SNA 2020 Public Policy Initiatives

The Voice® is the e-mail newsletter of the Special Needs Alliance (SNA). This installment was written by a consortium of members of the SNA's Public Policy Committee. The Public Policy Committee through our public policy consultant, Brian Lindberg, work with members of Congress and congressional staff to educate and advocate on issues of importance to individuals with disabilities and their families. Beginning with this installment, the Public Policy Committee will author periodic issues of the Voice® to introduce our readers to the Public Policy efforts the SNA is directly involved in.

March 2021 - Vol. 15, Issue 3

COVID -19

The SNA, particularly through its partnership with the Consortium for Citizens with Disabilities (http://www.c-c-d.org) has been advocating that Congress address the needs of individuals with disabilities during the pandemic. This includes work to increase funding for services under the Administration for Community Living (ACL) and Medicaid's Federal Medical Assistance Percentages (FMAP), as well as funding for community-based services in the CARES Act (which became law), the HEROES Act, the HEALS Act, and ultimately the COVID relief bill that passed and was signed into law in late December (Consolidated Appropriations Act, 2021). We have also supported anti-discrimination protections, accessibility for voting, and language to protect visitation and other rights for individuals with disabilities at home and in facilities.

On our website, we have a page devoted to resources related to COVID-19, and we invite you to visit the site for information about emergency paid sick leave, the Paycheck Protection Program, the P.A.I.D. Leave Act of 2020, and tax provisions related to employers contained in the Families First Coronavirus Relief Act, as well as resources for families who have been directly impacted by the pandemic. You can visit our COVID-19 resource page at https://specialneedsalliance.org/public-policy/covid-19/.

SECURE Act

In addition to addressing the myriad of issues generated by the pandemic, the SNA also began pointed advocacy efforts regarding the interpretation of the SECURE Act and specifically how that act will be interpreted in the context of Supplemental Needs Trusts being named as beneficiaries of the qualified retirement plans referred to in the SECURE Act.

Previously, the SNA successfully worked with Hill staff and like-minded colleagues to ensure that certain “stretch provisions” in the SECURE Act were modified. This advocacy was designed to ensure that special needs trusts would be exempted from these provisions to protect the interests of disabled individuals receiving retirement plan benefits directed into a special needs trust. As part of the SNA’s subsequent advocacy, we authored a letter (found at https://specialneedsalliance-oilyqzi36akjprmk.netdna-ssl.com/wp-content/uploads/2020/11/SECURE-Act-Final-Letter-to-Treasury-May-29-2020.pdf) to the United States Department of the Treasury and the Office of the Chief counsel of the Internal Revenue Service, urging an interpretation and guidance stating that the remaindermen (beneficiaries designated to receive trust property after the passing of the individual with special needs) of a special needs trust not be considered when determining the life expectancy payout of a retirement plan to a special needs trust. For those readers who don’t know, the SECURE Act made sweeping changes to the rules related to the payout of retirement accounts to an original owner’s designated beneficiaries. Prior to the SECURE Act, non-spouse beneficiaries and beneficiaries of qualifying trusts were able to use their life expectancies in determining how many years an inherited IRA could be paid out, resulting in a “stretch” and maximum income tax deferral generally resulting in lower income tax liability.

In contrast, before SECURE we had to advise our clients to pay close attention to whom they named as a remainder beneficiaries of a special needs trust because those remainder beneficiaries would affect the payout term available to the SNT. For example, if the remainder beneficiary was a much older beneficiary, that older beneficiary’s life expectancy would determine how long the IRA could be stretched. Moreover, if the remainder beneficiary was a charitable organization, the Trust would be deemed to have no designated beneficiary, and it would subject to much shorter payouts resulting in a loss of tax deferral and larger payouts being taxed each year.

Now under the SECURE Act, all beneficiaries that are not “eligible designated beneficiaries” will have a10-year pay-out regardless of their age. Fortunately, individuals with disabilities and trusts created for their benefit are considered “eligible designated beneficiaries” and are exempt from the 10-year payout rule and can use a life expectancy payout, allowing for greater tax deferral and savings. An ambiguity exists in the legislation as to whether certain remainder beneficiaries will impact the payout term, and we are advocating for a fix confirming that they do not. Specifically, we want to ensure that if a family names a charitable organization as a remainder beneficiary of a special needs trust, it will not impact the payout.

Many parents and other loved ones want to supplement existing government benefits by supporting charities otherwise reliant on Medicaid (e.g., local ARCs and similar organizations) at the end of their child's lifetime. With cuts in Medicaid reimbursement rates across the country we know all to well that the viability of many of these organizations depends on private support. The SNA believes that it is not consistent with broader public policy goals to insist that family members must choose between loved ones and the charities supporting loved ones in their trusts, nor do we believe the statute should be interpreted to require families to do so.

With Congress less focused on retirement policy in recent months and more focused on the pandemic, we will continue our advocacy on this issue in 2021.

Looking to 2021

In addition to maintaining our advocacy efforts related to issues generated by the pandemic and the SECURE Act, the SNA expects to take on an active advocacy roll related to Childhood Disability Benefits (CDB) seeking an amendment to the Social Security Act. Currently, under Section 1634 of the Social Security Act an individual must first receive Supplemental Security Income (SSI) in order for CDB income to be disregarded for Medicaid qualification. This rule creates an unintended trap of making individuals with disabilities subject to a Medicaid deductible if their parents die young, are older and retire, or who fail to apply to SSI in time. Depending on the state, these faultless individuals with disabilities may not be able to afford or receive Medicaid benefits simply by being unlucky in their uncontrollable personal life circumstances. We have secured support for our proposal from the Consortium for Citizens with Disabilities (CCD) and will be advocating for this legislative change in 2021.

As we progress with our existing advocacy efforts and take on new efforts, we will post them on the Special Needs Alliance Public Policy Page on our website found at https://specialneedsalliance.org/public-policy/. We invite you to visit our site for updates on these important initiatives. You'll hear from us again later in the year, when we hope to report progress in a post pandemic world.

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