

THE FUTURE OF PLANNING FOR PERSONS WITH DISABILITIES: WHAT CHALLENGES WILL ARISE?

By Kevin Urbatsch, Esq. and Michele Fuller, Esq.

I. INTRODUCTION	XX
II. A TOO BRIEF SUMMARY OF TREATMENT OF PERSONS WITH DISABILITIES THROUGHOUT HISTORY	XX
III. THE FUTURE PERSON WITH A DISABILITY	XX
A. Expected Number of Persons with Disabilities Will Increase Over the Next 30 Years	XX
B. Children with Disabilities over the Next 30 years: The Impact of Asthma, Premature Birth and Obesity	XX
1. Asthma	XX
2. Premature Birth	XX
3. Obesity and Diabetes	XX
C. The Dramatic Rise of the Number of Persons with Autism	XX
1. Number of People Diagnosed with Autism	XX
2. How Is Autism Defined?	XX
3. What is the Current Diagnosis for Autism?	XX
4. The Future Change to the Diagnosis of Autism/Asperger's, will be known as Autism Spectrum Disorder (ASD)	XX
5. What is the Cause of Autism?	XX
6. Personal Experience with Autism	XX
7. How Should the Future Special Needs Planner Prepare for the Person Diagnosed with ASD?	XX
D. Aging with Disabilities: Uncharted Territory	XX
E. The New Eugenics Movement? More Subtle and More Effective in Reducing the Total Number of Persons with Disabilities	27
1. The Recently Developed Genetic Test	XX
2. Number of Selective Abortions Under Former Prenatal Tests	XX
3. Ethical Considerations For Persons with Disabilities	XX

Kevin Urbatsch is a Special Needs and Elder Law planning attorney located in San Francisco, Calif. He is Co-Executive Editor for *NAELA Journal*, the National Director and Advisory Board Member for the Academy of Special Needs Planners (ASNP), and a Certified Specialist in Estate Planning, Trust, and Probate Law by the California State Bar Board of Legal Specialization. He is the author of several books on special needs planning, including *Administering the California Special Needs Trust*. He is a frequent lecturer on special needs planning and administration for national, state, and local organizations.

Michele P. Fuller is a Special Needs and Elder Law attorney in Sterling Heights, Mich. She is an Advisory Board member of the Academy of Special Needs Planners, member of the National Academy of Elder Law Attorneys, member of the Board of Directors of the Michigan NAELA Chapter, council member of the Elder Law and Disability Rights section of the State Bar of Michigan, Vice President of the Macomb County Probate Bar Association, and editor of their newsletter, *The Quarterly Petition*. She is a frequent lecturer and writer on Special Needs and Elder Law issues, and author of the pending *Michigan Pooled Trust Act*.

IV. THE FUTURE OF ACCESS TO FINANCIAL ASSISTANCE AND HEALTH CARE

BENEFITS FOR PERSONS WITH DISABILITIES..... XX

A. The Special Needs Trust..... XX

B. Fighting for the Preservation of Existing Rights..... XX

C. New Financial Planning Tools May be Available..... XX

D. Affordable Care Act..... XX

V. CONCLUSION XX

I. INTRODUCTION

The authors have been asked to contemplate the future of special needs planning. Special needs planning is a broad term that can mean different things to different people, but for purposes of this article, we use the term to encompass the legal, personal, and financial planning that enhances the quality of life of a person with a disability to allow that person to reach their full potential.

An inherent foolishness exists in attempting to predict future events. As one historical figure noted:

It is a mistake to try to look too far ahead. The chain of destiny can only be grasped one link at a time.

— Winston Churchill

But, as another historical figure of (almost) equal importance noted:

I look to the future because that's where I'm going to spend the rest of my life.

— George Burns (at age 87)

The authors will attempt to ignore the inherent foolishness of this endeavor, because the future is where the rest of their lives will be spent. To prognosticate the future, the authors spent considerable time looking into the past. By reviewing past developments and how the current status of special needs planning arose, the authors believe that certain future events will be better prophesized.

The problem the authors encountered is the overall size of the task. Persons with disabilities come from all walks of life; both the rich and the poor and everyone in between. Some persons with developmental disabilities have had such disabilities since birth, others acquired disabilities due to aging, or others became disabled as a result of injuries or accidents suffered during their lifetime. Some people have physical disabilities, while others have mental disabilities. Thus, the special needs planning issues for a person with autism or Down syndrome may be much different than for a person who is blind or uses a wheelchair for mobility issues that arose after he or she became an adult.

To divine the future, the authors concentrated on some common themes that the special needs practitioner can expect to see. The most significant issue the authors see will be the overall number of persons with disabilities who will require planning. Certain types of disabilities will significantly increase due to the explosion of autism cases and an ag-

ing population; while due to advances in genetic testing, other types of disabilities, such as Down syndrome and other developmental disabilities, may virtually disappear. Also, a new type of disability may arise, possibly called an avoidable disability or voluntary disability. Certain studies have indicated that the prevalence of childhood obesity and Type-2 diabetes will create a tsunami of disability and health-related conditions as these young, obese people age. Will the government agree to use ever-shrinking government programs to aid these persons or will private plans need to be developed?

The next major issue that will arise is maintaining the gains the disability rights movement has obtained for persons with disabilities. Recent efforts by the disability rights community have created several planning options for persons with disabilities that have never existed before. Historically, persons with disabilities were unable to participate in society due to barriers that excluded them from access to employment, health care, and society in general. Due to the efforts of many advocates, some of these barriers have been lessened. The issue that is arising is the backlash against the small gains made by persons with disabilities.

Government officials are attempting to reduce the benefits of many of the planning options available for persons with disabilities. The reasons are both political and practical. Politically, some government officials do not believe that any person should use government services if they (or family members) have any money available to them. Others are attempting to cut the number of persons with disabilities receiving benefits by creating additional barriers through “policy decisions” or overly stringent enforcement of public benefit eligibility rules. The special needs planner will need to be ever vigilant against these efforts by these misguided government officials and will need to have access to proper resources to advocate against these reductions.

The good news for persons with disabilities is the legal and technological advances made to allow better access to the community. The biggest of these is the recently passed Affordable Care Act (ACA). This Act will have a profound impact on the future health of persons with disabilities. The ACA is but one piece of legislation; others that have been proposed are the Achieving a Better Life Experience Act (ABLE) financial savings account for persons with disabilities. These, and other proposed planning tools would allow more freedom for persons with disabilities to plan and live independent lives.

The future of special needs planning will have its share of challenges, but special needs practitioners will have the dedication and can develop the tools to meet those challenges. It is imperative though, that the special needs planner remain watchful so he or she can combat the pervasive discrimination and biases that still color many aspects of the lives of persons with disabilities. Thus, to know where special needs’ planning is headed, it is imperative to see where it has been.

II. A TOO BRIEF SUMMARY OF TREATMENT OF PERSONS WITH DISABILITIES THROUGHOUT HISTORY

Current United States government policy towards persons with disabilities accepts that they are an integral part of society and, as such, should not be segregated, isolated, or subjected to the effects of discrimination. This is evident in the text of the American with Disabilities Act, which states:

The Congress finds that:

1. physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination; others who have a record of a disability or are regarded as having a disability also have been subjected to discrimination;
2. historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;
3. discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;
4. unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;
5. individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;
6. census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;
7. the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and
8. the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.¹

The enactment of the American with Disabilities Act in 1990 was a watershed mo-

1 42 U.S.C. § 12101(a).

ment in how the United States government changed its position in its treatment of persons with disabilities. While the government had created the world's leading law that benefited persons with disabilities, society at large has been slower to adopt the principles set forth in that law.

People's treatment of persons with disabilities throughout history is generally a mixed bag, most of it negative. As described by one author:

There is no unified worldview of disabilities and those who have them. The world's societal views appear to be somewhat schizophrenic with regard to persons with disabilities. On the one hand[,] some societies in an attempt to assist persons with disabilities attain some measure of freedom have taken a somewhat paternalistic approach. While well meaning, this approach often subjects the person with a disability to unwanted sympathy and pity. Too frequently, the paternalistic approach smothers the person with good intentions and stunts the person's emotional and psychological growth. On the other hand, some societies have tended to view persons with disabilities as expendable humans; persons of little societal value, to be segregated and separated from the mainstream of society and yes, in some cases, persons to be exterminated.²

Any generalization of society's treatment of persons with disabilities will fail to accurately detail all the differences that abound around the world. Researchers have attempted to generalize the treatment of persons with disabilities throughout history;³ one attempt is as follows:⁴

2 Willie V. Bryan, *In Search of Freedom, How Persons with Disabilities Have Been Disenfranchised from the Mainstream of American Society and How the Search for Freedom Continues* 13–14 (Charles C. Thomas 2009).

3 "Interpreting disability in antiquity is difficult in that the time span considered is vast, and competing attitudes toward disability are evident at many points. Writings from the Old Testament suggest paradoxical attitudes, which exhorted society to be generous and kind toward individuals with impairments, while also declaring that impairment was a mark of the wrath of God. Ancient Greece and Rome offer similarly complex interpretations of impairment. The killing of newborns with congenital impairments existed in some form throughout Greece and Rome, and society clearly perceived the birth of a child with congenital anomalies as the mark of the anger of the gods. However, the provision of pensions to soldiers injured on the battlefield was also a part of ancient Athenian life, and citizens with impairments were widely known to have worked at different trades. Impairment at the time of Christ was similarly fraught with different meanings, offering both redemption opportunities for kind strangers and signifying superstition. In the ancient world, impairment was accepted, at least in part, as an aspect of the course of life." David L. Braddock & Susan Parish, *Handbook of Disability Studies* 17 (Sage Publications 2001).

4 Table is from *Perspectives on the Historical Treatment of People with Disabilities*, in *Teaching for Diversity and Social Justice* app. 14C (Maurianne Adams et al. eds., 2d ed., Taylor & Francis 2007).

Years	Societal Perspective	Treatment
ICE - 1700s	Possessed by the devil, a sinner ⁵	Tortured, burned at the stake, left to die
1800 - 1920s	Genetically defective, inferior	Hidden away, displayed as freaks, beggars
1930-1940s	Genetically defective, polluting the race	Institutionalized, sterilized, exterminated
1940-1970	Unfortunate, object of charity, pity	Institutionalized, rehabilitated
1970-2000s	Independent, self-determined	Independent living, civil rights, mainstreaming ⁶

It is important to understand these historical perspectives as many people still have strong beliefs and opinions about persons with disabilities as colored by these ancient beliefs. One portion of history that is in danger of repeating itself is the extermination of certain persons with disabilities. An important (and often neglected) period of United States history is the segregation and sterilization of persons with disabilities in the 1900s. Around the turn of the 20th century, xenophobia toward persons with disabilities reached its zenith according to historian Kenneth M. Stampp. Persons with disabilities were lumped together in the category of “unassimilable aliens,” and the “solution” was state-imposed segregation.⁷ The “intellectual” underpinning of this treatment was eugenics.

Eugenics was defined by its proponents as “the science which deals with all influences that improve the inborn qualities of a race.”⁸ Many states used eugenics as the reason to institute laws authorizing the legal sterilization of persons with disabilities. In a widely criticized (but never overruled) Supreme Court opinion upholding the validity of a Virginia law allowing the forced sterilization of United States citizens with mental illness, Oliver Wendell Holmes Jr. stated:

It is better for all the world if, instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.⁹

5 Many disabling conditions, including intellectual disability, mental illness, deafness, and epilepsy, were thought to have supernatural or demonological causes during the medieval period. The devil was believed to cause epilepsy (Alexander and Selesnick 1964). Belief in demonic possession as a primary etiology of mental illness led to attempted cures based on religious ideas about exorcism (Clay 1966; Neaman 1978). Attempts to cure people with disabilities from early medieval times reflect supernatural beliefs in the abilities of magic and religious elements.” Braddock & Parish, *supra* n. 3, at 17–18.

6 *Teaching for Diversity and Social Justice*, *supra* n. 4.

7 Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality* (Georgetown U. Press 2003).

8 Francis Galton, *Eugenics: Its Definition, Scope, and Aims*, 10(1) *Am. J. Sociology* 1 (July 1904).

9 *Buck v. Bell*, 274 U.S. 200, 207 (1927).

In the United States, 32 states eventually adopted statutes and laws permitting sterilization of the insane and feeble minded.¹⁰ While no reliable data is available, estimates suggest that at least 65,000 sterilizations were performed in the United States.¹¹

In 1933, using California's program as a model, Nazi Germany enacted its own eugenic sterilization law... This legislation led to the forced sterilization of between 300,000 and 400,000 persons, a majority on the grounds of "feeble-mindedness." Most were institutional residents. This unprecedented oppression against disabled persons culminated in the murder by euthanasia of between 200,000 and 275,000 individuals with mental and physical disabilities between 1939 and 1945 in Germany.¹²

Due in part to the Nazi's atrocities during World War II, which were bolstered by eugenics ideology, support began to wane for the eugenics movement. Despite this, sterilizations of persons with disabilities continued in the United States.¹³ It was not until the 1950s and 1960s that states began to question the value (and legality) of sterilizing human beings in order to improve the human race.¹⁴ While many states repealed their sterilization laws (many not until the 1970s), two states still have them on the books.¹⁵ While a dark chapter in United States history, the eugenics debate is relevant again (and will be in the future) as advances in genetic testing have brought the same arguments to the forefront as to what should be done with those people whose genetic makeup does not meet "normal" expectations.

While governments were sterilizing hundreds of thousands of persons with disabilities, a large number of persons with disabilities were also being segregated from society and forced to live in government institutions. In 1940, persons in psychiatric hospitals reached 461,358 and peaked at more than 550,000 in 1955.¹⁶ Initially, mental illness was thought "curable" and institutions were created to hold persons with mental illness in order to cure them.¹⁷ However, "[b]eginning almost immediately after they were constructed, mental institutions experienced severe overcrowding as prisons sought to release their most dangerous and disturbed inmates to the newly available facilities."¹⁸ The inclusion of hardened criminals in the institutions created an unsafe living situation for persons with disabilities, turning many of the institutions into a prison-like environment even for those who had done nothing wrong.

Due to the horrible and inequitable conditions in these facilities, which were re-

10 Paul A. Lombardo, *Three Generations, No Imbeciles: Eugenics, the Supreme Court and Buck v. Bell*, app. C (Johns Hopkins U. Press 2008).

11 *Id.*

12 Braddock & Parish, *supra* n. 3, at 40.

13 Galton, *supra* n. 8.

14 *Id.*

15 *Id.* Washington and Arkansas still have eugenics sterilization laws.

16 Braddock & Parish, *supra* n. 3, at 41.

17 *Id.* at 32–33.

18 *Id.* at 33.

vealed in newspapers and other media, the legal rights of persons with disabilities began to be protected for the first time.¹⁹ The first case in which an American court recognized the right to treatment for persons with disabilities was the landmark 1966 case of *Rouse v. Cameron*,²⁰ which held that if an individual was involuntarily committed to a facility, at a minimum, he or she had the right to receive treatment because the purpose of confinement was treatment and not punishment.²¹ This was the dawn of the shift in how the rights of persons with disabilities were going to change. Despite this beginning in the 1960s, “American society still treated persons with intellectual disabilities as a group that needed to be controlled by segregation, sterilization, and isolation.”²²

The rights of persons with disabilities changed dramatically during the civil rights movements in the late 1960s and 1970s. This was the first time that persons with disabilities organized politically in such a way that American society was forced to recognize that individuals with disabilities have the same civil rights as all citizens.²³ The disability rights movement took time and many leaders emerged, many of whom were persons with disabilities.²⁴ The civil rights movement had many successes, but one of the most significant was the passage of the American with Disabilities Act of 1990 (ADA). As stated by one proponent:

The ADA represents a significant accomplishment in the evolution of society’s views and treatment of people with disabilities. . . . Nonetheless, the ADA is but one node in a continuum of progress, and it pales in relation to the extent overwhelming service and survival needs of people with disabilities. Ultimately, the full impact of the ADA will be realized only after the majority of people with disabilities gain access to certain basic services like attendant care, readers, interpreters, transportation, housing assistance, affordable health care, and medical and vocational rehabilitation. Formless as liquid in a vacuum, the con-

19 *Id.*

20 373 F.2d 451 (D.C. 1966).

21 Braddock & Parish, *supra* n. 3, at 46.

22 *Id.* at 45.

23 See Switzer, *supra* n. 7; Doris Zames Fleischer & Freida Zames, *The Disability Rights Movement: From Charity to Confrontation* (Temple U. Press 2001); Joseph P. Shapiro, *No Pity, People with Disabilities Forging a New Civil Rights Movement* (Random House Digital 1994).

24 One such leader was Ed Roberts, who is known as the father of independent living. He was a polio survivor and required the use of an iron lung. His vocational rehabilitation counselor asserted that he had no vocational potential. The University of California Berkley refused to admit him because he was too disabled. He sued California Vocational Rehabilitation. He eventually attended Berkley in 1962. He pressed the university for what he needed to succeed, such as wheelchair repair, ramps, accessible transportation, and accessible housing. Other persons with significant disabilities joined him and assisted other students with disability-related issues; the group became known as the Rolling Quads. Ed Roberts also started the Disabled Students Program and, with a \$1 million grant, founded the first Center for Independent Living in 1972, which has become a model for other centers for independent living throughout the United States. See Shapiro, *supra* n. 23, at 51–70; see also Susan P. O’Hara, *Oral History Interview with Edward V. Roberts* (unpublished ms. 1994) (copy on file with St. Govt. Oral History Program, Cal. Dep’t of State, Cal. State Archives).

cept of equality has little meaning for people who struggle to survive without the resources necessary to meet fundamental human needs.²⁵

In the present day, things have changed for the better for persons with disabilities in many aspects of daily living. There have been significant advances in prosthetics, wheelchairs, durable medical equipment, and all kinds of aids to allow persons with disabilities to have successful and independent lives.²⁶ The ADA has provided access and destroyed barriers to participation in government and social institutions in many cities and towns throughout the United States. However, much remains to be done if the promise of the disability rights movement is to be realized.

According to the 2010 Annual Disability Status Report, individuals with disabilities still are pervasively disadvantaged in all aspects of life.²⁷ Persons with disabilities are much more likely to be living below the poverty line and experience higher than average unemployment. For persons with disabilities, finding acceptable housing can be difficult (if not impossible), and access to appropriate medical care and to appropriate education (particularly higher education) remains a challenge. However, public perception of persons with disabilities still shows a profound ignorance of the reality of many persons with disabilities lives. In one study, researchers came up with seven images used by the media in its depiction of persons with disabilities:

1. **The disabled person as pitiable and pathetic.** This form of continuing negative stereotyping is found in charity telethons, which perpetuate the image of people with disabilities as objects of pity. Their stories often are told in terms of people who are victims of a tragic fate, rather than a social minority.
2. **The disabled person as Supercrip.** These heartwarming stories, says journalism professor Jack Nelson, depict great courage — or what is often referred to as “disability chic” — wherein someone likeable either succeeds in triumphing or succumbs heroically. The problem, one observer notes, is that a lot of ordinary disabled people are made to feel like failures if they haven’t done something extraordinary. Disability advocates are exceptionally harsh and critical of such individuals and their “inspirational” coverage [cite omitted]...
3. **The disabled person as sinister, evil, and criminal.** In this stereotype that plays on deeply held fears and prejudices, the disabled

25 Jonathan M. Young, *Equality of Opportunity: The Making of the Americans with Disabilities Act*, (Nat’l Council on Disability, 1997), citing, ADA: A Special Issue, 3(3) Worklife 15 (Fall 1990), quoting Lex Frieden.

26 A discussion of the advances in wheelchair technology describes the incredible advances that persons with disabilities have made, many times driven by persons with disabilities themselves. Shapiro, *supra* n. 23, at 227–252.

27 W. Erickson, C. Lee & S. von Schrader, *2010 Disability Status Report: United States* (Cornell U. Empl. & Disability Inst. 2012), http://www.disabilitystatistics.org/StatusReports/2010-PDF/2010-StatusReport_US.pdf?CFID=3335362&CFTOKEN=75496148&jsessionid=84303c2f5efa277edcc6257b5749327e7f1e.

villain — especially one with a psychiatric illness — is almost always someone who is dangerous, unpredictable, and evil. This perception may lead to unwarranted apprehension and ostracism of people with disabilities, robbing them of their sense of self by regarding them only as exemplars of a stigmatic trait.

4. **The disabled person as better off dead.** Nelson refers to the “better dead than disabled syndrome” as one way in which the media implies that with medical costs soaring and resources limited, a disabled person would seek suicide because life often is unbearable. Society (or the family) is thereby relieved of caring for the disabled individual, who is not whole or useful.
5. **The disabled person as maladjusted — his or her own worst enemy.** “If only disabled persons were not so bitter and would accept themselves, they would have better lives” is the translation of this common stereotype. Usually it involves a nondisabled person who helps someone with a disability see the “bright side” of his or her impairment — the mythology that persons with disabilities need guidance because they are unable to make sound judgments.
6. **The disabled person as a burden.** Family responsibility and duty form the core of this stereotype, which is built on the assumption that persons with disabilities need someone else to take care of them. Like the stereotype of disabled persons as better off dead, it engenders the belief that the burden, whether financial or emotional, is so compelling that it ruins families and their lives. In contemporary parlance, it has focused on the hot-button issue of physician-assisted suicide...
7. **The disabled person as unable to live a successful life.** The media has distorted society’s views of what it means to be disabled, according to Nelson, by limiting the presence of disabled persons in the portrayal of day-to-day life. Although more disabled people are beginning to appear in cameo-like scenes, they are seldom seen in workplace situations as happy, healthy family members. This legacy of negative images is both damaging and inaccurate.²⁸

These stereotypes form the basis of reactions many practitioners are still forced to address when representing persons with disabilities. Sometimes it is the judge hearing a case, sometimes the government bureaucrat refusing to provide service, sometimes an employer or landlord refusing to consider a person with a disability as an employee or tenant, and even sometimes it is the treatment of the person with a disability by his or her own family.

This problem in perception is not limited to the past or the present. The special

28 Switzer, *supra* n. 7, at 4–9, citing Jack A. Nelson, *Broken Images: Portrayals of Those with Disabilities in America Media, in The Disabled, the Media, and the Information Age 1* (Jack A. Nelson ed., Greenwood Press 1994).

needs practitioner will need to deal with these issues in the future by zealously advocating for inclusion in the community and person-centered planning to provide individuals and their families the necessary support to do so. As described by one author “the problem of ‘disability’ did not reside simply in the individual, but also in society, in the rehabilitation process, the physical environment, and the mechanisms of social policy. The full potential of persons with disabilities therefore could not be realized simply through trying to ‘rehabilitate’ the individual. ‘Society’ also had to be ‘rehabilitated’ by making the physical environment more accessible and destroying the attitudes that rendered persons with disabilities as helpless victims in need of charity.”²⁹

In moving forward, the special needs planning practitioner will need to make sure that the mistakes of the past are not repeated and that the ongoing fight for equality of all persons with disabilities is not forgotten because it is inconvenient or too expensive.

III. THE FUTURE PERSON WITH A DISABILITY

The immediate future of special needs planning will depend on a number of factors but the most important is the number of people who will require planning. A significant increase in the number of persons with disabilities in the next 30 years is anticipated. The increase is due (in part) to the Baby Boomer generation growing older because the prevalence of disability in society is directly correlated with aging. In addition, the United States has been involved in armed conflict in Iraq and Afghanistan and created another significant class of persons with disabilities.³⁰ Also, due to advances in medical care and treatment, persons with disabilities are living longer lives and will require more sophisticated plans that take into account longer life expectancies.

In the future, a new type of person with a disability will arise. As a result of the obesity epidemic in America, the overall number of persons with disabilities is likely to increase. These people may be considered to have a “voluntary” disability because the disability may be considered by strapped government programs as avoidable, much like how government programs have treated those with alcoholism or drug addiction. Persons with developmental disabilities face a new challenge to their very existence. Advances in genetic testing may create a eugenics-level loss of persons with developmental disabilities. These persons may never exist due to selective abortion or if permitted to live, may face discrimination, segregation, or sterilization similar to what happened during the eugenics movement.

The next 30 years should see an overall increase in the number of persons requiring special needs planning, but the types of disability may change and focus more on the person with a disability as a result of obesity and individuals with autism; while some with developmental disabilities may never have the opportunity to exist at all.

29 Nat'l Council on Disability, *supra* n. 25.

30 Nearly 45 percent of the 1.6 million veterans of the Iraq and Afghanistan wars are filing for veterans' disability benefits because of service-connected disabilities. Of those who have sought Dept. of Veterans Affairs care, more than 1,600 lost a limb, many others lost fingers or toes, at least 156 are blind, thousands of others have impaired vision, more than 177,000 have hearing loss, more than 350,000 report having tinnitus (noise or ringing in the ears), and thousands are disfigured, as many as 200 them so badly that they may need face transplants. Marilyn Marchione, *New Veterans Seeking Disability at Record Rate, with 45% Filing*, USA Today (May 28, 2012).

A. Expected Number of Persons with Disabilities Will Increase Over the Next 30 Years

The number of persons with disabilities is expected to skyrocket over the next 30 years according to the most recent study by the Institute of Medicine (IOM). The IOM has tracked disability for over 20 years, since it completed its first study in 1991. The most recent study, released in 2007, focused on predicting the future number of persons with disabilities.³¹ Due to the predicted swell in numbers, Alan M. Jette, MPF, PhD, chair of the committee that wrote the IOM report, stated:

If one considers people who are now disabled, those likely to develop a future disability and people who are or will be affected by the disabilities of family members or others close to them, it becomes clear that disability will eventually affect the lives of most Americans.³²

Around one in seven Americans is currently considered disabled, and that number is expected to swell in the next 30 years.³³ Citing the 2004 Census, the IOM predicted that as the baby boomer population ages, the number of individuals over age 65 will increase 20 percent, swelling from 35 million in 2000 to more than 71 million in 2030.³⁴ Historically, disability has been directly related to the age of individuals. Interestingly, the current number of older adults with disabilities has decreased since the first IOM study, due largely to advances in medical technology. However, the overall largest increase in the number of persons with disabilities is for those who are under age 65. The number of children with disabilities has increased due to greater numbers being diagnosed with conditions such as autism. Further, due to child obesity and Type-2 diabetes, many other children are expected to have disabling conditions.

For special needs planners, this means job security. As the numbers of individuals with disabilities increase over the next 30 years it will create greater pressure on available resources, both public and private. Special needs planning attorneys may need to do different things to be zealous advocates for their individual clients to maintain the rights fought for during the last 30 years. The role of organizations (such as NAELA) may need to be expanded in the future. These organizations will play a vital role in maintaining the advances already received by persons with disabilities.

Organizational assistance will become necessary due to the well-funded opposition to continuing programs for persons with disabilities. State and private insurance companies have a deeper well of financial resources than most persons with disabilities to defend actions and the ability to out-paper and out-spend their opponents with disabilities and their advocates. Thus, an individual will have a difficult (if not impossible) task fighting these battles. An organization, such as the Disability Rights Education & Defense Fund (hereinafter "DREDF"), will need to be expanded and better funded to fight the

31 Inst. of Med. Comm. on Disability in Am., *Introduction, in The Future of Disability in America* 1 (Marylyn J. Field & Alan M. Jette eds., Nat'l Academies Press 2007), <http://www.ncbi.nlm.nih.gov/books/NBK11426>.

32 *Id.*

33 *Id.*

34 *Id.*

overwhelming surge of expected litigation. This will allow certain inequities to be righted and level the playing field for persons with disabilities.

B. Children with Disabilities over the Next 30 Years: The Impact of Asthma, Premature Birth, and Obesity

The IOM study, citing the United States Census Bureau statistics, stated that in 2004, more than 4 million children ages 5-20 (6.5 percent of the population) had disabilities, while 20 million people ages 21-64 (12.1 percent of the population) had disabilities.³⁵ The IOM reported that, while “the risk of an individual experiencing disability is lower in this age group [under age 65], the total number of younger adults with disabilities currently *exceeds the total for the population ages 65 and over.*”(emphasis added.)³⁶ The study explains that the reason for this surge in numbers is due to advances in medicine and treatment that has lowered the rate of disability in the aged, and that much childhood illness and conditions previously fatal are now survivable, albeit the child has disabilities. The IOM study has received attention for identifying that among adults under age 65, disabilities arising from physical or mental conditions, such as autism, are not the major impact on the predicted explosion of disability. Rather, life style choices are at issue.

1. Asthma

According to the IOM study, the single most prevalent condition associated with childhood disability is asthma. The rate of disability among children due to asthma increased 232 percent from 1970 to 1995, while all other chronic conditions increased 113 percent. Since 1995, the rate of disability due to asthma has appeared to have leveled off. While the underlying contribution to this incredible rise in numbers is unclear, studies cited by the IOM surmise that, “the combination of control of infectious diseases, prolonged indoor exposure, and a sedentary lifestyle... is the key to the asthma epidemic and, in particular, the key to the rise in severity.”³⁷

2. Premature Birth

With advances in medical technology, babies born pre-term are surviving at a much greater rate than in the past. Further, multiple births, which are a common result of some methods of fertility treatments, have significantly increased. Premature babies and low birth-weight contribute to a number of conditions such as cerebral palsy, cognitive and sensory impairments, and attention deficit disorders.³⁸

3. Obesity and Diabetes

Poor nutrition, sedentary lifestyles, and complications arising from obesity and diabetes will cause this generation of children to experience a higher rate of disability than in any previous generation. The alarming rate of childhood and adult³⁹ obesity and Type-2

35 *Id.*

36 *Id.*

37 *Id.* at 3, Disability Trends.

38 *Id.*

39 Between ages 21 and 64.

diabetes are the major predictors impacting the expected rise in the number of persons with disabilities.

The IOM study states that “rates of disability are rising among America’s non-elderly adults, at least in part because of increases in the rates of obesity.”⁴⁰ Currently obese or Type-2 diabetic adults in middle years tend to predict impaired ability to perform activities of daily living and instrumental activities of daily living later in life. Citing the Center for Disease Control National Health and Nutrition Examination Surveys, the IOM reported that there has been more than a 12 percent increase in the number of obese children since 1963.⁴¹

The effect of lifelong obesity and diabetes significantly contributes to complications that can, and do, lead to disability in adulthood. The solution is often perceived to be voluntary. While there are certainly some cases of obesity that have a physiological nature, the increase in childhood obesity is a reflection of a dramatic change in lifestyle, such as more video games and less baseball. The cost of fresh food, especially “organic” produce being prohibitive to most family budgets, results in quickly available meals of poor nutritional value. American children (and adults) need to get out and play more, eat less, and make better food choices.

One future probable result of this type of disability will be a societal backlash against so called “voluntary disabilities” or those disabling conditions that are perceived as avoidable and resulting from someone who is obese and leads a sedentary lifestyle. The backlash could take the form of government agencies refusing to provide assistance to those with a “voluntary” disability. This is much like what already happened with benefits for people suffering from alcoholism and drug abuse.⁴² Because obesity and Type-2 diabetes disabling conditions can arise from personal choices to over-consume, make consistent poor food choices and live an inactive lifestyle, will disabilities that arise from these conditions be treated like alcoholism and drug abuse and not be considered disabling conditions for government benefits? The future will let us know.

C. The Dramatic Rise of the Number of Persons with Autism

One of the most noted and a recent controversy worldwide is the diagnosis, causation and treatment of autism. In recent years, the number of children diagnosed with autism has increased dramatically both in the United States and globally.⁴³ The definition of “autism” continues to evolve as the condition receives more attention. No definitive testing is available at this time, and the current method of diagnosis is largely the subjective opinion of professionals. Part of the difficulty in diagnosing an individual is the broad spectrum of characteristics exhibited by the individual and the varying degree of severity necessary to trigger a diagnosis.

40 *Id.*

41 *Id.*

42 In 1996, Congress passed legislation that removed drug and alcohol addictions as disability impairments. See Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105 (1996).

43 See Daniela Caruso, *Autism in the U.S.: Social Movement and Legal Change*, 36 Am. J. L. Med. 483 (2010); Editorial, *Silencing Debate Over Autism*, 10(5) Nat. Neuroscience 531 (May 2007).

Beginning in 2013, the definition of autism will change.⁴⁴ This will be of critical importance to special needs planners because how the condition is defined will exclude certain individuals who remain in need of services, but will not qualify for them because of the absence of an “appropriate” diagnosis.

Treatment for autism-related services is expensive and not always covered by private medical insurance.⁴⁵ Early diagnosis and treatment is necessary because with therapy, children may overcome their impairments to the degree that they no longer meet the standards for autism, even if the underlying impairment still exists. The goal of all special needs planners should be to reduce the impact of any impairment or deficiency to the extent that it would not interfere with a person’s ability to function and be independent. In the future, this will mean the special needs planning practitioner will need to know what services are available, and how best to access them for those persons diagnosed with autism.

Because autism is in such a state of flux and due to its prevalence in society, the authors go through the planning issues in some detail on how the future special needs planner can assist a person diagnosed with autism. The only way to fully understand what is necessary is to understand what it means to be diagnosed as “autistic.”

1. Number of People Diagnosed with Autism

The Centers for Disease Control and Prevention (CDC) released results of a 2008 study of 8-year-old children in 14 states. The study reported a large increase in the incidences of autism to one out of every 88 children, with boys having approximately five times greater occurrence than girls.⁴⁶ This is a large increase in the rate of diagnosis, even since 2000, when the rate of occurrence was one in 150 children.⁴⁷

The report has generated a maelstrom of media coverage touting an “epidemic” of autism and has parents and medical professionals searching for a cause. Many medical professionals believe that the increase in the rate of autism diagnosis is due to the expanded diagnostic criteria in the DSM-IV⁴⁸ and increased awareness by parents and pro-

44 See Am. Psychiatric Assn., *DSM-5: The Future of Psychiatric Diagnosis*, www.dsm5.org (accessed Feb. 16, 2013).

45 Treatment for autism ranges from homeopathic and largely antidotal, such as a gluten-free/casin-free diet, to the use of prescribed medications and therapy. The types of therapy available also range greatly, from medically based, behavioral, speech and language, physical, and occupational therapy to sensory, social, music, and horse and other animal-based therapy, and special education services. *The Research Basis for Autism Intervention* 9–24 (Eric Schopler et al. eds., Kluwer Academic Publishers 2002).

46 The ratio of diagnosis between boys and girls has not changed significantly since the 1950s, with boys today having approximately a five times greater diagnosis rate than girls. See John Baio, *Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008*, http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w (Mar. 30, 2012).

47 *Id.*

48 Am. Psychiatric Assn., *Diagnostic And Statistical Manual Of Mental Disorders* 69-71 (4th ed., text rev., Am. Psychiatric Assn. 2000). The DSM provides a common language and standard criteria for the classification of mental disorders. It is used in the United States and in varying degrees around the world by clinicians, researchers, psychiatric drug regulation agencies, health insurance companies, pharmaceutical companies, and policy makers.

professionals alike. Prominent pediatric neurologist Dr. James Coplan theorizes that despite the CDC findings, the prevalence of autism has not changed. In fact, the rate of incidence among adults is approximately the same. He opines that many adults who have anxiety disorders, obsessive-compulsive disorders, depression, bipolar disorder, attention deficit disorder, and alcoholism are misdiagnosed as having autism.⁴⁹

Regardless of the reasons for the increase, for purposes of special needs planning, an overall significant increase in the number of individuals diagnosed with autism has occurred. The special needs practitioner needs to be mindful of the foregoing so that he or she is prepared to discuss related issues with prospective clients because these issues are of paramount importance to those diagnosed with autism and their families.

2. How Is Autism Defined?

The term “autism” was first introduced in 1911 by Swiss psychiatrist Eugene Bleuler and is derived from the Greek word “autos” or “self.”⁵⁰ He used the term “autism” to describe a subset of his schizophrenic patients who demonstrated a pervasive and severe aloneness and were universally unable to make interpersonal connections:

The...schizophrenics who have no more contact with the outside world live in a world of their own. They have encased themselves with their desires and wishes ...; they have cut themselves off as much as possible from any contact with the external world. This detachment from reality with the relative and absolute predominance of the inner life, we term autism.⁵¹

In the 1940s, Leo Kanner, a noted child psychologist at Johns Hopkins, presented case studies of 11 children and identified what is largely considered the diagnostic hallmarks of autism.⁵² In his landmark study, he found that the fundamental characteristic of the children was their “inability to relate themselves” to others; that they were happiest in their own world.⁵³ Kanner identified other common characteristics, including delayed speech, excellent memory, echolalia (mirrored responses), literal interpretation of words, food issues, intolerance of loud noises or other stimuli, monotonous verbal or motor repetition, inability to tolerate change, lack of interaction with people, generally high intelligence, and normal physical appearance.⁵⁴ One year later, a German psychiatrist, Hans Asperger, identified a similar syndrome he described as “autistic psychopathy,” which has since evolved into a sub-type of autism to describe children who have the socialization

49 See James Coplan, *Making Sense of Autistic Spectrum Disorders*, www.DrCoplan.com (accessed Jan. 26, 2013); James Coplan, *The Autism “Explosion,” and What It Means for Your Child*, <http://www.drcoplan.com/media/CoplanAutismExplosionApril-4-2012.pdf> (April 4, 2012).

50 Josef Parnas, Pierre Bovet & Dan Zahavi, *Schizophrenic Autism: Clinical Phenomenology and Pathogenic Implications*, 1(3) *World Psych.* 131 (Oct. 2002)

51 Cited by resource in E. Bleuler, *Dementia Praecox oder Gruppe der Schizophrenien*, in *Handbuch der Psychiatrie* 29 (G. Aschaffenburg ed., Deuticke 1911).

52 Leo Kanner, *Autistic Disturbances of Affective Contact*, 2 *Nervous Child* 217 (1943).

53 *Id.*

54 *Id.*

impairments, but are of superior intelligence and typically very high functioning.⁵⁵

In 1987, autism appeared in the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association for the first time.⁵⁶ The DSM provides a common language and standard criteria for the classification of mental disorders used by those making diagnoses of autism.

3. What is the Current Diagnosis for Autism?

The current diagnosis for autism depends on a clinical determination. It is not determined by any one tool, but rather a clinical judgment.⁵⁷ In general, a diagnosis of autism requires a finding of at least six areas of impairment of function among the following:

- A. Social: (at least two) lack of non-verbal interpersonal communication skills such as eye contact, lack of peer relationships, and inability to make emotional connections;
- B. Communication: (at least one) delayed speech, inability to converse and have a coherent exchange of ideas, repetition of language or phrases, lack of make-believe or interactive play; and
- C. Behavioral: (at least one) obsessiveness, intolerance of change in routine, repetitive physical gestures such as hand-flapping, and preoccupation with parts of things.⁵⁸

One of the difficulties with evaluating a child who may be autistic is that these impairments may not be obvious to someone who does not know the child, especially if they are under the age of three. Additionally, many of the criteria can only be determined by observing a child interacting with peers. A doctor or clinician is not going to go to a child's care center, home, or school to make observations. As a result, the evaluating team of professionals is often relying upon surveys filled out by parents, teachers and caregivers.

4. The Future Change to the Diagnosis of Autism/Asperger's Will Be Known as Autism Spectrum Disorder (ASD)

DSM-V, which is expected to be published in May 2013, will contain revised diagnosis criteria that collapses autism, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Asperger's into one category, Autistic Spectrum Disorder (ASD).⁵⁹ Under the new criteria, there will be no distinction between classic autism, Asperger's, and PDD-NOS; instead there will be one Autistic Spectrum Disorder (ASD). In order to receive this diagnosis, an individual will have to demonstrate a higher level of impairment.⁶⁰ The stated reason for modifying the DSM criteria are advances in the

55 Bleuler, *supra* n. 51.

56 Am. Psychiatric Assn, *supra* n. 48.

57 Peter Carpenter, *Diagnosis and Assessment in Autism Spectrum Disorders*, 6(3) *Advances in Mental Health & Intell. Disabilities* 121 (2012).

58 Centers for Disease Control and Prevention, *Diagnostic Criteria*, <http://www.cdc.gov/nbddd/autism/hcp-dsm.html> (accessed Feb. 18, 2013), citing Am. Psychiatric Assn., *Diagnostic and Statistical Manual Of Mental Disorders 69-70* (4th ed., text rev., Am. Psychiatric Assn. 2000).

59 See Am. Psychiatric Assn., *DSM-5 Development, DSM-5: The Future of Psychiatric Diagnosis*, <http://www.dsm5.org/Pages/Default.aspx> (accessed Dec. 5, 2012).

60 Id. The new definition reflects a higher level of impairment.

understanding of what autism is and how to better diagnose it.⁶¹

After the American Psychiatric Association released the proposed revised diagnostic criteria, early media coverage estimated that there would be a significant impact on the number of individuals diagnosed with Asperger's and PDD-NOS under the new criteria, in that the vast majority would not meet the criteria for a diagnosis being on the "spectrum," most significantly by excluding those who are higher functioning.⁶²

The contraction of the criteria that defines autism will certainly impact the number of individuals diagnosed. Some believe the new criteria will eliminate the diagnosis for higher functioning individuals and end the autism "epidemic." Others opine it will have little or no effect. Parents and advocates fear that without the ASD diagnosis, individuals will be unable to qualify for services such as special education services. As budgets for resources are shrinking, access to the resources is dependent on the diagnosis, and the expenses related to treating autism are significant.⁶³

The new definition of autism as ASD will be of critical importance to the special needs planning practitioner. He or she must understand what services will be provided to persons with an ASD diagnosis and whether a high functioning, non-diagnosed person will still need appropriate services and how to access and maximize such services.

5. What is the Cause of Autism?

The cause of autism is a great source of debate. It was initially thought by child psychiatrists that autism was caused by a lack of parental affection, and mothers of autistic children were labeled "refrigerator mothers."⁶⁴ Later, Bernard Rimland and Michael Rutter were able to show through studies and empirical evidence that the cause was organic, and not the result of childhood trauma and lack of parenting skills.⁶⁵

Current theories of causation range from the organic, such as genetics and auto immunity, to external causes such as childhood vaccines, obesity during pregnancy, or lack of folic acid during pregnancy. Other theories espouse potential environmental causes such as pollution and the food ingested, such as genetically modified food products, pesticides, and the prevalence of gluten in the diet. Many other theories abound; some even rise to the level of conspiracy theories that link the rise in diagnosis of autism to fluoride in the water, genetically modified organisms, additives in the food such as MSG and the

61 Bryan H. King, *Doctor: Why We're Making Changes to Autism Diagnosis*, CNN Health (Apr. 6, 2012), <http://www.cnn.com/2012/04/06/health/king-dsm5-autism-changes/index.html>. Dr. King is one of the doctors working on revising the DSM-IV diagnosis criteria.

62 Benedict Carey, *New Definition of Autism Will Exclude Many*, *Study Suggests*, N.Y. Times (Jan. 19, 2012).

63 According to the CDC, average medical expenses for those with ASD were four to six times greater than those without. In 2005, Medicaid expenses for medical services were approximately six times greater for children with ASD than those without. Behavioral therapy for children with ASD was \$40,000 to \$60,000 per year. Centers for Disease Control and Prevention, *Data & Statistics*, <http://www.cdc.gov/ncbddd/autism/data.html#economic> (accessed Feb. 17, 2013).

64 Leo Kanner, *Problems of Nosology and Psychodynamics of Early Infantile Autism*, 19(3) *Am. J. Orthopsychiatry* 416 (1949).

65 Susan E. Folstein & Beth Rosen-Sheidley, *Genetics of Autism: Complex Aetiology for a Heterogeneous Disorder*, 2 *Nat. Revs. Genetics* 943 (Dec. 2001).

way food is processed and preserved.⁶⁶ No consensus exists on the cause.

Because the characteristics of autism can appear around age two, about the same time as the vaccine for measles, mumps and rubella, many parents believe that vaccinations cause autism. Scientific studies have shown there is no correlation, but many parents still refuse to believe the studies.⁶⁷ A recent study published in *Nature* indicates that age of the father plays a critical role in cell mutations, specifically, the genes related to brain functioning, and links the mutations to autism and schizophrenia.⁶⁸ Male sperm constantly regenerates from certain specific stem cells. The older the father, the more the cells have replicated, and the greater the chance for mutations. Most mutations are innocuous, but the link between genetic mutations and age of the father is a fairly new phenomenon, as is the idea that men also have a biological clock.

6. Personal Experience with Autism

These issues have hit home for author Michele Fuller who has a daughter diagnosed with autism. Autism adds to the flavor of her daughter's charming and quirky personality. The biggest impact and remaining hurdle is the social aspect of her autism. She has no friends, is never invited to play, and group assignments are done by herself. Those situations would make most of us cringe, but for her, it seems to have no effect.

Her daughter received early intervention and special education services beginning at age three. However, insurance coverage for medical-based services such as speech therapy, occupational therapy, and socialization-based therapy was absent. Medically based services are designed to teach coping skills and overcome deficits such as sensory issues, behavioral based impairments, and related issues. The therapy tends to be one-on-one and for a short duration. School-based therapy is done in small groups and the objective is to assist the child to learn.

With significant out-of-pocket costs to the family, her daughter did receive intensive therapy from age three to nine, and as a result was able to slowly drop off services. Any new skill achieved showed first in the private therapy setting, then at home, and then in school. The early therapies played a critical role in their daughter's ability to overcome any deficits. Today, her daughter requires virtually no academic support. The parents were routinely told by school social workers not to "waste" money on private therapy. The parents disregarded that advice, and their daughter received early medical-based therapy along with school-based services that has led to her improvements. Despite the fact that her daughter has made significant improvements, she still has autism. There is no cure. The lesson learned by the author is that access to affordable early treatment is critical for each child with autism's future development.

66 Jonathan Benson, *78 Percent Increase in Childhood Autism Rates over Past Decade Coincides with Sharp Uptick in Vaccination Schedules*, NaturalNews.com (Apr. 3, 2012), www.naturalnews.com/z035452_autism_vaccinations_children.html.

67 Paul A. Offit, *Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure* (Columbia U. Press 2008); Liza Gross, *A Broken Trust: Lessons from the Vaccine-Autism Wars*, 7(5) PLOS Biology e1000114 (2009).

68 Ewen Callaway, *Fathers Bequeath More Mutations as They Age*, 488 Nat. 7412 (Aug. 22, 2012).

7. How Should the Future Special Needs Planner Prepare for the Person Diagnosed with ASD?

To better assist clients and their families, future special needs planners need to be aware of the political dynamics of autism, including how it is defined. These clients will need the staunch support and advocacy of special needs planners to ensure those children who would otherwise fall through the cracks are receiving the services they need. Because of the cost of services, most families cannot afford critical therapies and must rely on school-based services, Social Security benefits, Medicaid, and insurance coverage.

Special needs planners will have to be adept at knowing how to connect families with local resources and services, including low-cost advocacy services. Many children with autism, especially those who will no longer meet the criteria for ASD, will have impairments that need to be assisted through planning. This impairment, while not obvious, may show itself in poor choices or an inability to sustain friendships or partners. It may also result in an inability to maintain employment. Special needs planners must recognize and accommodate this growing category of children with impairments by drafting fully discretionary spendthrift trusts that are like special needs trusts, but have more flexibility so that personal growth is rewarded and the effect of poor decision making or other impairments is limited.

D. Aging with Disabilities: Uncharted Territory

Young adults who were born with or acquired their disabilities in early childhood often experience advanced aging as early as their 30s or 40s.⁶⁹ As persons with disabilities age, they are at significant risk of developing additional disabilities.⁷⁰ Common secondary conditions are identified as depression, arthritis, pain, pressure ulcers, fatigue, contractures, and urinary tract infections, depending on the type of primary disability. The medical profession is struggling to meet the demands of this group of adults who are surviving childhood conditions that were once fatal. This is a new development for special needs planners and advocates. The future special needs plan will need to recognize the impact of premature aging for these persons and special needs families.

In addition to this population, certain of these individuals with disabilities are able to find employment, but will lose that employment as they prematurely age. The loss of employment for a person with a disability will likely result in a loss of independence. Lost independence will put greater pressure on family caregivers, and certainly affect the individual's physiological well being and diminish their overall quality of life. Health care education has not advanced quickly enough to accommodate this growing group of people aging with disabilities. They do not know how to effectively treat secondary conditions that arise with age. Even the facilities, themselves, are not accommodating for persons with disabilities and create barriers to effective care. Special needs planners will need to allow for and allocate resources for future home adaptations and equipment to support independence and community involvement. The future planner will also need to be able to access resources to monitor out-of-home living arrangements when it is not

69 Inst. of Med. Comm. on Disability in Am., *supra* n. 31 at 5, Secondary Conditions and Aging with Disability.

70 *Id.*

possible for the individual to remain in the community.

Special needs planners will need to be aware of the aging issues of persons with disabilities and understand how it impacts future planning. Persons with disabilities are living longer, and over time, due to age-related health issues, their care needs will increase at an accelerated rate. The practitioner will need to take into consideration the projected costs involved and be prepared to make modifications to that plan over time. It will be prudent for the special needs practitioner to work with an experienced financial advisor to plan for the financial needs of these individuals, preferably one that has experience creating financial plans for individuals who are unable to work. Further, drafting documents will not be enough. Keeping in touch with those planned for is important to make sure as needs change, their special needs plans change. This is especially important for families who wish to allow their family member with disabilities to age in the family home.

E. The New Eugenics Movement? More Subtle and More Effective in Reducing the Total Number of Persons with Disabilities

Recent advances in genetic testing may significantly reduce the total number of persons with developmental disabilities over the next 30 years. A non-invasive genetic test for fetuses was recently developed, which will be inexpensive and sold over the counter. The parents can then decide to selectively abort a fetus that does not meet their ideal genetic criteria. In the not too distant past, a test for only one or two conditions existed, like Down syndrome, which was difficult (and sometimes dangerous) to administer.

The new test (and new technology in mapping the human genome) will, in the future, allow tests for hundreds, if not thousands of conditions.⁷¹ For example, a DNA chip that can be read like a bar code will be able to list the child's basic personality predispositions, any behavioral illnesses (e.g., schizophrenia), and deviant behavioral characteristics (e.g., substance abuse) that the child is at risk of developing.⁷² What will be the effect of this new test on persons with disabilities?

1. The Recently Developed Genetic Test

In January 2011, researchers developed a non-invasive test to determine if a fetus has Down syndrome.⁷³ The test involves taking only a small amount of blood from the pregnant mother and saliva from the father.⁷⁴ "Prenatal genetic testing has been clinically available since the late 1960s but the costs, inconvenience and especially the miscarriage risks have limited its use."⁷⁵ "Each year, less than 2 percent of pregnant women in the United States undergo amniocentesis (in which a small amount of amniotic fluid containing fetal cells is taken for analysis) or chorionic villus sampling (in which fetal tissue is

71 A test that provides health risks, traits data, and ancestry information is available to individuals who mail in a sample of saliva for analysis and pay \$99. 23andMe, <https://www.23andme.com> (accessed Dec. 5, 2012).

72 Patrik S. Florencio, *Genetics, Parenting, and Children's Rights in the Twenty-First Century*, 45 McGill L.J. 527, 533 (2000).

73 Henry T. Greely, *Get Ready for the Flood of Fetal Gene Screening*, 469 Nat. 289 (Jan. 2011).

74 *Id.*

75 *Id.*

extracted from the placenta).”⁷⁶ Both procedures increase the risk of miscarriage. Until now, any given sample could be tested for only one or two conditions, typically ... Down syndrome.⁷⁷

The new technology may not only be applied to just fetuses with Down syndrome. With the new technology in place to sequence the fetal DNA carried in a pregnant woman’s bloodstream, geneticists predict the list of conditions that can be detected by non-invasive means will grow rapidly.⁷⁸

In the future, genetic testing will become powerful enough to provide couples with probability estimates of each and every disease characteristic as well as behavioral traits to which their children are genetically predisposed ... that the child is at risk of developing: “A new technology called DNA chips . . . will make an entire DNA blueprint as easy to read as a supermarket bar code.”⁷⁹

2. Number of Selective Abortions Under Former Prenatal Tests

Under the prior prenatal tests, a staggering number of fetuses were aborted when diagnosed with Down syndrome. An early study found that 92 percent of fetuses were aborted once it was discovered they were likely to have Down syndrome.⁸⁰ However, a more recent study within the United States shows a lower abortion rate of 67 percent to 85 percent.⁸¹ Still, this is a significant percentage.

Because the new prenatal test is noninvasive and easily obtained, the total number of persons receiving the test (and selectively aborting fetuses with Down syndrome) is expected to skyrocket. Currently, in California, about two-thirds of pregnant women opt for noninvasive screening for Down syndrome.⁸² In the United States, if the same fraction of women opts for this screening, prenatal genetic screening will increase from 100,000 a year up to about 3 million.⁸³ Will this mean that those fetuses with Down syndrome will still be aborted at a 67 percent to 85 percent rate? Will there be so few children with Down syndrome that children with Down syndrome will practically cease to exist?

76 *Id.*

77 *Id.*

78 Erika Check Hayden, *Fetal Gene Screening Comes to Market*, 478 Nat. 440 (Oct. 2011).

79 Florencio, *supra* n. 72.

80 Caroline Mansfield, Suellen Hopfer & Theresa M. Marteau, *Termination Rates After Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review. European Concerted Action: DADA (Decision-making After the Diagnosis of a Fetal Abnormality)*, 19(9) *Prenatal Diagnosis* 808 (Sept. 1999).

81 Jamie L. Natoli et al., *Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995–2011)*, 32(2) *Prenatal Diagnosis* 142 (Feb. 2012). “Our evidence suggests that termination rates are lower than noted in previous reports (67%–85% in this review vs 92% in Mansfield et al.) and that termination rates vary with maternal age, maternal race/ethnicity, and gestational age. Evidence also suggests that termination rates have decreased in recent years, which may reflect progress in medical management for individuals with Down syndrome and advances in educational, social, and financial support for their families. Importantly, the range of termination rates observed across studies suggests that a single summary termination rate may not be applicable to the entire US population and would not adequately address regional and demographic differences among pregnant women.”

82 Greely, *supra* n. 73.

83 *Id.*

This is the concern of many persons with disabilities and their families. As stated by one lawyer and disability activist:

If persons with disabilities are perceived as individuals who encounter insurmountable difficulties in life and who place a burden on society, prenatal screening may be regarded as a logical response. However, if persons with disabilities are regarded as a definable social group who have faced great oppression and stigmatization, then prenatal screening may be regarded as yet another form of social abuse. [cite omitted]. This is the essence of the disability community's challenge to prenatal genetic testing. We believe that the current promotion and application of prenatal screening has a potent message that negatively affects people with disabilities, influences women in decision making about their own pregnancies, and reinforces the general public's stereotyped attitudes about people with disabilities.⁸⁴

The effect on other persons with disabilities (and others with perceived undesirable traits) could be just as drastic. What if scientists find the gene responsible for homosexuality and parents can decide whether to abort that fetus? The implications are staggering. The future capabilities of genetic screening are best described by the following hypothetical:

Imagine a couple that, because of fertility problems, plans to use [in vitro fertilization] IVF. The clinician harvests fourteen eggs from the prospective mother and fertilizes them with the prospective father's sperm. Ten of the eggs are successfully fertilized, and eight of those develop normally to the eight-cell stage. At that point, [pre-implantation genetic screening] PGS is used to screen the eight remaining embryos for various chromosomal and genetic conditions. Results might indicate that chromosomal defects exist in embryos 1, 3, and 8 that make it unlikely that those embryos would result in a live birth. Embryo 2 can produce a baby, but the child would have Down syndrome. Embryo 6 would have cystic fibrosis. Embryos 1, 2, and 8 would carry one copy of the cystic fibrosis gene, which would not affect them but could result in their offspring having the disease. Embryos 5 and 7 have twice the normal chance of developing Alzheimer's disease in older age; embryos 1 and 7 have double the normal risk of breast cancer. Embryos 1, 3, 4, and 7 are female; embryos 3, 4, and 7 would likely be taller than average; embryos 1, 4, and 8 would have blue eyes.⁸⁵

84 Erik Parens & Adrienne Asch, *Prenatal Testing and Disability Rights* 145 (Georgetown U. Press 2000).

85 Jaime King, *Predicting Probability: Regulating the Future of Preimplantation Genetic Screening*, 8 Yale J. Health Policy, L. Ethics 283 (Summer 2008).

3. Ethical Considerations For Persons with Disabilities

The fear of many persons with disabilities is that if this genetic information is available without proper counseling, potential parents will selectively abort their fetuses until they achieve their “perfect” child. The hope is that, before parents selectively abort away generations of persons with disabilities, they consider that such persons have value and should not be done away with without at least considering modern alternatives.

The concern by many disability advocates is that for tens of thousands of years persons with disabilities were marginalized, pitied, demonized, and segregated. It has only been in the past 30 to 40 years that persons with disabilities have been able to fight to receive some semblance of civil rights and be seen as productive individuals. In one study on the media’s portrayal of prenatal testing for disabilities, the author noted:

Overall, it appears disability is being portrayed as a negative quality for a fetus, for which prenatal testing might be helpful. In fact, in many cases, termination of a fetus with a disability was presented as a matter of fact issue, with little regard to the controversy that might be embedded in such a position.⁸⁶

The lives of persons with disabilities are, thus, generally seen as tragic and difficult and that they would be better off dead.⁸⁷ Those families who have raised children with disabilities do not necessarily share this perception. Studies have shown that the difficulty of raising a child with a disability is greatly exaggerated by those who have never done it and that the lives of persons with disabilities are often no more difficult than those without disabilities.⁸⁸ Their challenges are just different and their difficulties arise more from a society that was built without any consideration for the disabled. As noted in another journal:

We recognize that people with disabilities and their families face difficulties in our present society and that perhaps some of those difficulties would remain even after comprehensive social reform. But we maintain that few disabilities are so undesirable that they provide good reason for abandoning a parental project, for declining to become a parent to the child who would develop from the diagnosed fetus. Given the difficulties that a disabled child is likely to face in our present society, a prospective parent may have good reason not to cause disability, but that is not reason enough to select against a fetus with a disability. In creating families, prospective parents should

86 Carol Bishop Mills, Elina Erzikova, *Prenatal Testing, Disability, and Termination: An Examination of Newspaper Framing*, 32(3) *Disability Stud. Q.* (2012), <http://dsq-sds.org/article/view/1767> (accessed Feb. 16, 2013).

87 Dov Fox & Christopher L. Griffin Jr., *Disability-Selective Abortion and the Americans with Disabilities Act*, 2009(3) *Utah L. Rev.* 845 (2009).

88 Robert A. Naseef, *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability* (Birch Lane Press 1997).

aspire to an ideal of unconditional welcome; an ideal opposed to the exercise of selectivity through prenatal testing. If a child develops a disease or disability — diabetes or attention deficit disorder — loving parents incorporate the challenges posed by that condition into the project of raising and nurturing him. We do not believe that parents should reject those challenges in bringing future children into their families. (It is important to recognize that most disabilities are caused by accidents or disease, not by genetic variations.)⁸⁹

An article questioning this bias noted that many proponents of aborting children with disabilities fail to account for the costs of raising a gifted child.⁹⁰ Noting that supporting a child who wished to pursue a career in professional hockey would place much more of a financial burden and time commitment on the family than raising a child with a disability. “The dichotomy lies in the appreciation society has of each of the two individuals. The fault is placed on a society that skews the perception of an ability and disability.”⁹¹

Worldwide attitudes are almost uniformly against allowing persons with disabilities to be brought into the world. Geneticists around the world, with the exception of Master’s-level genetic counselors in the United States, take a generally dim view of disability. Most do not think that all disabilities can be overcome, even with maximum social support. Most do not think that “the existence of people with severe disabilities makes society more rich and varied.” In 25 of 37 nations, not including the United States, majorities thought “it was unfair to a child to bring it into the world with a serious genetic disorder.” In 20 nations [cite omitted] majorities thought that “it is socially irresponsible knowingly to bring an infant with a serious genetic disorder into the world in an era of prenatal diagnosis.”⁹²

This worldwide (and national) public perception problem of what it means to be disabled or to raise a child with a disability could result because people who had no family members with disabilities seriously underestimate the quality of life of a person with a disability.⁹³ The author of this article explains that while raising a child with a disability can be extremely difficult and challenging, it can also be just as rewarding as raising any child. That it is possible for those living with disabilities to be just as happy and satisfied as those without disabilities. That the biggest issue is fighting the public perception of what it means to be a person with a disability, rather than dealing with the reality of the actual disability.

The possibilities of reducing the number of persons with disabilities through genetic screening and selective abortion are real and immediate. Genetic screening is a subtler

89 David Wasserman & Adrienne Asch, *Op-Ed, The Uncertain Rationale for Prenatal Disability Screening*, 8(1) *Am. Med. Assn. J. Ethics* 53 (Jan. 2006).

90 Peter Chipman, *The Moral Implications of Prenatal Genetic Testing*, II(ii) *Penn Bioethics J.* 13 (Spring 2006).

91 *Id.*

92 Dorothy C. Wertz, *Society and the Not-So-New Genetics: What Are We Afraid Of? Some Future Predictions from a Social Scientist*, 13 *J. Contemporary Health L. & Policy* 299, 338–340 (Spring 1997).

93 Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?* 30 *Fla. St. U. L. Rev.* 315 (Winter 2003).

and likely more effective eugenics program than was implemented by the world in the 1920s through the 1970s. The issues are not easy to resolve. Parental choice, abortion rights, and personal decisions about care of persons with disabilities will impact the decision of prospective parents.

The concern of many persons with disabilities and their advocates is that prospective parents only see that the life of a person with a disability is not worth living. The author had several conversations with long-term colleagues while writing this article who are not involved in special needs planning and was shocked to hear the almost universal condemnation of living a life as a person with a disability; almost all of those interviewed would opt to abort a child with a disability. Most admitted that they had no idea what it meant to raise a child with a disability, but would not even entertain the possibility that they could ever accept that responsibility.

To provide parents with real choices, it is important that persons with disabilities have opportunities to lead excellent lives and to reveal these lives to the community at large. This can be accomplished through the continued creation of opportunities for persons with disabilities to live in the community by working and interacting with society. Thus, the next topics covered will be describing how the future special needs planner will be able to create and maintain opportunities for persons with disabilities.

IV. THE FUTURE OF ACCESS TO FINANCIAL ASSISTANCE AND HEALTH CARE BENEFITS FOR PERSONS WITH DISABILITIES

Throughout history, most persons with disabilities have been unable to enjoy even modest material success. The main reason is lack of employment. As described in one article:

In 2009, about one-fifth of persons with disabilities were in the labor force compared to more than two-thirds of people without a disability. A higher proportion of people with disabilities actively look for employment but are unable to find work compared to those without disabilities. In November 2009, the unemployment rate was 14 percent for those with disabilities and 9 percent for those without. This disparity continues within the labor force: workers with disabilities tend to earn much less than those with no disabilities. In 2007, the median income of households with any working age people with disabilities was \$38,400 compared with \$61,000 for households without people with disabilities — a staggering difference of \$22,600.⁹⁴

Because persons with disabilities are chronically unemployed, they often have no access to private health care coverage. Further, many persons with disabilities have a pre-existing medical condition that private insurance companies refuse to cover no matter how large the premium the person with a disability is willing to pay.⁹⁵ As stated in the article:

94 Karen Harris & Hannah Weinberger-Divack, *Accessible Assets: Bringing Together the Disability and Asset-Building Communities*, 44 Clearinghouse Rev. 4 (May–June 2010).

95 See Jae Kennedy & Elizabeth Blodgett, *Health Insurance–Motivated Disability Enrollment and the ACA*, 367 New Eng. J. Med. e16 (Sept. 5, 2012), <http://www.nejm.org/doi/full/10.1056/NEJMp1208212>.

The United States relies on employer-based health insurance to cover working-age adults and their families. As a result, Americans who are unable to engage in full-time work because of a chronic health condition must not only seek out wage replacement but also pursue alternative sources of health insurance. Health insurance is often more valuable than cash benefits to disabled workers who have high levels of medical needs. However, purchasing private insurance is rarely an option, owing to high costs and structural barriers such as lifetime spending caps, waiting periods, and exclusions of preexisting conditions from coverage. Disabled workers often apply for public financial disability benefits in part to obtain public health insurance — a uniquely American phenomenon that we call health insurance–motivated disability enrollment (HIMDE).⁹⁶

The only access for many persons with disabilities to receive modest financial support and health care coverage has been through government programs like Supplemental Security Income (SSI) and Medicaid. To qualify for these government programs, the person with a disability is required to have a very modest estate, typically below \$2,000 for an individual and \$3,000 for a couple.⁹⁷ These resource numbers have stayed the same since 1989.⁹⁸ There has been no indication that these numbers will increase in the foreseeable future. As a result, many people do not seek employment because they would lose their eligibility for health care.

To allow persons with disabilities to have access to these government programs, it was common practice for persons with disabilities to be disinherited so they would not receive money from parents (or others) that would disqualify them from government programs. Money was then sometimes left to a relative to care for the person with a disability. The flaws in this planning are many. For example, what happens if the relative dies and the money goes elsewhere; what happens if the relative divorces and money is lost during divorce; what if the relative decides to spend money on other things; or what happens if the relative declares bankruptcy or has creditor problems? Thus, due to a need for access to health care and inability to find employment, many persons with disabilities remain impoverished.⁹⁹ A planning tool was required that kept the benefits reserved for

96 *Id.*

97 20 C.F.R. § 416.1201(a) (1986). However, certain assets are not counted, such as a principal residence, one automobile, household items, and a few other items. *See* 42 U.S.C. § 1382b(a).

98 “When the SSI program began in 1974, the asset limits were \$1,500 per individual and \$2,250 per couple. Asset limits were last revised over twenty years ago to \$2,000 per individual and \$3,000 per couple as specified in the law’s schedule of increases. That means that since 1989 no adjustments have been made for inflation or cost of living. If the 1974 limits had been even moderately adjusted for inflation, the 2010 limits would be \$6,592 and \$9,889 respectively.” Harris & Weinberger-Divack, *supra* n. 94.

99 Nearly 28 percent of those with disabilities ages 18 to 64 were living in poverty in 2010, according to statistics released from the U.S. Census Bureau. Meanwhile, the poverty rate for their peers in the general population reached 12.5 percent. *See* Carmen DeNavas-Walt, Bernadette D. Proctor & Jessica C. Smith, *Income, Poverty, and Health Insurance Coverage in the United States: 2010* (Sept. 2011), <http://www.census.gov/prod/2011pubs/p60-239.pdf>.

persons with disabilities, but did not disqualify them from access to their health care.

The primary planning tool for persons with disabilities became the special needs trust. But, as discussed below, certain issues have arisen that make the special needs trust impractical as a planning tool for certain persons with disabilities. Proposals have been made for new planning tools that will allow the future special needs practitioner to have additional tools at his or her disposal, (this includes the ABLE account). In addition, because of the passage of the ACA, special needs planners will have a valuable new tool to access health care that is not dependent on government benefit eligibility.

The future of special needs planning will be much like the past, finding ways to access health care, protect and grow assets, and enhance the quality of life of a person with a disability.

A. The Special Needs Trust

Special needs planners through the years created a variety of ways to allow persons with disabilities to lead more than a subsistence existence. This included a variety of trusts to hold money for the benefit of persons with disabilities. These trusts came of age in 1993 when the government passed the Omnibus Budget Reconciliation Act (OBRA '93), which provided exceptions to transfer penalties and counting rules for Medicaid for three unique trusts:¹⁰⁰

1. A trust that contains the assets of a disabled individual under age 65, established for his or her benefit by a parent, a grandparent, a legal guardian, or the court, if the State Medicaid agency will receive all amounts remaining in the trust on the beneficiary's death up to the amount of benefits paid.¹⁰¹ This trust is commonly known as a "(d)(4)(A) SNT."
2. A trust that is composed only of pension, Social Security, and other income in a state that does not allow income "spend-down."¹⁰² These trusts are commonly known as "Miller Trusts" (after *Miller v. Ibarra*, 746 F. Supp. 19 (D. Colo. 1990)).
3. A trust that contains the assets of a disabled individual if (a) the trust is established and managed by a nonprofit corporation and maintains separate accounts of pooled assets; (b) the accounts are established by a parent, a grandparent, a legal guardian, the individual beneficiary, or the court; and (c) the state will, on the beneficiary's death, receive all amounts remaining in the beneficiary's account (unless the account is retained by the nonprofit corpora-

100 The safe-harbor trust exceptions in 42 U.S.C. § 1396p(d)(4) apply to Medicaid eligibility rules. The federal special needs trust statutory exception was the first expression by Congress stating a congressional policy permitting special needs trusts and continuing eligibility for Medicaid for persons with disabilities. Prior to such time, there was much litigation involving common law special needs trust between applicants and the states. Many states opposed such trusts on policy grounds.

101 42 U.S.C. § 1396p(d)(4)(A).

102 42 U.S.C. § 1396p(d)(4)(B).

tion) up to the amount of Medicaid benefits paid.¹⁰³ These trusts are commonly known as “pooled SNTs.”

The same trust exceptions were expressly adopted for SSI.¹⁰⁴ In addition to these trusts, the statute also made an exception for trusts set up using other people’s assets, typically from an inheritance; this trust is commonly called the Third Party Special Needs Trust.¹⁰⁵ The special needs trust has become the primary tool for the special needs planner because it allows the planner to manage (in a legally binding fashion) the assets of a person with a disability while preserving eligibility for SSI and Medicaid. The special needs trust also allows the planner to establish a system of advocacy for the person with a disability to ensure he or she is receiving all of his or her education, health care, access to employment, housing, voting rights, and other services.

While the special needs trust has been an extraordinarily useful and powerful tool that enhances the quality of life for thousands of persons with disabilities, certain issues have arisen over the years that make it an unattractive option for some. Due to establishment requirements, the cost of setting up a special needs trust can be more than some persons can afford. The special needs trust can also be expensive to administer. Further, a requirement of the special needs trust is that the person with a disability loses control over his or her assets. This loss of control is problematic for many persons with disabilities who have capacity to manage their own financial affairs. Finally, due to the complicated rules surrounding the trust’s administration, many persons with disabilities end up losing eligibility for their benefits even when assets are placed into an otherwise qualifying trust.

Due to these issues, some persons with disabilities and lawmakers are looking at alternatives to special needs trusts, such as the creation of other types of accounts that will benefit persons with disabilities, without some of the limitations of a special needs trust. Does this mean there is no room for the special needs trust in the future? Absolutely not. Special needs trusts will still be an important tool of the special needs planner. The ability to set aside assets with written instructions in a legally binding format will still be required for many persons with disabilities. The trust will still be valuable because it protects a beneficiary with special needs who is susceptible to undue influence from financial predators. It still protects the beneficiary who does not have the capacity to manage his or her own affairs. It can provide written instructions from a parent or loved one on the best ways to provide housing, education, and living arrangements for their loved one with special needs. It can describe a system of advocacy in which the funds in the trust can be used to assist the person with a disability. Thus, the future of the special needs trust is bright. Nevertheless, concern remains for the future use of the special needs trust that is only being established to obtain Medicaid or SSI benefits. A steady erosion of its protection

103 42 U.S.C. § 1396p(d)(4)(C).

104 42 U.S.C. § 1382b(e)(5) (SSI financial eligibility will be preserved if assets are held in a qualifying trust). Title 42 U.S.C. § 1382b(e)(5) refers to the Medicaid safe harbor trust rules in 42 U.S.C. § 1396p(d)(4).

105 For Medicaid, a third party special needs trust established on or after August 11, 1993, is not affected by the OBRA ’93 trust rules. See 42 U.S.C. § 1396p(d)(2)(A). For SSI purposes, the regulations allow third party special needs trusts. See 42 U.S.C. § 1382b(e)(3)(A); 20 C.F.R. § 416.1201(a)(1). Some people use the phrase “Supplemental Needs Trust” to distinguish between a third party trust and first party trust.

has transpired from decisions made by state Medicaid programs and the Social Security Administration. The good news is that the ACA may mitigate some of the concern about the loss of Medicaid.

B. Fighting for the Preservation of Existing Rights

Despite the historical discrimination against persons with disabilities, the statistics showing the high level of poverty, and the barriers by society to full inclusion, some government officials are of the opinion that any person who has money should not qualify for government benefits. These officials pass policies that attempt to limit the use of special needs trusts so that they become a less viable or desirable option for the person with a disability. Special needs planners must be ever vigilant against these policies that continue the historical discrimination against persons with disabilities under the guise of law.

States and several government agencies are issuing opinions and “policy” statements that attempt to limit the rights of persons with disabilities. Due to shrinking budgets, many states have already attempted to limit the rights of persons with disabilities to obtain public benefits by the use of special needs trusts.¹⁰⁶ For example, in 2005, a Pennsylvania law limited the use of pooled special needs trusts by persons with disabilities.¹⁰⁷ This legislation would have strictly limited expenditures from trust accounts to only treat the person’s disabling condition and nothing else. Fortunately, due to the advocacy efforts of many special needs planners, the Third Circuit Court held that all of the limitations that were more restrictive than federal law for pooled special needs trusts were improper. The federal statute enacted by Congress permits pooled special needs trusts to retain any amount, does not limit how money is spent so long as it is for the benefit of the beneficiary, and allows people over age 65 to have such accounts. However, other courts have come to a different conclusion. For example, the Tenth Circuit, in an earlier opinion in dicta, stated that states had the right to limit access to its citizens of the use of special needs trusts.¹⁰⁸ In another opinion, the Eighth Circuit held that pooled trusts can be used for persons age 65 or older, but the North Dakota statute imposing a transfer penalty on those funds was enforceable.¹⁰⁹

In addition to states passing laws, the Social Security Administration (SSA) has become very active in attempting to limit the use of special needs trusts by persons with disabilities. Eligibility for Medicaid is often tied to eligibility for SSI.¹¹⁰ In all states, the

106 Bridget O’Brien Swartz & Angela E. Canellos, *The Wrongful Disregard of SSI Comparability by Some State Medicaid Agencies as It Relates to SNTs*, 5 NAELA J. 139 (2009).

107 Pennsylvania Act 42 of 2005 § 9, 62 Pa. Stat. Ann. § 1414 (West 2010).

108 The holding of this case is that an individual does not have the right to sue the state for enforcement of the Medicaid statute. However, this appeals court stated that 42 U.S.C. § 1396p(d)(4) did not unambiguously impose a binding obligation on the state. *Hobbs v. Zenderman*, 579 F.3d 1171, 1179 (10th Cir. 2009). It found that “Congress left the States free to decide whether and under what conditions to recognize such [§ 1396p(d)(4)] trusts” and that “States’ need not count [§ 1396p(d)(4)] trusts for eligibility purposes, but nevertheless may . . . opt to do so.”

109 *Ctr. for Special Needs Admin. v. Olson*, 676 F.3d 688 (8th Cir. 2012).

110 Mary F. Radford & Clarissa Bryan, *Irrevocability of Special Needs Trusts: The Tangled Web That Is Woven When English Feudal Law Is Imported into Modern Determinations of Medicaid Eligibility*, 8 NAELA J. 1 (2012).

determination of SSI eligibility is closely linked to access to Medicaid.¹¹¹ Thus, access to SSI is often used to become eligible for Medicaid, and it is therefore essential that the special needs planner understand how the SSA administers the SSI program.

The SSI program is administered by both local and district offices of the SSA. Administratively, the Social Security Act contains a provision for the SSI program, which is regulated by the Code of Federal Regulations, and which is enforced by the transcription of these regulations into the general and regional instructions compiled in the Program Operations Manual System (POMS). Functionally, the POMS is a handbook for SSA employees who are involved in the determination of SSI (and in some cases, Medicaid) eligibility. SSI eligibility determinations are made using the POMS and hearings for reconsideration are handled by Administrative Law Judges (ALJ's), whose decisions are binding on state Medicaid eligibility to a large degree.¹¹²

The POMS¹¹³ includes a section that discusses the way in which SSA workers shall determine whether the assets in a trust are countable resources for SSI eligibility purposes, including qualifying special needs trusts.¹¹⁴ If the SSA worker finds that the assets are countable, then the formerly eligible SSI recipient loses SSI and linked Medicaid eligibility. This is a crucial determination that has far-reaching implications for a person with a disability. If his or her special needs trust is found to be a countable resource, all access to government benefits could be eliminated. Thus, access to health care and cash benefits that provide for food and shelter will disappear for the person with a disability.

The SSA has issued several pronouncements over the past few years of changes to its POMS that restrict the use of special needs trusts for persons with disabilities. The SSA in the past has issued changes to the POMS that are simply wrong on the law.¹¹⁵ More recently, in 2010, the SSA released new POMS provisions on the issue of early termination of special needs trusts. The revised POMS is intended to address provisions in trusts that provide for termination before the beneficiary's death, e.g., if the trust beneficiary ceases to be disabled or if the trust no longer contains enough assets to justify its administration.¹¹⁶ The new provisions required that a state's Medicaid agency be paid back on any termination of a special needs trust, not just on death.¹¹⁷ Why the SSA feels compelled to intervene on the validity of a special needs trust's payback provision is puzzling because the SSA never sees a nickel from the trust's payback requirements. The SSA early termination rules apply not only to new special needs trusts, but also to previously established (and presumably SSA- approved) special needs trusts.¹¹⁸ Thus, if an already existing trust includes an early termination provision, it will lose its status as a qualifying special needs

111 *Id.*

112 *Id.* at 9–10.

113 POMS will receive deference from courts. While not law, POMS is persuasive and will be followed unless directly contradicting a statute or regulation. *See Wash. St. v. Keffeler*, 537 U.S. 371, 382 (2003).

114 POMS SI 01150.121, SI 01120.199, SI 01120.200, SI 01120.203 (A)(1)–(2).

115 Radford & Bryan, *supra* n. 110, standing for the proposition that application of the rule in Shelly's case and the doctrine of merger by SSA is inappropriate and wrong for purposes of determining intent for a special needs trust.

116 POMS SI 01120.199(D).

117 *Id.*

118 POMS SI 01120.199(A)(1)–(2).

trust if its early termination provisions do not meet all of the new requirements. However, the SSA does allow a trustee a 90-day period to fix the trust by eliminating or modifying the language in the early termination provision.¹¹⁹ The problem with this requirement is that the federal statute only requires that a “State Medicaid agency will receive all amounts remaining in the trust *on the beneficiary’s death*.”¹²⁰ It does not require a payback on the earlier termination of the trust, so this SSA requirement is also invalid as it violates the federal implementing statute.

In 2012, the SSA again modified the POMS to make the use of special needs trusts more difficult for persons with disabilities to use. This time it modified the section dealing with determining whether a distribution from a special needs trust is for the “sole benefit” of a person with a disability.¹²¹ While the example is limited to one scenario, more troubling is what Erik Skidmore, the SSA official in charge of the SSA POMS for SSI, stated during a presentation he made to the Academy of Special Needs Planners in March 2012 at its Fifth Annual program in Memphis. Mr. Skidmore stated that the SSA was considering taking the position that any distribution from a special needs trust to a family caregiver would not be considered for the “sole benefit” of a person with a disability.¹²² While insupportable in law and devastating to thousands of persons with disabilities, if the SSA were to take this step, many persons with disabilities will face the tough decision of hiring a non-relative caregiver at an exorbitant rate or forego all caregiving that allows them to reside in the community. This will lead many persons with a disability to move into government-subsidized housing at a cost that is demonstrably more than if that person were able to reside in the community. Thus, the future of special needs planning will be much like the past, the ongoing battle to facilitate the full inclusion of persons with disabilities in American society. The special needs planner will need to be ever attentive to protect the few gains made by the disability rights movement and prevent government bureaucrats from limiting access to these rights.

To show the benefits of effective advocacy, numerous high-level SSA employees have begun meeting with several national charitable groups for persons with disabilities

119 POMS SI 01120.199(A)(2).

120 42 U.S.C. § 1396p(d)(4)(A).

121 The SSA has taken the position that it will reject any first-party special needs trust containing a provision allowing payments that enable family members to visit the primary trust beneficiary. POMS SI 01120.201(F) contains two new examples that outline this policy. In the first example, the “trust document includes a provision permitting the trustee to use trust funds in order to pay for the SSI recipients family to fly from Idaho and visit him in Nebraska.” The SSA states that “[t]he trust is not established for the sole benefit of the trust beneficiary, since it permits the trustee to use trust funds in a manner that will financially benefit the SSI recipients family.” In the second example, the new POMS states that a trust provision allowing payments for a personal care attendant would be permissible because “payments made for attendant care are considered a payment to a third party for goods or services.” See <http://www.elderlawanswers.com/poms-changes-tighten-interpretation-of-sole-benefit-rule-ford4a-trusts-9915>.

122 On October 19, 2012, Mr. Skidmore clarified this statement during a presentation titled *Update From Social Security* made at the Stetson University College of Law conference titled 2012 Special Needs Trusts: The National Conference, by stating that family caregivers may be paid, but must be medically trained. What the term “medically trained” means is still uncertain. However, as noted below, the SSA has recently revised these new interpretations of policy and are now working with special needs planners in adopting more family friendly policies.

and special needs planning attorneys from around the country concerning the alarming changes being adopted by the SSA. The result of these advocacy efforts, spearheaded by attorney Mary E. O'Byrne is that the changes implemented by the SSA in 2012 have been eliminated, including the addition to the POMS of the examples concerning the sole-benefit issue. Also, the SSA has agreed to a series of ongoing meetings and it is hoped that the results of these advocacy efforts will result in further easing of some of the SSA's more onerous interpretations of the regulations concerning the administration of special needs trusts.

C. New Financial Planning Tools May Be Available

The future special needs planner may have tools in addition to the special needs trust to assist the person with a disability to achieve his or her financial goals. Providing planning for wealth preservation and financial stability for a person with a disability is one of the best missions a special needs planner can have. As noted in a law review article:

There is a clear and disturbing link between disability and unemployment, poverty, and material hardship. Asset building programs, which give people the opportunity to escape poverty permanently, have gained momentum in the academic, public, and nonprofit sectors. In general, however, these policies do not take into consideration, or give short shrift to, people with disabilities and the saving barriers unique to them. The barriers to saving that people with disabilities face demand the implementation of policies and programs to increase inclusion and promote wealth creation and financial stability.¹²³

One of these tools may be the ABLE account. The ABLE Act is currently in committee, but has sponsors from both parties.¹²⁴ If passed, the ABLE Act will establish an account that serves much like a 529 qualified tuition program for education. The same rules will govern ABLE accounts, including limits on the size of the account, rules for tax treatment of annual contributions, earnings, withdrawals, and reporting requirements. In addition, rollovers of cash will be allowed from an ABLE account to a traditional 529 if the beneficiary is no longer considered disabled, to another family member's ABLE account or to their 529 plan, and to a special needs trust allowed under Medicaid rules. The cost of setting up an ABLE account should be modest and accessible to many persons with disabilities who may have had trouble affording the fees to establish a special needs trust.

The ABLE Act allows a person with a disability to manage the account without having to rely on someone else. This is very valuable to persons with disabilities who have capacity to manage their financial affairs but had to terminate those rights in order to place funds into a special needs trust. However, some downsides to the ABLE Act are also being proposed. The Act limits the type and amount of qualified disbursements that can be

123 Harris & Weinberger-Divack, *supra* n. 94.

124 ABLE Act of 2011, H.R. 3423, 112th Cong. (Nov. 15, 2011); ABLE Act of 2011, S. 1872, 112th Cong. (Nov. 15, 2011).

made from the account to mostly disability-related expenses. These disbursements may be too narrow to assist a person with a disability to live fully within the community. The Act also includes a payback requirement to the state's Medicaid agency upon the death of a person with a disability. This is true even if the funds first belonged to a third party. This payback requirement is significantly greater than what is required for first party special needs trusts. Due to negative (and often contradictory) experiences with State's Medicaid payback agencies in administering first party special needs trusts, many special needs practitioners are concerned that this requirement will cause undue hardship to persons with disabilities and their loved ones.

The ABLE Act will not obviate the need for the use of special needs trusts. For example, a special needs trust will still be needed for those persons with disabilities who lack capacity to manage their own affairs or the recipients of large litigation settlements or inheritances that exceed the amount allowed to be funded into an ABLE account. Further, in order to avoid payback to state Medicaid agencies, setting up third party special needs trusts would generally be favored over the ABLE account because the funds in the third party trust could be distributed directly to the person with a disability's heirs and not to State Medicaid agencies. However, the ABLE account (or other similar financial planning) tool will still be a welcome addition to the future special needs planner's toolbox in many situations.

D. Affordable Care Act

The passage of the ACA will have a profound impact on the future of special needs planning. The ACA is scheduled to be fully implemented by January 1, 2014, and presuming its provisions survive the heated opposition to it, will provide health care coverage for many persons with disabilities. The Act was able to hurdle its first obstacle when the United States Supreme Court held that it was constitutional.¹²⁵

The ACA will directly affect many aspects of special needs planning because so much of it is focused on the needs of an individual with chronic, long-term physical or cognitive conditions. The ACA will provide:

1. Extension of private health coverage to those with pre-existing conditions, removal of lifetime limits, and guaranteed renewal — and subsidized premium costs;
2. Coverage of children on their parents' health care plans until age 26;
3. Extension of Medicaid to noninstitutionalized, nondisabled poor individuals under age 65 — that is, no "categorization" of persons eligible to get insurance versus those who are not, based on age or disability or pregnancy; and

¹²⁵ *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 132 U.S. 2566 (2012). The case was heard with *Florida v. Dep't of Health & Human Servs.*, 648 F.3d 1235 (11th Cir. 2011). However, the court struck down the federal government's plan to enforce the expansion of Medicaid by withholding all Medicaid funding from states choosing not to broaden their programs.

4. Care coordination efforts between home, facility, and hospital to reduce expensive hospital readmissions.¹²⁶

The ACA will allow persons with disabilities to have access to private health care. This is important for many because now the person with a disability has options they did not have before. Prior to its passage, persons with disabilities had to use the special needs trust to become impoverished in order to qualify for Medicaid, which was generally the only health care available to them. In the future, the person with a disability will be able to buy a private health plan. This means that no special needs trust will be needed to provide access to health care, except for long-term skilled nursing home care (or other Medicaid-paid only programs).

Will the ACA cause the “death” of special needs planning as prognosticated by some? No. Persons with disabilities will still require planning to cover financial issues if they do not have legal capacity to manage their affairs. Private insurance plans provide limited coverage for long-term care. Plus, some state Medicaid plans cover the cost of in-home caregivers, supports for independent living, and activities, such as sheltered workshops that are not covered by the ACA. Special needs planners will need to prepare their trusts so that the trustee may use funds to pay for a private health plan rather than limiting their coverage to Medicaid. The ACA will likely be a boon for persons with disabilities. Special needs planners will need to understand its intricacies so their clients can take full advantage of this wonderful law for persons with disabilities.

V. CONCLUSION

The future of special needs planning will be quite different albeit very similar to current practices. The practitioner should not be daunted by future challenges.

Never let the future disturb you. You will meet it, if you have to, with the same weapons of reason which today arm you against the present.

— Marcus Aurelius Antoninus
(121 AD - 180 AD), *Meditations*, 200 A.D.

The primary goal of special needs planning will remain the same, to provide persons with disabilities the best legal, personal, and financial planning that enhances their quality of life and to allow them to reach their full potential. The historical treatment of persons with disabilities has generally been poor. The disability rights movement brought forth many positive changes for persons with disabilities. These advances have always been hard fought, but easily watered down by later events. Thus, the future special needs planner will be required to remain ever vigilant to defend the gains made on behalf of persons with disabilities.

The future population of persons with disabilities will look much different than we see today. Advances in genetic testing may eliminate many developmentally disabled

¹²⁶ Materials and portions of discussion were inspired by David Lillesand’s presentation *The Impact the Affordable Care Act Will Have on Our Practices* at the Academy of Special Needs Planners 6th Annual Meeting (2012, Memphis). See <http://www.specialneedsplanners.com/conference2012>.

persons who were selectively aborted by parents looking for a “normal” child. However, the overall population with disabilities will increase due to the aging of the population and the abundance of overweight children and Type-2 diabetes. Further, the rise of autism may presage other types of disabilities increasing in a society that uses so many artificial means in sustaining its population through modified crops, pesticides, and other substances when there is little to no understanding of long-term effects.

The special needs planner will continue to use special needs trusts as a tool to aid in special needs planning. However, the special needs trust may only be one of many tools used. New planning tools may arise that will aid the person with a disability in achieving financial stability. This may include the ABLE account or a similar type account that will allow a person with a disability to keep more than \$2,000 in assets without jeopardizing eligibility for public benefits, namely, SSI and Medicaid. However, the passage of the ACA may have the most profound effect on the future of special needs planning. This Act allows persons with disabilities the right to buy private health care. This may lead many persons with disabilities to choose not to participate in public benefit programs to access health care. Perhaps the days of planning for a person with a disability to continue to receive public benefits for the sole purpose of obtaining health care will diminish (or become extinct) beginning in 2014.

While many things look bleak for persons with disabilities, there are many positive changes to come and the successful special needs practitioner will be prepared to meet those challenges.