



Special needs require special attorneys.

A report from the Special Needs Alliance on public policy issues impacting individuals with special needs.

SNA Capitol Connection



October 2011

Volume 2, Issue 3

A Word from the Chairs



Marielle Hazen, CELA
Co-Chair



John Kitchen, Esq.
Co-Chair



Bridget O'Brien Swartz, CELA
Co-Chair

Welcome to the next issue of Capitol Connection. When it comes to public policy and legislative affairs, summer is often associated with a slowing down of activities. This past summer proved an exception, however, with movement on raising the debt ceiling coming down to the proverbial wire and producing both drama and an agreement. With that out of the way, for now, we can focus on other issues as Congress returns to Washington, DC in late summer. Beginning in the fall, they'll be taking up pending legislation, some of which is important to special needs families and attorneys. In this issue, we give you a summary of what, where, when and who.

Also in this issue, we're honored to have Representative Tim Murphy (R-PA), Co-Chair of the Mental Health Caucus, in our Newsmaker Profile. Rep. Murphy has been serving the 18th district of the Keystone State since 2003. A psychologist by profession for three decades, he has been a champion of health issues, especially as they relate to mental health. He shares with us his knowledge and insights from his work in Congress and previously in the State Senate.

From the great state of Pennsylvania to the Grand Canyon State, our State Focus this quarter is on Arizona, which celebrates its Centennial on February 14th of next year. Bridget Swartz of Jaburg|Wilk helps us to understand what is happening with respect to special needs issues at the capitol in Phoenix.

Finally, you'll find useful information about your leadership in the SNA. Thoughts or comments? Email us at info@specialneeds.org And enjoy!



NEWSMAKER PROFILE

Rep. Tim Murphy (R-PA)

Co-Chair, Congressional Mental Health Caucus

SNA Since your early days in Congress, you have been a leader in healthcare issues, especially as they relate to mental health. Looking back, when did your interest in mental health begin?

Rep. Murphy: My interest in healthcare begins with my family. My mom was a nurse who instilled in each of us the values of family, education, and self-reliance. Growing up with eleven brothers and sisters meant that there was always someone who needed to be looked after, cared for, or supported.

Since I was part of a large family, working with children was a natural career choice. As a pediatric psychologist at Pittsburgh-area

(continued on page 2)

SNA Board of Directors

- Neal Winston, CELA (MA) • President
- Bridget O'Brien Swartz, CELA (AZ) • Immediate Past President
- Janet Lowder, CELA (OH) • President-Elect
- Pi-Yi Mayo, CELA (TX) • Vice President
- Brad Frigon, CELA (CO) • Treasurer
- Marielle Hazen, CELA (PA) • Secretary

DIRECTORS

- Rick Courtney, CELA (MS)
- Stephen Dale, Esq. (CA)
- Robert Fechtman, CELA (IN)
- Barbara Isenhour, Esq. (WA)
- Mary Alice Jackson, Esq. (FL)
- Brian Rubin, Esq. (IL)
- Dennis Voorhees, CELA (ID)
- Jeff Yussman, Esq. (KY)

SNA Public Policy Committee

- Marielle Hazen, CELA (PA) Co-Chair
- John Kitchen, Esq. (NH) Co-Chair
- Bridget O'Brien Swartz (AZ) Co-Chair
- Rebecca Berg, CELA (FL)
- Judith Bomster, Esq. (NH)
- Robert Brogan, CELA (NJ)
- Stephen Dale, Esq. (CA)
- Larry Frolik, Esq. (PA)
- Mary Alice Jackson, Esq. (FL)
- James O'Reilly, CELA (NV)
- Brian Rubin, Esq. (IL)
- Lois Zerrer, Esq. (MO)

1 - 8 7 7 - 5 7 2 - 8 4 7 2

www.specialneedsalliance.org

Newsmaker Profile: Rep. Tim Murphy

(continued from page 1)

hospitals, I spoke with parents whose newborn infants had physical disabilities. And having the opportunity to consult for local schools and Head Start programs, as well as opening my own private practice, I could see first-hand how policies in education, mental healthcare, and health insurance were impacting the lives of children.

SNA More than ten years ago, the U.S. Surgeon General issued a report on mental health suggesting that the field is “plagued by the disparities in the availability of and access to its services.” Has the mental health field made any real strides in this area since the report was issued? Does Congress have a role in addressing these disparities?

Rep. Murphy: Absolutely. We know that disparities in care can lead to higher costs for public health programs. And these disparities are exacerbated by the social stigma that discourages persons with mental illness from seeking treatment. Several changes in federal law have helped to remove the barriers to care associated with stigma.

Most recently, Congress enacted in fall 2008 the Paul Wellstone Mental Health and Addiction Equity Act, to require insurers provide the same benefits to those seeking mental care as persons seeking physical care. Prior to this, even federal healthcare programs have restricted access to treatment for mental illness. For many years, seniors on Medicare were charged more in co-payments for mental healthcare than for any other outpatient healthcare treatment: 50 percent co-payments for mental health treatments versus 20 percent co-payments for all other services. In 2008, I authored language to end Medicare’s discriminatory reimbursement policy. Those provisions were contained in H.R. 6331, the Medicare Improvements for Patients and Providers Act, which was enacted into law in July 2008.

SNA It has long been suggested that the stigma of mental illness is a major obstacle that prevents individuals from getting help. Is the Congressional Mental Health Caucus doing anything to tackle the issue of stigma?

Rep. Murphy: The Caucus has a number of priorities this year, including working to see that returning members of the military assimilate into society, and have access to and receive treatment for post-traumatic stress disorder.

To address the issue of stigma, consider the response to the January 2011 shooting in Tucson, Arizona. It perpetuated common myths associating violence and mental illness. There were some who wanted to brand the Tucson incident by using words like ‘crazy’ or ‘psychotic’ to describe the assailant. Efforts to classify this as a psychotic episode are quite harmful, because it allows us to be dismissive, and we therefore never get to the root of the problem, and ultimately never find sound solutions. With proper treatment, a person suffering from mental illness is no more violent than anyone else who is vulnerable to influence from violence seen on television, heard in music, access to weapons, hate speech, or drug and alcohol abuse.

After the shooting, Caucus Co-Chair Grace Napolitano and I went

(continued on page 3)



Legislative Actions

There are a number of pieces of legislation pending in Congress affecting the special needs community. Some are proposed bills while others haven’t yet been introduced but are previous pieces of legislation we believe might yet still be introduced. All need to be followed and monitored and with that, here is a quick recap of both pending and yet to be introduced legislation:

TEAM Legislation • Transitioning towards Excellence, Achievement and Mobility (TEAM), includes three separate bills: HR 602, the TEAM Education Act; HR 603, the TEAM Employment Act; and HR 604, the TEAM Empowerment Act. They were introduced by Representative Gregg Harper (R-MS) on February 10, 2011 and each has several co-sponsors. Currently, each bill is residing in the appropriate subcommittee.

ABLE Act • Achieving a Better Life Experience. This will be introduced by Representative Ander Crenshaw (R-FL) soon; his Legislative Assistant mentioned that this would be introduced into Congress this spring but the date slipped to summer and now we are waiting for fall. It had previously been introduced in 2009 and garnered 203 co-sponsors.

The Paulsen SSA Amendment • This is proposed legislation exempting SNTs from Estate Recovery and we are expecting Representative Erik Paulsen (R-MN) to introduce it.

SSI Savers Act of 2011 • Introduced by Representatives Niki Tsongas (D-MA) and Thomas Petri (R-WI) on June 2, 2011. It has been referred to the House Committee on Ways and Means.

Military Survivors Benefit • This was introduced in the 111th Congress as HR 2059 by Representative Bill Foster (D-14) of Illinois who was replaced by Representative Randy Hultgren (R) in the fall elections last year. There has been news that it might be introduced by Representatives Geoff Davis (R-KY) and Lois Capps (D-CA).

Newsmaker Profile: Rep. Tim Murphy

(continued from page 2)

on CNN's State of the Union program to discuss these misconceptions as well as how appropriate and timely mental health treatment can prevent certain tragedies from occurring. We also organized a briefing with mental health professionals for congressional staffers to learn more about mental illness and dispel the myths and stigmas that surround it.

SNA As a member of the House Energy and Commerce Subcommittee on Health, what health policy issues will you be considering in the remainder of the current session?

Rep. Murphy: The Energy and Commerce Committee is focused on ways we can improve both the access and quality of care, especially in federal healthcare programs. After decades of ad hoc changes and alterations, Medicare has simply failed to keep pace with medical advancements. It is an inefficient and costly system that could serve seniors so much better if it were only redesigned to deliver better care at a better price. Today, Medicare is not a system focused on health outcomes but one focused on paying for sickness.

As currently structured, Medicare discourages specialists, primary care physicians, pharmacists, and other healthcare providers from working together — or coordinating — a patient's care. For example, traditional Medicare will pay \$50,000 for an amputation procedure, but will not reimburse a nurse to call the diabetic patient to ensure they are taking their medications and following the prescribed medical regimen to prevent the drastic procedure. With chronic illnesses like diabetes consuming 95 percent of Medicare's budget, paying for hospitalizations and surgeries, but not the coordinated care necessary to prevent costlier complications, is penny-wise and pound-foolish. Medicare should

adopt disease management models where healthcare professionals practice evidence-based medicine together so that seniors are healthier and kept out of the hospital.

The Committee will also begin to examine ways to save money in Medicaid. Recently, the federal government has paid about two-thirds of Medicaid's costs. This is a stark increase since Medicaid began as a 50/50 cost-share program between the federal and state government. Much of the increased federal expense has occurred because of coverage expansions that added able-bodied childless adults to a program originally designed to care for the disabled and most indigent members of society. Since the new healthcare law intends to expand Medicaid to cover 18 million more Americans, we have to be especially mindful of how we can ensure those persons Medicaid was originally designed to help are not overlooked.

Some state governors have been asking the federal government to relieve them of Medicaid mandates, and grant states flexibility to run their own medical assistance programs. Rhode Island is the only state to have been granted flexibility, and shown to save money and improve care in Medicaid. The state implemented wellness programs, audited hospitals and nursing homes, prevented fraud, and helped seniors move from nursing homes back into their communities. This is a model worth greater study and possible replication.

SNA During your tenure in the Pennsylvania Senate, you wrote the Pennsylvania Patient Bill of Rights. In what way did that work influence your current work in Washington, DC?

Rep. Murphy: In the 1990s, "managed care" became associated with denials for doctors, hospitals or treatments because they were "out of network." As a state senator, I authored Pennsylvania's Patients Bill of Rights to outlaw many of those practices. One of

the lessons I learned in working to make the Bill of Rights law is that people with good intentions can put aside partisan differences and work to create real change. By coming together, we were able to improve the quality of care for patients.

Those experiences helped me in Congress, especially in healthcare and now that we have a divided government. Recently, I partnered with Congressman Eliot Engel (D-NY) to introduce legislation to allow home infusion therapy in Medicare. The bill, HR 2195, the Medicare Home Infusion Therapy Act, will take the simple, medically sound and fiscally responsible step of covering intravenous delivery of drugs in the home for all Medicare beneficiaries. It will reduce healthcare costs by \$6 billion and improve patients' quality of life, and bring Medicare into line with virtually every other significant payer in the country.

SNA How can special needs families and advocates support your work in the House to improve the quality of life for people with disabilities, especially those with mental illness?

Rep. Murphy: One of the most important things our society can do is to rid the stigma associated with mental illness once and for all. The healthcare industry and advocacy groups like the Special Needs Alliance have done a tremendous job raising awareness and educating the public that mental illness is treatable, but we're not all the way there yet. People with disabilities need to be given an opportunity to live healthy and productive lives. Moving away from institutional care settings toward the community-based model has afforded many disabled and mentally ill persons the chance to find meaningful employment and build successful lives. Until all mentally ill individuals know that there is help available to them, and until we achieve parity in our healthcare system, we still have work left to do.

Arizona's Medicaid Reform

Bridget Swartz, Jaburg|Wilk, Phoenix, Arizona

On March 15, 2011, Arizona's Governor, Jan Brewer, presented her plan to preserve Arizona's Medicaid program, which is known as the Arizona Health Care Cost Containment System (AHCCCS), with reforms to reduce growing costs to the State's General Fund. The plan was approved by Arizona's Legislature as part of the Fiscal year 2012 budget adoption and was subject to approval by the Center for Medicare and Medicaid Services (CMS). In addition, Arizona froze enrollment in its KidsCare (aka CHIP) Program over a year ago, for which the waiting list was in excess of 100,000 as of June 15, 2011.

One component of the plan included a freeze on the AHCCCS Care Program for childless adults and discontinuation of the Medical Expense Deduction Program, also primarily for childless adults, altogether. The AHCCCS Care Program serves childless adults who are not otherwise eligible for Medicaid and whose income is less than the federal poverty level. The Medical Expense Deduction Program enables those whose income exceeds the federal poverty level to become eligible by spending down their excess income on medical expenses to below 40% of the federal poverty level before Medicaid begins to provide coverage. Both programs were established by Proposition 204, a 2000 ballot measure that dramatically expanded AHCCCS eligibility, and the Voter Protection Act, which severely restricts the Legislature's ability to alter voter mandates.

CMS reluctantly approved the reforms, stating it "regret[s] the action Arizona is taking," which will result in



The Medical Expense Deduction Program enables those whose income exceeds the federal poverty level to become eligible by spending down their excess income on medical expenses to below 40% of the federal poverty level before Medicaid begins to provide coverage.

an estimated 250,000 childless adults being without coverage. The Medical Expense Deduction Program reforms were approved on April 29, 2011, with enrollment frozen effective May 1, 2011, and elimination of the program by October 1, 2011. The reforms to the AHCCCS Care Program were approved July 1, 2011, and enrollment was frozen as of July 8, 2011.

The Arizona Center for Law in the Public Interest (the Center) and two other groups filed a lawsuit arguing that the state has no legal right to freeze enrollment or terminate coverage for adults whose income is less than the

federal poverty level since voters in 2000 agreed they should have health insurance. Following the effective date of the freeze on enrollment, the court refused to block the cuts, saying the voter-approved law requiring health coverage for Arizonans below the federal poverty level does not force the Legislature to pay for it. The Center has appealed the decision, but in the meantime, individuals who would otherwise be eligible are being denied care. For those already enrolled, it is imperative that they timely renew their eligibility; otherwise, they will not be permitted to get back on the program. An effort spearheaded by Keogh Health connection called "Don't Get Dropped" is letting Arizonans know that AHCCCS eligibility may be changing and how to ensure that their eligibility is maintained.

Other aspects of the reform package include discontinuation of coverage of Medicare Part B Premiums for approximately 10,000 individuals eligible for Arizona's long term care Medicaid program, the Arizona Long Term Care System (ALTCs), a 5% reduction in provider rates, and changes in the uncompensated transfer penalty period policy for ALTCs eligibility. AHCCCS also threatened to reduce its coverage of up to 720 hours per year of respite care for the developmentally disabled, seriously mentally ill, as well as elderly and physically disabled population to one-half the amount. Family caregivers made a tremendous showing at a community forum held by AHCCCS regarding the proposed reduction in relation to the developmentally disabled population, and made their plea against the proposed reduction in service hours. As a result, AHCCCS backed off the original proposed reduction of 50% and instead will be reducing respite hours by 15%. The foregoing just goes to show that strong advocacy even in this economic climate can still make a difference.