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NEEDS PLAN  
that WORKS**

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for SPECIAL  
EDUCATION  
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**DISABILITIES &  
COUNSELING  
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2020

# EP GUIDE

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RESOURCES** *for*  
**PEOPLE WHO  
ARE BLIND**

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EP is pleased to begin a new decade with the third annual edition of the EP GUIDE: Navigating Special Needs Resources. EP continues to provide expert guidance and invaluable resources, including in-depth articles and up-to-date reporting on such topics as employment and entrepreneurship, educational and financial planning, and specialized counseling service. These thoughtful pieces have been developed by the most highly-regarded and experienced experts in the special needs field. Please enjoy this innovative format and share your thoughts with us at [vira@ep-magazine.com](mailto:vira@ep-magazine.com). *EP GUIDE 2020: Navigating Special Needs Resources begins on page 23.*

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FROM OUR FAMILIES... TO YOUR FAMILIES



# MILITARY



**MILITARY LIFE**  
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HOW TO CHOOSE A COUNSELOR OR THERAPIST  
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Information and Support for the Special Needs Community  
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 — Rick Rader, MD

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# On the Sensibility of Playing at an Off-Off-Off Broadway “Production”

Out of the 40 dentists who enthusiastically came into the lecture hall, 35 were already actively seeing and treating patients with intellectual and developmental disabilities. They came to see who else joined the camp... and they came to identify themselves as dentists who knew the joy of embracing this marginalized patient population.

I have always been amazed at how music impacts and manipulates the emotion, energy and pulse of a theatrical production. For years they have released the music score from plays, musicals, and movies. Sometimes the music becomes better known than the production it was created to enhance.

Since the earliest days of the theatre, music has been the cornerstone of the theatrical enterprise. Theatrical music has changed the heart rate and rhythm of the audience. Everyone is familiar with their own experience with the “earworm,” a song or melody that you can’t get out of your head. They typically enhance the dramatic narrative and the emotional impact of the scene in question. In its own way, music from Broadway has been a mainstay in the chronicles of leading us to somewhere else.

So I get into my car to drive to the Chattanooga airport to catch a flight to New York City. I turn on the radio and it begins,

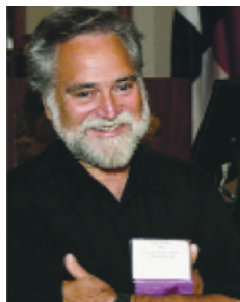
*They say the neon lights are bright  
On Broadway  
They say there’s always magic in the air*

*On Broadway  
But when you’re walking down the street  
And you ain’t had enough to eat  
The glitter rubs right off and you’re nowhere  
On Broadway*

And of course I’m no stranger to the Drifter’s version of the popular song “On

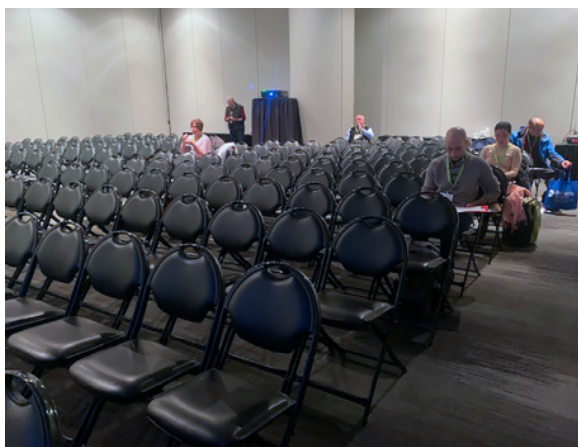
Broadway.” It was a major chartbuster in the early Sixties. And while the song reveals the harshness of trying to become a Broadway star, it has a positive upbeat ending.

*They say that I won’t last too long  
On Broadway, on Broadway  
I’ll catch a Greyhound bus for home, they all say  
On Broadway  
But no, no they’re wrong, I know they are  
I can play this here guitar  
And I won’t quit till I’m a star  
On Broadway*



the West Side of town, 11th Avenue to be precise. I was going to the Jacob Javits Convention Center, the mother of all conference centers. The Javits Center is a goliath. It has over 760,000 square feet of exhibit space and never-ending rows of classrooms, conference and meeting rooms and it certainly can be considered the “Broadway” of exhibit, trade and educational conferences. And while it’s “off-Broadway” it certainly doesn’t take a back seat to anywhere else.

The term “Off-Broadway” is actually a precise term; and not restricted to any specific address or location. An Off-Broadway theatre is any professional theatre venue in Manhattan with a seating capacity between 100 and 499. Some shows that premiere Off-Broadway are subsequently produced on Broadway. Originally the term “Broadway” referred to any theatre that was within a defined geographic box on or around



**PREACHING TO THE CHOIR:** Out of the 40 who enthusiastically came into the lecture hall, 35 were already actively seeing and treating patients with intellectual and developmental disabilities.

*I’m gonna make it, yeah  
On Broadway  
I’ll be a big, big, big man  
On Broadway  
I’ll have my name in lights  
On Broadway*

And while I was not on my way to Broadway I was on my way to the Big Apple,



Broadway. The switch to the term “Off-Broadway” was related to paying a lower salary to the union members for performing and working in smaller venues. Its history dates back to the 1950’s and according to theatre historians, “Off-Broadway” offered a new outlet “for poets, playwrights, actors, songwriters, and designers.”



And then there's "Off-Off-Broadway." This category of theatres started in 1958 with a "complete rejection of commercial theatre." Off-Off-Broadway theaters are smaller than Broadway and off-Broadway theatres, and usually have fewer than 100 seats. In a way, I was slated to appear in an "Off-Off-Broadway production."

I had both the honor and challenge of co-presenting at the Greater New York Dental Society's Annual Meeting. This is not a local, regional or state meeting. This is, in fact, the largest dental conference in the world. It typically attracts over 50,000 dental health providers who come to learn the newest procedures, techniques and treatments for dental and oral health. There are over 600 companies that exhibit the latest in materials, equipment, diagnostics, appliances, tools and strategies designed to improve the outcomes for people with oral health needs.

I was part of an all-star quartet including Dr. Jack Dillenberg, the doyen of Public Health Dentistry and a driving force in teaching dental students about special needs dentistry; Maureen Munnely Perry, DDS, MPA, MAEd, Professor of Special Care Dentistry and the Director of the Center for Advanced Oral Health at the Arizona School of Dentistry and Oral Health; and Neal Romano, the Chairman of the National Council on Disability.

We were charged with promoting, encouraging and incentivizing dentists and dental hygienists to treat patients with disabilities, especially those with intellectual and developmental disabilities. This was no small task considering that few dental schools in the United States mandate or provide any formal, competency-based training in this high-risk population.

Of course, our three-hour session was not the only option for the 53,000 dentists. The 200-page meeting guide listed an array of courses, lectures, workshops and seminars on a variety of topics. There was a myriad of

subjects and presented a ton of options for the dentists to choose from.

When our session was ready to begin, I left our meeting room to get a cup of coffee to get through the morning. On the way back to begin our presentation, I put my head into the room adjacent to ours and gasped when I saw the title slide for the scheduled class:

"PUMP UP YOUR PRACTICE: HOW TO GROW YOUR PRACTICE BY \$300,000...OR MORE...THIS YEAR"

It dawned on us what we were up against; a true David vs. Goliath ordeal. How do you compete with an invitation to the road to riches versus the obstacles of treating complex patients? Patients who may not understand you, cooperate with you, appreciate you, pay you, remember you, and who may assault you. But before we made our pre-



**MIGHT VS RIGHT:** How do you compete with an invitation to the road to riches versus the obstacles of treating complex patients?

sentation, we realized we needed an audience. The very thing the producers of "Off-Broadway" and "Off-Off-Broadway shows" needed. If "Off-Off-Broadway" shows had room for under 100 and under 50 respectively, we were thinking this might be considered, "Off-Off-Off Broadway." While there were 53,000 potential attendees, the grim reality of low attendance was palpable.

While it was no surprise, it was still disappointing that only 40 dentists showed up. That is .75% (less than one percent). Out of the 40 who enthusiastically came into the lecture hall, 35 were already actively seeing and treating patients with intellectual and developmental disabilities. They came to

see who else joined the camp, they came for camaraderie, they came for validation, and they came to identify themselves as dentists who knew the joy of embracing this marginalized patient population. That left us with a target audience of five dentists who we had the opportunity to encourage learning more about these folks, their needs, and their lives.

This is certainly not a condemnation of dentists. Their training and dedication provide them with the right to earn an attractive living. In fact, the high overhead of operating an active practice requires it. I want this to be thought of more like a "cautionary tale." If dentists don't take up the mantle to care for, and about this population, it will eventually become a condemnation of dentists for not honoring and committing to the code of ethics that distinguishes the practice of dentistry.

The four of us performed like troopers. We were as enthusiastic in sharing our passion, our experiences, and our vision as if all 53,000 dentists crowded into that room. Our reward, our justification, and our motivation were all based on the hope, the feasibility, and the potential that we converted all five of those curious dentists. Perhaps we succeeded, and perhaps all five of them will eventually encourage five more dentists to climb aboard.

All four of us left the lecture room, as a quartet, harmonizing like the Drifters, from our first performance in an "Off-Off-Off Broadway production."

*And I won't quit till I'm a star on Broadway,  
on Broadway  
On Broadway (on Broadway)  
I'm gonna make it, yeah (on Broadway)  
I'll be a big, big, big man (on Broadway)  
I'll have my name in lights (on Broadway)  
Everybody, everybody's gonna know me,  
yes (on Broadway)  
All up and down Broadway (on Broadway) •*

#### ANCORA IMPARO

In his 87th year, the artist Michelangelo (1475 -1564) is believed to have said "Ancora imparo" (I am still learning). Hence, the name for my monthly observations and comments.  
— Rick Rader, MD, Editor-in-Chief, EP Magazine  
Director, Morton J. Kent Habilitation Center  
Orange Grove Center, Chattanooga, TN

# WHAT'S HAPPENING

## AN ANNUAL CONFERENCE IN NEW YORK ON THE CARE OF THOSE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

BY VINCENT SIASOCO, MD, MBA

No rewards come without their challenges. It has been well documented that there's a dearth of available education and training for healthcare professionals on how to care for those with intellectual and developmental disabilities. Up until now, most medical school curricula still do not require special needs training and education as a required topic.

For the medical resident, there are not many opportunities (before they go out on their own and practice) to do a rotation in which to gain experience with the intellec-

tually and developmentally disabled patients. For the parent, the process to find a physician or dentist who has the background, experience, or even just the willingness to see their child with special needs can be an arduous one. Hiring a provider can be just as difficult. Resumes are received and reviewed with the understanding that most will not have this type of experience listed. Those that do, stand out as a shining light and give hope, regardless of how many years of experience they have, or even in what capacity they've previously worked with this population.

For the practicing healthcare provider, depending upon their discipline, one is required to maintain a regular amount of continuing education credits on an annual basis which can be obtained by attending a clinical conference. For students, residents, and working clinical professionals, there are occasional opportunities to attend a conference focusing on the care of patients with intellectual and developmental disabilities but

**A ROBUST SHOWING:** It is comforting to know there is now an established Multi-Disciplinary Clinical Conference on the Care of Patients with Intellectual and Developmental Disabilities held every fall in Saratoga, New York. The audience doubled this year from last year, and as before, the audience was made up of physicians, dentists, clinicians, nurses, and administrators.





these conferences are rare within New York. Each year begins a new search for this type of educational opportunities.

Two years ago, Dr. Maria Kansas and I, Co-Chairs of the Cerebral Palsy Associations of NYS Medical Director's Council and their organizer, Deb Williams, came together to present to their Council members the idea of putting together a one-day multi-disciplinary clinical conference. Council members, made up of representatives from each of the over 20 health centers and clinics affiliated with CP Associations of NYS across the state, immediately and unanimously agreed that this is what needed to happen and a Conference Planning Sub-committee was formed. The Council discussed and identified the most common clinical conditions seen by healthcare providers at the health centers as well as in the group homes across the state. It was

important to all that the need for integrated care was to be emphasized and the idea of panel discussions made up of different disciplines were favored to present at the conference. Over the course of a few months, the Conference Planning Sub-committee held conference calls, shared emails, reached out to hospitals, schools, providers, and community stakeholders to get their input and identify speakers as well as vendors to sponsor. Applications to be able to offer continuing educational credits of different disciplines were completed. It was a true grassroots effort. Most of the organizers had all attended conferences, however none of us had actually put together a conference with the exception of one – Deb Williams. Deb Williams' actual day job is as the VP of Reimbursement and Regulatory Compliance of CP Associations of NYS. Regardless, she took on the roles of organizer, facilitator, and task master working closely with the Planning Committee to transform this idea of a one-day multi-disciplinary clinical conference a reality.

On November 16, 2018 our simple idea came to fruition and our Council held the First Annual Conference on Multi-Disciplinary Clinical Care for Patients with Intellectual and Developmental Disabilities in Saratoga, N.Y. The Co-Chairs welcomed everyone in the audience to one of the first annual meetings of its kind in New York. Fast forward to a year later; we now just finished holding our second annual conference last November 15.

Our topics continue to include the most commonly-seen clinical conditions within the special needs patient population, such as constipation, how to avoid fecal impaction, dysphagia, how to avoid aspiration pneumonia, osteoporosis, and highlighting the importance of oral health and primary care/behavioral health integration. This year, we added the important topic of aging and dementia. The audience

doubled this year from last year, and as before, the audience was made up of physicians, dentists, clinicians, nurses, and administrators. Audience members included not only those with

extensive experience with this population but, more important, those just wanting to learn more as they near their graduation and start their careers. Though we couldn't include all the needed topics in a one-day conference, it's comforting to know there is now an established annual Cerebral Palsy Associations of NYS Medical Director's Council Multi-Disciplinary Clinical Conference on the Care of Patients with Intellectual and Developmental Disabilities held every fall in Saratoga, New York that all can learn from.

#### ABOUT THE AUTHOR:

Vincent Siasoco, MD, MBA, is a Family Physician and Chief Medical Officer at the Metro Community Health Centers, Inc. based in NYC.



**SCANT CHANCES:** Most medical school curricula still do not require special needs training and education as a required topic, and there are few opportunities for medical residents to do a rotation in which to gain experience with the intellectually and developmentally disabled patients.

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# E-CIGARETTES, JUULS, AND VAPING

BY NEVIN ZABLOTSKY DMD

**E**-cigarettes are electronic nicotine delivery systems which usually have a battery, heating element, and a place to hold a liquid. They produce an aerosol by heating a liquid that usually contains nicotine, flavorings and other chemicals to make the aerosol. The increase in the number of kids, teens, and young adults using e-cigarettes and Juuls is frightening. In the past year alone, there has been a 78% increase in high school students vaping, with the number of middle and high school students combined equaling 3.6 million users. Individuals with intellectual and/or developmental disabilities may be especially vulnerable to the deleterious effects of tobacco use, vaping products and dependence. Given that 40 million people use E-cigarettes worldwide, the likely impact on this population on a global level is great.

Part of the allure of these products can be attributed to the vast array of flavors offered, such as mint, mango, gummy bear, and cotton candy. In fact, researchers have identified that 97% of kids vaping use flavored products, with mint being the most popular. The C.D.C also noted that 39% of kids, teens, and young adults using e-cigarettes were exposed to family or friends using them, and 17.1% thought that given they were less harmful than cigarettes, they were safe. In fact, many young people were unaware that e-cigarettes and Juuls contain the addictive ingredient, Nicotine. It is likely that given the prevalence and advertising of these products, people with intellectual disabilities are equally, if not more vulnerable, to begin to use these products as well.



**SMOKE AND MIRRORS:** Individuals with intellectual and developmental disabilities might not be able to judge how potentially addictive the use of e-cigarette products are.

The latest research has shown that Juul e-cigarettes have a modified nicotine salt molecule that is absorbed almost as readily as cigarettes. They also have a diminished harshness on inhaling their aerosol, which allows new users to more readily become hooked. Juul e-cigarettes also have up to 5% nicotine content which is more than double of that of most e-cigarettes, with one of their pods equaling the same nicotine content as a pack of cigarettes.

The latest C.D.C statistics show that 2,290 cases have been reported of e-cigarette, vaping, and lung injuries (EVALI) in 49 states, the District of Columbia, and Puerto Rico and the Virgin islands, and 45 deaths ranging from the ages of 17-75.

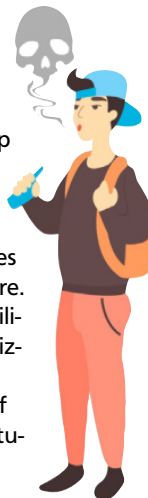
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Nevin Zablotsky D.M.D., is a Senior Consultant and Lecturer for Nova Southeastern University College of Dental Medicine.

## UP IN SMOKE : IMPORTANT E-CIGARETTE TAKEAWAYS

What are some important takeaways that parents, coaches, and healthcare professionals should consider in regards to these products?

1. E-cigarettes and Juuls are unsafe for children, young adults and vulnerable adults.
2. Nicotine can harm the brain as it continues to develop through one's early to middle 20 years of age.
3. E-cigarettes and Juuls may contain other harmful substances.
4. Statistics show that young people who use e-cigarettes are more likely to go on to smoke cigarettes in the future.
5. Individuals with intellectual and developmental disabilities suffer from the health, financial, and the stigmatizing effects of tobacco use including vaping products.
6. The use of tobacco products can reduce the effects of certain medications used by individuals with intellectual disabilities.
7. Learn where and whom to refer those already addicted to these products to help them break their addiction.
8. Safety: E-Cigarettes, Juuls, and Vaping product devices have been known to cause fires and explosions and require great caution in their use.
9. The dangers of second-hand vapor have just begun to be studied but according to the C.D.C. volatile organic compounds such as benzene, which is found in car exhaust; and heavy metals, such as nickel, tin, and lead may threaten those breathing in the aerosol.
10. That a recent study also showed that the residues from the aerosols emitted by e-cigarettes may settle on indoor surfaces in homes where they are used, which may create a potential environmental hazard.
11. That Individuals with intellectual and developmental disabilities might not be able to judge how potentially addictive the use of these products are.



## WHAT'S HAPPENING

# PROJECT ACCESSIBLE ORAL HEALTH: A CATALYST AND CHAMPION FOR CHANGE



**CHANGE AGENTS:** Dr. Robert Glickman, Michiko Toda, Dr. Kyoko Kuroiwa, Dr. Takehiko Kata, Guest & Deborah Weisfuse, John D. Kemp, Barbie Vartanian, Dr. Michael O'Connor and Steve Kess following a meeting at the NYU College of Dentistry

BY BARBIE VARTANIAN

In 2017, three people of influence, John D. Kemp, President and CEO, The Viscardi Center and Chairman, Project Accessible Oral Health; Steven W. Kess, Vice President of Global Professional Relations, Office of the Chairman & CEO, Henry Schein, Inc., Founding President of the Henry Schein Cares Foundation; and Dr. Mark S. Wolff, DDS, PhD, Morton Amsterdam Dean, University of Pennsylvania School of Dental Medicine realized that the access to oral healthcare issues facing individuals with disabilities needed to be addressed through a different, out of the box approach—thus creating Project Accessible Oral Health (PAOH) at The Viscardi Center. Its mission: to act as a collective catalyst for change that will not only improve access to competent oral healthcare, but also ultimately improve the overall health of the disability community.

PAOH is a global public-private partnership and the first to nationally assemble and connect a consortium of dental and medical professionals, corporations, organizations, policymakers, educators, people with disabilities, caregivers, and other stakeholders in the pursuit of equal access to culturally competent oral healthcare. The goal is to ensure that all individuals, including the disabled, have equal access to quality oral healthcare. PAOH plays a unique role, connecting stakeholders who are committed to achieving that goal. Through interconnected partners, unique positioning and tactical plan which features three strategic pillars (highlighted below), the group is poised to achieve oral health equity and improve access to care for individuals with special needs.

**Policy:** Identify shortfalls in governmental policy and create solutions relating to access to oral healthcare for people with dis-

abilities at local, state, federal and global levels.

**Education:** Create and maintain a digital hub of core competency materials and make available to a variety of stakeholders that include children and adults with disabilities, and their caregivers, on how to promote and achieve optimum oral health. For



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healthcare professionals and policy makers (governmental and non-governmental) to inform them of the oral health needs of this highly underserved community.

**Marketing:** Raise awareness of the size, scope, and urgency of the issue, its impact on people with physical and developmental disabilities, and the cost and pressure on our nation's healthcare system.

patient advocates, third-party payers, and the non-dentist health provider to elevate their awareness of the impact good oral health has on an individual's overall health. For the education of current and future dental professionals to competently deliver care to individuals with disabilities, and to communicate with caregivers. Lastly, to help educate other



# CONNECT AND DISCOVER

## Join EP's Facebook Community



**DON'T BRUSH IT OFF:** Faced with other issues and priorities, individuals with disabilities and their caregivers often place oral care lower on the priority list relative to other issues, which further exacerbates problems with good oral healthcare.

Good oral healthcare is a critical component of maintaining overall good health and well-being. The number one healthcare crisis for individuals with disabilities is unequal access to competent oral healthcare, as compared to those without disabilities. Lack of preventative information and regular oral care leads to higher costs, higher burden of disease and cavities, an increase in more significant oral health problems and medical conditions related to, and caused by poor oral health. Faced with other issues and priorities, individuals and caregivers often place oral care lower on the priority list relative to other issues which further exacerbates the problem.

In addition, there is an overwhelming necessity for education around the important contribution good oral health plays in overall health and quality of life. The group is working with organizations such as the American Academy of Developmental Medicine and Dentistry, National Council on Disability, Special Care Dentistry Association, Special Olympics, Special Care Advocates in Dentistry, International Association for Disability & Oral Health, and many others, to elevate and increase the health literacy around this social justice issue that up until now, has not been sufficiently addressed or seen significant change. We

ourselves, as well as caregivers, practicing dentists, dental students, hygienists, and related health professionals, must be made aware of this health care crisis within the disability community.

Project Accessible Oral Health is dedicated to improving the access to quality oral health care around the world and for the more than 57 million individuals with disabilities in the United States. Often, the individual and or their caregiver cannot find experienced, culturally competent practitioners willing to take them as patients, nor locate accessible facilities equipped to accommodate. As a result, they often cannot obtain the care they need.

Project Accessible Oral Health operates under The Viscardi Center's network of 501(c)(3) organizations, which educate, employ, and empower children and adults with disabilities. We implore everyone to join the conversation and help us choose where, when, by whom, and how our oral health care, and thus great overall health, is delivered. Follow our journey on Facebook [www.facebook.com/ProjectAccessibleOralHealth](http://www.facebook.com/ProjectAccessibleOralHealth)

### ABOUT THE AUTHOR:

Barbie Vartanian, is the Executive Director of Project Accessible Oral Health at The Viscardi Center, but her most important role is mother to her child with special needs.



EP's revamped Facebook page welcomes you to share stories, discover resources and connect with the special needs community.

Parents and families with members with special needs benefit greatly from meaningful interaction with peers facing the same challenges and joys. Facebook has provided the EP readership community with a convenient and effective platform to communicate, ask questions, promote events and share special moments.

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Visitors can access the latest news and articles from recent issues of EP Magazine, and provide feedback and insight of their own.

EP's Facebook page an open community group for parents, grandparents, family and friends of people with special needs family members. It's an ideal place for both parents and professionals to share information and resources.

Parents, teachers, academics and professionals that are willing to help each other by sharing knowledge and resources are a vital part of the EP community. Like us today!

## WHAT'S HAPPENING

# MOBILE RECREATION PROGRAM HELPS STUDENTS (LITERALLY) THINK OUTSIDE THE BOX



**MUTUALLY BENEFICIAL:** Not only did the students impact the lives of the individuals of Orange Grove Center but, more important, those individuals impacted each and every student in the Community Based Adaptive Fitness course.

BY NICOLE HARTY, ALLYNA KERLEY, MOLLY MELTON, CLAIRE MORRISON AND ABI WELCH

Research indicates that outside of the Special Olympics, most adults with intellectual disabilities do not meet the recommended amounts of physical activity necessary to improve health outcomes. This is due in part to a lack of access, and sometimes even a lack of opportunity to engage in inclusive recreational programming.

Through a community partnership between the Orange Grove Center (OGC) and the University of Tennessee at Chattanooga (UTC), OGC participants had the opportunity to experience how fun exercise could truly be.

This past Spring, students at the University of Tennessee at Chattanooga had the opportunity to prepare their clinical skills in a unique and practical way. Amanda Durall, an instructor in the Department of Health and Human Performance, developed an

experiential class where students could work in a hands-on capacity with adults with intellectual disabilities in their local community. The course, Community Based Adaptive Fitness, emerged from a strong partnership with the Orange Grove Center, a local, non-profit organization that provides a variety of services for individuals with intellectual disabilities.

The students spent the first three weeks of the course learning about the disability rights movement, using person-first language, applied behavioral analysis, and the community-based work of the center from the Orange Grove executive team. For the next 10 weeks, UTC students met twice a week for an hour with the individuals at their designated locations. Thanks to a grant from the University, students took their box of hula hoops, floor tape, bean bags, beach balls, parachutes, and other fun pieces of equipment to each site. What emerged from the box was surprising. Students were incredibly creative in their design of these play-based exercise programs. However, the crowd favorite was dancing! While these activities may not seem taxing to a neurotypical population, the focus of this program was to increase physical activity among this population through fun and functional activities.

This mutually-beneficial relationship between the OGC and UTC also gave undergraduate students the opportunity to interact with



adults with differing abilities, in turn preparing them for their future professions in healthcare. Students from the course this past Spring are attending graduate schools for physical therapy, occupational therapy and public health. This course also showed students the importance of making sure every single person, regardless of ability, has an opportunity to participate, have fun, and feel valued.

While this community partnership was an excellent experience for both OGC and UTC, it did not come without challenges. The students learned to navigate and overcome their primary barrier of communication. As the program progressed, they learned to adapt and communicate with participants in a manner that was specific and effective for each individual. Whether participants were non-verbal, deaf, or sometimes just difficult to understand, students flourished in their ability to effectively communicate with those whom they were serving, as well as their peer teams.

**“As relationships were strengthened, students truly began to grasp the concept of social justice, the need for advocacy and the benefits of inclusion for improved health and well-being.”**

Throughout the program, it also became increasingly difficult to come up with new games and activities that would be engaging and challenging. As individuals mastered skills, most wanted to continue to be challenged, but given the limited space and resources, this proved to be another unique hurdle to overcome. At some sites, there were a handful of individuals that used assistive devices.

In the beginning weeks of the program, most individuals just assumed they could not participate. Students had to get creative in thinking of ways to engage individuals with walkers in all activities. Although it was occasionally difficult to come up with activities that were inclusive to all individuals participating, teams were effective at challenging and engaging everyone. Students also developed new approaches to motivating participants in ways that stretched their personal abilities and encouraged physical and emotional growth. The key was to challenge individuals without making them feel pressured into doing something they were not comfortable with.

Going into this, many students agreed that it was somewhat intimidating, because most did not know what to expect. Fears of how to lead the fitness classes each week, what activities to implement to keep the participants engaged, and how to successfully connect with participants began to circulate amongst the class. However, as each team worked together to meet the needs, interests and abilities of their participants, they began to find their stride. Often times they would arrive to their site with participants waiting to help them set up for the day. Other times, participants would already be playing in anticipation of the day's events.

Over the semester, this course brought together each team of students to brainstorm ideas for fitness activities by thinking creatively and critically. Whether it be obstacle courses, dancing sessions, or group activities, each session fostered meaningful rela-

tionships between students, participants and OGC staff. As these relationships were strengthened and barriers of uncertainty were broken, it truly turned into an amazing learning opportunity that taught the students and the people of Orange Grove lessons that cannot be found in a traditional classroom. Students truly began to grasp the concept of social justice, the need for advocacy and the benefits of inclusion for improved health and well-being. Furthermore, students also began to see the immediate benefits of exercise in a special population.

The challenges and barriers that the students faced have forever changed their outlook of their future careers in healthcare. Not only did the students impact the lives of the individuals of OGC but, more important, those individuals impacted each and every student in the course. Students will no longer hesitate to serve or engage with an individual with an intellectual disability. They now look for those opportunities in their daily lives and plan to use their experiences to mold their character as future healthcare practitioners. They are better prepared to serve anyone that they may come into contact with and can effectively educate others on the need for inclusive healthcare and recreation for all people.

For more information on the course, contact: Amanda Durall, MPH, EP-C; University of Tennessee at Chattanooga, Department of Health and Human Performance; Email: [Amanda-Durall@utc.edu](mailto:Amanda-Durall@utc.edu); 423-425-1736. •

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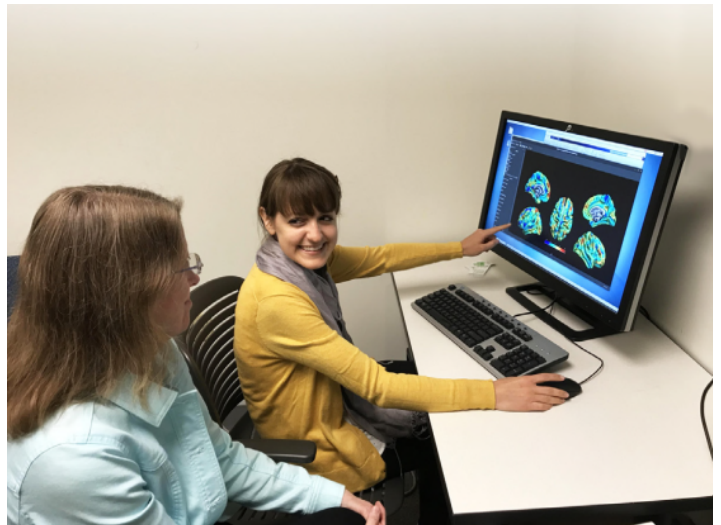
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This 4 Choice Sequential Scanner for the Visually Impaired is a communication device that illuminates icons so they are easier to see. Includes 12 levels, 4 fields, and 300 seconds of total recording time. This device provides four modes of scanning: Inverse, Automatic, Two Switch, and Step. Also includes adjustable scanning speed (1-12 seconds), on/off auditory cueing, volume control, and articulated arm that expands from 14 inches to 24 inches with a clamp. Weighs 4 ¾ pounds. Required 2 C and 4 AA.

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This Mini Budget Ball Pit uses four thick mat panels, with gymnastic-quality, closed-cell, cross-linked polyethylene foam. The mat panels securely attach to each other using Velcro. The floor base attaches by Velcro to the bottom of all four sides of the walls, keeping the ball pit balls within the pit. The floor allows you to slide the ball pit around the room with balls inside without the worry of any balls escaping from under the walls. The ball pit recommends 1,000 multi-colored balls to provide a good base for play and/or therapy. The 3 1/8 inch diameter balls are purchased separately; balls are not included. For care, wash surface with a soft cloth and mild liquid soap and water. For disinfecting, use up to ¼ cup household bleach diluted in one gallon of water, and rinse thoroughly with a wet cloth to remove bleach concentration.

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### ABLEDATA

The ABLEDATA database of assistive technology (AT) and rehabilitation equipment contains information on more than 50,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for these pages by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by New Editions Consulting, Inc., is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: ABLEDATA, 103 W. Broad Street, Suite 400, Falls Church, VA 22046; phone: 1-800-227-0216; TTY: 703-992-8313; website: <https://abledata.acl.gov/>; email: [abledata@neweditions.net](mailto:abledata@neweditions.net); Twitter: [www.twitter.com/AT\\_Info](http://www.twitter.com/AT_Info); Facebook: [www.facebook.com/abledata](http://www.facebook.com/abledata); Pinterest: [www.pinterest.com/AT\\_Info](http://www.pinterest.com/AT_Info)

# NEW PRODUCTS

## EXPLORE 'N GROW BUSY GEARS

This Switch Adapted Playskool Explore 'N Grow Busy Gears is a musical, light-up toy with an adaptive switch. When the user presses an adaptive switch, the colorful gears spin and swirl, with fun music and twinkling lights. This toy helps to encourage development of fine motor skills, cognitive learning, and sensory development. Features an automatic "shut-off" to help conserve battery life and a carrying handle allows users to take it on the go. This item has been adapted and the original switch inside is no longer functional. This toy will only work with a switch, and requires a connected switch to be pressed and released to activate in short bursts. This item is compatible with most switches (3.5-millimeter jack). Switch is not included.

### LDK ADAPTED TOYS

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## I CAN DO IT! MY DAILY CHECKLIST

I Can Do It! My Daily Checklist is a chart that parents can use to help their child with autism keep track of their morning, afternoon, and evening responsibilities. This chart allows the parent to list up to five tasks for each time of the day. When the child completes a task, they place a star next to the task in the "I did it" column. The bottom of the chart has a box for each day of the week – where the parent can write-in how many stars the child earned that day, and a Goal box – where the



parent can write or draw-in what the child is working for to keep them motivated. The plastic stars can be attached to the laminated chart using hook and loop coins. The set comes with 35 1.5-inch plastic activity squares that have a picture of the task and the name written beneath it (additional sets of themed activities are sold separately). The tasks on the activity

squares include: Get Up on Time, Make Your Bed, Take a Shower, Take Your Medicine or Vitamin, Pack Your Lunch, Pack Your Backpack, Put on Your Shoes and Coat, Get to School on Time, Put Your Things Away, Reading Time, Water the Plants, Practice, Set the Table, Eat Your Veggies, Help With the Dishes, Do Your

Homework, Put on Your PJ's, and 5 blank labels. The I Can Do It! set

includes one laminated chart, 35 activity squares, 18 stars, and one dry erase marker.

### NATIONAL AUTISM RESOURCES

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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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The essential lesson learned is that on their own, individuals and families may not be able to accomplish the needed changes to protect their children. However, a multitude of organizations are able to help.

# Raising children with disabilities... Now add adverse childhood experiences

BY H. BARRY WALDMAN, DDS, MPH, PHD, ANDREW G. SCHWARTZ, DDS, FACD,  
STEVEN P. PERLMAN, DDS, MSCD, DHL (HON) AND CHARLES D. LARSEN, DMD, MS

*“Adverse childhood experiences are potentially traumatic events that can have negative, lasting effects on health and well-being. These experiences range from physical, emotional, or sexual abuse to parental divorce or the incarceration of a parent or guardian. A growing body of research has sought to quantify the prevalence of adverse childhood experiences and illuminate their connection with negative behavioral and health outcomes, such as obesity, alcoholism, and depression, later in life.”*<sup>1</sup>

Living with a child with a disability can have profound effects on the entire family—parents, siblings, and their extended members. It is a unique shared experience for families and can affect all aspects of family functioning. “On the positive side, it can broaden horizons, increase family members’ awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a child with a disability can have far-reaching effects... The impacts will likely depend on the type of condition and severity, as well as the physical, emotional, and financial wherewithal of the family and the resources that are available.”<sup>2</sup>

For parents, having a child with disabilities will increase stress, take a toll on mental and physical health, make it difficult to find

appropriate and affordable child care, affect decisions about work, education/training, having additional children, and relying on public support. “It may be associated with guilt, blame, or reduced self-esteem. It may divert attention from other aspects of family functioning. The out-of-pocket costs of medical care and other services may be enormous. All of these potential effects could have repercussions for the quality of the relationship between the parents, their living arrangements, and future relationships and family structure.”<sup>2</sup> Having a child with a disability also affect parents’ allocation of time and financial resources to their healthy and unhealthy children, their parenting practices, their expectations of healthy siblings in terms of achievement, responsibility, short- and long-term contributions to the household and the siblings’ health and development. These and other potential effects on families have implications for the health and well-being of children with disabilities.<sup>2</sup>



**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.





**BRICK BY BRICK:** Adverse childhood experiences range from physical, emotional, or sexual abuse to parental divorce or the incarceration of a parent or guardian. These experiences may be connected to negative behavioral and health outcomes, such as obesity, alcoholism, and depression, later in life.

## NOW ADD ADVERSE CHILDHOOD EXPERIENCES

*“Twenty-two percent of children in the United States – more than 15.6 million kids total – have had two or more adverse experiences<sup>1</sup>, according to the latest results from the National Survey of Children’s Health.”<sup>3</sup>*

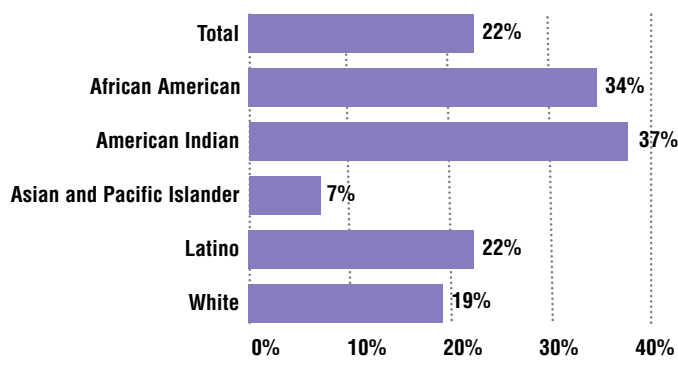
Such events can have negative and lasting effects on a child’s well-being which have been linked to increased risks of obesity, alcoholism and depression according to research.<sup>3</sup>

**At the state level:** Nationally, a slight majority of children have not experienced any adverse experiences, but in 16 states more than half of children have experienced at least one. Children living in the South and Southwest Regions are generally more likely to have multiple experiences when compared to their peers in other parts of the country. The highest rate is in Arizona, where 31% of children have two or more adverse experiences. At the other end of the spectrum are New York and Maryland, where 15% of children fit this statistic.<sup>3</sup> Some studies suggest that the experience of four or more adverse experiences is a threshold above which there is a particularly higher risk of negative physical and mental health outcomes. Prevalence at this threshold is lowest in New Jersey and New York, at around three percent, and highest in Oklahoma, Montana, and West Virginia, at 10 to 12 percent.

Data on adverse experiences also vary by race and ethnicity. American Indian (37%) and African American (34%) children are significantly more likely to have multiple experiences compared to their white (19%) and Asian (7%) peers, according to

<sup>1</sup> In this study, children were included if the respondent answered that the child had ever experienced two or more of the following adverse experiences: frequent socioeconomic hardship, parental divorce or separation, parental death, parental incarceration, family violence, neighborhood violence, living with someone who was mentally ill or suicidal, living with someone who had a substance abuse problem or racial bias.

**Chart 1. American Indian and African-American Children More Likely to Experience Two or More Adverse Experiences, 2015-2016<sup>3</sup>**



the National Survey of Children’s Health (please see Chart 1).

Economic hardship is the most common adverse experience reported nationally and in almost all states, followed by divorce or separation of a parent or guardian. Only in Iowa, Michigan, and Vermont is divorce or separation more common than economic hardship. In the District of Columbia, having been the victim of or witness to violence has the second-highest prevalence, after economic hardship.

- *“The prevalence of these experiences increases with a child’s age... except for economic hardship, reported about equally for children of all ages, reflecting high levels of poverty among young families.*
- *Abuse of alcohol or drugs, exposure to neighborhood violence, and the occurrence of mental illness are among the most commonly reported adverse childhood experiences (ACE) in every state.*
- *Just under half (46%) of children in the U.S. have experienced*

at least one ACE. In 16 states, a slight majority of children have had at least one experience. In Connecticut, Maryland, and New Jersey, 60% or more of children have never experienced an ACE.

- States vary in the pattern of specific ACEs. Connecticut and New Jersey have some of the lowest prevalence rates, while Oklahoma has consistently high prevalences.

## CHILDREN WITH DISABILITIES AND ADVERSE EXPERIENCES

“One in three children with an identified disability for which

they receive special education services are victims of some type of maltreatment (i.e., neglect, physical abuse, or sexual abuse) whereas one in 10 nondisabled children experience abuse. Children with any type of disability are 3.4 times more likely to be a victim of some type of abuse compared to children without disabilities.. (Note) Children with disabilities of any kind are not identified in crime statistic systems in the U.S., making it difficult to determine their risk for abuse.”<sup>4</sup>

Nationally, 78.3% of victims were neglected, 18.3% were physically abused, 9.3% were sexually abused and 8.5% were psychologically maltreated. In 2012, a nationally estimated

### WORTH MORE THAN A POUND OF CURE : RESOURCES FOR PREVENTION OF MALTREATMENT

Repeated efforts introduced to protect youngsters (especially those with disabilities) have made some progress against unthinkable adverse childhood experiences. The essential lesson learned is that **on their own**, individuals and families may not be able to accomplish the needed changes to protect their children. However, a multitude of organizations are able to help. **Try them!**

#### CHILD-FOCUSED PREVENTION



#### KIDPOWER INTERNATIONAL

Offers programs for children, youth, and adults, including those with special needs. Program areas include personal safety and strategies to prevent or respond to child abuse, neglect, bullying, and other threatening situations

[www.kidpower.org](http://www.kidpower.org)



#### IMPACT: ABILITY

A 10-session personal safety curriculum for individuals, including youth, with cognitive and/or physical disabilities. It uses realistic simulations to help teach people with disabilities how to respond to at-risk situations, including assertive communication and how to resist inappropriate sexual contact by a caregiver or other adult.

<http://impactboston.com/selfadvocacy>

#### FAMILY-FOCUSED PREVENTION



#### THE ARC

Provides individualized supports and services to people with intellectual or developmental disabilities and their families throughout the United States.

[www.thearc.org](http://www.thearc.org)



#### THE PACER CENTER

Based in Minnesota and offers numerous programs and informational materials for families of children with disabilities, such as

- 1) state parent centers for training and support and
- 2) the National Bullying Prevention Center.

[www.pacer.org](http://www.pacer.org)



#### PARENT TO PARENT OF PENNSYLVANIA

Matches parent mentors of children with disabilities with parents of newly diagnosed children with the same or similar disabilities.

[www.parenttoparent.org](http://www.parenttoparent.org)



#### SAFE (STOP ABUSE FOR EVERYONE)

Based in Austin, TX and offers disability awareness training for professionals and family members. It focuses on the risks of abuse faced by people with disabilities; strategies for preventing abuse; techniques for providing sexual education; and detecting, reporting, and responding to disclosures of abuse.

[www.safeaustin.org](http://www.safeaustin.org)

#### COMMUNITY-LEVEL PREVENTION



#### THE COALITION AGAINST SEXUAL ABUSE OF CHILDREN WITH DISABILITIES (CASACD)

Led by the Chicago Children's Advocacy Center, CASACD seeks to, among other goals, increase the prevention of and raise public awareness about the sexual abuse of children with disabilities. CASACD provides a variety of resources and trainings for providers, parents, and others about preventing sexual abuse amongst this population.

[www.chicagocac.org](http://www.chicagocac.org)



1,640 children died of abuse and neglect. Looking specifically at individuals with intellectual disabilities, they are 4 to 10 more times as likely to be victims of crime as others without disabilities.<sup>4</sup>

In a study of 4,155 students in special education, children with attention deficient hyperactive disorder (ADHD) experienced the greatest risk of victimization compared to children with other disabilities. Children with emotional disturbance were the second group of children with disabilities most likely to experience bully victimization.<sup>5</sup>

Children may not report abuse because they don't understand what abuse is or what acts are abusive. Communication problems that are inherent in many disabilities also make it difficult for children to understand and or verbalize episodes of abuse. Those with limited speaking abilities have had no way to talk about or report abuse.

**Why are these children more likely to be abused?** “According to researchers, disability can act to increase vulnerability to abuse (often indirectly as a function of society's response to disability rather than the disability in itself being the cause of abuse). For example:

- *Adults may decide against making any formal reports of abuse because of the child's disability status, making the abuse of those with disabilities easier for the abuser.*<sup>6</sup>
- *“Parents fear if they report abuse occurring in the group home, they may be forced to take their child out of the home with few options for other safe living arrangements. Often the abusers are parents or other close caregivers who keep the abuse secret and do not report out of fear of legal and other ramifications.”*<sup>4</sup>
- *They are at additional risk because of the increased likelihood that they will be separated from their families, accommodated in congregate settings where they encounter multiple caregivers, and are targeted on account of their visible difference or vulnerability.*<sup>7</sup>

## TOXIC STRESS: CONSEQUENCES OF ONGOING ADVERSITY

“Learning how to cope with adversity is an important part of healthy child development. When we are threatened, our bodies prepare us to respond by increasing our heart rate, blood pressure, and stress hormones, such as cortisol. When a young child's stress response systems are activated within an environment of supportive relationships (sic) with adults, these physiological effects are buffered and brought back down to baseline. The result is the development of healthy stress response systems. However, if the stress response is extreme and long-lasting, and buffering relationships are unavailable to the child, the result can be damaged, weakened systems and brain architecture. (sic) with lifelong repercussions.”<sup>8</sup>

### **Types of stress response:**

- **“Positive stress response** is a normal and essential part of healthy development, characterized by brief increases in heart rate and mild elevations in hormone levels
- **Tolerable stress response** activates the body's alert systems to a greater degree as a result of more severe, longer-lasting difficulties, such as the loss of a loved one, a natural disaster, or a frightening injury. If the activation is time-

limited and buffered by relationships with adults who help the child adapt, the brain and other organs recover from what might otherwise be damaging effects.

- **Toxic stress response** can occur when a child experiences strong, frequent, and/or prolonged adversity—such as physical or emotional abuse, chronic neglect, caregiver substance abuse or mental illness, exposure to violence, and/or the accumulated burdens of family economic hardship—without adequate adult support. This kind of prolonged activation of the stress response systems can disrupt the development of brain architecture and other organ systems, and increase the risk for stress-related disease and cognitive impairment, well into the adult years.”<sup>8</sup>

When toxic stress response occurs continually, or is triggered by multiple sources, it can have a cumulative toll on an individual's physical and mental health – for a lifetime. The more adverse experiences in childhood, the greater the likelihood of developmental delays and later health problems, including heart disease, diabetes, substance abuse, and depression. **Research also indicates that supportive, responsive relationships with caring adults as early in life as possible can prevent or reverse the damaging effects of toxic stress response.** (Emphasis added)<sup>8</sup> •

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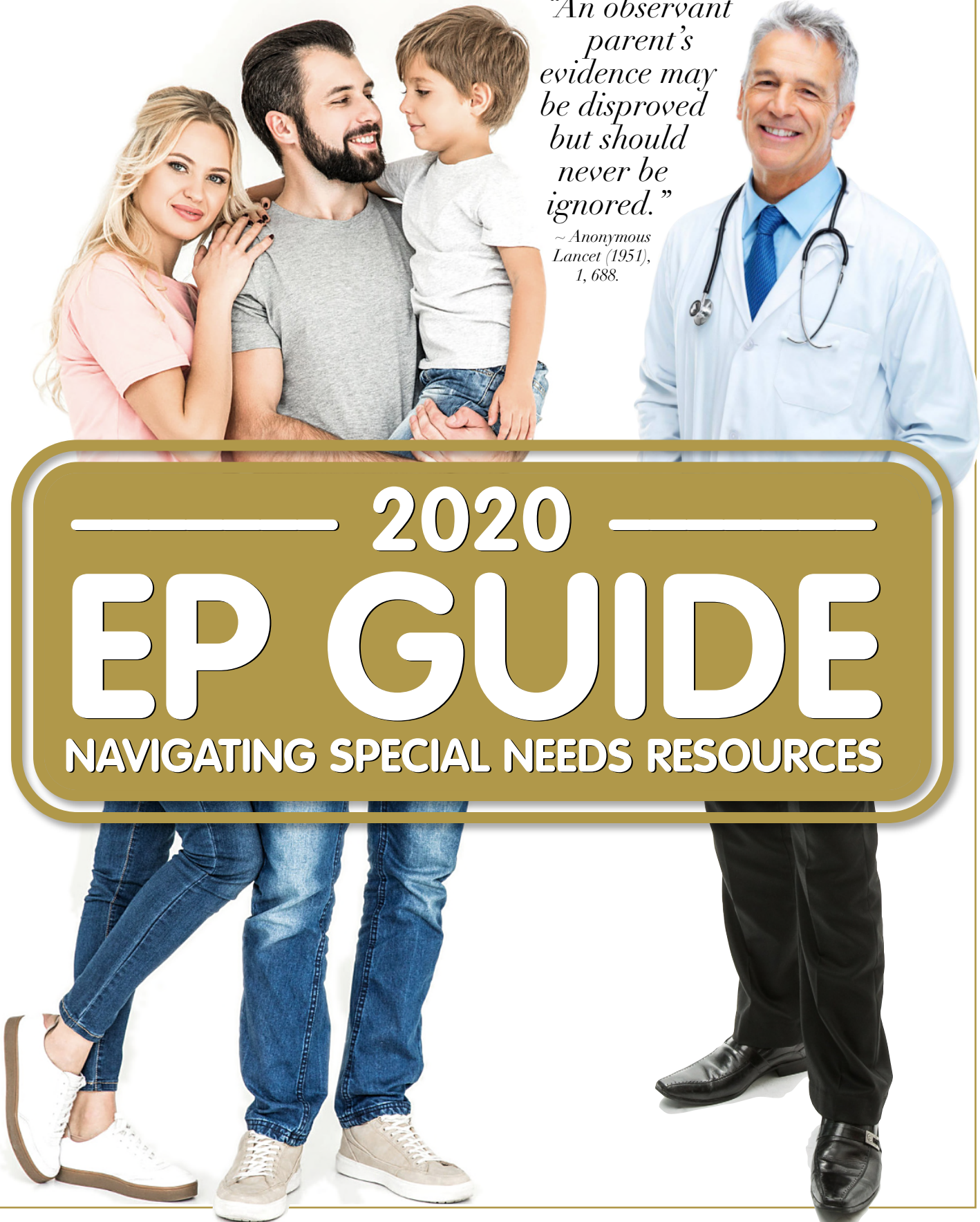
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\*Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:882–887. DOI: <http://dx.doi.org/10.15585/mmwr.mm6732a3>



*“An observant  
parent’s  
evidence may  
be disproved  
but should  
never be  
ignored.”*

*~ Anonymous  
Lancet (1951),  
1, 688.*



— 2020 —

# EP GUIDE

NAVIGATING SPECIAL NEEDS RESOURCES

# tips and tools for the **employment** of adults with disabilities



*Everyone is better off when people with disabilities work. The workers themselves have a livelihood as well as a place to contribute and build relationships.*

*Parents, siblings and friends have the opportunity to see their loved one grow and succeed.*

BY ALEXANDRA BAIG, MBA, CFP®

*A good friend of mine is a self-advocate – she has blindness – and a very strong advocate for her young adult son who has Down syndrome. She is a professional who has worked for the local ARC as well in other positions reaching out and supporting people with disabilities.*

**f**rom her multiple perspectives, she is adamant that not only is it important for adults with disabilities to work, but also, it is critical for families to begin to teach work skills from childhood because it is so challenging for adults with disabilities to find employment. She means her advice to encourage the understanding from both the point of view of people with disabilities themselves and also from the point of view of their parents that people with disabilities do have the capacity to work and should be expected to work. “Give your child with a disability the same opportunities as your other children to learn household chores and receive an allowance or another incentive for completing them regularly.”



**W**hile not every family with which I work started acclimating their child with a disability to work by kindergarten, I find that many more families expect work to be a component of their child's adult life that took that perspective, even 15 years ago, when I first started in practice.

Many typically developing youth move naturally into the world of work once they reach early to mid-teens as a way to afford the things they want that their parents cannot or will not buy for them. Youth with disabilities can do likewise, but they are going to need more involvement by, and support from both their families and their school. The Individuals with Disabilities Education Act (IDEA) requires public schools to provide services specifically designed to help the youth with disabilities to transition to adult life at a minimum from the child's age 16, to the date they age out of school. Many schools begin earlier. In my home state of Illinois, transition starts at 14 ½.

The United States Department of Education Office of Special Education and Rehabilitative Services' Transition Guide (2017, <https://sites.ed.gov/idea/files/postsecondary-transition-guide-may-2017.pdf>) is defined on its own front cover as a guide *To Postsecondary Education and Employment (emphasis mine) for Students and Youth with Disabilities*. The document mentions employment as a transition goal as early as page 4 where it says:

*Whether the student's next step is employment or entering a postsecondary training or an educational program, it is important for students with disabilities to obtain as much work experience as possible to prepare for adult life. The National Collaborative on Workforce and Disability for Youth (NCWD) reports that the value of a work experience, whether paid or unpaid work:*

- *Helps students acquire jobs at higher wages after they graduate; and*
- *Promotes students who participate in occupational education and special education in integrated settings to be competitively employed more than students who have not participated in such activities.*

I encourage parents of transition-aged students to arm themselves with this and similar material to support their son's or daughter's right to receive not just "work readiness" instruction in a classroom setting, but actually work experience in a community setting through the school district and with appropriate supports.

## collaborative projects

In addition to what schools can provide on their own, some students may have access to collaborative projects between their school and other partners. One such is Project Search, which coordinates and manages year-long practical internship programs around the country in conjunction with local school districts, vocational Rehabilitation offices, agencies that provide employment support services and community employers. You can find out about Project Search sites in your state by looking here: [www.projectsearch.us/find-a-program](http://www.projectsearch.us/find-a-program). And if your state does not yet have a program, you can find out what it takes to start one here: [www.projectsearch.us/start-a-project-search](http://www.projectsearch.us/start-a-project-search).

In my work as a special needs financial planner, I find that although many youth with disabilities want to work and their parents likewise want them to work, parents sometimes express concern that too much success at work while in school will preclude their child from qualifying for Social Security cash benefits or, more important, Medicaid, which by way of Medicaid waivers, funds virtually all adult services. I appreciate this concern because eligibility for these benefits does, in fact, hinge very directly on how much the applicant is capable of working.

For adults to meet the Social Security definition of "having a disability," the applicant must have "the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." SGA, in turn, is defined as the capacity to earn more than \$1,260/month or \$2,110 for individuals who are blind (For 2020. The SGA thresholds increase slightly most years from the year before.) Even if a student has met the children's criteria for

having a disability, s/he will still need to be reapproved at the age of 18, at which point Social Security considers the student to be an adult. Note that Medicaid eligibility often follows directly from Social Security eligibility.

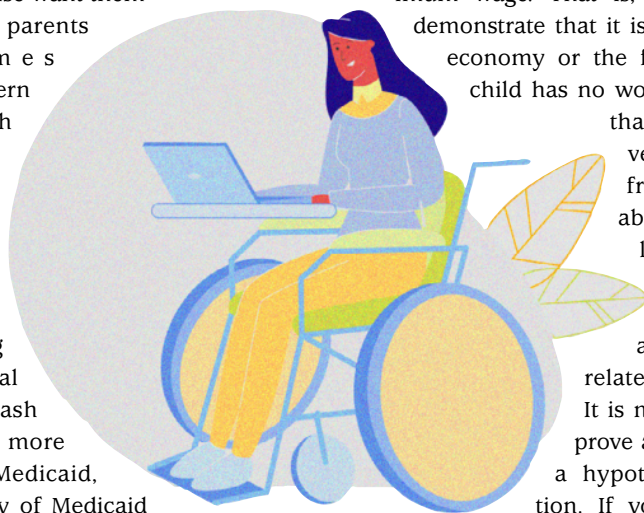
But in a kind of ironic inversion, the fact that your teen can work and earn money is very often exactly what proves they meet the definition of disability. Here's why. When you go with your eighteen-year-old to apply for adult disability benefits, you need to bring compelling evidence not only that your child has a disability and not only that the child is not earning above the SGA threshold, but that your child could not earn above the SGA threshold, even if they were offered a job on the spot. If you do the math, the SGA level is anywhere from 30-40 hours a week of work at a minimum wage job, depending on your local minimum wage. That is, you need to

demonstrate that it is not the local economy or the fact that your child has no work experience that would prevent her/him from working above the SGA level, but rather her/his disability and any related conditions. It is much easier to prove an actual than a hypothetical situation. If your child has

worked while at school, whether in a paid or unpaid capacity, you can then use work-related IEP goals and their data, or any written reviews from your child's work supervisor and job coach, to explain clearly and precisely your child's limitations when it comes to work. The very fact that your child requires a job coach, for example, may be evidence that your child could not earn more than the SGA level without that assistance and its associated cost.

## earning social security credits

Although volunteer work and work for which your child receives a stipend through the school district are just as valuable as competitively paid work for building real life experience and for providing



evidence to Social Security, there is a distinct advantage to having your child work as early as possible in a job that provides a standard paycheck through which s/he pays Federal Insurance Contributions Act (FICA) taxes. This is because a person with a disability who works earns Social Security credits just like any other worker.

When your child first applies for Social Security benefits at age 18, s/he will likely have insufficient credits to qualify for Social Security Disability Insurance (SSDI) and will only qualify for Supplemental Security Income (SSI). While SSI and SSDI both provide cash, SSDI has fewer limitations and a key opportunity, which we will discuss below.

Your child with a disability can earn one Social Security credit for every \$1,410 earned on which s/he pays FICA taxes, up to four credits per calendar year. Although it requires 40 credits to be fully insured for retirement benefits, it can require

significantly less credits to become fully insured for disability (SSDI) benefits. A young person who acquires six credits before the age of 24, for example, is fully insured. You can find more details here: [www.ssa.gov/planners/credits.html](http://www.ssa.gov/planners/credits.html) about how many credits one needs to be fully insured for SSDI at various ages.

If you, or someone in your family or among your friends has a business, it may be possible for your child to be hired in some capacity, even for occasional or seasonal work. If possible, your child should be added to the regular payroll. But even if your child is not paid regular wages from which FICA is deducted, there is a way to help her/him acquire credits if you are determined. If your child is paid a stipend through the school or if s/he can earn cash by doing yard work, dog-walking or baby- or pet-sitting for neighbors and you expect this cash to total more than \$1,410 within a year, you can take your child to a tax preparer and help her/him to file a 1040 as a sole proprietor with self-employment income. Because your child's earnings will

likely be below the Federal and even the state filing thresholds, s/he will not owe any income taxes but the FICA taxes paid through the return will start accumulating those credits. If you are detail-oriented, you can even submit estimated taxes on a quarterly basis.

Even though the work that your young adult or adult child with a disability performs will not necessarily preclude eligibility for SSI and, in fact, is necessary for your child to be eligible for SSDI, it is important to understand and anticipate the impact of earned income on each benefit. Because SSI is basically welfare, any income the SSI recipient has from another source reduces the amount of SSI s/he receives from the maximum award of \$783/month (2020).

Unearned income, such as bank interest, reduces a person's SSI dollar for dollar after the first \$20.

Earned income, which is of interest to us in this article, reduces a person's SSI by 50 cents on the dollar after the first \$65 (or after the first \$85, if there is no unearned income in the equation.) Once your child receives either kind of cash disability benefit and is also working and earning, it is imperative that you report those work earnings to Social Security on a monthly basis. Failure to do so may result in an overpayment. Due to processing time, any start, stop, increase or decrease in earned income will be reflected in subsequent month's SSI checks.

SSDI operates differently. It is an "all or nothing" benefit. As long as the person continues to meet the Social Security definition of disability and does not earn countable income above the SGA threshold, s/he can continue to receive her/his entire SSDI amount. In fact, as the person works longer and at higher income levels, the SSDI check will increase. In addition to this, SSDI has another valuable advantage. Once you have received it for 24 months, you become eligible for Medicare.

You might have noticed that I snuck the word "countable" into the above paragraph as a modifier for earned income. This is because Social Security has a number of work incentives that can reduce the amount of income that the agency counts when considering whether a person with a disability is eligible for benefits at all and, if eligible for SSI, how much. One way to reduce countable income is to claim Impairment Related Work Expenses (IRWE). If the worker with a disability has items or services that are needed because of the disability or related conditions AND that are needed for the person to work AND that are paid for out of pocket and not by Medicaid, Medicare or some other insurance, the person can seek to have the expenses for the items or services approved as IRWE.

If, for example, your child needs to see a physical therapist regularly to maintain her/his capacity to work and s/he pays for all or part of those therapy sessions out-of-pocket, those costs can be IRWE. If your child needs a mobility aid or assistive technology to communicate, the cost or those items can be IRWE. If your child has a service animal, all the costs associated with that animal can be IRWE. Once the IRWE are approved, they can be used to reduce monthly countable income in a manner analogous to how itemized deductions can reduce taxable income.

## claiming employer subsidy

Another way to reduce countable income is to claim employer subsidy. This is a bit more complicated, because it requires the employer to quantify in dollar terms any accommodations the employer has made for your child. Let us suppose that your son or daughter is employed at a small grocery store. Generally, all associates who work there are required to stock and face shelves, clean up any messes, assist customers, work the cash register, bag groceries and collect carts from the parking lot. Let us further suppose that your child can do all aspects of the job except work the cash register. The manager agrees to accommodate this. Your child will not be required to work the register. This is a kind of subsidy if the manager pays your child the same rate as a coworker who can do all aspects of the job.





Or suppose your child needs additional breaks because s/he gets tired more easily or has sensory issues. If the employer pays your child the same as coworkers but allows you child to take those addition breaks, that is a subsidy. If the employer is willing to quantify this in writing, you can request that Social Security exclude the value of the subsidy from countable income.

## plan to achieve self support (pass)

A third way to reduce countable income is to create a Plan to Achieve Self Support (PASS). If you child has a work goal and requires financial savings and expenditure to reach that work goal, a PASS can be useful. Suppose, for example, that your child wants to attend community college to earn a technical certificate of some kind, and that with that certificate, you child is expected to earn higher wages. You can then use Social Security's PASS application form [www.ssa.gov/forms/ssa-545.html](http://www.ssa.gov/forms/ssa-545.html) to detail the steps your child needs to take to obtain the certificate, how long they will take to complete, and how much each will cost. If the plan is accepted, money your child saves to accomplish the plan will not be counted as income (either earned or unearned) and, as an added bonus, will not count towards the \$2,000 asset limit required to maintain SSI and Medicaid eligibility. Of course, for this to work, the money saved must be used only to implement the PASS.

## other work incentives

In addition to those that can be used to reduce countable income, there are other Work Incentives that allow people with disabilities to try work without worrying that they are going to lose forever their benefits. This is especially true for SSDI, where there is an extended, multi-step process for going of the benefits, so that a person can work and earn for months, and even years, before they become ineligible.

Moreover, for both SSI and SSDI, there is "expedited reinstatement" which applies when a person who has worked enough to go off disability benefits is, within five years, unable to sustain that level of work due to the same disability. Various exceptions for workers with disabilities allow

them to extend Medicaid (including Medicaid waiver) and Medicare coverage for years, or even indefinitely for no cost, or only a very small premium. The Ticket-to-Work is an entire suite of services that is available to people with disabilities who receive any kind of Social Security cash benefit. These services are designed to support the person to enter the work force or upgrade her/his job skills while managing and maximizing benefits.

Everyone is better off when people with disabilities work. The workers themselves have a livelihood as well as a place to contribute and build relationships. Parents, siblings and friends have the opportunity to see their loved one grow and succeed.

Social Security, Medicare and Medicaid have money coming in as well as going out. This is not to say that it is easy for people with disabilities to gain employment. There are many structural barriers, from stereotypes and biases, to physical accessibility and insufficient transportation. As parents working within these lim-

itations, you can maximize your child's vocational opportunities by expecting from an early age that the child can and will work – and providing chances for early learning within your home, working with your child's transition team to make employment a priority, and understanding the Work Incentives built in to Social Security Medicaid and Medicare. •

## ABOUT THE AUTHOR:

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

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# FAMILIES OF CHILDREN WITH SPECIAL NEEDS

BY LAUREN AGORATUS, M.A., JEANNETTE MEJIAS AND DEEPA SRINIVASAVARADAN

*The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program is funded by the US Department of Health and Human Services Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB). Usually housed at University Centers of Excellence in Developmental Disabilities (UCEDDs), LEND Programs provide graduate level interdisciplinary training aimed at improving the health of infants, children, and adolescents with disabilities.*

**T**he Association of University Centers on Disabilities (AUCD) supports 52 LEND programs located in 44 US states, with an additional six states and three territories reached through program partnerships.

LEND programs prepare trainees from diverse professional disciplines (e.g. medicine, nursing, psychology, dentistry, social work, etc.) to assume leadership roles in their respective fields. A key strategy of LEND programs is to match professionals in training with families to gain a first-hand view of what it is like to raise children with disabilities and special healthcare needs.

## HOW IT WORKS

LEND programs are funded for five years at a time through the Autism CARES (Collaboration, Accountability, Research, Education, and Support) Act and are administered by the MCHB. The 52 LEND programs across the country help prepare the professional work-



force to address the needs of children with autism and other developmental disabilities. More important, LEND also includes family members and people with disabilities as fully participating fellows. These programs increase awareness of developmental disabilities, reduce barriers to screening and diagnosis, and promote culturally and linguistically competent delivery of evidence-based interventions. (Source <https://leader.pubs.asha.org/doi/full/10.1044/leader.AEA.22112017.18>). The goals of the LEND program are to:

- Advance knowledge/skills of child health professionals to improve health care.
- Provide interdisciplinary education that emphasizes the integration of services from local/state organizations, providers, and communities.
- Provide professionals with skills to foster community-based partnerships.
- Promote practices to enhance cultural competency, family-centered care, and interdisciplinary partnerships.

For more information, and to learn about LEND programs in your area, visit this website: [www.aucd.org/template/page.cfm?id=473](http://www.aucd.org/template/page.cfm?id=473)



**LEADING AND LENDING:** Read about developing future pediatric audiology leaders and the LEND experience in *ASHA Leader* magazine.

## NEW JERSEY LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL AND RELATED DISABILITIES

One state-specific example of these programs is the NJLEND program, a program of The Boggs Center on Developmental Disabilities, a division of the Department of Pediatrics at Rutgers Robert Wood Johnson Medical School and the state's UCEDD. NJLEND prepares graduate-level health and allied health fellows to provide high-quality, interdisciplinary, family-centered, culturally competent care addressing the complex needs of children with autism, related disabilities and other maternal and child health populations.

The long-term NJLEND training program is delivered across a nine-month academic calendar, and fellows are required to commit at least 300 hours to participation in the Didactic Seminar Series, experiential learning opportunities, leadership development, and clinical training. NJLEND provides trainees with the opportunity to learn from experts in the field, including parents of children with disabilities, and offers support and mentoring by faculty in their respective disciplines. NJLEND provides continuing education to families and practicing MCH professionals, as well as providing technical assistance to state agencies and community programs.

The NJLEND program is open to graduate-level students from Rutgers University/Rutgers Biomedical and Health Sciences participating in graduate, doctoral, and postdoctoral programs in dentistry, developmental behavioral pediatrics, genetic counseling, nursing, nutrition, psychology and social work. In addition to these academic disciplines, family members participate as full participants in the program and are considered an NJLEND disci-

pline. Parents and other family members are encouraged to apply as long-term trainees, and can learn more by visiting: <https://rwjms.rutgers.edu/boggscenter/student/LEND.html>.

## THE MENTOR FAMILY EXPERIENCE

Many LEND programs, including NJLEND, include a family matching component as part of the trainee experience. While this can take several forms across the LEND network, NJLEND partners with SPAN Parent Advocacy Network, a family-led one-stop organization in the state, to identify and prepare mentor families from diverse backgrounds. A Family Discipline Coordinator, part of the NJLEND Faculty, then matches trainees with their mentors based on a range of factors, including geographic proximity and trainee interest in a particular age group or disability.

The Mentor Family program provides the opportunity for NJLEND trainees to develop a richer understanding of the challenges and obstacles faced by families of children with special healthcare needs. As part of learning experience, NJLEND trainees share at least two unique experiences with the Mentor Family to which they are assigned. The first experience is a home visit, which allows the trainee to learn about, and from the child and

### LEND ME YOUR EARS : NOTABLE QUOTES

*"Honestly, I absolutely LOVE the idea of the program! I jumped right on the opportunity to apply once I saw it posted on FB. I feel that there are some things that students just CANNOT learn in a classroom, no matter how great the curriculum is, or how experienced the teacher is. If you want to learn about the needs of our children, the struggles our families face every day, and the challenges that present themselves when we are trying to connect with resources and good providers, the best way to go about it is to work directly with a family and learn firsthand. There is no better education than that! I love our mentee! She came on a day when we were really struggling as a family, and witnessed things that she never would have experienced in a classroom. She was at my house for 4 1/2 hours! We are a very complex family and she was able to witness a very unique way how a single-parent, special needs family manages life. Best education ever :)"*

– Quote from NJLEND Family Mentor

*"I think that the strength of having a Family Mentorship Program is that in addition to the material we are taught at the seminars, it gives us the chance to see some aspects in the lives of a family. The Family Mentorship Program is beneficial because as professionals or future professionals that may work with people with disabilities and their families, it is important to be able to observe it on a more personal level. I think these experiences influence or help shape up the way we may interact in the future with clients."*

– Quote from NJLEND trainee

*"Attending the Disability Policy Conference was a remarkable experience. It provided me the opportunity to advocate on behalf of families to prevent further cuts to Medicaid. My overall LEND experience is helping me partner with providers, strengthen communities, and build capacity in the families and self-advocates I am serving."*

– Jeannette Mejias  
NJLEND Family Fellow, 2016-2017

family, in their own environment. A second experience asks the trainee to walk alongside the family during an interaction with a formal service system. This second visit could include a therapy session, school IEP meeting, medical appointment, or interaction with a service system to access needed benefits and supports. Together, these experiences prepare the future health care professionals participating in NJLEND to provide family-centered care to diverse patients and families. For more information on NJLEND's mentor family program, go to <https://spanadvocacy.org/programs/njlend>.

## ADDITIONAL PARENT-PROFESSIONAL PARTNERSHIPS TO PROVIDE TRAINING TO FUTURE PROFESSIONALS

In addition to the Mentor Family component of the long-term NJLEND clinical leadership training program, The Boggs Center on Developmental Disabilities offers a number of opportunities for parents to serve as educators of future health care professionals. One notable opportunity for families to host medical students comes through the required Seminar on Family-Centered Care and Developmental Disabilities for all 3rd-year medical students at Rutgers Robert Wood Johnson Medical School. This long-standing educational effort incorporates parents both as educators sharing their stories, and matches students with a host family for a home visit. These visits have been credited with helping to shift students' perspective on disabilities, providing context for the lives of patients outside of the clinical setting. The experience also helps students understand the importance of listening, communication, and collaboration with both patient and family to promote optimal health outcomes. The medical students are quite positive towards

participating in the seminar. As one student wrote on their evaluation: "I thought it would be a lecture and that it wouldn't stick with me. However, I'll remember this experience forever..."

## BENEFITS OF LEND TRAINING

According to the 2018 LEND outcomes study (conducted by the University of WI-Madison, Ohio State University, and University of Pittsburgh), health care providers trained in a LEND program were more likely to work with Maternal and Child Health populations (85% vs. 48% control group) and more likely to work with underserved populations (85% vs. 68% control group) than health care providers who did not train in LEND programs.

Results also indicated that LEND trainees reported working with professionals from two more disciplines than controls, indicating an enhanced interdisciplinary approach to care. More important, LEND trainees also were more likely to engage in leadership activities regarding individuals with developmental disabilities relative to their counterparts who were not trained in a LEND program. For example, LEND trainees were more aware of systemic issues, more engaged in advocacy, and more likely to conduct research.

Another type of experiential learning that might be included as part of LEND training programs is for LEND trainees to have the opportunity to attend the Disability Policy Conference in Washington, DC. This Conference provides two days of panels and seminars where trainees learn about important disability policy issues. The last day of the seminar is Hill Day, where conference attendees visit Capitol Hill to meet with and educate their members of Congress. This is another way that LEND training programs provide real-world, lived experience to enhance the professional preparation of the trainees who participate in these programs. You can access the factsheet at: [www.aucd.org/docs/AUCD%20Outcomes%20Study%20Handout%202018.pdf](http://www.aucd.org/docs/AUCD%20Outcomes%20Study%20Handout%202018.pdf). The study presentation with complete details can be found at: [www.aucd.org/docs/AUCD%20Outcomes%20Study%20Presentation%202018.pdf](http://www.aucd.org/docs/AUCD%20Outcomes%20Study%20Presentation%202018.pdf)

In summary, these results demonstrate the advantages of families partnering with medical professionals in training. The collaboration helps better prepare future healthcare providers to work with individuals with neurological or developmental disabilities. It is a mutually beneficial experience for both parents and providers, and helps make care more family-centered. (Special thanks to Carrie Coffield, Training Director of the NJ LEND Program at The Boggs Center.)•

### ABOUT THE AUTHORS:

Lauren Agoratus, M.A. is the parent of a young adult with multiple disabilities. Her daughter Stephanie has five life-threatening conditions and autism just to keep it interesting. Lauren serves as the State Coordinator for Family Voices-NJ and as the central/southern coordinator in her state's Family-to-Family Health Information Center. FVNJ and F2FHIC are both housed at the SPAN Parent Advocacy Network (SPAN) at [www.spanadvocacy.org](http://www.spanadvocacy.org) or see program details at <https://spanadvocacy.org/programs/f2f/>.

Jeannette Mejias is the Director of the Special Education Volunteer Advocates, Family Support Integration Specialist with Family-to-Family Health Information Center, and the Statewide Bilingual Trainer for SPAN Parent Advocacy Network. She can be reached at [jmejias@spanadvocacy.org](mailto:jmejias@spanadvocacy.org).

Deepa Srinivasavaradan is a NJLEND Family Fellow. She is also the CDC's "Learn the Signs. Act Early" Ambassador for NJ, and the State Parent Lead for NJ's Early Childhood Initiatives – Help Me Grow, Early Childhood Comprehensive Systems Impact, and Home Visiting COIIN 2.0 and can be reached at [deepas@spanadvocacy.org](mailto:deepas@spanadvocacy.org).

### A LENDER BE : LEND PROGRAM RESOURCES



#### ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES LEND PROGRAMS

[www.aucd.org/template/page.cfm?id=473](http://www.aucd.org/template/page.cfm?id=473)

Find your LEND program:

[www.aucd.org/directory/directory.cfm?program=LEND](http://www.aucd.org/directory/directory.cfm?program=LEND)

#### STATE EXAMPLE

THE  
BOGGS CENTER  
ON  
DEVELOPMENTAL  
DISABILITIES

#### NJ LEND - BOGGS CENTER

<https://rwjms.rutgers.edu/boggscenter/student/LEND.html>



#### SPAN PARENT ADVOCACY NETWORK LEND PROGRAM OVERVIEW

<https://spanadvocacy.org/programs/njlend>



# Lesley University's Threshold Program

College-Based Transition Program  
Cambridge, MA



## Helping young adults to unlock their full potential.

Lesley University's Threshold Program is a 2-4 year college-based transition program. Here, we prepare young adults with intellectual, developmental, and other diverse learning disabilities (e.g. autism spectrum disorder) for the world of work and independent living. Students reside in Lesley dorms and join student clubs and activities on our Cambridge campus while learning how to budget, pay bills, use transportation, and be engaged members of their community. And best of all—they make friends for life.

### DISCOVER

Our new 6-week Summer Program  
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### THRESHOLD STUDENTS WILL

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- Gain lifetime support from our Alumni Center

### PROGRAM OUTCOMES

89% of alumni are satisfied with their social lives

64% of alumni spend time with friends at least once per week

95% of alumni are satisfied with their level of independence

85% of alumni are employed

Visit [lesley.edu/threshold-learning](https://lesley.edu/threshold-learning)  
or call 617.349.8181 to learn more.



# Selecting Summer Programs

## HOW DO PARENTS CHOOSE?

BY ERNST VANBERGEIJK, PH.D., M.S.W.

*The summer vacation break can seem exceptionally long for both students and parents. Without school, students lose structure, opportunities for learning, and social connections. They can regress in not only their academic skills, but their independent living, vocational, and social skills as well.*

What is a parent to do? Some parents are very creative at organizing their own summer programming for their children that includes opportunities for learning, practicing their independent living skills, socializing with friends, and even some vocational skills. However, this takes a great deal of time, effort, and energy. It is a full-time job.

Many of us do not have the luxury of being able to dedicate the time to constructing our own summer programming because of full-time employment. Then, how does a parent decide what to do for summer programming?





## STEP #1

### BE HONEST WITH YOURSELF.

Ask yourself, do I have the time and energy to devote planning and organizing perhaps up to twelve weeks of social, recreational, learning and vocational activities? Second question to ask yourself is, do I have the desire to spend all day working with my kids in this capacity? The third question to ask when taking this personal inventory is, do I have the resources to pull this off?

When speaking of resources, most people think of financial resources, but those are not the only resources you may need to conduct your own summer programming for your children. The other resources include having the simple bandwidth to get the job done, as well as personal connections with families of other special needs children who have similar interests in engaging in social, learning and recreational activities. If you can identify like-minded families, then you may be able to alternate days of the week where one family is in charge of the programming one day, and another family in charge another day. This takes a high degree of coordination to pull off.



pal recreation departments, libraries, religious organizations, and social service agencies like the “Y” may offer day camp experiences in your community. Many will even offer transportation out of the city to more rural location nearby. Day camps offer an opportunity for a young child to be autonomous from her parents under the supervision of trusted adults.

Older children may be ready for sleep-away camps. There are thousands of excellent sleepaway camps in North America. Some are for general campers. Others specialize in serving special needs children. Sleepaway camps are the natural progression from day camps. Being able to function away from the family is an important skill a young adult must master. By having an older child go away to camp, they learn how to separate from the family, as well as gain important independent living skills.

These skills are incredibly important especially when an older teen is making the transition to postsecondary education. Students who are successful in these transition to higher education often have spent periods of time away from their families. Many achieve this confidence through going to summer camp annually before going off to college. Summer camps come in a variety of formats and lengths from a few nights or one week to 3, 4, to 8 weeks or more. If the purpose of the summer program is to instill a sense of independence and confidence, then summer camps may be an excellent choice.

If the purpose of the summer programming is to gain pre-employment or employment skills, then getting a summer job might be an excellent choice for a teenager with a disability.

Research shows that if a student with a disability had paid employment during high school, then they are more likely to be employed for pay after high school. If the student was a camper at a younger age, some camps employ their former campers as counselors. In fact, many camps have counselor in training programs that help guide older campers into counselor positions. While in high school, the student can maximize her or his chances of being hired by a camp, day-camp, or city recreation program by taking an American Red Cross Life Saving



course which entitles the certificate Red Cross. The student not only gets to work as a lifeguard, but teach swimming lessons, and even progress into a leadership role as a waterfront director. This depends upon the student’s physical and cognitive capabilities, however. Checking with your city government might be another source of a potential summer job, as well as local offices of the State Office of Vocational Rehabilitative Services.

Ask about any at-risk youth programs and summer employment opportunities. They may even have pre-employment training summer programs that are funded by The Workforce Innovation and Opportunity Act (WIOA). An often-overlooked source of summer jobs is your personal social network. Over 80% of jobs are found through personal connections, not through job postings. Talk to your friends, relatives, fellow parishioners, and neighbors. Ask the local businesses you frequent if they are in need of summer help.

Summer college-based **camp**s and **educational programs** have two vastly different purposes. College-based camps are recreational in nature. They then must abide by state regulations that pertain to sleepaway camps. The college-based camps often are run by an outside entity that rents out their facilities, and the college does not get involved into the day to day running of the camp.

Many college-based camps operate along a theme like sports (e.g. baseball, soccer, or football, gymnastics camps) or robotics, art, creative writing, music, or gaming either using video game or role-playing games like Magic the Gathering™.

College-based summer educational programs, on the other hand, have vastly different purposes than the college-based summer camps. These programs are designed to do a number of things.

- *First, they are designed to offer a student the ability to “test drive” the university or college. This gives both the student and their family the chance to see if this setting is a good fit.*
- *Second, it provides the student the opportunity to learn a variety of independent living skills such as laundry, navigating around the campus and the city, and getting one’s self up in the morning.*
- *Third, summer educational programs*

## STEP #2

### DECIDE THE PURPOSE OF THE SUMMER PROGRAMMING FOR YOUR CHILD, TEEN, OR YOUNG ADULT.

The purpose of the summer programming will guide how to select a summer program that is right for you and your child. If the purpose is to retain academic skills, then having a discussion with your school district as to the appropriateness of summer school (referred to as extended year services, in special education terms) may be in order. If they do not provide those services in district, then the school may be obligated to pay for services out of the district. Consult with a special education advocate or attorney before engaging in this kind of discussion.

**If your child is young, then the summer programming may have multiple purposes such as childcare, recreation, social skills practice, and learning a new skill like swimming.**

Day camps are an excellent way to fill these kinds of purposes. Schools, municipi-

offer a logical and natural transition from high school to postsecondary life. By attending a college-based summer educational program, a student gets habituated to the college environment. She or he gets used to living in a dormitory with roommates and potentially sharing a bathroom. The student also gets used to having a variable schedule with down time, and classes that are scheduled throughout the day across the campus in a number of different buildings. Unlike high school, there are no bells to signal the change in classes, nor are the classes held in a single building. The student learns to navigate this on his or her own.

- Fourth, some college summer educational programs allow the student to test his or her academic abilities by taking a small number of classes for credit. Remember, once a special education student accepts his or her diploma and graduates from high school, the protections under IDEA and the potential modifications to the curriculum are gone. In the postsecondary environment, students are expected to advocate for themselves with the college office of disabilities under the Americans with Disabilities Act (ADA) in order to receive reasonable accommodations. A student with a disability is expected to complete the same course requirements as any other student.

A summer college-based educational program allows the student with disability to form a realistic appraisal of their academic skills and an opportunity to practice his or her self-advocacy skills. Other college-based educational summer programs focus upon the acquisition of pre-employment, social, and independent living skills. These programs will offer internship opportunities, travel training, budget and banking classes, and even cooking classes which are all non-credit bearing.

## STEP #3

### TALK TO OTHER PARENTS.

Find out what they are planning to do with their sons and daughters over the summer. Get recommendations from them. Other parents are an invaluable source of information. They will give you

the unvarnished truth about what their experiences were with a particular summer program. The parents of other children with a disability have no vested interest in whether or not your child joins a particular camp or summer program. Ask them what their son or daughter like best about the program. The flip side of that question, of course, is what did he or she like least about the summer experience. The answers will help you decide if the summer program you had in mind is the best fit for your child.

## STEP #4

### VISIT THE PROGRAMS.

Ideally, you and your child should do this together while the program is in operation. This means you might have to plan one year in advance to see how the staff and the children, teens or young adults interact. Ask the program directors questions like:

- How long have you been in business?
- What percentage of your attendees stay the entire length of summer program?
- What percentage of the attendees return?
- What percentage of your staff return?
- On average how long have your staff worked for you?
- What percentage of your program attendees remain employed after the summer ends?

If the program is a college-based educational program, ask:

- How many of the summer students return back to high school?
- How many students transition into your program in the fall?
- How many students transition into a degree-bearing program?

## STEP #5

### DO YOUR HOMEWORK.

Aside from visiting the programs when they are in operation, conduct a preliminary survey of a wide array of summer options that are available to you. Start with an internet search. Web sites like the American Camping Association ([www.acacamps.org](http://www.acacamps.org)) can help you find accredited camps of all kinds.

IncludeNYC sponsors New York City's

largest fair for young people with disabilities and their families, where over 100 different recreation programs gather. The representatives are from all over the U.S. and Canada; and offer both summer and year-round programs ([www.includenyc.org/resources/events](http://www.includenyc.org/resources/events)). This event provides families the opportunity to conduct side-by-side comparisons of various programs.

**If the purpose of selecting a summer program is to help the young person transition into postsecondary education, then there are a number of different resources available.**

The Musiker Summer Discovery Programs offer pre-college experience for middle and high school students in universities such as University of Michigan, UC Santa

Barbara, Georgetown, Cambridge University & London, Yale NUS-Singapore to name a few locations. These programs are not specifically designed for students with disabilities; however, it is incumbent upon the parent to ask if sufficient supports are in place for his or her son or daughter ([www.summerdiscovery.com](http://www.summerdiscovery.com)).

Looking for postsecondary transition programs and colleges dedicated to teaching individuals with disabilities is another way to find summer programs. Often their websites will list a description of their offerings. Comprehensive listings of these programs are often hard to find. Thinkcollege.net (<https://thinkcollege.net>) is an excellent starting point in identifying colleges that support people with disabilities included in college-based transition programs.

George Washington University's Heath Resource at the National Youth Transitions Center is a clearinghouse on postsecondary education for individuals with disabilities ([www.heath.gwu.edu](http://www.heath.gwu.edu)). Lesley University Threshold Program published an e-Book entitled Comprehensive Guide to Transition Programs ([www.lesley.edu/six-qualities](http://www.lesley.edu/six-qualities)).

#### ABOUT THE AUTHOR:

Ernst VanBergeijk, Ph.D., M.S.W. is a professor at Lesley University in Cambridge, MA and is the Director of the Threshold Program which is a postsecondary transition program for students with a variety of disabilities. [www.lesley.edu/threshold](http://www.lesley.edu/threshold). He also oversees the Lesley University Threshold Alumni Center which provides life-long support for graduates of the Threshold Program. Beginning Summer 2020 the Threshold Program will be offering a 6-week summer program focusing upon the acquisition of preemployment, independent living and social skills.





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# EMPLOYMENT RESOURCES FOR PEOPLE WHO ARE BLIND OR VISUALLY IMPAIRED



BY CHRISTINA LLANES MABALOT

*Being employed means being productive, financially secure and fulfilled. However, for persons who are blind or visually impaired, seeking employment may sometimes seem as difficult as driving a vehicle. As one hits the road to find a job, countless hurdles may emerge. Some issues to resolve include tech-*

*nology, as well as resources that could make work accessible and adaptive to persons with visual impairment, availability of support, mobility, transportation, the work environment, and so on. The good news is, there are workarounds for almost every obstacle.*



For individuals with visual limitations, such as myself, the first barrier one encounters in seeking employment is self-doubt. If you don't have faith in your abilities, nobody will. Remember, you are as capable, competent, and productive as your sighted peers!

Visually impaired individuals have become successful astronomers, lawyers, judges, professors, engineers, scientists, journalists, customer service representatives, app developers, architects, computer programmers, surgeons, and business owners. The list could go on, but the point is, many visually impaired persons have become what society once thought was impossible for them to become. These successful, visually impaired individuals didn't obtain success through miracles. They are not Superman nor Wonder Woman either; many are regular persons like you and me. I'm sure that they've encountered disappointments and formidable obstacles along the way. Fortunately, it is in the depths of failure and fear, that real courage shines. These notable, visually impaired persons have chosen to develop and keep a heart of courage. Thus, they have turned their vision into reality. You and I can do the same.

## DREAM BIG

Visual impairment should not limit your capacity to dream. Remember, no matter what it is you want to accomplish, if you say "I can't," then you won't. Say "I'll try," and you'll be on your way.



### Eyes On Success

#### EYES ON SUCCESS PODCAST

Listening to stories of actual visually impaired go-getters inspires us to dream big. You can find them on this half-hour weekly radio program and podcast that features distinguished visually impaired achievers.

[www.eyesonsuccess.net](http://www.eyesonsuccess.net)

## DISCOVER YOUR PURPOSE

The first step to gainful employment is to search within you what you want to be. As mystical as this may sound, finding your life's purpose is simple. Ask yourself these two questions:

"What do I love to do?" and "Where do I excel?" Make an inventory of your talents and rank them accordingly. Your top-rank talents usually tie in with, or support the

work you love to do. Once you find the answers to these questions, determine to devote your 100% to developing your abilities through formal education, training, mentorship, and hard work.

## COME OUT

Pursuing a dream lays out difficulties that one could overcome more effectively with the help of a community. Several persons with special needs find themselves on the lonely island of exclusion because they feel that "I am the only one," or "I'm not as good as others." This is especially true among people who've just lost their vision due to ailments or injuries. There is nothing more redeeming than finding one's way out of this segregation into a welcoming community who will be your support system. The sooner you come out to link up and get involved, the more reliable the bridges you can build. I recommend you start your journey with the following organizations:



### NATIONAL FEDERATION OF THE BLIND

An all-blind organization with chapters and affiliates nationwide. At the NFB, a visually impaired person could find peers, mentors, and role models who share more commonalities than differences with you. Moreover, through their network, the NFB coordinates programs, services, and resources that could set up their members to "live the life they want."

[www.nfb.org](http://www.nfb.org)



### AMERICAN COUNCIL OF THE BLIND

A national organization of blind, visually impaired, and sighted individuals. Here, a visually impaired person could readily acquire a healthy balance between sighted and visually impaired peers. The ACB provides Information for referrals and directs inquiries to partner organizations.

[www.acb.org](http://www.acb.org)

## EDUCATION MATTERS

The formula to success is no secret – more education, more job opportunities.

Education may include, but is not limited to a college degree, vocational training, a career, or technical education. Your career choice will determine the type of education you'll need. Whether you're born visually impaired or you're someone who just lost vision, whatever training it takes to prepare you for your envisioned career, go for it!

A visually impaired person has the right to equal opportunity to education and employment. The Americans with Disabilities Act (ADA), a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, provides this right.



### THE AMERICANS WITH DISABILITIES ACT (ADA)

Know your rights.

[www.adata.org/learn-about-ada](http://www.adata.org/learn-about-ada)

Despite laws that protect our rights, however, there are still several challenges that a person with visual impairment needs to overcome to benefit from education fully. Here are general resources for visually impaired learners and employees:

## COMMISSION FOR THE BLIND

### COMMISSION FOR THE BLIND

A government agency that will partner with the school, family, or workplace to provide support. Search online for your specific state's agency.



### AMERICAN PRINTING HOUSE FOR THE BLIND (APH)

An example of the services they offer is making print accessible for the blind and visually impaired.

[www.aph.org](http://www.aph.org) or email [info@aph.org](mailto:info@aph.org)

Individuals who lose their vision later in life may especially benefit from supports to help them regain their confidence and get back in the workforce. Rehabilitation services offer this assistance. Some examples are daily living skills, orientation and mobility, assistive technology, and other life skills. These are necessary to help the

persons who have just become visually impaired bounce back to productivity. I recommend taking rehabilitation courses before deciding your next step when experiencing vision loss. Search for the agency that offers rehabilitation services that meet your specific needs from the following:



### LIVING WELL WITH LOW VISION

Provides a database of information and network for people who are losing their vision.

<https://lowvision.preventblindness.org>



### FUTURE IN SIGHT

Focuses on areas that enhance independent living, such as cooking, banking, personal grooming, and household management.

<https://futureinsight.org/services/adult-services/rehabilitation-therapy>



### VISION AWARE

Sometimes, it is much easier for people going through vision loss to stay in their current job and adapt to the present work situation through technology. Most employers would rather keep their valued staff than hire new people. Work with your boss to identify challenges and to set up accessibility components in the workplace.

[www.visionaware.org/info/working-life/talking-to-your-employer/15](http://www.visionaware.org/info/working-life/talking-to-your-employer/15)

If it is not feasible to keep your current job, there are still options. Consider going back to school or taking vocational training courses to be eligible for other employment opportunities. Search the resources listed above and explore resources to help you.

<https://www.visionaware.org/info/working-life/training-resources/12>

If, after weighing all your options, you are inclined to take early retirement or apply for Social Security Disability Insurance benefits (SSDI), or Supplemental Security Income (SSI), you can get more information here:



### DISABILITY-BENEFITS-HELP

[www.disability-benefits-help.org](http://www.disability-benefits-help.org)

I was a college student when I realized that my vision was quickly deteriorating. At the crossroads between denial of my forthcoming blindness and taking action, I searched for a self-help resource that would keep me anonymous. I found the Hadley Institute for the Blind and Visually Impaired, through which I studied Braille and other correspondence courses that helped me adjust to and embrace my disability. If you're like me, or someone motivated and would like to earn continuing education credits for a work promotion – or if you're simply a fantastic self-starter, visit:



### HADLEY

[www.hadley.edu](http://www.hadley.edu)

### SEEKING TRADITIONAL EMPLOYMENT

As soon as you are eligible for work, the following may prove helpful for searching jobs that match your qualifications.



### NFB-NEWSLINE

A free audio news service that offers access to numerous publications, including multiple job listings.

[www.nfb.org/programs-services/nfb-newsline](http://www.nfb.org/programs-services/nfb-newsline)



### AMERICAN COUNCIL OF THE BLIND

Provides a range of job opportunities and other employment-related information.

[www.acb.org/jobs](http://www.acb.org/jobs)



### AMERICAN PRINTING HOUSE FOR THE BLIND (APH)

A one-stop site for all your needs.

[www.aph.org/thriving-with-vision-loss-introducing-the-aph-connectcenter/](http://www.aph.org/thriving-with-vision-loss-introducing-the-aph-connectcenter/)



### IFB SOLUTIONS

Provides opportunities for people who are blind or visually impaired in need of training, employment and services. We believe all people who are blind or visually impaired have the right to succeed in every area of life.

[www.ifbsolutions.org](http://www.ifbsolutions.org)



### LC INDUSTRIES

Operating under the auspices of the AbilityOne program, LCI has grown and diversified for over 75 years to become one of the largest employers of people who are blind in the US. Through the AbilityOne program, LCI has maintained a longstanding, mutually-beneficial relationship with the federal government. By manufacturing over 400 products on the federal procurement list, LCI provides legally blind individuals with meaningful employment opportunities.

[www.lcidistribution.com/about-lc-industries](http://www.lcidistribution.com/about-lc-industries)



### INDEED.COM

Includes a section for people with visual impairments

[www.indeed.com/q-The-Visually-Impaired-jobs.html](http://www.indeed.com/q-The-Visually-Impaired-jobs.html)

Once employed, please consider the following tips to stay the job:

- *Educate yourself, the company, your employer, and co-workers.*
- *Advocate for yourself. Show and tell what you can bring to the table, primarily with technology.*
- *Inquire what else can be done to maximize productivity and be open to collaboration.*

For employers, please invite qualified visually impaired persons for an interview. If you are considering a visually impaired applicant, but feel apprehensive about performance, you can consult:



### AMERICAN FOUNDATION FOR THE BLIND

Connect with the accessibility consulting team

[www.afb.org](http://www.afb.org)





### HIREPOTENTIAL

Provides expertise and service solutions in navigating the complexities of disability compliance and inclusion.

[www.hirepotential.com](http://www.hirepotential.com)

## ARE YOU PLANNING TO START A BUSINESS?

I believe that starting your own business is your best bet for independence. Owning your business means that you're working for something you enjoy, believe in, and have created yourself. Additionally, running your own business will give you the freedom of time, as well as allow you to be your own boss. You could sell products or services. If you want to sell a product, think of something that isn't readily available in the market. Start by thinking of your own need for a commodity that other people may want to purchase. You could even buy ready-made goods and modify or customize them with your brand, then re-sell them. Your product should have the edge over the others in the market.

Identifying a stable clientele is also an excellent way to start your business. Examine the needs of a particular group and the products that they use regularly and determine if there's something you can offer these perspective customers.

Marketing services is another business option. You can offer writing, tutorial, English language teaching, massage, music, audio, technology, and other services that people need. Begin by asking yourself these questions:

- *What is one thing that I love to do?*
- *Can I turn this passion into a profession and earn from it?*

If your answer to the last question is yes, write down the steps that you need to take to earn from your passion.



### HADLEY

Learn more about how to start, operate, and expand your own business with the Forsythe Center for Employment and Entrepreneurship.

[www.hadley.edu/fce.asp](http://www.hadley.edu/fce.asp)



### HADLEY

After completing a course, you have the opportunity to join the Hadley New Venture competition. This forum is for aspiring entrepreneurs to present their business plans and compete for cash prizes to help jump-start promising ventures.

[www.hadley.edu/nvc](http://www.hadley.edu/nvc)



### INDEPENDENT VISUALLY IMPAIRED ENTREPRENEURS

For continuing support, the IVIE will mentor aspiring business owners.

[www.ivie-acb.org](http://www.ivie-acb.org)

When you've launched your business, I recommend that you give yourself some time to learn your trade and to enjoy it. The next step, growing your business, may be the most exciting but challenging. Promoting your product will increase profits; the resources mentioned above provides information on how to market. I strongly recommend social media marketing, the fastest and easiest way to get the word out there. Tell-it-to-the-world marketing will assist in promoting your product, provide networking services, and even help you learn how to use social media for marketing. Check out this site:

## Campbells World

### PATTY FLETCHER

[www.campbellsworld.wordpress.com](http://www.campbellsworld.wordpress.com)

## ASSISTIVE AND ADAPTIVE TECHNOLOGY

According the ATiA website ([www.atia.org](http://www.atia.org)), "Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities."

Not only is assistive technology a tool that can help visually impaired individuals be on the same level playing field as their sighted peers, it also provides leverage in personal and household management. We can pay bills, conduct bank transactions, do online shopping, order groceries, and so much more. Following are recommendations for assistive technology.

### SCREEN READERS

According to the AFB website, "Screen readers are software programs that allow blind or visually impaired users to read the text that is displayed on the computer screen with a speech synthesizer or braille display. A screen reader is the interface between the computer's operating system, its applications, and the user."



### JAWS®

#### OR (JOB ACCESS WITH SPEECH)

According to the Freedom Scientific website, "JAWS, Job Access with Speech, is the world's most popular screen reader, developed for computer users whose vision loss prevents them from seeing screen content or navigating with a mouse. JAWS provides speech and Braille output for the most popular computer applications on your PC. Navigate the Internet, write a document, read an email and create presentations from your office, remote desktop, or from home."

#### ZOOMTEXT MAGNIFIER/READER

According to their website is "a fully integrated magnification and reading program tailored for low-vision users.

Magnifier/Reader enlarges and enhances everything on your computer screen, echoes your typing and essential program activity, and automatically reads documents, web pages, email."

[www.freedomscientific.com](http://www.freedomscientific.com)



### NVDA OR (NON-VISUAL DESKTOP ACCESS)

A free, open-source and globally accessible screen reader for Microsoft operating systems available at

[www.nvaccess.org/download](http://www.nvaccess.org/download)

## ADAPTIVE EQUIPMENT

Adaptive equipment is designed to help people perform daily tasks. It includes mobility assistance, (e.g., canes), sensory assistance, (e.g., visual aids and electronic readers), and self-care assistance (e.g., adaptive appliances). Before purchasing any technology, make sure to identify what you need for the most cost-effective price. The

following resources will help you decide the equipment best suited for your needs and your wallet.



### FUTURE IN SIGHT

An organization that incorporates assessments and adequate training to clients so they can optimize the use of technology within daily activities.

<https://futureinsight.org/services/technology-braille>



### ACCESSIBLE WORLD

Offers a guide for buying assistive technology. Click on resources "assistive technology buying guide"

[www.retailmenot.com/blog/assistive-technology-buying-guide.html](http://www.retailmenot.com/blog/assistive-technology-buying-guide.html)



### MAXI AIDS

An online catalog of independent living products.

[www.maxiaids.com](http://www.maxiaids.com)



### ACCESSIBILITY MINUTE

Provides a weekly technology podcast. Archives of podcasts provide some discussions about gadgets you may need.

[www.eastersealtech.com/category/accessibility-minute](http://www.eastersealtech.com/category/accessibility-minute)



### ACCESS WORLD

AFB's monthly online technology magazine with reviews of technology products and online resources for people with vision loss. It includes a searchable listing of assistive technology and independent living products.

[www.afb.org/blindness-and-low-vision/using-technology](http://www.afb.org/blindness-and-low-vision/using-technology)

## HELPFUL APPS

Download the following apps on an Apple or Android smartphone for enjoyment and independent living:



### BE MY EYES

A free app that connects blind and low-vision people with sighted volunteers and company representatives for visual assistance through a live video call.

[www.bemyeyes.com](http://www.bemyeyes.com)



### SEEING AI

A talking camera app that describes and identifies people, objects, color, currency, lights, images, pictures, scenes, and products. It can also speak text and read handwritten documents when in front of the camera.

[www.microsoft.com/en-us/ai/seeing-ai](http://www.microsoft.com/en-us/ai/seeing-ai)



### KNFB READER

Gives you access to print and files anytime, anywhere, by converting text to speech.

<https://knfbreader.com>



### BARD MOBILE

Delivers free talking books and Braille to your smartphones and connected devices. This utility is from the National Library Service for the Blind and Print Disabled.

[www.loc.gov/nls/enrollment-equipment/register-for-bard-get-bard-mobile](http://www.loc.gov/nls/enrollment-equipment/register-for-bard-get-bard-mobile)

## ORIENTATION AND MOBILITY (O & M)

Orientation is knowing where you are, your bearing from a physical reference in your home, or outside. Mobility is the ability to move from one point to another, including transportation. Orientation and mobility, or O&M, is part of rehabilitation training mentioned earlier, since most traditional jobs require workers to report to a brick and mortar location. O&M training includes getting to and from the workplace.

Considering the advice of O&M experts, the choice of whether one should use a cane or a guide dog is determined by what works best for the individual. But, if one

were to choose a dog guide, I recommend applying to The Seeing Eye School, Inc.



### THE SEEING EYE SCHOOL

The oldest and one of the largest guide dog schools in the world, Seeing Eye shows the highest success rate for matching dogs with handlers, conducts maximum training in traffic and gives 100% ownership of the dog.

[www.seeingeye.org](http://www.seeingeye.org)

With O&M skills, a guide dog, or adaptive equipment, a visually impaired person can get around independently. Travel has never been more comfortable using apps on smartphones. For example, with Uber and Lyft, one only needs to click a button to get a ride.

However, if public transportation is not very accessible, or if the transportation cost is unreasonable, one can apply for paratransit services through the local rehabilitation service organizations. <https://lowvision-preventblindness.org/resources/>

## AFB DIRECTORY OF SERVICES LISTINGS

To find services specific to the needs of people who are blind or visually impaired, visit <https://www.visionaware.org/directory.aspx>. This is the web address for the AFB Directory of Services Listings. Choose the category of service you'll need, your state, and the name of the organization from the dropdown menu to populate the listings.

To my friends with visual impairment: This guide can only be as good as what we make of it. Together, as a community, we can grow a heart of courage to fight for gainful employment. •

### ABOUT THE AUTHOR:



Christina Llanes Mabalot is physically blind from aniridia, but has a vision. She enjoys touching people's lives to bring out the best in them. She contributes a monthly column, "Heartsight," to this magazine. Christina earned her B.A. degree and Masters in Education from the

University of the Philippines, Diliman, specializing in Early Intervention for the Blind. Christina is blissfully married to Silver Mabalot, also physically impaired, her partner in advancing noble causes. Their children are Paulo and Jem, who has aniridia. Visit [leadershipvision.com](http://leadershipvision.com)



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# TAKING CONTROL OF YOUR CHILD'S IEP EXPERIENCE

I read up on IEPs and I studied my daughter's 28-page document. I learned an IEP was written to provide access and accommodations while protecting her educational rights as she moved through the education system. I learned it is a federal document which crosses state lines in our country. I learned the law and my rights as a parent.

BY E. GAY GROSSMAN

*S is for September, school, and stress... and replacing stress with serenity. OK, serenity is too strong a word. I am sure I never would have used the word **serenity** and **school** in the same sentence when I was guiding my daughter through her years of schooling. I'll admit, this past September was the most pleasant September in 19 years. Why? Because my daughter graduated from college in May and there was no need to consider educational access and accommodations as I flipped the calendar past summer.*

**W**hat a relief, I'll admit, but for those of you in the throes of education for your special needs child, it's tough to see a light at the end of the tunnel. Looking back, there are things I did right and things I did wrong. I'll share my experiences with you in hopes of making your educational experience more productive and successful for you, your child, and the school.



In this article, I'll tell you how to advocate for your child. I am an advocate of taking control of your child's IEP (Individualized Educational Program). Be involved in the preparation, the writing, the IEP meeting, and the follow through of the IEP goals.

If you do your homework upfront, it will pay off in multiples down the road. I spent the first few years figuring out the system. I learned



things like: there would be 10 or more people from the school at an IEP meeting, the needs of my child would be read first, reports and assessments would be read from therapists who worked with her, goals would be shared, and finally, my concerns would be read. Last is where my concerns as a parent fell on the agenda.

In the beginning, these meetings took up to three hours. As the time would tick by, people got up and left for prior commitments and at the end, I would be sitting at a large conference table with two or three others from the school. In the end, I'd leave without my concerns being fully addressed. I'd be tired, frustrated, and yes... angry.

I decided I needed to change the WHO from the school... to me.

A side note here is that some readers will disagree with me on this point. Many parents feel the job of education falls to the schools and the schools need to figure it out. There are times I agree with this, but as a whole, imagine how difficult it is for a teacher, with a full classroom, to figure out how to best accommodate each of her students – and then follow through on each and every accommodation necessary for the success each student. For the success of your own child, make it a team effort and engage; be a part of the process.

I read up on IEPs and I studied my daughter's 28-page document. I learned an IEP was written to provide access and accommodations while protecting her educational rights as she moved through the education system. I learned it is a federal document which crosses state lines in our country. I learned the law and my rights as a parent. I learned about IDEA and what her rights were as a student who had special needs.

You can learn about IDEA here: <https://ideapublicschools.org/>

What I read in my daughter's early IEP made me think the goals being proposed could be better thought out and more suited for her needs. I wanted an IEP written specifically for her. An IEP is an *Individualized* Education Plan. It is written and designed for each student individually. I sat down with a pen and made obvious updates like phone and address, as well as things less obvious like the goals set out for her.

I took the lead and wrote her IEP.



I didn't know what an IEP was when I started, I had to read and learn about it. You can start learning by looking up information on where your child should be today. What grade are they in and what skills has the typical child mastered by this age or grade? This is the first step to writing the IEP. Choose a couple areas where your child needs support.



**PEN TO PAPER:** What I read in my daughter's early IEP made me think the goals being proposed could be better thought out and more suited for her needs. I took the lead and wrote her IEP.

For example: You may notice yourself that your child needs help with coordination and communication.

Now go to a website for your child's age or grade to get a resource saying they should be able to master a particular skill by a certain age. Print it out so you can have it as a resource. Be sure to note the website link since it often doesn't print out on the page.

Here is an example of a site sharing ages and tasks to master by age: [www.scholastic.com/parents/school-success/school-life/grade-by-grade/preparing-kindergarten.html](http://www.scholastic.com/parents/school-success/school-life/grade-by-grade/preparing-kindergarten.html).

This link takes you to a list which prepares for kindergarten. Review the list and see what your child is missing in mastered skills for their age. Choose one for physical therapy, occupational therapy, and speech therapy. Some examples of goals to consider are below:

	<b>Goals</b>	<b>Objectives</b> <i>(should be measurable)</i>
<b>Physical Therapy</b>	Bouncing a ball. This falls within your concern of coordination.	Susie will be able to bounce a ball five times.
<b>Occupational Therapy</b>	Using scissors unassisted. This also falls within your concern of coordination.	Susie will be able to cut a circle using scissors, unassisted.
<b>Speech Therapy</b>	Speak using complete sentences. This falls within your concern of communication.	Susie will be able to tell a story three sentences long.

Here is an article on how to write SMART goals:  
[www.atlassian.com/blog/productivity/how-to-write-smart-goals](http://www.atlassian.com/blog/productivity/how-to-write-smart-goals)

These are clear and defined goals with measurable objectives or outcomes. If each therapist wants three goals to work on, create them just like the above. You can ask the therapists for their ideas too. Work as a team.

Learn the IEP meeting structure: I learned I could request who would attend the IEP meeting from school and I could find out prior to the meeting who would be attending. I could take anyone I wanted to the meeting, as long as I gave the school advance notice. I learned to request the teacher's and therapists' reports one week prior to the IEP. This gave me the time to read them and formulate questions prior to the IEP meeting. I learned I could take the lead on the agenda to keep the meeting moving along. These things took years to learn and I wish I had taken the lead of getting reports and leading the agenda earlier.



To be honest, getting the reports one week ahead of time was not something the school wanted to provide, but I requested it in writing and insisted on it, knowing my rights.

The first time I requested the reports ahead of time, it didn't happen. One week prior to the meeting, I didn't have two reports so I cancelled the meeting. The school was not happy because they had worked hard to coordinate the meeting with all the different teachers, therapists, and staff. I understood this and referred back to my email of request and suggested they explain the inconvenience to those who had not submitted the reports on time.

The meeting was rescheduled after I had all the reports. This is not being difficult; this is advocating for your child. You are going into the meeting blind if you don't have time to prepare. Having those reports lets you know what needs and supports your child has at this time from the perspective of the teacher and the therapists. This information is necessary to move forward with recommendations for the upcoming year.

I also flipped the meeting around and made my own agenda. I put my concerns at the top so everyone in the room could start off thinking about what I felt needed to happen to help my daughter be successful. After, we moved to the reports, sharing only the highlights, and how we were going to set up accommodations for her needs. I ran the meeting and I kept it to one hour. I would argue any IEP meeting over an hour is not productive.

There is a lot to listen to in these meetings and they are filled with emotion. I always felt like this was the time I would be reminded of what my daughter couldn't do, rather than what she could. It reminded me of how difficult things were for her, and I usually had to fight an individual at the school, the school as a whole, or the district to get what she needed. It was exhausting. I'm telling you this so you

won't feel you are the only one with challenges. It's not easy, but there are things you can do to make it more manageable. I learned, but not until high school, to lead these meetings in a positive manner, speaking of what she COULD do and what she WANTED to master and how we could set up accommodations to help her succeed.

The school IEP is something to manage as you do your child's healthcare. You learn as you go. Don't be afraid to reach out to other parents who have a child with special needs. They may have tips too. Stick with the parents who are positive and making progress by being a part of the IEP team.



Where do you go for help when things don't work, or people don't agree? First, know your rights. Here the law is explained: <https://www.wrightslaw.com>

If you need to hire an advocate or attorney, it's ok. Sometimes it takes a third party to explain the two sides. This is an investment in your child's future so having the support you need is important.

Be aware of the social services provided in your city and state. Some states will provide an educational advocate for no charge. You can find out if this service is available to you through your child's case manager or social worker. The social worker can be found through your child's pediatrician or specialist.

Have your child tested by a professional outside of the school system. It's helpful to have the opinion and suggestions from someone who is independent of the schools. Your child's pediatrician can refer you to a neuropsychologist who can access how your child best learns and accommodations which may help in school.

You can always take a friend with you to the IEP meeting for moral

## FURTHERMORE : OTHER THINGS I THAT I HAVE LEARNED

**IEP meetings:** These can be called at any time of the year, multiple times a year. Make your request by email so there is documentation of the request. The school is required by law to set up a meeting. Here is a link explaining timelines.

<https://adayinourshoes.com/iep-timeline-how-long-does-the-school-have-to/>

**Emergency Evacuation Plan:** Be sure there is an Emergency Evacuation Plan in place for your child. What happens during drills? How does your child get out of the building if there is an emergency? Get a copy of the plan from the principal's office and go over it with your child's teachers so they all know the plan to exit safely. There are laws to give our children access **into** a building, but there is no law to see they get **out** safely. Here is a place to learn about it.

[www.wrightslaw.com/info/emer.evac.plans.scott.htm](http://www.wrightslaw.com/info/emer.evac.plans.scott.htm)

**Off-site field trips or On-site activities:** Every student has the right to attend school field trips and participate fully in activities on campus. This can be challenging for a lot of kids, but if you do the legwork ahead of time, it will be more enjoyable for your child and you too. Find out the details of the trip as soon as you can. How are students traveling? How long is the ride? Where are they eating? Is the location accessible? What about the bathrooms? What are the activities? There were many times I called the location to speak with someone about the upcoming day so I could be sure to troubleshoot any issues which may arise.

**Moving forward:** Remember the IEP is for your child. The goals can be anything you want to have happen for your child. If you want it to be attending a field trip, incorporate it into the goals. If you want to be sure there is support for an oral presentation in front of your child's peers, make it a goal to work on it with the speech therapist.

There are many options after high school which aren't college, but if college fits your child's goals, help your child achieve this dream. The IEP doesn't carry over to college, but it's a helpful tool to use when asking for accommodations. Your child will need to submit their request for services to the Disability Office before each semester starts. The IEP can be used as a guide and the requests can come from the list of accommodations used in previous years. There are multiple books available on this subject. Each semester of college, my daughter submitted her same requests of accommodations from high school to the Disability Office on campus, as well as each professor.

**Document, document, document:** I made sure to correspond with the school and the district by email, so the correspondence was timestamped and documented. This alone is the single most important piece of advice I can share.

support or to take notes for you. This will allow you to focus on the meeting. Be sure to give the school notice, by email, who you will be bringing.

## WHEN

I found the best time to have yearly IEP meetings was February. It made it easy for me to research what my daughter should be doing because it was the month of her birthday. It also meant the meetings were held at a time of year when most other IEP meetings are not. The majority of IEP meetings are scheduled for the end of the school year, in preparation for the next. This comes at a time when teachers are more stretched for time and spring is in the air, leaving more focus on the weather than what is happening in the classroom.

When do you sign the IEP? I *n-e-v-e-r* signed an IEP at the IEP meeting. I wanted to take it home, read it over, and sign it in my own time. Remember this is a federal document and it should be read over carefully, before you agree and sign it. There is no law saying you need to sign the IEP at the meeting. You want to be able to go home and compare the number of therapy visits they are agreeing to with last year's IEP. This is a federal contract and you want to be sure it is just the way you want it. Every single year, I would be asked to sign it on the day and be told why it was more efficient to do so. I still never did. Even when we agreed to everything we had discussed, I didn't sign it that day.

## WHY

Your child is the why. Sometimes you will be able to make changes in the system so other children will benefit as well, but remember you are at the IEP meeting for only your child.

## HOW

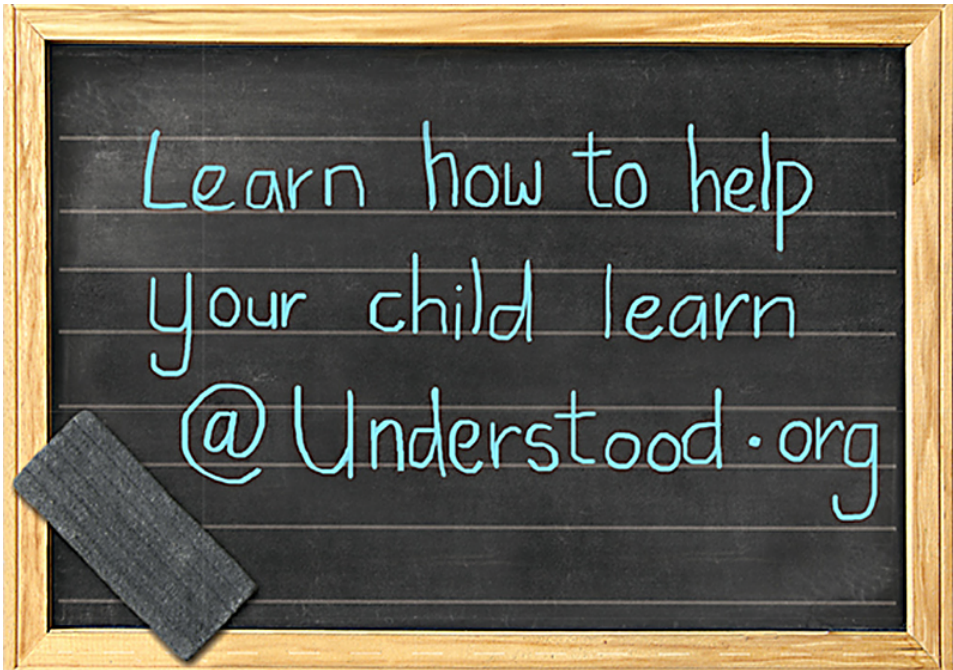
I found it helpful to know the details of the IEP document. Read it carefully. I met with teachers to be sure they agreed with the goals and made sure they had the support needed to help my child obtain these goals. I wanted the teacher to know I supported them, as I expected the teacher to support my child.

**K**ee in mind this is for your child and their future. Use the IEP to build their confidence and talk with them about their goals. What would they like to have support doing?

Good luck and keep reading to learn how you can best support your child. Every child can do anything with the proper support to accommodate for their needs. •

### ABOUT THE AUTHOR:

Gay Grossman has been active in the Rare Disease community for over two decades and continues her efforts to build and support patient and family advocacy. She co-founded ADCY5.org, the foundation for ADCY5-related dyskinesia with her husband, Steve. ADCY5.org supports families affected by the disease as well as their clinicians and world-renowned researchers who study the gene and its variant. Together, they continue to build a community of hundreds with this disease, when they started with only their daughter, Lilly. Gay and Lilly co-authored a children's Rare Disease book, *We Are All Rare*, providing a Rare Disease learning tool for elementary school-aged children. Gay successfully advocates in a variety of environments including, but not limited to, educational classrooms, private, state, and federal insurance, as well as collaborating in the Rare Disease community to gain access to clinical trials and medical therapies. Connect with Gay on LinkedIn.com <https://www.linkedin.com/in/gaygrossman/>



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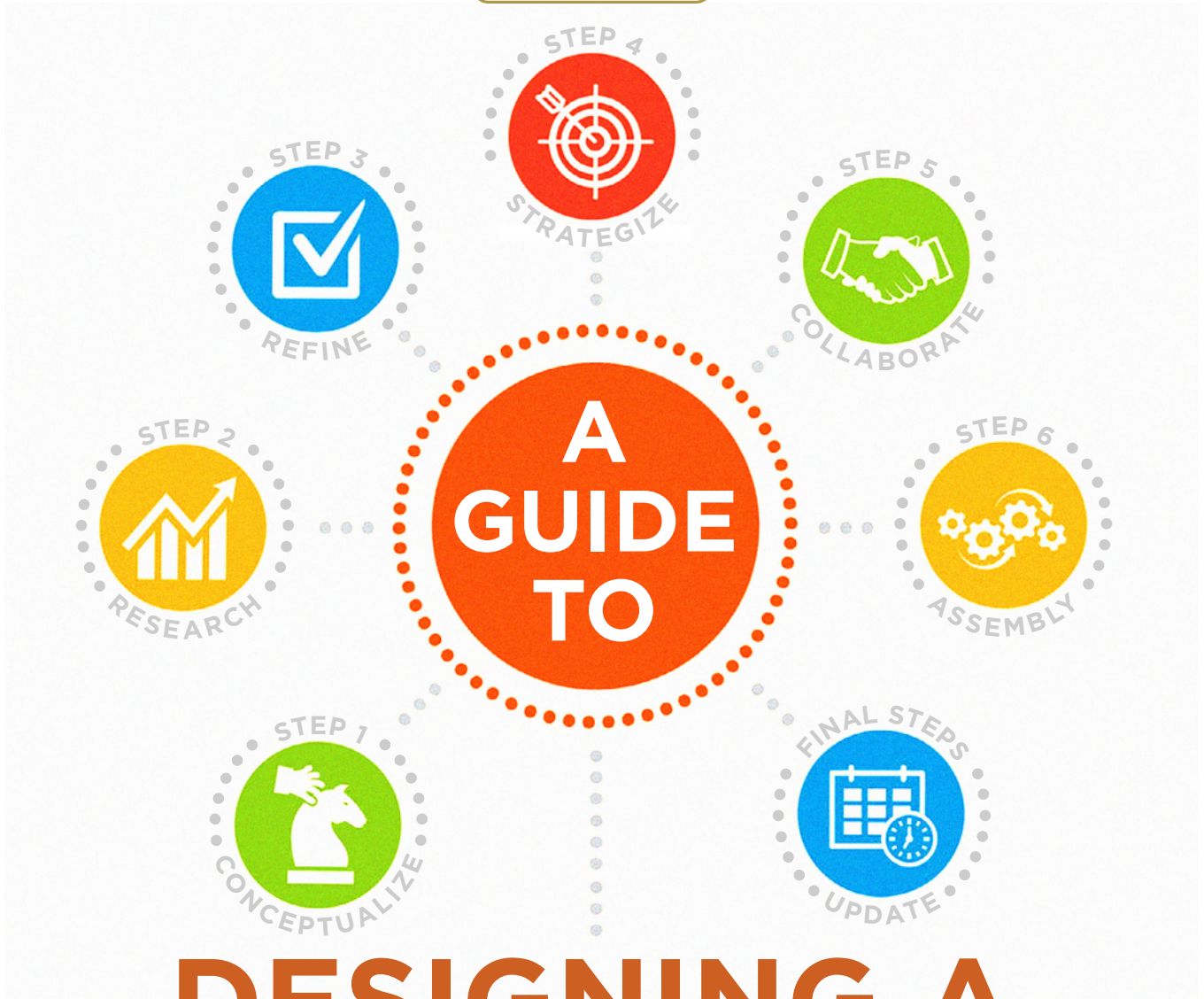
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# DESIGNING A SPECIAL NEEDS PLAN THAT WORKS

BY ALEXANDRA BAIG, MBA, CFP®

My husband is a mechanical engineer. He designs concrete, practical things like machines that put lids on jars. When we first met, I thought that his work had nothing in common with my work as a financial planner for people with special needs. But the more I watched him work, the more parallels I saw between the process each of us uses.



**M**y husband first creates a concept which broadly captures what the machine or machine part will accomplish. He discusses it with his team and his boss, and they alter aspects here and there until they are all in agreement with the concept. Then, he begins the hard work of translating the concept into reality, keeping in mind the manufacturable machine with each of its component assemblies and sub-assemblies. Eventually, he needs to design every last component, down to tiny screws. He needs to specify the size and orientation of each thing, whether it will be made in-house or purchased elsewhere, how big it will be, and how it will fit together with every other part it needs to touch.

Sometimes, based on feedback from the machine shop workers, or other engineers, or the end customer, parts of the design need to be adapted or amended along the way in order for the final product to both work and be affordable. The process for creating a plan for your family member with a disability is actual very similar.

## FIRST STEP

**The first step is for your family member, supported by parents, siblings, friends, and other invested parties to come up with a high-level concept for your child's adult life:**

- *Would the person rather continue to live in the family home or move to another location?*
- *Does he or she prefer to live alone, or with roommates?*
- *Will the person have a job? Part-time or full-time? Paid or volunteer, or some of each?*
- *Does the person want to have a life partner?*
- *What is important to the person besides work: for example, hanging out with friends, traveling, doing team athletics or personal exercise, having a pet, attending movies or concerts or plays, doing art, spending time in nature, learning new things or possibly attending a house of worship.*
- *What kinds of support will the person need to enjoy these things?*
- *How much of the supports will be natural from family, friends and co-workers, and how much will require paid workers? What kinds of physical, psychological or psychiatric health care needs does the person have? What kinds of transportation access will the person need to access work, as well as social, recreational and health care activities?*



Your family member with a disability might use MAPs and PATH to generate and refine the initial concept of adult life into an actionable plan. Frequently, these processes have a strong visual component to help the person with a disability participate more fully in planning her/his own future. **You can read more about MAPs and PATH here:** <https://inclusion.com/path-maps-and-person-centered-planning>.

Circles of support and a structure called Star Raft can help to identify, mobilize and sustain relationships with people beyond the immediate family who can provide insight, opportunities and support to the person with a disability. **You can read more about Star Rafts here:** <https://thestarraft.com>.

## SECOND STEP

**The second step is for your family member, you, and other members of the support team to understand how your state's public funding works.** In most states, adult services are funded primarily through what are called Medicaid waivers with a small amount of additional funding coming through local grants. Medicaid waivers are programs that permit states to use Medicaid



dollars to fund supports and services in small community-integrated settings rather than large, congregate institutional settings. The first thing to be clear about is that your family member needs to have and maintain Medicaid in order to access any services funded by a Medicaid waiver, whether for employment, recreation or general living support. Some states can fund a variety of kinds and levels of service through one very broad waiver that is highly customizable for each individual who is eligible. In other states, there are a number of waivers with each designed to fund a particular type and level of service.

My home state of Illinois is an example of the latter. Illinois has the "Home Services" waiver, which is managed through the Department of Human Services Division of Rehabilitation and is more directed towards people with physical disabilities. Then, there are several developmental disability waivers. The "Home-Based" waiver is basically a budget which, for adults over 18, is equal to three times the maximum Supplemental Security Income or  $3 \times \$783 = \$2,349/\text{month}$ . The funding can be used to pay for any type of support program or service, including paying one of the parents or a sibling to be a support worker.

There are also various levels of Community Integrated Living Arrangement (CILA) Waivers, ranging from a few hours a week worth of intermittent support to 24/7 support in what one might term a "group home." Because each state has the freedom to organize its own Medicaid waivers, it is important to understand how your state's waivers work and what are the criteria for eligibility. To take Illinois as an example again, here, eligibility is complicated. You can be eligible either because you have no living natural caregivers (parents) or because your need for support exceeds what untrained caregivers can provide or because your "number" was "pulled" randomly under the state's attempt to comply with a consent decree and reduce its waiting list.

In Illinois, the range of waiver funding types and levels, complicated further by the variety of ways to become eligible, means that no one can predict with much accuracy when an adult with a disability will receive funding, nor how much the person will receive. As one of the main advantages of any kind of financial planning is to run "what if" scenarios, I run multiple variations on each client's plan. In the best-case scenario, we assume the family member with a disability receives a generous level of funding at exactly the moment s/he wants to move out of the parental home—perhaps when the parents retire and want to downsize. In the worst-case scenario, we assume that same family member does not receive any funding until the parents are so old they cannot, literally, provide support anymore. Especially if the person with a disability is a child, adolescent, or young adult, we may also run variations based on a range of assumptions for that person's future independence as s/he matures.

### THIRD STEP

Before working as a financial planner for people and families with special needs, I spent seven years running a faith-based community where people with and without disability live together. The primary living expenses of the community members with disabilities—room and board, utilities, transportation, employment supports, or daytime activities—were covered by the waiver. But I quickly became aware of how many expenses that the rest of us take for granted are NOT covered by the waiver. **Identifying such non-covered expenses is the third step in the special needs planning process.**

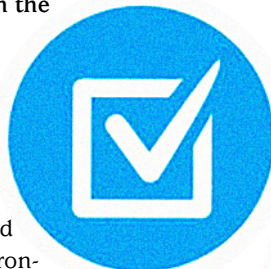
In our community, people liked to go out for coffee, lunch and dinner, see movies, go bowling, attend concerts, go to the zoo and the arboretum, travel, and buy each other and family members presents. None of these expenses are covered by the waiver. Neither are personal electronics, cell-phone plans, clothes beyond very utilitarian basics, sheets, personal care products, room decorations, bicycles or sports equipment, alcohol or any other special dietary preferences that had no medical justification. These are just examples, but there are hundreds of other such un-covered “luxuries.”

Moreover, some very necessary items, such as eyeglasses, hearing aids and certain kinds of therapy may be covered—but only with certain frequency, even though the person may need them provided, updated or replaced more often. Alternative medicine, such as massage, acupuncture or herbal supplements are not covered at all. Some dental work is covered, but it may be very hard, for example, to find an oral surgeon who takes Medicaid, if that is the person’s only insurance.

In Illinois, every person with a disability is permitted to keep \$60 of her/his Social Security benefit per month, but it would be naïve to assume that this will begin to cover all the extra expenses. In order to have these kinds of items and activities that make life enjoyable, somebody needs to supplement the public benefits.

When I build a plan with a person with disabilities, I ask that person to be very clear about what he or she enjoys. Many times, the family is so used to covering these additional expenses, that they underestimate their aggregate size. I then advise very clearly on what the Waiver will and won’t cover. And I ask the family to understand very clearly that the gap between what the waiver pays for, and what the person needs and wants, will need to be plugged every year for the rest of that person’s life. If the person with a disability is working or is expected to work, we first consider what portion of these non-covered expenses can be paid from the person’s own work earnings, keeping in mind that an agency that provides full-time supported living is expected to collect not only most of the Social Security paid to the people they support, but also a portion of those peoples earned income, if there is any.

In almost all cases, even when the person with a disability is well-employed, the amount of earnings left after the agency’s bill are insufficient to cover all the extra expenses. Moreover, even a person who has a strong work ethic may get laid off and at some point, s/he will, like the rest of us, retire. At that point, if no earlier, the family must take over providing supplemental financial resources to plug the gap.



### FOURTH STEP

**Determining the aggregate amount needed is the fourth step in the special needs planning process.** Let us assume, for example, that a couple had a child when they were both age 30. The child has a disability that does not impact her/his life expectancy. As a result, the child is likely to outlive her/his parents by at least 55 years. If the child needs \$10,000 per year to cover all the extras, then the parents are going to need to leave the then adult child \$225,000 to \$275,000, depending on one’s expectations regarding future inflation and the rate of return that will be earned on the money as it is invested.

Of course, this money cannot be left to the person with a disability outright if s/he has Medicaid waiver-funded supports—because the person needs to maintain Medicaid eligibility to maintain services, and with a very few exceptions for workers with disabilities, Medicaid has a countable resource limit of \$2,000/person. A person with a disability who abruptly inherited several hundred thousand dollars or even a significantly smaller sum, would lose her/his Medicaid-funded supports until such time as the overage was “spent down.” That would either require a long time, or see the assets depleted hastily, thus undermining the parents’ intent to keep them invested to provide supplemental funding over the long term.



### FIFTH STEP

Instead, the inheritance from the parents or, indeed, any other individual, should be left to a properly-written special needs trust. **At this point, if not before, it is necessary to engage an attorney who specializes in creating such trusts and related documents. This is the fifth step.** The trust must contain certain language in order to serve its purpose, and that language must be reviewed and updated to keep up with any changes in public benefit eligibility. I cannot stress enough that for both financial and legal planning, it is imperative to engage professionals who have a solid understanding of the rules around Social Security, Medicaid eligibility.

A trust, special needs or otherwise, is not a type of account. Rather, it is a type of legal ownership. The trust, itself, is a legal person. Assets held in accounts titled in the name of the trust are owned BY the trust itself and NOT by the person with a disability. This is why assets held in a properly-written special needs trust do not count for purposes eligible for Medicaid, including Medicaid waivers and Supplemental Security Income, the means-tested cash benefit administered by Social Security.

The trust may own checking and savings accounts, stocks, bonds and mutual funds in brokerage accounts, a house, a car, gold, collectibles—or pretty much any other asset that could be owned by an individual. The trust may also be the beneficiary of life insurance policies as well as annuities, qualified retirement accounts and, sometimes, pensions. While having a trust as the beneficiary of a life insurance policy is straightforward, having one as the beneficiary of the other three financial instruments is more complicated and requires detailed planning.





Since their advent in 2016, ABLE accounts have also been available to hold money in such a way that it will not disrupt benefit eligibility. However, since ABLE accounts can only accept cash contributions, and since annual contributions are limited, it is impractical to use an ABLE account to hold all but the smallest of inheritances.

## SIXTH STEP

The second to last step in the special needs planning process is to determine the most cost-effective and lowest-risk way to fund a special needs trust. Certain investments, such as the stock of small, startup technology companies, may have a high expected return, but also carry a high risk. Some investments like US treasury bonds, may carry low risk, but generate a return that barely keeps up with inflation. Any asset that is traded on a market from stocks and bonds to commodities and real estate may experience a weak period, sometimes a prolonged one. Qualified assets, such as IRAs, have both tax benefits and tax consequences when the money is withdrawn either too quickly or too slowly. One can count on the return within a non-variable life insurance policy purchased from a reputable, well-rated company, but it may be hard to access the funds if they are required before the death of the insured parent. It is, therefore, very important to consider funding a special needs trust with a variety of assets with different expected returns, risk profiles, tax characteristics and dates of availability. When considering all financial instruments, it is also crucial to consider fees, since the return on an investment is not what the investment makes, but what the investor keeps after fees and taxes.

The process for creating a viable special needs plan is, as it turns out, very similar to the process for designing a workable physical product. You start with a concept, work downwards to identify the



systems and components required to build it, understand the various sources for the components, run multiple scenarios to stress-test success under a range of potential scenarios, and figure out the most cost-effective, lowest-risk process for acquiring and assembling the components to make the product.

## THE FINAL STEP(S)

The final step in creating a functional special needs plan, like the final step in designing a product, is not really one step, but many. Coke™, having introduced many flavors and sweeteners for its flagship soda recently introduced Cinnamon Coke™ for the holidays. Apple has introduced the iPhone 11, the latest iteration providing more and better features than previous versions. Like these and pretty much all products and services, the plan must be reviewed and updated on a regular basis to reflect changes in the life of the person with a disability and her/his family, as well as changes in the local mechanisms for funding disability support, and changes in the broader economy. •



### ABOUT THE AUTHOR:

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

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# KNOW THE RANGE OF OPTIONS FOR SPECIAL EDUCATION PLACEMENT

BY LINDA HELMIG BRAM, PHD

*What type of special education is best for your child?*

*Families are empowered when they have knowledge of what is available by law.*

Inclusion of children with special needs in general education classrooms is an important legal right. This model works well for many children. But what about children whose learning needs are more extensive and cannot be served in an inclusion classroom at their neighborhood public school?

Parents are often unaware that public schools are legally obligated to provide a continuum of educational placements for children with disabilities. These range from general education inclusion classrooms to private placements paid for by the district (see Table). In this article, I empower families with the knowledge they need about the range of special education placements in order to improve their ability to advocate effectively for their children.

Range of Education Placements Required by Law	
In-District (Public School)	General Education Classroom (Full or Partial Inclusion)
	Substantially Separate Classroom
	Separate Day School, e.g., Collaborative
Out-of-District (Private School)	Private Day School
	Residential School

As a psychologist, I work with many children who struggle in school and parents who feel lost and don't know what to do. As a parent of children with special needs, I have also been unsure of how to proceed when their learning needs were not being met. There can be many reasons for a child's lack of academic progress. In my experience as a psychologist, all of the child's needs – academic, social, emotional – should be considered when trying to

identify the source of their challenges at school. Does the child have an undiagnosed learning difficulty? Are they being bullied because of poor social skills? Does the child require additional services or testing to identify what's going on?

Schools are legally obligated to evaluate any area of concern or "suspected disability," including social and emotional challenges. There are a small percentage of children on Individual Education Plans (IEPs) who, despite the best efforts of the public school's general and special education teachers, require more specialized teaching methods, smaller classrooms, or other modifications to their learning environment. For example, children with visual or hearing impairments are often referred to publicly-funded specialized private schools.

Public schools may be hesitant to refer children to private schools in part because:

- (1) These placements can be costly.
- (2) Schools have a legal obligation to educate children with disabilities in the "least restrictive environment" (LRE) alongside peers without disabilities.

Public schools are also unlikely to change a child's placement or services as long as they are making "adequate progress" on their IEP goals (another legal requirement). Some parents and students prefer a shift from the inclusion classroom and to a special education classroom or private school that is technically more "restrictive" but also provides more specialized, expert intervention. Advantages include exposure to highly-trained teachers and to peers with similar profiles. Disadvantages include less exposure to and modeling by typical peers and families feeling less connected to their neighborhood community.





**KNOWLEDGE EQUALS POWER:** All of the child's needs should be considered when trying to identify the source of their challenges at school.

## BALANCING ALL THE STUDENT'S NEEDS

Consider Emily, a girl with spina bifida, whose parents worked tirelessly to keep her in a general education classroom, though she struggled in and hated school. When she was 13, she attended a summer camp for children with physical and developmental disabilities and, for the first time, felt socially at ease and genuinely happy. Her parents came to realize that they had been achieving “inclusion” in the legal sense (i.e., she attended her neighborhood public school with typical peers) but that Emily never felt truly included with her peers, a growing need as she approached her teenage years. Her parents pursued a school serving a similar population so that her academic, social, and emotional needs could be more fully met by teachers with greater expertise in her disability.

It is important to note that the process for securing a specialized classroom or private school can be slow (e.g., 1-3 years or more). Parents cannot simply choose the next option along the continuum (see *Table*). The child's IEP team must refer the child to a more restrictive setting and can only legally do so when they conclude that the child is not making adequate progress on their IEP goals.

As a first step, public schools may refer to their in-district programs—“substantially separate classrooms” or “Collaboratives”—that serve a particular population (e.g., children with autism, emotional/behavioral difficulties, or learning disabilities). For some children, this works well. However, others may not make adequate progress and require referral out-of-district. These decisions are rarely clear-cut or easy. Parents and schools alike are faced with complicated decisions around when a referral to a special education private school is warranted. Parents sometimes hire educational advocates or attorneys to help resolve the disagreements. Some states offer more affordable options for families, including mediation, and free or low-cost advocacy and legal consultation.

“Caleb” is a boy I worked with who had autism and anxiety and was prone to behavioral outbursts. During kindergarten, his teachers and parents agreed that he could benefit from moving from the inclusion classroom to a specialized class for children with autism. This worked well for about a year. In 2nd grade, Caleb regressed in his communication, life skills, and behavior.

The family collaborated with their school to try different approaches and add more services. Caleb continued to struggle, and his parents felt like they were at the end of their rope. They researched special education private schools and discussed promising options with the IEP Team. Although it took another year of negotiating—a process that unfortunately necessitated their hiring an attorney to make their case – Caleb was referred to a private placement. His parents noticed a difference within the first two months. In fact, once his challenging behaviors settled down, his teachers discovered that he could read! Caleb also began to learn a host of new skills that his parents never imagined he could, especially given his past regression. This family was happier than I had ever seen them!

As a parent, I have also seen firsthand the benefits of a publicly-funded private school. My daughter has severe autism, intellectual disability, and seizures. She is a preschooler in our public school's special education program where her teacher informed me that they didn't understand why the other children were making gains in communication, but my daughter was

not. The school district went above and beyond to figure out how to meet her needs. They paid for her teacher to receive behavioral training from an agency two hours away. I will always be grateful to them for their efforts to educate her and keep her in the public school setting as long as possible. However, with the combination of her lack of progress on any IEP goals, increased self-injury and physical aggression at school and home, her IEP Team agreed that a highly specialized private school was necessary.

## MAINTAINING COLLABORATIVE RELATIONSHIPS WITH TEACHERS

When more restrictive placements are made, I want to be clear that it is not a failing of the public schools by any means. Consider this analogy: public schools are similar to general practitioners or pediatricians who are capable of treating many conditions that come their way. However, there are times when a more complex medical problem emerges, and doctors refer to specialists who can offer more in-depth care. Similarly, special education private schools fill in the gaps that public schools cannot be expected to.

Finally, parents should take care to maintain collaborative relationships with the child's teachers when resolving disagreements about school placement, particularly if these become contentious. When I attend IEP meetings as a professional or parent, I try to remember that we are all on the same side – the side of the child! – and want the child to succeed. When parents know the range of options available, they can better advocate for their child and know that there is hope. •

### ABOUT THE AUTHOR:



Linda Helmig Bram, PhD, is a psychologist who specializes in supporting children, adolescents, and adults with disabilities and their families. She is a Part-time Lecturer at Cambridge Health Alliance/Harvard Medical School, and a consultant at the Federation for Children

with Special Needs, a parent advocacy organization in Boston. Dr. Bram created a website to empower parents called Special Education Placement Options at [fcsn.org/sepo](http://fcsn.org/sepo). She is also a parent of children with special needs.

# DISABILITIES AND COUNSELING SERVICES

The foundation for any discussion of counseling services is an understanding of the basic types of disabilities and counseling services that exist.

There are thirteen categories of disabilities recognized by the Department of Education as being covered by the Individuals with Disabilities Act, the nation's special education law.

BY JOHN T. SPOEDE, JR., PH.D., D.MIN., LPC-S, LCDC, NCC, CSC

*Parenting children through the highs and lows of growing up in the twenty-first century can be daunting under any circumstances. For parents of children with exceptionalities, that process can be even more complicated. Given the scope and wide variety of disabilities that exist, it can be overwhelming to navigate and determine which types of counseling therapies would be useful, what types of outcomes should be expected, and understanding how to make the best decision and best advocate for you and your child while receiving counseling services.*

## WHAT TYPES OF DISABILITIES & COUNSELING SERVICES EXIST?

The foundation for any discussion of counseling services is an understanding of the basic types of disabilities and counseling services that exist.

There are thirteen categories of disabilities recognized by the Department of Education as being covered by the Individuals with Disabilities Act (IDEA), the nation's special education law. (20 U.S.C. § 1400 (2004)).

These categories include:

1. autism
2. deaf-blindness
3. deafness
4. emotional disturbance
5. hearing impairment
6. intellectual disability
7. multiple disabilities
8. orthopedic impairment
9. other health impairment
10. specific learning disability
11. speech or language impairment
12. traumatic brain injury
13. visual impairment (including blindness)

(34 C.F.R. § 300.8, <https://sites.ed.gov/idea/regs/b/a/300.8>, containing regulations for implementing the IDEA).

Basic counseling services can be a benefit to children diagnosed with one or more of these disabilities. Types of counseling include individual counseling, group therapy, and family therapy. Mental health counseling can address both short-term, acute concerns that arise in a child's life, and it can provide long-term, ongoing support to children and families navigating life with a



disability. Finding the counseling paradigm that will work for a particular child involves consideration of many different factors.

## IS COUNSELING APPROPRIATE?

This is a common question. The very short answer is, one will find it worth one's time and effort to schedule an appointment with a mental health professional – whether that someone is in acute mental distress, or experiencing mental health issues that negatively impact his or her day-to-day functioning, or if he or she has been referred to therapy by another professional, such as a medical doctor, school personnel, or member of the clergy,



Well-qualified mental health professionals will be able to help potential new clients assess whether counseling would be beneficial. Many times, the therapist will use the first session to learn about the presenting issues, make an initial diagnosis from the DSMV, and determine if therapy is appropriate or if a referral is needed. There are some things that counseling therapy cannot fix, so an open and honest discussion between the client and therapist about the things the clients would like to work on ensures that everyone is on the same page about the scope of the treatment plan. It allows the therapist to honestly assess the viability of therapy in each individual case.

Another consideration in determining whether to seek counseling is whether your child is receiving services through the school. Just as there are IEPs (individual education plans) for so many areas in school, there is also the option for the school to recommend

## WHEN IS COUNSELING MOST HELPFUL?

Most research supports that earlier interventions have better long-term outcomes rather than delayed interventions. It is also commonly supported that if interventions are started earlier, the intervention takes less time and costs less money. Further, if there is an established relationship with a therapist prior to a crisis or an emergency, then accessing and utilizing counseling resources will be a much smoother process. As mentioned in the previous section, counseling is appropriate when there are emotional or relational issues that are causing problems in day-to-day functioning, or to address acute crisis, or address cyclical concerns, or to prepare for particularly challenging transitions. If the child might benefit, seek out a counseling therapist to evaluate if now is the right time for entering counseling. A good therapist will help figure out the best timing for therapy.



counseling services through a counseling IEP. In general, counseling IEP's are put in place to assist the student with being successful in the educational setting. This implies that a counseling IEP will not address family issues, or issues that are not directly impacting the educational process or the student's learning environment.

If someone is unsure about the appropriateness of counseling, you may want to also ask if you are utilizing and taking advantage of non-counseling resources such as formal and informal support groups, organizations, publications, conferences, and community support related to the child's disability or presenting issues. There are numerous local, state, national, and international resources available; be sure to find the ones that are helpful to you; access and use them.

In summary, as a rule of thumb, counseling of some kind is appropriate when the child has unmet social, emotional, or developmental needs resulting from their disability or their experiences, either generally or in a specific situation or circumstance.

## WHAT TYPES OF THERAPY EXIST?

There are three major type of counseling: individual, family and group.

**Individual therapy** focuses on a therapeutic relationship between a mental health professional and an individual client. A therapeutic counseling "hour" typically lasts between 45 and 60 minutes, and the treatment plan accounts for the theoretical orientation of the therapist and the presenting issues of the client. Individual counseling can last as few as eight sessions or can continue for years, depending on the diagnosis and agreed-upon treatment plan. Individual counseling allows the client to focus on and address their own issues, but it can sometimes be difficult to address larger family issues in individual therapy. Further, the therapist is dependent on the individual client to provide the most important information related to counseling – i.e., insight into the presenting issue and mental health condition – and sometimes clients, especially

younger or more immature clients, are not a good judge of which information is needed to progress in the therapeutic process. Parents can assist by providing information to the therapist.

**Group counseling** ideally entails groups of approximately eight individuals with one therapist, or twelve individuals with two therapists. The exact nature of group counseling can vary widely depending on the participants and practitioner involved: groups can be smaller or larger, be open to new members or closed, can last for as little as a few weeks or can continue for years, and can provide therapy from a large variety of theoretical orientations in sessions lasting one hour or several hours. Group counseling's strength lies in helping clients not feel isolated. It allows people to work in a group setting on issues and to learn to support others in similar situations. Drawbacks of group counseling are that the individual does not get to focus only on their issues, some special needs can be hard to fully accommodate, and confidentiality cannot be guaranteed because there are other clients in the room.

Finally, there is **marriage, couple, and family therapy**. Family therapy focuses on issues related to family dynamics, and the entire family is the client of the therapist (instead of the individuals). There are times when what is best for the family may not align with what is best for an individual within the family. There will also be a theoretical orientation (think Cognitive-behavioral therapy, DBT, solution focused therapy, etc.) and prescribed treatment plan, and the number of sessions can vary widely. Family counseling sessions can span 50 minutes all the way up to two hours. In family therapy, the therapist can observe family interactions in real time, to work on issues, and provide immediate feedback and strategies for the family to implement during the session. However, in family therapy, each individual's needs are secondary to the development and healing of the family system as a unit. Further, family therapy may not be the best setting for addressing issues that are bubbling beneath the surface, such as in cases where families struggle to be open and honest with each other.

## WHAT TYPES OF COUNSELORS PROVIDE RELEVANT MENTAL HEALTH SERVICES?

There are so many kinds of counselors in the world today; it is important to discuss differences that exist between various therapists. This will not be an exhaustive discussion, but an introduction. Common among all the mental health professionals is that they are governed by state rules and regulations, although the exact name, title, or designation can vary from state to state.

### CERTIFICATIONS

One counseling credential is the Certified School Counselor (CSC). These mental health professionals work in the school setting, and are specifically trained in education counseling, crisis counseling, and other school-related and developmental issues. ([www.schoolcounselor.org](http://www.schoolcounselor.org))

### LICENSED MENTAL HEALTH PROFESSIONALS

**Licensed counselors** can have different designations depending on the state in which they practice. The American Counseling Association has a chart summarizing the different designations for licensed counselors: ([www.counseling.org/docs/licensure/72903\\_excerpt\\_for\\_web.pdf](http://www.counseling.org/docs/licensure/72903_excerpt_for_web.pdf)). Many states use the "LPC" designation, standing for Licensed

Professional Counselor. After completing a master's degree, the counselors must go through a supervised internship before they can be fully licensed to see clients. The scope of the counselor's practice is dictated by each state, but generally includes all types of counseling except in the areas of projective personality counseling or severe mental illness such as clients who are dissociative (i.e., not aware of time and place and current reality).

**Marriage and family therapists (LMFT)** are trained in family systems. These mental health professionals are trained to work with couples and families on system issues, including family dynamics, communication, and boundaries within families. (<https://aamft.org>)

**Psychologists** are doctoral level, trained mental health practitioners who can practice in virtually any area of mental health treatment. There are many kinds of psychologists, such as counseling psychologists, clinical psychologists, or school psychologists, most of whom graduated from programs associated and accredited with the American Psychological Association. Psychologists complete a one-year approved internship as part of the licensure process. There are also master's level psychology mental health practitioners, such as psychological associate and licensed specialists in school psychology. ([www.apa.org](http://www.apa.org) and <https://www.nasponline.org>)

**Social workers** are known for understanding systems and how to help clients work within systems to obtain maximum benefits. Though the exact designations can vary by state, there are two main designations for social workers: Licensed Master Social Worker (LMSW) and Licensed Clinical Social Worker (LCSW). The LMSW works mainly in mental health settings, connecting clients with services and acting as a case manager. The LCSW has specific training and post-master's degree supervision in providing counseling services to clients. They generally complete a 2-year internship after completing their-master's degree. ([www.socialworkers.org](http://www.socialworkers.org))

**Psychiatrists** generally do not provide counseling services. They are classically trained as medical doctors and are tasked with prescribing medication, as well as monitoring the effects of the medication on their clients. ([www.psychiatry.org](http://www.psychiatry.org))

Obtaining all of these certifications and licenses also involves passing tests.

### SPECIALIZATIONS AND ADDITIONAL CREDENTIALS

**Art therapists** incorporate art in the therapeutic relationship. "Art therapy is an integrative mental health and human services profession that enriches the lives of individuals, families, and communities through active art-making, creative process, applied psychological theory, and human experience within a psychotherapeutic relationship." (<https://arttherapy.org>)

Another designation is related to **Applied Behavior Analysis (ABA)**. The Board-Certified Behavior Analyst® (BCBA®) is a designation related to completing education and supervised training prior to becoming certified to provide independent behavior analysis services. ([www.bacb.com](http://www.bacb.com))

Many states have specific licenses for **chemical dependency counselors**. These counselors with the credentials have specific training and experience working with addictions and substance-specific disorders. The exact nature and scope of services available from chemical dependency counselors varies by state. It is also important to note that many other credentials include chem-





ical dependency counseling in their scope. This means that other licensed professionals such as counselors, social workers, and psychologist can provide services related to chemical dependency issues. However, chemical dependency counselors should only practice in the areas of chemical dependency. ([www.naadac.org](http://www.naadac.org))

**Music therapy** is defined as the clinical and evidence-based use of music interventions to accomplish individualized goals for people of all ages and ability levels within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program ([www.musictherapy.org](http://www.musictherapy.org)).

There are also **national credentials** for mental health professionals. These national credentials do not allow mental health professionals to practice within a state, but they can signify that the mental health professional's training and practice meets higher standards. One example of this type of credential is the National Certified Counselor (NCC). ([www.nbcc.org](http://www.nbcc.org))

A **registered play therapist** (RPT) is a mental health practitioner who has been educated and has completed supervised experience in the area of play therapy. In short, play therapy is a type of therapy that can be used with any age, where creative forms of expression and therapeutic progress are encouraged. Many times, play therapy is used with children who are not mature enough for traditional talk therapy, but it can also be used with adolescents and adults. ([www.a4pt.org](http://www.a4pt.org))

This is in no way an exhaustive list, but it is intended to introduce the idea that there are varied mental health professionals who work with individuals with exceptionalities.

### HOW LONG SHOULD THERAPY LAST?

*The length of therapy is dependent on the presenting issue, the identified disability, and the context for each person. In an ideal world, a counselor is constantly working with their client to work themselves out of a job.* Meaning, as a therapist, my goal is to help my client get to a healthier place than they would doing things on their own; or get to a healthier place more quickly than they would on their own. Then once my job is done, the counseling relationship is terminated. This means that the client returns to living their day-to-day life without meeting regularly with me.

It has been my experience that insurance companies like to allot 8-12 sessions per presenting issue. This time allows the therapist and client to cover psychoeducational materials, strategies to implement to address the issue, and learn about transferable skills that can be applied by the client on their own, in other setting. On the other hand, some clients will require a more long-term counseling relationship. These types of counseling relationships can even span years. This type of counseling is for people who have presenting issues that are resistant to treatment or disabilities that require a more intensive, long-term approach and intervention. Quality therapists will set goals and develop a treatment plan setting out the amount of counseling that would be beneficial, early in the counseling relationship.

### WHAT ARE THE SHORT-TERM OR LONG-TERM GOALS?

As you enter a counseling relationship with a therapist, it is important to understand both the short- and long-term goals of therapy. Therapists create an individualized treatment plan for each client. The treatment plan should include a combination of the pre-

senting issues, or the reasons the client sought therapy in the first place and goals related to the clinical judgement of the therapist. For example, a client may seek out therapy to improve communication within the family, because there is a lot of yelling and fighting. The therapist may identify the cause of the fighting to be unresolved trauma, anxiety, or stress. Therefore, the treatment plan would most likely include goals related to improved communication and increased coping strategies for stress.



*The short-term goals will be goals that are achievable in the near future (think weeks to a few months). Long-term goals extend beyond months, or, even if they can be obtained quickly, have a maintenance component associated with them.* The treatment plan and the goals

should act as a road map for the overall therapy the client receives. It is important to note that the treatment plan and goals can evolve and change over the course of the therapeutic relationship, depending on the client's need and the therapist's professional judgement.

### HOW DOES ONE PICK A COUNSELOR?

For many, there is a challenge associated with finding a mental health professional. Some will turn to the internet to search and some will access their network of families who have similar experiences to themselves. When selecting a mental health professional, it is important to acknowledge that not all providers are the same. Part of the selection process includes finding providers who are available and compatible with clients. This means that you should actively try to screen therapist as you work at selecting the right one to meet your needs.

*Many times, therapists will speak at conferences, universities, or at community organizations such as churches.* If you can participate in these types of events, you may get a chance to hear from, or meet a perspective therapist. Many therapists have front office staff who can assist with answering general questions and assist with scheduling appointments and answer billing questions. Some will also return phone calls to perspective clients, to introduce themselves and screen the clients to make sure they are a good fit for the services they provide. However, the introductory phone call is not a therapy session, or a time for the perspective client to share their entire story. Many times, phone calls are limited and brief.

It is my opinion that all parents, especially parents with children of exceptionalities, should have a network of other parents to access as a resource. Many times, these networks will have a combined knowledge and experience that will assist you in the process of finding a provider. Doctors, pediatricians, schools, churches, and other organizations will often create and maintain a referral list. In many cases, it is worth your time to access these types of referral lists. Some lists are vetted, some are put together via internet searches, and some are created based on request from therapists to be added to the list. However, the list is created, it has the potential to be useful in your search, and it is worth inquiring about how the list was created and maintained.

*There are also many online directories that can assist you with finding clients.* Some of these directories are subscriptions that the providers pay for (i.e. *Psychology Today*), while other networks are associated with licenses or professional organizations. Many insurance companies will also create a list of providers that list in-network mental health professionals. However, when all is said and done, there is an element of choice associated with selecting a therapist.



It is also important to note that there are times where a therapist is not accepting new clients, but you can be asked to place on a waitlist. At one point, I had a waiting list six months out, and there were a few clients who opted to wait for an opening with me over finding a different therapist. At the end of the day, it is important that you find a therapist that you are comfortable with that is a fit for you and your family. Do not feel like you must persist with the first therapist you meet with, especially if it is not a good fit. You have the option to seek out additional professionals until you find the right therapist to address your specific needs.

There are a few main ways to pay for counseling therapy: out of pocket, insurance, and EAP (employee assistance program). Out of pocket refers to the entire cost of counseling being paid for by the client or guardian. When one uses an insurance company, the individual is expected to pay their portion of the cost, while the insurance company pay their portion. An EAP usually pays for a limited number of sessions per person. There are pros and cons to each of these payment options. For those who have an EAP, there is generally a prequalification process and there are a limited number of therapists who are approved to accept EAP clients. There are even some programs where you are assigned a therapist.

There are some obvious down sides to this system, and lack of choice associated with it. However, EAPs may cover up to 100% of the cost of the counseling sessions for a limited number of sessions. However, once the allotted number of sessions have been used, the client then reverts to insurance or out-of-pocket payments.

For those who use insurance, there will most likely be therapists who are in-network and out-of-network. If you find a therapist who is in-network, the therapist has entered into the prearranged agreement with the insurance company. This agreement dictates the reimbursable rate for procedures being provided, and the portion or amount that the client will owe for each session. The downsides to this arrangement is that there is a third party now involved in the counseling process, and the insurance company can dictate the number of sessions you are approved to use and who you are allowed to use. They will also require a diagnostic code, which means your mental health provider will be required to share with an outside party, aspects of the counseling assessment, relationship, and details you have shared during the therapy session. Insurance companies can even go so far as to require a therapist to submit copies of progress notes for each session that is provided. At this point, aspects of your therapy are shared with a third party and can have various repercussions.

In addition to in-network therapy, there are out-of-network options on some insurance plans. This means that you find a therapist who meets the criterion of the insurance company, you pay the entire price of therapy, and then you submit to the insurance company for reimbursement of the services you have purchased.

In general, the therapist must be fully licensed (not a student or a supervised intern). Additionally, the reimbursement rate is generally at a lower percentage than an in-network provider, and the insurance company will only reimburse based on a predetermined allowable rate. For example, if a therapist charges \$150 per session, but the insurance company only has an allowable rate of \$60 per session with a reimbursement rate of 50%, then you would only

receive a reimbursement of \$30 per session (even though you paid \$150 per session). Additionally, you will be required to submit additional paperwork in order to get the reimbursement approved by the insurance company. However, the cost of the therapy, may count towards your annual healthcare costs. These details vary so check with your insurance company.

For those who decide to pay out-of-pocket, the entire cost of therapy is paid for by the client. Many providers take most forms of payment (cash, check, and credit cards), but you need to confirm with you selected provider. Additionally, many of the services provided can be paid for, or reimbursed from a federal FSA (flex spending account). In this arrangement, the entire counseling relationship exists between the client and the therapist, and no third party dictates the number of session or receives information about the therapy or services being provided.

Additionally, you have the ability to select a student, or intern to provide services. Many times, the services provided by these types of mental health professionals are heavily discounted, because they are new to the profession. On the other hand, you will also have access to some elite specialized counselors who have experience and expertise that allow them to opt out of being an in-network provider. Though these services come at a premium, there is the expectation of advanced and high-quality services being provided.

There are pros and cons, regardless of the arrangement you enter with a therapist.

## WHAT CAN I EXPECT? WHAT KIND OF OUTCOMES?

During your initial, or intake, session there will be a lot of paperwork to complete. Amid the paperwork is usually a statement of expectations for therapy and the possible outcomes associated with therapy.

In short, there are no guarantees associated with the outcomes of therapy. Therapy is not a miracle cure. On the other hand, there have been many research studies and evidenced-based treatment protocols created. While there is no guarantee associated with the outcome of therapy, there are many research studies that report the potential benefits to therapy. Here is a link to an article entitled “50 Signs of Good Therapy” ([www.goodtherapy.org/blog/50-signs-good-therapy-0110119](http://www.goodtherapy.org/blog/50-signs-good-therapy-0110119)). Number three on the list states, “Your therapist explains the therapeutic process and how you can benefit from it, without guaranteeing your success or promising that “everything will be okay.” The bottom line is that no one can make such guarantees – neither the therapist, nor you.”

## CONCLUSION

Though the process of starting counseling therapy may seem daunting, the long-term benefits are well worth the time and effort. I strongly recommend that parents with children who are exceptional, lean into their peer networks and learn more about the best counseling service providers in your area. •

## ABOUT THE AUTHOR:

John Spoeede, Ph.D., D.Min., LPC-S, LCDC, NCC, CSC is Director, Center for Research and Doctoral Studies; Program Coordinator, Ed.D. in Mental Health and Human Services; Assistant Professor, Houston Baptist University. He currently practices counseling at Renewing Hope Counseling Center in Houston, TX.





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# HOW TO RECOGNIZE DYSLEXIA IN YOUR CHILD

BY JILLIAN KASTER

*Growing up, I had beautiful name: Jillian Rose Periolat. Periolat is French and pronounced /pair/e/o/lay – four syllables that are meant to roll off the tongue. Of course, even adults meeting me for the first time would not know how to pronounce this foreign name, so whenever I joined a new recreational*

*activity as a child, the first question was, “Hey, kid! How do you say your last name?” I’d look up at these coaches and want to say, “You’re the adult – you tell me!” The truth was, I didn’t know how to pronounce my last name, and I was embarrassed to admit it.*



# A reading program coach shares her struggle with dyslexia, helps identify common situations children with dyslexia experience – and suggests initial steps to help your child get needed support.

**W**hen my family members would say it, I'd repeat it, but I was constantly taking out a syllable, pronouncing it /pair/ /o/ /lay/, which now feels like stop and go traffic in my mouth. My brother would tease me about not even knowing how to pronounce our last name, but every time I'd compare my way to his, I couldn't hear the difference and continued to stumble. This resulted in years of me doing everything in my power to avoid ever having to say my last name.

Other areas in language, most obviously reading, posed challenges for me throughout schooling. Eventually, at 34 years old, I found out that my sense of confusion and shame stemmed from the fact that I have dyslexia.

## TURNING DESTRUCTIVE THOUGHTS INTO OPEN CONVERSATION

As a child, I'd spent a lot of energy hiding my struggles from my parents and teachers, but when I was diagnosed, I made the decision to turn my destructive thoughts into open conversation. I was an implementation coach for a reading program when my diagnosis was confirmed, so I've had the opportunity to share my newfound information on what dyslexia looks and feels like with educators across the country. Most of the time, they're surprised to hear that one in five ([www.dyslexiacenterofutah.org/Statistics](http://www.dyslexiacenterofutah.org/Statistics)) children has a language-based learning disability – the most common of which is dyslexia.

Many educators I've met, like myself until recently, don't have the training to properly identify students with dyslexia. There's a common misconception that students with dyslexia see letters and words backwards. That's simply not true. This myth and others like it can often impede a student from getting a proper diagnosis and the support they need. Students with dyslexia often fall through the cracks and develop astonishing coping mechanisms to make it as far as I did.

The first thing parents and family members need to know is that having dyslexia has nothing to do ([www.nih.gov/news-events/news-releases/nih-funded-study-finds-dyslexia-not-tied-iq](http://www.nih.gov/news-events/news-releases/nih-funded-study-finds-dyslexia-not-tied-iq)) with a person's IQ – of course, no student who

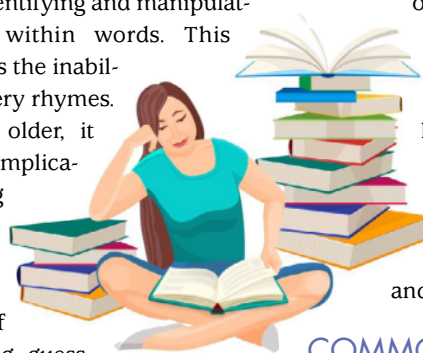
struggles to read is going to inherently think that. That's something an authority figure needs to tell the child until they believe it. Before offering that essential support, parents need to know what dyslexia looks like. Here's how you can recognize the characteristics of dyslexia, identify common situations children with dyslexia experience, and take initial steps to help your child get the support they need.

## RECOGNIZING THE CHARACTERISTICS OF DYSLEXIA

Dyslexia is rooted in a lack of phonemic awareness, which is the ability to hear and manipulate sounds in words. This shows up for young children in the form of delayed speech and then, later, difficulty pronouncing words and identifying and manipulating phonemes within words. This might manifest as the inability to recite nursery rhymes. As children get older, it shows itself as complications mastering the names and sounds of letters, weak spelling, lack of fluency in reading, guessing at words while reading, or laborious reading that leaves the child exhausted.

All of this can be happening while other areas of the child's development seem to be on track or even above average, especially when it comes to insight, higher-order thinking, imagination, empathy, problem-solving, and strong comprehension of stories read aloud to them. Students who have weak phonemic awareness might have a hard time:

- *Identifying the beginning, middle, or ending sounds of words;*
- *Breaking apart spoken words, such as compound words, into separate words;*
- *Correctly mirroring/repeating uncommon spoken words;*
- *Reading or pronouncing words correctly (even though they might know the definition of words when they're read); or*
- *Hearing and producing rhymes.*



**W**hen I was in junior high, we'd be given a list of about 10 vocabulary words that we would be tested on weekly. We'd have to correctly spell and give the definition of each word. Often, I would know the meaning of the word because there was enough context in the definition for me to get the gist. However, when it came time for me to accurately read and pronounce the word, I was lost.

Part of the weekly assessments was matching, where you'd draw a line from each vocabulary word in the left column to its definition on the right. I remember thinking things like "The word that starts with 'r-a-m' is the one that means 'noisy and out of control.'" Given my weak decoding, I'd stumble to find a definition, but once I did, I'd match it to the r-a-m word, not even knowing that the word I was referring to was rambunctious. These vocabulary assessments were just a tiny part of an entire day filled with what felt like traps and puzzles for me to navigate – all while still trying to look cool and be popular!

## COMMON BEHAVIORS OF CHILDREN WITH DYSLEXIA

**Avoiding work:** As you can imagine, reading assignments were exhausting for me. I spent more time with the book cracked open fake-reading than actually reading. Why? Because reading left me feeling defeated. When you're not taught to decode to mastery and you're left trying to decipher what feels like every single word in the text, it leaves you drained. Reading aloud was like asking me to put my shame on display, something I was not willing to partake in. Lucky for me, I was on the swim team and the chlorine from the pool left me constantly congested. Whenever I'd anticipate being called on to read aloud in class, I'd excuse myself to blow my nose. I kept that up for about eight years through middle school and high school. Students don't need to develop these coping mechanisms, but they have no choice if they aren't getting the help they need.

**Mispronunciation of words:** Just as I had confusion with my last name, I'd stumble over a plethora of other words. "Nail polish" was "pol-nalish," "specific" was "pacific," and for some reason I couldn't keep living room and family room straight, either!

Thankfully, at some point in grade school, I finally got my last name down. It wasn't until decades later, when I started teaching phonemic awareness lessons to my students, that I realized the missing link and how much I benefited from the explicit instruction in phonemic awareness.

**Lack of Rote Memorization:** Troubles with rote memorization can often be associated with dyslexia. It might feel like you quizzed your child on letter names and sounds, or states and capitals, or multiplication facts a million times. Just when you think they have it mastered, they miscue again. For people with dyslexia, sometimes the "easiest" material causes the most trouble. But give a child with dyslexia a chance to engage in meaningful work of higher order thinking skills, and they will shine.

## EFFECTIVE FIRST STEPS TO HELP YOUR CHILD

If any of these scenarios have played out with your child, an effective first step is to have your child take a free dyslexia screener. ([www.readinghorizons.com/dyslexia/dyslexia-resources/dyslexia-test/screener](http://www.readinghorizons.com/dyslexia/dyslexia-resources/dyslexia-test/screener)) This informal

screening does not provide a diagnosis, but it may assist in identifying common indicators in your child. A significant number of positive responses to the screener might indicate the need for further assessment. One thing I particularly like about this screener is that, for each question, it gives you the option to view research explaining why the question is being asked so you can better understand what dyslexia is.

You should also voice your concerns to your child's teacher. They'll give you great insight into your child's reading abilities and keep an eye out for work avoidance and phonemic awareness abilities. Work with the teacher to see how you can utilize their teachings and, most important, incorporate your child's strengths at home and in the classroom. Children with dyslexia have heaps of talents, and often develop advanced reasoning and problem-solving skills.

Parents should be aware, though, that through no fault of their own, many educators are not allowed to use the word "dyslexia" (<https://dyslexia.yale.edu/dyslexia/declaration-of-rights/use-the-word-dyslexia/>) Some also do not have the proper training to identify and support students with dyslexia. Legislation is making progress on this, but not fast enough.

Being your child's advocate will ensure that your child's needs are met. You can start by picking up the books *Overcoming*

*Dyslexia* by Sally Shaywitz and *The Dyslexic Advantage* by Brock Eide, M.D., M.A. and Fernet Eide, M.D. These are the books that made me connect the dots and realize that I don't just have a learning disability – I have dyslexia. Shaywitz's work confirmed what I had noticed in myself through the years. Multi-sensory, phonics-based literacy programs are the most effective way students with dyslexia learn to read. Once I had access to this type of instruction, I was able to fill gaps in my learning that I had been longing for my whole life.

When I found out I had a learning disability, I was filled with shame. I had gone on so long wondering what was "wrong" with me. By educating myself and sharing my story, I've realized that dyslexia doesn't have to be seen as a bad, scary thing – it's just a challenge to work through. It also happens to come with many gifts.

Support your struggling reader by opening the dialogue and providing reassurance and tools. This will allow them to develop the confidence that's essential to hone their skills and work through problems in an effective, positive way. •

### ABOUT THE AUTHOR:

Jillian Rose Perolat Kaster is an implementation coach for Reading Horizons and a former kindergarten teacher of 10 years. She can be reached at [jillian.kaster@readinghorizons.com](mailto:jillian.kaster@readinghorizons.com)

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Exceptional Parent Magazine is proud to announce the launch of [www.ep-magazine.com](http://www.ep-magazine.com) – our all new website which coincides with our expanding role as a leader in the field of special needs publishing and communications.

[www.ep-magazine.com](http://www.ep-magazine.com) now features a bold new design and intuitive site-wide navigation system with improved menu functionality that directs you to the information most relevant to you. It is also fully responsive with mobile devices, making it easy to navigate on a wide range of web browsers and portable devices.

We've introduced a range of new content to the website, including In This Issue that highlights selected content from our latest issue, and

From Our Contributors, which features the most recent offerings from regulars such as Genetic Alliance and the AADMD.

Our eNewsletter is the latest innovation in our digital strategy, enabling you to sign up for updates right on the homepage, and access the articles that matter to you each and every week. We also plan to continue adding more video content and product information to provide you with all of the resources you need to care and plan for your loved one with special needs.

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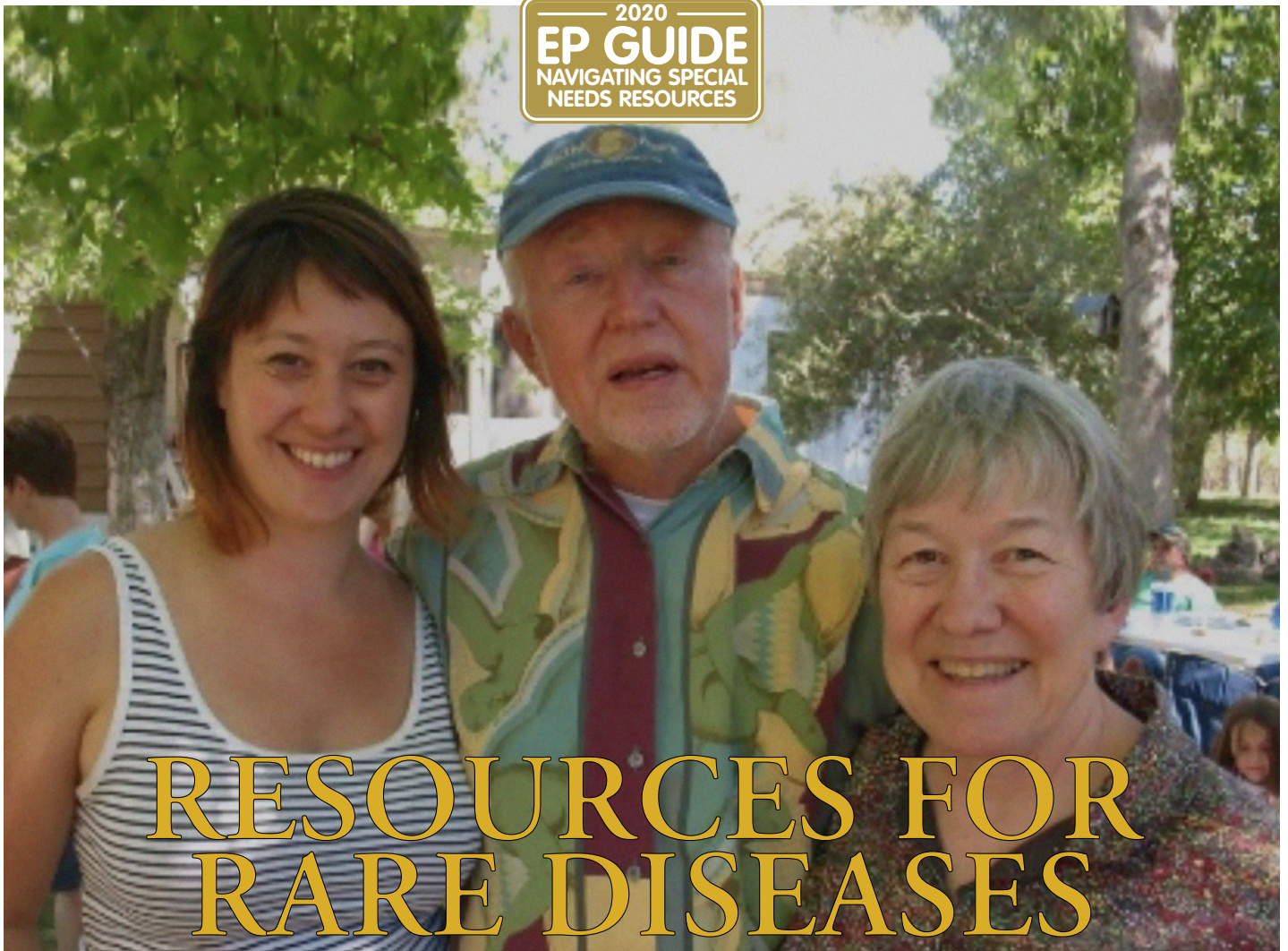
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# RESOURCES FOR RARE DISEASES

BY LINDSEY CUNDIFF

*My name is Lindsey and I am the Associate Director of Patient Engagement at the EveryLife Foundation for Rare Diseases, an organization I joined in August 2016.*

**A**bout three weeks after my official start date, and after several years of the diagnostic journey, my father was diagnosed with a disease called Myasthenia Gravis. Myasthenia Gravis (MG) is a chronic autoimmune neuromuscular rare disease that is characterized by weakness and rapid fatigue of any of the muscles under your voluntary control. It affects roughly 36,000 individuals in the US and is considered a rare disease. **Coincidence? Not so much when you look at the facts of rare disease:**

- *In the US, classification of Rare Disease is a condition that affects fewer than 200,000 people.*
- *This definition was created by Congress in the Orphan Drug Act of 1983 ([www.fda.gov/downloads/ForIndustry/DevelopingProductsforRareDiseases/Conditions/HowtoapplyforOrphanProductDesignation/UCM517741.pdf](http://www.fda.gov/downloads/ForIndustry/DevelopingProductsforRareDiseases/Conditions/HowtoapplyforOrphanProductDesignation/UCM517741.pdf)). Rare diseases became known as orphan diseases because drug companies were not interested in adopting them to develop treatments. The Orphan Drug Act created financial incentives to encourage companies to develop new drugs for rare diseases.*

- *By definition, each rare disease is RARE, but if you pool together, all rare diseases; there are over 7,000. That means 30-35 million Americans are affected by rare disease (that's higher than cancer). That's 1/10 Americans. That doesn't even count the undiagnosed, and the extended network that is affected, like family members and caregivers.*
- *95% of rare disease have no approved FDA treatment.*
- *50% of people with rare disease are children.*

I get it, these stats either pull at your heartstrings because you have a personal connection, so it is relatable – or it flows right through you because it feels like it doesn't affect you. I'm telling you, it does.

If the name of a person living with a rare disease does not immediately come to mind, chances are you have crossed paths with someone in the rare disease community at some point in your lifetime. Or, you can relate to some of the challenges the community faces because you know someone who is living with a chronic illness, or is an individual with a disability.

We all are connected through the complications that life throws at us. It's up to each of us to come up with ways to make these challenges a bit easier for each other. One of the best ways I have found to make my every day a little bit easier is through advocacy. •

## **ABOUT THE AUTHOR:**

Lindsey Cundiff is Associate Director of Patient Engagement, EveryLifeFoundation.org based in Washington, D.C.





**RARE SPIRIT:** (Opposite page) The author with parents Richard and Susan Cundiff, advocates, patient and caregivers for Myasthenia Gravis; (Above, left to right) Tracy VanHoutan, parent advocate for Batten's Disease on Capitol Hill; Becky Abbott, Congressman Butterfield, Aidan Abbott, Thomas Abbott, and little brother Ryder Abbott at the 2019 Caucus Briefing during Rare Disease Week on Capitol Hill; and 2018 Rare Artist Awardee Michaela Oteri.

## RARE FORM : RESOURCES FOR RARE DISEASES



### EVERYLIFE FOUNDATION FOR RARE DISEASES

A patient organization dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science driven public policy. We provide training, education, resources, and opportunities for all members of the rare disease community.

Several of the EveryLife programs are highlighted below.

For a full scope of resources available at EveryLife, please visit:

<https://everylifefoundation.org> Email: [info@everylifefoundation.org](mailto:info@everylifefoundation.org) Phone: 202-697-RARE (7273)



### RARE DISEASE LEGISLATIVE ADVOCATES (RDLA)

Designed to support the advocacy of all rare disease patients and organizations. We provide free resources, tools and events for patients, caregivers and organizations. RDLA is your advocacy partner!

- Action Alerts
- Congressional Scorecards
- Online Advocacy Tools
- One-on-One Policy Consulting
- Monthly Conference Calls/Webinars
- Advocacy Events

<https://rareadvocates.org> Direct Contact: RDLA Director Shannon Von Felden  
Email: [svonfelden@everylifefoundation.org](mailto:svonfelden@everylifefoundation.org)



### RARE DISEASE WEEK ON CAPITOL HILL

Brings rare disease advocates from across the country together to learn about federal legislative issues, meet other advocates and share their unique stories with legislators. FREE events throughout the week offer patients, caregivers and family members the opportunity to engage with the community, join forces and drive change.

- Rare Disease Congressional Caucus Briefing
- Hill Day
- Group Photo on Capitol Hill
- Legislative Conference
- Documentary Screening and Cocktail Reception
- Lobby Day Breakfast
- Young Adults Meet-Up
- Rare Artist Reception
- Rare Disease Day at NIH

*\*RDLA does provide Travel Stipends for advocates who need a little extra financial support (See website for application details).*

<https://rareadvocates.org/rdw> Direct Contact: RDLA Director Shannon Von Felden  
Email: [svonfelden@everylifefoundation.org](mailto:svonfelden@everylifefoundation.org)

## RAREARTIST

### RARE ARTIST

Established to exhibit the unique gifts of individuals affected by rare diseases and to promote the expression of their stories through art. Through its online gallery, the program provides a free, virtual space where "rare artists" can express themselves and submit their work for public viewing. Awardees of the annual Rare Artist Contest are presented with prizes and invited to speak during Rare Disease Week on Capitol Hill. Additionally, their artwork is showcased throughout the year at various patient and industry conferences.

[www.rareartist.org](http://www.rareartist.org)

Direct Contact: Program Curator Lindsey Cundiff  
Email: [lcundiff@everylifefoundation.org](mailto:lcundiff@everylifefoundation.org)



### THE YOUNG ADULT REPRESENTATIVES OF RDLA (YARR)

A group of highly motivated 16-30 year olds from the rare disease community, YARR instills confidence in the next generation of rare disease advocates and provides support in their advocacy journey, especially during their transition from childhood to adulthood. The group hopes to have representation in each state and is always looking for more young adults who are passionate about having an impact on public policy.

<https://everylifefoundation.org/young-adult-representatives>

Direct Contact: Program Curator Lindsey Cundiff  
Email: [lcundiff@everylifefoundation.org](mailto:lcundiff@everylifefoundation.org)

This article seeks to help the parent or caregiver recognize the importance of treatment techniques that emphasize proper auditory and vestibular function, the goals it can help to accomplish, and if it is a method your child's therapist is using.

# TREATMENT TECHNIQUES FOR PROPER AUDITORY AND VESTIBULAR FUNCTION

BY ROBIN ABBOTT, MS, OTR/L

*Almost all speech-language pathologists, physical therapists and occupational therapists (SLPs, PTs and OTs) have graduate degrees, thus it would be easy to assume they are trained uniformly within their disciplines. There is such a diverse field of practice for SLPs, PTs and OTs, that it is impossible for a*

*few years of education to encompass every area of practice. Thus, many daily-use, clinical skills are developed through professional workshops and classes, collectively referred to as "continuing education," in which a practitioner can focus more precisely on a specific client population and their needs.*





**B**ut all continuing education is not created equal. There is no governing body that indicates to therapists which classes might give them the most benefit for their clients; the most “bang for their buck,” as it were. There is one vein of continuing education that is particularly useful among the pediatric population, because it addresses the central systems on which further skills and senses develop. Those central systems are housed in the inner ear; the auditory and vestibular systems. These systems make the inner ear the center of our awareness of ourselves and the world around us.

Commercially-available programs with names like Integrated Listening, the Listening Program, Therapeutic Listening or Bal-avis-x are all predicated on the similar methods regarding rehabilitation of the inner ear. Each of these programs, and others like them, has a slightly different focus. Some concentrate on rehabilitation of the auditory system, some on the vestibular system, some do both. Because of the variety of continuing education available, your child’s therapists may not have been exposed to these treatment methods and the ideas on which they are based. The focus of this article is for you, the parent or caregiver, to be able to recognize the importance of this type of therapy, the goals it can help to accomplish, and if it is a method your child’s therapist is using. You may decide to seek out a professional that uses treatment techniques that emphasize proper auditory and vestibular function.

## The Glue

The simple act of tying one’s shoes involves the requisite skills of attention, visual control, finger isolation, fine motor control, reach and grasp, ability to sequence, an understanding of perspective—and finally, the ability to evaluate success and learn from failure. While an OT may work on all these individual skills through games, drills or crafts, the “glue” that ties them all together—that allows a child to become someone who ties their own shoes—is an awareness of the goal and a plan regarding how to get there. Knowing where one is in space, within the sequence of an activity, and what comes next, is a very complicated cognitive process that depends on the child being able to create a “mental map” of their world. Creating a mental map is done through a cooperation of vestibular and auditory function. The vestibular system senses stillness and movement, giving us knowledge of where we are in a space, and the auditory system gives us an image of the size, shape and content of the space around us. These two informational streams allow our brain and body to plan our actions within the world, much as the GPS in your phone can tell you how to get to a destination and what is nearby. For your GPS to give you the information you seek, you must first tell it where you are and where you want to go. The auditory system informs your brain about where you are, and the vestibular system, in its ability to help predict the consequences of physical action, plans where you want to go. With these pieces of information, the brain and body execute your will.

It’s possible that information from these systems may not be reliable for your child. There are variations from the normal course of development that can affect the accuracy and dependability of these systems. In my practice I see many children with

a history of prematurity, repeated ear infections, and chronic allergies, children with no definitive diagnosis, as well as children diagnosed with ADHD, autism or Down syndrome. How these systems become impaired may be a mystery, but addressing them through appropriate treatment can help skills learned during therapy become more easily integrated into a child’s daily activity.

## Vestibular and Auditory Information Build Capacity to Learn

The vestibular system is composed of specially-shaped, fluid-filled chambers that sense movement and stillness of the body. The information it provides about movement does not depend on information from muscles, joints or vision. The sensations provided by the body and eyes are not as accurate, nor do they allow for as rapid a response in dangerous situations, like tripping and falling, as the vestibular system does.

Imagine we were dependent on only our eyes to sense movement or stillness. That may work, as a lot of our navigation through our world is done visually. However, that wouldn’t give us many opportunities to use our eyes for other purposes.

Imagine we were dependent on only our eyes to sense movement or stillness. That may work, as a lot of our navigation through our world is done visually. However, that wouldn’t give us many opportunities to use our eyes for other purposes.

Because the vestibular system provides independent information about our movement, we can choose to keep our eyes on a single point as we move through space. This is imperative for the newborn, who learns to lock his eyes on an object as he is carried, to learn that the same object can look different based on where he is in the space around it. Because a chair is still a chair from any perspective, it can develop its definition as “that thing people sit

on” no matter the shape it takes in the baby’s vision.

The perceptual anchor provided by the vestibular system also allows a child to send her eyes from place to place at will. This most often occurs in response to a sound within the environment. The ears’ ability to locate a sound within the 360-degree surround of the head is very accurate. But it can become much less accurate if a child does not have an accurate sense of where they are in a given situation. If a child’s vestibular system is not providing a sense location, their brain might be depending on visual information to stay oriented. This limits their ability to move their eyes at will:

As the vestibular system gives a child singular perspective on the world, the ability to understand and direct their attention is primarily developed by the auditory system. For example, the

most rudimentary way in which we locate sounds around us is by using our binaural hearing. When a sound travels to us from our right, the sound waves “hit” our right ear, then our left. Thus, if the sound triggers our attention, we turn to the right to attend to it. In early childhood, this allows for head, neck and trunk muscle development, as well further refinement of sound localization.

The process of accurately locating sound within an environment is complex, but when that process functions well, it allows a child to focus on a speaker’s face; to associate facial expression with emotional content of speech, and view the lips and teeth of the speaker to learn how those sounds were made. In this way, accurate eye movements, as developed through accurate vestibular sense and sound localization, directly impact speech and communication for a young child.

A child’s ability to hear the sound content within speech also directly affects their ability to communicate. The content of speech is much more than the words chosen by the speaker. Although word-choice is an integral part of speech communication, a child most often learns the meaning of words based on *how* they are spoken.

Vocal inflection is just as important as word-choice. For example, you can warn someone about impending danger with any number of phrases, but chances are you will yell or speak strongly to communicate the immediacy of the situation, regardless of the words you use. Conversely, humor and sarcasm are often communicated using the exact same wording as *the lack* of humor and sarcasm; it’s one’s tone of voice that communicates the meaning.

The ability to hear these subtle differences in communication is dependent on the proper function of two muscles in the middle ear, the tensor tympani and the stapedius muscles. The tensor tympani’s role is to protect our hearing from potential damage caused by excessively loud sounds, such as the sound of our own voice when we speak. If the tensor tympani is not engaging when appropriate, a child might over-react to noises, even those tolerable to others. In this situation, they are not able to engage with the auditory world around them, thus missing opportunities to develop speech and communication.

## The Stapedius

The second listening muscle is the stapedius. It allows the ear to focus on certain sounds within the environment; particularly speech. With a minimally functioning stapedius, a child may hear words with accuracy, but a fully-functioning stapedius can hear the subtle differences in vocal inflection that give rise to rich language. For example, when a child is exhibiting a behavior that is not dangerous or strictly off-limits, but is irritating, a parent may say the child’s name sternly. If the child cannot hear the irritation in a parent’s voice, they remain oblivious to the parent’s impending anger. Thus, when the child finally “goes too far,” they are truly surprised by the parent’s anger. That surprise seems unfair to the child, and sometimes a tantrum ensues. The situation is most unfortunate, because given a functional ability to hear vocal intonation, the child may have had two or three opportunities to empathize with their parents, correct their behavior and “get it right.”

The ability to hear what another person is thinking through the tones of their voice is an essential skill for developing both empathy and the idea that other people are separate creatures with separate ideas. If dinner is served and the platter of broccoli is uncovered, hearing a sibling say “oh, great!” allows a child to develop the idea that, although they may not like broccoli, their sister does. Conversely, if sister says, “oh great,” then a child has a chance to understand sarcasm and the idea that dislike of broccoli is something they have in common.

Another cognitive skill developed through our sense of hearing is an awareness of time and sequencing. Listening is an event that takes place over a period of time. For example, if I say the word “pitch,” my mouth produces three distinct sounds. The /p/ sound, /i/ sound, and /tch/ sound each create a separate neural impulse from the ear to the brain. The brain has to take these three distinct impulses and order them correctly to hear the word “pitch,” as opposed to “chip,” before its meaning can be understood. In addition, the brain must also sequence the word into the greater context of the situation or the sentence; “pitch” could mean a sound, or it could mean the act of throwing a ball. The word’s placement in the scenario and within the sentence are sequencing factors the brain must analyze to understand language. When a child learns language, they are also learning the fundamental principles of timing, sequencing, and patterns.

## What to Look For

It may be that your child’s therapist is already using techniques that address these systems. If your child is using specialized headphones and sounds, or music prescribed by his or her therapist, either during treatment sessions or at home on a schedule, it’s very likely they are receiving some form of auditory therapy. You may want to ask what program your child is using and spend some time on the internet researching on your own. You can also ask your child’s therapist what they are listening to and what it is meant to work on, and how you can recognize progress based on specific changes.

For example, when I prescribe an album intended to enhance a child’s eye-movement accuracy, I’d expect behaviors such as more eye contact, longer visual attention to tasks, and a calmer demeanor as a child begins to trust their ability to react to a change in the environment, if they need to. I tell the parents this at the outset, and state that if we haven’t seen some improvement in this vein within two weeks, that I appreciate their feedback to allow me to make changes as necessary.

**When a child exhibits a behavior that is irritating, a parent may say the child’s name sternly. If the child cannot hear the irritation in a parent’s voice, they remain oblivious to the parent’s impending anger.**



Vestibular treatment is also fairly easy to recognize, as it involves some combination of movement and stillness. However, your therapist may have to explain precisely what skills are being addressed, since it so often looks like play (as it should!). During some, if not all, therapy sessions, there should be an opportunity for a child to participate in three types of movement, as their abilities and goals dictate:

1. *Movement the child controls, such as running, sliding, crawling, etc. This allows for the element of fun that a child so often look forward to.*
2. *Movement the child cannot control. Most commonly, this movement is provided in the form of a swing, but it might also be through falling into a crash pad, climbing through Lycra sheets or being pushed on a scooter board. These activities allow a child to develop the ability to*

**By addressing the vestibular and auditory systems as necessary for each child, therapists can help them develop their own "mental maps" for navigation of their world in a way that makes sense to them.**

*predict movement and react to it.*

3. *Stationary activities. This may be as brief as holding still during an obstacle course to complete a fine-motor task, or as long as being seated for a game, based on the child's skills level and goals.*

Having these three activities in each treatment session, in a balance that is appropriate for your child, offers the appropriate opportunities for him or her to develop specific vestibular-dependent skills. It is more than appropriate to ask your child's therapist why a specific activity was chosen and what skill it was chosen to develop.

**B**y addressing the vestibular and auditory systems as necessary for each child, therapists can help them develop their own "mental maps" for navigation of their world in a way that makes sense to them. This is the glue that will hold together the specific skills involved daily life, from speaking, to tying shoes, to reading and writing. •

**ABOUT THE AUTHOR:**

Robin Abbott, MS, OTR/L is an occupational therapist with 12 years' experience working with families and children with autism, ADHD, SPD and Down syndrome. Her practice is a theoretically-based, structured framework of auditory and vestibular activities to promote better sensory integration. She currently works as a Rehab Liaison in Davenport, IA. She can be reached through her website, [www.rabbottwriter.com](http://www.rabbottwriter.com).

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# MILITARY

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# MILITARY LIFE

## UNDERSTANDING CONFIDENTIAL NON-MEDICAL COUNSELING



*You never have to be without support. Military OneSource and Military and Family Life Counseling provide free, short-term, confidential non-medical counseling services for a wide range of issues from marital conflicts and stress management to coping with grief and deployment adjustments.*

Confidential non-medical counseling is effective for finding answers to common emotional and interpersonal difficulties. This overview explains the kinds of issues addressed by confidential non-medical counseling and how you can access it.

### ELIGIBILITY FOR NON-MEDICAL COUNSELING

Confidential non-medical counseling services are free and available to the following groups through Military OneSource and your installation's Military and Family Support Center (<https://installations.militaryonesource.mil>):



**Hear an example of a call center experience.**

00:00



05:28



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- Active-duty service members and their immediate family members
- National Guard and reserve service members (regardless of activation status) and their immediate family members
- Designated Department of Defense expeditionary civilians and their immediate family members
- Survivors

Review the full eligibility guidelines at [www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/military-onesource-confidential-help-eligibility](http://www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/military-onesource-confidential-help-eligibility)

### CHILDREN AND YOUTH SERVICES

Children are eligible to receive confidential non-medical counseling services under the following circumstances:

- Children ages 12 and younger may attend face-to-face sessions through Military OneSource with a parent or guardian, but not on their own.
- Youth, ages 13 through 17, are eligible for individual, face-to-face counseling through Military OneSource, but a parent must attend the first session.
- Children younger than age 18 are eligible for counseling with a child and youth behavioral military and family life counselor with parental consent.
- All military and family life counseling with children occurs within line of sight of another adult.

### Contact Military OneSource 24/7.

You can get personalized help 365 days a year by telephone and online.

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Overseas? See **OCONUS** calling options.

Prefer to live chat? **Start now** 

- Marital problems
- Stress management
- Communication
- Parenting skills
- Decision-making
- Grief and loss

Non-medical counseling services don't address certain issues. If you need help with any of the following issues, contact the Military Crisis Line at 1-800-273-8255 and Press 1 or visit [www.veteranscrisisline.net/ActiveDuty.aspx](http://www.veteranscrisisline.net/ActiveDuty.aspx):

- Active suicidal or homicidal thoughts
- Sexual assault
- Domestic violence
- Mental health conditions such as depression
- Child abuse
- Alcohol and substance abuse

Non-medical counseling isn't suitable for individuals:

- Prescribed psychoactive medication
- Receiving therapy with another practitioner
- Involved in Family Advocacy Program cases
- Undergoing fitness-for-duty evaluations
- Undergoing court-ordered counseling

### ACCESSING FREE COUNSELING SERVICES

Face-to-face confidential non-medical counseling ([www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/free-confidential-face-to-face-non-medical-counseling](http://www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/free-confidential-face-to-face-non-medical-counseling))

may occur in an office setting with a counselor located in the local community or with military and family life counselors on an installation. Military OneSource offers counseling sessions in three other formats:

- Telephone: 800-342-9647
- Secure online chat: [www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/military-onesource-live-chat](http://www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/military-onesource-live-chat)
- Secure video [www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/10-things-you-should-know-about-confidential-video-non-medical-counseling](http://www.militaryonesource.mil/confidential-help/non-medical-counseling/military-onesource/10-things-you-should-know-about-confidential-video-non-medical-counseling)

Service members and their families can request counseling services at any time of the day or night, any day of the year, from anywhere in the world by calling Military OneSource at 800-342-9647. A consultant will assess your needs and give you a referral. You can also access Military OneSource counseling services online.

To speak with a military and family life counselor, contact one of the following:

- Military and Family Support • Unit commander
- National Guard and reserve family programs

Whether it's getting to the next level or juggling responsibilities, we all need help sometimes. Tap into your military network to get the support you need. Confidential non-medical counseling is available to help you manage the stressors of military and family life anytime, anywhere.

– Military One Source

### CONFIDENTIALITY

The non-medical counseling services through Military OneSource and the Military and Family Life Counseling Program are confidential. The Military and Family Life Counseling Program is also anonymous. This means:

- A family member can receive counseling without the service member's knowledge.
- A service member can receive counseling without a family member's knowledge.

Privacy protections ensure your personal information will not be:

- Provided to the military or chain of command
- Shared with family or friends
- Released to other agencies

Exceptions to privacy include:

- Duty to warn
- Suspected family maltreatment (domestic violence, child or elder abuse or neglect)
- Harm to self or others
- Illegal activity

### ISSUES ADDRESSED IN NON-MEDICAL COUNSELING SERVICES

Confidential non-medical counseling addresses issues such as:

- Adjustments (including deployments)

# HOW TO CHOOSE A COUNSELOR OR THERAPIST

*The military knows that everyone needs help at times and offers a variety of support options to service members and their families. In addition to the confidential, free non-medical counseling available through Military OneSource, there are other types of counseling and therapy available through other avenues. Understanding your options is the best way to make sure you choose the right counselor or therapist for your individual needs.*

## WHAT'S THE DIFFERENCE BETWEEN NON-MEDICAL AND MEDICAL COUNSELING?

During a counseling session, you'll work with a trained professional who will talk to you about issues you're concerned with and help you find ways to cope with them. Your sessions can be individual (between just you and your counselor), with another person (such as your spouse) or in a group (perhaps your whole family).

Non-medical counseling, like the free, confidential counseling provided through Military OneSource and the Military and Family Life Counseling program, addresses other issues like:

- Relationship concerns at home or work
- Managing stress
- Adjusting to change or dealing with a transition
- Parenting difficulties
- Dealing with grief or loss
- Returning from deployment

Medical counseling, which is not provided through either Military OneSource or the Military and Family Life Counseling program, specifically addresses medically diagnosable issues such as:

- Drug and alcohol abuse
- Mental illness
- Post-traumatic stress disorder
- Traumatic brain injuries
- Child abuse or neglect
- Domestic violence
- Thoughts of suicide

If you or someone you know is in crisis, contact the Military Crisis Line ([www.veteranscrisisline.net/ActiveDuty.aspx](http://www.veteranscrisisline.net/ActiveDuty.aspx)) at 800-273-8255, then press 1, or access online chat by texting 838255.

## WHAT ARE THE DIFFERENT TYPES OF COUNSELORS?

- **Social workers** are trained to understand how people are affected by their environment, including their family and culture.

- **Marriage and family therapists** are trained to deal with interpersonal relationships, including family and couple conflicts.
- **Mental health counselors** help people cope with a particular concern or difficult life event. Some may specialize in a particular area, such as educational or religious counseling.
- **Psychologists** have a master's or doctorate degree and use different kinds of testing to help identify and resolve problems.



**CHOOSE WISELY:** Everyone needs help at times, and understanding your options is the best way to make sure you choose the right counselor or therapist for your individual needs.

• **Psychiatrists** are licensed medical doctors specially trained to assess, diagnose and treat a patient's mood disorder. They can hospitalize patients and prescribe medication.

• **Certified pastoral counselors** are members of the clergy with specialized training in psychotherapy. All service members have access to pastoral counseling by trained, qualified military chaplains through their commands and installations.

• **Licensed professional counselors** generally have a master's degree in counseling or in a related field and

provide general mental health counseling services.

## WILL MY COUNSELING SESSIONS BE CONFIDENTIAL?

Yes, with a few exceptions. State laws or federal and military regulations may require your counselor to report specific instances, such as:

- Domestic violence
- Child abuse
- Threats of self-harm or harm to others

## HOW CAN I CHOOSE THE BEST COUNSELOR FOR ME?

Choosing a counselor is a personal decision specific to your individual needs and concerns. Military OneSource consultants, available at 800-342-9647, can help you figure out the best option for you. Regardless of which type of counselor or therapist best suits you, it is important that you find the help you need when you need it.



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# MILITARY ONESOURCE'S NEW MILPARENT SPECIALTY CONSULTATION

*If you're getting ready to welcome a new baby or are currently parenting a young child, you may be ready to lean on your support system. Parenting is an adventure – but it's not one to be taken alone. New military parents need back-up from their family, friends, unit and the entire military community.*

That's why Military OneSource has launched the New MilParent specialty consultation, designed with expectant parents and parents of children up to the age of 5 in mind. It's free, individualized, confidential support for new and expecting military parents

The New MilParent specialty consultation is flexible. You can set up a series of video or phone sessions with experts whenever it is most convenient for you. The consultation provides service members and families access to support and resources on a wide variety of parenting topics.

## SUPPORT FOR PARENTING CHALLENGES

We know that new parenting affects every corner of your life, and we can help. From general parenting best-practices to more specific issues like discipline, single parenthood and potty training, we've got tools and solutions.

Feel like you haven't slept in weeks? Talk to a New MilParent specialty consultant. Struggling to find child care when your leave comes to an end? Let us help with your search. Confused about developmental milestones? We can help cut through the information clutter.

Military OneSource can connect you with confidential help to get you the resources you need to tackle your parenting challenges. Get help with:

- *Developing a routine*
- *Solving sleep issues for yourself or your child*
- *Understanding developmental milestones*
- *Finding child care*
- *Managing difficult behaviors*
- *Preparing for pre-school*
- *Mastering potty training*
- *Taking care of yourself so you can take care of baby*
- *Connecting with your partner after baby arrives*
- *Navigating single parenthood*
- *Expanding your parent network*
- *Discovering community resources*



**CHALLENGE ACCEPTED:** We know that new parenting affects every corner of your life. We've got tools and solutions, from general parenting best-practices to more specific issues like discipline, single parenthood and potty training.

The specialty consultation also has lots of information specific to parenting in the military.

- *Find branch and base-specific military programs for children.*
- *Connect with the military parenting community.*
- *Get expert tips for parenting through deployment and preparing young children for separation.*
- *Make the most of specialized information for dual active-duty new parents.*

Consultants have working knowledge of the resources available to assist the unique situations of military families. So, no matter the MilParent challenge you are tackling, you can get help from a highly trained professional.

## WHO IS ELIGIBLE?

Eligible service members and spouses include expectant parents and parents of children up to age 5. Access is available to eligible participants for an unlimited number of sessions. Service members and military families are also eligible for Military OneSource services for a full year after separating from the military.

Call 800-342-9647 or start a live chat to schedule an appointment with a New MilParent consultant. OCONUS/International? [Click here for calling options.](#)

– Military One Source

### Support for Parents

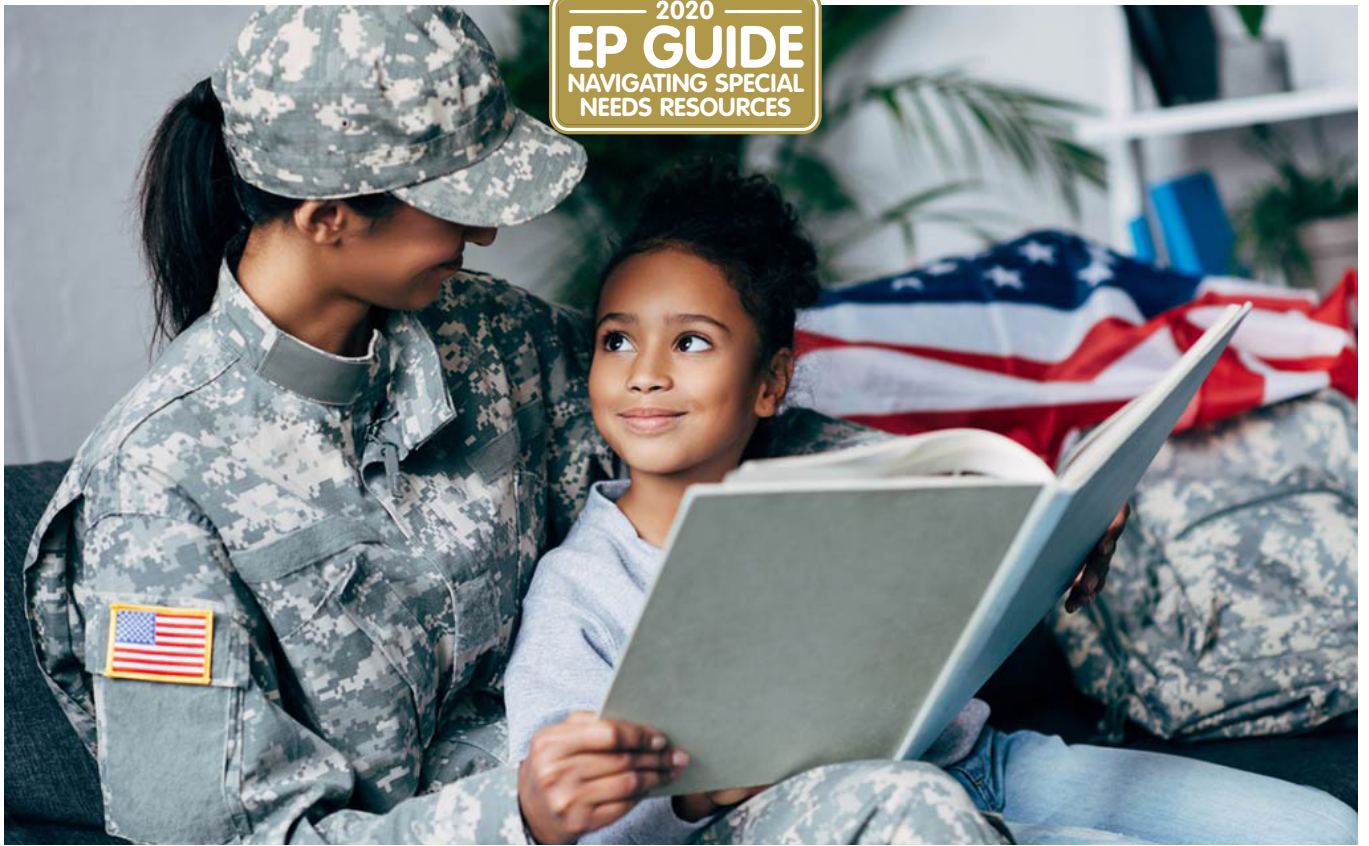
Call Military OneSource 24/7 or start a live chat to schedule your New MilParent session.

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# FOR OUR MILITARY-CONNECTED CHILDREN: RESOURCES IN SUPPORT OF A SMOOTHER TRANSITION TO THE NEW PCS

BY ANGELA SHAW

*The military-connected child's life is often filled with adventures and excursions across the nation, or the globe, that are experienced as a result of being a member of a military-based family. An extremely mobile life may contribute greatly to the child's joyful journeys.*

On the other hand, faced with a unique set of factors that come with the military-family-life package – which may include worry of deployment, frequent moves, and school transitions – the same child may also have to deal with some visible or invisible consequences of war. Military-connected children are often resilient, adaptable, and courageous individuals beyond their years. But they may also face many several hurdles along the way.

Due to frequent moves – a product of military assignments termed “permanent change of station” (PCS), which are essentially temporarily permanent until the next move – the average military child will attend six to nine different school systems in their lives, from kindergarten to the 12th grade, according to the Department of Defense Education Activity (DoDEA). Teachers and parents have learned through experience that common childhood stressors may include anything that requires the child to adjust or change. So, there is greater potential for the military-connected child to experience ongoing stress relating to situations such as those listed below:

- ✓ Spending time away from familiar and trusted sources of comfort and support, such as family, friends, and familiar teachers.
- ✓ Worrying about school or grades.
- ✓ Worrying about parental health and wellbeing.
- ✓ Family stress such as divorce, separation, or parental conflict.



✓ *New situations and changes, such as a new house, new neighborhood, new sibling, new school, new teacher, new parental job, etc.*

The above-mentioned situations play out regularly in the life of the highly mobile, military-connected child. While these children may experience universal transitions in accordance with physical development, cognitive development, and social development that are comparable to peers of the same age, the uniqueness of the military life results in life changes at an intense trajectory than that of their civilian cousins. Honoring the tempo and developmental nuances of childhood is an essential support for our military-connected children.

As guardians of our country, service men and women carry the dual responsibility of caring for their children and protecting our nation's population. As these military parents wind their way through the various stages of relocation, remembering that their children are children first is essential in supporting repeated transition experiences.

Further, although moving is the beginning of a wondrous family adventure, challenges when relocating with a child who has special needs requires extra preparation. Additional work on the front-end can provide a smoother transition for the child with special needs and his/her siblings. Once orders are received for a PCS, consider these three strategies to prepare a smoother relocation launch for your children so that you and your family can better focus on the upcoming experiences and exciting opportunities ahead:

**1. CALL A FAMILY MEETING TO DISCUSS THE MOVE.**

Alert your children about the move, ASAP. Once orders are received, your kids will need time to prepare, adjust to the idea of moving, and say goodbye to their friends – sometimes even extended family, like grandparents and cousins in the area. Be mindful of the ebb and flow of development, which does have some predictable and universal patterns. Consider that each child will go through the predictable stages at their own unique rate of speed. Though a child

may have gone through the transition with ease and grace three years ago, he or she may be at a different stage of development with this move.

Be sensitive to each child's particular needs relative to his or her age and developmental stages, prior to the family meeting. Consider scaffolds of support that address special needs. A child on the autism spectrum may require a social narrative to support understanding about the upcoming move or changes ahead, whereas his or her similar-age sibling may respond to a children's book about a family move. Reaching out to your child's current teacher, school librarian, or school counselor for recommended books or literature about family moves is a great access point for parents seeking resources. Also, consider that siblings depend upon one another. They look to each other as role models, and for stability. If one sibling is a middle or high schooler, he or she may need to be alerted to the move ahead of the others, to provide them ample time for processing at the level that's needed before meeting with the family.

✓ *Before the family meeting, attempt to research the new area and discover some points of interest for each child, relative to what their specific interests are.*

✓ *Together, build in family traditions and common practices when PCS-ing. Buy a souvenir from the region that you will use and reuse in daily routine in your new home, such as a welcome mat displaying the theme or name of your current retail establishment. Have each child pack an "Open First" box. Label it with the words "Open First" and the child's name. Have the child pack things that are important to them that they want to be sure to open first in their new home.*

✓ *Plan to celebrate the favorite things in the area. Take a jaunt to a favored family restaurant or neighborhood park in the area. Invite friends and family over for a lasting memory for an ice cream social, special brunch, ping pong tournament, and so on. Peruse the pictures and videos taken of the current locale and previous*

*PCS's that have been called home for a time. Enjoy gathering pictures, brochures, and simple souvenirs like a printed napkin from a favorite family spot, ticket stubs to a local movie or event, or a flyer or two from interesting places that were enjoyed at the current PCS. Memorialize the treasures within the pages of a family PCS scrapbook or slideshow.*

**2. LISTEN TO YOUR CHILDREN.**

Answer the questions that you can and research those questions that cannot be as easily answered. Be approachable as your children respond with both their positive and negative reactions. Let them know that you hear their concerns and that you also respect those concerns. For teens, this may be even more essential. If feasible, consider a return visit to the neighborhood for a special event or provide an early fieldtrip experience for those that are upcoming and may be missed due to the move. Extend extra patience with your children and yourself, as the process unfolds.

✓ *Involving the children at their appropriate developmental level will help them to transition and to feel a part of the process. Employ the internet for virtual visits to new schools and parks, traverse the streets of the town and neighborhood streets, and research their special interests and history of their new hometown. Teens may be able to navigate online for new homes, fun activities, or touristy activities at the new locale, while younger children can gather 'round the screen to explore interests of their own with their parents, or with their older sibs.*

✓ *Connect with relatives or friends already there. Military families often run into one another downstream, so it is a great idea to stay connected through social media, correspondence, video chats, and phone calls with those you meet on your PCS ventures.*

✓ *Make one of your time-honored PCS traditions a gathering of the minds at regularly-scheduled family PCS meetings, where discussions and short presentations can be shared about newly-discovered information and treasures at the new PCS.*



**PRIME MOVERS:** Although moving is the beginning of a wonderful family adventure, challenges when relocating with a child who has special needs requires extra preparation. Additional work on the front-end can provide a smoother transition for the child with special needs and his/her siblings.

**3. REASSURE YOUR CHILD.** Be mindful of your child's developmental levels to provide the crucial guidance required at a level that they will comprehend. Younger children will ease into the transition with clear and simple explanations while older children may require deeper knowledge about the upcoming where and when. Holding off on making other big changes at the brink of the move, such as moving a toddler from crib to youth bed, or refurnishing your teenager's bedroom, may be a good idea to limit the scope of changes in your child's life. The comfort found in routine and everyday objects may also scaffold the move for your littles and your older children.

✓ Remember that everyone (including yourself and your spouse) transitions and adjusts to changes on their own timelines. In addition to considering your child's age and current stage, be mindful of their personality. Is your child an introvert or an extrovert? Does he or she tend toward pessimism or optimism? Are their interests and passions a natural part of the new location?

✓ Taking care of the present is beneficial to future ventures. Provide extra focus on spending time as a family so everyone continues to feel connected to the family unit. Make favorite meals together. Plan to visit places at the current PCS that you have not gotten to yet. Talk about favorite things and places the family has been to, and the moments that made each of you laugh. By discussing challenges that were surmounted since the family had arrived at the current hometown, this helps remind your child that the present home was once new, and yet they made friends and found happiness. Chat about future ventures in store and help them to see that they will find friends and happiness again in their new home.

In addition to coping strategies before the departure, planning a smooth arrival at the new duty station goes a long way toward settling in and adjusting. Military installations can support parents with the technical realities of the move, to provide the military-connected child a smooth transition to their new home.

Military-focused websites provide a robust assortment of supports to assist with connecting to school liaisons at the new destination. They also provide opportunities to review initiatives and special programs created to support our military-connected children with special needs.

#### **SCHOOL LIAISON PROGRAM**

(SLP) coordinates to assist military parents of school-aged children with the information to succeed in an academic environment. According to the U.S. Department of Defense School Activity (DODEA, 12/01/2019), the goals of this program are to:

- ✓ Identify barriers to academic success and develop solutions.
- ✓ Promote parental involvement and educate local communities and schools regarding the needs of military children.
- ✓ Develop and coordinate partnerships in education.
- ✓ Provide parents with the tools they need to overcome obstacles to education that stem from the military lifestyle.



**SLP RESOURCES**

Look for Liaison Directories that are available within each branch of the military. The DoDEA (12/01/2019) provides an overview of the SLP and a downloadable guide specific to each particular branch at [www.dodea.edu/Partnership/schoolLiaisonOfficers.cfm](http://www.dodea.edu/Partnership/schoolLiaisonOfficers.cfm)



**ARMY**

Each installation has an active School Liaison Officer program. The Army SLO serves active Army service members, National Guard/Army Reserve/Accessions Commands and geographically-dispersed families within a one-hour distance of their installation.



**MARINE CORPS**

School Liaisons (SLs) support transitioning families in obtaining educational information and assistance from local school districts. The role of the USMC SL is noted to be very comprehensive and adapted to the needs of the community at each installation.



**NAVY**

A K-12 support to military families through Child and Youth Education Services at all major Navy installations is being implemented for the families of service men and women.



**AIR FORCE**

Each base has a point-of-contact (POC) for local military child education matters that advocates for the educational needs of military children, assists Airmen and families with information regarding local school districts, home-schooling, private schools, charter schools, and cyber schools.



**COAST GUARD**

Family Resource Specialists (FRS) and/or Child Development Service Specialists (CDSS) are available at each Health, Safety & Work-Life – Regional Practice to assist Coast Guard service members and their families with school-related issues.

A robust system of additional military sponsored initiatives and programs are available in support of military-connected children and their families. For families that include a child with special needs, the supports exist, as they are important. Connections through the channel of the military installation can provide linkage to the systems available, to deal with unique situations faced by military-connected families.

**Military Interstate Children’s Compact Commission (MIC3)** developed in 2006 to ease educational challenges that military children encounter and support uniform treatment as they transfer between public schools in all 50 states, the District of Columbia, and the Department of Defense Education Activity (DODEA) supports navigation between public school education systems from kindergarten through 12th grade, in order to prepare and provide for an array of transitional situations met ([www.mic3.net](http://www.mic3.net)).

**The Exceptional Family Member Program (EFMP)** can support a smoother transition for families who are relocating to a new PCS with a child who has special needs. Coordination with the EFMP provides an organized approach that leads to ensuring appropriate supports available within the new PCS. According to Military OneSource (11/13/2019), EFMP takes on the task of helping families navigate the medical and educational systems in order to ease peace of mind about a family member’s care.

The EFMP Quick Reference Guide (9/2016), available within Military OneSource (11/13/2019), advises that registration with EFMP is mandatory within the Army, Navy, Marines, or Air Force – whether the dependent with special needs is a spouse or a child. In addition to coordinating critical aspects of assignment by EFMP in relation to guidance with specific aspects of the

special education system, the military family is supported in navigating the military medical system through this program. A quick overview of coordination services provided by EFMP includes (Military One Source, 11/13/2019):

- ✓ *Identification and enrollment of family members with special medical or educational needs.*
- ✓ *Discovery of services available at the present or future duty station.*
- ✓ *Support with information, referrals, and non-clinical case management to access services.*

Three avenues of entrance are available for the military family’s quality of life within the home-front that the EFMP will afford (Military One Source, 11/13/2019):

- ✓ *Communicate with local installation’s Military and Family Support Center.*
- ✓ *Obtain paperwork from the EFMP medical point of contact at the local military treatment facility.*
- ✓ *Contact Military OneSource and ask for a referral to a special needs consultant.*

Parents are a vital support to their child; their guidance during relocation can provide a smoother road during relocation. They need to arm themselves with knowledge of systems of support that are provided through military installations, along with vocabulary unique to the lives of military families. Guiding and supporting children during the relocation process, and organizing for the move, requires extensive coordination between home, school, and medical circumstances relative to the unique circumstances of each child.

For children with special needs who have an Individualized Education Plan (IEP), parents provide the expert knowledge and understanding of their child at the transfer meeting that IEP teams rely upon to remain solution-focused. Note that this may require outreach and support from military programs, and initiatives to counter the rigors of raising a family. Connection, therefore, is a critical factor in coordinating a smooth move for the military-connected child.

A COMPILATION OF WEB-BASED RESOURCES IN SUPPORT OF A SMOOTHER TRANSITION TO THE NEW PCS

The following guide provides a comprehensive list of supports to meet the highly- mobile needs of today’s military family; resources with a focus on smoother transitions for the military-connected child. Summaries provided include civilian-based resources that focus on the transitional supports of the military-connected family, as well as military specific resources. Navigation of sites within the summaries below may provide a point of arrival, or may launch a journey toward unexpected discoveries.



**AUTISM CARE TODAY (ACT)**

A national non-profit organization striving to provide necessary services so that each child with autism can reach his or her highest potential. Their mission is to raise awareness and provide financial assistance – to help defray out-of-pocket costs for families who cannot afford the autism treatments and other quality-of-life services their children require. ACT recognizes that military families impacted by autism face extraordinary challenges to include ongoing relocation and lengthy combat deployments. In honor of the heroic service and sacrifice in defense of our nation, ACT has launched The Autism Care Today for Military Families. In addition to resources, there is a blog to support military families who have children on the autism spectrum.

[www.act-today.org/our-funds/autism-care-today-for-military-families](http://www.act-today.org/our-funds/autism-care-today-for-military-families)



**AMERICAN MILITARY FAMILIES AUTISM SUPPORT (AMFAS)**

An award-winning Facebook page, founded in 2008, in support of military families, by military families. Connecting with the community is one essential step in providing smooth transitions. The mission of AMFAS is to provide news, information, community and support to military families that are dealing with autism spectrum disorder.

[www.facebook.com/militaryautism](http://www.facebook.com/militaryautism)



ARMED SERVICES YMCA

**THE ARMED SERVICES YMCA (ASYMCA)**

A military non-profit designed to strengthen our military family providing programs and services to the service men and women of all five branches of the service: Army, Marine Corps, Navy, Air Force, and Coast Guard. The exclusive focus of ASYMCA are the military families, in support of a wide array of programs at a local level, tailored to their specific needs.

[www.facebook.com/militaryautism](http://www.facebook.com/militaryautism)

ASYMCA work in coordination with the Department of Defense and installation commands, in order to identify gaps in programs and services with a focus in three areas:

- **Youth Development** • **Healthy Living** • **Social Responsibility**

Click the “What We Do” tab to discover programs provided through ASYMCA to meet the unique challenges of military life; included are programs such as:

- **Operation Little Learns.** An education program in support of parents as their child’s first teacher, with a focus upon activities created to enhance cognitive, emotional, social, motor and other skills of children ages 2 to 5 years old. The classes provided for parents and children are coordinated to address the stressors of mobility that come with the life of a military family. The goal of the program is to enhance resiliency through connection and establishing a strong foundation for future social and academic success.
- **Operation Hero.** A program geared to supporting military-connected kids, ages 6-12 years, in grades 2nd through 8th, get back on track in school and at home. The no-cost after-school program is accessed through referral by school personnel and/or the child’s parents. The 10-week course provides guidance and navigation relative to management of feelings, friendships, and conflicts in a team atmosphere. The course is facilitated by a trained profession specializing in military youth, who helps guide children through the unique stressors associated with frequent moves, parental deployment, and trauma of war.
- **YMCA/DoD Military Outreach Initiative.** Through partnership of ASYMCA and the Department of Defense (DoD), a nationwide program (offering gym memberships and respite child care services) is provided to promote youth development, healthy living, and social responsibility. Statistics reported relative to the scope and success of the initiative are included under the “What We Do” tab on the site:
  - Military family memberships provided to:
    - ✓ more than 82,000 YMCA memberships
    - ✓ more than 39,000 private fitness memberships
  - More than 157,000 military children have benefited
  - Facilities in support of this initiative:
    - ✓ more than 1,700 YMCA’s
    - ✓ more than 2,300 private fitness facilities





DEPARTMENT OF DEFENSE EDUCATION ACTIVITY

**DEPARTMENT OF DEFENSE EDUCATIONAL ACTIVITY (DODEA)**

Charged with providing high-quality education for military-connected children domestically and overseas. Explore this website that highlights their mission of educating, engaging and empowering military-connected students to succeed in a dynamic world.

[www.dodea.edu](http://www.dodea.edu)

The website provides access to resources and information relating to the basics of school enrollment, school calendars, immunization requirements, transportation, student meals, curriculum and graduation requirements—as well as a variety of other education-based services that may support the highly-mobile life of the military family, such the following:

- **Special education**, which includes early intervention, education and related services, as well as DoDEA overseas-related services through development intervention services.
- **Interstate Compact on Educational Opportunity for Military Children**, which addresses key educational transitions issues encountered by military families of enrollment, placement, attendance, eligibility, and graduation.
- **Communications**, such as parent guides, press releases, and multimedia clips.



MILITARY INTERSTATE CHILDREN'S COMPACT COMMISSION

**MILITARY INTERSTATE CHILDREN'S COMPACT COMMISSION (MIC3)**

Eases the educational challenges that military children encounter, and supports uniform treatment as they transfer between public schools in member states. Visit: [www.mic3.net](http://www.mic3.net) The Compact was developed in 2006 and has been adopted by all 50 states, the District of Columbia, and the Department of Defense Education Activity. The website states, "Through the Interstate Compact, MIC3 addresses key educational transition issues encountered by children of military families." The vision expressed is "Successful Educational Transitions." The values represented by the MIC3 website include:

- **Doing the right thing for children**
- **Resolving issues fairly** • **Respect for all** • **Transparency in all we do**
- **Commitment to make a difference**

In addition to newsletters and articles highlighting the Compact, under the "News & Media" tab, parents can find information relating to their state, and a Guide for Parents and Schools, under the "Parent" tab. A flow chart to support contact with School Liaison Officers (SLO), MIC3 State Commissioner, and MIC3 National Office, is offered under the "Parent" tab. Under the "Resources" tab, State Statutes, Compact rules, including a section on special education services, useful links, and publications can be accessed.



**MILITARYBYOWNER.COM**

MilitaryByOwner.com (MBO) is a "go-to" site for military families in search of housing, as well as those who are selling or renting homes near military bases. The mission of MBO is to provide a comprehensive, low-cost means for military members and their families to advertise their homes for sale or rent, with service encompassing all locations nationwide where military members may be stationed (as well as Guam and Puerto Rico).

[www.militarybyowner.com](http://www.militarybyowner.com)

By clicking the "Resource" tab, MilitaryByOwner delivers a "wealth of information that will help you along your journey," such as:

- **Home buying** • **Home selling** • **Military Life**
- **Renting** • **Property Management** • **Financing**
- **Relocating/Moving** • **Decorating** • **Website Help**

In addition to articles focused on the topics above, such features as a glossary of terms specific to the topic, e-books, and videos can be accessed through the "Resource" tab. Check out the Pre-PCS School Checklist within the Relocating/Moving topic. Discover an array of topics unique to military families through the informative and well-written blogs available on the MBO site. This includes tips to help your child transition to their new school and community, as well as family activities available within the PCS.



**THE MILITARY CHILD EDUCATION COALITION**

Has the following mission: "To ensure inclusive, quality educational opportunities for all military and veteran-connected children affected by mobility, transition, and family separation."

[www.militarychild.org](http://www.militarychild.org)

Within this website, military-connected families can access an array of resources and topics relevant to the military family raising kids. There is a broad range of information available to students, parents, and professionals in education, specific to supports for military-connected children and their highly mobile lifestyle.

- This includes the following tabs and their content:
- **"Programs, Training, & Initiatives."** Navigate and discover a wealth of resources such as, parent support webinars and workshops, student mentoring programs, and professional development opportunities for education professionals serving military-connected families.

- **“Resources.”** Explore a range of digital resources. Engage in media formats presenting topics of changing schools, information about the unique challenges of a highly mobile lifestyle, and transitioning together. Peruse E-News publications to learn solution-focused strategies in support of the mobile lives of the military-connected child.
- **“Shop.”** To provide quality educational opportunities, a link to the Military Child Education Coalition store is available for families, to shop online for a multitude of topics and products pertinent to the military-connected family.



**NATIONAL MILITARY FAMILY ASSOCIATION (NMFA)**

Shares in their mission statement that they are the “go-to” source for Administration Officials, Members of Congress, and key decision-makers for people who want to understand the issues facing military families. NMFA reports that they have “boots on the ground” with families and understand better than anyone that “military families serve too.”

[www.militaryfamily.org](http://www.militaryfamily.org)

In addition to a varying amount of military family specific topics, the tab “Info + Resources” provides a nice overview of the Exceptional Family Member Program (EFMP), which serves the essential function of coordinating the assignment process – to ensure families that include children with special needs are connected to locations that provide access to adequate medical or educational resources. Additionally, a link of the Interstate Compact on Educational Opportunities for Military Children is available within this website. There is also a link to “Kids + Operation Purple” that provides an overview of programs available to military families and kids. Content includes:

- **Operation Purple Camp:** A free week of summer camp where kids can connect with other kids like them.
- **Family Retreats:** Opportunities to spend quality time reconnecting with family after deployment, separation, or during a time of transition.
- **Buddy camp:** An opportunity to share one-on-one bonding and resiliency-strengthening camp for children ages 5-8 and their adult “buddy.”



**MILITARY ONESOURCE**

Shares that their mission is to connect families to their best MilLife. The Department of Defense’s Military OneSource provides trusted information, answers, and support on every aspect of military life 24/7/365 – private non-medical counseling and a range of specialty consultations are available at no cost to active duty, National Guard, reserve members (regardless of activation status), their families, and survivors.

[www.MilitaryOneSource.mil](http://www.MilitaryOneSource.mil) or call 800-342-9647

Military One Source recognizes that moving is part of the adventure and provides practical guidance and support on the multifaceted topic of relocation. Particularly relevant to military families on the move is the category of “Moving and Housing”, which includes topics and tool-kits to support families and their children before, during and after the move across the nation, and across the globe. Military OneSource provides a portal to service-specific news, resources and social media.

**MILITARYSPOUSE**

Military Spouse is a digital magazine. Their masthead states, “Simplify your crazy, wonderful military life.”

[www.militaryspouse.com](http://www.militaryspouse.com)

In addition to the free digital magazine Military Spouse, there is a bounty of information available for the military-connected family under tabs to include areas of:

- Life • Employment • Education
- Deals • Moving • Book Club
- Money & More



**CENTER FOR PARENT INFORMATION AND RESOURCES**

A broad-reaching support for families and professionals. Serving as a central resource of information and products to the community of Parent Training Information (PTI) Centers, as well as the Community Parent Resource Centers (CPRCs), military families can discover a wealth of information, with a range of resources and information with nearly 100 PTIs and CPRCs in the U.S. and Territories.

[www.parentcenterhub.org](http://www.parentcenterhub.org)

Direct services are available for children and youth with disabilities, as well as families, professionals, and other organizations that support them to include a range of activities such as:

- Working with families caring for children and youth with disabilities from birth to 26 years of age.
- Helping parents to effectively participate in their child’s education and development.
- Partnering with professionals and policy makers to improve outcomes for all children with disabilities.

Learn about their “Parent Support” websites, which includes links to:

- Branch Military Parent Technical Assistant Center (MPTAC) – building the capacity of parent centers to provide effective services to military parents of children with disabilities in military families.
- Center for Parent Information and Resources (CPIR) – Funded through the Office of Special Education Programs (OSEP) at the U.S. Department of Education. Supports the Parent Center network and the role that Parent Centers play in educating parents and improving outcomes for children with disabilities.





### TRICARE

The official website of the Defense Health Agency (DHA), a component of the Military Health System. In addition to providing an overview of TRICARE plans, costs, and benefits, guidance about Special Needs is available under the “What’s Covered” tab. There, you can download a fact sheet, Extended Care Health Options (ECHO), which provides services for active duty family members with special needs. Navigate the “Plans & Eligibility” tab to learn about which TRICARE plan fits you and your family’s needs.

[www.tricare.mil](http://www.tricare.mil)



### ZERO TO THREE

Early connections last a lifetime

#### ZERO TO THREE

Provides a wealth of information on a broad range of topics involving early development and well-being, and parenting.

[www.zerotothree.org](http://www.zerotothree.org)

The website provides families and professionals access to an array of information through the specialized lens of the military family—to increase awareness and collaboration throughout the military community, and increase effectiveness in the care of very young children. This can be accessed through: [www.zerotothree.org/our-work/military-family-projects](http://www.zerotothree.org/our-work/military-family-projects).

# BRIDGING THE GAP OF LONG-DISTANCE GRANDPARENTING

Being a grandparent can be pure joy beyond description. The love and connection felt between grandparent and grandchild is a special bond that can have the power to heal hurts and seal family connections. For grandparents who experience the PCS loop, the empty-nest sensation can be shortened. Connection can be cultivated by means of today’s communication technologies.

In addition to the array of family topics that can be found in this article’s resources, discover the digital resources listed below which highlight family portals for this 21st Century’s extended families. Through technology, connections with remote family members are made possible – helping build communication systems and direct links to the hearts of your child’s Poppy and Nana.

**AARP** shares their mission of empowering people to choose how they live as they age. According to the fact sheet within the site, this organization is the nation’s largest nonprofit, nonpartisan organization dedicated to this empowerment. Visit: [www.aarp.org](http://www.aarp.org)

AARP provides a range of information for those aged 50-plus, with a focus on health security, financial stability and personal fulfillment. The website provides helpful grandparent information as well as articles covering such topics as:

- ✓ *Surviving distance during the holidays.*
- ✓ *Embracing changing attitudes and technology*
- ✓ *Joys and challenges*

**GRAND** is an upbeat lifestyle digital magazine platform geared for today’s grandparents. Visit: [www.grandmagazine.com](http://www.grandmagazine.com)

Plugging into the website will deliver a treasure trove of inspirational and solution-focused information that speaks to a balanced life filled with partnership, possibilities, and positive aging. GRAND Magazine provides ideas for fun and celebration, as well as pro-active solutions to challenges that the 21st century lifestyle may present to today’s grandparents. Christine Crosby, editorial director of GRAND Magazine, shares easy/free access to GRAND. The portal offers features for grandparents who seek inspiration and wisdom;

including some of the following content:

- ✓ *Positive aging*
- ✓ *Fun and healthy lifestyles*
- ✓ *Connecting generations*
- ✓ *Livable communities*
- ✓ *All things GRANDparent - grandparent nicknames, grandchildren gifts, long-distance grandparenting, kinship care, grandparents’ rights, etc.*
- ✓ *Alienated grandparents*
- ✓ *Children’s health and development*
- ✓ *Multi-generational travel and reunions*
- ✓ *Family money*
- ✓ *Fun and games to do with grandchildren*
- ✓ *Food and family gatherings*
- ✓ *Fashion*
- ✓ *Inspiration •*

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## ABOUT THE AUTHOR:



Angela Shaw is a special educator who synthesizes her diverse education and experience to collaborate with families and staff, encouraging students in her care to be life-long learners. Her publishing focus is on special education and family topics. Shaw’s son-in-law is an active duty U.S. Coast Guard. Shaw and her husband spend much of their free time adventuring to various PCS locations and enjoying every single possible minute with their son-in-law, daughter, and baby grandson.

# Connection and Understanding

I have a son with autism. I, of all people, would know not to make assumptions about anyone, but here I was, doing it. I knew what I needed to do. I needed to close the gap and reach out to this man.

## I read a story a few days

ago on social media that stuck with me over the weekend. A mom, along with her child with autism, had just experienced trying to maneuver through a busy airport while attempting to console the child. As she described his meltdown due to him feeling overwhelmed, she continuously reverted back to how hard she tried to keep it together and do all the right things to help her child. I couldn't help but feel like I was right there with her since she was so descriptive with his behavior and what she was doing to try and calm him. I could feel her stress and worry because I have been there.

She felt she needed to journal her experience once she had calmed her son on the plane because she realized she couldn't keep her emotions hidden any longer. She broke down crying. She shared a picture of herself with swollen, tear-filled eyes. Seeing her face after reading her honest and vulnerable post hit home even harder. One of her last comments was, "I sit down silently sobbing next to a man on the plane who probably has no idea what the heck is wrong with me."

As I read that line over and over again, I wish I could have teleported myself to that place in time and asked that man to

say something. Anything. He wouldn't have had to say anything poetic. He could have asked a simple question like, "Are you ok?" or "I see that you are crying." It would have been up to her to decide how much information she wanted to disclose, but at least she would not be living in a vacuum, something I've noticed that I have done from time to time. Something that I realized I needed to be more aware of and change.

In the mornings after I drop Broden off at clinic, I drive straight to the gym that is located nearby. I know that if I head home and go later on, I will find 100 reasons why I should not go later on that day. Every morning, I treat my exercise class or time on the treadmill like a meeting. Since I've done a pretty good job with making it to class over the past few months, I've had the pleasure of getting to know some of the regulars and also, unfortunately, taking time to make plenty of assumptions about people while pleasantly living day to day in a vacuum. For example, there are a few people

that always secure a spot in front of a weight class that I take twice a week. They very rarely miss a class and if they do, that area stays vacant almost out of



a sense of respect for the individuals who normally choose that spot.

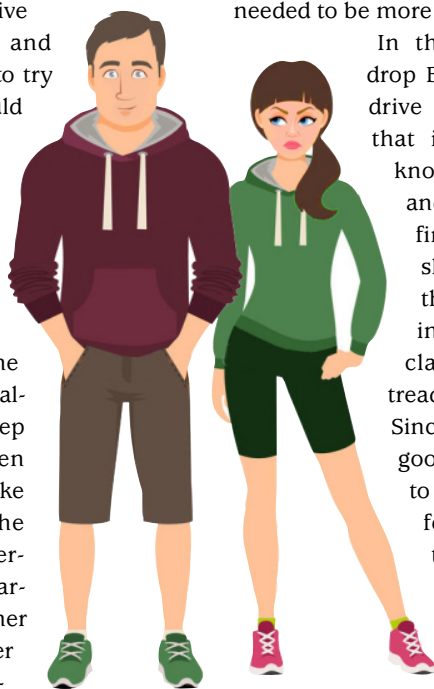
I admit, if I'm having a bad morning and I'm seeking out situations that annoy me, I think to myself, "Oh look at those teacher's pets up there.

They just have to be up front." I tried to be nice to the guy whose workout bench was in the center of the group and I've said hello many times, but he would just walk on by like he didn't see me. I thought that maybe I wasn't cool enough to be acknowledged. Was I not considered a regular yet? How long would it take to establish that title?

One day, I overheard a person in the front row tell someone else to move over for her friend who was running late. As I started to roll my eyes in infinite disgust, I heard her say, "My friend is legally blind and needs to be close to see the instructor. That is why we always hold his spot for him."

Once I heard her comment, my mouth dropped and I felt tremendous guilt and disgust. I can't believe I did the one thing that I complain about with so many people. I knew better than this. I have a son with autism. I, of all people, would know not to make assumptions about anyone, but here I was, doing it. I knew what I needed to do. I needed to close the gap and reach out to this man. Most of all, I needed to clear my conscience.

The next week, I approached him on the stairs after class, "I apologize if I am too direct, but I heard you are legally blind." He looked in my direction and confirmed what I thought to be true. I said, "I'm writing a column and I was going to write about you. I thought you were ignoring me these past few



**BLIND SPOT:** "I tried to be nice to the guy at my exercise class whose workout bench was in the center of the group. I've said hello many times, but he would just walk on by like he didn't see me. I thought that maybe I wasn't cool enough to be acknowledged."



months, but you weren't. You couldn't see me. I'm sorry for misjudging you. To be perfectly honest, I thought you were being a snob."

At the bottom of the stairs he stopped and giggled. We spent about 30 minutes talking about autism, disabilities, and what it was like to be blind. He told me about how much he used to love cutting hair when he could see and how his life changed once he became blind. He has been determined to live a productive life.

As we said goodbye, he asked for my name. Then he looked very close at my face and examined my eyes and the

curve of my face. He then examined my hair. He took a step back and said, "Shelly, when you see me again, call out my name and say who you are. Then I

will know to smile and say hello." Once I told him that I would keep him anonymous when writing about him in my column, he said, "You write in the column that my name is Sam."

The next day, I looked for Sam. I ran over to say hello and yelled out, "It's me! Shelly!" He walked over to me and looked close and

said, "Hello Shelly. I see that you're wearing your hair down today." Even though he is considered legally blind, he had such an eye for detail that others would

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**"The next day, I looked for Sam. I ran over to say hello and yelled out, 'It's me! Shelly!' He walked over to me and looked close and said, 'Hello Shelly. I see that you're wearing your hair down today.' For a man who is legally blind, he took time to see me."**

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deem unnoticeable. For a man who is legally blind, he took time to see me.

I hope there is someone that will cross paths one day with the woman who was silently sobbing on the plane this weekend. Someone who will take time to reach out and connect with her. Everyone has a story and their story is worth sharing. Shared stories lead to shared meaning. Shared meaning leads to feeling more connected in the world. •

#### **PUZZLES & CAMO**

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



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