

# SNA Capitol Connection

August 2009

Volume 1, Issue 1



Bridget O'Brien Swartz, CELA  
Chair, Public Policy Committee  
Special Needs Alliance

## A Word from the Chair

On behalf of the Special Needs Alliance, I am pleased to welcome you to the inaugural issue of *SNA Capitol Connection*! The SNA is dedicated to promoting responsible public policies that meet the many needs of individuals with disabilities, and this newsletter is designed to give our readers a snapshot of these important issues.

While individuals with disabilities and their families face many challenges, it is in the area of financial planning where the questions seemingly outnum-

ber the answers. The SNA is committed to helping families across the country to demystify the special needs planning process and identify solutions tailored to their unique situations. Public policy can promote financial independence of those with special needs, and the SNA works aggressively to promote policies that enrich their quality of life.

As you will learn from reading this newsletter, the SNA and our member attorneys across the country are strategically represented among the co-

alitions helping to shape good, sound, and realistic public policy. In the spirit of collaboration, we encourage our readers to join this dialogue, and invite you to submit your comments and questions about our work in this area. Please send an e-mail to [info@specialneedsalliance.org](mailto:info@specialneedsalliance.org), and we will respond promptly.

Thanks for your interest in the public policy work of the SNA!

*Bridget O'Brien Swartz, CELA  
Chair, Public Policy Committee*

### SNA Board of Directors

Bernard Krooks, CELA (NY)  
*President*

Andy Hook, CELA (VA)  
*Immediate Past President*

Bridget O'Brien Swartz, CELA (AZ)  
*President-Elect*

Neal Winston, CELA (MA)  
*Vice President*

Kemp Scales, CELA (PA)  
*Treasurer*

Brad Frigon, CELA (CO)

Ruthann Lacey, CELA (GA)

Brian Rubin, Esq. (IL)

Nell Graham Sale, CELA (NM)

### Public Policy Committee

Bridget O'Brien Swartz, CELA (AZ)  
*Chair*

John Kitchen, Esq. (NH)  
*Vice Chair*

Donna Bashaw, CELA (CA)

Rebecca Berg, CELA (FL)

Bob Brogan, CELA (NJ)

Stephen Dale, Esq. (CA)

Brad Frigon, CELA (CO)

Marielle Hazen, CELA (PA)

Mary Alice Jackson, Esq. (FL)

Ron Landsman, Esq. (MD)

Brian Rubin, Esq. (IL)

Neal Winston, CELA (MA)

Lois Zerrer, Esq. (MO)

## The Long Wait May Be Over

In 1972, Medicare coverage was extended to persons receiving Social Security Disability Insurance (SSDI) after a 24 month waiting period from determination of eligibility for the benefit<sup>1</sup>. This waiting period has created untold financial burdens, as well as pain and suffering for the disabled, forcing many to forego care, further complicating their condition. The long wait may, at long last, be coming to an end.

The original reasons for the two year wait were first, to keep costs down, second, to avoid overlap with private insurance coverage and, third, to limit coverage to those with severe and long-lasting disabilities. The flaw is primarily in the second reason: Too many SSDI recipients are not, in fact, covered by private or other insurance such as

Medicaid during all or part of the waiting period. A 2003 Commonwealth Fund study estimates that nearly forty percent of people with disabilities are without health insurance coverage at some point during their 24 month wait and that 24 percent have no health insurance during the period at all (See the July 2003 Commonwealth Fund Report - *Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs*).

Those with sudden disability onset (such as being in an accident) are more likely to have private insurance and thus may maintain employer-sponsored health insurance under what most people know as COBRA. The eligibility period



*(continued on page 2)*

# Amending Title 10 to Allow Military Retirement Pensions to go into a SNT

In accordance with Title 10 of the U.S. Code, Survivor's Benefit Plan annuity (SBP), which pays 55 percent of a retired officer's pension to a spouse and/or dependent child, cannot currently be paid to a child's special needs trust – an issue that creates significant problems for the disabled children of retired military officers.

Members of the military pay a percentage of their retirement pension each month for this benefit. While the SBP is a significant benefit for the spouse, it is most often problematic for the adult disabled child who receives Supplemental Security Income (SSI) and Medicaid. Unfortunately, a large number of retired officers are unaware of these problems. The amount of the SBP usually makes the child ineligible for SSI and, in most states, the child will also lose Medicaid benefits. This can lead to significant problems for the family. For example, if an adult disabled child resides in a group home, which is paid for by Medicaid through the Med-Waiver program, and loses Medicaid benefits, he or she typically does not receive enough in SBP benefits to pay the private cost of the group home and must find somewhere else to live.

To remedy this long-time, overlooked problem, Rep. Bill Foster from Illinois introduced legislation, H.R. 2059 on April 23, 2009, amending Title 10 of the U.S. Code. The amendment will provide for the payment of monthly annuities under the SBP to a supplemental or special needs trust established for the sole benefit of a disabled dependent child of a participant in the SBP. Having these funds go directly into a trust would allow the disabled person to maintain Medicaid and SSI benefits. The bill was referred to the Committee on Armed Services.

The SNA had hoped to have this legislation attached as an amendment to the National Defense Authorization Act, which is revised and voted on each year, but the Act was recently passed without the amendment. The SNA and its allies on Capitol Hill continue to evaluate future opportunities to correct this SBP inequity. To strengthen the case for a new law in this regard, the SNA is looking for real stories to share with members of Congress. If you know of someone experiencing this issue who is willing to discuss their circumstance, please contact us at [info@specialneedsalliance.org](mailto:info@specialneedsalliance.org).

*By Rebecca L. Berg, CELA*

## The Long Wait May Be Over

(continued from page 1)

for COBRA is seven months short of the two year waiting period and, more importantly, is often cost prohibitive, with the former employee paying 102 percent of the combined employee and employer share of the cost for 18 months, and up to 150 percent for the additional 11 months.

Those with chronic illness, especially those with mental illness, are not likely to have employer sponsored health insurance before qualifying for SSDI. These individuals are more likely to qualify for Medicaid coverage for the two year wait but are often over the meager \$2,000 asset limit and may not want to impoverish themselves to qualify for Medicaid - a quandary faced by far too many.

On March 25, 2009, legislation was introduced (S. 700 and H.R. 1708) with the goal of eliminating the Medicare waiting period. The bill will shorten the waiting period at a rate of two months each year, with eventual elimination of the waiting period beginning in 2019. The bill will also immediately eliminate the wait for people with life-threatening illnesses as determined by the Secretary of Health and Human Services in consultation with the National Institutes of Health, the Centers for Disease Control and Prevention, the National Science Foundation, and the Institute of Medicine of the National Academy of Sciences. The

Secretary will also annually review the Social Security Administration's Compassionate Allowance list which was created to provide benefits quickly to applicants who obviously meet disability standards.

Several other approaches have been set forth to eliminate or lessen the burden of the 24 month wait (See Coalition letter dated May 22, 2009, of 120 organizations including SNA and NAELA). The coalition favors an option that reduces the waiting period in six month increments rather than two month increments, completing the elimination period in one and a half years.

Of course, with health reform and universal coverage currently being widely discussed and considered, the issue of a Medicare waiting period could become moot. However, waiting to see what happens in the general health care arena is too risky. This problem has been in place for 37 years. It currently affects 1.8 million people. The problem is urgent and the time to solve the problem is now.

*By Donna R. Bashaw, CELA*

(Endnotes)

1 Currently, individuals receiving Social Security benefits or railroad retirement benefits and who suffer with end-stage renal disease are eligible for Part A Medicare benefits after satisfying a three-month waiting period. As of July 1, 2001, individuals with amyotrophic lateral sclerosis (ALS) are entitled to Medicare benefits without a waiting period.

**Special thanks to SNA member Kelly Thompson from Virginia for her ongoing work in identifying sponsors for the legislation amending Title 10 and getting it off the ground.**

# Alternatives to SNTs – tracking the new federal “ABLE” proposals

At the urging of a number of national disability advocacy groups, federal legislation to “*Achieve a Better Life Experience*”, more commonly known as “ABLE,” has been proposed in both houses of Congress (HR 1205 and SB 493). The legislative purpose for this initiative is two-fold:

- (1) To encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life; and
- (2) To provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, federal benefits, the beneficiary’s employment, and other sources.

ABLE is an addition to the Internal Revenue Code (IRC), *not* primarily a change to existing Social Security or Medicaid laws. However, the bill does provide that a new subparagraph would be added to U.S. Code Title 42, which primarily concerns special needs trusts, to include ABLE accounts.

The bill would allow the creation of tax-exempt “trust” accounts providing that: (a) The accounts are created under the IRC, (b) total aggregate lifetime contributions be limited to \$500,000, (c) contributions be made only for individuals under age 65, (d) a provision ensuring payback to Medicaid is included, (e) a “trustee” is identified, and (f) funds not be invested in life insurance contracts. Accounts that meet these requirements may be used for the benefit of “individuals with a disability” to pay certain “qualified disability expenses.”

In the bill, an “individual with a disability” is defined as one who is eligible to receive certain Supplemental Security Income benefits under the Social Security

Act. “Qualified disability expenses” are defined as the following: Education; housing; transportation; employment support; health, prevention and wellness; life necessities; assistive technologies and personal support services; and “other” approved expenses which might be defined by the IRS at a later date.

In addition to the account’s tax exempt status, contributors to an ABLE account would be entitled to up to a \$2,000 annual tax deduction for their contribution, encouraging family members and others to support persons with disabilities. Distributions to the beneficiary are income

and for purposes of determining eligibility for other means-tested federal programs, giving participants an alternative to special needs trusts.

The IRS will require annual reporting from the Trustee of an ABLE account. It is unclear whether anyone designated as a potential trustee could actually establish the trust, or whether the account could be established by any party on its own initiative. In addition, although a payback provision is mandated, there is no indication of who might be authorized to take custody of the account and arrange for the payback after death.

There are many individuals who cannot or do not take advantage of SNT laws due to the small amounts of money which may be involved, and the high costs of establishing SNTs. Some of those individuals may be well served by the passage of this legislation.

tax free if the qualified disability expenses of the beneficiary during the taxable year are not less than the aggregate distributions during the taxable year. The legislation also permits rollovers into ABLE accounts from, among other things, HSAs, qualified tuition programs, Coverdell education savings accounts and certain IRAs from a parent or grandparent. Existing custodial accounts could be converted by banks into ABLE accounts if the intent to use the funds with ABLE parameters was expressed. There is no mention of how or whether Uniform Transfers to Minors Act laws might need to be altered if this were done.

Critical to the special needs planning community is that funds held in ABLE accounts would be disregarded in determining eligibility for Medicaid benefits

SNA supports the ABLE legislation in concept, although we have raised a number of concerns about administration and accountability, including the potential for abuse and exploitation. We know that there are many individuals who cannot or do not take advantage of SNT laws due to the small amounts of money which may be involved, and the high costs of establishing SNTs. Some of those individuals may be well served by the passage of this legislation. However, ABLE accounts will not be a substitute for comprehensive special needs planning. If the bills continue to move forward, look for a discussion of possible concerns and advantages in the next newsletter.

By Mary Alice Jackson, Esq.