



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

May 26, 2016

Speaker Paul D. Ryan
U.S. House of Representatives
U.S. Capitol Building, Room H-232
Washington, DC 20515

Minority Leader Nancy Pelosi
U.S. House of Representatives
U.S. Capitol Building, Room H-204
Washington, DC 20515

Dear Speaker Ryan and Leader Pelosi,

As you develop plans to reduce poverty and increase opportunity in America, we write as Co-Chairs of the Consortium for Citizens with Disabilities (CCD) Poverty Ad Hoc Task Force to offer recommendations and considerations related to people with disabilities and their families.

CCD is a working coalition of national consumer, advocacy, provider, and professional organizations working together with and on behalf of the approximately 57 million children and adults with disabilities and their families living in the United States. The CCD Poverty Ad Hoc Taskforce works on federal legislation and policies to reduce poverty and increase opportunity among people with disabilities and their families.

The Intersection of Disability and Poverty

The CCD Poverty Ad Hoc Task Force is encouraged that poverty is becoming a stronger part of our national dialogue. To be fruitful, these conversations must engage and involve the disability community. Any proposal to reduce poverty and its effects must take into account the lives and realities of people with disabilities and their families.

Americans with disabilities and their families have a major stake in conversations about expanding opportunity and decreasing poverty. Disability and poverty intersect in many ways: you are twice as likely to experience poverty if you have a disability, and if you live in poverty, you are more likely to experience a disability of your own or in your family. Certain groups – including African Americans, Native Americans, women, seniors, and veterans – are more likely to experience both disability and poverty.

Twenty-five years after the passage of the American with Disabilities Act, working-age people with disabilities and their families have made progress but continue to face many barriers to economic success. These range from persistent discrimination and low expectations; to lack of access to adequate education, employment, health and long-term services and supports, housing, food, and transportation; to inadequate paid sick and family leave; to limited opportunities for savings and asset building. Major gaps and complexities in the existing public support system often further limit opportunities for financial independence and security.

Significant financial hardships and economic challenges are often inherently associated with being an individual with a disability or a family member of an individual with a disability. Policy makers must also recognize, understand, and address in a thoughtful manner the funding and policy gaps in services and supports that hinder upward economic mobility.

CCD Resources and Recommendations

Over the years, CCD has developed numerous resources and recommendations that are available to assist Congress to craft responsible policies to address poverty and increase opportunity for Americans with disabilities.

Our resources include:

CCD Poverty Ad Hoc Task Force, “Twelve Questions on How Anti-Poverty Proposals Affect People with Disabilities and Their Families”, [attached](#).

CCD letter on expanding the Earned Income Tax Credit and Child Tax Credit: <http://c-c-d.org/fichiers/CCD-EITC-letter-7-14.pdf>

Our resources also include detailed recommendations by many of CCD’s standing Task Force that, if fully implemented, could play a significant role in reducing poverty and increasing opportunity. Highlights, and contact information for the Co-Chairs of each Task Force, are available below.

CCD Employment and Training Task Force

Co-Chairs: Kelly Buckland, National Council on Independent Living, kelly@ncil.org; Alicia Epstein, SourceAmerica, aepstein@nish.org; Susan Goodman, National Down Syndrome Congress, susan@ndscenter.org; Susan Prokop, Paralyzed Veterans of America, susanp@pva.org; Tony Stephens, American Council for the Blind, astephens@acb.org

The CCD Employment and Training Task Force concerns itself with issues affecting the employment of people with disabilities - from programs funded under the Rehabilitation Act and Workforce Innovation Opportunity Act, to efforts promoting employment of people with disabilities by the federal government and federal contractors, to initiatives designed to enhance competitive, integrated employment of all people with disabilities. This task force works in concert with other CCD task forces addressing employment of individuals receiving Social Security benefits and veterans with disabilities.

Key resources and recommendations include:

CCD Employment Task Force Statement of Principles on Employment of People with Disabilities:
<http://c-c-d.org/fichiers/CCD-Emp-TF-Statement-of-Principles-Summary-Final.pdf>

CCD Employment Task Force documents on CCD website:
http://c-c-d.org/rubriques.php?rub=taskforce.php&id_task=4

CCD Financial Security Task Force

Co-Chairs: Dara Baldwin, National Disability Rights Network, dara.baldwin@ndrn.org; Marty Ford, The Arc, ford@thearc.org; Susan Goodman, National Down Syndrome Congress, susang1961@aol.com; Sarah Meek, Lutheran Services in America, smeek@lutheranservices.org; Chris Rodriguez, National Disability Institute, crodriguez@ndi-inc.org

The CCD Financial Security Task Force works to promote responsible public policy aimed at increasing the financial security of all individuals with disabilities and their families.

For the latest recommendations from the CCD Financial Security Task Force concerning recent legislation please visit:

http://c-c-d.org/rubriques.php?rub=taskforce.php&id_task=24

CCD Health Task Force

Co-Chairs: Mary Andrus, Easter Seals, mandrus@easterseals.com; Bethany Lily, Bazelon Center for Mental Health Law, blily@bazelon.org; Rachel Patterson, Christopher and Dana Reeve Foundation, rpatterson@christopherreeve.org; Peter Thomas, Brain Injury Association of America, peter.thomas@ppsv.com; Julie Ward, The Arc, ward@thearc.org

The CCD Health Task Force works on all the issues encompassed in the very broad term "health". Specific emphasis is placed on private health insurance; public programs such as Medicaid and Medicare; managed care, as well as quality assurance and consumer education and protections. Key resources and recommendations include:

Medicaid:
<http://www.c-c-d.org/fichiers/CCD-Health-and-LTSS-Task-Force-Medicaid-Leave-Behind-Final.pdf>

Medicare:
[http://www.c-c-d.org/fichiers/CCD_Letter_on_Medicare_Reform_with_Sign-ons_\(D0518895\).pdf](http://www.c-c-d.org/fichiers/CCD_Letter_on_Medicare_Reform_with_Sign-ons_(D0518895).pdf)

Affordable Care Act:
<http://www.c-c-d.org/fichiers/ACA-letter-with-sign-ons.pdf>

CCD Housing Task Force

Co-Chairs: Andrew Sperling, National Alliance on Mental Illness, asperling@nami.org;
T.J. Sutcliffe, The Arc, sutcliffe@thearc.org

The CCD Housing Task Force works with Congress and the Department of Housing and Urban Development (HUD) to increase access to decent, safe and affordable housing for all people with disabilities and to protect the rights guaranteed under the Fair Housing Act. Key resources and recommendations include:

FY 2017 Appropriations for HUD Section 811 Program:

<http://www.c-c-d.org/fichiers/CCD-811-FY17-Appropriations-FactSheet03-09-16.pdf>

Recommendation to Modernize the Delivery of Federal Housing Assistance:

<http://www.c-c-d.org/fichiers/Hensarling-Submission1.pdf>

CCD Long Term Services and Supports Task Force

Co-Chairs: Dan Berland, National Association of State Directors of Developmental Disability Services, dberland@nasdds.org; Sara Meek, Lutheran Services in America, smeek@lutheranservices.org; Rachel Patterson, Christopher and Dana Reeve Foundation, rpatterson@christopherreeve.org; Laura Weidner, National Multiple Sclerosis Society, laura.weidner@nmss.org

The CCD Task Force on Long Term Services and Supports addresses the issues concerning non-acute health, community living, employment supports, recreational assistance, and other supports that enable individuals with disabilities of all ages to be independent and productive members of the community. Key resources and recommendations include:

Principles for Long Term Supports and Services (Joint principles with Leadership Council of Aging Organizations):

<http://www.c-c-d.org/fichiers/LCAO-CCD-Principles-for-LTSS-Final.pdf>

Letter regarding per-capita-caps:

<http://www.c-c-d.org/fichiers/CCD Letter on Per Capita Caps.pdf>

CCD Rights Task Force

Co-Chairs: Dara Baldwin, National Disability Rights Network, dara.baldwin@ndrn.org; Samantha Crane, Autistic Self Advocacy Network, sscrane@autisticadvocacy.org; Sandy Finucane, Epilepsy Foundation, afinucane@efa.org; Jennifer Mathis, Bazelon Center for Mental Health Law, jenniferm@bazelon.org; Mark Richert, American Foundation for the Blind (AFB), mrichert@afb.net

The CCD Rights Task Force focuses on civil rights and protections for people with disabilities, and on enforcement of rights provisions by federal agencies. Key resources and recommendations include:

Addressing Poverty Among People with Disabilities: Key Principles:
<http://www.c-c-d.org/fichiers/CCD-Rights-TaskForce-Addressing-Poverty-Key-Principles.pdf>

Comprehensive legislative and regulatory Rights Task Force recommendations:
http://www.c-c-d.org/rubriques.php?rub=taskforce.php&id_task=11

CCD Social Security Task Force

Co-Chairs: Lisa Ekman, National Organization of Social Security Claimants' Representatives, lisa.ekman@nosscr.org; Kate Lang, Justice in Aging, klang@justiceinaging.org; Jeanne Morin, National Association of Disability Representatives, jeanne.morin@akerman.com; T.J. Sutcliffe, The Arc, sutcliffe@thearc.org; Web Phillips, National Committee to Preserve Social Security and Medicare, phillipsw@ncpssm.org

The CCD Social Security Task Force focuses on disability policy issues in the Title II disability programs and the Title XVI Supplemental Security Income (SSI) program. Key recommendations and resources include:

Social Security Disability Insurance Benefit Offset Proposal:
<http://www.c-c-d.org/fichiers/CCD-Benefit-Offset-Proposal-2015-update-final.pdf>

Recommendations to Improve SSDI:
<http://www.c-c-d.org/fichiers/CCD-SSTF-re-SSDI-Program-Improvements9-1-15.pdf>

Stop Taxing Death and Disability Act:
<http://www.c-c-d.org/fichiers/Stop-Taxing-Death-and-Disability-Act-Sign-on-letter-final4-16.pdf>

CCD Veterans and Military Families Task Force

Co-Chairs: Heather Ansley, Paralyzed Veterans of America, heathera@pva.org; Susan Prokop, Paralyzed Veterans of America, susanp@pva.org; Maynard Friesz, Easter Seals, mfriesz@easterseals.com, Ron Drach, National Organization on Disability, consultrwd@yahoo.com

Veterans with disabilities and military family members with disabilities encounter unique circumstances because not only are they people with disabilities but they are also affected by laws governing VA and military programs and services. The CCD Veterans and Military Families Task Force seeks to ensure that these populations are taken into account in policy deliberations concerning income security, disability work incentives, health care, education and any other discussions affecting individuals with disabilities. The task force also works with allies in the veterans' and military service organization community to amplify attention to the particular concerns of veterans and military family members with disabilities. Key resources and recommendations include:

Annual report of the CCD Veterans and Military Families Task Force:

<http://c-c-d.org/fichiers/CCD-Veterans-and-Military-Familites-TaskForce-Annual-Report2015.pdf>

Chapter on Education, Training and Employment from The Independent Budget - Veterans Agenda for the 114th Congress:
http://www.independentbudget.org/2016/07_eet.pdf

Conclusion

We hope that you will find these resources and recommendations helpful as you seek to reduce poverty and open up opportunity for all Americans, including people with disabilities and their families. Please do not hesitate to contact us if we can be of any further assistance.

Sincerely,

Co-Chairs, CCD Poverty Ad Hoc Task Force:

Lisa Ekman, National Organization of Social Security Claimants' Representatives
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Members, U.S. Senate



Twelve Questions on How Anti-Poverty Proposals Affect People with Disabilities and Their Families

Our nation's 57 million Americans with disabilities and their families have a major stake in ongoing conversations about increasing opportunity and reducing poverty. Disability and poverty intersect in many ways: you're more likely to experience poverty if you have a disability, and if you live in poverty, you're more likely to experience a disability of your own or in your family. Any proposal to reduce poverty and its effects must take into account the lives and realities of people with disabilities and their families.

Here are 12 questions that Congress, the media, and the public should consider when evaluating anti-poverty proposals:

1. Does the proposal set up cuts to services and benefits?

Historically, initiatives to consolidate federal programs and transition them to block grants typically lead to funding declines over time, often dramatically – setting up cuts to effective, essential services and benefits. Flat funding under block grants erodes purchasing power over time, and flexibility often means that states use block grant dollars to plug gaps in state budgets rather than continue necessary investments. Effective federal programs such as Medicaid, the Supplemental Nutrition Assistance Program (SNAP), public housing and Section 8 housing assistance, and the Low Income Home Energy Assistance Program (LIHEAP) play a critical role in leveling the playing field by helping low-income Americans meet their basic needs. Any cuts to services and benefits under these essential programs could have devastating effects, particularly for people with disabilities and their families.

2. How does the proposal define “people with disabilities”?

People with disabilities are incredibly diverse, including people with typically "visible" disabilities – such as people who use wheelchairs or mobility devices – as well as people with often “invisible” disabilities, such as mental illness, epilepsy, or diabetes. For people with "invisible" disabilities, misconceptions persist that because a person appears “able-bodied” they should not be eligible for needed services and supports. Proposals that define the disability population narrowly will be drastically under-inclusive. Examples of overly-narrow definitions include those that look only at people who are not “able-bodied adults without disabilities”, or that look only at Social Security or Supplemental Security Income (SSI) disability beneficiaries. These definitions also fail to include families –

including spouses, children, and parents – of the majority of people with disabilities.

3. Does the proposal include work requirements?

Our nation’s anti-poverty programs seek to increase opportunity while meeting peoples’ basic needs, such as housing, food, and health care. Without these services and supports, many people with disabilities and their families would not be able to work. For example, Medicaid specifically covers services, such as attendant care, that are critical to enable people with significant disabilities to have basic needs met, to get to and from work, and to do their jobs. Requiring individuals to work in order to qualify for these programs would create a situation in which people cannot access the services they need to work without working—setting up a completely contradictory policy. Any policy proposal with the goal of increasing work must ensure that a person’s basic needs are met and that people with disabilities have access to the services and supports they need, including employment-related services.

4. Does the proposal strengthen, preserve, or narrow eligibility pathways, including for people with disabilities and their families?

People with disabilities access essential programs such as Medicaid, SNAP, public housing and Section 8 housing assistance, and LIHEAP through diverse eligibility pathways. Many of these programs provide categorical eligibility, such as eligibility for people who receive SSI. Categorical eligibility must be maintained; it reduces unnecessary, burdensome administrative hurdles for both individuals and the state. Additionally, many people with disabilities access these programs through other pathways, such as income-based eligibility. For example, only 6.1 million people receive SSI on the basis of a disability, while an estimated 57 million Americans have a disability. Both categorical and non-categorical eligibility pathways must be maintained.

5. Does the proposal strengthen, preserve, or erode federal assurances and standards for the types and amounts of services provided?

All too often, proposals that seek to increase flexibility at the state or local level encourage states to serve more people, but with less adequate services or benefits. Services and benefits must be adequate to meet individual needs. This includes people with disabilities who in some cases may require intense supports and services to meet their basic needs for food, shelter, health, income, and employment and to prevent dire and even life-threatening consequences if those needs go unmet. Additionally, federal assurances and standards help ensure basic consistency across states. Consistency is critical for people with disabilities and their families – such as frequently-transferred military families raising children with disabilities, or people with disabilities who need to move to a different state for employment – to be able to maintain services if they have to move for work or family reasons.

6. Does the proposal strengthen, preserve, or erode federal quality standards?

When housing is substandard, all tenants suffer. For some people with disabilities – such as individuals with severe asthma or advanced lung cancer – substandard housing can be life-threatening. This is just one example of why federal quality standards play an important role in ensuring that programs like Section 8 and SNAP continue to foster opportunity, and not put people at risk.

7. Does the proposal strengthen, preserve, or erode federal due process rights for people who are denied benefits or services?

Removing or limiting the right to appeal a denial of benefits or services would set up obstacles that could be particularly harmful for people with disabilities and their families. People with disabilities often face unique barriers to accessing benefits and services – for example, when web sites are not accessible to people who are blind or have visual impairments, when telephone help lines are not accessible to people who are deaf, or when service offices are in remote areas that are inaccessible or difficult to travel to for people with physical disabilities. Adding new hurdles would only harm people with disabilities who are eligible for, but find themselves unable to access, essential benefits and services.

8. If the proposal affects Medicaid, does it protect benefits for people with disabilities and older adults?

People with disabilities have the right to live in the community like all Americans. Medicaid services and supports are critical to the health, independence, and well-being of people with disabilities and chronic conditions. Medicaid provides comprehensive, affordable coverage to 68 million Americans, including 10 million Americans with disabilities. Cuts to Medicaid benefits that help people with disabilities to live at home and work in the community would put people at risk of harmful, costly, and unnecessary institutionalization.

9. Does the proposal include protections for children with disabilities?

Despite significant strides in public policy, people with disabilities continue to experience high levels of poverty, unemployment, and underemployment and to face significant barriers accessing pathways to opportunity such as education. To reverse this trend, proposals must focus on ensuring that children with disabilities receive the services, education, and job training needed to increase opportunity and reduce poverty. A crucial first step is ensuring that children who receive Medicaid have access to the full array of Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services. Without EPSDT services, children with disabilities often cannot live up to their potential, succeed in school, and be part of the inclusive society we all wish to build. These services also help ensure families with children with disabilities have the supports and services they need to become more financially stable.

10. Does the proposal offer people with disabilities opportunities to achieve competitive, integrated employment?

People with disabilities need and want opportunities to work in the community with competitive wages and benefits. The Bureau of Labor Statistics regularly reports that the percentage of working-age people with disabilities in the labor force is about one-third that of people with no disability. On average, workers with disabilities face significant gaps in pay and compensation, compared to workers with no disability. Additionally, about one in three employment discrimination charges filed with the U.S. Equal Employment Opportunity Commission allege discrimination on the basis of disability. At the same time, many employment programs for people with disabilities, as well as basic services and supports that many people with disabilities need to work, are underfunded, resulting in waiting lists and/or inadequate levels of service. Many programs also include policy and program barriers. Proposals must ensure adequate funding and access to service, and should reduce any policy or program barriers.

11. Does the proposal strengthen, preserve, or erode opportunities for people with disabilities and their families to plan responsibly for the security of their economic futures?

People with disabilities must be afforded adequate supports to enable them to pursue opportunities to gain and maintain competitive integrated employment. In addition, people with disabilities and their families should have the opportunity to save for the future without risk of losing the benefits that allow them to live independently in the communities alongside “typically abled” peers. Any proposal aimed at reducing poverty among people with disabilities and their families must encourage, not prohibit, their ability and opportunity to save reasonable resources to assist in the security of their economic futures.

12. Does the proposal strengthen, preserve, or erode opportunities for youth with disabilities?

Guideposts for success for youth with disabilities include adequate school preparation, youth development and leadership, career preparation, connections to opportunity and resources, and positive family involvement. Proposals that reduce access to these necessary supports, and to basic needs, will only impede the positive development of youth with disabilities.

Prepared May 26, 2016, CCD Poverty Ad Hoc Task Force. For more information contact Lisa Ekman, National Organization of Social Security Claimants' Representatives, lisa.ekman@nosscr.org; Chris Rodriguez, National Disability Institute, crodriguez@ndi-inc.org; and T.J. Sutcliffe, The Arc, sutcliffe@thearc.org.