

## Advising Military Families with Special Needs Children: A Legal Primer

Major Mary E. Meek\*

*It is in the whole process of meeting and solving problems that life has meaning. Problems are the cutting edge that distinguishes between success and failure. Problems call forth our courage and our wisdom; indeed, they create our courage and our wisdom. It is only because of problems that we grow mentally and spiritually. It is through the pain of confronting and resolving problems that we learn.<sup>1</sup>*

### I. Introduction

The alarming rise in the rate of diagnoses of children with autism has garnered worldwide attention. According to researchers at the Centers for Disease Control and Prevention, between 2007 and 2009, America experienced a fifty percent increase in the number of children diagnosed with autism spectrum disorder.<sup>2</sup> Whereas the government estimated the rate of children with autism to be one in 150 of America's eight-year-olds in 2007, by 2009 the reported diagnosis rate rose to one in 100 for this same age group.<sup>3</sup> A 2013 government study now reveals that the rate of autism diagnosis among schoolchildren has doubled since 2009 to the record rate of one in fifty.<sup>4</sup> Children with autism, however, remain only one component of the special needs<sup>5</sup> community, which includes children who are mentally, physically, or emotionally disabled.

\* Judge Advocate, U.S. Army. Presently assigned to Army Litigation Division Military Personnel Branch as Litigation Attorney, at Fort Belvoir, Virginia LL.M., 2011, The Judge Advocate General's Legal Center and School, Charlottesville, Virginia; J.D., 2001, College of William & Mary School of Law; B.A., 1997, Olivet Nazarene University. Previous assignments include Regimental Judge Advocate, 3d US Infantry Regiment ("The Old Guard"), Fort Myer, Virginia, 2009–2010; 8th Theater Sustainment Command, Fort Shafter, Hawaii, 2007–2009 (Civil Law Attorney, 2008–2009; Chief, Legal Assistance, 2007–2008); 25th Infantry Division, Schofield Barracks, Hawaii, 2004–2007 (Chief Client Services, 2007; Trial Counsel, 2006–2007; Chief, Labor Law, 2006; Labor Law Attorney, 2004–2006); US Army Medical Department Center & School and Fort Sam Houston, Fort Sam Houston, Texas, 2003–2004 (Officer-in-Charge Tax Assistance Center, 2003–2004; Legal Assistance Attorney, 2003). Member of the bars of Virginia, the U.S. District Court for the Eastern District of Virginia, the U.S. Court of Appeals for the Fourth Circuit, the Court of Appeals for the Armed Forces, and the Supreme Court of the United States. This article was submitted in partial completion of the Master of Laws requirements of the 59th Judge Advocate Officer Graduate Course.

<sup>1</sup> M. Scott Peck, *Adversity, in THE TREASURE CHEST: MEMORABLE WORDS OF WISDOM AND INSPIRATION* (HarperCollins 1995) (1965).

<sup>2</sup> Trine Tsouderos, *1% of 8-year-olds Diagnosed as Autistic*, L.A. TIMES, Oct. 5, 2009, at A10 (detailing the results of a survey conducted by the Centers for Disease Control and Prevention and the Health Resources and Services Administration).

<sup>3</sup> *Id.*

<sup>4</sup> Alan Zarembo, *Autism Diagnoses on the Rise, Study Finds*, L.A. TIMES, Mar. 20, 2013, <http://articles.latimes.com/2013/mar/20/science/la-sci-autism-20130321> (quoting Stephen Blumberg, lead author of the Centers for Disease Control and Prevention study, for the proposition that the increased rate of autism diagnosis is "most likely due to better ascertainment").

<sup>5</sup> See *infra* Part III.B (providing a discussion of the definition of "special needs" as used in this primer).

Disabilities are non-discriminatory, can occur at birth or any time thereafter, and are found in all nationalities, race, and economic categories. According to the 2000 Census, approximately 3.9% of American families are raising at least one child between the ages of five to seventeen with a disability.<sup>6</sup> For reasons that remain unclear, military families experience an even higher rate of incidence of disabilities among their children than exists among civilian families.<sup>7</sup>

In addition to the normal challenges of raising a special needs child, mobile military families face numerous additional issues. For instance, the transitory nature of military service requires military families to secure services and support not just one time, but to reapply for state benefits and negotiate education plans every time they move. Congress has even recognized the growing need for additional support for military families with special needs. Under the National Defense Authorization Act for Fiscal Year 2010, Congress established the Office of Community Support for Military Families with Special Needs (the "Office").<sup>8</sup> The Office has the mission to "enhance and improve Department of Defense support around the world for military families with special needs (whether medical or educational needs)."<sup>9</sup> However, the legislation does not address the legal needs of military families with special needs.

<sup>6</sup> QI WANG, U.S. CENSUS BUREAU, *DISABILITY AND AMERICAN FAMILIES*: 2000, at 3–4 (2005) (reporting that approximately twenty-nine percent of the 72.3 million families in the 2000 Census have at least one family member with a disability); see also *Study Finds Rate of Birth Defects Higher in Older Women, Hispanics Mass. Statistics Compared for '99*, BOSTON GLOBE, Mar. 26, 2002, at B7, available at 2002 WLNR 2566906 (noting that rate of birth defects for America's children comprises between 3 to 5% of all children born).

<sup>7</sup> The rate of autism spectrum disorder in particular has increased among military families. See, e.g., Assemb. J. Res. 46, 2009–10 Leg., Reg. Sess. (Cal. 2010) (noting that "for reasons . . . unknown, the incidence for autism spectrum disorders among military families is higher than among civilian families"). But cf., e.g., Gregory H. Gorman et al., *Wartime Military Deployment and Increased Pediatric Mental and Behavioral Health Complaints*, 126 PEDIATRICS 1058 (2010) (concluding after surveying the fiscal year 2006 and 2007 military treatment records of children aged three to eight years that mental and behavioral health visits increased by 11% for these children when a military parent deployed).

<sup>8</sup> National Defense Authorization Act for Fiscal Year 2010, Pub. L. No. 111-84, § 563, 123 Stat. 2190, 2304–08 (2009) (codified as amended at 10 U.S.C. § 1781c (2011)).

<sup>9</sup> § 563, 123 Stat. at 2304.

Clients often call upon legal assistance attorneys to address very complex issues, even though the military legal assistance attorneys may lack experience or training related to these matters. As the diagnosed rate of children with special needs increases among military families, it is imperative that legal assistance attorneys become familiar with their common legal concerns. This primer provides an overview of three key areas a legal assistance attorney is likely to encounter when advising military families with special needs. First, it will focus on assisting the client identify and secure available services and support, to include Supplemental Security Income and Medicaid. Second, the article will provide an overview of special education benefits and protections. Finally, it will outline long-term considerations for special needs families, to include guardianship planning and special needs trusts.

## II. Background

The mission of the Army legal assistance program is to assist clients with their personal legal affairs in both a timely and effective manner.<sup>10</sup> Although the assistance provided to clients is personal in nature, the program recognizes the necessity of personal legal readiness in maintaining a fighting force. Specifically, the legal assistance program, established by Army Regulation (AR) 27-3, serves the following military needs: improving Soldier readiness for immediate mobilization and deployment; fostering high morale among Soldiers; ensuring discipline in the ranks, given the strong correlation between unresolved legal difficulties and discipline problems; and recruiting and retaining a quality force.<sup>11</sup>

Legal matters within the scope of the program include family law, estates, real property, personal property, economic, civilian administrative matters, military administrative matters, torts, taxes, and civilian criminal matters.<sup>12</sup> The AR further specifies which categories of cases are “optional” in nature, as well as the types of cases and services that fall outside the scope of the legal assistance program.<sup>13</sup> Generally, provision of “optional” legal services

or assistance with “optional” categories of cases is subject to the availability of expertise and resources at a particular legal office.<sup>14</sup>

Eligible legal assistance clients include active duty and retired servicemembers and their families.<sup>15</sup> This client population, accordingly, includes a wide variety of individuals as reflected by age and employment status, ranging, for example, from eighteen-year-old high school graduates to eighty-eight-year-old retirees. Although limited information is available regarding the special needs of retired servicemembers or their dependents, the eligible client population includes at least 72,454 active duty military dependents with special needs as reflected by their enrollment in the Army’s Exceptional Family Member Program.<sup>16</sup>

Given the diverse client base, the legal issues and needs encountered by military special needs families vary widely. The variable nature of the child’s disability itself impacts a military family’s legal concerns and may drive the family’s requests for assistance. For example, the military parents whose child has an acute, life-threatening medical condition may seek immediate help obtaining medical or financial assistance in order to cope in a time of crisis. By contrast, the parents of a child with chronic developmental disorders or physical disabilities may be struggling with how to plan for the child’s future or prepare an estate plan. Even for a particular family, individual legal needs change over time depending on the life stage of the child and the parents.

Despite the significant number of military families whose children have special needs, the Army does not possess or

<sup>10</sup> U.S. DEP’T OF ARMY, REG. 27-3, THE ARMY LEGAL ASSISTANCE PROGRAM para. 2-1a. (21 Feb. 1996) (RAR, 13 Sept. 2011) [hereinafter AR 27-3] (detailing that, pursuant to the mission of the program, legal assistance attorneys are to meet their clients’ need for “information on personal legal matters,” and “resolv[e] their personal legal problems whenever possible”).

<sup>11</sup> *Id.* para. 2-1b.

<sup>12</sup> *Id.* para. 3-6.

<sup>13</sup> *Id.* paras. 3-6 to 3-8 (specifying limitations on the type of assistance and kinds of cases regarding which services which may be provided under the legal assistance program as excluding, for example, legal advice on military justice matters, private business activities, litigation against the United States, or employment matters). Specified, limited legal assistance may be provided regarding the following types of cases: claims or civil lawsuits against the United States; contingent legal fee cases; prepaid-legal-representation cases; standards of conduct issues; and service as a victim or witness liaison for a particular criminal case. *Id.* para. 3-8b.

<sup>14</sup> Even for the types of cases identified as within the scope of the program, supervisory attorneys may refuse eligible clients certain optional legal services when they determine that “available resources, personnel, or expertise are insufficient to provide the legal assistance needed.” *Id.* para. 3-5c(2). In the event an eligible client is refused optional legal services, however, a legal office should make every effort to refer this client to attorneys capable of providing the needed assistance. *Id.*

<sup>15</sup> *Id.* para. 1-1 (listing two statutory authorizations for receipt of legal assistance, 10 U.S.C. §§ 1044, 3013g, which further permit the provision of assistance to Reserve component Soldiers and Department of Defense civilian employees in certain situations).

<sup>16</sup> E-mail from Marcia O’Connor, Exceptional Family Member Program (EFMP) Manager, Joint Base Myer-Henderson Hall, to author (May 10, 2013, 09:30 EST) (on file with author). Enrollment in the Army’s EFMP is mandatory for active Army, Army Reserve Soldiers in the USAR Active Guard Reserve Program, and Army National Guard personnel serving under authority of Title 10 or Title 32 of the U.S. Code. U.S. DEP’T OF ARMY, REG. 608-75, EXCEPTIONAL FAMILY MEMBER PROGRAM para. 1-7 (22 Nov. 2006) (RAR, 24 Feb. 2011) [hereinafter AR 608-75]. As of August 2007, there were 87,516 military families with special needs as represented by the respective services as follows: 50,006 Army, 17,500 Navy, 6,272 Marine Corps, and 13,738 Air Force. U.S. Dep’t of Def., *Special Needs Brief*, MILITARY ONESOURCE [http://www.militaryonesource.mil/12038/Project%20Documents/MilitaryHOMEFRONT/Troops%20and%20Families/Special%20Needs%20EFMP/Facilitator%20Guide/Special\\_Needs\\_Brief\\_PPT.pdf](http://www.militaryonesource.mil/12038/Project%20Documents/MilitaryHOMEFRONT/Troops%20and%20Families/Special%20Needs%20EFMP/Facilitator%20Guide/Special_Needs_Brief_PPT.pdf) (last visited Apr. 20, 2013) [hereinafter DoD *Special Needs Brief*] (supplementing U.S. DEP’T OF DEF., FACILITATOR’S GUIDE TO THE DoD SPECIAL NEEDS PARENT TOOL KIT (n.d.)).

provide any specialized training or resources to prepare its legal assistance attorneys to help these clients.<sup>17</sup> Topics such as disability planning, special education law, and special needs trusts are lacking in the curriculum for the Judge Advocate Officer Basic Course, the Legal Assistance Course, or the Graduate Course.<sup>18</sup> With the exception of guardianship and estate planning, for which provision of legal services is mandated under AR 27-3, the common legal concerns of military families with special needs children are most readily categorized as “optional” and thus subject to the availability of expertise and resources.<sup>19</sup> To address this deficit, this primer is designed to enhance the resources available to the legal assistance practitioner, and thus augment the otherwise “optional” legal assistance provided to eligible clients.

### III. Client Consultation

Generally, no parent plans to have a child with special mental, physical, or emotional needs. The stress of diagnosis, challenge of trying to treat the condition, and struggle of balancing competing life concerns place tremendous demands upon the family. It is little wonder that divorce rates in families with special needs children are extremely high.<sup>20</sup> Consequently, at the time the client comes to the legal assistance office seeking help, it is often a time of tremendous personal crisis. Sensitivity on the part of the legal assistance practitioner to the client’s experience is a key component to the establishment of rapport.

#### A. Establishing Rapport

Author Emily Perl Kingsley famously described the experience of learning that her child had a disability as analogous to taking a much-anticipated vacation to Italy. After planning and packing with great excitement and care,

learning important Italian phrases and purchasing guidebooks, the parent boards a plane bound for Italy. When the parent’s plane lands, however, the pilot announces, “Welcome to Holland.” The parent reels, shocked with surprise and disappointment. Italy was where she always wanted and expected to go. Italy is where she planned for and prepared to go. But, when the parent departs the plane, she sees that although Holland does not have the historic landmarks and bustling cities she sought, it is not a terrible place filled with pestilence or disease. It is just a different place. Holland may not be as glamorous or fast-paced, but it has windmills, tulips, and even Rembrandts.<sup>21</sup>

Like the lost trip to Italy, the legal assistance client may have experienced the loss of a lifelong dream upon receiving the diagnosis of his or her child’s special needs. Simultaneous to this loss, however, the parent may be fiercely protective of the special child and respond very poorly to pity or perceived slights. Legal assistance attorneys should take great care to remain positive at all times when welcoming and consulting with their clients. If the child with special needs is present, the attorney should greet the child as well unless instructed otherwise by the parent. Similarly, although acknowledgment of the client’s challenges may be appropriate, do not offer an apology or expression of sympathy regarding the child’s condition.<sup>22</sup>

---

<sup>21</sup> Abigail Van Buren, *Dear Abby*, WASH. POST, Oct. 28 2003, at C11 (reprinting in full Emily Perl Kingsley’s essay “Welcome to Holland” due to frequent reader request). The well-published essay, “Welcome to Holland,” is often disseminated by organizations to new parents of children with special needs. In light of its power, an excerpt is provided below:

They’ve landed in Holland and there you must stay. The important thing is that they haven’t taken you to a horrible, disgusting, filthy place full of pestilence, famine, and disease. It’s just a different place. So, you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It’s just a different place. It’s slower paced than Italy, less flashy than Italy. But after you’ve been there for a while and you catch your breath, you look around. You begin to notice that Holland has windmills. Holland has tulips. And Holland even has Rembrandts. . . . And the pain of that [lost] experience [of going to Italy] will never, ever, ever, go away. The loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn’t get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

*Id.* Emily Kingsley’s son, Jason Kingsley, was diagnosed as having Down syndrome following his birth in 1974. Jacques Steinberg, *Opening a Window Despite a Disability*, N.Y. TIMES, Mar. 20, 1994, <http://www.nytimes.com/1994/03/20/nyregion/opening-a-window-despite-a-disability.html>.

<sup>22</sup> An expression of sympathy that the client’s living child has certain medical conditions or disorders is generally inappropriate and clients may find such expression to be offensive. The preferred practice is to congratulate the parent on the child’s birth, if a newborn, and affirm

---

<sup>17</sup> The U.S. Marine Corps, by contrast, employs several attorneys to assist and support families belonging to the EFMP. U.S. MARINE CORPS, ORDER 1754.4B, EXCEPTIONAL FAMILY MEMBER PROGRAM (EFMP) ch. 4 (20 Sept. 2010) [hereinafter MCO 1754.4B] (“EFMP attorneys support EFMP by providing individual attorney-client representation for EFMP families, primarily to obtain benefits and services for the EFM under state and federal education laws, including the IDEA and related disability laws and regulations benefiting individuals with disabilities.”).

<sup>18</sup> Interview with Lieutenant Colonel John Ohlweiler, Chair, Admin. & Civil Law Dep’t, The Judge Advocate Gen.’s Legal Ctr. & Sch., in Charlottesville, Va. (Mar. 1, 2011).

<sup>19</sup> Whereas AR 27-3, paragraph 3-6b provides that legal assistance “will” be provided on, *inter alia*, wills and guardianships, it contrarily provides in subparagraph 3-6g that legal assistance “may” be provided for civilian administrative matters within the “primary jurisdiction of a municipal, state, Federal, or foreign agency.” AR 27-3, *supra* note 10, paras. 3-6b, 3-6g.

<sup>20</sup> See, e.g., Judith L. Poller & Alicia Fabe, *Legal and Financial Issues in a Divorce When There Is a “Special Needs” Child*, 22 AM. J. FAM. L. 192, 192 (2009) (claiming that whereas the divorce rate in the United States is “between 40 and 50 percent,” the divorce rate rises to “between 85 and 90 percent” for parents of a child with special needs).

## B. Defining “Special Needs”

The U.S. Department of Health and Human Service’s Maternal and Child Health Bureau defines children with special health care needs as being “children who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”<sup>23</sup> Since 2001, the U.S. Department of Health and Human Services has repeatedly increased its estimates regarding the number of U.S. children younger than eighteen years of age who are estimated to have a special health care needs from 12.8% in 2001, to 13.9% during 2005 to 2006, to 15.1% during 2009 to 2010<sup>24</sup> Generally, “special needs” fall into one of three major categories: (1) medical conditions which are acute or life-threatening (e.g. severe asthma or Type I diabetes); (2) developmental disorders which are chronic or pervasive (e.g. learning disabilities or pervasive developmental spectrum disorders); and (3) disorders that are psychological or behavioral (e.g. anxiety or depressive disorders).<sup>25</sup>

The Department of Defense (DoD), by contrast, has established a functional definition of “special needs”: an individual has “special needs” if diagnosed with a qualifying medical condition, or is in receipt of state special education or early intervention services.<sup>26</sup> Department of Defense

---

positive attributes or actions as appropriate. Remain cognizant that the child’s condition does not define that individual. Utilize “people first” language by describing the individual first, then naming his or her condition. For example, describe a person with Down syndrome as being a “child with Down syndrome,” rather than a “Down syndrome child.” See, e.g., Ruth Torkelson Lynch et al., *Person-First Disability Language: A Pilot Analysis of Public Perceptions*, 60 J. REHAB. 18, 18 (1994) (“A focus on people first puts the focus on the individual, not on the particular functional limitation. Therefore, the use of people-first language has been promoted as the preferred terminology.”).

<sup>23</sup> Merle McPherson et al., *A New Definition of Children with Special Health Care Needs*, 102 PEDIATRICS 137, 138 (1998).

<sup>24</sup> U.S. DEP’T OF HEALTH & HUMAN SRVS., HEALTH RESOURCES AND SERVICES ADMINISTRATION, 2009–2010 NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS, <http://childhealthdata.org/browse/survey/results?q=1792&r=1> (15.1%); U.S. DEP’T OF HEALTH & HUMAN SRVS., HEALTH RESOURCES AND SERVICES ADMINISTRATION, THE NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS CHARTBOOK 2005–2006 (13.9%); U.S. DEP’T OF HEALTH & HUMAN SRVS., HEALTH RESOURCES AND SERVICES ADMINISTRATION, THE NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS CHARTBOOK 2001, <http://mchb.hrsa.gov/chscn/pages/prevalence.htm> (12.8%).

<sup>25</sup> Poller & Fabe, *supra* note 20, at 193. Although it is beyond the scope of this primer to provide a comprehensive list of specific conditions that a special needs child might have, the National Dissemination Center for Children with Disabilities provides contact information for national and state organizations and programs pertaining to particular disabilities. NAT’L DISSEMINATION CTR. FOR CHILDREN WITH DISABILITIES, <http://nichcy.org/> (last visited on May 6, 2013). Additionally, websites for a particular disability are often extremely informative and serve as abundant resources of information for both advocates and parents.

<sup>26</sup> See U.S. DEP’T OF DEF., INSTR. 1315.19, AUTHORIZING SPECIAL NEEDS FAMILY MEMBERS TRAVEL OVERSEAS AT GOVERNMENT EXPENSE 12-13 (20 Dec. 2005) (C1, 16 Feb. 2011) [hereinafter DODI 1315.19]; see also U.S. Dep’t of Def., DD Form 2792, Exceptional Family Member Medical

Instruction 1315.19 specifically provides a list of qualifying medical and educational needs.<sup>27</sup> In order to address the special needs of military families, the DoD created the Exceptional Family Member Program (EFMP). All active duty personnel and active duty reservists in the Army, Marines Corps, Navy, and Air Force are required to enroll their “exceptional” dependent children or other family members in their respective service’s EFMP.<sup>28</sup> The servicemember’s command is to take “appropriate” disciplinary action, moreover, should a Soldier refuse to or knowingly fail to enroll a family member in the EFMP.<sup>29</sup>

The EFMP serves two primary functions: a mandatory personnel function employing consideration of noted needs in assignments processes; and an optional family support function providing services to EFMP members.<sup>30</sup> First, military personnel agencies are to consider the medical and special education needs of the exceptional family member (EFM) and “assign Soldiers to an area where the EFM’s medical and special education needs can be accommodated.”<sup>31</sup> Second, family support centers can offer assistance to enrolled military families by providing information and referral to medical, educational, and community resources to assist in caring for the family

---

Summary (Apr. 2011); U.S. Dep’t of Def., DD Form 2792-1, Exceptional Family Member Special Education/Early Intervention Summary (Apr. 2011).

<sup>27</sup> DODI 1315.19, *supra* note 26, at 12–13. Qualifying medical conditions for EFMP enrollment include, for example, asthma, autism, the need to use adaptive equipment, and certain mental health conditions. *Id.*

<sup>28</sup> AR 608-75, *supra* note 16, paras. 1-7a. (stating that certain categories of “Soldiers with exceptional Family members (EFMs) (children and adults) will enroll in the EFMP”) (emphasis added); U.S. DEP’T OF AIR FORCE, INSTR. 40-701, MEDICAL SUPPORT TO FAMILY MEMBER RELOCATION AND EXCEPTIONAL FAMILY MEMBER PROGRAM (EFMP) para. 1.1 (15 Feb. 2012); U.S. DEP’T OF NAVY, SEC’Y OF THE NAVY INSTR. 1754.5B, EXCEPTIONAL FAMILY MEMBER PROGRAM para. 5.b. (14 Dec. 2005); U.S. NAVY, CHIEF OF NAVAL OPERATIONS INSTR. 1754.2D, EXCEPTIONAL FAMILY MEMBER PROGRAM para. 4.b. (3 Nov. 2010); MCO P1754.4B, *supra* note 17, at 2-3. Once enrolled in the EFMP, the family member remains enrolled permanently unless the Soldier is separated from the Army or “medical or special education needs warrant closure.” AR 608-75, *supra* note 16, para. 1-7c.

<sup>29</sup> AR 608-75, *supra* note 16, para. 1-8.b (noting that “knowing that failure or refusal to enroll in the EFMP or willfully disregarding the mandatory update review of the EFM condition may constitute a dereliction of duty in violation of UCMJ, Art. 92”). The regulation specifies that appropriate disciplinary action is to include, “at a minimum a general officer letter of reprimand” if supported by the evidence. *Id.* Once a dependent is enrolled in the EFMP, Soldiers must provide an update review of the EFM condition at least once every three years. *Id.*

<sup>30</sup> See *id.* para. 1-9. The stated “concept” of the EFMP is to work together with other military and civilian agencies to provide “a comprehensive, coordinated, multiagency approach for community support, housing, medical, educational, and personnel services to families with special needs.” *Id.* para. 1-6. Clients may express concern that enrollment in the EFMP may hurt their career. However, enrollment in the EFMP does not affect selection for promotion or schools and selection boards receive no information regarding EFMP enrollment status or data. See *id.* para. 1-24f.

<sup>31</sup> *Id.* para. 1-9c.

member with special needs.<sup>32</sup>

The fact that a child is enrolled in the EFMP does not necessarily mean the EFM has a qualifying disability for purposes of Social Security benefit programs, accommodations, services, or other legal protections. The definition of an EFM is quite broad.<sup>33</sup> Contrarily, the definition of a person with a “qualifying disability” for purposes of a particular state or federal program is generally statute-specific and far more restrictive. In evaluating the potential legal protections of a client’s child, take care first to ascertain whether an evaluation or eligibility assessment of the special needs child has or should be made.<sup>34</sup> To assist in this process, provided in the next two sections are synopses of several key public benefit programs.<sup>35</sup>

#### IV. Maximizing a Client’s Current Resources

Providing care for a child with special needs can prove emotionally, physically, and financially draining with each new life stage posing new challenges (see Appendix A). Families often require medical, financial, or other assistance from multiple sources to provide adequate care for their disabled child.<sup>36</sup> Servicemembers and their families can not

only utilize the DoD’s healthcare system, TRICARE,<sup>37</sup> but may also qualify for additional benefits for their special children under federal and state programs. Assisting such clients in maximizing the resources available for the care of their children requires knowledge of entitlement programs, federal and state laws concerning eligibility, and other potential resources. An overview of two of the most important federal and state programs from which many military families receive assistance follows.

##### A. Supplemental Security Income

The Supplemental Security Income (SSI) is federally funded and administered program designed to provide monthly income assistance for the purpose of helping aged, blind, and disabled individuals who have limited income and resources pay for food, clothing, and shelter.<sup>38</sup> SSI payments are not to be used for the payment of medical care, however, as Medicaid or Medicare provide for these expenses.<sup>39</sup> To qualify for this entitlement, applicants must establish the existence of a disability, as defined by SSI, and limited income and assets.<sup>40</sup> Complex rules govern what income is to be attributed to the disabled individual, which may include the income of the disabled child’s parents and work to reduce or eliminate the child’s eligibility for SSI.<sup>41</sup> With respect to assets, the resource limit for eligibility is \$2,000.<sup>42</sup>

<sup>32</sup> See *id.* para. 1-9e.

<sup>33</sup> Major Michael R. Renz, *The Special Needs Trust and the Military Client: The Critical Issue-Spotting Role of the Legal Assistance Attorney*, 59 NAVAL L. REV. 45, 48 (2010) (noting that an exceptional family member “can be an individual with a food allergy or mild learning disability” whereas a person with a qualifying disability for purposes of the Supplemental Security Income program must have “marked and severe functional limitations for a period of 12 months”).

<sup>34</sup> Ordinarily, the determination of whether an individual has a qualifying disability is “made by the state in which the dependent lives.” *Id.* Diagnosis of a child as having particular special needs is of critical importance to securing both treatment and legal protections. In addition to establishing potential eligibility for special medical or educational services and legal protection from discrimination, an individual’s disability diagnosis may serve as evidence explaining or excusing misconduct should the individual engage in violent and disruptive conduct related to the individual’s disability. See, e.g., *Timothy B. ex rel. J.B. v. Neshaminy Sch. Dist.*, 153 F. Supp. 2d 621 (E.D. Pa. 2001) (finding plaintiff stated claim of procedural violation of the Individuals with Disabilities in Education Act and Section 504 of the Rehabilitation Act sufficient to deny defendant’s motion to dismiss when defendant had no determination as to whether the plaintiff’s behavior in making threatening remarks was a manifestation of his Tourette’s Syndrome prior to suspending him).

<sup>35</sup> The information contained in this primer is intended to serve as a checklist, counseling guide, and starting place for further research. A discussion all the government benefit programs that may be available for special needs families is beyond the scope of this article.

<sup>36</sup> In addition to the website listing disability-specific contact information provided, *supra*, in note 25, two resources available to military families warrant particular mention. First, military families may draw upon the invaluable resources available at a local installation’s EFMP Office. Additionally, Military OneSource provides free Special Needs Assistance through telephonic consultations at (800) 342-9647, and user-friendly materials that can be ordered online at [www.militaryonesource.com](http://www.militaryonesource.com).

<sup>37</sup> TRICARE offers multiple healthcare plans and programs which may benefit military families with special needs. For further information, direct clients to the installation TRICARE or EFMP office. Confirmation of eligibility for TRICARE benefits can, similarly, be made at the nearest uniformed services identification card center. If an unmarried adult child of a military sponsor is disabled due to a condition that existed prior to the child’s 21st birthday, the child may be entitled to TRICARE benefits and other identification card privileges. Army personnel can inquire further regarding the Incapacitated Children Over 21 program by calling (317) 510-2772. The Navy and Marine Corps refer to the program as the Incapacitated Dependents Program and can call (910) 874-3360, or (703) 784-9529, respectively. Air Force families can call (210) 565-2089 for more information. Additional information is also available on the TRICARE website at [www.tricare.osd.mil](http://www.tricare.osd.mil).

<sup>38</sup> 42 U.S.C. §§ 1381–1385 (2011).

<sup>39</sup> Sebastian V. Grassi, Jr., *Special Needs Requires Special Attention: Estate Planning for a Family with a Special Needs Child*, 43 INST. ON EST. PLAN. ¶ 903.2 (2009).

<sup>40</sup> See 42 U.S.C. § 1381a. Disability for the purposes of SSI is defined differently for adults and children under eighteen. See *id.* § 1382c(a)(3).

<sup>41</sup> 20 C.F.R. § 416.1165 (2012); Renz, *supra* note 33, at 50. Pursuant to the Heroes Earnings Assistance and Relief Tax Act (HEART Act), military families who receive SSI from the Social Security Administration for a special-needs family member receive no reduction of assistance due to receipt of cash payments for housing, AmeriCorps benefits, or certain State annuity payments paid to veterans who are blind, disabled, or aged. Heroes Earnings Assistance and Relief Tax Act of 2008 §§ 201–203, 42 U.S.C. §§ 1382a, 1382b (2011). Other regulations exclude from countable income combat-related pay. See 20 C.F.R. §§ 416.1124(c)(19), 416.1161(a)(28).

<sup>42</sup> 42 U.S.C. § 1382(a)(3)(B). The Social Security Administration defines “resources” as “cash or other liquid assets or any real or personal property that an individual . . . owns and could convert to cash to be used for his or her support and maintenance.” 20 C.F.R. § 416.1201(a).

In most states, children who qualify for SSI also qualify for Medicaid.<sup>43</sup>

## B. Medicaid

Medicaid is a federally sponsored, state-administered program that pays for medical treatment and assisted living costs for eligible beneficiaries.<sup>44</sup> Because the program is administered by each individual state, its specific eligibility requirements vary. Nevertheless, each state program has disability, asset, and income qualification requirements.<sup>45</sup> The asset restrictions differ slightly among the states, permitting beneficiaries to have only a very limited asset allowance ranging from \$999 to \$2,000 in order to remain eligible.<sup>46</sup> Although some military families with special needs children may be financially ineligible for regular state Medicaid programs, not all programs are based on the parents' income.

Pursuant to section 1915(c) of the Social Security Act, for example, states can provide a broad array of home and community-based services (HCBS) through Medicaid waivers.<sup>47</sup> Medicaid waivers vary from state to state and serve as an alternative to institutionalization, which the family is "waiving" in order to provide care in community settings. With a waiver, states can base eligibility for

<sup>43</sup> In thirty-nine states, receipt of SSI automatically qualifies the SSI recipient for Medicaid benefits. Grassi, *supra* note 39, ¶ 903.2. (noting that the eleven states for which receipt of SSI does not result in Medicaid benefits are known as "209(b) states" and include Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia). Consequently, establishing and maintaining SSI eligibility is crucial for most clients as it facilitates access to Medicaid and the myriad health care and other benefits Medicaid provides. *Id.*

<sup>44</sup> 42 U.S.C. §§ 1396–1396w-5.

<sup>45</sup> With the exception of "209(b) states," the state guidelines for Medicaid eligibility and services can be broader but not more restrictive than the federal minimum guidelines. *See* Grassi, *supra* note 39, ¶ 903.3.

<sup>46</sup> To find more information on Medicare and Medicaid, visit the U.S. Department of Health & Human Services web site at [www.cms.gov](http://www.cms.gov).

<sup>47</sup> 42 U.S.C. § 1396n(c). With the home and community-based (HCB) waiver, Congress allowed states to use Medicaid funds in order to pay for services not otherwise allowed by the Medicaid Act so long as the services are necessary to keep a person from being institutionalized and no more expensive than institutional care. *See id.*; 42 C.F.R. § 441.300 (2012). The HCB waiver allows a state to decide not to count the family's income for children who otherwise meet SSI disability criteria and would be eligible for Medicaid if they were in an institutional setting, and further allows states to pay for care and services that do not fall within other Medicaid categories such as respite care, transportation, and home modifications. *See* Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History*, 26 GA. ST. U. L. REV. 937, 963 (2010). Currently, forty-six states and the District of Columbia offer services through HCB (1915(c)) waivers, and there are approximately 291 current HCB waiver programs nation-wide. MEDICAID.GOV, *Waivers*, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html> (last visited Apr. 30, 2013) (once on the site, under "Filter by Status," select "Current." Then in the table below, sort by the "Waiver Authority" category to find the states and programs with 1915(c) waivers).

Medicaid on the disabled individual's income and assets and not on the disabled person's age or the parents' income or assets.<sup>48</sup> As a consequence, the disabled child may be eligible for a Medicaid even if the parents' income is too high to qualify for the family for Medicaid.

Offering a significant additional benefit, individuals receiving waiver services are also entitled to all other services available to regular Medicaid recipients. Posing a distinct disadvantage to the military client, however, Medicaid services do not "transfer" between states when a servicemember is reassigned to a new state because the services are state-specific. Instead, the disabled beneficiary must reapply for Medicaid services in the new state and risks a reduction or termination of Medicaid benefits.<sup>49</sup> As is outlined in the next section, relocation also complicates the preservation of special education public benefits.

## V. Advocating for a Client's Educational Needs

Even for military children without special needs, the negative educational impacts caused by frequent relocations have recently received much-needed attention. In a 2010 presidential directive, President Obama challenged all cabinet secretaries and agency heads to discover improved ways by which to provide military families with help.<sup>50</sup> In their response, approved by President Obama on 8 December 2010, the federal executive departments and agencies identified four strategic priorities to provide care and support for military families.<sup>51</sup> One of the four identified presidential-approved priorities addressed education and detailed the goal to "[e]nsure excellence in military children's education" with an identified need to "[r]educe negative impacts of frequent relocations and absences."<sup>52</sup>

<sup>48</sup> *See* 42 U.S.C. § 1396n(c)(3).

<sup>49</sup> George France, *The Form and Context of Federalism: Meanings for Health Care Financing*, 33 J. HEALTH POL. POL'Y & L. 649, 663 (2008) ("Given the substantial interstate differences in eligibility rules and benefit packages under [Medicaid], persons changing state risk seeing their benefit package curtailed, possibly quite drastically, and they could even lose the right to Medicaid completely.").

<sup>50</sup> *See* Press Release, The White House Office of the Press Sec'y, First Lady Michelle Obama Announces Presidential Directive on Military Families (May 12, 2010), *available at* <http://www.whitehouse.gov/the-press-office/first-lady-michelle-obama-announces-presidential-directive-military-families>.

<sup>51</sup> U.S. DEP'T OF DEF. ET AL., *STRENGTHENING OUR MILITARY FAMILIES: MEETING AMERICA'S COMMITMENT* (2011), *available at* [http://www.defense.gov/home/features/2011/0111\\_initiative/strengthening\\_our\\_military\\_january\\_2011.pdf](http://www.defense.gov/home/features/2011/0111_initiative/strengthening_our_military_january_2011.pdf) (describing the following primary, government-wide initiatives: (1) "Enhance the well-being and psychological health of the military family;" (2) "Ensure excellence in military children's education and their development;" (3) "Develop career and educational opportunities for military spouses;" and (4) "Increase child care availability and quality for the Armed Forces").

<sup>52</sup> *Id.* at 2.

For children with special needs, the devastating impacts of frequently changing schools are profound. As a threshold matter, all children crave routine; the need for a predictable routine is even more pronounced for a child who has difficulty understanding or navigating a new environment.<sup>53</sup> Further complicating the child's transition to a new school, the school and parents may have different views regarding what constitutes "comparable services" under an existing special education individualized education program.<sup>54</sup> As a consequence, the new school might provide a different level of assistance than what the child had previously received. Therefore, advocates for a special needs child, including legal assistance attorneys and parents, need to have a working knowledge of the major federal statutes and legal benefits and protections governing special education.<sup>55</sup>

#### A. Section 504 of the Rehabilitation Act and the Americans with Disabilities Act

Section 504 of the 1973 Rehabilitation Act (Section 504) and the Americans with Disabilities Act (ADA) of 1990 have significantly impacted the availability of education for individuals with disabilities through their prohibition of discrimination on the basis of disability.<sup>56</sup> Section 504

generally adopts the definition "disability," as set forth in the ADA, and protects students if they have a physical or mental impairment that substantially limits a major life activity, have a record of such impairment, or are regarded as having such impairment.<sup>57</sup> Once an otherwise qualified student is identified as having a disability under Section 504 or the ADA's expansive definition, the student is entitled to access to an "appropriate public education" and permitted "reasonable accommodation"<sup>58</sup> to participate in its programs or activities.<sup>59</sup>

In application, both Section 504 and the ADA's definition of "disability" are broader than the definition under the Individuals with Disabilities Education Act (IDEA) because they encompass the concept of "impairment." By contrast, to qualify for protection under the IDEA, an individual must need special education and related services.<sup>60</sup> Consequently, some children who do not qualify for special education under IDEA may qualify for special accommodations and modifications under Section 504 or the ADA.<sup>61</sup> As a corollary, however, neither Section 504 nor the ADA require schools to provide a special education program to meet the specific needs of a disabled child, and thus provides fewer legal protections than are available to a child under the IDEA.<sup>62</sup>

<sup>53</sup> See, e.g., Thomas Knestrict & Debora Kuchey, *Welcome to Holland: Characteristics of Resilient Families Raising Children with Severe Disabilities*, 15 J. FAM. STUD. 227, 234-35 (2009) (observing in a study examining resiliency factors that families developed in response to the challenges of raising a disabled child that for all of the more resilient families "[r]outines were seen as crucial in the family's pursuit of resilience" and "seem[ed] to benefit all of the family members"). This assertion is also based on the author's experiences as the mother of three children, one of whom is a child with Down syndrome.

<sup>54</sup> Under the Individuals with Disabilities in Education Act, a receiving school must provide a child who transfers schools with comparable services to the sending school's individualized education program (IEP) until it develops and implements a new IEP. 20 U.S.C. § 1414(d)(2)(C)(i) (2011).

<sup>55</sup> In the United States, special education is regulated by four major federal statutes: Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (2011), the Americans with Disabilities Act, 42 U.S.C. §§ 12101-12213 (2011), the Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400-1482, and the No Child Left Behind Act, 20 U.S.C. §§ 6301-6578. ALLAN G. OSBORNE, JR. & CHARLES J. RUSSO, *SPECIAL EDUCATION AND THE LAW: A GUIDE FOR PRACTITIONERS* 9 (2d ed. 2006). Although for purposes of brevity this primer does not include a discussion of the No Child Left Behind Act (NCLB), the NCLB promises to have a great effect on education in America though its requirements that schools be accountable for achieving academic results, provide scientifically-based instruction, and utilize highly qualified teachers and paraprofessionals. See 20 U.S.C. § 6301. Of note, schools are to hold students with disabilities to the standards for the grade in which the child is enrolled and provide students with appropriate accommodations, if needed, to take the statewide assessment. MITCHELL L. YELL, *THE LAW AND SPECIAL EDUCATION* 188-90 (2d ed. 2006).

<sup>56</sup> Although Section 504's applicability to a particular school is predicated on its receipt of "federal financial assistance," it has been expansively interpreted to apply to practically all schools. OSBORNE & RUSSO, *supra* note 55, at 10. "No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, or denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . ." 29 U.S.C. § 794(a) (2011). It is Section 504, rather than the ADA, that is applicable to

the Department of Defense, to include DoD schools. See *id.*; 42 U.S.C. § 12111(5)(B)(i). The ADA applies to elementary and secondary education at public schools and similarly provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." *Id.* § 12132; 28 C.F.R. § 36.104 (2012).

<sup>57</sup> 29 U.S.C. § 705(9).

<sup>58</sup> "In making modifications for students, educators must provide aid, benefits, and/or services that are comparable to those available to children who do not have impairments." OSBORNE & RUSSO, *supra* note 55, at 12. Determination of whether a school has provided a student with a "reasonable accommodation" is fact-specific, and may involve environmental or academic modifications. *Id.* Schools are not required to grant all requests for accommodations, however, and need not provide accommodations beyond that which are considered "reasonable" in terms of cost, risk to school staff, or modification of a program's purpose. *Id.* at 12, 15-16.

<sup>59</sup> See 34 C.F.R. §§ 104.33, 104.39 (2012).

<sup>60</sup> OSBORNE & RUSSO, *supra* note 55, at 9-10.

<sup>61</sup> Students who might be protected under Section 504 or the ADA, but not the Disabilities Education Act (IDEA), include, for example, students with attention deficit disorder. See, e.g., Lyons v. Smith, 829 F. Supp. 414, 415-16 (D.D.C. 1993) (finding that a child with attention deficit and hyperactivity disorder was not "other health impaired" under the IDEA, but might be covered under the definition of disabled under the Rehabilitation Act). The Supreme Court clarified in *Smith v. Robinson* that a student could use Section 504 of the Rehabilitation Act to redress wrongful treatment by schools if the Education of the Handicapped Act, now the Individuals with Disabilities Education Act, failed to provide a remedy. *Smith v. Robinson*, 468 U.S. 992, 1012-13 (1984) (stating that where the Education of the Handicapped Act provides a remedy to a student, it is the exclusive avenue for redress).

<sup>62</sup> See PETER W. D. WRIGHT & PAMELA DARR WRIGHT, *WRIGHTSLAW: SPECIAL EDUCATION LAW* 291 (2d ed. 2007) (noting that school personnel often erroneously advise parents that their children will be "better served

If a family disputes the school's evaluation or placement of a child, both Section 504 and ADA regulations permit due process procedures similar to but less robust than those under the IDEA.<sup>63</sup> Parents are entitled, for example, to impartial hearings should parents disagree with a child's identification, evaluation, or placement; however, these statutes do not include such safeguards as a written notice before a change of placement such as provided under the IDEA.<sup>64</sup> Nevertheless, a key benefit under Section 504 and the ADA is that they provide a legal remedy should a school retaliate against individuals for exercising their rights.<sup>65</sup>

## B. The Individuals with Disabilities Education Act

In 1975, Congress enacted the Education for All Handicapped Children Act that, over the years, was both renamed and amended.<sup>66</sup> Now, the Act is known as the "Individuals with Disabilities Education Act."<sup>67</sup> By its stated purpose, the IDEA provides an expansive mission statement: "to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living," and "to ensure that the rights of children with disabilities and parents of such children are protected"<sup>68</sup> Understanding of the IDEA's purpose is particularly important when interpreting its provisions.

---

with a 504 Plan, not an IEP" under the IDEA when in fact the opposite is true). In explaining the differing protections available for students under Section 504, as opposed to IDEA, authors Peter and Pamela Wright explain that Section 504 provides "access to an education," such as accomplished by making a building accessible for a child who uses a wheelchair. Unlike the IDEA, however, Section 504 does not entitle the child to an education "from which the child receives an educational benefit" such as would be needed if the child had a problem affecting the ability to learn. *Id.* at 293.

<sup>63</sup> 29 U.S.C. § 794a (2011); 42 U.S.C. § 12133 (2011); 34 C.F.R. § 104.36 (2012); PAM WRIGHT & PETE WRIGHT, *WRIGHTSLAW: FROM EMOTIONS TO ADVOCACY* 196 (2d ed. 2006). In contrast to the IDEA, which recognizes no defenses for noncompliance, under Section 504, school officials can posit three defenses to excuse a failure to accommodate an otherwise qualified student: (1) making the accommodation would result in a "fundamental alteration in the nature of [a] program;" (2) the accommodation would impose an "undue financial burden;" and (3) inclusion of the otherwise qualified student in a program poses a "substantial risk of injury to himself, herself, or others." OSBORNE & RUSSO, *supra* note 55, at 13 (quoting *Se. Cmty. Coll. v. Davis*, 442 U.S. 397 (1979), in describing the first two defenses and citing *Sch. Bd. of Nassau County v. Arline*, 480 U.S. 273 (1987), regarding as authority for the third defense).

<sup>64</sup> WRIGHT & WRIGHT, *supra* note 63, at 196.

<sup>65</sup> WRIGHT & WRIGHT, *supra* note 62, at 291.

<sup>66</sup> *Id.* at 7. Prior to its enactment, school boards routinely excluded students with disabilities. OSBORNE & RUSSO, *supra* note 55, at 6.

<sup>67</sup> 20 U.S.C. ch. 33 (2011); *see also id.* § 1400(a).

<sup>68</sup> *Id.* § 1400(d).

The IDEA now mandates that all American school systems provide each qualifying child with a free appropriate public education (FAPE).<sup>69</sup> The Act, codified in Chapter 33 of the Title 20, U.S. Code, is divided into four parts: General Provisions under Subchapter I;<sup>70</sup> Assistance for Education of All Children with Disabilities under Subchapter II;<sup>71</sup> Infants and Toddlers with Disabilities under Subchapter III;<sup>72</sup> and National Activities to Improve Education of Children with Disabilities under Subchapter IV.<sup>73</sup> IDEA Subchapters II and III are of particular interest to special needs families and thus discussed below.

### 1. Early Intervention

In 1986 and again in the 2004 amendments to the IDEA,<sup>74</sup> Congress enacted legislation to provide a program of early intervention services to ensure that children with disabilities would not be required to wait until they were school age to receive services. Early intervention is designed to lessen the effect of a disabling condition.<sup>75</sup> Under Subchapter III of the IDEA, states are now required to provide early intervention services for all children with disabilities from birth until the child attains the age of three years.<sup>76</sup> At the state's discretion, children qualifying for early intervention services may also include "at-risk" infants and toddlers.<sup>77</sup>

States vary, however, in their implementation of early intervention services. Although most services are free, states may charge fees to a child's family.<sup>78</sup> If charged for early intervention services, military families can seek coverage for such fees under TRICARE, private insurance, or Medicaid.

---

<sup>69</sup> *Id.* § 1401(9).

<sup>70</sup> *Id.* §§ 1400–1409.

<sup>71</sup> *Id.* §§ 1411–1419.

<sup>72</sup> *Id.* §§ 1431–1444.

<sup>73</sup> *Id.* §§ 1450–1482.

<sup>74</sup> Education of the Handicapped Act Amendments of 1986, Pub. L. No. 99-457, 100 Stat. 1145 (1986); Individuals with Disabilities Education Improvement Act of 2004, Pub. L. No. 108-446, 118 Stat. 2647 (2004).

<sup>75</sup> 20 U.S.C. § 1431(a) (recognizing that "significant brain development . . . occurs during a child's first 3 years of life" and finding a need to "enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay").

<sup>76</sup> *Id.* §§ 1413(f), 1432–1443. The IDEA defines an "infant or toddler with a disability" to include, at a minimum, a child "under 3 years of age who needs early intervention services because the individual— (i) is experiencing developmental delays . . . ; or (ii) has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay." *Id.* § 1432(5)(A).

<sup>77</sup> *Id.* § 1432(5)(B); *see also id.* § 1432(1) (defining "at risk infant or toddler" as being a child "under 3 years of age who would be at risk of experiencing a substantial developmental delay if early intervention services were not provided to the individual").

<sup>78</sup> *Id.* § 1432(4)(B).

In advising a client, do not neglect to consider the potential role of a military treatment facility or TRICARE to supplement services a parent deems necessary to address a child's particular needs but a state fails to provide.<sup>79</sup>

## 2. School Age Children

In contrast to Section 504, which has fairly broad standards, qualification for services under IDEA Subchapter II requires demonstration of three statutory requirements: the child must be between the ages of three and twenty-one; the child must have a disability which is specifically identified; and finally, the child must require a specially designed instruction in order to receive a FAPE in the least restrictive environment (LRE).<sup>80</sup> For qualifying students, in turn, the school is charged with providing a free individualized education that is designed to take into account the child's unique needs and confer a meaningful educational benefit in the LRE.<sup>81</sup> In establishing the child's education plans in the child's individualized education program (IEP), which details the placement and services provided, the school and parents must work together.<sup>82</sup>

---

<sup>79</sup> Unlike Subchapter II of the IDEA related to Individualized Education Programs, Subchapter III does not require that receiving states provide "comparable services" to an infant or toddler with an individualized family service plan (IFSP) who transfers to another state. *Id.* §§ 1414(d)(2)(C)(i), 1436. Nevertheless, military families may discuss their concerns regarding services they feel the child needs but is not receiving with the child's primary care manager (PCM) at a local military treatment facility (MTF). In turn, the child's PCM may provide a referral for the child to receive needed treatment or therapy. For example, hypothetical family Smith moved from Hawaii to Virginia. Although the Smith's two-year old child with special needs received physical, occupational, and speech therapy through early intervention services in Hawaii, Virginia informed the Smiths that it would only provide speech therapy to the child and that receipt of such services was indefinitely delayed due to a long waiting list. Rather than rely only on the delayed, reduced early intervention services, the Smith family might consult with the child's PCM regarding a referral for physical and occupational therapy to obtain these services either at a MTF or from a TRICARE-approved provider.

<sup>80</sup> *Id.* §§ 1401(3), 1401(9), 1412(a)(1)(A), 1412(a)(5).

<sup>81</sup> *Id.* § 1401(9). The IDEA defines free and appropriate public education as:

special education and related services that—  
(A) have been provided at public expense, under public supervision and direction, and without charge; (B) meet the standards of the State educational agency; (C) include an appropriate . . . education in the State involved; and (D) are provided in conformity with the individualized education program . . .

*Id.*

<sup>82</sup> *Id.* § 1412(a)(4). IDEA defines an IEP as "a written statement for each child with a disability that is developed, reviewed, and revised in accordance with" the procedures spelled out in a later section of the title. *Id.* § 1401(14).

Although FAPE is now statutorily defined,<sup>83</sup> its definition remains open to interpretation as it fails to establish substantive standards by which to assess services provided.<sup>84</sup> The IDEA leaves undefined the meaning of the phrases "least restrictive environment," "meaningful benefit," and what is "appropriate" for the child.<sup>85</sup> Fortunately, the IDEA provides students with disabilities and their families with procedural safeguards designed to ensure parents are able to participate in their child's education. Nevertheless, parents and schools often disagree about the meaning of these phrases because parents ordinarily want more for their child than the school is either willing or able to provide.<sup>86</sup>

## 3. IDEA Due Process Procedures

Parents are the primary enforcement mechanism of the IDEA.<sup>87</sup> The law affords them the opportunity to interface with and challenge educators regarding the identification, evaluation, development of IEPs, and placement of their children in special education and related services.<sup>88</sup> As such, it is particularly important that parents understand that the IDEA does not guarantee their child the very best educational services possible; instead, it requires schools to provide an appropriate IEP that is designed to confer a meaningful educational benefit to the child.<sup>89</sup> In the event of a disagreement with the school system regarding the education program for the child, there are generally three mechanisms to resolve this discord.

Within the limits set by the IDEA, specific procedures for the resolution of disputes vary from state to state but generally include a resolution session, mediation, and due process hearing.<sup>90</sup> Once the parents file a complaint, the IDEA first requires the parents and local educational agency to hold a resolution session unless both parties agree either to waive such meeting or to pursue mediation.<sup>91</sup> In

---

<sup>83</sup> *Id.* § 1401(9).

<sup>84</sup> OSBORNE & RUSSO, *supra* note 55, at 23.

<sup>85</sup> Dorene J. Philpot, *Special Education Law Primer*, RES GESTAE, Mar. 2004, at 24, 24.

<sup>86</sup> *Id.*

<sup>87</sup> Appendix B provides an information paper to help parents understand the special education processes and procedural safeguards set forth in federal law. Parents may also find the DoD Special Needs Parent Tool Kit to be a particularly helpful guide in accessing and advocating for special education services. Available for download on the internet, the Tool Kit contains six modules addressing many topics of interest to military special needs families. Its practical guidance and sample letters to schools are especially useful. U.S. DEP'T OF DEF, DOD SPECIAL NEEDS PARENT TOOL KIT (3d ed. 2011), available at [http://www.militaryonesource.mil/efmp/parent-tool-kit?content\\_id=268726](http://www.militaryonesource.mil/efmp/parent-tool-kit?content_id=268726).

<sup>88</sup> 20 U.S.C. §§ 1414(a)(1), 1414(b), 1414(d), 1415.

<sup>89</sup> *Id.* § 1401(9); Philpot, *supra* note 85, at 24.

<sup>90</sup> 20 U.S.C. §§ 1415(e), 1415(f)(1)(A), 1415(f)(1)(B); Philpot, *supra* note 85, at 24.

<sup>91</sup> 20 U.S.C. § 1415(f)(1)(B)(i).

recognition of the potential harm to the student and benefits of alternate dispute resolution, schools must offer mediation procedures to resolve disputes.<sup>92</sup> If the parents and educational agency forgo mediation, waive or hold a resolution session, or the parents' complaint remains unresolved thirty days after received by the educational agency, parents are entitled to a due process hearing.<sup>93</sup>

### C. Interstate Compact on Educational Opportunity for Military Children

Military attorneys should be aware of one additional special education resource that may be uniquely available to their clients. The DoD and the Council of State Governments collaborated to develop the Interstate Compact on Educational Opportunity for Military Children to address relocation-related challenges facing military families relating to education.<sup>94</sup> Although the Compact does not expand the special education services or protections beyond those under existing federal law, it is possible that the Compact may provide additional remedies.<sup>95</sup> By its own terms, provisions of the Compact are to be enforced by the "executive, legislative, and judicial branches of state government in each member state," or by the Interstate Commission acting in its discretion against a defaulting state.<sup>96</sup>

---

<sup>92</sup> *Id.* § 1415(e)(1).

<sup>93</sup> *Id.* § 1415(f)(1)(B). Under the IDEA, the parties are accorded the following hearing rights: (1) right to be accompanied and advised by counsel and experts on child disabilities; (2) right to present evidence and confront, cross-examine, and compel attendance of witnesses; (3) right to obtain a verbatim record of the hearing; and (4) right to written findings of fact and decisions. *Id.* § 1415(h).

<sup>94</sup> MODEL LANGUAGE OF INTERSTATE COMPACT ON EDUCATIONAL OPPORTUNITY FOR MILITARY CHILDREN (2007) [hereinafter COMPACT], available at <http://mic3.net/pages/resources/documents/InterstateCompactonEducationalOpportunityforMilitaryChildren-ModelLanguage.pdf>. As of 9 April 2013, forty-five states and the District of Columbia have signed the Compact into law. Press Release, Military Interstate Children's Compact Comm'n, Idaho Adopts the Interstate Compact on Educational Opportunity for Military Children (Apr. 12, 2013), available at <http://mic3.net/documents/MIC3PressRelease-Idaho.pdf>. A current list of states that have enacted the Compact and the status of any pending legislation may be accessed at the website for the Military Interstate Children's Compact Commission, <http://mic3.net/>. The Compact addresses the following relocation concerns: transfer of records; course placement; graduation requirements; exclusion from extra-curricular activities; redundant or missed entrance or exit testing; kindergarten or first grade entrance age variations; graduation requirements; and support for children of deployed servicemembers.

<sup>95</sup> Article V of the Compact recites but does not expand upon the protections required under the Individuals with Disabilities Act (IDEA), Section 504 of the Rehabilitation Act, and Title II of the Americans with Disabilities Act. COMPACT, *supra* note 94.

<sup>96</sup> *Id.*

Should the continued development, implementation, and enforcement of the Compact give rise to an alternate grievance procedure, such change stands to benefit military children significantly. Given the lengthy duration of IDEA's due process procedures, military families may be required to relocate prior to a conflict's resolution. If the Compact were to facilitate a faster resolution of grievances, as a legal assistance attorney might advocate, schools would have less incentive to draw out the process waiting for military families to move. Maximizing educational opportunities for the special needs child is only one aspect of preparing for the child's future, however. As detailed in the next section, parents must also evaluate the child's anticipated capabilities and needs, and plan accordingly.

## VI. Planning for the Child's Future

In order to help clients prepare for the future of the special needs child, legal assistance attorneys should inquire regarding the nature of the child's disability and level of capacity. Obtain details regarding the disability to include whether it is progressive, how long it is anticipated to last, and its impact on the functional abilities of the child. Of particular importance, ascertain the anticipated future needs of the special needs child: whether the child can manage personal affairs and live independently, whether the child receives government benefits such as SSI or Medicaid, and whether the child will receive an inheritance or family assistance. Answers to these questions will help determine whether the clients should seek guardianship of their adult child, or execute a special needs trust to safeguard receipt of public benefits.<sup>97</sup>

### A. Adult Guardianship<sup>98</sup>

A critical component of planning for the future of the special needs child is to assess whether the child will be able to live independently and, if not, make arrangements for the future. Ordinarily, when a child attains the legal age of majority, eighteen years of age in most states, it is assumed that the child is capable of making personal health, finance, and other planning decisions. If doubt exists as to whether the child will be capable of making these decisions responsibly, however, it may be appropriate and necessary for the client to secure legal guardianship of the special needs child after the child reaches majority.

---

<sup>97</sup> See, e.g., Anthony J. Enea, *The ABC's of SNTs (Special Needs Trust)*, 35 WESTCHESTER B.J. 25, 25-26 (2008) (detailing a sample checklist of questions for attorneys preparing to draft a special needs trust).

<sup>98</sup> Some states use the term "conservatorship" instead. See, e.g., CAL. PROB. CODE div. 4, pt. 3 (West 2013) (Conservatorship); CONN. GEN. STAT. ANN. tit. 45a, ch. 802H, pt. IV (West 2013) (Conservators).

Although parents of special needs children are not legally required to become their adult child's guardian, if no affirmative action is taken when the child reaches the age of majority, the child will be considered an autonomous adult regardless of the child's disabilities. As a consequence, the parents would be excluded from financial or medical information or decisions relating to the adult child.<sup>99</sup> Simultaneously, the adult child could enter into contracts or be deemed by medical personnel to be incompetent to approve needed but non-emergent medical services.

The procedure by which to obtain legal guardianship varies from state to state by statute.<sup>100</sup> Typically, a guardianship petition requires an evaluation by a physician as well as a psychologist or psychiatrist showing that the child is not mentally capable of operating independently. The court will also appoint a guardian ad litem to protect the interest of the disabled individual who is the subject of the petition. If the client moves to a new state after establishing guardianship, the client must reapply for guardianship of the special needs child in the new state.<sup>101</sup>

## B. Special Needs Trust

For the client whose child qualifies for receipt of Medicaid, SSI, or other public programs, future planning must also address methods to safeguard receipt of these benefits.<sup>102</sup> In light of how limited the child's resources can be to establish and maintain eligibility for such benefits, attorneys should exercise great care to help the client avoid a variety of potential estate planning pitfalls. Of particular concern is the client who gives no thought to what happens to her assets when she dies, fails to re-visit her estate plan despite the onset of the dependent child's disability, or requests a "simple" will leaving all her assets first to her spouse and next to her children.

<sup>99</sup> In the absence established guardianship or valid general durable power of attorney, the impact of the privacy rules of the federal Health Insurance Portability and Accountability Act (HIPAA), 42 U.S.C. § 1320d (2011), can prove particularly disastrous for an adult special needs child requiring medical treatment who is unable to give informed consent. See Sebastian V. Grassi, Jr., *Estate Planning for a Family with a Special Needs Child*, PROBATE & PROP., July–Aug. 2009, at 14, 20. Under HIPAA, which applies to all patients over the age of 18, medical personnel would not be able to discuss the adult child's medical condition with the parents without the child's consent upon penalty of being fined or jailed. *Id.*

<sup>100</sup> See *Guardianship Information by State*, BRIDGING REFUGEE YOUTH & CHILDREN'S SERVS., <http://www.brycs.org/guardianship/guardianship-information-by-state.cfm> (last visited May 15, 2013) (providing state by state information on minor guardianship, which can be used as a starting point for finding information on adult guardianships/conservatorships).

<sup>101</sup> See Sally Balch Hurme, *Crossing State Lines: Issues and Solutions in Interstate Guardianships*, 37 STETSON L. REV. 87, 110–12 (2007).

<sup>102</sup> The knowledge of estate planning techniques needed to safeguard receipt of public assistance is more complex than simple will or trust planning. It is beyond the scope of this primer to address property transfers or asset reduction techniques utilized for or by disabled individuals to qualify for Medicaid subsidization of long-term care needs.

Generally, there are four estate planning options available to special needs families.<sup>103</sup> However, significant risk is associated with three of these options: giving assets directly to the special needs child; disinheriting the special needs child by specifically excluding him by name in the will; and distributing property by the will to a client's relative or friend with the expectation or understanding that the property will be used for the special needs child. Only the fourth option ensures that the special needs child remains eligible for basic government subsidies while making assets available to enhance the child's standard of living: establishing a Special Needs Trust (SNT), either through a will ("testamentary")<sup>104</sup> or during the client's lifetime ("inter vivos").<sup>105</sup>

The Omnibus Budget Reconciliation Act of 1993 (OBRA 93) defines two categories of SNTs funded by the assets of the individual with special needs, known as "self-settled trusts," that allow the beneficiary to receive benefits from public programs.<sup>106</sup> First, a self-settled "(d)(4)(A)" trust,

<sup>103</sup> See Grassi, *supra* note 39, ¶ 907; Grassi, *supra* note 99, at 16. Mr. Grassi describes five estate planning options including not only the four set out in this primer, but also the possible creation of a third-party discretionary support trust for the special needs child; Mr. Grassi does not, however, recommend this option as it may serve to disqualify the child from receiving certain government benefits and it is not further discussed herein. Appendix C provides an information paper to help parents understand the four estate planning options for a special needs child as discussed in this primer.

<sup>104</sup> Although the Army does not specifically prohibit legal assistance attorneys from drafting testamentary SNTs, unlike the Navy and Marine Corps, Army practitioners may lack the necessary experience or training to become competent to do so. See, e.g., *supra* note 18 and accompanying text; Renz, *supra* note 33, at 46 (noting that Navy and Marine Corps legal assistance attorneys "are not authorized to draft SNTs"). For a more in-depth discussion regarding counseling legal assistance clients about SNTs, see Renz, *supra* note 33. Nevertheless, consultation and client pro bono referral information is available to enrolled, military attorneys through the American Bar Association's Military Pro Bono Project, available at [www.militaryprobono.org](http://www.militaryprobono.org). This invaluable and likely underutilized resource makes it possible for military attorneys to connect with subject matter experts the Army lacks, yet which are needed to understand and assist their clients. Although it is the author's recommendation that the Army follow the example set by the Marine Corps through the hire of attorneys dedicated to the provision of legal support to special needs families, in the absence of such change, legal assistance attorneys should utilize all available resources to assist their clients with this critical legal assistance mission. See AR 27-3, *supra* note 10, para. 3-6b (noting that "[l]egal assistance will be provided on wills"); *supra* note 17 (discussing Marine Corps EFMP attorneys).

<sup>105</sup> Inter-vivos SNTs are beyond the scope of the legal assistance program, but are generally preferred by practitioners as they provide the trustee with the "maximum flexibility to meet the beneficiary's needs and maintain the beneficiary's eligibility for government benefits." Grassi, *supra* note 99, at 16–17 (noting that the third-party created and funded special needs trust can, for example, be structured to receive gifts, bequests, and inheritances from other relatives or friends in addition to the parents and obviate the need for separate third-party created and funded SNTs).

<sup>106</sup> Omnibus Budget Reconciliation Act of 1993, Pub. L. No. 103-66, § 13611, 107 Stat. 312, 622 (1993) (amending 42 U.S.C. § 1396p (2011)). The Foster Care Independence Act of 1999, Pub. L. No. 106-169, § 205, 113 Stat. 1822, 1833–34 (1999) (codified at 42 U.S.C. 1382b(e) (2011)), clarified the use of these trusts to preserve SSI eligibility. See Grassi, *supra* note 39, ¶ 911.1; see also Gail C. Eichstadt, *Essay: Using Trusts to Provide for the Needs of an Adult Child with a Disability: An Introduction to Family*

named for the applicable subsection number in the U.S. Code, may be used to qualify a Medicaid applicant otherwise disqualified due to having assets or income in excess of state restrictions.<sup>107</sup> The “(d)(4)(A)” SNT is subject to a Medicaid payback requirement upon the death of the beneficiary, however.<sup>108</sup> Second, “pooled” or cooperative master trust (“(d)(4)(C)” trust) combines together the assets of multiple beneficiaries and are managed by a nonprofit association.<sup>109</sup> When the beneficiary dies, the balance of the “pooled” SNT is retained for the benefit of other trust beneficiaries.<sup>110</sup>

Whereas self-settled SNTs, above, find their origin in federal statutes, trusts funded with the assets of third-parties (“non-self-settled trusts”) should originate in state common law.<sup>111</sup> Although it is possible to draft a non-self-settled SNT funded with the assets of parents or grandparents under OBRA 93,<sup>112</sup> this practice is not recommended in order to avoid the requirement of a Medicaid payback when the beneficiary dies.<sup>113</sup> Whatever the origin of the SNT, such trusts are designed to supplement funds available for discretionary expenses without displacing receipt of public benefits for people with disabilities.<sup>114</sup> Whereas SSI provides cash payments for food and shelter and Medicaid pays for medical bills, trust proceeds can be used for all other needs identified in the trust document, such as special equipment,

vacations, or a personal attendant.<sup>115</sup>

## VII. Conclusion

Legal assistance attorneys should be aware of the life-long needs of clients with special needs children and be prepared to provide counsel regarding available benefits, special education law, guardianships, and wills. The consequences of unresolved legal problems for these families demand that attorneys develop a working knowledge of the applicable legal concerns, rights, and remedies in order to advise them competently. Similarly, the incalculable negative impact on a child’s potential and wellbeing if not connected with all available resources inspires the practitioner to address not only the client’s stated concerns, but also the legal needs of which the client might be unaware.

For the growing number of families who find themselves in “Holland” raising a child with special needs, the myriad legal issues that present themselves come without a passport or guidebook.<sup>116</sup> The stress and difficulties inherent in raising a child with a physical, developmental, or behavioral impairments increase exponentially for mobile, military families that must secure anew needed services and support every time they move. In addressing these challenges, legal assistance attorneys may serve as navigators by working to illuminate and resolve for their clients problems both seen and unforeseen.

---

*Concerns for Lawyers and a Primer on Trusts for Parents*, 45 S.D. L. REV. 622, 630–34 (2000).

<sup>107</sup> 42 U.S.C. § 1396p(d)(4)(A).

<sup>108</sup> *Id.*

<sup>109</sup> *Id.* § 1396p(d)(4)(C).

<sup>110</sup> *Id.* “Pooled” trusts have not gained widespread use. April Caudill, *Special Needs Trusts and Retirement Benefits*, 34 TAX MGMT EST., GIFTS & TR. J. 257, 257 (2009).

<sup>111</sup> MARGARET “PEGI” S. PRICE, *THE SPECIAL NEEDS CHILD AND DIVORCE* 192 (2009) (reproducing a section on estate planning for a special needs child written by Joseph A. Burcke, a Missouri estate planning attorney). Estate planning attorney Joseph Burcke identifies eight provisions either a testamentary or inter-vivos non-self-settled SNT should contain: (1) a statement that the trust is irrevocable, as required by SSI; (2) a “spendthrift” provision, to exempt inclusion of trust assets for public benefit eligibility; (3) the trust should *not* contain any provision that provides the child a “power of appointment” over any of the trust’s principal or income; (4) a statement that the trustee’s discretion in making distribution is absolute and the special needs child is not entitled to any distribution “as a matter of right;” (5) a statement of trust purpose, the purpose being “to provide for the disabled beneficiary’s needs that are *not provided by public benefits*;” (6) if the child owns assets, a statement that precludes the trustee from including such property in the SNT; (7) a provision allowing the trustee to use trust funds to defend claims by federal or state officials seeking to count trust assets as resources of the special needs child; and, finally, (8) a “savings” clause. *Id.* at 194–95 (emphasis in original); *see also* Caudill, *supra* note 110 (discussing drafting challenges for funding special needs trusts with retirement benefits).

<sup>112</sup> *See* 42 U.S.C. § 1396p(c)(2)(B)(iii).

<sup>113</sup> Grassi, *supra* note 99, at 16.

<sup>114</sup> Patricia Tobin, *20/20 Foresight: Planning Ahead for Special Needs Trusts*, PROBATE & PROP., May–June 1997, at 56, 57–58.

---

<sup>115</sup> *Id.*; *see also*, e.g., Andrew H. Hook, *Special Needs Trusts*, ALI-ABA COURSE OF STUDY MATERIALS: COURSE no. SM054 (Sept. 2006).

<sup>116</sup> *See*, e.g., Van Buren, *supra* note 21 (reprinting in full Emily Perl Kingsley’s essay, *Welcome to Holland*).

## Appendix A

### Checklist of Life-Stage Special Needs Planning Considerations

#### Stage I: Birth to Age 3 of Child

- **Diagnosis**
  - What is the child's current prognosis, treatment, and life expectancy?
  - Is the child enrolled in the Exceptional Family Member Program (EFMP)?
  - Is the child eligible for assistance under public benefit programs such as Supplemental Security Income (SSI), Medicaid, or Medicaid waivers?
  - Are the parents connected to recent and relevant information regarding their child's disability?
- **Education.** Is the child receiving early intervention services pursuant to an individual family service plan (IFSP) under the Individuals with Disabilities Education Act (IDEA)?
  - If the state fails to provide early intervention services or they are inadequate, is the child receiving needed services or therapy under TRICARE?
  - Have the parents consulted the local EFMP manager regarding other potential medical, educational, and community resources?
- **Estate Planning.** Have the parents updated their wills subsequent to the child's diagnosis as having special needs? (See Appendix C). If so, do the wills contain Special Needs Trusts (SNT)? If not or if existing wills do not contain a SNT, is a SNT needed? Sample factors and questions to help determine whether a SNT is required and, if so, what it should contain include the following:<sup>117</sup>
  - (1) What is the nature of child's disability and level of capacity? If incapacitated, is the incapacity mental or physical? How long has the child been disabled? Is the underlying illness progressive? What is the expected duration of the disability?
  - (2) What are the functional limitations and capabilities of the child?
    - (a) Can the child attend to personal hygiene, cook, or clean? Can the child handle finances and live independently?
    - (b) Can the child participate in decisions?
    - (c) Is the child employed? If so, what kind of job does the child have and how much does it pay?
    - (d) What is the child's educational level? Does the child have any special training or skills?
  - (3) Where does the child currently reside? What housing will the child need in the future: apartment rental; living with family; group home; institutional? Is the anticipated housing subsidized by the federal government?
  - (4) What government benefits is the child receiving: SSI; community-based Medicaid benefits; institutional benefits?
  - (5) What are the anticipated needs of the child?
  - (6) What potential sources of assets does the child have?

#### Stage II: Age 3 to Age 18 of Child

- **Education.** Is the child receiving special education services pursuant to an individualized education program (IEP) under the IDEA? (See Appendix B).
- **Estate Planning.** Have the parents reviewed their child's finances and parental estate plan consistent with the child's capabilities and needs? (See "Estate Planning," above, and Appendix C). If the child were to acquire named as a beneficiary under, for example, a Uniform Gift to Minors Act account, this might jeopardize the child's eligibility for government benefits when the trust terminates at age 18 or 21. Parents should take care to evaluate the following common assets and beneficiary designations to ensure that they will not be paid directly to the special needs child receiving government benefits:<sup>118</sup>
  - (1) retirement benefits including IRAs, 401(k)s;
  - (2) life insurance;
  - (3) insurance benefits provided through credit cards for accidental death and travel insurance;
  - (4) annuities;
  - (5) savings bonds;

---

<sup>117</sup> Enea, *supra* note 97, at 25–26 (listing sample questions for client assessment from which this excerpt is derived).

<sup>118</sup> Grassi, *supra* note 99, at 18–19.

- (6) any non-probate or non-trust property;
- (7) Uniform Gifts to Minors Act (UGMA), or Uniform Transfers to Minors Act (UTMA) accounts;
- (8) designations on accounts, savings bonds, or securities which are Transfer on Death (TOD), Pay on Death (POD), or In Trust For (ITF);
- (9) any inheritance, gift, or bequest to the child through another person's will or trust;
- (10) deeds;
- (11) joint accounts;
- (12) an jointly owned property including real estate;
- (13) final paycheck;
- (14) any collectibles, antiques, or family heirlooms;
- (15) personal injury and wrongful death proceeds payable to the parent's estate; and
- (16) homestead laws, such as contained in Florida law, that give the surviving spouse a life estate in real property and minor children a vested remainder interest in the property.
- **Transition Planning.** Have the parents begun to plan for when the child turns 18?

### Stage III: Adult Child

- **Education.** Is the adult child still receiving special education services pursuant to an IEP under the IDEA? The child remains eligible for special education services until he or she turns 21. (*See Appendix B*)
- **Estate Planning.** Have the parents reviewed their estate plan consistent with the child's capabilities and needs? (*See "Estate Planning," Stages I-II above, and Appendix C*).
  - Who will act as advocate for the adult child once parents die?
  - Letter of intent: guide for a future caregiver regarding parent's wishes for child and child's medical, social, and personal information
  - Child's likes and dislikes: food, clothes, doctors, music, therapy, medications, religious wishes
- **Transition Planning.**
  - Self-sufficiency versus Guardianship/Conservatorship?<sup>119</sup>
    - Is the adult child is capable of making personal health, finance, and other planning decisions? (This decision may need to be made by an appropriate medical professional). If so, should the child name an agent through a Power of Attorney to make decisions or assist with certain tasks such as handling financial or medical decisions?
    - Does the adult child lack the capacity to name agents to act on his or her behalf? If so, parents may need to secure legal guardianship.
  - Is the adult child eligible for SSI? The test of disability is different for children and adults, and turning 18 requires review of SSI eligibility. Living arrangements?
  - Social Support?
  - Medical Support? Health care and health insurance:
    - If an unmarried adult child of a military sponsor is disabled due to a condition that existed prior to the child's 21st birthday, the child may be entitled to TRICARE benefits and other identification card privileges.
      - Is the adult child eligible for Medicaid?
  - Transportation?
  - Daily activities?
  - Job?
  - Day program?
  - Sheltered workshop?

### Stage IV: Retirement, Disability, or Death of a Parent

- Is a parent eligible for Medicare? If so, the parent's spouse, minor children, and disabled adult children may also qualify for Medicare benefits.
- Is a parent of the child disabled, retired, or deceased? If so, it is possible for a dependent special needs child who was disabled before the age of 22, and not a worker, to qualify for Social Security Disability payments based on the parent's past earnings record.
- Have the parents reviewed their estate plan recently consistent with the child's capabilities and needs?

<sup>119</sup> Nicole Vandiver Bryan, *Planning Ahead for When Your Special Child Turns 18*, EXCEPTIONAL PARENT, Mar. 2010, at 57–58.

## Appendix B

### Sample Special Education Information Paper

The information contained below is suitable for use in an information paper provided to a client in a Legal Assistance Office either upon consultation with a legal assistance attorney, or for “self-service” with other preventative law materials. As laws and regulations in this area can change, always ensure the information is still accurate before providing to clients.

1. Purpose. To inform special needs families regarding critical special education services, processes, and procedural safeguards set forth in federal law.

2. References.

a. Individuals with Disabilities Education Act (“IDEA”), 20 U.S.C. §§ 1400–1482.

b. Family Educational Rights and Privacy Act (“FERPA”), 20 U.S.C. § 1232g

c. NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES, QUESTIONS OFTEN ASKED BY PARENTS ABOUT SPECIAL EDUCATION SERVICES (2009), *available at* <http://nichcy.org/wp-content/uploads/docs/lgl.pdf>.

3. Discussion. Special education is instruction that is specially designed to meet the unique needs of children who have disabilities. Special education and related services are provided in public schools at no cost to the parents and can include special instruction in the classroom, at home, in hospitals or institutions, or in other settings. This definition of special education comes from the Individuals with Disabilities Education Act (IDEA). This law gives eligible children with disabilities the right to receive special services and assistance in school.

a. Eligibility. Children with disabilities are eligible for special education and related services when they meet IDEA’s definition of a “child with a disability” in combination with state and local policies. IDEA’s definition of a “child with a disability” lists 13 different disability categories under which a child may be found eligible for special education and related services:

- (1) Autism;
- (2) Deafness;
- (3) Deaf-blindness;
- (4) Hearing impairment;
- (5) Mental retardation;
- (6) Multiple disabilities;
- (7) Orthopedic impairment;
- (8) Other health impairment;
- (9) Serious emotional disturbance;
- (10) Specific learning disability;
- (11) Speech or language impairment;
- (12) Traumatic brain injury;
- (13) Visual impairment, including blindness.

b. Determination of Eligibility. You can ask the school to *evaluate* your child. Call or write the director of special education or the principal of your child’s school. Describe your concerns with your child’s educational performance and request an evaluation under IDEA, to see if a disability is involved. The school does not *have* to evaluate your child just because you have asked, however. Alternatively, the public school may also be concerned about how your child is learning and developing. If the school thinks that your child may have a disability, then it *must evaluate your child at no cost to you*. The school must ask your permission and receive your written consent before it may evaluate your child. The evaluation and placement process is as follows:

(1) Parent, teacher, or other knowledgeable person refers student who is suspected of having a disability and needing special education to school officials.

(2) School officials notify student’s parents or caregivers that the student has been referred for evaluation, and provide the reasons for the referral.

(3) School official request parental consent to evaluate the student.

(4) Within 60 days of obtaining parental consent, the multidisciplinary team completes an evaluation of student which addresses all areas of suspected disability.

(5) School officials meet to discuss the results of the evaluation and determine whether special education services are needed by the student and, if so, develop an individualized education program (IEP).

(6) Educators draft and present an IEP to the student's parents. The parents may accept, reject, negotiate an alternative IEP, or delay making a decision regarding the IEP to seek an independent evaluation. If accepted, the IEP is implemented immediately. If rejected, the IDEA's dispute resolution procedures are triggered.

(7) School officials ensure that the IEP is reviewed annually, and the student is re-evaluated at least once every three years.

c. Required Elements of an IEP: After a child has been found eligible for special education services, the next step is to write and implement an IEP. After an eligibility determination, educators and parents must hold a meeting within 30 days to develop the IEP. The IEP has two general purposes: to set learning goals for your child; and to state the supports and services that the school district will provide for your child. Required elements of the IEP include the following:

- (1) Statement of a child's current level of academic and functional performance;
- (2) Measurable, annual academic and functional goals for the child;
- (3) Description of how school officials will measure the child's progress towards meeting annual goals, and when periodic reports will be provided;
- (4) Statement of special education and related services or aids the child will receive;
- (5) Explanation of the extent to which child will not participate in regular classes with non-disabled peers;
- (6) Statement of the accommodations necessary to assess the child's academic achievement and functional performance on state and district assessments;
- (7) Anticipated date of initiation and duration of special education services the child will receive;
- (8) For an IEP to be in effect for a student who is 16 years old or older, a statement of measurable post-secondary education goals and transition services;
- (9) For an IEP for a child who will reach the age of majority in no less than one year, a statement that the student has been informed of his or her rights, if any, which will transfer at the age of majority.

d. IEP Meeting. The law is very clear that parents have the right to participate in developing their child's IEP. In fact, your input is invaluable. You know your child so very well, and the school needs to know your insights and concerns. That's why IDEA makes parents equal members on the IEP team. Parents can prepare for this meeting by:

- (1) Making a list of your child's strengths and needs;
- (2) Talking to teachers and/or therapists and getting their thoughts about your child;
- (3) Visiting your child's class and perhaps other classes that may be helpful to him or her;
- (4) Talking to your child about his or her feelings toward school;
- (5) Writing down what you think your child can accomplish during the school year;
- (6) Looking at your state's standards for your child's grade level;
- (7) Making notes about what you would like to say during the meeting.

e. IDEA Related Services. The IEP team will also talk about the *related services* your child may need to benefit from his or her special education. Review of these services prior to an IEP meeting may prove beneficial. The IDEA lists many related services that schools must provide if eligible children need them, including the following:

- (1) Audiology;
- (2) Counseling services (including rehabilitation counseling);
- (3) Interpreting services;
- (4) Medical services for diagnostic or evaluation purposes;
- (5) Occupational therapy;
- (6) Orientation & mobility services;
- (7) Parent counseling and training;
- (8) Physical therapy;
- (9) Psychological services;
- (10) Recreation (including therapeutic recreation);
- (11) Speech-language pathology services;
- (12) School health services and school nurse services;
- (13) Social work services in schools; and
- (14) Transportation.

f. Parental Rights. You have the right to disagree with the school's decisions concerning your child. This includes decisions about: your child's identification as a "child with a disability;" his or her evaluation; his or her educational placement; and the special education and related services that the school provides to your child. IDEA provides parents with many due process safeguards:

- (1) Opportunity to examine all of the child's records;
- (2) Opportunity to participate in all meetings related to the identification, evaluation, and educational placement of child;
- (3) Receipt of a free appropriate education for the child;
- (4) Opportunity to obtain an independent educational evaluation of child at own expense. An independent evaluation of the child at public expense is only permissible if the parents demonstrate that the school board's evaluation was inappropriate.
- (5) Notification in writing of any proposed change in child's placement and an opportunity to contest the change. The notification should include the following: a description of the proposed change; if other options were considered, an explanation as to why they were rejected; a description of any assessments or relevant factors used in determining the proposed change; and an explanation of IDEA's due process safeguards.
- (6) A due process hearing regarding proposed change in the child's placement to which the parents object.

## Appendix C

### Sample Supplemental Information Paper Regarding Estate Planning for Special Needs Children

The information contained below is suitable for use as a supplement to an estate planning information paper provided to a client in a Legal Assistance Office either upon consultation with a legal assistance attorney, for preparation in anticipation with consulting with an estate planning attorney, or for “self-service” with other preventative law materials. As laws and regulations in this area can change, always ensure the information is still accurate before providing to clients.

1. Purpose. To provide special needs families basic information regarding estate planning considerations either in preparation for, or as a supplementation to consultation with an attorney.

2. References.

a. Omnibus Budget Reconciliation Act of 1993 (“OBRA 93”), 42 U.S.C. §§ 1382b(e)(5), 42 U.S.C.A. § 1396p(d)(4).

b. Sebastian V. Grassi, Jr., *Special Needs Requires Special Attention: Estate Planning for a Family with a Special Needs Child*, 43 INST. ON EST. PLAN. ¶ 907 (2009).

3. Discussion.

a. In preparing for the future needs of your child with a disability, you must first determine your goals for the child and what living arrangements you want for your child during adulthood. You should make a conservative assessment regarding whether you expect that your child will continue to require lifetime care or oversight to manage his personal affairs. For purposes of this information paper, it is assumed that your special needs child is not capable of living autonomously.

b. Even if you want to support your special needs child for the child’s entire life, this arrangement may not be feasible financially or practically with expected life spans even for children with disabilities expanding with advancements in medical care. Although planning for your death and your child’s adult years may be difficult or even depressing, delaying this process is fraught with risk to our child. The alternative to full parental support is public assistance programs such as Medicaid and Supplemental Security Income (SSI). Receipt of public benefits contingent on the applicant having total assets of less than \$2,000, however. Should you fail to take action to ensure your child will not inherit assets or property directly from you so as to jeopardize receipt of public benefits, you may significantly compromise and impoverish your child’s quality of life.

c. Establishing an estate plan for your special needs child requires careful consideration of your goals, resources, and consultation with an attorney. Nevertheless and as a starting point for consideration or consultation, listed below are four potential estate planning options.

- (1) Giving assets directly to the special needs child. This option is not recommended because receiving the assets would likely disqualify the child from public benefits. Be advised that your failure to “choose” an estate planning option would likely result by default in the execution of this option. In other words, should you fail to establish an alternate estate plan, upon your death your child would likely inherit property from you outright under state law.
- (2) Disinheriting the special needs child by specifically excluding him by name in your will. Although this arrangement might maintain your child’s financial eligibility for Medicaid and SSI, it is not recommended. First, disinheriting your child would render him dependent on Medicaid and SSI for all support needs. Second, your child would have nothing to fall back on should government benefits later be reduced or eliminated.
- (3) Distributing property by your will to a relative or friend with the expectation or “understanding” that the property will be used for the special needs child, whom you have excluded by name in your will. As appealing as this option might appear because it is simpler than a trust, it is also not recommended. First, the arrangement would not be legally enforceable. You would have no way to insure that the recipient of the property would fulfill your wishes after you die; the recipient would be the legal owner of the property and could sell or squander the assets as the recipient desires. Second, even assuming the recipient desires to give effect to your wishes to use the property for your child, the assets might nevertheless be taken (“seized”) by the recipient’s creditors or ex-spouse.

- (4) Establishing a Special Needs Trust (SNT) either through your will (“testamentary”), or during your lifetime (“inter vivos”). Establishing a SNT is highly recommended because the funds in the trust would not be counted as assets of the child so that the child could continue to receive Medicaid and SSI for basic support needs. The SNT is designed to supplement but not replace the proceeds provided by Medicaid and SSI. Consequently, the law requires that the proceeds from the SNT cannot be used for the child’s food, shelter and clothing because these benefits are provided by Medicaid and SSI. Nevertheless, money from the trust can be used for things that may improve the child’s quality of life including such items as recreation and transportation, telephone and television services, mobility aids, prescription medications, and periodic outings and vacations.