ Gary Woodland play TPC Scottsdale's 16th hole, which is notoriously difficult because of both its layout and the crowds who come to watch.

Yet, not that long ago, attitudes were very different. When Eunice Kennedy Shriver wanted to create a summer camp for young people with ID, she was told myth after myth, including that physical exertion might even be harmful for people with ID. Later, when she wanted to hold a "Special Olympics" in Chicago that would include swimming, organizers heard more myths, including that people with Down syndrome had "negative buoyancy"—and would drop in the water like rocks.

For Shriver, the whole point of such sports events was to change people's attitudes. So she made sure swimming and other sports were included in those first Games in 1968—and ever since. Since then, athletes with Down syndrome have emerged as versatile sports stars—from swimming to golf to gymnastics to judo. Recently, Special Olympics celebrated athlete Amy Bockerstette.

On the Field

Amy Bockerstette is the first person with Down syndrome to receive a college athletics scholarship, and when she was a high-school junior, she became the first Arizona student with Down syndrome to play in the state high school playoff.

Bocerstette wowed visitors and professional golfers alike, when she had the chance to play TPC Scottsdale's 16th hole, which is notoriously difficult because of both its layout and the crowds who come to watch. Amy, an Arizona native, showed up to the course to support last year's Phoenix Open champ, Gary Woodland, and nine-time PGA Tour winner Matt Kuchar, as they practiced for the Arizona tournament. Then, the pros asked her if she wanted to hit a few balls, as captured in a now-viral clip tweeted out by the PGA Tour.

Woodland and Kuchar both offered the athlete hugs, and when they complimented her skills on the course, she enthusiastically responded, "Yes!" Then she picked up her clubs and put on her shoes, and with a little assistance from her dad, she took her first shot. It landed in a sand trap by the green, but that didn't deter Amy, who easily hit the ball out and within feet of the hole.

When walking from the tee to the sand trap, she made small talk with Woodland and Kuchar about the crowd. "They love me! Awesome!" she said as Woodland asked, "You like all these people?" referencing how the crowds at hole 16 are daunting to many more experienced golfers. "Yes!" she replied, all smiles.

After a little encouragement from her new friends and herself — "Why don't you go ahead and make that?" Woodland said as Amy mumbled, "You got this" — she sank the putt to an eruption of cheers from the crowd. It was a 3-par hole, and she made it. "That is so awesome! You are so awesome!" Woodland exclaimed, laughing. Then Amy answered, looking around at the crowd, "Yes! Thank you!"

Reveling in her victory, Amy waved and blew the spectators two kisses. "You're an inspiration, you're our hero," Woodland gushed. Amy's father, Joe, went into detail about the play, "She's a gamer," Joe said. "She doesn't get nervous. She gets excited." He continued: "We knew a 120-yard shot was a sweet spot for her… So we gave her one of her top clubs… We had a good feeling that she'd hit a good tee shot."

Despite Woodland's offer to get her out of the bunker, "She said, 'No, I've got this,'" Joe recalled. "She was right." Amy's mother, Jenny, told the outlet that she felt "overwhelmed" watching her daughter play. "It was so exciting," she said. "What an experience."

Off the Field

"People with Down syndrome are individuals with unique personalities," says David Egan—and he should know. In his own unique way, he's spent the last few decades shattering stereotypes

PERSONAL BEST: *(Above left)* David competes at a Special Olympics swimming event. *(Above right)* David is a born spokesperson and uses his voice to advocate for people with intellectual disabilities. He is the first person with an intellectual disability to be awarded the Joseph P. Kennedy Foundation Public Policy Fellowship, working with U.S. congressional offices on Social Security legislation.

as a medal-winning athlete, trusted employee and sought-after public speaker.

David's also been a role model to adults and children with intellectual disabilities and to those without. Why? Because he's shown them all the wide range of successes that someone with Down syndrome can achieve – even if they have to overcome early skepticism from those around them.

"People with Down syndrome may have challenges, but we can learn with those who believe in us…those who have patience to discover our skills and the determination to make us succeed," he says.

When David was born in the 1970s, doctors gave grim predictions for the life of someone with Down syndrome. Typically, parents were told their baby would never walk, talk or benefit from higher education. Such a child could expect a life span of a decade or so, if that.

Now 41, David has proved everyone wrong. He's become the first person with an intellectual disability to be awarded the Joseph P. Kennedy Foundation Public Policy Fellowship, working with U.S. congressional offices on Social Security legislation.

After nearly 20 years at Booz Allen Hamilton, David is now a community relations specialist at SourceAmerica, advocating for employment of people with disabilities. He's also a past Special Olympics Sargent Shriver International Global Messenger. For this, he traveled the world as part of a select group of global spokespeople for Special Olympics. He also serves on several Boards to promote abilities and collaborate with other advocacy groups.

In March 2011, David testified at the Senate Health Education Labor and Pensions Committee promoting competitive employment for people with disabilities. He also addressed a global audience at the United Nations in New York City on World Down Syndrome Day, celebrating the rights of people with Down syndrome. David speaks at various conferences and fundraising events, building awareness and thanking supporters for their involvement in promoting respect, inclusion, and dignity for all people.

Yet, David has proved that Down syndrome is only a part of his life. "Down syndrome does not define us as people," he says. "It is a condition that makes it harder for us to learn, but with patience and persistence, we are able to contribute to our society."

David acknowledges that people with Down syndrome might need help on various levels – but who doesn't? "While we need help, I think that we can also help others see what matters in life," he says. "My brother Marc says that I taught him how to be compassionate and open to differences, seeing what unifies us."

Through it all, David has been involved in medical research studies – from the University of Wisconsin to the National Institutes of Health. He says, "Maybe people with Down syndrome are here to unveil the secrets of the brain. Who knows what will be discovered? Our extra chromosome may be a clue to better understand many diseases that affect the larger population like Alzheimer's, cancer, diabetes and heart problems."

He adds, "No matter my age or the fact that I have Down syndrome, I am a citizen that matters and I belong in my community. Our world is a better place with us…We should be included at all levels of our society from the womb to the grave."

In Special Olympics, the power and joy of sport, shifts focus to what our athletes can do, not what they can't. Attention to disabilities fades away. Instead, we see our athletes' talents and abilities -- and applaud them for all that they can do. And they are doing a lot! •

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- ***Education, training and licensing.*** *Now you know where you want to be, but how do you get there? Employment readiness specialists can help you figure out what academic, licensing or credentialing requirements are needed for your dream job and help you find financial aid to go after them.*
- ***Employment readiness.*** *You've got all the skills needed for the job, but how do you find it and get it? Employment readiness specialists can help improve your self-marketing skills through job strategies and support, job searches and social media etiquette, finding jobs with the federal government, resume writing, dressing for success and interview skills.*
- ***Career connections.*** *Where do you find all those employers who want employees just like you? Employment readiness specialists can help you identify career connections that promote the hiring of military spouses. These include the Military Spouse Employment Partnership Career Portal (*https://msepjobs.militaryonesource.mil*), local and installation job fairs, online career networks, community partnerships and federal appointment authorities.*
- ***Referrals to other services.*** *Are you job-search ready and busy juggling everything else that your search keeps taking a backseat? Employment readiness specialists can also provide you with referrals to other services supporting well-being, such as health and fitness, family life education and personal financial management services.*

LOCATING AN EMPLOYMENT READINESS SPECIALIST

Each service has its own employment readiness program, and while the names may vary from one service to the next, they all share the common goal of assisting military spouses in finding meaningful employment. The names of the program for each branch of service are:

- Army: Employment Readiness Program
- Marine Corps: Family Member Employment Assistance Program
- Navy: Family Employment Readiness Program
- Air Force: Employment Assistance Program

As a military spouse, you are welcome to visit any employment readiness office or Military and Family Support Center (https://installations.militaryonesource.mil).

Your installation employment readiness specialist can provide you the tools, resources and personalized services you need for a successful job search. Let them help you find your next job or start your new career today.

– Military One Source

WHAT SERVICE MEMBERS NEED TO KNOW ABOUT EMPLOYMENT

Maybe you're closing the chapter on your military life and opening a new one, or you're in the process of making long-term plans. This means transitioning from being a service member to a civilian employee in a company, nonprofit organization or maybe the government.

As a service member, you have many resources available to help you with this significant change. Here's an overview of what you need to know as you seek employment.

EXPLORE YOUR CAREER PATH

There's a difference between a job and a career. One pays the bills – the other gives you a sense of meaning and accomplishment.

Finding a career (**www.militaryonesource.mil/military-life-cycle/separation-transition/employment-education/your-career-path-finding-the-right-job**) that matches your skills and interests is the key to job satisfaction. Invest some time in a little soul-searching before you begin your search to make sure you're going down the right path. CareerOneStop (**www.careeronestop.org**) offers tools for job searching, training, and information about careers and industries.

CREDENTIAL YOUR MILITARY EXPERIENCE

Your military experience has given you training that converts to skills in the civilian world. The COOL program (**www.militaryonesource.mil/military-life-cycle/separation-transition/employment-education/credentialing-your-military-experience**) helps you translate your training into civilian credentials and speak better to what employers are looking for. Here are links to individual service branch programs:

- Army: **www.cool.army.mil/index.htm**
- Marines: **www.cool.navy.mil/usmc/overview/index.htm**
- Navy: **www.cool.navy.mil/usn/index.htm**
- Air Force: **https://www.jble.af.mil/**

BUILD YOUR RESUME

How do you condense your entire military history, skills and knowledge onto one piece of paper? These tips (**www.militaryonesource.mil/military-life-cycle/separation-transition/employment-education/how-to-write-a-resume**) will help you build a resume that will stand out.

- *Collect your assets. Get a copy of your Verification of Military Experience and Training* (**www.dmdc.osd.mil/tgps/**) *through the Department of Defense.*
- *Include essential components like contact information, job objective, summary of qualifications, employment history, education and training, and special skills.*
- *Tailor your resume for the job. Translate everything into civilian terms and include volunteer experience.*
- *Write a cover letter. Get the name of the person in charge of hiring, keep it to one page and always follow up.*
- *Tap into resume-building tools. Check out Veterans.gov* (**www.veterans.gov**) *and VA.gov* (**www.va.gov**).

FIND THE RIGHT CIVILIAN JOB

Your military experience is valuable to many employers, but it's up to you to get out there and sell it. Start with these tips (**www.militaryonesource.mil/military-life-cycle/separation-transition/employment-education/12-ways-to-land-that-civilian-job**):

- *Network. Get in touch with friends and fellow veterans. Organize your contacts and connections.*
- *Tap into the services of your transition assistance offices. Get referrals for employment agencies and recruiters, job leads and career counseling.*
- *Hit job fairs. Look for upcoming events to meet potential employers.*
- *Look for veteran-friendly companies. Many organizations* (**www.militaryonesource.mil/military-life-cycle/separation-transition/employment-education/programs-that-hire-veterans**) *are committed to helping veterans find a good job. Look for programs such as the U.S. Chamber of Commerce Foundation's Hiring Our Heroes initiative. Check out organizations like Soldier for Life, Marine for Life, the Military Officers Association of America, Non-Commissioned Officers Association or Enlisted Association, and United Service Organizations.*

IDENTIFY RESOURCES AND BENEFITS

Check out these employment benefits and assistance programs (**www.militaryonesource.mil/education-employment/for-service-members/for-service-members-benefits**) available before and after you leave the military. Review some of the top services and programs offered by the military and the government, focused on jobs for veterans and helping you find your new career.

Match your military skills to civilian jobs, find transition resources, and start your military-to-civilian job search with the resources and information provided above. Check out all the resources for employment on Military OneSource.

– Military One Source

START YOUR CAREER WITH MILITARY KIDS
COME GROW WITH US

The Department of Defense is the nation's largest employer-sponsored child care system and one of the largest youth development programs in the country. Through the Department of Defense’s career opportunities initiative, Come Grow With Us, you can apply for both entry and management-level positions in many child development programs and youth programs world-wide.

DEPARTMENT OF DEFENSE CHILD AND YOUTH DEVELOPMENT CAREERS

Watch this video of the career opportunities available within military child development and youth programs (www.youtube.com/watch?v=LbH4k6dv0X4&feature=youtu.be)

As a Department of Defense child development and youth program employee, you’ll enjoy competitive pay and benefits, including:

- Health and life insurance
- Paid leave
- Retirement and 401K benefits
- Tuition assistance
- Training, mentoring and professional development
- Career advancement opportunities

Plus, many of the Department of Defense’s 850+ high-quality child development and youth programs are located on or near military installations worldwide. And, for military spouses seeking employment, spousal preference is offered as well.

STEPS TO SUCCESS: Few careers offer the chance to directly support military children and youth, offering them the foundation they need to succeed as adults.

If you are interested in a career that offers flexibility and advancement, while providing a vital service to our military families around the world, this employment opportunity is for you.

Some available jobs that may be open in your area include:

- Child development directors and assistant directors
- Training and curriculum specialists
- Before and after school directors
- Youth program directors
- Direct care staff

Both entry and career-level positions with Department of Defense programs can be found at:

- The Navy’s Child & Youth Programs Careers (www.navycyp.org/careers)
- USAJOBS (www.usajobs.gov) by searching for “Department of Defense Child Development and Youth Program” jobs in your area. You can also search by entering the name of your service branch and “Child and Youth,” for example “Army Child and Youth.”
- The Air Force’s NAF Jobs (www.nafjobs.org)

ASK AN INSTALLATION EMPLOYMENT READINESS SPECIALIST

Both military spouses and recent college grads from military families can talk to their installation’s employment readiness specialist.

SKILLS YOU NEED TO SUCCEED AS A CHILD AND YOUTH DEVELOPMENT STAFF MEMBER

If you’re considering a career field in early care and education or youth development, ask yourself these questions to see if you’d fit the qualifications for many entry and management-level positions.

- ***Do you have experience with children?*** *Previous experience working with children and youth may give you an advantage when seeking employment. Don’t just count formal student teaching or training, though – an employment history of babysitting or camp counseling will look great to potential employers.*
- ***Do you have formal early childhood education or youth development training or certifications?*** *Most employers request candidates have at least a GED/high school diploma. Having an associate’s or bachelor’s degree in child development, education, psychology, social work, youth development, or physical education can set your application apart from others. Child care-related certifications like the Child Development Associate, or CDA, or the Child Care Professional, or CCP, credentials may also increase your employability, as do basic first aid and CPR certifications.*
- ***Are you looking for a rewarding, meaningful career?*** *Few careers offer the chance to directly support military children and youth, offering them the foundation they need to succeed as adults. If you enjoy a challenge and are passionate about working with children and youth, this job opportunity is for you.*

– Military One Source

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The D-Bomb

With all the filth flying out of my mouth, I have braced myself for Broden to one day drop one of those words during therapy. I knew it was only a matter of time. He's a smart kid and he's fully aware of what is going on around him.

Each deployment was different, yet there were a few things that seemed to be the same. Of course, we missed not being all together as a family, something usually broke, or we experienced being near a natural disaster for some reason. Mark is currently on a work trip and Hurricane Dorian has decided to travel north up to visit us. I should have known. One thing is certain and I'm sure it can be graphed if data were taken, I cuss more when Mark is gone. It's something I'm not proud of, but the jury is out. The jury being my oldest son, Hayden. I have a tendency to have more inappropriate language when I'm managing the house alone. After Hayden agreed that I do cuss more when his Dad is gone, he did tell me I was still a lot fun. I guess that makes me feel a little bit better.

With all the filth flying out of my mouth, I have braced myself for Broden to one day drop one of those words during therapy. I knew it was only a matter of time. He's a smart kid and he's fully aware of what is going on around him. A few years ago, a tutor asked him what the person was drinking in a picture and he said, "beer". Clearly, he is my husband's child. Yes, it was probably beer. I couldn't count how many times Broden has broken into song to realize that he had heard a song I was playing in the car that morning. Eminem has quite a few catchy tunes if I do say so myself, and "Don't Stop Believing" by Journey is a gem. Broden has started singing this song in church and I've heard it during dinner too. He's got great taste, but bad language? Not until recently, but not like you would think to hear it.

Last month, my parents were visiting and my Mom came with me to pick Broden up from ABA therapy. He had a full cup of juice on ice. When he picked the cup up, the lid came off and the entire cup of cold juice fell in his lap. My Mom was in the front seat and was trying to reach back to help him. I was busy driving the car so all I could do was look back in the rear view mirror in horror. "Broden, just hang in there honey. We are getting home as fast as we can." Broden started to squirm and yell out, "Lightning McQueen!" as loud as he could. He grit his teeth and then tried to lift his bottom off the chair, but his seatbelt would not let him budge. With beady eyes he belted out, "Dinosaur! Dinosaur!"

I SWEAR: It's something I'm not proud of, but I have a tendency to use more inappropriate language when I'm managing the house alone.

I knew he was miserable because the more he squirmed, you could imagine the ice cubes starting to melt and slide between his legs. He was stuck in this cold sticky liquid until we got home and there wasn't a thing he could do but cuss, "Lightning McQueen!! Dinosaur! Dinosaur!" My Mom and I knew what those words meant and I'm sure "dinosaur" was the worst cuss word out of them all. Dinosaur had to be the F bomb. I mouthed the word while I was driving. What a great word to yell if you're frustrated.

Driving on post was the worst. I was driving 35-37 miles an hour looking frantically to see if an MP was around and then I swung into our neighborhood pushing the limit on the speed to get to the driveway. Broden slipped out of the seat with soaked pants and waddled into the house. My Mom got him bathed while I dismantled the backseat and scrubbed it down. The windows were rolled down that night in the garage to make sure things were aired out before we headed to ABA again the next morning.

A few weeks later heading to pick up the boys, a car slammed on his brakes in front of me to turn right without using his turn signal. I screamed out, "Lighting McQueen!" I have to admit, it felt pretty good. I'm saving the D-word for a special occasion. •

PUZZLES & CAMO

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

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