

Working with Experts and Families with Special Needs Children

by

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Introduction

One size does not fit all when it comes to families, particularly families with minor children. Any doubts about this statement are quickly dissipated with a review of some recent statistics. It is estimated that about one in every fifty-four children has Autism Spectrum Disorder (ASD).¹ The most recent National Survey of Children's Health reveals that almost 10% of children under the age of 18 have had an Attention Deficit Hyperactivity Disorder (ADHD) diagnosis at some point during their childhood.² The World Health Organization estimates that about 34 million children have disabling hearing loss and, by 2050, about one in every ten people will have disabling hearing loss.³ Down Syndrome, the most commonly occurring chromo-

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¹ *Data and Statistics on Autism Spectrum Disorder*, U.S. DEPT. OF HEALTH & HUMAN SERVS., CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/ncbddd/autism/data.html> (last updated Sept. 25, 2020). Autism Spectrum Disorder is a developmental disorder affecting an individual's communication and behavior. As of the publication of the *Diagnostic and Statistical Manual of Mental Disorders (DSM) V* published in 2013, this diagnosis now includes a number of prior diagnoses and labels including Autistic disorder, Asperger's, and pervasive developmental disorder not otherwise specified (PDD-NOS). For more on ASD, see generally *Autism Spectrum Disorder*, <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>, NATIONAL INST. OF MENTAL HEALTH (last updated Mar. 2018).

² *ADHD: Data & Statistics*, U.S. DEPT. OF HEALTH & HUM.SERVS., CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/ncbddd/adhd/data.html> (last updated Sept. 4, 2020).

³ *Deafness and Hearing Loss: Key Facts*, WORLD HEALTH ORG., <https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss> (last updated Mar. 1, 2020).

somal condition, is estimated to occur in approximately one in every seven hundred births.⁴ Approximately one thousand new cases of Cystic Fibrosis, a genetic disease affecting major organs including the lungs, are reported each year, most of which are identified in children two and younger.⁵ More than four hundred babies are born with hemophilia, an inherited bleeding disorder negatively affecting the blood's ability to clot.⁶ These statistics are by no means comprehensive. Hundreds more illnesses and diseases affecting minor children exist, some of which require extraordinary parental and professional support to ensure the child's success.⁷

The Model Rules of Professional Conduct call for the lawyer to provide clients with "competent representation," which is defined as "the legal knowledge, skill, thoroughness and preparation reasonably necessary for the representation."⁸ It is important to note that competence goes beyond simple legal knowledge to include skill, thoroughness, and preparation that is reasonably necessary to represent the client.⁹ The *Bounds of Advocacy* published by the American Academy of Matrimonial Lawyers in 1991 provides "[t]hat knowledge is not limited to legal information . . . custody and visitation cases require knowledge of child development and, at times, understanding of mental and emotional disorders."¹⁰ Families with one or more

⁴ *Down Syndrome Facts*, NATIONAL DOWN SYNDROME SOC'Y, <https://www.ndss.org/about-down-syndrome/down-syndrome-facts/> (last visited Oct. 13, 2020).

⁵ *About Cystic Fibrosis*, Cystic Fibrosis, CYSTIC FIBROSIS FOUNDATION, <https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/> (last visited Oct. 13, 2020).

⁶ *Data & Statistics on Hemophilia*, U.S. DEPT. OF HEALTH & HUMAN SERVS., CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/ncbddd/hemophilia/data.html> (last updated Sept. 14, 2020).

⁷ For a comprehensive overview of the various definitions of *special needs*, see Margaret A. "Peggy" Graham, *The Many Meanings of "Special Needs"*, FAM. ADVOC., Winter 2020 https://www.americanbar.org/groups/family_law/publications/family-advocate/2020/winter/the-many-meanings-special-needs/.

⁸ MODEL RULES OF PROF'L CONDUCT r. 1.1 (2020).

⁹ *Id.*

¹⁰ *Bounds of Advocacy*, AMERICAN ACADEMY OF MATRIMONIAL LAWYERS, § 1.1 (2000), <https://aaml.org/store/viewproduct.aspx?id=12875928>. Adapted and updated in 2018, The Florida Bar Family Law Section, *Bounds of*

children who have a unique medical, educational, or emotional need face additional stressors and challenges often on a daily basis.¹¹ The challenges and complications of daily life can be exacerbated when the family unit experiences a major transition such as divorce, death, or separation.¹² It is, therefore, of paramount importance that a lawyer representing a parent of a special needs or disabled child be familiar with the unique challenges involved in the day-to-day life of that child to help advocate for that client's interests and needs throughout the course of representation.

The world of children with special needs and disabilities are full of special terminology and acronyms which may be new to a family law practitioner. To begin, four key terms used throughout this article should be defined: First, *family law cases* references proceedings involving conflict within a family, such as child custody, child support, support unconnected with divorce,

Advocacy, https://familylawfla.org/wp-content/uploads/2018/05/Fla-Bar-Magazine_5-18_text_final_electronic-version.pdf.

¹¹ See generally *Parenting Children with Special Needs*, Boston University, <https://www.bu.edu/fsao/resources/parenting-children-with-special-needs/> (last visited Oct. 13, 2020) (discussing the challenges frequently faced by raising special needs children and providing help and resources to faculty and staff); Michelle Diamant, *Autism Moms Have Stress Similar to Combat Soldiers*, DISABILITY SCOOP, <https://www.disabilityscoop.com/2009/11/10/autism-moms-stress/6121/> (Nov. 10, 2009) (discussing two studies published in the *Journal of Autism and Developmental Disorders* which reveal that mothers of adolescents and adults on the autism spectrum experience chronic stress comparable to combat soldiers); Vidya Bhushan Gupta, *Comparison of Parenting Stress in Different Developmental Disabilities*, 19 J. DEV. & PHYSICAL DISABILITIES 417 (2007) (comparing levels of stress experienced by parents of children with differing disabilities and special needs).

¹² See generally *The Unfortunate Reality of Divorce in Couples with a Child with Special Needs*, MYCHILD AT CEREBRALPALSY.ORG, <https://www.cerebralpalsy.org/blog/the-unfortunate-reality-of-divorce-in-couples-with-a-child-with-special-needs> (Aug. 9, 2016) (discussing the additional challenges faced by parents of special needs children who divorce); Tina Persels, Shena McAuliffe, & Gina Pola-Money, *When Parents of Children with Disabilities Divorce*, MEDICAL HOME PORTAL, <https://www.medicalhomeportal.org/living-with-child/legal-issues/when-parents-of-children-with-disabilities-divorce>, (last updated Jan. 2019) (discussing special considerations for divorcing or separating parents who have special needs children).

parenting plan or custody agreement, parentage,¹³ temporary custody by extended family members, concurrent custody, dependency, and adoption. Second, *child* refers to a person under the age of 18 and not otherwise emancipated under the law. Third, *special needs child* references a child who has been determined by a qualified expert to require assistance beyond what is required by similarly situated children in education, medical attention, emotional health, or behavior, and, will include a child with a disability. And, finally, *parenting plan* refers to a document that outlines decision making authority¹⁴ over the child and a timesharing schedule¹⁵ identifying with which parent the child is spending time.¹⁶

A family law practitioner representing a parent of a special needs child should take special care to gain a general understanding of the family's unique situation. This may involve asking additional questions during the initial consultation process,¹⁷ reviewing documents that may provide additional insight, and speaking with third party professionals. This article is intended to provide the family law practitioner with a high-level overview of terminology, common professionals who might be involved, and issues that often arise during family law cases involving special needs children or children with disabilities. This is not meant

¹³ Recently, the term "parentage" has been substituted for what has traditionally been termed "paternity." This term is intended to mean a proceeding that determines the legal parents of a minor child.

¹⁴ The term "parental responsibility" may be used throughout this article interchangeably with the term "decision making authority" or "legal custody" to reference a person's rights to make major decisions about a child's health and welfare.

¹⁵ The term "timesharing schedule" may be used interchangeably throughout this article with the term "visitation schedule" or "physical custody" to reference a person's rights to have time with a child and the schedule followed for that time.

¹⁶ A parenting plan may also be known as "custody agreement" or another similar name. The term "parenting plan" will be consistently used throughout this article to reference such document.

¹⁷ For more suggestions on specially tailoring initial consultations for parents of children with special needs, see generally Beth C. Manes & Amanda S. Trigg, *Initial Consults with Clients with Special Needs Children: The Good, The Bad, and The Necessary*, FAM. ADVOC., Winter 2020, at 11, 12, https://www.americanbar.org/groups/family_law/publications/family-advocate/2020/winter/initial-consults-clients-special-needs-children-good-bad-and-necessary/.

to be a comprehensive list or a detailed handbook, but rather a primary starting point to help the practitioner better understand clients as well as identify areas that may require additional research as well as provide resources to help in those efforts.

Part II introduces the family law practitioner to professionals with whom families who have special needs children will work. Part III provides the practitioner with a broad overview of educational considerations for families with special needs children, best practices for drafting parenting plans, and essential documents that the family law practitioner should consider reviewing. Part IV explores caregiver resources comprised of respite care and parenting skills. Part V identifies unique considerations for families with special needs children during the child's transition into adulthood. Part VI lists community resources for further reading and resources for both the family law practitioner and the child's caregivers.

II. Essential Professionals

As much as each child with special needs is unique, so are the professionals and experts with whom the child's family may work. This section is designed to provide a overview of common professionals available to help meet the needs of the special needs child. Depending on the nature of the case, these professionals may simply serve as resources of information for the family law practitioner, or it may become necessary for the practitioner to hire one as an expert witness¹⁸ or as a consultant to educate the judge as to the child's best interest. To begin, the family law practitioner should become familiar with common titles and roles.

A. Educational Professionals

The three primary groups of professionals that families may wish to use to help advocate for their child's academic success

¹⁸ For more on using experts in custody cases involving special needs children, see generally Margaret "Pegi" Price, *The Use of Experts in Custody Cases*, FAM. ADVOC., Winter 2020, https://www.americanbar.org/groups/family_law/publications/family-advocate/2020/winter/the-use-experts-custody-cases/.

are: the educational institution's compliance personnel, educational advocates, and a special education attorney.¹⁹

1. *School and District Coordinators and Compliance Officers*

All educational institutions will have an individual who is responsible to coordinate and monitor compliance with Section 504, Title II of the ADA, and IDEA. For public schools, typically it is a team with personnel at the school district administration level all the way down to each individual school. It is not unusual for the school-level personnel to be holding multiple roles and, therefore, have more of a superficial understanding of the laws than their counterparts higher up in administration. Therefore, if a parent is questioning proper adherence to the laws, the best practice is to work up through the hierarchy to discuss the matter with district-level personnel. Often, this is most easily achieved with help of an educational advocate or special education attorney.

2. *Educational and Family Advocates*

These are trained professionals who can assist families in advocating for the educational rights of a child with special needs under Section 504 and IDEA. In many jurisdictions, no formal certification or training process for these professionals exists, although many have college degrees or higher in special education or related fields.²⁰ Often, they are other parents who have had to advocate for their own children's rights, a former school em-

¹⁹ For more on different types of advocacy, see generally *What Is Advocacy?*, LEARNING DISABILITIES ASS'N OF AM., <https://ldaamerica.org/advocacy/what-is-advocacy/> (last visited Oct. 14, 2020).

²⁰ However, three popular sources for training exist: COPAA offers Special Education Advocacy Training (SEAT) training. See generally *SEAT*, COUNCIL OF PARENT ATT'YS & ADVOC., <https://www.copaa.org/page/SEAT> (last visited Oct. 21, 2020). William & Mary Law School offers the Institute of Special Education Advocacy Summer Conference. See generally *The William & Mary Law Institute of Special Education Advocacy Summer Conference*, WILLIAM & MARY LAW SCHOOL, <https://law.wm.edu/academics/programs/jd/electives/clinics/specialed/isea/index.php> (last visited Oct. 21, 2020). And Wrightslaw offers programs and clinics normally sponsored by non-profit organizations. See generally *Full Schedule of Programs*, WRIGHTSLAW, <https://www.wrightslaw.com/speak/schedule.htm> (last visited Oct. 21, 2020).

ployee, or a related services employee – such as a speech language pathologist – who learned through their own professional experiences and either changed fields or advocates for special needs children as a side business. It is not unusual for a family to find an educational advocate through word-of-mouth referrals from other parents. However, one of the most respected nationwide organizations for educational advocates and special education attorneys is the Council of Parents Attorneys and Advocates (COPAA)²¹ which has a member directory and parent resources to assist in the selection process. Educational advocates can assist families with many aspects of educational advocacy except when it spills into what would be considered the practice of law, such as initiating a legal proceeding on the child's behalf. At that point, a special education attorney's assistance is required.

3. *Special Education Attorneys*

Special education attorneys are licensed attorneys who practice law in state and/or federal courts to advocate for a child's educational rights.²² It is not unusual for an educational advocate to have a professional relationship with a special education attorney. The special education attorney can and will attend IEP (individualized education plan) meetings at a parent's request or can simply provide consultations and advice to parents who prefer to attend meetings on their own or with their educational advocate. The special education attorney can draft and review settlement agreements, initiate legal actions such as due process proceedings, Office of Civil Rights complaints, and state complaints. Families usually use their services when all other efforts to resolve the issues have failed.

B. *Medical Professionals*

When a child has special needs, multiple professionals may be involved with the child's evaluation, treatment, and support. Below is an alphabetical list of common experts that may be in-

²¹ COPAA's website and additional information is available in the Community Resources section below.

²² For more on special education training and advocacy clinics for law students and attorneys, see generally *So You Want to Go to Law School? Special Education Law & Advocacy Clinics*, WRIGHTSLAW, <https://www.wrightslaw.com/lawschool/> (last updated Oct. 23, 2019).

volved with children with which a family law practitioner should be familiar:

1. *Applied Behavior Analysis (ABA) Therapy*:²³ This is therapy based on learning and behavior focused on increasing helpful behaviors and decreasing harmful behaviors or those that negatively affect learning. The child is evaluated by a Board Certified Behavior Analyst® (BCBA®) who then develops a treatment plan and supervises its implementation often by a Board Certified Assistant Behavior Analyst® (BCaBAs®) and Registered Behavioral Technician (RBT).
2. *Board Certified Behavior Analyst® (BCBA®)*:²⁴ This is a graduate-level certification in behavior analysis. Professionals holding this certification are independent practitioners who may provide behavior analysis services. BCBAAs can evaluate a child to develop a behavior treatment plan and supervise its implementation by a Board Certified Assistant Behavior Analyst® (BCaBAs®) and Registered Behavioral Technician (RBT). A professional who has completed doctoral training in behavior analysis may qualify for a Board Certified Behavior Analyst-Doctoral™ (BCBA-D™) designation.
3. *Board Certified Assistant Behavior Analyst® (BCaBA®)*:²⁵ This is an undergraduate-level certification in behavior analysis. These professionals work under the supervision of a professional holding a BCBA® level degree or higher to implement a behavior treatment plan such as ABA therapy.
4. *Clinical Psychologist*: A clinical psychologist may be necessary to provide regular and periodic treatment to a child with special needs or other disabilities. Determine

²³ *Applied Behavior Analysis (ABA)*, AUTISM SPEAKS, <https://www.autismspeaks.org/applied-behavior-analysis-aba-0> (last visited Oct. 13, 2020).

²⁴ *Board Certified Behavior Analyst (BCBA)*, BEHAV. ANALYST CERTIFICATION BOARD, <https://www.bacb.com/bcba/> (last visited Oct. 13, 2020).

²⁵ *Board Certified Assistant Behavior Analyst (BCaBA)*, BEHAV. ANALYST CERTIFICATION BOARD, <https://www.bacb.com/bcaba/> (last visited Oct. 13, 2020).

if the psychologist is a board certified child and adolescent psychologist or if they treat children and adolescents with behavioral disorders and children with disabilities.

5. *Forensic Psychiatrist*: To assess a child's special needs, it may be necessary to have a forensic psychiatrist evaluate the child for diagnosis and/or appropriate treatment of mental disorders. A forensic psychiatrist is a medical doctor with training in psychiatry and a forensic psychiatrist blends the world of mental health with the law.
6. *Occupational Therapist (OT)*:²⁶ Occupational Therapists help people participate in desired activities and life functions through the therapeutic use of everyday activities. Occupational therapy is often used to help persons with disabilities fully participate in educational and social settings and persons with injuries regain lost skills. Occupational therapists can evaluate a person's home and common environments (such as a school or work setting) and make recommendations for adaptive equipment as well as provide training in its use.
7. *Physical Therapist (PT)*:²⁷ Physical Therapists focus on movement to improve their clients' lives through prescribed exercise, education, and hands-on care. Physical therapy can occur in a wide range of environments including hospitals, outpatient clinics, fitness facilities, offices, educational environments, assisted living facilities, schools, and the home.
8. *Registered Behavior Technician® (RBT®)*:²⁸ This is a paraprofessional certification in behavior analysis. These paraprofessionals normally work under the guidance or supervision of a professional holding a BCaBA® designation or higher. Their primary service

²⁶ *About Occupational Therapy: What Is Occupational Therapy?*, AMERICAN OCCUPATIONAL THERAPY ASSOCIATION, <https://www.aota.org/About-Occupational-Therapy.aspx> (last visited Oct. 13, 2020).

²⁷ *Becoming a PT: What Physical Therapists Do*, AM. PHYSICAL THERAPY ASS'N, <https://www.apta.org/your-career/careers-in-physical-therapy/becoming-a-pt> (last visited Oct. 13, 2020).

²⁸ *Registered Behavior Technician (RBT)*, BEHAV. ANALYST, <https://www.bacb.com/rbt/CERTIFICATION BOARD> (last visited Oct. 13, 2020).

is usually to implement a behavior treatment plan such as ABA therapy.

9. *Speech Language Pathologist (SLP)*:²⁹ These professionals evaluate and treat individuals who have special needs or disabilities affecting their abilities in any of the following areas: articulation or comprehension in sounds, comprehension and use of language, literacy, pragmatics (social communication), voice, fluency (stuttering), cognitive communication, and dysphagia (feeding and swallowing). Speech language therapy can occur in a wide range of environments, including hospitals, outpatient clinics, educational environments, rehabilitation centers, assisted living facilities, schools, and the home.
10. *Vision Therapist (VT)*:³⁰ Vision therapy is a drug-free intervention implemented to retrain the learned aspects of visual skills such as tracking. The goal of visual therapy is to alter how the patient processes or interprets visual information to improve visual comfort and efficiency. Vision therapy is not meant to improve visual acuity (the “20/20” aspect to vision which is often achieved through glasses) but rather the visual skills.

III. EDUCATIONAL CONSIDERATIONS

Among the major lessons that the COVID-19 pandemic of 2020 taught was the enormous role that school plays in the physical, financial, academic, and emotional wellbeing of families with children. School does not exist simply to give out grades, but also serves as a center of nutrition, and a source for cultivating essential life skills, trade skills, socialization, and career planning. When a child struggles in school, it can have immediate and massive effects on the entire family and potentially life-long effects for the child. Conversely, securing success in school for a special needs child can represent not just improving the academic, physi-

²⁹ *Who Are Speech-Language Pathologists, and What Do They Do?*, AM. SPEECH-LANGUAGE-HEARING ASS'N, <https://www.asha.org/public/Who-Are-Speech-Language-Pathologists/> (last visited Oct. 14, 2020).

³⁰ *What Is Vision Therapy?*, COLLEGE OF OPTOMETRISTS IN VISION DEV., https://www.covd.org/page/vision_therapy (last visited Oct. 13, 2020).

cal, and emotional health of the child, but also provide a positive financial and emotional impact on the child's family. This section will discuss the primary laws that exist to help promote success in school for a special needs child, a brief overview of advocating for a special needs child in school, and general education considerations when drafting or modifying a parenting plan.³¹

A. Essential Laws

The two primary laws that protect and assist children with special needs and disabilities within educational environments are: Section 504 of the Rehabilitation Act of 1973, as amended (Section 504)³² and the Individuals with Disabilities Education Act (IDEA).³³ A child with a disability may be entitled to accommodations under Section 504, often referred to as a *504 Plan*, or special services and accommodations under an individualized education plan (IEP) or both. All students who qualify to receive an IEP qualify for protections under Section 504; however, not all students who qualify for protections and accommodations under Section 504 qualify to receive an IEP.³⁴ Each will be briefly explained in turn.

³¹ For an overview of educational plans and their implementation in public schools, see generally Andrew M. I. Lee, *Introduction to Educational Plans in Public Schools*, FAM. ADVOC., Winter 2020, https://www.americanbar.org/groups/family_law/publications/family-advocate/2020/winter/introduction-educational-plans-public-schools/.

³² 29 U.S.C. § 794 (2020). Subsection (a) states, in part “No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.” Title II of the Americans with Disabilities Act of 1990, 28 C.F.R. Part 35 (2020), extends the prohibition of discrimination on the basis of disability afforded by Section 504 to all services, activities, and programs by state and local governments, irrespective of if they receive federal financial assistance. *Information and Technical Assistance on the Americans with Disabilities Act*, U.S. DEP'T JUST. CIV. RTS. DIVISION, https://www.ada.gov/ada_title_II.htm (last visited Oct. 13, 2020). For purposes of this Article, only Section 504 will be discussed.

³³ 33 U.S.C. §§ 1400-1482 (2020).

³⁴ For an easy to understand general overview of the difference between Section 504 and the IDEA, see generally *Understanding the Differences: IEP vs. 504 Plan*, OFF. OF THE STUDENT ADVOC., <https://sboe.dc.gov/sites/default/>

1. *Section 504 of the Rehabilitation Act of 1973, as Amended*

Among the first civil rights laws passed in the United States was Section 504 of the Rehabilitation Act of 1973.³⁵ The law, in short, prohibited a program receiving federal funds from discriminating against a *qualified* person based on the person's disability. To be protected by Section 504, the person has to be a *qualified handicapped person* as defined by the applicable federal regulations.³⁶ For purposes of education, Section 504 protects persons with disabilities who are of an age for which preschool, elementary, secondary, or adult education services are provided or required by law and who has "any condition or characteristic" that renders a person as "handicapped" as defined within the regulations.³⁷ The definition of "handicapped" is a "physical or mental impairment which substantially limits one or more major life activities" such as "caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working."³⁸ Section 504 is relevant because public schools receive federal funding. The resulting 504 Plan will outline what accommodations will be implemented to provide access to the child with a disability.³⁹

A simple example of Section 504 in action would be as follows: If a child requires a wheelchair for mobility, Section 504 prohibits a public school from denying the child access to the school or access to transportation to the school due to that disability. Under Section 504, the school must make reasonable accommodations so the child may participate in the school like the non-disabled peers such as providing ramp access into the school or wheelchair-friendly transportation to the school. Section 504 is not as focused on protecting the child's academic progress as it

files/dc/sites/sboe/publication/attachments/Understanding%20the%20Differences%20-%20IEP%20vs%20504%20Plan%20.pdf (last visited Oct. 13, 2020).

³⁵ Kitty Cone, *Short History of the 504 Sit In*, DISABILITY RTS. EDUC. & DEF. FUND, <https://dredf.org/504-sit-in-20th-anniversary/short-history-of-the-504-sit-in/> (last visited Oct. 13, 2020).

³⁶ 45 C.F.R. § 84 (2020).

³⁷ 45 C.F.R. § 84 (l) (2020).

³⁸ 45 C.F.R. § 84 (j) (2020).

³⁹ *Frequently Asked Questions About Section 504 and the Education of Children with Disabilities*, U.S. DEPT. OF EDUC. OFF. OF CIV. RTS., <https://www2.ed.gov/about/offices/list/ocr/504faq.html> (last updated Jan. 1, 2020).

is getting the child access to education in the publicly funded school through accommodations such as ramps, interpreters, preferred seating, and the like. IDEA focuses in on promoting the child's academic success inside the school through a specialized education program tailored to the child's unique educational needs.

2. *Individuals with Disabilities Education Act (IDEA)*

In 1975, Congress passed landmark legislation⁴⁰ titled the Education for All Handicapped Children Act (sometimes called EACHA or EHA, or Public Law (PL) 94-142) which compelled all public schools receiving federal funding to provide “free and appropriate public education” (FAPE), evaluate the children, and create educational plans for the children with their parents’ input that would help emulate as closely as possible the disabled children’s educational experiences to those of their non-disabled peers.⁴¹ EACHA evolved over the years until the Individuals with Disabilities Education Act was re-authorized in 2004 and is now known as IDEA 2004.⁴² Like its predecessor laws and unlike Section 504, IDEA was not created merely to ensure that children with disabilities and special needs are simply accessing the school, the laws seek to ensure that the children are also accessing the *education* and *learning* that are taking place within the school through the creation of an IEP for each qualifying child.

⁴⁰ For a succinct history of the genesis of special education laws, see generally *History: Twenty-Five Years of Progress in Education Children with Disabilities through IDEA*, U.S. OFF. OF SPECIAL EDUC. PROGRAMS, <https://www2.ed.gov/policy/speced/leg/idea/history.pdf> (last visited Oct. 13, 2020).

⁴¹ Pub. L. No. 94-142, 89 Stat. 773 (codified as amended at 20 U.S.C. § 1400 (2004)). The full text of the original statute is available at <https://www.govinfo.gov/content/pkg/STATUTE-89/pdf/STATUTE-89-Pg773.pdf> (last visited Oct. 13, 2020). For a comprehensive history of the statute, see generally Jeffrey J. Zettel & Joseph Ballard, *The Education for All Handicapped Children Act of 1975 PL 94-142: Its History, Origins, and Concepts*, 161 J. EDUC. 5 (Summer 1979).

⁴² 20 U.S.C. § 1400-1482 (2020). For a brief history of special education laws, see generally Pete Wright, *The History of Special Education Law*, WRIGHTSLAW, <https://www.wrightslaw.com/law/art/history.spec.ed.law.htm> (last updated Jan. 6, 2020). The federal regulations governing special education are found at 34 C.F.R. § 300.1-300.818 (2020).

Under the IDEA, public schools that receive federal funding must identify and locate all children from birth through age 21 who have disabilities of any severity and evaluate them to determine if they qualify for special education and related services.⁴³ For children not yet of traditional school age, states will have a program in place often called “Child Find” which a parent or caregiver can call to initiate the evaluation process. For children who are already enrolled in school, the process can be initiated by making the request of the school administration. Once a parent’s consent to evaluate is given, the school has a timeline to follow to complete the evaluation, meet with the parents, and decide if the child qualifies for special education or related services under the IDEA. If the answer from the school is no and the parents disagree, the parents can appeal the determination through a due process hearing before an administrative law judge. If the answer is yes, then an IEP is written with input from the teachers, related services personnel, parents, and school administration (IEP Team). The IEP Team meets annually to discuss the child’s progress and what, if any, changes should be made to the IEP to ensure the child is making “progress appropriate in light of the child’s circumstances.”⁴⁴

To secure federal funding, each state has adopted state statutes and administrative codes which implement the mandates of Section 504, Title II of the ADA, and the IDEA within the state’s public educational system. The state laws cannot contradict the federal laws and must provide qualified children and their parents *at least* the same protections *or better* than what the federal laws afford. If a parent, educational advocate, or special education attorney suspect that the public school or district is not following the mandates of Section 504, Title II of the ADA, IDEA, or their state equivalents, then they can advocate for the child’s rights.

B. *Educational Advocacy*

If a child is experiencing difficulties in school, whether they are behavioral issues or academic, and the parent or a treating

⁴³ Pamela Wright & Pete Wright, *The Child Find Mandate: What Does It Mean to You?*, WRIGHTSLAW, <https://www.wrightslaw.com/info/child.find.mandate.htm> (last updated Jan. 8, 2019).

⁴⁴ *Andrew F. v. Douglas Cnty. Sch. Dist.* Re-1, 137 S. Ct. 988 (2017).

professional suspects those issues may be caused by a special need or disability, a parent has the right to request that the school evaluate the child to determine eligibility for supports and services under the IDEA.⁴⁵ Normally a precursor to initiating the evaluation process is implementing less robust support systems called Response to Intervention,⁴⁶ however, that can be implemented simultaneously with the evaluation process. The evaluations can include, but are not limited to: psychoeducational evaluation,⁴⁷ Functional Behavioral Analysis (FBA),⁴⁸ occupational therapy evaluations, vision evaluation, physical therapy evaluation, assistive technology evaluation,⁴⁹ psychological evaluation, speech language evaluation, cognitive/intelligence evaluation, verbal intelligence evaluation, nonverbal intelligence evaluation, auditory evaluation, motor skills evaluation, and more. It is not uncommon for a parent to obtain a private evaluation and present it to the school for use in determining the child's eligibility for exceptional student education (ESE) services⁵⁰; however, under special education laws, the school is required to provide the evaluation free of charge to the family *and* the school is not required to accept the private evaluation results

⁴⁵ 20 U.S.C. §§ 1400-1482 (2020).

⁴⁶ Response to intervention is normally referred to by its acronym RTI.

⁴⁷ Chad C. Nelson, *A Parent's Guide to Psychoeducational Evaluations*, AM. FOREIGN SERV. ASS'N, <https://www.afsa.org/parents-guide-psychoeducational-evaluations> (last visited Oct. 19, 2020).

⁴⁸ *What Is a Functional Behavioral Assessment and How Is It Used? An Overview for Parents*, PACER CTR., <https://www.pacer.org/parent/php/php-c215a.pdf> (last visited Oct. 19, 2020). Once completed, the FBA may result in the drafting of a Personal Behavior Improvement Plan (PBIP) which identifies supports to implement to promote a child's success in the learning environment. PBIPs seek to implement *replacement* behaviors that are constructive within the academic, home, and/or community environment(s).

⁴⁹ Assistive technology is defined as "any item, piece of equipment, or product system, whether required commercially off of the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability." 20 U.S.C. § 1401 (1)(a) (2020). For more on assistive technology devices and services, see generally *Assistive Technology*, WRIGHTSLAW <https://www.wrightslaw.com/info/atech.index.htm> (last updated Aug. 21, 2017).

⁵⁰ Many people consider ESE (also known as special education) services to be for disabilities only; however, gifted programs are considered part of ESE services. 20 U.S.C. § 1481 (d)(3)(J); *see also* 25 C.F.R. § 39.115 (2020) (explaining the identification and qualification of gifted and talented students).

as valid, although sometimes they do “validate” the results to use as their own.

Sometimes simply initiating the evaluation process requires a significant amount of advocacy by the parent, educational advocate, or special education attorney. Other times the school or district will be the one advocating to have the child evaluated and receive special education and related services. Regardless, one thing is certain – parents are an integral part of the process and, under federal and state laws, considered key members of the “team” that assembles to determine what, if any, services and supports the child’s needs to succeed in school. A parent⁵¹ must receive prior notice of all meetings, must provide consent for the school to evaluate the child, and can provide input throughout the evaluation, drafting, and IEP revision process.

If the mandates of Section 504, Title II of the ADA, the IDEA, or their corresponding state rules are not being followed, the parent or school district⁵² may initiate administrative proceedings in state court called *due process proceedings*, a parent may file a complaint with the U.S. Department of Education Office of Civil Rights (OCR),⁵³ or a case may be initiated in federal court. Which of these paths is most appropriate will depend on the facts and circumstances of the situation. If a client is reporting issues with their special needs child in school, a family law practitioner’s best practice is to refer the client to consult with an

⁵¹ Under federal laws, only one parent’s consent is required for the child to be evaluated for ESE services. See 34 C.F.R. § 300.300 (2020) (referencing only “parental consent” and “the parent” when discussing parental consent for an initial evaluation under the IDEA). This conflicts with the shared decision-making presumptions or requirements under family laws in many states. See e.g. FLA. STAT. § 61.13(2)(c)(2) (providing for a presumption in favor of shared parental responsibility); FLA. STAT. § 61.046 (17) (defining shared parental responsibility as a relationship “in which both parents retain full parental rights and responsibilities with respect to their child and in which both parents confer with each other so that major decisions affecting the welfare of the child will be determined jointly).

⁵² The school district is required to initiate a due process proceeding in some instances. Details of the process are beyond the scope of this article.

⁵³ The U.S. Department of Education has an Office of Civil Rights whose mission is “to ensure equal access to education and to promote educational excellence through vigorous enforcement of civil rights in our nation’s schools. *Office of Civil Rights*, U.S. DEPT. OF EDUC., <https://www2.ed.gov/about/offices/list/ocr/index.html> (last updated June 29, 2020).

educational advocate or a special education attorney to understand what options exist to help the child succeed.

C. *Best Practices and Parenting Plan Considerations*⁵⁴

Parents are often unaware of the existence of educational advocates and special education attorneys. In the courtroom setting, it is not uncommon for judges to rotate between the civil, criminal, dependency, domestic violence, probate, and family divisions. As a result, some judges in the family division may also be unaware of the existence of these important educational professionals who can assist children and families that appear before them. It is also not unusual for parents to not fully understand their and their child's rights under Sections 504 or the IDEA and to follow statements or guidance from ineffectively informed school-level personnel. So, a best practice for family law practitioners is to encourage their clients to consult with a special education attorney or educational advocate to help the parents make informed decisions about how to meet their child's educational needs and ensure their progress.

Often government-funded scholarships are available to pay for private school tuition and related services, normally as an alternative to the child attending public schools.⁵⁵ Parents should be aware of circumstances where the scholarship amounts can be adjusted, and the best practice is to consult with an experienced educational advocate or special education attorney before submitting a scholarship application. Also, parents should be mindful of application deadlines because some scholarships can become depleted.

⁵⁴ For additional suggestions on best practices for drafting parenting plans for families with special needs children, see generally Lynne C. Halem, *Creating Parenting Plans for Families with Children with Special Needs*, Winter 2020, https://www.americanbar.org/groups/family_law/publications/family-advocate/2020/winter/creating-parenting-plans-families-children-special-needs/.

⁵⁵ In Florida, the two biggest ones are the McKay Scholarship and the Gardiner (also known as Step Up for Students) Scholarship. Information can be found at: *McKay Scholarship*, FLORIDA DEPT. OF EDUC., <http://www.fl DOE.org/schools/school-choice/k-12-scholarship-programs/mckay/> (last visited Oct. 14, 2020); *Gardiner Scholarship*, STEP UP FOR STUDENTS, <https://www.stepupforstudents.org/for-parents/special-needs/how-the-scholarship-works/> (last visited Oct. 14, 2020).

School grades and standardized test scores are often a poor indicator of potential success for a child with special needs or disabilities, so parenting plans favoring the parent “whose address is in a school with the highest ranking in academic grading, i.e. ‘A’ versus ‘D’” are likely not in the child’s best interest. A better practice when discussing educational concerns while drafting or modifying a parenting plan is to discuss the following topics with the client:

1. What schools in the area receive the best and worst reviews and parent feedback on resources and attitudes about special needs children like your child?⁵⁶
2. Have there been any recent OCR resolutions for any of the local schools or school districts that may affect children with special needs or disabilities like your child?⁵⁷
3. What types of related services (OT, SLP, PT, VT, FBA, PBIP, ABA Therapy, etc.) does your child need or do you *think* your child needs to succeed at school? Does the school actively advertise having those services? What does the school counselor say when you ask him/her about them? What of these services can be obtained through a well-written IEP at the public school versus paying out of pocket at a private school or through insurance?
4. What steps does the school take to promote understanding and inclusion for special needs children? Does the school celebrate one or more disability-awareness days? How frequently do the school staff receive training on disability rights and disability awareness?
5. How many ESE and related services personnel are posted as staff on the school’s website?
6. Federal laws do not require the consent of both parents to initiate evaluations under IDEA.⁵⁸ How do you propose handling it if you and the other parent disa-

⁵⁶ This can often be answered by on-line searches.

⁵⁷ Case resolutions can be found at: *Reading Room*, U.S. DEPT. OF EDUC. OFF. FOR CIV. RTS., <https://www2.ed.gov/about/offices/list/ocr/frontpage/faq/readingroom.html> (last updated Aug. 28, 2020).

⁵⁸ See 34 C.F.R. § 300.300 (2020) (referencing only “parental consent” and “the parent” when discussing parental consent for an initial evaluation under the IDEA).

- gree about whether an evaluation should be done or disagree with the outcome of an evaluation?
7. Are you and your spouse able to attend IEP meetings together? Why or why not? If not, how do you propose the scheduling of IEP team meetings given that federal laws consider both parents part of the IEP team?
 8. Are there government-funded scholarships available to pay for private school tuition or disability-related expenses? Are those monies available regardless if the child attends public or private schools? How should the parents address use of the scholarship funds?
 9. Are there any local educational advocates or special education attorneys with whom one or both parents should consult to discuss experiences at the local schools for children with special needs or disabilities similar to your child?
 10. What transportation services are needed for the child to attend the school? What practical considerations are needed to ensure the transportation services can be provided to and from both homes?
 11. What before and after-care programs are offered at the school? How special-needs friendly are the programs? What steps do the programs take to promote understanding and inclusion for special needs children? How frequently are the program personnel trained on disability rights and disability awareness?
 12. For older students, what kinds of vocational training, life skills training, and transition services are offered at the school? Are there any other schools in the area where transportation is provided?

D. *Essential Documents*

A family law practitioner representing a parent of a special needs child or child with disabilities should take special care to gain a general understanding of the family's unique situation. This may involve asking additional questions during the initial

consultation process,⁵⁹ reviewing documents that may provide additional insight, and speaking with third party professionals.

1. Psychoeducational evaluations
2. Psychological evaluations
3. Speech language evaluations
4. Occupational therapy evaluations
5. ABA session notes and behavioral charts
6. FBA evaluations and PBIPs
7. School grades, counselor notes, quizzes, tests, and examinations
8. Copies of all IEPs and 504 plans
9. Medical progress notes
10. Medical treatment records
11. Special needs trusts
12. ABLE account statements
13. Applications for government benefits
14. Social security applications and related documents
15. Records pertaining to any Medicaid waiver support coordinator
16. Letters of intent or letter of instruction from a child's caretaker to future caretakers of the child
17. Estate planning documents
18. Advanced directives
19. Life insurance policies and beneficiary designations

IV. Caregiver Resources

A. Respite Care

At first glance, when one thinks of respite care, someone who needs assistance because they are engaged in the care of an elder may come to mind. However, an estimated 2.8 million families, or 1.3% of families in the United States, reported raising

⁵⁹ For more suggestions on specially tailoring initial consultations for parents of children with special needs, see generally, Beth C. Manes & Amanda S. Trigg, *Initial Consults with Clients with Special Needs Children: The Good, The Bad, and The Necessary*, FAM. ADVOC., Winter 2020, at 11, 12, https://www.americanbar.org/groups/family_law/publications/family-advocate/2020/winter/initial-consults-clients-special-needs-children-good-bad-and-necessary/.

two or more children with a disability.⁶⁰ Likewise, the National Alliance for Caregiving estimates that 29% of the adult U.S. population (65.7 million) served as family caregivers for an ill or disabled relative.⁶¹ It is important to care for a child with disabilities, but it is equally important that the loved one who serves as the primary caretaker get a break, both physically and mentally. Caretakers have numerous options for levels of respite care. For example, respite care can be for a number of hours, days, or weeks dependent on the need. The family may opt for in-home care, a day care facility, or a temporary residential care facility. Forms of respite care include meal preparation, running errands, bathing, dressing, and medication management.

B. Parenting Skills

“Parenting” skills is truly a misnomer because raising a child is broader than just the parents and the practitioner should not ignore or minimize that many other family and non-family members also serve the role of a traditional “*parent*” in many families. For example, stepparents, grandparents, siblings, aunts and uncles, and significant others or partners also fill this role. Whoever serves the role of caretaker for a child with special needs would be best served to draft a letter of intent outlining important day-to-day living needs of the child. The client should resist the temptation to be the only parent with all (or most) of the valuable information regarding the proper care of the special needs child. Instead, insist that the other parent be equally informed and further arrange for other back-up emergency caretakers who are equally informed. Doing so will insure protection for the child in the primary caretaker’s absence. Consider including the following in a letter of intent or letter of instruction to a future caretaker⁶²:

⁶⁰ *M&L Special Needs Planning*, citing “Disability and American Families: US Census Bureau Report,” <https://specialneedsplanning.net/statistics/> (last visited Oct. 31, 2020).

⁶¹ *Who Are Family Caregivers?*, AM. PSYCHOL. ASS’N, www.apa.org/pi/about/publications/caregivers/faq/statistics (last visited Oct. 31, 2020) (reporting data from the National Alliance for Caregiving).

⁶² For more ideas and information on letters of intent or letters of instruction to future caretakers, see Jerry S. D’Aniello & A. Nichole Cipriani, *The Divorce Case Involving Children with Special Needs*, 32 N.J. FAM. LAW. 57

1. Detail all prescription medications and over the counter medications
2. Medical history
3. Certified copy of birth certificate
4. Physician contact information
5. Tests or evaluations performed
6. Test results
7. Location of vital records
8. Detail of all medical devices utilized
9. Therapists' contact information
10. Counselors' contact information
11. Educational history and needs
12. Copies of any IEPs and dates for follow-up IEPs
13. Camps history
14. Detail of all government benefits received
15. Bed-time rituals
16. Family contact information
17. Favorite activities
18. Detail any sources of income, assets, special needs trusts
19. Goals for the child
20. Calendar of follow up due dates

Support, education, and resources are a powerful combination to assist parents and caretakers in improving their parenting skills when caring for a special needs child or child with disabilities. The ultimate goal of a parent should be to see their child reach their full potential. Improving or sharpening parenting skills will help achieve this goal. The client should consider implementing the following, in no particular order of importance:

1. Read one or more parenting books with particular focus on special needs children.
2. Consult blogs as an excellent means of information and insight to learn about successes and failures of other families in a similar situation.
3. Learn about alternative forms of education.
4. Closely monitor homework and schoolwork.

(Sept. 2011), <https://norrismclaughlin.com/pdf/JSD%20and%20ANC%20-%20Special%20Needs%20article%202011.pdf>.

5. Be prepared to fully participate in the child's treatment plans.
6. Locate local community-based organizations such as *Best Buddies International*⁶³ which match individuals with disabilities with typical peers in a social setting.
7. Learn about safety, both inside the home and out in the real world, including water safety and drowning awareness and prevention.
8. Provide effective supervision of the child.
9. Be prepared to implement consistency, structure, and routine in the child's schedule.
10. Acquire the ability to consult with professionals to perform the appropriate and necessary assessments, evaluations, and treatment for the child.
11. Comply with administration of prescribed medications.
12. Acquire the ability to apply for available educational scholarships and grants.
13. Attend parenting and co-parenting skills classes.
14. Research employment resources for when the time comes for the child to reach adulthood.
15. Consider the unique needs of the child and how to meet them with the transportation to facilitate timesharing.⁶⁴

In light of the importance of acquiring and improving parenting skills, it is important for parents to share resources and information with each other and with other caretakers involved in the day-to-day responsibilities of caring for a special needs child. It should come as no surprise in this age of remote technology that numerous applications or “apps” exist which offer a variety of

⁶³ *Mission*, BEST BUDDIES INT'L, <https://www.bestbuddies.org/what-we-do/mission-vision-goals/> (last visited Oct. 31, 2020), is a nonprofit 501(c)(3) organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment, leadership development, and inclusive living for individuals with intellectual and developmental disabilities.

⁶⁴ Certain forms of transportation, such as air travel, present unique challenges for special needs children. To read more on the challenges that air travel presents for persons with intellectual and developmental disabilities, see generally *Making the Skies Friendlier for Everyone*, THE ARC, <https://thearc.org/our-initiatives/travel/> (last visited Oct. 20, 2020).

different means to improve communication between parents. Here are some suggested apps to consider:

Co-Parenting App	Website
2Houses	2houses.com
AppClose	Appclose.com
Coparently	Coparently.com
Coparenter	Coparenter.com
Cozi	Cozi.com
Divorceify	Divorceify.com
Fayr	Fayr.com/
Google Docs, Drive, & Calendar ⁶⁵	Google.com
Mend	Letsmend.com
Our Family Wizard	Ourfamilywizard.com
SupportPay	Supportpay.com
Talking Parents	Talkingparents.com

V. Adulthood

Under most laws, a person is considered to have reached adulthood and legal independence upon reaching their eighteenth birthday. However, persons with special needs and disabilities may require additional support and have resources available to them to meet all their needs.⁶⁶ This section will talk about training, employment, guardianship, and financial considerations to assist the child as the child transitions into adulthood.

A. Training and Employment

As a child with disabilities sees adulthood on the horizon, parents are encouraged not to hesitate and to seek out information in their local community for organizations and businesses

⁶⁵ Google is not a co-parenting *app*; however, families can use shared Google calendars and documents as a central location to communicate with each other.

⁶⁶ For more on the considerations for a special needs child transitioning to adulthood, see generally Sheila O. Zakre, *My Child Is an Adult – Now What? Guardianship, Powers of Attorney, and Other Options*, FAM. ADVOC., Winter 2020, https://www.americanbar.org/groups/family_law/publications/family-advocate/2020/winter/my-child-an-adultnow-what-guardianship-powers-attorney-and-other-options/.

that help educate, train, and employ persons with disabilities. Many organizations provide quality programs which exist with these goals in mind. For example, the Massachusetts Department of Career Services provides an excellent template to consider when the family is ready to explore employment opportunities for the adult child.⁶⁷ Also, the Job Accommodation Network (JAN) is a leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues.⁶⁸ Some of the areas in which the child may benefit from assistance include:

1. How to prepare a resume
2. How to interview
3. Recruiting
4. Job and skills training
5. Professional training
6. Career development

Another source for career development and employment opportunities include vocational schools as well as higher education institutions such as colleges and universities which offer training and positions for special needs children on the spectrum. As an example, *The College Program for Students with Autism Spectrum Disorder* at Marshall University in West Virginia offers “academic, social and independent living skills support to individuals with autism spectrum disorders, so that they may have a successful college experience and learn skills necessary to enter a competitive workforce.”⁶⁹ The family can research local colleges and universities for similar comprehensive programs.⁷⁰

⁶⁷ See generally *MassHire Department of Career Services Helping Workers with Disabilities Find Employment*, MASS.GOV, <https://www.mass.gov/service-details/helping-workers-with-disabilities-find-employment> (last visited Oct. 20, 2020).

⁶⁸ Homepage, JOB ACCOMMODATION NETWORK (JAN), <https://askjan.org/> (last visited Oct. 20, 2020).

⁶⁹ For more on the program and links to additional resources, see generally *The College Program for Students with Autism Spectrum Disorder Sponsored by the West Virginia Autism Training Center at Marshall University*, <http://mucollegesupport.blogspot.com/> (Jan. 8, 2014); *WV Autism Training Center*, <https://www.marshall.edu/atc/> (last visited Oct. 20, 2020).

⁷⁰ For further information about colleges and universities that are specially tailored for students with learning differences, see MARYBETH KRAVETS

B. *Guardianship and Guardian Advocates*

Guardianships: A legal guardian is a surrogate decision-maker appointed by the court to make either personal and/or financial decisions for a minor or for an adult with mental or physical disabilities. A guardian may be appointed for the person, property, or both of the ward. The scope of the guardianship may be limited or plenary. In an adult guardianship, the court may determine whether a person is totally or partially incapacitated. If found to be incapacitated in any respect, the court recommends that a guardian be appointed as a guardian to perform only those rights that the ward is incapable of exercising or a plenary guardian to perform all rights. Typical legal rights reviewed by the court include the right to marry, vote, maintain employment, apply for government benefits, choose a residence and social environment, maintain a driver's license, and enter into contracts, among others.

Guardian Advocate: Depending on the laws in the particular jurisdiction, a guardian advocate⁷¹ may be appointed by court order to assist and enable an adult with developmental disabilities (i.e., retardation, spina bifida, cerebral palsy, autism, Prader-Willi syndrome) to be as independent as possible. The Florida statute, for instance, is limited to these five developmental disabilities. This type of proceeding does not remove any rights from the adult who continues to retain their legal rights, but, instead, permits the guardian advocate to have authority to make decisions for the adult child. Unlike a guardianship proceeding discussed above, the adult child is not adjudicated incapacitated. The adult child merely “lacks the decision making ability to do some, *but not all*, of the decision making tasks necessary to care for his or her person or property.”⁷²

In the case of separated or divorced parents, the parents should discuss and agree whether one or both parents will be appointed as either guardian, co-guardians, guardian advocate, or

& IMY F. WAX, *K&W GUIDE TO COLLEGES FOR STUDENTS WITH LEARNING DIFFERENCES*, 14th Edition: 338 Schools with Programs or Services for Students with ADHD, ASD, or Learning Differences (College Admissions Guides) (2019).

⁷¹ FLA. STAT. ch. 393.

⁷² FLA. STAT. § 393.12(2)(a).

co-guardian advocates prior to the child turning eighteen years of age. If a parental conflict arises relating to the appointment of either parent to act on behalf of the adult child, and a need for a guardianship or guardian advocate arises, the family law practitioner should consider discussing whether a petition should be filed to be able to properly care for the adult child and avoid the need for appointment on an emergency basis.

C. *Financial Consideration*

It is important to better understand the healthcare system and available benefits and resources to meet the family's needs. Consider an evaluation by a legal nurse consultant to assist the parent or family caretaker in accomplishing long-term goals. Doing so may provide great comfort and emotional relief and benefits. The legal nurse consultant can develop a comprehensive special needs financial life plan or life care plan. The plan looks at what the costs for the life of the special needs child are presently and when their parent or caretaker is gone. A life care plan is specific to the individual based on their needs. It considers medical care and medical management, the cost, frequency and replacement of services and equipment over time, medications, diagnostic testing, support services, respite care, therapies, personal care, housing, transportation, and travel.

A government benefits specialist or counselor is aware of what government benefits are available to assist the child such as Medicaid and/or Medicare, social security disability income (SSDI), or supplemental social security income (SSI).

1. *Social Security Income*

Children who have one or more qualifying disability⁷³ may be eligible to receive monthly payments from Social Security, known as Social Security Income (SSI).⁷⁴ Many rules and regula-

⁷³ The Code of Federal Regulations for Social Security defines "disability" as "the inability to any substantial gainful activity by reason of any medically determinable physical or mental impairment 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." 20 C.F.R. § 404.1505 (2020).

⁷⁴ *Benefits for Children with Disability (2020)*, SOC. SECURITY ADMIN., <https://www.ssa.gov/pubs/EN-05-10026.pdf> (last visited Oct. 15, 2020); *Childhood Disability: Supplemental Security Income Program A Guide for Physi-*

tions governing who qualifies for the payments and income levels exist, and those will affect eligibility to receive payments. The qualification and application process is sufficiently complex to cause some attorneys to specialize in assisting parents or caregivers interested in applying for SSI on behalf of their minor children.

2. *Public Assistance Programs*

Several public assistance programs exist to help persons with disabilities, including cash assistance, Medicaid, and food assistance.⁷⁵ Cash assistance programs include SSI, optional state supplementation (OSS), and home care for the disabled adult (HCDA). Medical assistance is available through Medicaid, a federal and state program which is administered by each state. Food assistance programs help persons with low-income to purchase food. Eligibility for some food assistance programs can be automatic upon eligibility for other public assistance programs.⁷⁶

3. *Medicaid Waiver*

Each state has the authority to establish its own Medicare and Medicaid program's eligibility, premiums, cost-sharing schedules, optional benefits, payments to providers, and system for delivery; however, federal laws establish minimum standards regarding eligibility criteria⁷⁷ and the federal agency Centers for

cians and Other Health Care Professionals, SOC. SECURITY ADMIN., <https://www.ssa.gov/disability/professionals/childhoodssi-pub048.htm> (last visited Nov. 11, 2020) (describing the SSI program for professionals).

⁷⁵ For example, of an overview of information regarding these types of programs, see generally *SSI-Related Medicaid Programs Fact Sheet*, FLORIDA DEPT. OF CHILDREN & FAMILIES, <https://www.myflfamilies.com/service-programs/access/docs/ssifactsheet.pdf> (last visited Oct. 15, 2020).

⁷⁶ See *supra* note 67 (providing an example of assistance programs and eligibility requirements).

⁷⁷ *Medicaid Waivers in the States, Seven FAQs*, NAT'L CONF. OF STATE LEGISLATURES, <https://www.ncsl.org/research/health/medicaid-waivers-in-the-states-seven-faqs.aspx#:~:text=in%202016%2C%20all%2050%20states,active%20HCBS%20Waiver%20programs%20nationwide> (last visited Oct. 20, 2020).

Medicare & Medicaid Services (CMS)⁷⁸ oversees administration of the programs. States can apply to CMS for waivers to offer alternative benefit plans for a certain group of enrollees, extend coverage for additional populations not otherwise eligible to receive benefits, or other flexibility to specially tailor their Medicaid and Children's Health Insurance Programs (CHIPs). Therefore, Medicare and Medicaid programs vary greatly throughout the nation.

Some states, such as Florida, have used this waiver to establish programs where families with a child who has a qualifying disability, may be eligible to receive Medicaid benefits regardless of the family's income. In Florida this is called a Medicaid Crisis Waiver⁷⁹ which can be applied for through Florida's Agency for Persons with Disabilities (APD),⁸⁰ the state's administering program. Often attorneys who specialize in representing families with special needs children seeking to obtain social security income for the child are familiar with the state's Medicaid benefits programs. So, if a client has a child with a severe disability, the best practice for a family law practitioner is to encourage the client to speak with an attorney knowledgeable regarding the state's Medicaid eligibility criteria to help the client familiarize him/herself with all the governmental benefits that may be available to the child.

4. *Special Needs Trusts*

A special needs trust (SNT)⁸¹ is a specialty trust designed to support a special needs child or adult without the beneficiary be-

⁷⁸ For more on CMS, see generally *About CMS*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/About-CMS/About-CMS> (last visited Oct. 20, 2020).

⁷⁹ FLA. ADMIN. CODE 65G-1.047, *Waiver Enrollment for Children in the Child Welfare System* (2007), <https://www.flrules.org/gateway/ruleno.asp?id=65G-1.047>.

⁸⁰ For more about APD, see generally *Agency for Persons with Disabilities*, AGENCY FOR PERSONS WITH DISABILITIES, <https://apd.myflorida.com/> (last visited Oct. 20, 2020).

⁸¹ For more on special needs trusts, see generally Rebecca A. Iannantuoni & Keith Bradoc Gallant, *For Children with Special Needs: Special Needs Trusts and Other Planning Options*, FAM. ADVOC., Winter 2020 https://www.americanbar.org/groups/family_law/publications/family-advocate/2020/

coming disqualified from receiving government assistance.⁸² SNTs are like any other trust in that they can provide creditor protection and they are overseen by one or more trustees. Three common types of SNT exist. Each is briefly described below.

- (1) *Self-Settled or First Party Trust*: This type of trust may be used if the beneficiary owned property whether outright or received property from a third party such as through a court settlement or inheritance. Upon the passing of the beneficiary of a self-settled trust, the remaining assets must be used to reimburse any states that provided Medicaid benefits to the trust's beneficiary during her or his lifetime.
- (2) *Third Party Trust*: A third party funds this this kind of trust for the benefit of the person with a special need (beneficiary). Unlike the self-settled trust, a third-party trust can allow the grantor control over the disposition of remaining funds upon the beneficiary's passing.
- (3) *Pooled Special Needs Trusts*⁸³: These trusts are organized by a non-profit organization, often experienced in caring for similarly situated persons with disabilities. Pooled SNTs may be appropriate for grantors who cannot identify or decide on an appropriate trustee or if insufficient resources exist to establish a stand-alone First Party or Third Party Trust. Assets are pooled together, and separate sub-trusts are established for the benefit of the various beneficiaries. Upon the beneficiary's passing, the circumstances will dictate the disposition of the remaining funds, including possible payback back to the state for medical assistance services, retention of the funds by the non-profit manager, or distribution to the

winter/for-children-special-needs—special-needs-trusts-and-other-planning-options/.

⁸² For a basic general overview of special needs trusts, see generally Rob Clarfeld, *Special Needs Trusts: What They Do and How They Work*, FORBES (Dec. 17, 2018), <https://www.forbes.com/sites/robclarfeld/2018/12/17/special-needs-trusts-what-they-do-and-how-they-work/#2ef044395dc7>.

⁸³ For an overview of pooled SNTs, see generally *An Introduction to Pooled Special Needs Trusts*, THE ARC WISCONSIN WEBINAR SERIES (Sept. 12, 2018), <https://arcsi.org/content/uploads/sites/17/2018/08/The-Arc-Wisconsin-Special-Needs-Pooled-Trust-Webinar-9-12-18.pdf>.

remainder beneficiary(ies) named in the trust agreement.

5. *ABLE Accounts*

ABLE accounts are the result of the Stephen Beck Jr. Achieving a Better Life Experience Act of 2014, also known as the ABLE Act.⁸⁴ They are tax-free savings accounts which can be used to pay for qualified disability expenses.⁸⁵ ABLE accounts are designed to largely not affect the beneficiary's eligibility for government assistance through social security income, Medicaid, and programs such as FAFSA, SNAP/food stamps, and HUD. Only individuals whose disabilities had an onset prior to the individual's twenty-sixth birthday are eligible for an ABLE account. Any individual may make contributions to an ABLE account; however, third party contributions cannot exceed the annual gift tax exemption under IRS regulations.⁸⁶

6. *Family Law Considerations*

A family law practitioner should be aware of these potential sources of funds from third parties or tax-advantaged payments. These may benefit not just the child, but the client as well, and it is not unusual for parents, particularly those with children who are newly diagnosed, to be unaware of all the options and resources available to them. Some of the financial matters involved in raising a special needs child may impact certain family law calculations such as child support calculations and parental responsibility to pay for out-of-pocket, educational, or activity expenses. Depending on the financial circumstances of the family, it may be best to prepare a child support trust.⁸⁷ Given that

⁸⁴ Pub. L. 113-295, *The Stephen Beck, Jr., Achieving a Better Life Experience Act (ABLE Act)* (Dec. 19, 2014). For a comprehensive explanation of ABLE accounts, see generally SI 01130.740, *Achieving a Better Life Experience (ABLE) Accounts*, SOC. SECURITY PROGRAMS OPERATIONS MANUAL SYS. (POMS) (2020), <https://secure.ssa.gov/apps10/poms.nsf/lnx/0501130740>.

⁸⁵ *Spotlight on Achieving a Better Life Experience (ABLE) Accounts – 2020 Edition*, , SOC. SECURITY, <https://www.ssa.gov/ssi/spotlights/spot-able.html#:~:text=the%20Stephen%20Beck%2C%20Jr.%2C,to%20cover%20qualified%20disability%20expenses> (last visited Oct. 14, 2020).

⁸⁶ For 2020 the amount cannot exceed \$15,000: I.R.S. Rev. Proc. 2019-44.

⁸⁷ For more on child support trusts, see generally Laura W. Morgan, *The Child Support Trust*, FAM. ADVOC., Fall 2015, at 26.

many of the financial considerations are particular to special needs children or, in some cases, specific disabilities, family law practitioners who have clients with one or more children with special needs or disabilities should keep handy the contact information of individuals or organizations which specialize in each of these areas to provide referrals to clients and to educate themselves on the issues.

VI. Resources

A. Community Resources

“If you’re not sure where you’re going, you’re liable to end up someplace else. If you don’t know where you’re going, the best made maps won’t help you get there.”⁸⁸ This Article was intended to serve as a high-level road map for the family law practitioner to help identify major landmarks and common road travelled by a family with a special needs child. There is a vast ocean of organizations and literature available to help provide the practitioner and the child’s family with more detailed information to help meet the child’s unique needs. This section is intended to provide information about national and local community organizations that are available to assist the family law practitioner and families with children with special needs or disabilities through research, education, training, support groups, and more.

1. *ABLE National Resource Center*: This organization was created to provide an inclusive source of information about federal and state-related ABLE activities and programs as well as links to relevant federal agencies and other organizations. Website: <https://www.ablenrc.org/>
2. *American Academy of Child & Adolescent Psychiatry (AACAP)*: AACAP’s mission is “to promote the healthy development of children, adolescents, and families through advocacy, education, and research, and to meet the professional needs of child and adolescent

⁸⁸ Attributed to Robert Mager, psychologist, writer, and educator. PAM WRIGHT & PETE WRIGHT, *FROM EMOTIONS TO ADVOCACY* 115 (2d ed. Harbor House Law Press, Inc. 2006)

- psychiatrists throughout their careers.” Its website provides a wealth of resources for families and youth, medical students, and residents, and for its general membership. Website: <https://www.aacap.org/>
3. *American Psychiatric Association*: The vision of this organization of psychiatrist is “to ensure humans care and effective treatment for all persons with mental illness, including substance abuse disorders,” to be “the voice and conscience of modern psychiatry,” and to help build “a society that has available, accessible quality psychiatric diagnosis and treatment.” Website: <https://www.psychiatry.org/>
 4. *Anxiety and Depression Association of America (ADAA)*: This organization was founded in 1979 to help prevent, treat, and cure anxiety, depression, obsessive compulsive disorder, post-traumatic stress disorder, and co-occurring disorders “through education, practice, and research.” Website: <https://www.adaa.org/>
 5. *The ARC*: This organization “promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.” The website contains a vast amount of links and resources on policy, advocacy, initiatives, employment, and more. The ARC has chapters throughout the United States. Website: <https://thearc.org/>
 6. *Autism Society of America (ASA)*: Dr. Bernard Rimland, Dr. Ruth Sullivan, and other parents of children on the autism spectrum founded ASA in 1965 to provide a leading and trusted source of information about the disorder. ASA proudly hosts a well-attended national conference on ASD each year. Website: <http://autism-society.org/>
 7. *Autism Speaks*: A non-profit organization dedicated to advocacy and support for individuals on the autism spectrum and their families. Website: <https://www.autismspeaks.org/about-us>
 8. *Center for Appropriate Dispute Resolution in Special Education (CADRE)*: This National Center on Dis-

pute Resolution in Special Education is focused on “encouraging the use of mediation, facilitation, and other collaborative processes as strategies for resolving disagreements between parents and schools about children’s educational programs and support services. It is funded by the Office of Special Education Programs at the U.S. Department of Education.” Website: <https://www.cadreworks.org/>

9. *Consortium for Citizens with Disabilities*: This is among the largest of coalitions of national organizations focused on advocating for “federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.” Website: <http://www.c-c-d.org/>
10. *Council of Parent Attorneys and Advocates (COPAA)*: This is an independent and non-profit organization of attorneys, advocates, parents, and related professionals whose mission is to protect “the legal and civil rights of and secure excellence in education on behalf of tens of thousands of students with disabilities and their families each year at the national, state and local levels.” Website: <https://www.copaa.org/>
11. *Learning Disabilities Association of America (LDA)*: LDA was formally created and incorporated in 1964 “to create opportunities for success for all individuals affected by learning disabilities through support, education, and advocacy.” Website: <https://ldaamerica.org/>
12. *M&L Special Needs Planning*. This website provides links to resources, workshops, and statistics relevant to families with children with disabilities or special needs. Website: <https://specialneedsplanning.net/resources/>
13. *National Center for Education Statistics (NCES)*: This is a branch of the U.S. Department of Education which tracks statistics relevant to educational matters including statistics related to the implementation of the IDEA such as the number of students aged 3-21 served under the IDEA by disability type. Website: https://nces.ed.gov/programs/coe/indicator_cgg.asp

14. *National Institute of Mental Health (NIMH)*: This is the lead federal agency providing research on mental disorders. It provides research, events, and resources on mental health issues including schizophrenia, depression, bipolar disorder, suicide, post-traumatic stress disorder, eating disorders, autism spectrum disorder, anxiety disorders, and more. Website: <https://www.nimh.nih.gov/index.shtml>
15. *Next for Autism: Advancing Futures for Adults with Autism (AFAA)*: This organization's mission is to transform "the national landscape of services for people with autism by strategically designing, launching, and supporting innovative programs." Website: <https://www.nextforautism.org/>
16. *Office of Disability Employment Policy (ODEP)*: This is an agency within the U.S. Department of Labor whose mission is "to develop and influence policies and practices that increase the number and quality of employment opportunities for people with disabilities." The website contains a wealth of resources, research, news, publications, and other information relevant in some way to all persons with disabilities. Website: <https://www.dol.gov/agencies/odep>
17. *Pacer Center*: An information and training center for families of children and youth who have any kind of disability. The center is located in Minneapolis; however, it serves families across the nation through publications, workshops, and other resources to help parents make decisions about education, employment, training, and other services for their children. Website: <https://www.pacer.org/>
18. *Stetson University National Conference on Special Needs Planning and Special Needs Trusts*: For more than twenty years, Stetson University has hosted a conference on special needs planning and special needs trusts to provide "an in-depth review of major issues presented in the creation, administration, monitoring and planning of special needs trusts." The conference often includes "boot camps" and intensive pre-conference trainings for related issues including the mechan-

ics of the Social Security Administration, tax laws, and veterans' benefits. Typically, the event is held each October. Website: <https://www.stetson.edu/law/conferences/snt/index.php>

19. *University of Miami-Nova Southeastern University Center for Autism & Related Disabilities (UM NSU CARD)*: This is a free community-based program hosted by the University of Miami and Nova Southeastern University and funded by the Florida Department of Education through an annual grant. The organization is "dedicated to optimizing the potential of people with autism spectrum disorders (ASD), dual sensory impairment, sensory impairments with other disabling conditions, and related disabilities." The related disabilities include deaf-blindness, sensory impairments, and developmental delays. Website: <https://www.umcard.org/home/>
20. *University of South Florida Center for Autism and Related Disabilities (CARD at USF)*: This is a free community-based program hosted by the University of South Florida and funded by the Florida Department of Education through an annual grant. CARD's mission is to provide "support and assistance with the goal of optimizing the potential of people with autism and related disabilities." Website: <http://card-usf.fmhi.usf.edu/index.html>
21. *U.S. Department of Education IDEA*: This is a website dedicated to providing information about IDEA, reports, and resources from the U.S. Department of Education. Website: <https://sites.ed.gov/idea/>
22. *U.S. Department of Health and Human Services: Parenting a Child with a Disability*: This website has a comprehensive list of questions and answers by the U.S. Department of Health and Human Services on programs for families with children. Website: <https://www.hhs.gov/answers/programs-for-families-and-children/index.html>

B. Secondary Sources

This section provides additional resources that go more in-depth in discussing the various topics addressed within this article. This section is by no means a comprehensive bibliography, but rather a sampling of resources that inspired the authoring of this article or that hold particular esteem within their community.

1. *Navigating a Divorce with a Child with Special Needs*, AMERICAN ACADEMY OF MATRIMONIAL LAWYERS, <https://aaml.org/store/viewproduct.aspx?id=12928785>.
2. *A Guide to the Individualized Education Program*, U.S. DEPT. OF EDUC., <https://www2.ed.gov/parents/needs/spced/iepguide/index.html> (last updated Aug. 30, 2019).
3. Ingrid A. Keller, *Raising Children on the Spectrum in Florida: Navigating Roads Less Traveled*, 83 FLA. B.J. 35 (Jan. 2009).⁸⁹
4. JENNIFER LAVIANO, YOUR SPECIAL EDUCATION RIGHTS: WHAT YOUR SCHOOL DISTRICT ISN'T TELLING YOU (Skyhorse, 2017).
5. MARGARET "PEGI" S. PRICE, A GUIDE FOR PARENTS: DIVORCE AND THE SPECIAL NEEDS CHILD (Jessica Kingsley Publishers 2010).⁹⁰
6. MARGARET "PEGI" S. PRICE, THE SPECIAL NEEDS CHILD AND DIVORCE: A PRACTICAL GUIDE TO EVALUATING AND HANDLING CASES (ABA 2009).⁹¹
7. WILLIAM B. REICHHARDT, *Legal Considerations when Advocating for Children with Special Education Needs*, 21 J. VA. TRIAL L. ASS'N. 5 (2010).
8. Karl W. Topor, *Resource Guide for Attorneys Representing Families with Children with Special Needs*, Fam. Advoc., Winter 2020. <https://www.americanbar.org/>

⁸⁹ Also available at <https://www.floridabar.org/the-florida-bar-journal/raising-children-on-the-spectrum-in-florida-navigating-roads-less-traveled/>

⁹⁰ Margaret "Pegi" S. Price also authored a brief article highlighting suggestions for the family law practitioner. Margaret "Pegi" S. Price, *Essential Issues when Handling Cases with Special Needs Children*, FAMILYLAWYERMAGAZINE.COM, <https://familylawyermagazine.com/articles/handling-cases-with-special-needs-children/> (last visited Oct. 14, 2020).

⁹¹ Available for purchase at <https://www.americanbar.org/products/inv/book/214329/>.

groups/family_law/publications/family-advocate/2020/winter/resource-guide-attorneys-representing-families-children-special-needs/.

9. PAUL WEHMAN, VALERIE BROOKE, & JOSHUA TYALOR, ET AL, *ESSENTIALS OF TRANSITION PLANNING* (Brookes Pub., 2d ed., 2020).
10. BRIAN A. WILK, *A LIFETIME OF LESSONS FROM THE PARENT OF A SPECIAL NEEDS CHILD: A CARE-TAKER'S GUIDE TO DISABILITY MANAGEMENT* (Outskirts Press, 2020).
11. PETER W.D. WRIGHT & PAMELA DARR WRIGHT, *WRIGHTSLAW: ALL ABOUT IEPs*, (Harbor House Law Press, Inc. 2010).
12. PETER W.D. WRIGHT & PAMELA DARR WRIGHT, *WRIGHTSLAW: SPECIAL EDUCATION LAW* (2d ed., Harbor House Law Press, Inc. 2007).

VII. Conclusion

Mark Twain is attributed with the quote: “It ain’t what you don’t know that gets you into trouble. It’s what you know for sure that just ain’t so.”⁹² It is very easy for a practitioner to manage a case involving a special needs child like any other case; however, doing so could cause a child to miss out on significant opportunities to receive services that could improve social, educational, emotional, or medical growth. Conversely, if the practitioner manages the case appropriately, it should result in a child receiving valuable benefits which will likely change the course of that child’s world and which in turn provide a positive economic impact for the entire family. This article is by no means a comprehensive *How-to Manual* for family law cases involving children with special needs. Instead, it highlights certain fundamental areas so family law practitioners will recognize that they may not have all the answers and gives them some direction and resources necessary to know what questions to ask, where to look and how to best meet their client’s and the child’s needs.

⁹² Peter Alfeld, *Favorite Quotes: Alphabetical by Author*, UNIVERSITY OF UTAH DEPT. OF MATHEMATICS, <http://www.math.utah.edu/~alfeld/quotes.html> (last visited Oct. 20, 2020).

This is critical because one size does not fit all when it comes to society's most unique individuals – special needs children.

