



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

**Disability Policy Recommendations  
for the 117<sup>th</sup> Congress  
December 2020**

## Message from the Board

The Consortium for Citizens with Disabilities (CCD) is pleased to present our policy recommendations to the 117th Congress outlining the needs of people with disabilities and their families.

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society.

The COVID-19 pandemic has exacerbated the problems effecting people with disabilities, particularly those who are people of color. The pandemic has affected the policy areas under the purview of nearly every CCD task force. From decreased access to public transportation, to limited services for school-aged children with disabilities, to concerns about health care rationing, and the spread of the virus among individuals living in institutions, no area has gone unaffected.

Our recommendations seek to address the critical issues people with disabilities and their families are facing as our nation continues to grapple with the effects of the pandemic. We look forward to working with Congress to implement the solutions outlined in this document that we believe will ensure people with disabilities are able to live fuller lives in their communities. We encourage members of Congress and their staffs to work closely with our task forces and our member organizations to learn more about the programs and policies that will assist the broader disability community.

Sincerely,



Heather L. Ansley, Esq., MSW  
CCD Chair

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## **Background on CCD**

The Consortium for Citizens with Disabilities (CCD), headquartered in Washington D.C., is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. Since 1973, CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families. CCD has worked to achieve federal legislation and regulations that assure that the millions of children and adults with disabilities are fully integrated into the mainstream of society.

Task Forces: CCD's work addresses a broad range of issues that affect people with disabilities and their families. The vast majority of CCD's work is carried out by Task Forces which focus on specific areas of policy touching the lives of people with disabilities. Task Forces are established and reviewed annually at CCD's annual meeting. Throughout the rest of the year, the Task Forces are the locus of work on policy areas. Task Forces are led by volunteer Co-Chairs who work with their colleagues across Task Force lines to ensure consistency. The policy areas covered in this document are organized by Task Force. Each topical page includes contact information for the Co-Chairs for the Task Force who taken the lead on that issue. Additional information can be found on CCD's website ([www.c-c-d.org](http://www.c-c-d.org)) or by contacting the Co-Chairs.

CCD Task Forces are: Developmental Disabilities, Autism, and Family Support; Education; Emergency Management; Employment & Training; Financial Security & Poverty; Fiscal Policy; Health; Housing; Long-term Services & Supports; Rights; Social Security; Technology & Telecommunication; Transportation; and Veterans.

## **CCD Values**

CCD works to ensure that federal policy supports the goals of the Americans with Disabilities Act (ADA), which was signed into law in 1990 with strong bipartisan support: equality of opportunity, full participation, independent living, and economic self-sufficiency. CCD envisions a society in which people with disabilities exercise their full rights and responsibilities and are empowered to participate in and contribute to society to the full extent of their abilities.

For many people with disabilities, programs that provide economic security and individualized supports and services are vital to making this vision a reality. Community integration is not possible without affordable and accessible housing and transportation that enable people with disabilities to live independently instead of in nursing homes or other costly institutions. Education and job training are integral to assisting people with disabilities to learn the skills necessary to maintain and increase their economic self-sufficiency. Access to supported employment, habilitation, personal assistant, and other employment services and supports are essential to ensuring that people with disabilities can obtain and maintain employment and are empowered to take advantage of the career opportunities that arise. Federal and state programs form the bedrock of these essential supports and services.

The importance of affordable access to comprehensive health care, whether financed through private insurance, Medicaid, or Medicare (including robust durable medical equipment and rehabilitation benefits), cannot be overstated. Technology, both assistive technology and accessible commercially available technology, can be crucial to all of aspects of independent living. The availability of wage replacement and income support through Social Security and Supplemental Security Income is critical when a person's disability limits their employment or earnings. Strong enforcement of civil rights laws, including but not limited to the ADA, the Individuals with Disabilities Education Act and the Rehabilitation Act, must be a high priority to

ensure that discrimination does not prevent people with disabilities from achieving the goals of the ADA.

Although each individual with a disability's needs for supports and services will vary and a particular person's needs might change over time, continued progress towards achieving the goals of the ADA for people with all types of disabilities at all ages requires a continued commitment to an adequately funded safety net that contains a full of the array of training, supports, and services.

## Developmental Disabilities, Autism and Family Support

The mission of the Task Force is to advocate for federal public policies that directly relate to individuals with developmental disabilities, including research on autism spectrum disorders; family supports; primary prevention; and the prevention of abuse and neglect of children and adults with developmental disabilities. These include, but are not limited to, the Developmental Disabilities (DD) Act; the Autism Collaboration; the Accountability, Research, Education, and Services Act (CARES Act); the Family and Medical Leave Act (FMLA); the Lifespan Respite Care Act; and the Child Abuse Prevention and Treatment Act (CAPTA).

**The Developmental Disabilities Assistance and Bill of Rights Act** - The DD Act has five main programs: 1) State Councils on Developmental Disabilities – governor-appointed bodies that promote self-determination, integration and inclusion in the community through advocacy and cooperative community grants; 2) Protection and Advocacy Systems (P&A) - provide legally based advocacy to protect civil and legal rights; 3) University Centers for Excellence in Developmental Disabilities (UCEDD) - deliver interdisciplinary training and conduct research; 4) Family Support - help states provide supports and services to families supporting members with disabilities; 5) Projects of National Significance (PNS) - collect longitudinal data and provide technical assistance.

**Autism Spectrum Disorder (ASD)** - The prevalence of ASD in children, defined as the rate of known cases in the community, has increased from 1:150 in 2002 to 1:54 in 2016. The Autism CARES Act coordinates and invests in research, interdisciplinary training of health professionals, and public education. However, it does not provide direct services; the Medicaid program and the Individuals with Disabilities Education Act (IDEA) fund the vast majority of community-based services for people with ASD. Much more needs to be done to support people with ASD in the community, including early intervention, education, transition, employment, vocational rehabilitation, housing, and transportation programs.

**Family Caregiver Support.** The vast majority of people with developmental disabilities live at home with their family caregivers. Unfortunately, these caregivers often receive few services and may lose jobs and income as they try to support their loved ones in the community. Counseling, support groups, respite, training, cash assistance, family and medical leave, tax credits, and information and referral programs can support caregivers to help their family members live in their own homes instead of in costly and unwanted institutions. Medicaid home and community-based services waivers provide the vast majority of family support services, and several discretionary programs focus on various needs of family caregivers - the [Lifespan Respite Care Program](#); the [National Family Caregiver Support Program](#); [Parent Training and Information Centers](#); and [Family-to-Family Health Information Centers](#).

**Primary Prevention.** Disability can often be prevented or mitigated through prenatal health care, limiting prenatal exposure to alcohol and environmental toxic chemicals, and early childhood intervention, among other things. While there is [mounting scientific evidence](#) of the contribution of environmental toxic chemicals (such as air pollution, lead, and pesticides) to the incidence of developmental disabilities, regulation of such harmful exposures is very limited. Medicaid is the primary federal program to ensure healthy birth outcomes through its [prenatal care benefit](#) and for providing early intervention through [Early and Periodic Screening, Diagnostic, and Treatment \(EPSDT\) services](#).

**Child Abuse Prevention.** Child maltreatment can cause or exacerbate disability and children with disabilities are at greater risk for maltreatment. [Nearly 13 percent of child maltreatment victims had a reported disability in 2013.](#) According to the [2018 Maltreatment report](#), 50,000 children were referred to early intervention services. CAPTA is one of the key laws that guides child protection and provides services to prevent abuse and avoid more costly foster care placements.

**The Task Force urges Congress to support these priorities by:**

**1. DD Act**

- Protecting the ability of DD Act's P&A systems to engage in class action litigation.
- Fully implementing and funding all DD Act Programs, including the Family Support program, which has never been funded.
- Fully funding the COVID-19 related activities assumed by the DD Act sister organizations to protect the health and safety of the IDD population during the pandemic.
- Working with DD Act grantees to ensure full stakeholder participation from the IDD community in all regulatory and policy activities at the Agency for Community Living.

**2. Autism Spectrum Disorder (ASD)**

- Following the recommendation of the Interagency Autism Coordinating Committee (IACC), doubling federal funding of autism research over 2015 levels, and focusing on areas identified by the IACC as needing the most investment, such as adult services and research across the lifespan.

**3. Family Caregiver Support**

- Reauthorizing the Lifespan Respite Care Program and providing increased appropriations to enable every state to receive a grant to build respite capacity, help families pay for respite, and improve services.
- Expanding eligibility for job protected leave under the FMLA to include siblings, domestic partners, and others who serve as caregivers.
- Ensuring that adult dependents are eligible for any dependent stimulus payments.
- Increasing the value of the tax credit for families with adult dependents, the [Credit for Other Dependents](#).
- Providing increased funding for IDEA's Parent Training and Information Centers, and HRSA's Family-to-Family Health Information Centers; creating a navigator program for family caregivers of adults with IDD who are not served under these existing programs.

**4. Primary Prevention**

- Enacting and enforcing legislation to limit the use of chemicals that contribute to the incidence of intellectual and developmental disabilities.

**5. Child Abuse Prevention**

- Reauthorizing CAPTA and fully implementing Title II, the Community-based Child Abuse Prevention program, to ensure that the needs of children with disabilities and their families, and parents with disabilities, receive respite and other critical abuse and neglect prevention services.

The above priorities are those that fall uniquely under the Developmental Disabilities, Autism, and Family Support Task Force. However, there are numerous other priorities that are of great importance to our task force. These include: protecting the structure of and increasing funding for the Medicaid Program, particularly for home and community based services; banning the use of electric shock devices, restraint, and seclusion; and protecting the rights of parents with developmental disabilities.

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