



Special needs require special attorneys.

SNA Capitol Connection



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A Word from the Chairs

Welcome to this October issue of the Capitol Connection! We've got a packed edition for you this quarter and we believe you'll enjoy the slightly different take assigned to our Newsmaker Profile.

We regularly profile elected Members of Congress for the Capitol Connection and readers have been treated to learning their thoughts and perspectives on disability issues for quite some time now. In this edition, however, we're honored to have Aaron Bishop, the Executive Director of the National Council on Disability (NCD) featured in our Newsmaker Profile. Mr. Bishop has been



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with the NCD for almost two years and has an extensive background in disability rights. He has been a Professional Staff Member for the U.S. Senate Health, Education, Labor and Pensions (HELP) Committee for Senator Mike Enzi, where he handled disability related policy and he has also worked for Senator Judd Gregg on the HELP Committee, when the Senator chaired the committee. You'll learn a bit more about him and the unique role this organization plays in assisting policy and decision makers.

You'll also read a detailed article on the Affordable Care Act (ACA) written by SNA member and member of the Public Policy Committee Mary Alice Jackson, an attorney with Boyer Jackson from the Sunshine State, Florida. Ms. Jackson has been with the firm since 1995 and focuses exclusively in the area of elder law, with an emphasis in special needs trusts for persons with disabilities, long term care and incapacity planning, guardianship, probate and end-of-life issues. Her article on the ACA begins with this introductory phrase: "The proof of the pudding is in the eating." Now that is one unique way of introducing one of the biggest changes to health care in America in decades! Read on to learn more!

Attorney, SNA member and Public Policy Committee member Morris Klein, of Bethesda, Maryland, gives a thorough update on the work of the Consortium of Citizens with Disabilities (CCD), a 100 plus nation-

wide member organization that SNA has been a part of since earlier this year. Morris attends monthly meetings of the Social Security Task Force and reports back to the Public Policy Committee on important happenings in the disability community in Washington, DC.

Finally, and a nifty tie-in with our Newsmaker Profile, you'll find a little sidebar on the annual report recently released by the National Council on Disability. But you'll have to keep reading to learn about the highlights of the report!

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

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NEWSMAKER PROFILE

Aaron Bishop

Executive Director, National Council on Disability

In this issue of the SNA Capitol Connection, we continue our series of interviews with the nation's leading thinkers on disability policy. This issue features Aaron Bishop, who joined

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Newsmaker Profile: Aaron Bishop

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the National Council on Disability as its Executive Director in November of 2010. Mr. Bishop has nearly 20 years of experience in disability policy and spent many years on Senate staff, first with Senator Judd Gregg and then with Senator Mike Enzi. While working with both, he was assigned to the Committee on Health, Education, Labor and Pensions.

SNA: Your work in the disabilities community spans more than two decades, including time spent on Capitol Hill working on disabilities legislation as well as in academia. When and how did you first get interested in special needs advocacy?

BISHOP: My work in disability policy issues and advocacy stems from my graduate school work at the University of Wisconsin-Madison School of Social Work and the Waisman University Center for Excellence in Developmental Disabilities. It was a policy discussion during the second week of training that sparked my interest when I learned about Public Law 94-142, the Education of All Handicapped Children Act, which legally required schools to develop and implement policies that assure a free appropriate public education to all children with disabilities. That statement stopped me in my tracks. I'd assumed that *Brown v. Board of Education*, in which the Supreme Court declared state laws establishing separate public schools based on race unconstitutional, applied to all children, with and without disabilities. Learning that students with disabilities had to wait another 21 years after the *Brown* decision for the right to go to school with students without disabilities is where my individual passion began. The knowledge and understanding gained from working with my colleagues with disabilities, close friends with disabilities, and family members who have disabilities continues to drive and inform my work at the Council.

The fight for equal rights has many access points, each unique to every individual and situation, but the destination is always the same: fairness and equality for all. In those ways, the fight for disability rights has, through time, become my own.

SNA: You joined the NCD as Executive Director in 2010, which was a milestone year for the disabilities community – the 20th anniversary of the signing of the ADA. What has been the NCD's role in maximizing the full potential of this landmark law?

BISHOP: The NCD provides leadership in the disability policy arena by building on our community's traditions of innovation, nonpartisanship, interdependence, and working across silos to meet the changing needs of society. Since the ADA was passed, NCD has reviewed and evaluated key civil rights statutes and regulations affecting federal programs that assist Americans with disabilities to assess how well they work. The statutes and regulations range from the Air Carrier Access Act; the Individuals with Disabilities Education Act; the Fair Housing Amendments Act; Sections 504 and 508 of the Rehabilitation Act; and, of course, the ADA itself. We publish these evaluations in formal reports that are distributed to decision makers in the White House, all members of the U.S. Congress, key leaders

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in the Executive Branch of the Federal Government, and various stakeholders across the nation. Influencing the Federal Government's policy process is central to the work we do.

SNA: The NCD is active in 13 public policy areas, including financial assistance and incentives for individuals with special needs. What are some of the issues under this policy area in which the NCD has been particularly active?

BISHOP: Regular, meaningful engagement with our stakeholders which consists of Americans with disabilities, policy and decision makers, groups and organizations who work with people with disabilities, families and support systems, and society at large are essential to fulfilling our mission. NCD Council members and staff develop project proposals based on the information gleaned from stakeholders. Members then vote on Council priorities and staffers carry-out the day-to-day work we do. Over the past few years NCD has paid particular attention to financial assistance and mandatory programs, namely, Medicaid and Social Security Disability programs. In 2011, NCD hosted a hearing on Capitol Hill titled "Disability in the Budget: Why It Matters" to bring the real life concerns facing over 50 million Americans with disabilities to the forefront which, to that point, had been largely absent from budget debates. As a result of this hearing, NCD made two of the aforementioned projects policy priorities.

One of the most frequently suggested policy measures put forward in earned benefit reform proposals has been the conversion of Medicaid from an entitlement program to a federal block grant to the states. While proposals to convert Medicare into a voucher system have sparked widespread backlash from seniors, comparable attention has not been paid to what would happen to people with disabilities if Medicaid was converted to block grants. To help inform the community about this issue, we've conducted research

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Newsmaker Profile: Aaron Bishop

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and started a series of papers to explore the subject further. We also commissioned a paper to outline what managed care is, how it can be administered properly and improperly and some critical considerations for state and federal policymakers to consider when adopting managed care options for their Medicaid programs. Finally, one of the points raised by both family and self-advocates who spoke at NCD's hearing was the value of being able to determine what they wanted in terms of service-provision and who provided the service. NCD is continuing to review the efficacy of Medicaid self-direction as one way to control costs while improving service-provision and overall quality of life for Americans with disabilities and their families. In light of the importance of the Social Security Disability programs for Americans with disabilities and their families, and the impending threat to the fiscal stability of the Social Security Trust Fund, NCD recognizes that responsible reforms are needed to ensure the fiscal integrity of these programs while preserving vital benefits that people rely on. Our nation needs to modernize and preserve the Social Security Disability programs in ways that optimize employment opportunities for working Americans with disabilities while preserving the safety net for those who do not work.

SNA: Two years ago, the National Summit on Disability Policy was convened by the NCD to ultimately produce a slate of recommendations for disability policy in the years to come. Of the recommendations discussed among the delegates, which have been NCD's top priorities? Have any of these been implemented?

BISHOP: Since the Summit, NCD's priorities have been as diverse and wide-ranging as the delegates who raised them. Our priorities continue within the "Living, Learning and Earning" framework as we play the role of convener, utilizing and

refining successful engagement models such as regional forums, experts' symposiums, and town halls. These convening models have informed the scope, findings, and targeted recommendations of our policy projects, including prioritized work on Medicaid reform, private health insurance, vocational rehabilitation, quality of home- and community-based services and supports, and the ongoing implementation of recommendations from the reports we've released in the last two years. Those reports include:

- * The Power of Digital Inclusion: Technology's Impact on Employment and Opportunities for People with Disabilities
- * Exploring New Paradigms for the Developmental Disabilities (DD) and Bill of Rights Act
- * U.S. Marine Corps Exceptional Family Members: How to Improve Access to Health Care, Special Education, and Long-Term Supports and Services to Family Members with Disabilities

I also want to note three upcoming reports:

- * Toward the Full Inclusion of People with Disabilities: Examining the Accessibility of Overseas Facilities and Programs Funded by the United States, which advances inclusion of people with disabilities in all foreign assistance programs by the United States
- * Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children
- * The Case for Deinstitutionalization: Unfinished Business

SNA: Given the NCD's responsibility to advise both the President and the U.S. Congress on disability policy matters, what measures can we expect to see taken up when the 113th session of Congress convenes in January?

BISHOP: Some of the Council's projects for the 113th Congress include continuing NCD's work regarding the phase out of subminimum wages for people with disabilities and conducting research on effective communication for people

with disabilities before, during, and after emergencies. We'll also be continuing our work on Medicaid and Social Security Disability programs, and starting a project which seeks to eliminate the obstacles faced by military personnel returning from service with medical and other claims when attempting to access services through the Veteran's Administration; analyzing outcomes for special education students, including assessment benchmarks like getting a diploma, and access to postsecondary education to help determine if IDEA is appropriately serving students with disabilities; identifying what barriers remain for people with disabilities in transportation, including rural transportation; working through NCD's Tribal Consultation Coordination workgroup, to plan a Consortia of Administrators for Native American Rehabilitation; and continuing to work on education reforms.

SNA: How can individuals with disabilities, their families and their advocates become more involved in the public policy process, particularly as it relates to the important work of the NCD?

BISHOP: Civil engagement and meaningful involvement are extremely important in the public policy and legislative process. People can become involved with NCD in many ways: public testimony, attending our national and regional forums, sending electronic mail or letters, and contacting us via Facebook and Twitter. As a former Capitol Hill staffer, the most important piece of advice I can offer is for people to build a relationship with their elected officials and their staff. The way to become a change agent is to be engaged. Get to know your elected officials and their staff. Meet with them in Washington, DC as well as in your home state and district. Invite them to functions so they get to know you. People telling their story is essential. Becoming a trusted confidant of your member of Congress is critical and perhaps the best way to get more involved.



The Affordable Care Act

By Mary Alice Jackson, Boyer & Jackson, Sarasota, Florida

“The proof of the pudding is in the eating” – a phrase that apparently dates back to the fifteenth century, remains apropos in today’s world. While we are reviewing what the Affordable Care Act (ACA) says about improvements which our clients with disabilities can hope to see as a result of the ACA, it will take some time to see those changes become a part of our everyday counseling. This article will focus upon those parts of the ACA which may be the most beneficial to clients with disabilities, and how to access the information necessary about the implementation of programs and demonstrations in your state or community.

Many of the provisions of the ACA which are detailed in this article are found within what is known as the “Patient’s Bill of Rights” section of the law. Included in the Patient’s Bill of Rights are the removal of pre-existing condition limitations for children and adults, requiring that at least 80% of health care insurance premiums be spent on direct medical care, providing health insurance coverage for young adults,

What do individuals with disabilities need which the ACA could provide? Reduction in Medicaid waiting lists so that needed services can be accessed more quickly; increased levels of supports and services in the home; respite for family member caregivers; safe and stimulating living environments are among those which come to mind.

no arbitrary rescissions of coverage when you suddenly need expensive treatment and eliminating annual and lifetime limits on coverage.

Note: Changes to existing law raise questions about health insurance plans which were in effect when the ACA was passed on March 23, 2010. These plans are known as “grandfathered” plans. A group based plan in existence on March 23, 2010, will maintain its grandfathered status even if new employees are added or if the employer changes insurance company providers; however, if the job based plan makes significant changes to its plan, it will

lose its grandfathered status.

What do individuals with disabilities need which the ACA could provide? Reduction in Medicaid waiting lists so that needed services can be accessed more quickly; increased levels of supports and services in the home; respite for family member caregivers; safe and stimulating living environments are among those which come to mind. Will the demise of the pre-existing condition restrictions on private, non-group health insurance create opportunities for a client who has previously accessed Medicaid benefits, because benefits available through a health insurance exchange may offer an equal or better coverage? Questions and fact scenarios abound.

Health care coverage for children with disabilities has been greatly expanded because the ACA prohibits job based or new individual health insurance policies from denying or excluding coverage for any child under the age of 19 because of a pre-existing condition. This could open doors for many parents of children with disabilities who have previously been unable to enroll their children under their plans. However, there are concerns that states which provide premium assistance to allow people who qualify for Medicaid to enroll in private insurance instead of Medicaid will look for

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The Affordable Care Act

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a way to send high cost children and adults into the private marketplace. States could save money by limiting the amount of premium assistance currently being paid.

For adults with disabilities, this pre-existing condition exclusion elimination will begin on January 1, 2014. As we near that date, planning for persons with disabilities should include consideration of the purchase of health insurance as an alternative to, or a function of, a special needs trust. One factor in the decision making process will be the price of the insurance policy; the ACA does allow insurers to engage in age rating (allowing variation in premiums for individuals over 55 at a rate of 3:1). While rating has been done on a variety of levels before the ACA, beginning January 1, 2014, insurers may only adjust premiums for age, geographic area variances, tobacco use and individual v. family enrollment.

A very popular portion of the law has been the extension of medical coverage for young adults, through age 26, via their parents' existing insurance policies. This applies regardless of whether the child is in school, married, living in the home, etc. (but insurers don't have to offer this coverage before 2014 if the adult child is eligible for his or her own group coverage outside of a parent's plan).

The ACA enhances the Money Follows the Person (MFP) program which allows individuals with disabilities who are currently institutionalized to return to a home setting. This program already exists in 30 states and other states are joining the program. Transition coordinators perform the task of making the move happen by arranging for adaptive environments, transportation to medical appointments and home care assistance. Combining the funds which are provided through MFP with distributions from a special needs trust might allow a more comprehensive set of supports and services which would permit the at-home arrangement to last for a long period of time, and where funds are

plentiful, could result in the individual with a disability never returning to an institutional setting when a home based setting is preferable.

The Community First Choice (CFC) program is a new Medicaid state plan option under which states will receive a 6 percentage point increase in their FMAP (federal matching percentage) when they provide community based services and supports as an alternative to institutional care. CFC differs from Money Follows the Person because its goal is to prevent insti-

It's not difficult to see a pattern in the approach to health care services for persons with disabilities – home based care, care coordination, preventive care. All of these can and will benefit many clients, either augmenting or in some instances replacing the costs of care being borne by a special needs trust fund. More bang for the buck, although getting more bucks to go along with the changes will be a challenge as some states push back.

tutionalization, rather than to re-integrate already institutionalized individuals back into home settings. In a CFC program, the individual participants plan how services will be provided for themselves.

An attractive but limited demonstration project is known as "Independence at Home" (IAH)– a set of contracts with physicians who will make house calls to Medicare beneficiaries who have multiple health problems, in order to make living at home a reality for those who are non-mobile. To date, 15 independent practices and three consortia from 13 states have agreed to participate in the IAH

Demonstration. Some of these efforts will be managed by Aging Resource Centers, others will be contracted out to qualified providers.

Since January 1, 2012, states have been permitted to submit state plan amendments allowing them to develop "Medicaid health homes." A health home is not a place to live, contrary to my first thought. Health homes are described as "person centered systems of care" that promote better coordination and management of health services. To be eligible for the medical health home program, individuals must be eligible for Medicaid, have two or more chronic health conditions or have one condition and be at risk for another, or have one serious, ongoing mental health illness. Asthma, diabetes, heart disease, obesity, mental health and substance abuse have been approved as chronic conditions for purposes of eligibility for the health home program. Health home services include care management, coordination and health promotion, transitional care from inpatient to home settings, individual and family supports and referrals to community services. States which participate in health home waivers will receive a 90% match for the program for a limited period of time.

It's not difficult to see a pattern in the approach to health care services for persons with disabilities – home based care, care coordination, preventive care. All of these can and will benefit many clients, either augmenting or in some instances replacing the costs of care being borne by a special needs trust fund. More bang for the buck, although getting more bucks to go along with the changes will be a challenge as some states push back. Knowing where your own states fall in providing these programs and services will be essential to advising your clients who are considering or administering special needs trusts.

As always, good resources for reading more about these programs and policies include the Kaiser Family Foundation, Families USA, AARP, the ARC, Autism Speaks, NAMI and many other advocacy organizations.

INSURANCE

The Consortium for Citizens with Disabilities: An Update

By Morris Klein, CELA, Bethesda, Maryland

I have been attending the monthly meetings of the Social Security Task Force of the Consortium for Citizens with Disabilities (CCD) since the SNA joined the group last May. CCD is a Washington, D.C.-based coalition of national consumer, advocacy, provider and professional organizations who advocate for persons with physical and mental disabilities and their families.

In the past few meetings, the Social Security Task Force has focused on the following issues:

1. Continuation of funding for Protection and Advocacy for Beneficiaries of Social Security (PABSS) and Work Incentives Planning and Assistance (WIPA). These programs allow SSI and SSDI beneficiaries to return

to work without immediately losing benefits. PABSS provides information and advice about obtaining vocational rehabilitation and employment services, and WIPA funds community-based programs through which counselors help beneficiaries understand how to use SSA work incentives. Authorization for the funding for these two programs has expired, but SSA was

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able to set aside funding to sustain PABSS until September 30, 2012 and WIPA until June 30, 2012. Legislation is pending in Congress to extend these programs (H.R. 6061).

2. Testimony before the House Ways and Means Committee's Subcommittee on Human Resources concerning use of technology to improve the administration of SSI financial eligibility requirements. Marty Ford testified on behalf of several CCD members including the Arc, Easter Seals, National Disability Rights Network, NAMI, and National Organization of Social Security Claimants' Representatives. Her testimony offered the following recommendations: 1) Congress should increase funding for SSA so it has sufficient resources to administer its programs; 2) SSA should use enhanced automation to improve customer service and outcomes for beneficiaries, such as allowing SSI applicants to complete applications on-line, allow SSDI beneficiaries to use SSA's toll-free number to report earnings, and improve methods to correct errors in earnings reported to SSA, and act to prevent overpayments before they occur through use of algorithms; 3) ensure continuation

of PABSS and WIPA programs; 4) increase SSI asset and income disregard limits to at least take into account inflation since the last changes occurred in 1989; and 5) support demonstration programs that benefit dual SSI and SSDI beneficiaries.

3. Reaction supportive to Government Accountability

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The Consortium for Citizens with Disabilities: An Update

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Office (GAO) report on Children

applying for SSI. The report found that growth in the number of children receiving SSI is a result of a 41% increase from 2000 to 2010 in the number of children living in poverty, increased awareness and improved diagnosis of many mental impairments, and improved healthcare coverage. The full GAO report can be found at <http://www.gao.gov/products.GAO-12-497>.

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4. Insight into POMS changes.

Through contacts with CCD members, we obtained additional insight regarding the revisions to the POMS sole benefit rule as it relates to special needs trusts. An SSA official in Baltimore informally stated that SSA had not changed its policies regarding SNTs and the sole benefit requirement but merely recently added some examples to POMS in order to clarify its policies. This was in response to feedback from regional offices regarding treatment of the sole benefit requirement when determining SSI eligibility.

“Section 1917 (d)(4)(A) of the Act states that special needs trusts must be established for the benefit of the individual. SSA interprets “for the benefit of” in the same manner as the language in section 1917(d)(4)(C) that requires a trust be established “for the sole benefit of” the individual. This means that a trust excluded under either of those provisions must benefit no one other than the trust beneficiary, whether at the time the trust is established or for the remainder of the individual’s life. With

very limited exceptions, trusts that benefit anyone other than the trust beneficiary violate the sole benefit requirement. However, trust payments to a third party that result in the receipt of goods or services by the trust beneficiary are considered for the sole benefit of the individual and comply with the requirement (SI 01120.201F2). Generally, trusts that allow payments to family members to accompany the beneficiary on travel do not comply with the sole benefit requirement, because money from the trust is then used for the benefit of the family member(s). However, if the family member represents a third party that is providing goods and services, such as a medically-qualified caregiver or assistant, we will consider such payment to be for the sole benefit of the trust beneficiary. SSA does not require that the certification or approval must come from a specific organization or agency such as a State Medicaid Agency.”

Another SSA official stated: “SSA does not require that a family member be certified or approved by a specific organization or agency in order for it to be permissible for the trust to pay for the family member to accompany the trust beneficiary on trips, etc. However, the family member must be providing medical care or services that are necessary in order for the trust beneficiary to go on the trip. For example, if the trust would have to pay for a non-family member to provide medical care or services for the beneficiary on a trip and they pay a family member instead to provide that medical care or service, the requirement would be met. In that situation, the family member is playing two roles, one of which is accompanying the trust beneficiary on the trip in their role as, say, a nurse’s assistant or personal attendant to a wheelchair-bound individual. On the other hand, the requirement would not be met in a case where the trust paid for a family member to accompany the trust beneficiary on a trip because the beneficiary wanted someone to come along and take photographs, or help translate into a foreign language, or serve as a guide.”

National Council on Disability Releases Annual Report

The National Council on Disability released its annual report on national disability policy in September. Covering the period from the summer of 2011, through the spring of 2012, the report covers broad policy areas including living, learning and earning and “reviews top-level policy developments and their effects on the lives of Americans with disabilities, including notable federal actions and state trends,” according to the press release issued by the NCD.

Along with the release, the NCD Chairman, Jonathan Young, weighed in stating “[I]n the current era of fiscal restraint, our nation’s long-term fiscal stability depends, in part, on creating meaningful opportunities for Americans with disabilities to contribute to our nation’s collective well-being and eliminating policies that trap people with disabilities in cycles of poverty and dependence. Effective coordination and collaboration of supports and services that meet individual needs has never been more essential. As the Administration and Congress prepare to tackle obstacles that have stymied greater achievement of the goals outlined by the Americans with Disabilities Act, NCD stands ready to assist all branches of government in making the most of the progress our nation has made to date – and increase access and opportunity for our nation going forward. Failure to do so not only jeopardizes the lives of people with disabilities; it also threatens our national recovery.”