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NOVEMBER 2021
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FINANCIAL PLANNING:

FOR LIFE'S PRESSURE POINTS

PLUS:

SENSORY INTEGRATION *in* MEDICAL CARE

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Information and Support for the Special Needs Community

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— Rick Rader, MD

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RAISING THE BAR: Dunbar is not that far off when it comes to 150 people being a manageable number in a variety of settings. “It’s the number of people you would not feel embarrassed about joining uninvited for a drink if you happened to bump into them in a bar.”

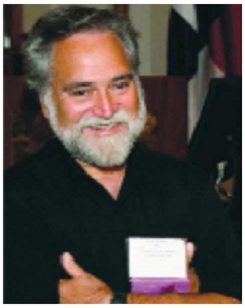
On Walking Into a Bar with a Guy Named Dunbar

Of all the things that people with disabilities come up short with are the number of friends they have. As clinicians, teachers, DSPs, advocates, therapists, counselors and policy makers, we do a poor job of providing opportunities for them to make friends (not to mention opportunities for them to walk into bars).

You would have had to be living under a rock if you didn’t hear at least one joke about “walks into a bar.” It’s one of the classical scenarios or “set ups” for jokes. It seems as if there has been no limit on “who” actually walks into the bar.

We have seen lawyers, rabbis, ministers, drunks, doctors, monkeys, aliens, blondes, giants, zombies, guys, two-headed beasts, hookers, two blind mice, parrots and politicians all walking into a bar to set the stage for the punchline.

According to the blog “Bars and Bartending” the exact origin of the standard walks-into-a-bar joke is said to have started with a joke involving a dry martini that appeared in the New York Times. Maybe. We’re paraphrasing a bit here, but this is the basic joke as it apparently appeared in a 1952 *New York Times* paper in April. “A man walks into a bar and orders a very, very dry martini, telling the bartender to make it at a ratio of 25 to 1. Somewhat startled by the request, the bartender precisely measures and pours the drink into the correct glass and proceeds to ask the man if he’d like a twist of lemon peel with his martini. To which the man pounds his fist on the bar and yells, ‘If I wanted a damn lemonade, I’d ask for one!’” While it’s not the funniest bar joke you’ve heard, most “first” things seldom are memorable. While it’s been said that the veracity of this “origin story” is up for debate, it’s certainly true that the bar jokes started shortly after the establishment of the first pub or bar itself.



One walks-into-a-bar joke that you never heard is that a hundred fifty one friends walk into a bar.

While there is no record of this ever being a "bar joke," according to British anthropologist Robin Dunbar, it would be impossible.

In the 1990s, Dunbar proposed that humans could only maintain 150 stable relationships or friends. He based his rule on the size of the human brain. He found a correlation between primate brain size and average social group size. There is some evidence that brain structure predicts the number of friends one has, though causality remains to be seen.

None of my neuroscience colleagues have been able to define what constitutes the parameters of friends, so we have to revert back to Dunbar who informally explains his "number".

> "The richness of life has its roots in relationships, friendships and hanging out with folks who know us, forgive us, tease us, support us and root for us."

"It's the number of people you would not feel embarrassed about joining uninvited for a drink if you happened to bump into them in a bar." How that is correlated to the neocortical processing capacity of the brain is waiting to be addressed. He's not that far off when it comes to 150 people being a manageable number in a variety of settings.

A research article in *The New Scientist* provides that "Historically, 150 was the average size of English villages. It is also the ideal size for church parishes, and is the size of the basic military unity, the company. Although an individual's social network may include many more people, 150 contacts marks the cognitive limit on those with whom we can maintain a stable social relationship involving trust and obligation – move beyond 150 and people are mere acquaintances."

"Of course, acquaintances come and go, and we therefore cherish a smaller inner circle. There are numbers that define these other relationships. In an article published by the BBC (British Broadcasting Corporation) the tightest circle has just five people – loved ones. That's followed by successive layers of 15 (good friends), 50 friends (meaningful contacts), 500 (acquaintances) and 1500 (people you can recognize). People migrate in and out of these layers, but the idea is that space has to be carved out for any new entrants."

Of all the things that people with disabilities come up short with are the number of friends they have. As clinicians, teachers, DSPs, advocates, therapists, counselors and policy makers, we do a poor job of providing opportunities for them to make friends (not to mention opportunities for them to walk into bars). The richness of life has its roots in relationships, friendships and hanging out with folks who know us, forgive us, tease us, support us and root for us.

I tested myself against Dunbar's number and struggled to remember half of those I am supposed to be capable of having in my life.

Dunbar was recently asked how (as a social scientist) he felt about having his name synonymous with a number, a bragging right typically reserved for a famed mathematician. His sense of humor was obvious when he quipped, "The odd thing about it is most people who have things named after them are actually dead." One wonders how many of his 150 stable social relationships would show up at his funeral.•

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
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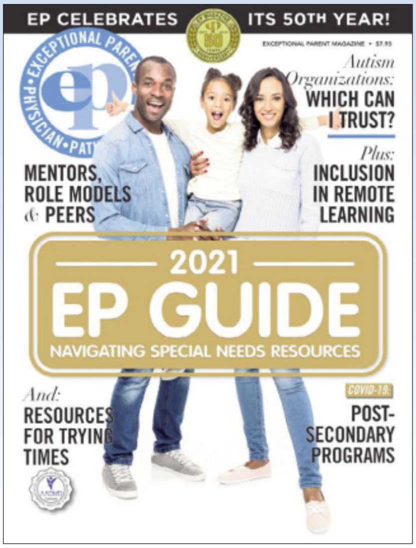
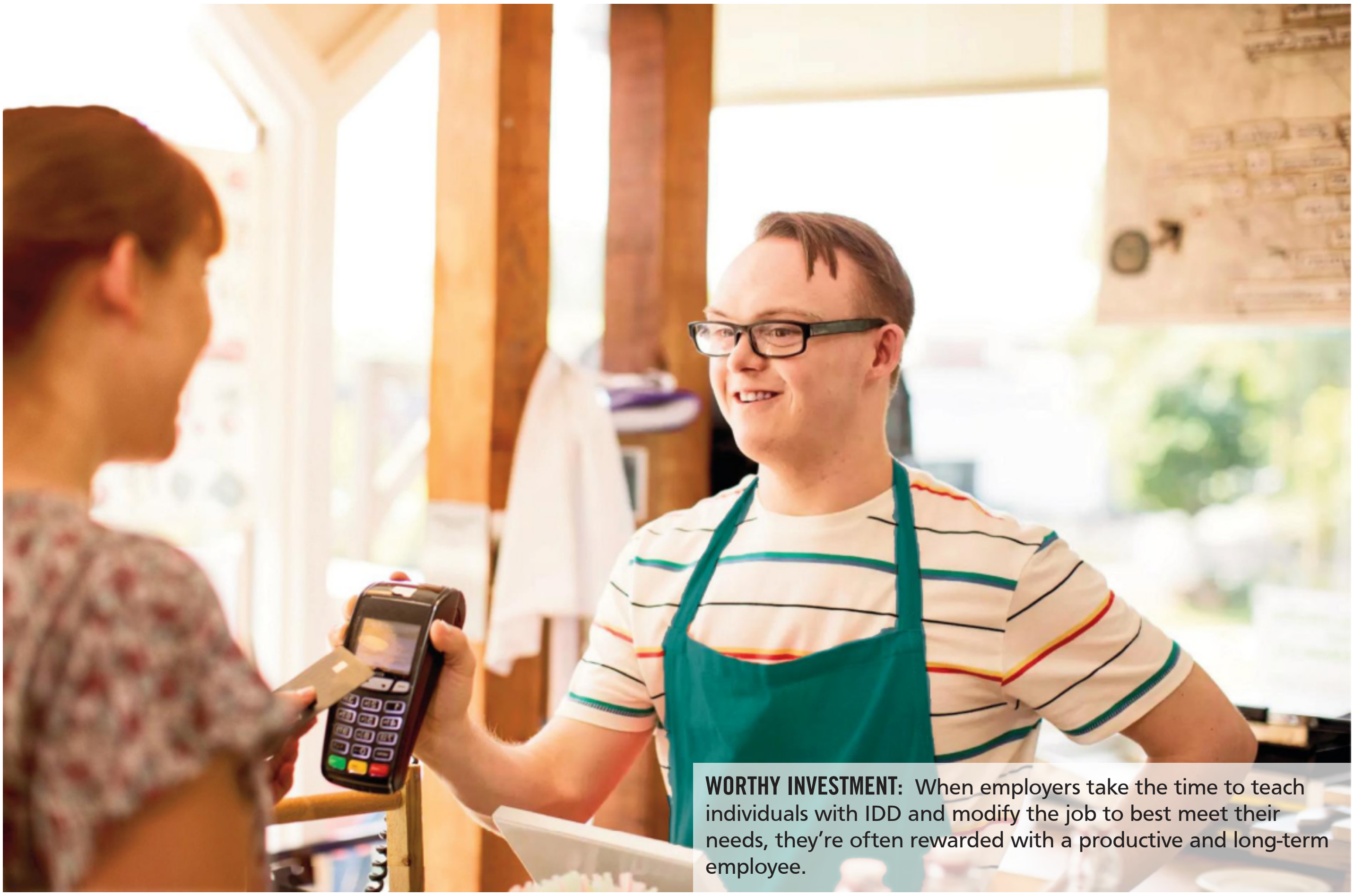


PEOPLE WITH IDD OVERLOOKED FOR JOBS



WORTHY INVESTMENT: When employers take the time to teach individuals with IDD and modify the job to best meet their needs, they're often rewarded with a productive and long-term employee.

Even in the midst of a hiring crisis, many employers are hesitant to hire people with intellectual or developmental disabilities. However, as IntellectAbility's Dr. Craig Escudé explains, hiring these individuals often results in motivated, dedicated employees who contribute greatly to their employer and society as a whole.

According to recent estimates, the United States has about 10 million job openings, yet over 8.4 million unemployed individuals are still looking for work.[1] As business owners complain about staffing issues and Americans are confronted with longer wait times for services due to inadequate staffing, there is a way to help alleviate the labor shortage. Dr. Escudé says, "People with intellectual and developmental disabilities (IDD) can be valuable assets to our workforce. Unfortunately, many businesses and employers are reluctant to hire these individuals, even though, in many cases, they perform as well or even better than other employees."

Employers may pass over people with IDD because they: [2]

- *Are concerned about negative coworker reactions to the hiring of a person with IDD,*
- *Assume it will cost more to hire, train, and maintain employment for people with IDD,*
- *Believe people with IDD won't be as productive or will never develop the knowledge, skills, and attitudes necessary to complete job tasks,*
- *Fear litigation associated with the hiring and firing of people with IDD,*
- *Hold on to negative stereotypes about people with IDD,*
- *Want to avoid negative customer reactions which may lead to fewer business transactions, and*
- *Won't gain any economic incentives, such as tax credits, for hiring people with IDD.*

But many people with IDD are successful at work. In Australia, a McDonald's employee with Down Syndrome retired after 32 years of loyal, productive service.[3] In Colorado, a thrift store chain employs around 350 people with IDD in various roles, including donation coordinators, clothing hangers, and room attendants.[4] Perhaps most notably, a café in Middletown, NJ, is staffed almost entirely by adults with IDD. The owners, whose daughter has Down Syndrome, employ 34 adults with IDD and 4 with neurotypical disability. [5]

"As an employer myself, I would tell other employers that the vast majority of folks with IDD are typically more dependable, honest, and have way more desire to please than those without IDD. They are absolutely more capable than most people might think and they bring a lot of positive energy into a workplace that can be extremely contagious. I can say that I simply don't hear of employers who regret hiring individuals with IDD but often do hear how they believe their workplace wouldn't be the same without them," says Scott Stills, Enrichment Center Director at Reach for Independence, a North Carolina service provider agency which, among their many services, helps individuals with IDD gain employment.

> ***"Implementing programs that reward companies who hire people with IDD does not need to be complicated. The government might provide companies with tax credits or other financial reimbursements."***

Part of the solution involves providing opportunities for young people with IDD to receive an education that can transfer to the workplace. After high school, programs such as those in vocational schools can put a person with IDD on the path to long-term employment by connecting them to their interests and developing skills that will help them succeed.

Unfortunately, many employers still believe the misconception that a person with IDD cannot be educated or trained. However, when employers take the time to teach individuals with IDD and modify the job to best meet their needs, they're often rewarded with a productive and long-term employee. Additionally, these companies often reap the benefits of goodwill from the community, who view the hiring and retention of people with IDD as a boon.

"Most individuals with IDD are supported by a trained paraprofessional that will be there to help the individual get through their job duties in a timely and professional manner. Also behind each individual is a team that consists of a case manager, a qualified professional, the paraprofessional's supervisor, a parent or support giver, and of course, the paraprofessional, if they need one. This team works well at making sure that the job the individual will have is appropriate for him or her. Success for this individual is vitally important to this team and their support continues for the entirety of the individual's employment," adds Stills.

An a broader level, the government could help these individuals find employment by incentivizing their hiring. Implementing programs that reward companies who hire people with IDD does not need to be complicated. The government might provide companies with tax credits or other financial reimbursements. It could also help develop agency programs similar to those connecting military veterans with employment opportunities.

Many employers gain dependable, motivated employees when they hire people with IDD. There are benefits for the individual too – by having a job, a person develops greater self-esteem as they contribute to society while earning money that allows them to live a more independent life. Ultimately, this results in happier, healthier workers who can help drive the country's economic recovery.

The hiring crisis is real, but it can be solved by actively including people with intellectual and developmental disabilities in recruitment and hiring efforts. Unfortunately, many employers remain fearful of doing so. However, better education for these people, plus incentives for companies to hire people with IDD, can help.

Dr. Escudé says, "When we're employed, we have a sense of purpose, of responsibility and knowing that people are counting on us. It's a very rewarding experience that everyone wants, and people with disabilities should also be able to enjoy contributing and feeling satisfied with their work."

References

1. Long, Heather, et al. "Why America Has 8.4 Million Unemployed When There Are 10 Million Job Openings." The Washington Post, WP Company, 8 Sept. 2021, washingtonpost.com/business/2021/09/04/ten-million-job-openings-labor-shortage/.

2. "Why Employers Don't Hire People with Disabilities: A Survey of the Literature." CPRF, 3 Feb. 2015, cprf.org/studies/why-employers-dont-hire-people-with-disabilities-a-survey-of-the-literature/.

3. "After 32 Years of Service in a McDonald's This Man with Down's Syndrome Is Finally Retiring." Bored Panda, boredpanda.com/mcdonalds-employee-32-years-down-syndrome-retiring/?utm_source = google&utm_medium = organic&utm_campaign = organic.

4. Lewis, Lloyd. "Opinion: Unemployment May Be Dropping in Colorado, but for at Least One Vulnerable Group It's Rising." The Colorado Sun, 1 July 2021, coloradosun.com/2021/07/11/jobs-disabled-opinion/.

5. Carino, Jerry; "No Labor Shortage At Café Staffed By Workers With Intellectual Disabilities"; 01 Oct 2021; Originally published in the Asbury Park Press/TNS and reprinted in DisabilityScoop; disabilityscoop.com/2021/10/01/no-labor-shortage-cafe-workers-intellectual-disabilities/29514/

WHAT'S HAPPENING

SURVEY RESULTS: IMPACT OF COVID-19 ON FAMILY VISITS TO SENIORS WITH DEMENTIA

TOUGH CALL: Seniors with dementia face significant challenges when using their phone and most individuals with memory loss have difficulty making a call, despite having to rely on phones to stay connected to help reduce the social isolation.

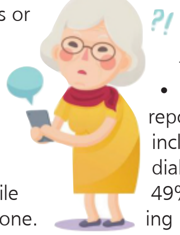
RAZ Mobility, a provider of mobile assistive technology and the creators of the RAZ Memory Cell Phone, recently announced the results of its latest industry survey regarding the impact of COVID-19 on family visits to seniors with dementia, and the use of phones to bridge the communication gap. Now more than ever, families are forced to rely on phones to stay connected to help reduce the social isolation experienced by seniors with dementia.

However, they face significant challenges when using their phone. For example, most individuals with memory loss have difficulty making a call and many accept calls from spammers.

The online survey was presented to more than 250 caregivers, healthcare workers and individuals with family members suffering from dementia in the first week of October. It was designed to gain a better understanding about the needs of these individuals when it comes to staying in contact with family members and caregivers.

COMMUNICATION BREAKDOWN : RAZ MOBILITY SURVEY

- According to survey results, 48.5% of respondents see their senior with dementia significantly less because of COVID-related visitation restrictions or out-of-fear of infecting their loved one.
- The significant majority of respondents said their family members with dementia or Alzheimer's use a mobile phone or a landline phone.



- Of the 41% of respondents that say their family member with dementia or Alzheimer's use phones, 49% said they frequently have difficulties using the phone and 8% have difficulties some of the time.
- The top two challenges reported by those respondents include 51% having difficulty dialing phone numbers, and 49% getting confused and dialing phone numbers late at night.

"While there is a large number of individuals with dementia and Alzheimer's using a phone as their main form of communication, there are still many challenges they experience when trying to navigate the technology," said Robert Felgar, CEO of RAZ Mobility. "The RAZ Memory Cell Phone specifically addresses the needs and challenges faced by seniors with dementia when using their mobile device." RAZ Mobility offers mobile assistive technology solutions for people with disabilities. These solutions take the form of mobile devices or mobile applications.

WHAT'S HAPPENING

ACCESSIBILITY SHORTCOMINGS STILL OFTEN OVERLOOKED IN REMOTE WORK

The rise of remote work has increased the talent pool for companies to draw from, as people with disabilities, who may have been unable to regularly commute to the office, can now apply to a greater range of positions.

WORK TO DO: Business should not be lulled into thinking that present-day video call accessibility tools are enough to offer inclusivity for people with hearing impairment.

Following the work-from-home (WFH) trend, video conferencing tools became essential and were quick to introduce video captioning on their platforms to better serve the diverse workforce. However, according to Mindaugas Caplinksas, CEO at Go Transcript – which specializes in easy-to-use, quality-focused human-powered transcriptions delivered online around the world – the current solutions fail to properly support people with hearing disabilities.

Closed captions (CCs) provide more than a written dialogue of what is being said by giving the viewer a description of what is taking place on-screen. Despite the progress that has been made regarding its accuracy, many auto-generated subtitles and CCs are often garbled, as well as unable to provide context, register sarcasm, or word emphasis.

> *“A more properly fitted environment could increase employee loyalty and productivity.”*

“Business should not be lulled into thinking that present-day video call accessibility tools are enough to offer inclusivity for people with hearing impairment,” commented Caplinskas, cautioning against the reliance on AI-powered video captioning alone to ensure accessibility. “The video call has opened up many opportunities for inclusivity and that should not be taken for granted. However, transcribing important meeting information could bring additional benefits to businesses – not only because synchronous transcription is still not up to par with accessibility needs, but also as more crucial details can be captured and conveyed.”

In addition, Caplinskas notes that despite their underpinning voice-to-text technologies, artificial intelligence-based solutions are still unable to understand foreign accents, multiple speakers, and specialist vocabulary.

“Live-captioning on video calls is not just inaccurate in such cases, and it can be very difficult to navigate in the conversation. With multiple speakers in the meeting, the issues get more profound, for instance, when there are different accents, or when people use sign language, often not recognized by these systems,” he explained. “That’s the main focus of our team – to render information taking all of these nuances into account. Detailed notes of strategic sessions can help businesses with accountability, accuracy, and, most importantly, inclusivity, as more people will be on the same page and will not have missed important details that transpired in the meeting.”

Major market players have taken a more serious approach towards providing more intricate solutions for the hearing impaired. For example, Google has recently come up with an idea to enable a person signing to be recognized by the closed captioning systems. As described in a research paper, the system would use a virtual audio source to generate a 20 kHz tone, which is outside the range of human hearing, but noticed by computer audio systems to make the system aware that a person is now using sign language.

However, it may be a while until this, or similar solutions are launched, thus Caplinksas concluded by emphasizing that companies should aim to be more in tune with employee accessibility needs at present. “A more properly fitted environment would portray the employers’ attitude towards their team, which, in turn, could increase employee loyalty and productivity,” he commented. “For this, it is really important to make sure that any improvements are made with people with hearing impairment in mind – not what hearing people think they need.” •

BOOK REVIEW

PHOTO COURTESY DW TAYLOR/WIKICOMMONS

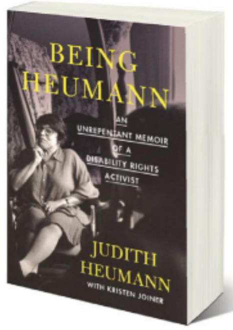
BEING HEUMANN

BY HAL BAKER, FAAIDD

Judy Heumann opens her memoir with a poignant portrayal of growing up with a physical disability resulting from a case of polio she contracted at 18 months of age. She recounts her childhood playing with friends in her Brooklyn neighborhood, of going to Synagogue and enjoying the love and support of her close family, but not of going to school.

She remembers the first day of kindergarten, when she was excited to be with her friends in class and getting to pick out the dress she would wear, only to be met at the door by the principal of her neighborhood public school, after she was carried up the steps. He told her mother that she couldn't go to school as she posed a danger to the other students in case of an emergency – she was using a wheelchair, she was a fire hazard.

This incident, along with other denials of her rights, such as not being allowed to become a teacher after she had earned a degree with the highest honors and passed all or the required exams, certainly laid the foundation for her to become one of the most accomplished activists for the rights of people with disabilities in our nation's history.



Title: **Being Heumann: An Unrepentant Memoir of a Disability Rights Activist**

Author: **Judith Heumann with Kristen Joiner**

Publisher: **Beacon Press**
Publication Date**: February 2020**
Paperback: **240 pages**
ISBN-13: **978-0807019290**
Available at: Beacon Press, amazon.com and www.barnesandnoble.com

Her story is full of the indignities suffered by those who have to depend on others for so much of their daily activities. While she never displayed the anger you would expect directed to individuals who shunned or denied her access or inclusion, she often remarked that she felt anger, however, it was directed at the system that failed to accommodate all of the individuals with disabilities, both in the US and eventually, all around the world.

She directed her frustration to changing the systems, and she had incredible success after many long, hard fought battles at the highest levels of government. Along the way, she learned the art of community activism and how to be completely transparent and inclusive of everyone's ideas and opinions, no matter the lengths she had to go to get everyone on the same page.

She takes the reader through all of the momentous changes in laws and practices from 504 of the Rehabilitation Act to IDEA and the ADA. Her involvement and leadership in these Civil and Human Rights Acts is remarkable. As a teacher and professional in the field, I was able to benefit from the changes she led and fostered while never recognizing the tremendous efforts which were needed to cause the changes. I was one of thousands who have benefited from her activism and it is exciting to be able to hear her tell of the processes that it took to achieve these landmark accomplishments.

The back story of the organizing and political maneuvering is remarkable in light of the difficulties the individuals faced from an unaware public body. Also remarkable is that she shows no animosity for those who were intolerant to her and her fellow activists. She does conclude by showing concern that the climate she worked in was one where compromise was possible across the aisles, as it were, while today she is fearful that the cooperation it takes to move forward with protecting and assuring civil and human rights is missing.

She paints a picture of what it is like to be included, as in a camp for kids with disabilities, and excluded, as in what it was like not to be able to go to school with her friends. She knows it is possible for all the accomplishments to be negated if we are all not diligent in continuing to actively advocate. •

ABOUT THE AUTHOR:

Hal Baker, FAAIDD, is the Community Advocate, The Arc of Tennessee.

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

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Sensitizing Health Insurance Companies for the Care of Individuals with Disabilities

BY H. BARRY WALDMAN, DDS, MPH, PHD, RICK RADER, MD, FAAIDD, FAADMD, DHL (HON) AND STEVEN P. PERLMAN, DDS, MSCD, DHL (HON)

Providing necessary healthcare for youngsters (and the not so young) with special health care needs can be difficult for the patient and the provider. For example:

> **"Some people neglect their health because of phobias about dentists, needles, diseases and germs."** [1]
>
> "… a routine dental checkup may seem more like a nightmare: a masked dentist towers above them poking sharp objects into their mouth, loudly scraping or drilling their teeth as debris flies left and right. When that fear becomes a phobia, the experience can become even more intense, leading to a rapid heartbeat, heavy breathing, sweating and even fainting." [1]
>
> "…another group of health phobic people doesn't so much fear treatment for a disease as the disease itself. And, the public's health anxieties may be getting worse. A recent study shows that the more a society promotes healthy lifestyles, the more people worry about their health and the sicker they feel… Often, disease phobias go hand-in-hand with obsessive-compulsive disorder – in which patients might wash their hands continuously to avoid becoming 'contaminated'… Some may become so frightened of contracting a disease that they are unable to leave their home." [1]

Third party private health insurance companies also have their difficulties, as they compete in the open insurance market with the continuing increases in health insurance costs. At end of 2019, the national average annual cost for private health insurance for a family of four was $20,576.[2]

The issue of costs for health insurance is compounded for families that are unable to secure needed insurance payments for desensitization (a behavioral technique commonly used to treat fear, anxiety disorders and phobias). Instead practitioners all too often refer patients with disabilities to operating rooms for care in community hospitals; thereby avoiding their private practice expenses and risks.

Systematic desensitization is engaged in some type of relaxation exercise and gradually exposed to an anxiety-producing stimulus, like an object or place. [3]

According to systematic desensitization, a learned response (e.g. fear of spiders) can be unlearned through classical conditioning and a new response – relax when seeing a spider, can be induced.

STEPS

1. The patient is taught a deep muscle relaxation technique and breathing exercises. For example: Control over breathing, muscle relaxation or meditation. This step is very important where one response is inhibited because it is incompatible

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.

FEAR FACTOR: Public health anxieties may be getting worse. A recent study shows that the more a society promotes healthy lifestyles, the more people worry about their health and the sicker they feel.

with another. In the case of phobias, fears involve tension and tension is incompatible with relaxation.

2. The patient creates a "fear grading" starting at stimuli that create the least anxiety (fear) and building up in stages to the most fear-provoking images.
3. The patient works their way up the "fear grading" starting at the least unpleasant stimuli and practicing their relaxation technique as they go.[4] Example: **"Fear grading" for spiders"**[4]

Behavior	Fear Rating
Think about a spider	10
Look at a photo of a spider	25
Look at a real spider in a closed box	50
Hold the box with the spider	60
Let a spider crawl on your desk	70
Let a spider crawi on your shoe	80
Let a spider crawl on your pants leg	90
Let a spider crawl on your sleeve	95
Let a spider crawl on your bare arm	100

THEN THERE ARE COST FACTORS

"It has been nearly a decade since Congress passed the Mental Health Parity and Addiction Equity Act, **with its promise to make mental health and substance abuse treatment just as easy to get as care for any other condition.** *(emphasis added)* Yet today, amid an opioid epidemic and a spike in the suicide rate, patients are still struggling to get access to treatment. (Nevertheless) health insurers are still skimping on mental health coverage."[5]

Among the study findings:

- "In 2015, behavioral care was four to six times more likely to be provided out-of-network (health insurance rates) than medical or surgical care… The high proportion of out-of-network behavioral care means patients with mental health or substance abuse problems were far more likely to face the high out-of-pocket costs that can make treatment unaffordable, even for those with insurance… For years, insurers have maintained that they are making every effort to comply with the 2008 federal mental health parity law, which was intended to equalize coverage of mental health and other medical conditions…
- Insurers paid primary care providers 20 percent more for the same types of care than they paid addiction and mental health care specialists, including psychiatrists.
- State statistics vary widely. In New Jersey, 45 percent of office visits for behavioral health care were out-of-network. In Washington, D.C., it was 63 percent."[5]

SO HOW DO INSURANCE COMPANIES WORK? FOR EXAMPLE:

1. **A required diagnosis of a mental illness:** "The rule is that insurance companies only pay for services that are considered 'medically necessary'. This means that in order to utilize your medical insurance for mental health treatment, you must be diagnosed with a mental illness disorder. Additionally, the clinician must prove that your mental health condition is affecting your health and overall functioning on a daily basis."[6]
2. **It has to be medical necessary:** "This is the term used by medical insurance to describe procedures or treatments they

believe must occur, or if not, the person may suffer insurmountable consequences.”[6]

3. **The loss of confidentiality:** “One of the biggest concerns about using medical insurance for mental health treatment is the possibility of losing confidentiality. When your insurance is billed, not only do they require a diagnosis, but they gather information about the type of treatment you are receiving and whether you have improved or not (this is important to them because their goal is stop paying as quickly as possible).” [6]
4. **Loss of control of treatment:** “When you see an in-network provider through your insurance, neither you nor the clinician get to decide how you spend your time in treatment. Insurance companies require that a treatment plan be submitted in order to approve the number of sessions and ultimately, they use this to determine how your time in therapy is spent. The number of sessions is determined ahead of time by the claims specialist (a non-mental health professional who you have never met and does not know your plight) and is not based on need.” [6]

> “If you are entitled to a specific service or support, you have the right to appeal the decision. If you feel you are being denied care unfairly, there are federal and state laws to help protect you.”

5. **Now add COVID-19:** “10,000 Tennessee children could lose therapy as insurance companies deny telehealth coverage … Many therapists in Tennessee are out of work because insurance companies in Tennessee are refusing to pay them for telehealth services that have replaced in-person care in the era of social distancing.” [7]
6. **What to do if you’re denied care by your insurance:** Treatment of mental illness can be denied by health insurance companies for a number of reasons and using a variety of methods that determine whether a type of treatment is considered medically necessary or a part of your benefits. If you are entitled to a specific service or support, you have the right to appeal the decision from the insurance company… If you feel you are being denied care unfairly, there are federal and state laws to help protect you.” [8]

UNDERSTANDING INSURANCE TERMS

- **Medical necessity criteria** are standards used by health plans to decide whether treatments or health care supplies recommended by your mental health provider are reasonable, necessary and appropriate.
- **Utilization review** is the process used by insurers to decide whether the requested mental health care is medically necessary, efficient and in line with accepted medical practice.
- **Prior authorization** is a type of utilization review and is when you or your service provider must ask for approval before your health plan will agree to pay for a service, treatment plan or prescription drug.
- **Step therapy** is a type of prior authorization in which you must try a less expensive prescription drug or service before you can move to a more expensive prescription or service. 8
- **Appeal** – Most health plans are required to follow federal and state mental health equivalence laws. ***You may want to appeal the denial.*** Inequality may be indicated if:

1. *Higher costs or fewer visits for mental health services than for other kinds of health care.*
2. *Having to call and get permission to get mental health care covered, but not for other types of health care.*
3. *Getting denied mental health services because they were not considered medically necessary, but the plan does not answer a request for the medical necessity criteria they use.*
4. *Inability to find in-network mental health providers that are taking new patients, but you can find providers for other health care.* [8]

INSURANCE COMPANIES AND DESENSITIZATION

The inner workings of the broad spectrum of health and social services for the young and not so young with and without disabilities is dependent upon the smooth integration of care providers, insurance companies, governmental agencies and the recipients of services. The refusal by any one of these parties to participate precludes the delivery of the needed care; particularly for those who increasingly are recognized to be in desperate need of new and different advances. Institutions of learning are presenting more comprehensive approaches to the next generation of health providers for them to reach traditionally underserved populations – **yes, even by insurance company payments for desensitization. •**

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References

1. Dittmann M. American Psychological Association. When health fears hurt health. Available from: https://www.apa.org/monitor/julaug05/fears Accessed May 5, 2020.
2. Fontinellee A. Where you live and work are just two factors that influence the price. Available from: https://www.investopedia.com/how-much-does-health-insurace-cost-4774184 Accessed May 16, 2020.
3. Google definitions: Systematic desensitization. Available from: https://www.dictionary.com/browse/google Accessed May 5, 2020.
4. McLeod S. Systematic Desensitization. Available from: https://www.simplypsychology.org/Systematic-Desensitisation.html accessed May 5, 2020.
5. Gold J. Health insurers are still skimping on mental health coverage. Available from: https:// www.npr.org/sections/health-shots /2017//11/29/567264925 29/567264925/health-insurers-are-still-skimping-on-mental-health-coverage Accessed May 7, 2020.
6. Barbash E. Reasons to not use insurance for mental health treatment. Available from: https://tampatherapy.com/2017/01/25/reasons-not-use-insurance-mental-health-treatment/ Accessed May 7, 2020.
7. Apple A. 10,000 Tenn. children could lose therapy as insurance companies deny telehealth coverage. Available from: https://www.msn.com/en-us/health/health-news/we-are-dead-people-with-disabilities-fear-they-will-be-on-losing-end-of-doctors-life-or-death-choices-amid-coronavirus-crisis/o Accessed May 8, 2020.
8. National Alliance on Mental Illness. What to do if you’re denied care by your insurance. Available from: https://www.nami.org/Your-Journey/Individuals-with-Mental-Illness/Understanding-Health-Insurance/What-to-Do-If-You-re-Denied-Care-By-Your-Insurance Accessed May 8, 2020.

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FINANCIAL PLANNING
THE ANNUAL ISSUE

ACHIEVE THE BEST RESULTS: START YOUR PLAN EARLY AND WORK STEP BY STEP

BY ALEXANDRA BAIG, MBA, CFP®

Better late than never applies just as well in financial planning as in any other field. Many of my clients come to me when their child with a disability is about to turn 18 because their child's transition team or another parent in their support group has told them that their child should apply for Supplemental Security Income (SSI) and Medicaid. But even though age 18 is an important inflection point, to be really successful, financial planning for your child with a disability must start much earlier, with the following steps at the following points

AT DIAGNOSIS you know that there is a possibility that s/he will need services in the future. Because some of those services will have asset and income eligibility criteria, the safest approach is to avoid putting assets in your child's name until s/he is closer to adulthood, and you have a sense of whether those means-tested benefits will be a necessary part of her/his financial support structure. Explain this to well-meaning friends and relatives to prevent cash gifts going directly to your child on the occasion of birthdays, holidays, religious ceremonies and similar.

SOON AFTER DIAGNOSIS it is a good idea for you, the parents, to engage in some basic estate planning. If there are grandparents or other relatives that plan to contribute financially to your child's future, they should as well. At the least, each responsible adult will want to have a will. If the family is not ready yet to create a stand-alone special needs trust for the benefit of the child with a disability, then the will of each responsible adult should contain language that would cause such a trust to be created if the death of the adult would otherwise result in the child with a disability inheriting assets directly. This kind of trust, which is triggered by the death of the grantor, is called a testamentary trust. Generally, creating a stand-alone special needs trust from the beginning is the most secure way to create your estate plan because it is difficult to embed in a will language complex enough to set up the special needs trust to accommodate a wide range of circumstances. Please consult an estate planning attorney with experience to create your wills and trusts.

THROUGHOUT CHILDHOOD AND ADOLESCENCE, you may need to invest a considerable amount of energy to master the process for requesting and effectively gaining services within your school district. Ideally, you will still reserve a little learning energy to begin to educate yourself on the workings of the adult service delivery and funding system while your child is still a child. Even the least functional school district is required by law to provide a certain level of services as an entitlement. There is no minimum entitlement in the world of adult services. Moreover, depending on your state, there may be a plurality of methods by which one applies for and manages services as well as more than one way that these services are funded. Each avenue may have its own rules. A complex system, such as the one we have in my home state of Illinois, is difficult to understand without repeated exposure via workshops and lectures. Your local ARC is a good place to start to obtain low cost, quality education.

AT THE AGE OF 14 AND A HALF your child will become eligible for transition services through your responsible public school district and/or special education cooperative. The transition years, between your child's age 14 and a half and your child's age 22 (or older in states that permit youth with disabilities to remain in the school system longer). Your child will make the strongest entry into adult life if her/his transition services are geared towards obtaining employment after high school.

AS YOUR CHILD APPROACHES 18, it is important to amass the evidence that your child's disability significantly impacts her/his capacity to work because the definition of "having a disability" that Social Security, Medicaid and other government programs use hinges on the applicant's capacity to work. It is critical, therefore, that your child's documents present accurately her/his need for supports and accommodations. It is perfectly possible, with descriptive language, to present in these documents, both your child's strengths and her/his support needs. For example, the IEP may state that:

- *"Joe gets As and Bs in his classes. Joe's assignments and tests are adapted by reducing the number of questions and Joe is allotted extra time to complete his work." Or…*
- *"Jane generally gets along well with her classmates and follows classroom instructions well. When Jane's anxiety and sensory processing challenges make her agitated, she moves to the sensory room and uses breathing techniques and listens to waterfall sounds on her iPad to calm herself down." Or…*
- *"Eric follows classroom instructions and completes his work with 2-3 verbal prompts from the instructor or classroom aid."*
- *It is particularly helpful if your child's school documents include concrete details about the supports your child requires in a work-type environment. To this end, it is extremely helpful for future benefits eligibility if your child's IEP can provide for on- or off-campus work experience during which an instructor or job coach collects data on both strengths and weaknesses.*

AT AGE 18, then, you will want to help your child apply for benefits. Typically, it is difficult for children under the age of 18 to qualify for disability benefits except in cases where the child is severely impacted by the disabling condition and/or a parent is elderly, disabled or deceased. This is because some of the key benefits are "means-tested," meaning in addition to having a disability, one must have low income and few assets to qualify. Prior to age 18, a portion of the income and the assets of the parents are "deemed" to the child and this deeming precludes the child's eligibility. Once the child turns 18, however, s/he can be considered a household of her/his own even if still living with parents. The Social Security definition of "having a disability," which is also the definition followed by most government programs is this. To be eligible, an applicant must have

- *A medically determinable physical, mental or emotion condition that is expected to last more than a year or end in death and,*
- *That condition must prevent the person from performing Substantial Gainful Activity (SGA), which is defined, for 2021, as the ability to earn $1,310/month or more from work activity.*
- *Most people are readily able to provide the medical evidence supporting the diagnosis. Where they fail is in demonstrating that the disabling conditions are significant enough to prevent them from performing SGA. This is where school records that accurately depict the supports your child does or would need to work become so crucial.*

In 35 states and the District of Columbia, Medicaid eligibility is conferred automatically with SSI eligibility. Nine states use the same eligibility criteria, even though one has to file a separate application. In all states, concurrent SSI and Medicaid eligibility allow a person with a disability to access Medicaid continuation programs even if their income from work or a parental-based benefit (described below) later exceeds the SSI threshold. Even if the SSI cash is not an integral part of the financial plan, the funding for services that comes through Medicaid or Medicaid waiver is generally a critical plan component and worth hundreds of thousands of dollars over the person's lifetime.

BETWEEN 18 AND YOUR STATE'S END-OF-TRANSITION AGE you will want to explore adult services to find out which one's your child may want to access, which agencies would be a good fit to provide those services, how much of them will be covered by your state's Medicaid waivers or other government programs and how much you may have to pay out of pocket.

WHEN YOU, THE PARENTS, RETIRE and begin to collect Social Security or a pension, you will want to understand how your adult child with a disability may be able to receive benefits based on your work history, either while you are still alive or, at least, if you die. Certain claiming strategies may maximize the benefits for the entire family for the remainder of each person's lifetime, so you will want to work carefully with a financial planner who has experience in this kind of analysis. You will also want to carefully consider how you will fund both your own retirement and long-term care needs and the ongoing support and quality-of-life expenses of your adult child that exceed what government benefits will cover.

Financial planning for your child with a disability is a lifelong project. Plans are most successful when you know what steps to take at each stage of your child's life and when you work together with a planner who understands the complex and sometimes state-specific worlds of government benefits and adult services. •

ABOUT THE AUTHOR:

Alexandra Baig maintains her own national financial planning practice, Companions on Your Journey, and also acts as the Benefits Specialist for Clancy & Associates, a Chicago-based law firm focusing on special needs planning. Alexandra 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. 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.

FINANCIAL PLANNING
THE ANNUAL ISSUE

FINANCIAL PLANNING FOR LIFE'S PRESSURE POINTS

BY JOHN W. NADWORNY, CFP®, CTFA

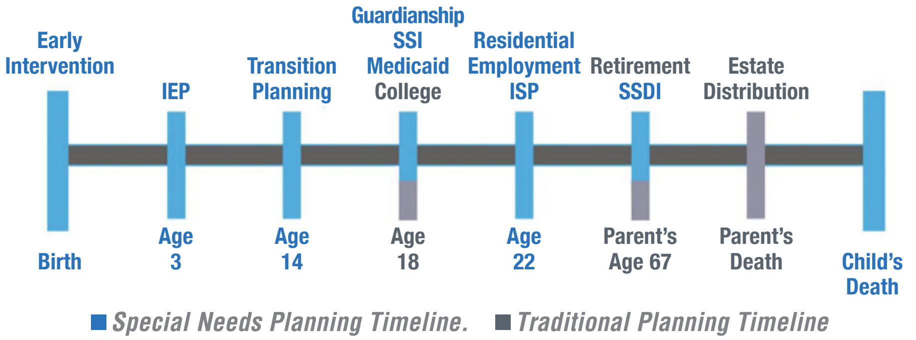
As a parent, one of the great advantages of planning for the future is that it provides you with a tangible guide to keep your energy and actions focused on specific goals and challenges at each stage of life for your family. Even with all of life's uncertainties, a plan will map out the time periods of change, what our practice calls planning pressure points, that lie ahead. This gives you the invaluable tool of time to prepare financially, legally, and emotionally.

WHILE WE RECOGNIZE THAT EACH FAMILY'S CIRCUMSTANCES ARE UNIQUE AND OUR BUSY LIVES ARE OFTEN COMPLICATED, HERE ARE A FEW PRACTICAL AND ACTIONABLE TIPS TO HELP YOU DEVELOP A PLAN.

THE SPECIAL NEEDS PLANNING TIMELINE

When your child receives a diagnosis, regardless of their age, your life will most likely begin on a different course than you had anticipated. To help you chart a path for all the members of your family's future, we developed the Special Needs Planning Timeline™.

Chart 1. *The Special Needs Planning Timeline*



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The timeline will provide you with an overview of the key planning pressure points in the lives of all your family members. For example, finding the time when your mortgage will be fully paid and/or when you might begin to receive social security benefits on the timeline, will help you to visualize the stage of life for your child with special needs. You may not know the details of your financial situation at that time, but you can start to build a framework and budget for the future.

PLANNING TIPS TO THINK ABOUT AT EACH STAGE

Birth to age 3 ~ All in the Family: While it may sound odd coming from a financial professional, our first piece of advice to new parents is to focus on your child. When a child receives a diagnosis at birth or an early age, it is key for parents to focus their energy on their child's and their family's needs.

Early intervention (EI) services are individualized and family-driven; take advantage of this time to build a framework for the future. Initial steps to focus upon include:

- Plan for catastrophic events. Create a basic estate plan and include a special needs trust. Purchase life and disability insurance.
- Complete a Letter of Intent (LOI). The LOI contains the details of daily living and specific instructions necessary to care for your child. This is information a caregiver needs to have just in case the unthinkable happens. Download a fillable Letter of Intent at https://info.specialneedsplanning.com/en-us/parents-guide-to-the-special-needs-letter-of-intent
- Learn who provides the services and supports your child requires, what agencies are involved and who pays for them. A helpful resource: Talking the Talk: Terms and Acronyms Frequently Used in the Disability Community (https://info.specialneedsplanning.com/blog-1/do-you-talk-the-talk).
- Network. The personal and professional relationships you form when your child is young will many times deepen and endure throughout both your lifetimes.

Ages 3-14 ~ Welcome to School: When your child enters school, it may feel as though you have lost control and the professionals have taken over. In addition to advocating for an appropriate educational program and facilitating a social life for your child, there are subtleties to be conscious of.

- It is important to identify allies to help you advocate for your child.
- Be aware that there are individuals in the school setting whose philosophies about your child's development will differ from yours.
- Review your overall financial situation.
- Begin to save on a regular basis.
- Maximize the benefits your employer offers.

Age 14 ~ Your Child is Transitioning into High School and Government Benefits: Begin planning for your child to enter the world of adult services. At age 18, in the eyes of the law, your child is no longer a child. It is important to plan in advance for this birthday as there are various legal and financial issues that will affect their eligibility for government benefits.

- Be sure your child has no more than $2,000 in their name (see Federal Benefits below).
- Begin to consider the steps needed for guardianship or alternatives and supported decision making, if appropriate.
- It is easy to get overwhelmed thinking about your child's lifetime needs. Concentrate on planning for your own financial security first. Developing disciplined savings habits for yourself will allow you to continue to save for your child as they grow.

Ages 18-22+ ~ Your Child is Transitioning to Adult Services AND You Are Able to Save: At age 22, your child's entitlements through the education system will end but they may now be eligible for various government benefits.

Understanding the Basics of Government Benefits: There are 2 types of government benefits: entitlement programs funded by the Federal government and non-entitlement benefits funded by state governments through appropriation. It is important to know and understand the differences.

Federal Government Benefits ~ Entitlements

- If your child meets the definition of disabled by Social Security AND the income and asset test (No more than $2,000 in your child's name) they are eligible for needs-based entitlement programs.
- The second type of entitlement benefits require that the parent or the individual themselves have contributed to the fund.

Entitlements: Needs Based	Entitlements: If Contributed
Supplemental Security Income (SSI)	Social Security (SSDI)
Medicaid	Medicare
Premium Reimbursement	Veterans Benefits
Adult family Care (AFC)	Federal & Military Benefits
Personal Care Assistance (PCA)	Civil Service Benefits

State Government Benefits ~ Non-entitlements

Your state of residence may appropriate the funding necessary to pay for the following non-entitlement programs. Since funding is limited, individuals may often be prioritized. Understand the process your state follows and advocate in advance.

Non-Entitlement Programs
Housing subsidy- under Housing and Urban Development or HUD
Rental subsidy – under Section 8 housing- HUD
Flexible family supports
Residential supports
Transportation services
Adult day service programs
Supported employment services

For more information, read How to Identify, Maximize and Protect Government Benefits at https://info.specialneedsplanning.com/en/en-us/identify-maximize-and-protect-eligibility-for-government-benefits

At this point, the goal is to have set aside savings to help secure your future and that of your adult child with a disability. There are numerous financial planning techniques to consider that will combine government benefits with your personal resources to fund a full life for your child. Here are a few examples of creative uses of common planning tools.

SPECIAL NEEDS PLANNING STRATEGIES

Combining Personal Resources and Government Benefits ~ The ABLE Account: The ABLE or 529 (A) account is a tax- advantaged account for individuals with disabilities to save to help support their health, independence, and quality of life.

Keep in mind that the ABLE was designed primarily as a savings vehicle, not an estate planning tool. Here are a few examples of how an ABLE account may be used in special needs planning. All examples are subject to the rules and regulations governing ABLE accounts; please refer to the ABLE National Resource Center at www.ablenrc.org or nast.org for details.

- The ABLE allows the account owner to have savings in their name.
- The diagnosis of a qualifying disability must be prior to age 26.
- Families have added flexibility in their savings as they are able to transfer money from a 529 College Savings Plan to a 529(A) ABLE account.
- Money in an ABLE account may be used to pay for housing expenses without impacting the owner's social security benefit. A Special Needs Trust (SNT) may distribute funds to a beneficiary's ABLE account which may then be used to pay for their rent or other housing and qualified expenses.

Using Life insurance to Fund a Special Needs Trust (SNT): There are two ways to fund a Special Needs Trust with life insurance.

1. Make a properly drafted SNT the beneficiary of the life insurance policy. This may result in the proceeds being included in the insured's estate. In some states, there may be estate tax due.
2. When it is important to exclude life insurance proceeds from the insured's estate for tax purposes, Crummey provisions may be used. We suggest working with a qualified estate planning attorney to determine the best structure to use.

Special Needs Trusts (SNTs) and Retirement Accounts ~ The Roth IRA: A Roth IRA is a retirement account funded with after-tax dollars. The contributions are not tax deductible but when you start withdrawing funds, qualified distributions are tax-free. There are many rules and restrictions that apply to a Roth IRA as detailed by the IRS (www.irs.gov/retirement-plans/roth-iras).

Grandparents (and parents) should consider a Roth IRA for themselves, rather than funding an ABLE Account, when thinking about gifting options. A Roth IRA would allow the account owners to save with tax-free growth and retain control of the contributions, enabling them to allocate and use the funds when they choose and for any purpose. They may consider making a SNT the beneficiary.

Qualified Retirement Plans – It is important to review the beneficiary designations of your retirement plan accounts. With recent changes from the SECURE Act (effective 1/1/2020), there may be advantages in your personal planning to name your child's qualified SNT as a beneficiary. Individuals with disabilities who have a qualifying SNT meet the IRS definition of exception beneficiaries.

We hope you have found this information to be helpful. As each family's situation is unique, we recommend working with an experienced and knowledgeable Certified Financial Planner Professional (CFP®), Chartered Special Needs Financial Consultant (ChSNC ®), CPA, or attorney before implementing the financial planning ideas above. We have additional information and significant resources to help families plan available for free on our website, Special Needs Financial Planning at www.specialneedsplanning.com

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FINANCIAL PLANNING
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TAX LEVERAGED FINANCING OPTIONS FOR MEDICAL EXPENSES INCURRED BY FAMILIES CARING FOR THOSE WITH SPECIAL NEEDS:

ARE HOME EQUITY LOANS AND RETIREMENT PLAN DISTRIBUTIONS STILL VIABLE UNDER RECENT LEGISLATION?

BY THOMAS M. BRINKER JR., LL.M., CPA

As the number of children diagnosed with autism, Asperger's syndrome, and other intellectual disorders continues to skyrocket, the lives of all of those concerned are dramatically impacted. Recent statistics indicate that as many as 1 in 54 children born today have an autism spectrum disorder (Centers for Disease Control, March 27, 2020… citing an increase from 1 in 59 according to the CDC on April 26, 2018 and 1 in 68, according to the CDC on both March 28, 2014 and March 31, 2016 with boys 4 times more likely to be identified with an ASD than girls).

In addition, the CDC cites in this same 2020 report that about 1 in 6 (17%) of all children aged 3 to 17 have been diagnosed with a developmental disability (such as autism, ADHD, blindness, and cerebral palsy among others) with almost 1 in 4 American adults nationwide having a disability. Parents caring for those with special needs are often unaware that substantial tax benefits may be available to them and often forego hundreds, if not thousands, of potential tax deductions and reductions in their tax liability. Although we have previously focused on the expanded definition of medical care as an income tax deduction and other tax benefits for our families, another reality inevitably surfaces… finding the wherewithal to finance these expenditures. Parents of children with special needs quickly discover that medical care expenditures for their child can prove astronomical. As a result, parents and their advisors need to become familiar with some unusual Internal Revenue Code provisions

that may assist in and/or hinder this process. This article focuses on two common resources often utilized in financing medical care: home equity loans and distributions from retirement plans and individual retirement accounts (IRA).

OVERVIEW OF THE MEDICAL EXPENSE DEDUCTION

Only individuals itemizing deductions on their federal individual income tax returns can claim a medical expense deduction. Unreimbursed medical expenses are currently deductible only to the extent they exceed 7.5% of a taxpayer’s adjusted gross income or AGI as of 2017 (Sec. 213(a)). The 7.5% AGI threshold represents a permanent reduction in the AGI threshold as of 2021 under December of 2020’s Taxpayer Certainty and Disaster Tax Relief Act of 2020 (The Tax Cuts and Jobs Act “TCJA” had reduced the threshold for deducting medical expenses from 10% of AGI to 7.5%, but only for 2017 and 2018 originally with extensions of the 7.5% threshold occurring thru 2020.) Alternatively, parents who are eligible to participate in tax-advantaged plans through their employers for funding medical expenses, such as flexible spending accounts or health savings accounts, can set aside limited amounts of money to finance medical care expenses on a pre-tax basis while bypassing the AGI limitation. Unfortunately, pre-tax contributions are currently limited to $2,750 as of 2020, receiving annual indexed adjustments for inflation (Patient Protection Act, as amended by the Health Care and Education Reconciliation Act of 2010).

FINANCING OPTIONS FOR THE MEDICAL EXPENSE DEDUCTION

Treasury Regulation 1.213-1(e)(1)(v) permits the unreimbursed cost of attending a *special school* for an individual having an intellectual or physical disability as a medical expense deduction if the principal reason for the individual's attendance is to alleviate the disability through the resources of the school or institution. This deduction may also include amounts paid for lodging, meals, transportation, and the cost of ordinary education incidental to the special services provided by the school. Also, any costs incurred for the supervision, care, treatment and training of an individual with a physical and/or intellectual disability are deductible if provided by the institution. Unfortunately, it is not uncommon for this expenditure alone to exceed tens of thousands of dollars.

Furthermore, qualifying capital expenditures, medical conferences and seminars, prescribed vitamin therapy, therapeutic assistance, various therapies, and special diets can add thousands of dollars to the medical expense deduction annually.

Barring savings, investments, and extended family assistance, many parents caring for children with special needs are often left with few choices for financing their child’s medical expenses and resort to home equity loans and retirement plan distributions. These rules also apply to any taxpayer with significant unreimbursed medical expenses.

ARE HOME EQUITY LOANS STILL A VIABLE SOLUTION?

Families commonly borrow against their homes in financing their medical expenses. Although interest expense incurred on a home equity loan is no longer deductible as an itemized deduction, there are exceptions as discussed below.

In general, home equity loans represent borrowings other than the indebtedness incurred in acquiring a principal residence and/or a second home. Under prior law, in order to qualify the interest expense for an itemized deduction, the tax law limited home equity indebtedness to the lesser of:

- The excess of the fair market value of the qualified residence (principal and/or second home) over the balance of the original/acquisition indebtedness incurred with respect to the residence(s), or
- $100,000 with a $50,000 limit for married couples filing separately (Sec. 163(h)(3)(C)).

The $100,000 limit, as well as the $1,000,000 limit on acquisition indebtedness, was applied on a per-taxpayer basis, and not as a per-residence limitation. These are separate limitations. The maximum amount of indebtedness qualifying for a mortgage interest expense deduction was therefore $1,100,000 ($550,000 for married couples filing separately) under prior law (Sec. 163(h)(3)).

Under the TCJA, the rules have changed (See Sec. 163(h)(3)(F): “Special Rules for taxable years 2018 through 2025”). As of 2018, the home mortgage interest deduction is limited to acquisition indebtedness of $750,000 (from prior law’s $1,000,000) for homes acquired after 2017. Further, the home equity loan interest deduction is being suspended through 2025. As of 2018, parents seeking an interest expense deduction for home equity indebtedness will only be permitted a deduction if the loan is to purchase, construct, or substantially improve a residence. A home equity loan interest deduction will be permitted if the parents secure the loan for medical capital expenditures (i.e., substantially improving the home) made to the home in accommodating the child with special needs (with total indebtedness limited to $750,000). However, utilizing a home equity loan to finance ongoing medical care will not result in an interest expense deduction.

EXAMPLE:

Michael Cynthia Plear made a $200,000 down payment and borrowed $550,000 to purchase a residence worth $750,000 in 2015. Their home is currently valued at $925,000 with an acquisition debt remaining of $500,000. In 2020, they borrow $200,000 to provide for the ongoing medical care of their 16-year-old daughter with special needs, and use their residence to secure this note.

They may deduct interest on the $500,000 of remaining acquisition debt only unless the $200,000 home equity loan was utilized to improve the home, such as a medical capital expenditure (e.g., installing an elevator or therapeutic swimming pool, constructing entrance ramps, widening doorways and halls, lowering kitchen cabinets, and adding railings.)

ARE RETIREMENT PLAN AND IRA DISTRIBUTIONS THE ANSWER?

In addition to obtaining home equity loans, families caring for children with special needs often take early distributions from their retirement plans, IRAs, and annuities to finance their medical expenses. Although a 10% penalty exists as a disincentive for early retirement and pre-retirement withdrawals (i.e., prior to age 59 ½), there are exceptions to the penalty for distributions not in excess of the medical expense deduction.

The 10% penalty does not apply to distribution amounts that are less than or equal to an individual's allowable medical expense deduction in excess of 7.5% of AGI *(regardless of whether the individual actually itemizes deductions)* if the distributions are used to pay for the medical care during the year (Sec. 72(t)(2)(B)). The penalty waiver only applies to that component of the distribution which is included in gross income. The income tax still applies to the taxable component of the distribution. The law does not require that individuals first deplete the 10% penalty exception for medical care by using the non-taxable component of a distribution, such as a non-taxable return of investment (Argyle v. Commissioner, T.C. Memo, 2009-218). A Form 5329 with an accompanying medical expense worksheet (or Schedule A for itemizers) must be attached to Form 1040, indicating Exception 5 on Line 2 of the Form.

LIGHTENING THE LOAD: It is important to understand that substantial tax benefits are available to those caring for children with special needs.

EXAMPLES:

1. **Without Itemizing Deductions and Claiming the Standard Deduction:** Mr. and Dr. Nolan, both age 50, have an AGI of $40,000 for the year 2020, which includes an early retirement plan distribution. The Nolan family incurs and actually pays $9,500 in qualifying medical expenses during the year. The allowable medical deduction will be the amount of medical expenses that exceeds 7.5% of $40,000 or $3,000. Although the Nolans claim the standard deduction of $24,800 for 2020, their allowable medical expense deduction for 2020 would have been $6,500 ($9,500 in medical expenses less $3,000) had they itemized deductions on their Schedule A. In this example, a $5,000 taxable distribution from an IRA or retirement plan would not be subject to penalty. However, if the taxable distribution was $8,000, only $6,500 would escape the 10% penalty. The balance of the distribution, $1,500 will be subject to a 10% penalty of $150.

2. **When Itemizing Deductions:** Dr. and Mrs. Kim, both age 40, have an AGI of $150,000 for the year 2020, which includes an early retirement plan distribution. The Smiths incur (and actually pay) $27,500 in qualifying medical expenses during the year. The allowable medical deduction will be the amount of medical expenses that exceeds 7.5% of $150,000 or $11,250. Their allowable deduction for 2020 is $16,250 ($27,500 in medical expenses less $11,250). In this example, a $15,000 taxable distribution from an IRA or retirement plan would not be subject to penalty. However, if the taxable distribution was $21,000, only $16,250 would escape the 10% penalty. The balance of the distribution, $4,750 will be subject to a 10% penalty of $475.

Note: The key to this penalty exception in both examples – The taxpayers must have actually paid the medical costs during the year. ***However, there is a caveat: to the extent the distribution is included in gross income, AGI increases, reducing the medical expense deduction and increasing the distribution's exposure to the penalty!***

It should also be noted that with regard to an IRA distribution, the law applies the medical expense exception before other exceptions; notably, the first-time homebuyer and education exceptions (Sec. 72(t)(2)(E) and (F)). As a result, families with significant unreimbursed medical expenses may wish to consider utilizing the medical expense exception first with regard to retirement plan distributions, availing themselves of the first-time homebuyer and educational exceptions under the IRA distribution rules (Blankenship, Vorris "Retirement Plans, IRAs, and Annuities: Avoiding the Early Distribution Penalty" The Tax Advisor, April 2011, p. 260).

CONCLUSION

This article provides a brief overview on the medical expense deduction and two common tax-savings opportunities in financing the medical expense deduction. As parents and advisers, it is important to understand that substantial tax benefits are available to those caring for children with special needs and the medical care financing options available that provide either a tax incentive or disincentive.•

(Reprinted in part with permission from MassMutual's SpecialCare Spring 2020 Newsletter)

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INDIVIDUALS WITH DISABILITIES HAVE BEEN STRUGGLING AS COVID-19 HAS EXACERBATED HEALTH AND FINANCIAL DISPARITIES.

HOW BUILD BACK BETTER WILL HELP PEOPLE WITH DISABILITIES

BY LAUREN AGORATUS, M.A.

A recent op-ed, "The cost of staying alive is driving us into poverty," highlighted our present difficulties, and is particularly applicable to the disability community. The op-ed notes that Americans can't afford the healthcare they need.

The cost of all medical services – hospitalization, surgery, medical supplies, durable medical equipment, and doctor visits/specialists – continues to rise. According to the *Journal of the American Medical Association,* medical debt has risen to $140 billion. Medical debt is the single largest cause of bankruptcies. Up to 2/3 of families who file for bankruptcy attribute medical debt as the cause.[1] This is especially true in states that did not expand Medicaid under the ACA (Affordable Care Act).

Building on the success of Medicare and Medicaid, and expanding these programs, can help. This would mean expanding eligibility to the uninsured. One proposal would be to expand current Medicare benefits. Increasing Medicaid services, and also adding broader Medicaid coverage in the states that did not expand Medicaid under the ACA, would also help.

The White House plan, "Build Back Better," has a section on healthcare which will positively impact people with disabilities. These proposals include:

- **Reducing insurance premiums:** This would save each family member approximately $50/month.
- **Adding benefits to Medicare:** This would include coverage for vision, hearing, and dental care.
- **Closing the Medicaid gap:** This would include states that did not expand Medicaid under the ACA.
- **Expanding Medicaid HCBS:** Home and Community Based Services keep individuals with disabilities in their homes with community-based supports, and out of institutions. This is probably the most important topic for self-advocates and their families.
- **Direct Service Providers:** Improving pay and jobs would increase the workforce supporting people with disabilities as there is currently a national shortage of home care workers.

Families and self-advocates can examine these issues, see which are most important to them, and advocate for those policy improvements. Measures to decrease healthcare burden, reduce poverty, and improve community inclusion will benefit individuals with disabilities and their families. •

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is a parent of a medically-complex young adult and serves as the Coordinator for Family Voices-NJ and as the regional coordinator in her state's Family-to-Family Health Information Center, both housed at the SPAN Parent Advocacy Network at www.spanadvocacy.org.

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[1] https://www.cnbc.com/2019/02/11/this-is-the-real-reason-most-americans-file-for-bankruptcy.html

STACKING UP : BUILD BACK BETTER RESOURCES

nj.com True Jersey.

NJ ONLINE OP-ED

www.nj.com/opinion/2021/07/the-cost-of-staying-alive-is-driving-us-into-poverty-opinion.html

JAMA

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION

Network information on medical debt

https://jamanetwork.com/journals/jama/article-abstract/2782187

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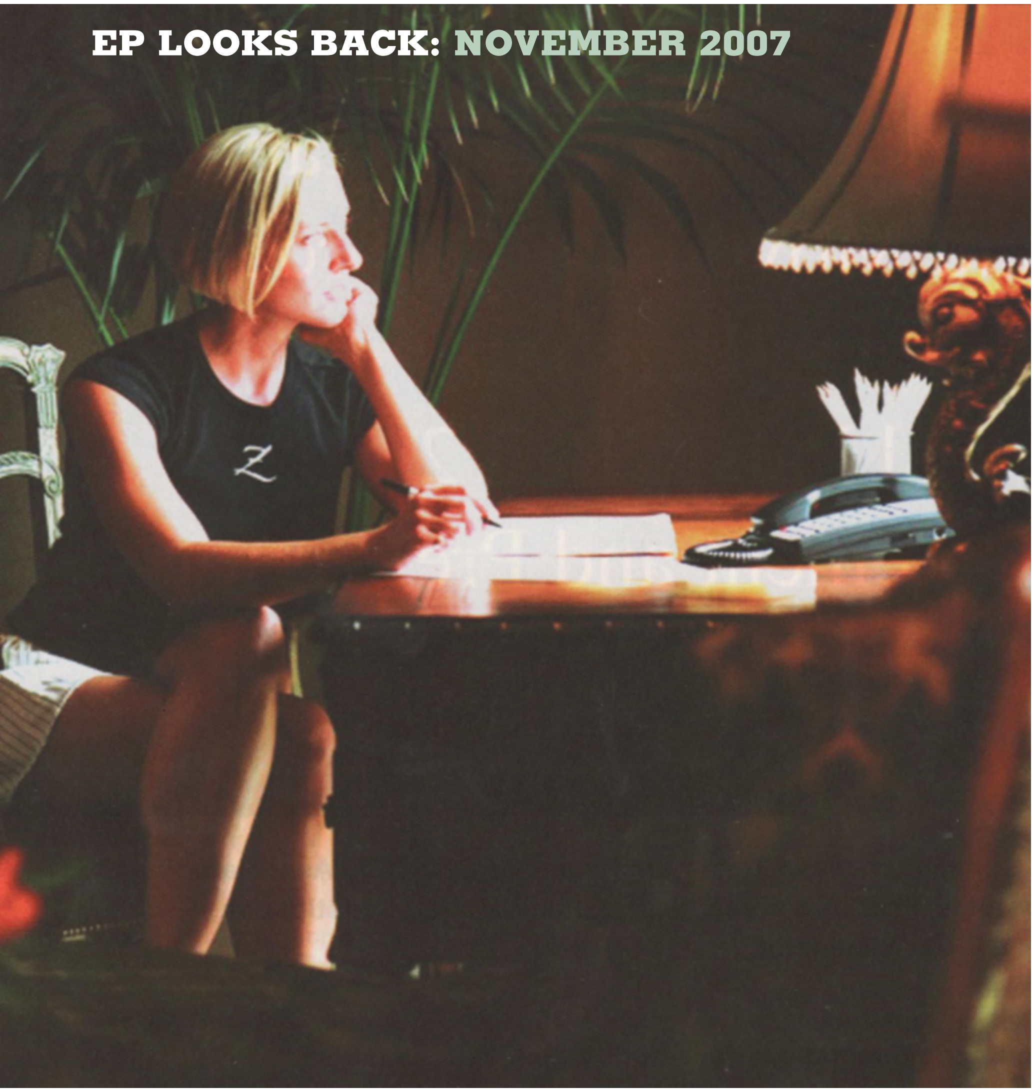

Securing Your Family's Financial Future

By Joanne M. Gruszkos, Director, Special*Care*^{SM} Program

You've now accepted the reality of the diagnosis. You've navigated a bewildering maze of medical specialists and insurers. You've learned a new language of tests, assessments, and therapies. You've taken on grinding battles with school districts. And, finally, you have created an environment in which your child with a disability or other special need can live productively and happily.

Now, ask yourself this one important question: If something happened to you, your spouse, and/or other caregiver whom you depend on tomorrow, what would happen to your child and the world you've created for him or her?

Who would take care of your child? Do those people know that you're expecting them to take over? Would they know what co do? Would they be up to the task? Would they understand your child's special personality? Would they be aware of your hopes, dreams, and plans for your child? Would they have the financial means to support your child in the manner that you would want? Would they be equipped to balance the needs of your other children as well?

If those questions feel overwhelming, it's OK, because they are. That's why many dedicated and caring parents understandably postpone, do very little or nothing at all in the area of creating a life care plan or preparing financially for the future. The challenges of the present are often so monumental as to discourage any thought of the future. Yet addressing these questions is a critical step in care giving, not only for your child with special needs but for other family members and yourself as well.

Tuke comfort. With knowledgeable help, you can create a life care plan to put your family on sound financial footing today and prepare your family for a secure future tomorrow.

You're not alone in facing this need. Nearly seven percent of the population in this country has at least one physical, mental or emotional disability, according to the U.S Census. Many of these Americans require lifelong support and, furthermore, are outliving their parents thanks to improved care and advances in medical technology. As a result, parents and caregivers are increasingly faced with the prospect of providing support – even after they have died – to their loved ones with a disability.

Getting started is not as hard as you might think. Here are a few first steps to help you get going.

GET HELP. This isn't a "do-it-yourself" job. Preparing a life care plan for the financial future and security of your family and child requires specialized expertise and working with a financial professional who specializes in special needs is a wise move. In securing a financial services professional. make sure the person you work with is qualified, experienced, and involved in the area of special needs.

> ***If you are under-prepared for retirement and, as a result, begin pulling retirement income out of the resources you intend to be part of your estate, you will undermine your best-laid plans.***

BUILD A TEAM. It is important that the family seek out advisors who embrace the team planning approach to ensure proper coordination of all efforts. Besides a financial professional, you will need an attorney (preferably one who is experienced in special needs planning), a CPA, and others, such as social workers and medical professionals, all working together. A financial professional should be able to refer you to qualified professionals and will welcome working closely with them on your behalf. If the financial professional you're considering resists working closely with these other professionals, you might consider looking for a new financial professional.

WRITE A LETTER OF INTENT. Although not a legal document, a letter of intent provides you with an opportunity to put in writing important information such as your child's routines. important contact information, medical issues, your preference for how the child should be schooled, your desire for raising your child within the traditions of a specific religion, and other such matters. Preparing this letter can be a clarifying and edifying process that causes parents to crystallize their intentions and verbalize their sentiments, leaving little to interpretation for the future caregiver. The letter is a "living" document that you will update frequently to reflect changing information or preferences. Financial professionals who specialize in special needs usually have sample letters of intent they can provide to get you started. You also can obtain a CD with a sample letter of intent that you can customize by visiting www.massmutual.com/specialcare.

PICK A SUCCESSOR CAREGIVER. Many families simply assume a child's aunt or uncle or sibling will step in as a primary caregiver should anything happen to the parents, but assuming so without verifying is a dangerous proposition. Sometimes family members do not feel emotionally or psychologically equipped for the task. Sometimes they might be prepared for one aspect of the job, e.g. providing daily care, but not for other aspects of the job, e.g. managing finances. In fact, families sometimes split duties among two or more people. So, for example, one trusted person could become the primary caregiver to your child while a second trusted person could manage money. Whichever decision you make, decide carefully. Be certain that the person or people you choose can do the very difficult work before them.

CONSIDER A SPECIAL NEEDS TRUST. Many parents may be unaware that if their child were to inherit as little as $2,000 in assets they could be disqualified from many governmental programs, such as Medicaid or Supplemental Security income. A special needs trust, if properly structured, is a mechanism that provides for the child without jeopardizing his or her benefits. For example, a trust can be funded by a donor – usually a parent, sibling, or guardian and the trustee can manage assets in the best interest of the trust's beneficiary, in this case the child. Because the assets are owned by the trust, the child still remains eligible for government programs. A trust can fund a wide range of supplemental needs, such as transportation, equipment, education and rehabilitation, to name a few. There are many ways to fund a trust account; one common one is life insurance.

WRITE – OR RE-WRITE – YOUR WILLS. Assuming you create a special needs trust, write or re-write your wills to ensure that they coordinate with the trust and your other planning documents. The wills will dictate how you want your estate to be distributed, and by coordinating with the trust, you will avoid unintentionally harming your child's eligibility for governmental programs.

ONE FINAL PIECE OF ADVICE: DON'T FORGET YOURSELF OR OTHERS IN YOUR FAMILY. As parents who spend every waking hour – and many of the hours you're supposed to be sleeping, too – worrying about or caring for a child with a disability, it often is possible to overlook your own financial needs, such as retirement, and/or those of your other children. All of these needs are related and can impact each other. For example, if you are under-prepared for retirement and, as a result, begin pulling retirement income out of the resources you intend to be part of your estate, you will undermine your best-laid plans.

A truly effective life care plan will address not only the needs of your child with disabilities, but also the needs of the whole family, securing your and their financial futures.•

Joanne M. Gruszkos is responsible for creating and developing Massachusetts Mutual Life Insurance Company's (MassMutual) SpecialCare^{SM} program, offering information, specialists. and financial solutions for people with disabilities and other special needs and their families. A sales and marketing professional at MassMutual for many years, Joanne has created a variety of marketing initiatives to help financial services professionals reach their targeted audiences. She holds industry certifications and securities licenses and most recently earned the certification of "Special Care Planner" from The American College in Bryn Mawr, PA.

SENSORY INTEGRATION IN MEDICAL CARE

BY BEN HUDSON

Equality in care demands a focus on sensory needs.

Imagine going to a fancy restaurant. There's soft lighting, quiet background music, and comfortable seating.

Now imagine that same restaurant, but lit like a Home Depot.

No matter how incredible the food tastes, the harsh warehouse lighting completely transforms the experience.

All of us have sensory preferences and expectations which impact how we relate to our environments. These preferences influence the way we organize our workspaces, our homes, and our lives. When we design spaces to be used by others, we must take these concepts into account.

For individuals with developmental disabilities, certain sensory environments can cause extreme distress, requiring potentially injurious interventions and increasing the likelihood of lasting trauma. According to the CDC, one in six children in the United States is impacted by a developmental disability. The population of people with sensory needs expands to include adults with developmental disabilities, and individuals with PTSD, dementia, and Alzheimers. Most medical environments do not account for the sensory environment, creating a significant barrier to healthcare for this population.

COMMON SENSE: Most medical environments do not account for sensory environment, creating a significant barrier to healthcare for this population.

A person with sensory needs has difficulty integrating external stimuli from the environment. What a neurotypical person may find annoying but tolerable – the low drone of a fluorescent tube, the bustle of a crowd, the buzz of a dental drill – can be physically painful to a person with sensory needs.

In recent years, there has been a push for more inclusive medical education. Groups such as the American Academy of Developmental Medicine and Dentistry (AADMD) work with institutions to improve provider understanding of developmental disabilities. Better education helps providers understand this population and feel empowered to provide care to the best of their abilities. Better medical understanding plays a role in increasing access to quality care for this population, but strict medical education is just one piece of a larger puzzle. To truly address barriers to care, we must combine education with a focus on sensory environments.

Going to the doctor can be stressful for everybody. Setting aside the reason for the visit, which may be a stressor on its own, a typical clinical environment introduces a barrage of new sensory inputs. Evidence suggests that many of the behaviors deemed difficult by providers are a result of negative reactions to sensory stimuli. No amount of provider education and training can prevent a stress reaction to an unchangeable environment. Only by altering the environment to better accommodate the patient can we lower these risks.

MEDICAL HISTORIES

We rightfully include allergies in a patient's medical history so as not to present a treatment option that will do more harm than good. For patients with sensory needs, the physical response to negative sensory stimuli is just as critical to developing a treatment plan. An unaccommodating sensory environment leads to potential distress. A patient in distress is much less likely to receive a diagnosis and, therefore, a treatment plan.

Why, then, do we not include a patient's sensory profile in their medical record? Patients and their caretakers know that works best for them; they are the experts and would happily provide this information if asked.

In a 2016 study published in the *Journal of Pediatric Healthcare,* providers were given a "Quick Tips Card" in advance of seeing pediatric patients with autism. The card was provided by parents and gave information around the child's likes and dislikes, sensory triggers, and communication abilities. Of the providers who participated, 73% of them found the child's sensory dislikes to be valuable information, and over 85% highlighted the importance of knowing both what upsets and calms the patient.

Patients and caretakers are the ultimate authorities of their own histories. We must use this information in our push for more equitable care.

EMERGENCY CARE

Neurodiverse patients require emergency room services at a higher rate than neurotypical patients for a variety of reasons, including higher rate of self-injurious behavior and difficulty finding adequate primary care providers. From the moment a patient enters an emergency room, they are presented with unfamiliar sights, sounds, and smells. No matter how well-trained the ER staff may be, the sensory environment is unwelcoming, frightening, and potentially physically painful to a patient with sensory needs.

As the last resort for patients who cannot find care in other areas, it is incumbent upon emergency departments to take sensory needs into account. A handful of emergency departments around the country have developed incredible sensory-friendly ERs due to the

MINOR CHANGES, BIG IMPACT : IMPROVING SENSORY-FRIENDLY CONDITIONS IN HEALTHCARE SYSTEMS

In order to build a more sensory-friendly healthcare system, we must understand that there is a middle ground between the standard environments of today and the full-blown multi-sensory environments we see in therapeutic practices. It would be unreasonable to expect a small medical practice to purchase potentially tens of thousands of dollars of specialized equipment and learn how to effectively operate it. For healthcare providers to see the value of becoming more sensory-friendly, it helps to understand how small adjustments to their medical environments can go a long way. Creating a common baseline expectation gives all parties more confidence in a successful appointment.

LIGHT

A majority of office environments rely on fluorescent lighting. These lights are inexpensive, long-lasting, and have long been accepted as the norm. However, these lights are highly likely to trigger a negative response in an individual with sensory needs. Before considering a large outlay on specialty equipment, examine the lighting in the space and consider full-spectrum, flicker-free LED lights. While slightly more expensive, these lights have been shown to have positive effects on individuals with anxiety symptoms, and can make a clinic more accommodating from the moment the patient walks into the waiting room.

SOUND

Medical equipment makes noise. We can prepare the patient for what type of noise to expect, but we cannot necessarily eliminate it. We can, however, make the ambient noise environment in the exam room more pleasing with something as simple as a white noise phone app. Asking the patient or the patient's caretaker in advance of the appointment what sounds they find relaxing can create a sense of calm upon entering the exam room.

FEEL

A patient must be allowed to feel secure in their body, especially in a medical setting where personal space will be encroached upon. Simple things such as fidget toys, weighted blankets, or even a favorite stuffed animal from home all foster a comfortable space where the patient's sensory needs are respected.

Not every practice has control over every aspect of the environment. Perhaps there's a shared waiting room full of sensory triggers standing between the hallway and the sensory-friendly exam room. Are there other entrances? Can the patient wait in the car until the exam room is ready and go straight there? Some providers may even have the flexibility to block a few hours for only their patients with sensory needs, so as to ensure a quieter, less crowded office setting.

There is no one right way to create an accommodating environment. The previous paragraphs provide general guidelines and will become more refined as these environments become more widespread. Of utmost importance for providers at this stage is to involve the patient and their support network in the process, to be adaptable based on patient needs, and to realize that even small steps make a meaningful difference.

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tireless efforts of nurses and advocates within those institutions.

Methodist Children's Hospital in San Antonio, for example, recently redesigned its entire pediatric emergency department. Exam rooms are equipped with adjustable lights and a suite of interactive objects, and previous patient preferences are included in the medical record for future visits. Additionally, child life specialists are more involved in every step of the process to ensure understanding and comfort for both child and caretaker.

While these developments are encouraging, relying on individuals to drive needed widespread adoption will take time that individuals with sensory needs do not have.

RIPPLE EFFECTS

By increasing the number of providers who are equipped with both with the medical training and a sensory-friendly environment, we can begin to give this population something they have historically not had: a medical home.

Rather than a physical space, a medical home is a patient-centered approach that seeks to provide a patient with comprehensive, coordinated care so that care is delivered in a way that meets the patient where they are. A medical home can be a safe place for a patient with a developmental disability, building trust over time and enabling more treatment to occur in the office setting as opposed to the emergency room or under sedation.

Enabling more care to take place in a regular office setting can help reduce the trauma this population commonly experiences when receiving healthcare. As we push to better educate the next generation of providers, we must develop and promote their understanding of environmental impacts on their patients. Awareness of sensory needs are important for all patient groups, not just those with developmental disabilities. Incorporating sensory profiles into our general understanding of medical care will benefit everyone, including the staff.

The national conversation around developmental disabilities has changed dramatically. Neurodiversity is a mainstream term, and popular shows like Love on the Spectrum attempt to bring awareness to the neurotypical population. With this broader cultural awareness comes more attention to the areas where systems and historical structure have fallen short. We must take full advantage of this moment and demand inclusive, sensory-friendly care for all patients.•

ABOUT THE AUTHOR:

Ben Hudson is the CEO and Co-Founder of Sensory Health. Sensory Health is building a national network of sensory-friendly healthcare providers to remove barriers to care for patients with sensory needs.

If you get caught staring, smile and say, "I'm sorry for staring."

That's it. That's the beginning of choosing kindness.

Smiling.

REACTING TO STARES

BY DINA ZUCKERBERG

As a society, we are brought up to believe that staring is rude, that it is not polite. If you stare at someone, you may hurt their feelings. Often, when we see people who look different than we do, we tend to divert our eyes. Or, we might look right through them, pretending not to notice that they stand out.

PHOTOS PROVIDED BY DINA ZUCKERBERG

Our impulse to stare at them might stem from fear or nerves. For me, I think it is more about curiosity, wanting to understand, rather than to judge. We learn at a very young age to categorize people. Are you short or tall? Do you have brown eyes or blue? So, when we see someone who has a prominent scar or is missing a limb, the inclination is to let our eyes linger on this one feature, something we are not accustomed to seeing in everyday life.

I was born with a craniofacial difference and, as a child, I didn't like it when kids stared at me. I would look away. I did not want to talk about my differences; I wanted to blend in. However, that started to change when I was in my early twenties. I joined a group called the Inner Faces, and all of its members had craniofacial differences like me. Together, we wrote and performed a show telling the story of our lives. For many of us, it was the first time stepping on stage and publicly sharing our stories of growing up with craniofacial differences. After each performance, we had "talkback" sessions with the audience, and I recall someone saying that it felt like she had permission to stare and really see us, something that she wouldn't normally feel comfortable doing.

NICE ADVICE: *(Opposite page)* The author with myFace patient Anibel, who was born with a condition called Nager's Syndrome, a very rare syndrome related to Treacher Collins Syndrome. When speaking to students about craniofacial differences, she tells them it is okay to notice someone who looks different. But you have the power to choose your words and choose a kind reaction to difference.

It has taken me many years, but I now realize that it is naive to think that people, especially children, won't notice differences. We all have things that make us unique and I think noticing them can actually be healthy. What isn't healthy is having a negative reaction to these attributes.

I am the Director of Family Programs at myFace, a leading nonprofit organization that helps children and adults with craniofacial differences lead full and productive lives. One of the things that I do is share my own story with students from kindergarten through high school and encourage them to choose kindness and be an active upstander instead of a passive bystander. One of the things that we explore is how to address the anxiety or distress that some might experience as a result of seeing someone different than themselves. There have been laughs. There have been stares. There have even been tears. But I believe children, while sometimes careless, are not naturally cruel. There is one thing we tell them repeatedly, and it has been well received at every single school we've been to: "It is okay to notice someone who looks different. But you have the power to choose your words and choose a kind reaction to difference."

We teach the kids to ask respectful questions and use thoughtful words. Rather than staring, or laughing, or asking, "What's wrong with you?" we suggest alternative questions like, "May I ask you about your face?" "May I ask why you're different?" "May I ask about your scar?" We explain that many of our myFace kids are happy to share this information, while others would prefer to get to know someone first, and that's okay, too. When we say this, there seems to be a feeling of relief from both the kids – and the adults – in the audience, because it validates their observations and questions.

But how do you react when there is no time for a conversation? A parent once asked my colleague after a presentation, "What is a kind reaction if you see someone who looks different but it's not on the playground or at school? What if you're never going to see that person again but you get caught staring?"

My colleague thought for a moment, because our focus is largely on relating to people with differences in long-term settings. What if you react to someone different on the street? On the subway? At a stoplight? How do you choose kindness if your interaction is only going to be fleeting?

Her response was, "Most of all, don't ignore the person. Don't look away. Don't deliberately pretend they aren't there. That erases a basic element of human interaction that we all crave." If you have time, say hello.

And here's something I truly think would have an impact. If you get caught staring, smile and say, "I'm sorry for staring." That's it. That's the beginning of choosing kindness. Smiling.•

ABOUT THE AUTHOR:

As Director of Family Programs at myFace, Dina Zuckerberg brings her life experience growing up with a craniofacial difference to the programs she helps implement for the individuals and families they serve. Whether it's through their emotional support groups, online educational series, family networking events, or public awareness initiatives, her goal is to advocate for the craniofacial community and make sure their voices are heard. She wants everyone with a facial difference to know that they are not alone. She hosts a monthly podcast, "myFace, myStory: Voices from the Craniofacial Community."

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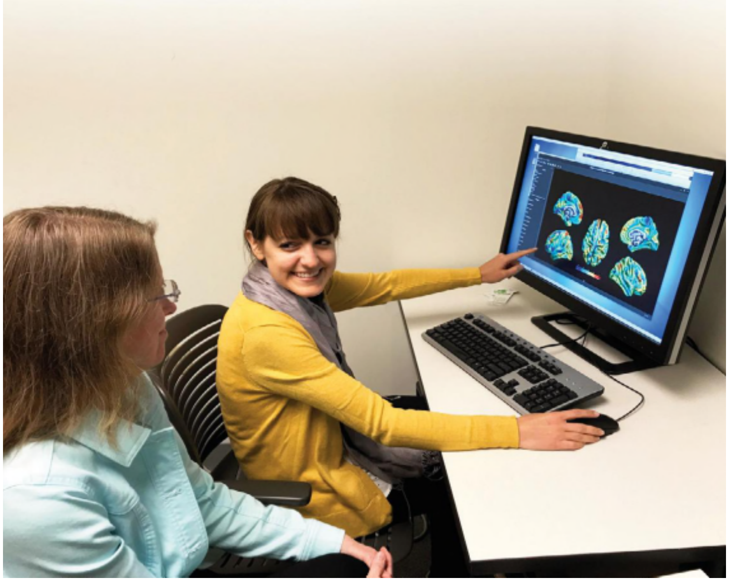

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PARTNERING WITH YOUR COUNCIL ON DEVELOPMENTAL DISABILITIES: ONE STATE'S MODEL

There is a Council on Developmental Disabilities in each state. Some have mini-grants for local groups to develop new programs for students with disabilities.

BY LAUREN AGORATUS, M.A.

WHAT IS A COUNCIL ON DEVELOPMENTAL DISABILITIES?

State Councils on Developmental Disabilities (Councils) are federally-funded, self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. Councils are committed to advancing public policy and systems changes that help individuals with Intellectual/Developmental Disabilities gain more control over their lives. The 56 Councils across the United States and its territories work to address identified needs by conducting advocacy, systems change and capacity-building efforts that promote self-determination, integration and inclusion. Council members are appointed by a state's governor and by law, the majority (60%) must consist of individuals with I/DD or their family members. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions and community partnerships, encouraging citizen participation and keeping policymakers informed about disability issues *(See resources to find the Council in your state).*

NJ PROJECT ON EMERGENCY PREPAREDNESS

The New Jersey Council on Developmental Disabilities (NJCDD) awarded the Hackettstown Elks Lodge #2331 a $3,500 grant to purchase outreach kits for first responders. Celebrate the Children School (CTC) (www.celebratethechildren.org) developed the outreach kits. The kits are used to help first responders communicate more effectively with people with I/DD during a crisis. The Hackettstown Elks purchased the kits from the CTC. Every police department in Warren County, as well as five Morris County police departments, received free kits. Each kit contains tools to help first responders support people with disabilities during traumatic events.

IMPROVING SYSTEMS : I/DD COUNCILS

NJ COUNCIL ON DEVELOPMENTAL DISABILITIES

https://njcdd.org

NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES (by state)

www.nacdd.org/councils

READY, SET, GO : CREATING AN OUTREACH KIT

What helps children with special needs during emergencies? There were many considerations when creating the content of the bags. These include:

- **Sound canceling headphones:** Headphones can help children who are sensitive to loud noise, like sirens.
- **Sunglasses:** Dark glasses can help with sensory issues such as bright lights from emergency responders.
- **Social story on riding in an ambulance:** The story helps children know what to expect and helps reduce anxiety.
- **Fidget items:** These things can help with waiting and increase self-regulation.
- **Pain chart, body cutout, and yes/no cards:** These can help children with speech issues to communicate where and how much it hurts and answer simple yes/no questions.
- **Toys/hat/stickers:** Because they're kids!

CTC also provides free training sessions for first responders in how to use the kits. Sessions also include Q&A and tips from educators, autism experts, occupational therapists, and physical therapists.

This is just one example how Councils on Developmental Disabilities can help organizations improve systems for children and adults with I/DD. •

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is a parent of a medically-complex young adult and serves as the Coordinator for Family Voices-NJ and as the regional coordinator in her state's Family-to-Family Health Information Center, both housed at the SPAN Parent Advocacy Network at www.spanadvocacy.org

OVERCOMING MEDICAL EDUCATION AND TRAINING BARRIERS IN THE BRONX

BY VINCENT SIASOCO, MD, MBA AND JOANNE SIEGEL, LCSW

Over 15 years ago, in a study sponsored by Special Olympics, it was noted that "56% of medical school students in the United States reported that graduates were "not competent" to treat people with intellectual disabilities."[1] *Fast forward to today, the state of education and training for medical students on how to care for those with intellectual and developmental disabilities (I/DD) has made some progress, but still has a way to go to implement curriculum in all medical schools.*

PHOTO COURTESY EINSTEINMED.EDU/NEWS/ARCHIVE

THE HEART OF MEDICINE: Albert Einstein College of Medicine prepares a diverse body of students to become knowledgeable, compassionate physicians and innovative scientific investigators, and to create new knowledge.

It's been shown that most medical schools do not offer formal training on how to care for people with I/DD. Currently it's up to each medical school to decide on whether or not, and how, topics involving I/DD are covered. This is in comparison to dental schools in which the Commission on Dental Accreditation has required all U.S. predoctoral dental education programs to educate students on managing patients with intellectual and physical disabilities.

Through the U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, Healthy People provides science-based, 10-year national objectives for improving the health of all Americans. Healthy People 2020 states that compared to individuals without disabilities, individuals with disabilities are more likely to "experience challenges in obtaining preventive healthcare services." To address these and other health determinants, the World Health Organization (WHO) recommended to achieve health equity among individuals with disabilities, "The expansion of disability and health training opportunities for public health and healthcare professionals." [2]

CHALLENGES & BARRIERS

In order to understand the importance and need for education and training, one should consider the challenges and barriers that those with intellectual and developmental disabilities face. Disparities in care for those with I/DD continue to exist. It has been noted that approximately 6.5 million people in the United States have an intellectual disability. Despite the increase in life expectancy, adults with any type of developmental disabilities die on average 20 years earlier than adults without I/DD. The World Health Organization reports that those with disabilities are more likely not to have preventative cancer screenings and are more prone to obesity and high blood pressure. Studies have revealed that among adults with I/DD, two thirds had two or more co-morbidities, including obesity and chronic mental health needs. More than 40% were diagnosed with four or more chronic conditions in addition to I/DD. In an individual without I/DD, aging is not accompanied by high rates of medical and functional problems until after 70 to 75 years of age whereas in persons with a disability, these problems can present 20 to 25 years earlier.[3] Adults with I/DD are nearly four times as likely to incur high annual healthcare costs than those without I/DD.

The different barriers to access of care are numerous, with lack of education, experience and training for health professionals at the top of the list. Without an understanding of the healthcare needs of people with I/DD, this can lead to poor communication and coordination of care. In addition, a common problem referred to as "Diagnostic Overshadowing" can occur when all the changed or unusual behaviors and behavioral symptoms are attributed to the intellectual disability or, conversely, everything is attributed to a psychiatric disorder without acknowledgement of the impact and interrelationship between one's physical symptoms and behavioral expressions.[4] For example, a patient with an intellectual disability who is non-verbal, is being evaluated for new-onset head banging behavior. The patient is diagnosed with a psychiatric problem and prescribed medication. In actuality, the patient has communication challenges and can't express the pain in their mouth due to a dental abscess.

OVERCOMING EDUCATIONAL & TRAINING BARRIERS

National Curriculum Initiative in Developmental Medicine: In 2019, the Albert Einstein College of Medicine received a grant to develop a special curriculum for medical students on how to treat adults with intellectual and developmental disabilities addressing educational gaps in medical schools in order to reduce health disparities for this population. The grant, part of the National Curriculum Initiative in Developmental Medicine (NCIDM) was funded by the American Academy of Developmental Medicine and Dentistry (AADMD) in partnership with Special Olympics International, and has been led by Joanne Siegel, Co-Director of the Rose F. Kennedy University Center for Excellence in Developmental Disabilities at Albert Einstein College of Medicine. In addition to a didactic piece, 2nd year medical students engaged in small group discussions with adults with I/DD who are self-advocates, as well as with their family members. What started out as a one-year grant funded project, has now been embedded into the curriculum at Einstein and is taught to 2nd year medical students every year.

The National Curriculum Initiative for Developmental Medicine has provided a tremendous impetus in exploring various ways in which medical students can engage directly with adults with developmental disabilities. Within the five years of the NCIDM effort, 18 medical schools across the country have participated in a unique set of program models. At Einstein, in addition to the curriculum enhancement, this effort has led to the creation of an Einstein AADMD Student Chapter under the mentorship of Vincent Siasoco, MD in which there are now over 50 members participating in activities online and in the community that focus on breaking down barriers to effective healthcare, enhancing knowledge, building experience, and developing relationships between future medical providers and people with intellectual and developmental disabilities.

American Academy of Developmental Medicine and Dentistry Student Chapter: Founded in 2002, the American Academy of Developmental Medicine and Dentistry (AADMD) is a non-profit membership organization of interdisciplinary health professionals that includes physicians, dentists, medical specialists, and other clinicians. Its mission is to provide a forum for healthcare professionals who provide care for those with intellectual and developmental disabilities and improve the quality of healthcare for this population. At the height of the pandemic, the Einstein College of Medicine turned to virtual teaching like everyone else across the country. The ability to socialize and connect with classmates and teachers was more than difficult. To bring like-minded people together, a Student Chapter of the AADMD was formed and officially recognized at the Einstein College of Medicine in late 2020.

VISION FOR THE FUTURE: Special Olympics Mexico swimmer Michelle Falcon has her vision tested; Healthy Athletes programs provide athletes health services and education in seven different disciplines, including hearing and vision screenings, oral health care, and coping skills.

As word got out about the Chapter, its membership rose, bringing together students, residents, and fellows who may not have otherwise connected with each other. Each member brought their story as to why they wanted to join the Chapter, be it through a family member they had with I/DD or just an interest to get involved. Through the Chapter, members were able to network and learn from monthly virtual grand round lectures through the AADMD. Members were introduced to the Bronx Community Self Advocacy group made up of adults with I/DD living in the community. In addition to this, they connected with Special Olympics New York and the Healthy Athletes Program.

Healthy Athletes Program: Established in 1997, the Special Olympics Healthy Athletes program provides free health screenings and education to athletes in a fun and welcoming environment. There are eight different health areas that the program focuses on, including medical, dental, eye, nutrition, and hearing. The members of the Einstein AADMD Student Chapter were able to get involved with Special Olympics athletes, coaches, and family members virtually educating on healthy lifestyles, nutrition, and even providing healthy cooking classes. Students who may never have met an individual with I/DD, have now begun to break down stereotypes, remove fears or hesitations, and are more comfortable in treating people with I/DD. Special Olympics reported that attitudes can be changed through increased quality interactions that challenge prevailing stigmas, as research has shown that structured and positive interactions can lead to attitude change. Special Olympics reported that “84% of health care providers feel better prepared to treat people with intellectual disabilities as a result of volunteering with Healthy Athletes.”

“The Special Olympics Healthy Athletes program offers free health screenings and education to Special Olympics athletes that would otherwise not be available. The Healthy Athletes program is not only a program for athletes but, through hands-on experience at screenings, is also a program for healthcare students; an opportunity to increase their knowledge of best practices in caring for people with intellectual disabilities. Trained healthcare providers have demonstrated improved awareness and self-efficacy in providing care for and communicating with patients with intellectual disabilities after completing the training,” stated Leanne Fusco, Director of Statewide Health at Special Olympics New York.

CONCLUSION

Though there needs to be more national curriculum guidelines in medical school and clinical hands-on training, any steps that are offered to students in order to learn, engage, and listen to those with I/DD is a step in the right direction. Medical students are already learning about the importance of both social determinants of health and patient-centered medical home model of care. Medical students who are on the right educational path learn about the patient holistically and their surroundings to ensure that quality of care is provided and can be attained. However, more needs to be done to focus a light on the care of this most underserved population – those with intellectual and developmental disabilities.

We need to work on supporting a national curriculum for all medical schools, but in the meantime, any opportunities to expose and engage medical students to better understand this population is valuable for all future physicians.•

ABOUT THE AUTHOR:

Vincent Siasoco, MD, MBA, is a Board-certified Family Physician in NY. He is an Assistant Professor in the Department of Family and Social Medicine and Pediatrics at the Albert Einstein College of Medicine of the Montefiore Health System. He is the Director of Primary Care at the Rose. F. Kennedy Center Children’s Evaluation and Rehabilitation Center at Montefiore. He is the Medical Director of the ADAPT Community Network (formally known as United Cerebral Palsy of NYC). He is a Board member of the American Academy of Developmental Medicine and Dentistry, Clinical Director for Special Olympics, and Chairs the Special Olympics NY Health Advisory Council.
Joanne Siegel, LCSW, is the President of the Bronx Developmental Disabilities Council. She is a Principal Associate in the Department of Pediatrics at the Albert Einstein College of Medicine. She is the Co-Director of the Rose F. Kennedy Center, University Center for Excellence in Developmental, Service, Training and Research of the Montefiore Health System.

References

1. Holder, M. (2004). CAN project: Curriculum assessment of needs. Washington, DC: Special Olympics, Inc).
2. https://health.gov/healthypeople
3. http://www.jik.com/awdrtcawd.html
4. Bradley, Elisabeth; Hollins, Sheila. “Assessment of Patients with Intellectual Disabilities Psychiatric Clinical Skills.” Psychiatric Clinical Skills. Mosby, 2006, Pages 235-253

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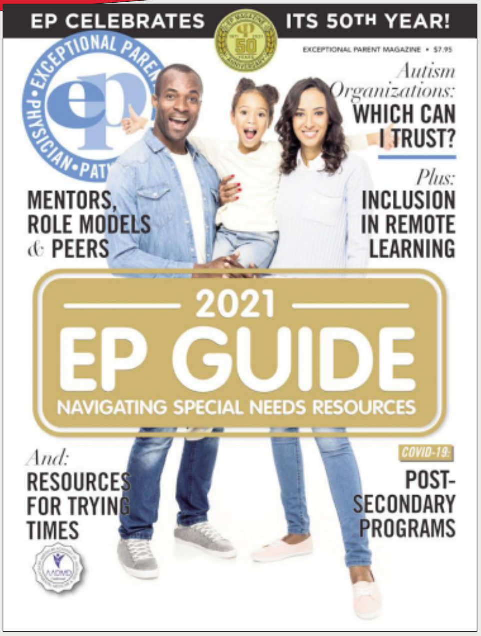

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PART VI: EP MAGAZINE SLEEP SERIES

DREAMS & PARASOMNIAS

BY BENJAMIN MARGOLIS, M.D.

> *"We are such stuff as dreams are made on, and our little life is rounded with a sleep."*
> *– William Shakespeare,*
> The Tempest, *(IV.i.148-158)*

A dream is among the most mysterious realms of human experience: we are conscious but not conscious. We can control our journeys through them, but perhaps not completely. We can remember them, but often in fragments and whispers of memory. The rules of linear time may not apply and recall may not be perfect. Ask yourself – what did you dream last night? How long did you spend dreaming? Do you remember them all? What senses do you remember being engaged? Did you dream in color or black-and-white? Were you able to smell, or to taste in your dreams? Did you have one dream or more than one? Did you have a nightmare? What made it a nightmare? Most difficult of all, what did your dreams mean? Is there a way to find out?

AN EP SPECIAL SLEEP SERIES
PART VI

Experimental scientists can now create tools with a scale larger than the earth itself, when in the LIGO experiment the brightest minds in physics detected and translated the faintest traces of the Big Bang into a sound we can hear with our ears.[1] Things seemingly impossible to detect are now within our reach – but the journey within, into dreams and their meaning, remain largely hidden.

Clinical neuroscientists and researchers can study the workings of the living brain in great detail and resolution. We can determine brain structure with CT (Computer Assisted Tomography) and MRI (Magnetic Resonance) imaging. Using an MRI technique called fMRI, we can observe networks within the brain functioning in real time. We can observe the electrical discharges of neurons with a routine EEG (electroencephalography) by placing electrodes on the skin. We can observe the magnetic fields generated by groups of neurons communicating with each other (MEG, or magnetoencephalography). We can even see the uptake of glucose or individual neurotransmitters such as dopamine in specific regions of the brain to help us diagnose conditions such as Parkinson's disease.

In sleep, we have polysomnography (PSG), which includes EEG and captures sleep stages, breathing patterns, heart rate, and a variety of other factors. Yet with PSG and all of these other tools at our disposal, dreams have one remarkable feature that keep them out of reach of these tools: we can't report them in real time, while we're asleep. We can utilize any of our sophisticated tools to observe the sleeping person, but the only way to know what someone is dreaming is to wake them up and ask them. Imagine designing a method for measuring your experience of dreaming. With the least invasive tools we have, we could hypothetically let you fall asleep and then repeatedly awaken you, asking whether or not you were dreaming. Would you be able to remember, and how accurately? Would you be able to report the content of your dream?

All of this is not to say we can't study dreams at all, nor that we can learn nothing about them. Indeed, using all of the tools above and with repetition, we have been able to generate reasonable hypotheses. We do know that most dreams happen during rapid eye movement (REM) sleep, which is defined by rapid eye movements, and decreased muscle tone on the EEG, and that most people spend about two hours per night dreaming. To quantify the most elusive task of all, interpreting dream content, systems for quantitatively studying reported dream content have been developed by a team at UC Santa Cruz.[2]

There are clear links between psychiatric illness and dreams – indeed, nightmares following trauma are among core diagnostic criteria for PTSD (post-traumatic stress disorder), and we can even reduce the frequency of nightmares in people suffering from PTSD. Prazosin is not a sleeping pill per se, but rather an anti-nightmare medication that can tune down the fight-or-flight mechanisms that are active even in sleep with some forms of PTSD.[3]

"Some dreams may be part of learning, some dreams may be reflective of our fears, some may help us learn about ourselves."

There are anecdotal and stereotyped dream experiences that are remarkably consistent across cultures and may guide us toward questions about innate learning and experience – dreams of falling, flying, being chased. Some dreams we associate in memory with anxiety – many have reported dreams of being in school or work naked, dreams of being underprepared. There are hobbyists and enthusiasts who attempt to hold on to self-awareness and experience so-called lucid dreaming, and some report being able to direct and remember their dreams.[4]

We look to dreams for insight and for inspiration. They are a wellspring for narratives that enrich our human experience and they can guide us toward decisions we didn't realize we were making. Problem solving, learning and consolidation of memories are proposed to be embedded in dreaming and sleep. The 19th Century German chemist August Kekulé, who discovered the ring structure of benzene, reported that he visualized the structure after dreaming of a snake eating its own tail.[5]

So far, no adaptive function of dreaming has been demonstrated, yet history is rife with stories of revelatory dreams. Some dreams may be part of learning, some dreams may be reflective of our fears, some may help us learn about ourselves. There may be several different dream states that we will one day parse into specific functions that operate discretely or simultaneously. For now, the meaning and function of dreaming lie just beyond our reach.[6]

Much more amenable to study are the nuts and bolts of how we sleep, and what parts of our brains are active while we are sleeping. Falling asleep, we become drowsy, we drift through an invisible transition where we begin the cycles between the stages of sleep, and then we normally awaken equally seamlessly, ideally rested and ready to take on another day. We can observe sleep and the stages of sleep using the objective tools previously described. Our brains have a series of steps that we go through in that process of falling asleep. When the process of seamless transition from waking to sleep is misaligned and the steps don't occur in the usual order, we can experience significant problems. There are a fascinating and well described (and fortunately treatable) set of sleep disorders called parasomnias, which occur during either REM sleep or NREM (non-REM) sleep. In NREM sleep, we see large amplitude slow waves on EEG.

NREM sleep patterns are distinct from REM sleep, with deeper stages of NREM sleep (also called delta sleep) having EEG waves that are slow and large in height. Seizures or epilepsy can present in similar fashion to many parasomnias, and so comprehensive evaluation is needed.

Shortly after falling asleep, and when we think most dreaming begins (about at the onset of REM sleep), there is a cellular switching mechanism located in the pons and midbrain (parts of the brainstem, the critical and very small part of the central nervous system between the brain and spinal cord), which stop you from moving, a state of relative atonia. You can still breathe, adjust your positioning and roll over (though some of those things happen during arousals when the switch is temporarily turned off, when you are partially but not completely awake), and your heart still beats as always, but volitional skeletal muscles won't move. This stops you from acting out your dreams, potentially a very dangerous situation.[7]

A few of the most common parasomnias involve problems in that switching process. If that internal switch mechanism is engaged too early while you are falling asleep, stopping you from moving volitionally, you can be awake and alert, but unable to move for a time until the rest of sleep is engaged. This REM parasomnia is called Sleep Paralysis, and the disorder associated is called Sleep Paralysis Disorder. Sleep paralysis can be addressed sometimes with medication but often does not require treatment and a regular sleep schedule with good sleep habits are all that's needed.

Another set of parasomnias involves a problematic lack of paralysis during sleep, where the atonic switch should be engaged, but is instead allowing us to move when we shouldn't, as seen in REM-sleep behavior disorder. In REM-sleep behaviors, individuals can act out their dreams. Shouting, kicking or more complex behaviors can manifest. This poses a significant potential safety risk as someone completely asleep and unaware of their behavior can walk out of a window, walk into the road or injure others in fight/flight dreams. REM-sleep behaviors are commonly seen as a symptom of Parkinson's Disease, but it can also occur on its own. Loved ones can be injured when someone with sleep behavior is shouting and striking out in sleep occurs. REM-sleep behavior disorder can be treated with a benzodiazepine such as clonazepam before bed. [8]

The fact that we are able to easily demonstrate that these behaviors occur during REM sleep provides some powerful evidence to support the hypothesis that dreaming occurs during REM sleep, especially since we see REM sleep-behavior can be complex. However, sleep behavior isn't limited to REM sleep. Some parasomnias occur during NREM sleep. These NREM parasomnias have a variety of causes and contributors, including genetic predisposition and triggers such as obstructive sleep apnea or leg movements.

Most widely known among the non-REM sleep disorders is sleepwalking or somnambulation, which can be accompanied by complex behaviors, even with driving a car. Somnambulation can occur in both children and adults. Good sleep habits are a first-line treatment for non-REM sleep behaviors, but medications such as benzodiazepines or antidepressants may sometimes be needed. Another of the NREM sleep disorders, sleep-related eating disorder, may be associated with sleep medications. such as zolpidem (brand name Ambien) or eszopiclone (brand name Lunesta), and either medication can rarely lead to the curious phenomenon of awakening in the morning to find that half of the contents of the refrigerator have been eaten.

"With the limits of our ability to quantitatively and objectively study our dreams, we may find meaning in the subjective, personal and unique stories when we remember them."

A non-REM sleep disorder of childhood is known as sleep Terrors, a frightening thing for parents who are helping their children get through them. Night terrors are distinct from nightmares. Children will appear to be awake, but are in fact in deltaNREM sleep, the deepest phase of sleep. They will open their eyes and without warning can scream and cry uncontrollably, with parents unable to console or awaken them. Children invariably have no memory of the episodes and treatment involves lots of reassurance and support for understandably traumatized parents along with a regular sleep schedule. Fortunately, night terrors don't last into adulthood and go away on their own. However, episodes of sudden night time terror are also seen in PTSD and in the setting of trauma. If a loved one is awakening with night terror-like experiences, it is important to screen for actual nightmares and trauma, or PTSD among the adolescents and adults with intellectual or developmental disabilities. [9]

Some people can be bothered by sudden, rapid muscle contractions can occur upon falling asleep. These movements, called hypnic jerks, are sudden muscle contractions that can look like seizures, but they are a benign phenomenon that can be treated with reassurance. Some people will have periodic movements of their arms or legs that can look like seizures while they are sleeping, a disorder called Periodic Limb Movement Disorder, or PLMD, also called Periodic Limb Movements of Sleep or PLMS. People with PLMD will rhythmically and sometimes violently move their arms or legs while they sleep, often awakening loved ones and sometimes awakening themselves. [10]

Apart from motor function, a cognitive and sensory disconnection occurs in sleep. Our senses are muted to an extent on falling asleep, and then sight, hearing and touch come back fully online upon awakening. While we are asleep, we are not usually aware of the process and we are a very unique and special kind of unconscious – we are not aware of the outside world but can be aroused by intense input in any sensory modality. During this period, our senses are relatively disconnected and we are free to dream. Two mysterious parasomnias involve dysregulation of that sensory dampening. Sometimes, we can have dream intrusions into our waking world, where we can have complex hallucinations hearing and seeing things that aren't there while we are drifting off or awakening. When they occur during the transition to sleep, they are called hypnogogic hallucinations, and on the transition to waking they are called hypnopompic hallucinations.

One of the most dramatically named hypnogogic parasomnias is the Exploding Head Syndrome (I promise, that's a real thing), which is characterized by a sudden and loud sound, often described as metallic, upon falling asleep or shortly thereafter, and which is often evaluated as a potentially serious headache but which is in fact a sleep disorder. [11]

Among people with intellectual and developmental disabilities, reports of hallucinations need to be very carefully evaluated. In the general population, illnesses that are associated with hallucinations fall into potentially narrower categories than amongst people with I/DD. In addition to sleep disorders, auditory hallucinations are more commonly associated with many types of schizophrenia. Visual hallucinations are less common but are seen in vision loss (called Charles Bonnet Syndrome), in Parkinson's Disease and related syndromes. Tactile hallucinations are very common in many types of substance withdrawal and are seen in delirium. Olfactory (scents and odors) and gustatory (taste) hallucinations are hallmarks of many types of seizures. Evaluating complex hallucinations, or hallucinations that are experienced in more than one sensory mode, takes extra time and care.

In working with people with developmental disabilities, it is not uncommon for caregivers to seek neurologic or psychiatric evaluation when an individual with I/DD is seen to have interactions or conversations with a person who isn't there. Often, these clinic visits can lead to a diagnosis of schizophrenia or a psychotic disorder when in fact the experiences may not be related to a thought disorder at all.

Complex hallucinations among individuals with I/DD can be many things. Is this a fantasy being acted out and a harmless expression of an imaginary friend? Is it an expression of trauma and PTSD? Is it another medical illness? Or is it a parasomnia? It takes care and patience to discover the meaning of hallucinations in caring for someone with I/DD, and a team approach. A very careful history may be supplemented with an EEG and polysomnography in addition to some basic medical tests in order to sort it out. When a sleep disorder is suspected, the sets of disorders discussed above may assist families and caregivers to ask the same questions that we do as clinicians.

In reviewing parasomnias and sleep disorders, we can appreciate the wondrous processes operating while we are conscious and the systems operating just hidden from view while we're asleep. With the limits of our ability to quantitatively and objectively study our dreams, we may find meaning in the subjective, personal and unique stories when we remember them. We can try to observe our own dreams, and our own sleep. We can pay attention to our sleep habits and respect the investment in quality of life that can come from good sleep habits and make room for our dreams, the realm of which may be our final frontier.•

ABOUT THE AUTHOR:

Benjamin Margolis, M.D. is board-certified in neurology and psychiatry, having completed the combined residency program at Brown University. He specializes in neuropsychiatric care of adults with I/DD in the New York Hudson Valley and is Senior Psychiatrist and Staff Neurologist at Access: Supports for Living. He attended medical school at the Albert Einstein College of Medicine after the postbaccalaureate premedical program at Columbia University, and holds a BFA from the School of Visual Arts in New York City. He is an active member of the American Academy of Developmental Medicine and Dentistry (AADMD) and is working to improve behavioral and mental health care of individuals with I/DD on local, state and national levels, along with serving on the Health Advisory Board for Special Olympics New York for the Strong Minds Program.

References

1. https://www.ligo.org/science.php . Retrieved October 1, 2021
2. Schneider, A., & Domhoff, G. W. (2021). The Quantitative Study of Dreams. Retrieved October 1, 2021 from http://dreamresearch.net/.
3. Koola MM, Varghese SP, Fawcett JA. High-dose prazosin for the treatment of post-traumatic stress disorder. Ther Adv Psychopharmacol. 2014;4(1):43-4
4. Voss, U. Holzmann, R. Hobson, J. Lucid Dreaming: A State of Consciousness with Features of Both Waking and Non-Lucid Dreaming. Sleep. 2009 Sep 1; 32(9): 1191-1200.
5. Robinson, A. Chemistry's visual origins. Nature 465, 36 (2010).
6. Siclari F, Baird B, Perogamvros L, Bernardi G, LaRocque JJ, Riedner B, Boly M, Postle BR, Tononi G. The neural correlates of dreaming. Nat Neurosci. 2017 Jun;20(6):872-878.
7. Peever, J. Fuller, P. The Biology of REM Sleep. Current Biology. 2017 Nov 1; 27(2): PR 1237-R1248.
8. Lima FCB, do Nascimento Junior EB, Teixeira SS, Coelho FM, Oliveira GDP. Thinking outside the box: cataplexy without narcolepsy. Sleep Med. 2019 Sep; 61:118-121.
9. Van Horn NL, Street M. Night Terrors. 2021 Jul 10. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2021 Jan–.
10. Lesage S, Hening WA. The restless legs syndrome and periodic limb movement disorder: a review of management. Semin Neurol. 2004 Sep;24(3):249-59.
11. Ceriani CEJ, Nahas SJ. Exploding Head Syndrome: a Review. Curr Pain Headache Rep. 2018 Jul 30;22(10):63.

WEPC: A PLACE WHERE WE RECOGNIZE THE UNKNOWN SUPERHEROES!

WEPC RADIO

EXCEPTIONAL PARENT CAREGIVER

BY LAURA GEORGE

Good morning, everyone! How are we today? Tired? Overwhelmed? Frustrated? Today we have a special show and I am excited for you! This month of November, more specifically this moment, is now dedicated in your honor and I am so humbled to be in your presence. Why? November is National Caregiver Month. Never heard of it? Well, it is just as real and true as New Year's Day. My dear audience of caregivers, today we are standing up and applauding you! Today we shout to the world that caregivers exist, they overcome challenges, and they do so easily for the children they love.

Host: Before I introduce our special guest of the day, we are going to a commercial break and will be right back!

COMMERCIAL: *Today's WEPC show is sponsored by Energy Coffee. Morning comes and your child who has a disability is making sounds. It is discovered that they your child is wide awake and needs assistance. Without getting yourself dressed, you take care of your child's daily needs, and get her ready for the day. As long as you are on a roll, medications and supplies are refilled, messages are left at the doctor's office and then your stomach growls. With a kiss and a hug, you get your child off to school and sit down at the table to absorb what just happened. Relishing the moment of silence, you pick up your Energy Coffee, savoring each sip for the day. Energy Coffee! Enjoy your quiet moment with your favorite, Energy Coffee! After all, WEPC and Energy Coffee are recognizing all caregivers today!*

Host: And we're back! Remember folks WEPC is the station where we support all caregivers all the time. So let's get right into our show. Today we are thrilled to have Bobbie as our guest. Bobbie is a two-time caregiver and I will stop there. Bobbie, welcome to the show!

Bobbie: Thank you for having me.

Host: So Bobbie, what types of people are caregivers?

Bobbie: They are school principals, first responders, executives, plumbers, and so forth. They are grandparents, young children, spouses, friends, and more. They come from all walks of life.

Host: How did you become a caregiver?

Bobbie: Well, some go to school to be professional caregivers. According to caregiving.org (www.caregiving.org/caregiving-in-the-us-2020) "there are 53 million family caregivers as of 2020" which they say is about "1 in 5 Americans." But I think there are more. I did not know I was one until someone told me I was. There was no education and I certainly never signed up or desired to be one when I grew up. It happened in a few brief moments. My spouse was in a hit/run accident, became paralyzed, and needed help. Caregiving became my calling upon my loved one's diagnosis and until his passing. However, I am a caregiver once again.

Host: Wait! What? How did that happen? Doesn't it only occur once?

Bobbie: No, sometimes caregiving roles happen multiple times. Sometimes it is once for a few months or can last for 30 or even 50 years. I became a caregiver again, or 2.0 as I like to say, when my child was diagnosed with functional neurological disorder; a glitch in the brain.

Host: Caregivers aren't just for the elderly?

Bobbie: Oh no! Caregivers can be for anyone, any age, any time, anywhere, with any diagnosis that requires their assistance to live in society. Some children have developmental disabilities, some have stomas, some have the absence of a limb, some cannot speak, the list of those children who would need a caregiver is very long. Some babies and some teens need caregivers. A loving parent does not let age dictate when caregiving love ends. Can I offer a thought?

Host: Yes, please!

Bobbie: In my humble opinion, family caregivers are the most unknown, unrecognized, underpaid, and overlooked people. They take on a second job "for more than 40 hours a week" according to an article by the National Alliance for Caregiving in collaboration with the AARP in November 2009 [https://www.caregiveraction.org/resources/caregiver-statistics]. Many of these caregivers care for their child, without days off and yet are still expected to operate a normal daily life like everyone else. If a family caregiver were given a salary, how much would it be?

Host: Hold that thought, Bobbie. We have to break for another commercial and make our sponsors happy.

COMMERCIAL: *It's impactful! It's contagious! It burns calories! You cannot crave too much of it. Coming to a location near you! Go get, "Smile!" It will always remind you how amazing you are and more. That's "Smile"! Go out and get one today! Smile!*

Host: So Bobbie, you wanted to know how much a caregiver, if paid yearly would make. My staff went and looked it up. According to ziprecruiter.com (www.ziprecruiter.com/salaries/Caregiver-salary-per-hour), "professional caregivers make about $26,000 a year or $12 per hour." Additionally in another article by the National Alliance for Caregiving in collaboration with AARP (www.caregiveraction.org/resources/caregiver-statistics) says that "there are about 8.4 million parents caring for their own children with disabilities under the age of 18." Did you also know that the National Family Caregiver Support Program created in 2000 is available to provide financial assistance and other resources in some states and some situations to help parental caregivers?

Bobbie: I would be happy for any financial assistance! Caregivers do not get the chance to save money, take care of their health or even get respite because there is no funding. What little funding there is usually ends up being for a brief hour or so and only if it is deemed medically necessary by the insurance providers.

Host: Are those the only challenges?

Bobbie: Oh no! Are you kidding me? When you become a caregiver, you also take on any multitude of other jobs such as social worker, therapist (PT/OT/ST), psychologist, driver, carpenter, mechanic, and of course my favorite, advocate! Do not forget that you are also

ILLUSTRATIONS BY LAURA GEORGE

running a house, the financier who saves money by fixing their own sprinklers, the cook making specific food safe for your child to eat, and is a business executive! It is imperative that all the different types of paperwork for insurance, medical suppliers, and school are maintained while following up to coordinate with school teachers, therapy appointments, and others.

Host: You said your favorite job is advocate, why?

Bobbie: Well, I initially meant that sarcastically.

Host: Why?

Bobbie: It is so frustrating going to doctor after doctor when your child has a rare disorder and be accused of too much parenting, not enough parenting, or that your child is faking their condition. To watch a doctor say to your child's face, "You are not trying hard enough" or "it's obvious you are deeply depressed because you can't get your way in life - shame on you"…*(Bobbie softly cries)*… I'm sorry.

Host: No. Here are some tissues. Really! Doctors don't say that!

Bobbie: Talk to any parental caregiver and I doubt or at least it will be very hard to find one who says that all their child's medical professionals speak pleasantly, listen to the concerns and support the child's needs 100% of the time. If such a caregiver exists who has had it that easy, ask them what their secret is and take it as your own. Being your own advocate also has its rewards too. You always learn of new information or resources, help to create awareness, and if you are determined, will create a societal change for your child along with many other families as well. Ask how many laws or nonprofits there are for children with disabilities and it will be learned that for each one created, there is probably a parental figure creating the answer to address a problem.

Host: *(Loud breath)* I don't know whether to sob uncontrollably or pump my fist up in the air. WEPC is going to pause for a moment so you can sip your Energy Coffee and reflect on Bobbie's wonderful determination. When we come back, we will ask her why she has such a glowing smile on her face with everything we have just discussed.

Host: So, Bobbie, you told us about the technical aspects of being a caregiver, the multitudes of frustrations a caregiver experiences and in spite of all of that, you spent the morning here smiling. How? Where do you find your strength?

GUARANTEED TO MAKE YOU SMILE : HAPPY MONTH! HAVE FUN!

31 days of things to smile about with room for you to add in your own! Share with co-workers, friends, family, dog, or cat.

1. Have a cup of "Energy Coffee!"
2. Spend some time with your pet and buy them a funny toy.
3. Get an art journaling book and doodle or color.
4. Using a notebook, write about whatever you want and share it only if you want to.

5. Connect with a caregiving support group through National Family Caregiver Association, Caregiving.com, or any of your favorite associations.
6. Call an old friend and have a long call.
7. Cook your favorite meal or try a new recipe.
8. Go see a movie.
9. Invite a friend to share a meal in honor of caregivers.
10. Find a cleaning activity - it's therapeutic. (Clean desk, wash car, sort garage)
11. Brag all day long for one day about how great it is to be a caregiver.
12. Get a haircut.
13. Take a long walk.
14. Eat a decadent dessert.

15. Treat yourself to a new book and curl up in your favorite chair.
16. Pick a museum and visit it: https://ecobnb.com/blog/2020/03/online-museums-free
17. Smile! It burns calories and makes you feel great.
18. Join a book club or card game club.
19. Participate in a community activity at your house of worship.
20. Invite a chef or chef wanna-be chef to cook a special meal in your home. (Personal favorite! - LG)
21. Take a nap.
22. Go to a football, basketball, or base ball game.
23. Spend time working on a craft (wood or metal or string) or a jigsaw puzzle.
24. Pick and choose to do something new with your child: https://twokidsandacoupon.com/2017/01/25-free-things-for-kids-by-mail.htm]

25. Treat your child unexpectedly to something fun they want to do.
26. Go to the theatre: https://WhatsOnStage.com/ London-theatre/news/stage-shows-musicals
27. Add more items on this list that make you smile.
28. Make a collage of pictures of your career to put on display or near your nightstand.
29. Nominate a fellow caregiver for an award. (Enter "nominate caregiver award" in your favorite search engine and pick an organization to use.)
30. Design your own T-shirt that says "I'm a Superhero Caregiver!"
31. Go fly a balloon or let some butterflies go free!

COMMERCIAL: *Bored from everyday life? Looking for something fun to do to break up the monotony? Download your free, "Happy Month" today! Happy Month is a 30-item-plus list of things (with room for more) that you can do that are guaranteed to make you smile. Print it off. Share it with your co-workers, family, friends, or even the dog. Share the "Happy Month!" What is your happy?*

Bobbie: The answer is easy. I can smile because my child is my world. They can wake up in the morning and ask for me with or without a voice, with or without sight, with or without mobility, and in their own special way say, "Good Morning," which on some days is an accomplishment worth waiting for. At the end of the day, it is easy to smile after changing the PICC line, recharging the batteries for an iPad or power chair, helping them with their therapies, driving them to their appointments or sports practice, making their no egg/dairy/gluten-free cupcakes and know that I played a part in helping them to become an upstanding person in life. Smiling is also easy when I had to stand up to different professionals reminding them that my child has the same right to life as everyone else. Sometimes it is a little more tersely than I would like, but when my child finally gets the accommodations or services they need and succeeds as a result of those changes, then I am smiling. Did I tell you about how wonderful my child is? Oh my goodness! Their bad days, their good days, their intelligence, their softness are just some of the things I love about them. One time…

CERTIFICATE OF APPRECIATION

2021 Superhero Caregiver of the Year

I. M. ACAREGIVER

Recognized for Rising Above Challenges Faced, Having Amazing Energy & Enthusiasm, Being a World Class Advocate, and Proudly Displays Love for Their Exceptional Child!

The World is a Better Place as a Result of your Selfless Donation of Time, Hard Work and Dedication!

WEPC RADIO

WEPC Radio: Home of the Exceptional Parent Caregiver

HOST

Energy Coffee

Energy Coffee

SPONSOR

IT'S OFFICIAL: "This certificate of appreciation is something that an EP reader can print and hang in their room, so that every time they read it, it becomes an affirmation of themselves." – *LG*

Host: Wow! Your child must be wonderful, yet sadly, we are running out of time. Bobbie let me ask you one more question. What is something you wish the world would do in your life that would be helpful?

Bobbie: My biggest wish is I would not be told that someday in the future you will help out. I have learned to ignore those words because they never come true. If you truly want to fill a wish for me, come up to me one day and say, "I am going to do such and such for you on a particular day because you need it. What do we need to do to make that happen? Let me make the arrangements. Let me give you a moment in time for you to understand that you are special and important in the world."

Host: Thank you for sitting down with WEPC today, Bobbie, and teaching us about who a caregiver is, the challenges they face, and the advocacy that is sometimes needed. More important, you demonstrated how to smile in the face of adversity while setting an example for our children who depend on us. Bobbie, we here at WEPC want you to understand that we feel you and the other 8 million-plus caregivers are not only amazing but are the WEPC "Superhero Caregivers of the Year," while simultaneously juggling the world for your child. It is my pleasure to present you with a Certificate of Appreciation and our sponsor, "Energy Coffee" will be reaching out to you tomorrow morning with more energy for you.

Folks, today's show may be coming to a close, but the strength and resilience of what you do never will. I always say that life is not about the challenges faced, but about what comes after in facing those challenges. To all the caregivers out there, you are my superheroes and here at the WEPC studio I am standing on my desk, and applauding loudly for you. Bravo! Bravo!

COMMERCIAL: *Need energy? Need enthusiasm? Want to start each day with a smile? Find a caregiver! Brought to you by, WEPC and today's sponsor, "Energy Coffee," suppliers of energy and rewarding moments. A caregiver's superhero way to start the day!* •

ABOUT THE AUTHOR:

Laura George, EMDL (Emergency Management Disability Liaison) has long advocated for the improvement of emergency preparedness planning of people with disabilities. She is a presenter, author (*Emergency Preparedness Plan: A Workbook for Caregivers, People with Disabilities, the Elderly and Others*), has a Bachelor's Degree from Nova Southeastern University, assisted in many disasters, and has received awards and accolades for her work. Her spare time is spent with her daughter (functional neurologic disorder) and dog.

ILLUSTRATION BY LAURA GEORGE

SPECIAL OLYMPICS ATHLETES TEAM UP WITH MAJOR LEAGUE BASEBALL PLAYERS FOR AN ONLINE FITNESS CAMPAIGN

ESCUELA DE FUERZA

SUBMITTED BY SPECIAL OLYMPICS

Fun, determined, having a love of fitness. Those are some of the qualities you want in a health coach or workout buddy. But those traits combined with fitness skills only come naturally to a select few. Meet Special Olympics athletes Belem Chavez and Ramón Jimenez – who are both charismatic and passionate fitness leaders.

Belem, an athlete from Chicago, is an enthusiastic leader in her community. She volunteers routinely at a local community center and loves to support and educate those around her. Ramón, an athlete from Las Vegas, strives to do his best in every situation, including in his position on the janitorial team at his local airport. Together, they form part of a group of Special Olympics athletes who have made it their mission to help fellow athletes and peers to get fit and be the healthiest version of themselves possible.

SCHOOL'S IN SESSION: Belem Chavez *(left)* and Ramón Jimenez *(right)* pose alongside Tamara, who starred in Escuela de Fuerza as head trainer and helped to lead the athletes through each workout.

PHOTOS PROVIDED BY ANNABELLE GIBSON

IT'S A HIT: *(Above)* Escuela de Fuerza, the brand-new fitness campaign created by Special Olympics, targets Hispanic athletes across the U.S. and aims to encourage individuals with intellectual disabilities to commit to a lifetime of fitness habits. *(Below)* Belem, Tamara, and Ramón lead a warmup in the first video of the Escuela de Fuerza campaign.

Their combined love for teaching and supporting others made them the perfect fit to take part in the brand-new Special Olympics online fitness campaign, Escuela de Fuerza, which translates as School of Strength. Building off the success of the original School of Strength fitness campaign launched last spring, Special Olympics saw the need to provide a similar fitness resource targeted to an entirely new audience, Spanish-speaking individuals with intellectual disabilities across the U.S. Data shows that the Hispanic population is the second largest demographic in the United States and makes up one of the largest populations worldwide. The goal of the campaign is to provide a resource to keep Hispanic Special Olympic athletes fit and healthy and encourage them to commit to a lifetime of fitness habits.

Escuela de Fuerza, a free and fun fitness resource, targets Hispanic Special Olympics athletes in their late teens and 20s and lives on **www.specialolympics.org/escuela-de-fuerza-espanol**. Major League Baseball players Gleyber Torres (New York) and Willson Contreras (Chicago) – who are both native Spanish speakers – are commentators and hosts of the series. The videos are accompanied by a downloadable interactive toolkit for coaches, fun games, and a healthy cookbook made up of traditional Hispanic recipes. The campaign, developed in an interactive style, encourages athletes to work out and exercise on a regular basis.

Five Special Olympics athletes help lead each video by demonstrating the various exercises in the four-part series. For Ramón, that meant stepping up as an athlete leader, which he did with ease and confidence. When asked about his experience starring in the campaign he said, “Being in the videos was so fun. I loved getting to meet the other athletes and production crew. I’m glad that I’ll be able to give fitness advice and motivate other Hispanic athletes, like me.”

Ramón and Belem, along with other Special Olympics athletes, helped instruct four types of workouts in the series, including a quick warmup, strength exercises, balance exercises, and an endurance section.

“I’m excited to have worked on this series of workouts alongside baseball catcher Willson Contreras, representing my own city of Chicago. I already let my other teammates know to get ready, because this workout is going to burn!” exclaimed Belem Chavez.

Special Olympics fitness programs focus on physical activity, hydration and nutrition and offer year-round fitness clubs, fitness challenges for friends and families, as well as wellness classes. The impacts of Special Olympics fitness programming have demonstrated increased health behaviors and health outcomes for athletes. To date, over 150,000 athletes with intellectual disabilities have taken part in Special Olympics fitness programming worldwide, and data collected by Special Olympics reveals that over 60% of Special Olympics athletes are overweight or obese, and one in five lower their blood pressure from high to normal after taking part in Special Olympics fitness programming.

“Our athletes are fierce competitors who should have the same opportunities as everyone else to be active, work out, and be healthy. We are changing the face of inclusive health by giving our athletes opportunities to enhance their fitness,” said Special Olympics Chief Health Officer Dr. Alicia Bazzano. “People with intellectual disabilities die on average 16 to 20 years earlier than those without intellectual disability often due to preventable causes. Becoming and staying fit can reduce those gaps. Escuela de Fuerza is a fantastic series of videos and materials to encourage our Hispanic community of athletes to not only stretch their fitness goals, but stay committed to their health journeys.” •

Letting Go

BY KIMBERLEE MCCAFFERTY

Dear Justin,

This past week I took you to the Point Pleasant boardwalk with a friend, hoping we'd harken back to times of "yore" when everything went smoothly and we both enjoyed ourselves. You see, my son, our last few trips there have been quite stressful, and despite using my "bag of tricks" with you I'm not comfortable taking you there alone anymore.

There are just certain attractions that your aging mother can no longer tolerate, but sometimes there is no reasoning with you and your implacable will. When you want something, you want it. And all the social stories in the world aren't going to change that.

We had two bad experiences there recently, but I was hoping the third time would be the charm, plus your mom is ridiculously stubborn. I am loathe to give up a pastime that we've been able to do just the two of us for 15 years, and I was hoping your behavior was just a blip on the radar, nothing permanent.

I quickly found out that despite my own implacable will to get you out in the community, you had other ideas, my son.

I had help with me so it wasn't that difficult to get you back to the car when things went south, yet, I was still left sweating and filled with regret. This used to be one of our easy trips, occasions where if I said "no" to a ride, you'd listen without complaint. You were just happy to be out of our house.

I've noticed since we've been going out into the world post-COVID, you are asserting your wants more now, and I understand. We had 15 months of pretty much being in lockdown chez McCafferty, and there are things you want to do, things you want to see. I get it.

The only problem is, you can't have your way every single time.

We've been in this situation before. I remember taking you and your brother on the Great Adventure safari years ago, and listening to your low-grade whine throughout the ride in our car. I recall that for perhaps the first time I wasn't kvetching that you were annoyed. You were safe, hydrated, and inconvenienced for an hour so your brother could do something he loved. For once, I wasn't upset that you were unhappy.

I remember feeling liberated.

Now you are bigger than me – taller, and you outweigh me by a few pounds (if I haven't had too much ice cream recently). I can no longer negotiate or block you from your chosen path by myself. I simply don't have the strength. But I do have the strength to learn to let go.

The truth is, it is no longer feasible to take you back there alone. There may be more trips in the future with our family friend and perhaps the BCBAs from your school when that program starts up again.

I'm not ruling out the boardwalk entirely. I am, however, letting it go for just the two of us. I'm acknowledging that now that you're older I may be letting go of other things too.

And letting go is okay.

I will always help you live your best life. The landscape of that life will change, and I need to be on board with that.

I am trying.

I love you, my boy. •

ABOUT THE AUTHOR:

Kimberlee Rutan McCafferty, mother to two sons on the autism spectrum and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of a blog at autism-mommytherapist.wordpress.com. Kim's book *Raising Autism: Surviving the Early Years* is on sale on Amazon here.

PHOTO PROVIDED BY KIMBERLEE RUTAN MCCAFFERTY

EXCEPTIONAL PARENT • PHYSICIAN • PATIENT • PEOPLE

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY

SECTION

MILITARY LIFE

PUZZLES AND CAMO

BENEFITS FOR FAMILIES WITH SPECIAL NEEDS

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

SUPPLEMENTAL SECURITY INCOME

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

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

Check your family member's eligibility by completing the SSA Benefit Eligibility Screening Tool and learn everything you need to know before applying.

TITLE V PROGRAMS

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

- ***Delivery of health services:*** *Organization and delivery of health care services that meet the emotional, social and developmental needs of children.*

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

State Maternal and Child Health agencies maintain a toll-free hotline for information about Title V programs and providers. Check https://mchb.tvisdata.hrsa.gov to locate your local Title V program or call the national Title V toll-free number at 800-311-2229.

THE FAIR HOUSING ACT AND OTHER HOUSING PROGRAMS

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

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

If you live in privatized housing on a military installation, your property managers are required—at no cost to you—to make reasonable accommodations that abide by the Americans with Disabilities Act (www.ada.gov/2010_regs.htm).

Families with special needs have the right to accessible housing. Your installation housing office or your Exceptional Family Member Program coordinator can help you look for affordable housing on and off the base. Visit MilitaryINSTALLATIONS to find contact information.

MEDICAID BENEFITS FOR INDIVIDUALS WITH DISABILITIES

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

Every state has its own Medicaid program with income restrictions and criteria for eligibility. Check www.medicaid.gov/state-overviews/index.html for your state to see if you qualify and for more information. You can also find more information through the Military OneSource eLearning module on government assistance at https://millifelearning.militaryonesource.mil/f?p=SIS:9:::::P9_ID:66

MEDICARE

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

UNITED FRONT: As a military family, you can count on the support of the Exceptional Family Member Program, or EFMP, and Military OneSource special needs specialty consultants. In addition, there are federal and state programs committed to providing additional assistance for families with special needs.

ADDITIONAL GOVERNMENT PROGRAMS

Supplemental Nutrition Assistance Program and the Women, Infants and Children program are designed to aid children with special needs. More information about these benefits is provided at www.usa.gov, an official government website search engine that links to government agencies, programs and services.

– Military OneSource

EFMP & ME IS HERE

Military families with special needs —
Take time to explore services and supports using this
personalized tool as your guide. Online, 24/7.
Learn more at:
www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member/efmp-me-online-tool-for-military-families-with-special-needs

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Learn about the benefits available to you with the
Special Needs Parent Toolkit
and use them to take good care of your family.
www.militaryonesource.mil/products/special-needs-parent-toolkit-downloadable-146

U.S. MILITARY ★

HOW TO IDENTIFY AND ADDRESS BULLYING BEHAVIOR

WHAT IS BULLYING?

The Centers for Disease Control and Prevention defines bullying as “any unwanted aggressive behavior(s) by another youth or group of youths, who are not siblings or current dating partners, that involves an observed or perceived power imbalance and is repeated multiple times or is highly likely to be repeated.”

Bullying may inflict physical, psychological, social or educational harm on the targeted youth.

Bullying behaviors include:

- *Teasing, name-calling and taunting*
- *Spreading rumors about someone or intentionally embarrassing someone in a public setting*
- *Hitting, kicking, tripping, punching or spitting*
- *Taking or damaging someone else’s belongings*

The real or perceived imbalance of power can result from:

- *Being physically able to hurt others*
- *Participating in a group that outnumbers the targeted individual or group*
- *Being more assertive and confident to initiate the behavior or engage in sophisticated, subtle ways to make fun of someone in a way that goes unnoticed by adults*
- *Possessing higher social status and the ability to turn others against the target of the bullying*
- *Having access to embarrassing or private information*

WHY CHILDREN AND TEENS ENGAGE IN BULLYING BEHAVIORS

Children engage in bullying behavior for a number of reasons.

- *They may be struggling to manage strong emotions such as anger, frustration or insecurity. Unloading these emotions on another child can make the child or teen feel more important, more popular or more powerful.*
- *Youth may not understand that their behavior is not OK. They target those who are not like them — in looks, race, religion, social or economic standing and numerous other ways children differ from each other — because they have not learned the skills to understand how to accept differences or work out conflicts or disagreements.*
- *Children are copying aggressive or unkind behavior they see at home. Youth who are taunted at home — by siblings, parents or other family members and caregivers — learn that they can control others through bullying behavior.*

Bullying is a behavior, not an identity. Anyone can be bullied, and anyone can engage in bullying behaviors — male or female, popular or unpopular, those doing well in school and those who are not. But new behaviors can be learned, and bullying can be curtailed or stopped.

SIGNS YOUR CHILD COULD BE BULLYING OTHERS

The following information could be helpful in determining if your children are expressing their stress in the form of bullying. Children who are bullying others often exhibit one or more of these traits:

- *Are unwilling to accept responsibility for their actions and behaviors, either at home or in school*
- *Are quick to blame others for their problems or unwanted situations*
- *Lack empathy, compassion or understanding of others’ feelings*
- *Are being bullied themselves*
- *Seem overly worried about their reputation or popularity or are trying to fit in with peers who engage in bullying behavior*
- *Want to be in control or are highly competitive in sports, academics or recreational games (while it is common for youth to be competitive in their academic or recreational pursuits, parents should be concerned if this behavior accompanies others on this list).*
- *Are frequently sent to the principal’s office or to detention*
- *Do not recognize that their behavior is aggressive or believe they are just teasing or joking*
- *Have frequent physical or verbal fights that are fueled by frustration, anxiety, depression or the inability to control anger*
- *Are increasingly aggressive with parents or guardians, siblings and friends*
- *Hang around with individuals who bully others*
- *Have unexplained extra money or unfamiliar belongings in their possession*

TAP INTO RESOURCES

- *Equip your children with the skills necessary to cope with anger, frustration, conflict and difficult situations. Consult resources such as StopBullying.gov, which is aimed at helping children and adults deal with bullying behavior. Professionals or Military OneSource child and youth counselors* (www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/child-counseling-helps-kids-develop-healthy-habits) *can assist your child or teen in dealing with the behavior.*
- *Explore children and youth counseling services available through Military OneSource. Licensed counselors can help with changes at home, communication and relationships at home and school, and behavioral issues. You can also contact your installation’s Military and Family Support Center* (https://installations.militaryonesource.mil/?looking-for-a=program/program-service=26/focus=program) *and ask to be connected to child and youth behavioral counselors near you.*
- *Contact your local school liaison. They can connect parents and guardians to school and district personnel to facilitate*

BREAK THE CYCLE : HOW TO HELP A CHILD ENGAGING IN BULLYING BEHAVIORS

Bullying behavior is common, and there are successful interventions to correct behavior. The most important thing is to deal with the behavior immediately. There are numerous ways to help your family cope with and correct bullying behavior, as well as tools and resources to help restore stability to your child's school, home and social environments. Here are some ways parents or guardians can address bullying behaviors and the underlying issues:

- Talk to your children about bullying. Begin by letting them know it is not OK.
- Be specific about what behaviors are acceptable and not acceptable. Review the list of behaviors that constitute bullying, and discuss how you would like to help them expand their skills to respond differently in future situations.
- Ask your children to describe the situations and how they feel in those circumstances that lead to the unwanted and repeated behaviors. Listen to their feelings and consider their actions and reasons for engaging in such behavior. Develop an action plan to help them develop different coping skills (**www.cdc.gov/mentalhealth/stress-coping/help-children-cope/index.html**).
- Teach your children to treat everyone, even those who are different, with respect and kindness. Set an example at home, but also talk about how they might have reacted differently in the situations they have experienced.
- Be open with your children when conflicts occur in your own life, and share how you're trying to handle them with respect. Yelling, name-calling, put-downs and harsh criticism are behaviors the entire family should work to eliminate.

conversations and resolutions and help you find the resources you need. See **www.dodea.edu/Partnership/SLO.cfm?cssearch=501416_2**

- *Seek help if there are relationship or domestic violence problems at home. If you feel someone is in crisis, contact the Military Crisis Line at* **www.veteranscrisisline.net/ActiveDuty.aspx** *Experts are available 24 hours a day. Call 800-273-8255, then press 1. Start a conversation via an online chat* **www.veteranscrisisline.net/get-help/chat** *or text 838255 from your mobile phone or device.*

PUT A PLAN IN PLACE

- *With assistance from child and youth counselors or trusted school administrators, create a plan for addressing the behavior that is specific to your child's situation. A behavior-modification plan should provide structure and boundaries for specific behavior expectations, frequent involvement and discussion with parents and guardians, exploration of feelings in difficult situations and consistency of discipline and rules.*
- *Encourage good behavior. Positive reinforcement of appropriate behavior is more effective than negative discipline.*
- *Should discipline be necessary, be consistent. Attach meaningful, time-limited consequences to slip-ups in behavior. Logical, situation-specific consequences are best. If damage was done as a result of the bullying behavior, have your child provide restitution by paying for damages. If the behavior is taking place during sports or other recreational activities, have your child take a short break from participation. If logical consequences aren't practical or even feasible in a particular situation, behavioral slip-ups can be handled with a loss of privileges – from TV or video games to missing a social outing with friends.*
- *Consult age-appropriate child and parenting resources to better understand how you can support your child. Information and resources are available through:*
  - **Stopbullying.gov**, *a federal government website with additional reading materials and information to help prevent and address bullying behaviors, including videos and webisodes for children*
  - *American Academy of Child & Adolescent Psychiatry – Bullying Resource Center* **www.aacap.org/AACAP/Families_and_Youth/Resource_Centers/Bullying_Resource_Center/Home.aspx**
  - *Military Kids Connect parenting resources at* **https://militarykidsconnect.health.mil/Caring-for-Our-Youth/Parents**
  - *Thrive, an online parenting-education program for parenting questions and issues for children up to age 18 at* **www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/thrive-online-program-for-military-parents**
  - *Bullying is a Pain in the Brain at* **www.militaryonesource.mil/products/bullying-is-a-pain-in-the-brain-1**
  - *How to Help a Child Being Bullied at* **www.militaryonesource.mil/family-relationships/parenting-and-children/parenting-youth-and-teens/how-to-help-a-child-being-bullied**
- *Monitor the bullying behavior to figure out what is triggering it. Was your child aggressive or angry? Sulky or withdrawn? Spiteful or secretive? What day and time did the behavior take place? What activities did your child engage in before the behavior worsened? How long did it take for your child to calm down and what helped? Being aware of the situations that trigger these reactions can help shape conversations with your child, other parents, professionals, teachers and administrators.*

Take the time to get to know your child and to understand what may be behind the behaviors. Resources such as those available through the Centers for Disease Control and Prevention (**www.cdc.gov/mentalhealth/stress-coping/help-children-cope/index.html**) can help you teach your child better coping and social skills so they can handle difficult situations. Talk openly with your children about bullying to help prevent reoccurrences (**www.cdc.gov/violenceprevention/youthviolence/bullyingresearch/fastfact.html**). Share age-appropriate information with them and teach them to be aware of their behaviors.

Military OneSource can connect you with the resources and information you need to help your children heal, including child and youth counseling. Call 800-342-9646, find OCONUS dialing options or start a live chat.

– Military OneSource

Morally Bankrupt

Applied Behavior Analysis has been put under scrutiny for as long as I can remember and insurance companies or, in this case, entitlements such as Tricare, have capitalized on this issue in order for them to offer less support to military children with autism.

Broden has taught me many things. He has shaped me into the person I am today. If Broden was not who he is, then I truly feel I would be someone completely different. I'm not sure I would be half as empathetic towards others, and I think I would care more about what others thought of me. Broden's pureness burns through my chest and warms my heart each morning as he rolls over and looks at me, to the time I lean over to kiss him on the cheek before he goes to bed. Broden does not judge and he never asks for things he feels he does not need. Both of my children are my path to authenticity, my journey to goodness, my map to pure unadulterated love and joy. Because of both of my children, autism or typical, I love harder and work harder.

Does raising Broden make life easier? My answer is no, but I would rather live in a world with him as my son than not. Would I want to take his autism away? When he was two years old, I may have said yes out of confusion and fear, but now I don't think I would have the same answer because autism is a part of Broden. I love him for who he is and I spend less time thinking about who he would be without that part of him. I spend more time thinking about what Broden can accomplish with autism now and in the future. That part of him is melted too deeply into who he is as a person.

I can only speak from my experience raising a child with autism and I have never come from a place where I think I can speak for anyone else. Over the years, the narrative has shifted about services for our children and the more I listen, I realize that there is no one-size-fits-all answer. Applied Behavior Analysis (ABA) has been put under scrutiny for as long as I can remember and insurance companies or, in this case, entitlements such as Tricare, have capitalized on this issue in order for them to offer less support to military children with autism. Years ago, I probably would have written these last few sentences with anger and resentment, but now I just state them as fact. To Tricare, our children are dollar signs. They will always be dollar signs, nothing more, nothing less.

Over the years, Tricare's playbook to spend less money on our children with autism has been to create barriers for care. This is not a new innovative idea. It's a reality that our military families face each day. There are two things that stay true in our lives; autism will be a part of it. Another thing that sadly stays true in our family's lives is wondering what Tricare is going to do next to make it more difficult for our children to access care. Our fear is real and they continue to create and pursue these tactics relentlessly that only create more stress in our lives while we continue to serve our country, their country.

The latest tactic, ironically a tactic that creates more undue stress, is having our families fill out the SIPA (Stress Index for Parents of Adolescents, third edition). According to Tricare, the SIPA is a "standardized assessment that gives families and provider teams clear, consistent measurements of progress over time" in order to "measure the stress and dynamics within a family system specific to raising adolescents." Tricare states that these scores "will not be used for treatment planning, nor are they meant to diagnose dysfunction in the parent-adolescent relationship or

COUNTERPRODUCTIVE: "The SIPA assessment encompasses statements that lead the parent to question their own worth."

as a screening tool for parental mental health.” The only reason they want our families to fill out this assessment every six months is so our children’s ABA providers can identify if we need any additional support. After taking these assessments, it is clear that the focus has shifted away from identifying what our children with autism need and it has moved towards what we are not doing as parents.

Health Net Federal Services (HNFS) states that the SIPA will prompt the “clinical reviewer to evaluate parent training recommendations, parent engagement, and unique circumstances.” Without taking the SIPA, one may think that Tricare makes sense in this requirement. The more information about the family, the better to support them. My question is, why is Tricare the only funding source that requires this assessment? This question still remains unanswered.

Why fight filling out the SIPA every six months? It’s just one more assessment to fill out in order for our children to receive services. The reason is plain and simple. The SIPA is an intrusive and insulting assessment that is being used as a tool to bully parents out of seeking services for their children for services. It is Tricare’s sleaziest attempt to shame our military families from access to the appropriate care they need. Tricare’s acts are discriminatory against our families and it is criminal that we need to answer questions about the most private parts of our lives in order for our children to receive care.

When the assessment is researched and taken, there is even a question if the assessment was created for the purpose in which it is being used. In the *Journal of Autism and Developmental Disorders,* a paper entitled “Parent and Family Outcomes of PEERS: A Social Skills Intervention for Adolescents with Autism Spectrum Disorder by Karst et al, the SIPA was used as an assessment tool to study the level of stress a family is under while raising a child with autism, but the study was done with “64 families of adolescents with high-functioning ASD.” This is a very important variable in the level of efficacy in forcing our families to complete the SIPA every six months, because a large percentage of the assessment cannot truly be completed for adolescents with moderate to severe autism. Many children with moderate to severe levels of autism have difficulty with expressive language. If the parent is to take the time to fill out this assessment honestly, they are unable to successfully complete the task. In turn, this confuses and frustrates the parents even more as to why they are filling the SIPA out every six months in the first place.

> “After being subjected to filling out the SIPA, I’ve experienced a sense of emotional rape that I have never experienced before because frankly, my sex life is none of Tricare’s business.”

For this assessment, we are given statements and tasked to either “strongly disagree, agree, state we are not sure, agree, or strongly agree.” Statements in this assessment are “My child never seems to do anything”, “My child gets upset over little things”, “My child does things for me that make me feel good”, “My child thinks I do not love him or her”, and “I find myself giving up more of my life to meet my child’s needs than I ever expected.” I am forced to respond to statements that seem outlandish and trivial concerning an adolescent who has severe autism, such as, “I believe that my child drinks more alcohol than I would like.” This, again, leads me to question the validity of the assessment concerning my son qualifying for ABA services. My son only drinks a high caloric nutrition supplement. The idea of my son drinking alcohol is asinine.

The SIPA assessment encompasses statements that lead the parent to question themselves as a person and their own worth, such as, “I often have the feeling that other people my own age don’t particularly like my company” and “I can’t make decisions without help.” After the experience of having to respond to these statements, my thoughts are, “What is Tricare trying to accomplish with this assessment?” The only response I could find was good old fashioned shame and guilt.

The SIPA then veers our military families to a darker side. Statements such as, “I feel every time my child does something wrong it is really my fault” and “I expected to have closer and warmer feelings for my child at this age than I do.” Just when you feel the statements you are being told to respond to couldn’t get any more insulting, you receive a statement about your sex life. “Since my child became a teenager, my sexual relationships ‘have’ been less satisfying.”

In the late 1940’s to early 1950’s, there was a theory entitled, “The Bettelheim’s Theory of Autism” or in more layman’s terms, “The Refrigerator Mom Theory”. This unproven theory states that the reason a child has autism is because the mother lacks warmth to their child. After filling out the SIPA, I can’t help but feel as if I’m being put on trial for not loving Broden enough and, even further, being asked if I think my sex life is related to Broden’s autism.

I’ve seen Tricare reach to treacherous depths to cut costs, but after being subjected to filling out the SIPA, I’ve experienced a sense of emotional rape that I have never experienced before because frankly, my sex life is none of Tricare’s business. •

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.

ADAPTIVE/SPECIAL NEEDS BEDS

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E: ruthann@kayserbettenus.com
W: www.kayserbettenus.com
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