## NATIONAL COUNCIL ON DISABILITY

### *An Independent Federal Agency*

#### FISCAL YEAR 2017

#### CONGRESSIONAL BUDGET JUSTIFICATION

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**FISCAL YEAR 2017 BUDGET JUSTIFICATION**

This document presents the National Council on Disability’s budget justification for fiscal year 2017. We are requesting a total budget authority of $3,468,000 (see Appendix A).

# Organization

National Council on Disability (NCD) is an independent, nonpartisan federal agency that provides the Administration and the U.S. Congress with thoughtful and timely analysis and recommendations to inform policy development, revision and enforcement efforts. As a federal voice for 56 million Americans with disabilities, NCD is committed to advancing policy solutions that create a more inclusive country in which all Americans have equal opportunities to contribute to society. NCD was initially established in 1978 as an advisory board within the U.S. Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency and required NCD to provide expert advice to Congress and the Administration. Changes were also made to NCD’s statutory mandate by the Rehabilitation Act Amendments of 1992 and 1998, the Education of the Deaf Act Technical Amendments of 1993, and most recently, by the Workforce Innovation Opportunity Act (WIOA) of 2014 (Public Law 113-128).

NCD’s governing body is the Council, which is currently comprised of 10 members total (seven Presidential appointees and three Congressional), including a Chair, whom the President appoints, and a Vice Chair, determined by the Chair. With the recent passage of the Workforce Innovation and Opportunity Act (Public Law 113-128), Council membership will transition through attrition to nine members, including five members appointed by the President of the United States and four members appointed by the leadership of Congress, including one member appointed by each of the following: the Speaker of the House, the House Minority Leader, the Senate Majority Leader and the Senate Minority Leader.

Council Members live across the country and each brings a unique perspective informed by varied personal and professional experiences. Council Members are people with disabilities, disability service providers, parents or family members of people with disabilities, or other people who have substantial knowledge of or experience with disability policies and programs. Council Members are appointed to represent people with disabilities, national organizations concerned with disabilities, providers and administrators of services to people with disabilities, people engaged in conducting medical or scientific research related to disabilities, business concerns and labor organizations. The majority of the current Council Members are people with disabilities.

# Mission, Vision, Goals & Objectives

NCD has a unique mission among federal agencies because it is charged with reviewing all programs and policies across the Federal Government, not merely one aspect of policy affecting all people with disabilities or all policy areas affecting only one disability population.

| **Table 2: Mission, Vision, Goals & Objectives** |
| --- |
| **Mission** | Promote the goals of the Americans with Disabilities Act (ADA) -- equality of opportunity, full participation, independent living and economic self-sufficiency -- for people with disabilities of all ages and backgrounds by providing advice, analysis and recommendations on disability policy to the President, Congress and other federal agencies. |
| **Vision** | NCD works toward fulfillment of the goals of the ADA so that all Americans with disabilities can live free and full lives in communities of their choosing; can learn in ways that enrich their lives and enable them to reach their full potential; and can provide financially for themselves and their families.  |
| **Strategic Goal** | Advance the goals of the Americans with Disabilities Act by promoting policies, programs, practices and procedures that guarantee equal opportunity and provide for **economic self-sufficiency**, **independent living**, and **inclusion and integration** into all aspects of society for individuals with disabilities. |
| Stakeholders | All Americans with disabilities – a population diversified by geography, age, race, gender, ethnicity, sexual orientation, income, education, political party, type of disability, and other affiliations and identities.Policymakers and decision makers – including the President and all federal agencies, Congress, state, tribal, and local governments and communities – who create and implement federal policies and programs that affect people with disabilities.Groups and organizations concerned with people with disabilities.Families and support systems of people with disabilities, including parents and guardians. Society at large – employers, educators, manufacturers, service providers, engineers, designers, entertainers, and other individuals and organizations who influence inclusion and participation of Americans with disabilities. |

| **Strategic Objective #1** | **Engagement –** Engage stakeholders in order to assess concerns and priorities and build a network of NCD partners. |
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**FY2015 – Results**

In FY 2015, NCD continued its role as a convener, utilizing successful convening models such as policy forums and topically-focused public comment sessions at its quarterly meetings. NCD hosted these important stakeholder meetings to continue honoring its outreach / policy development cycle of hearing from the community, pursuing policy research and developing policy recommendations, and then returning to the community with updates, receiving feedback, and continuing to gather information to inform future work. Information gleaned from these events informed the scope, findings and targeted recommendations of proposed policy projects. It is imperative to the Council that engagement activities serve to drill down on existing areas of policy work and also elevate new potential areas of work.

In FY15, NCD continued its engagement activities to promote policy collaborations and inform its own policy recommendations development. Although much of this activity took the form of ongoing congressional and federal agency engagement, a few quick highlights of stakeholder engagement activities that were tied to policy initiatives outlined in Objective 1 include:

* In October 2014, NCD hosted a policy forum in Atlanta, Georgia regarding the school-to-prison pipeline for students with disabilities in collaboration with the Office of Special Education and Rehabilitative Services (OSERS), the Disability Rights Education and Defense Fund (DREDF) and the HSC Foundation. This forum serves as a bridge between the Council’s previous juvenile justice work and its upcoming work on Mental Health in postsecondary education, as the data shows that students with mental health disabilities are clearly part of the pipeline.
* In January 2015, NCD released its “Securing the Social Contract: Reforming Social Security Disability” report through a congressional briefing and brought together a politically diverse panel of policy experts to discuss Social Security reform.
* In February and August 2015, NCD met in Louisiana and Wisconsin respectively to continue facilitating cross-disability stakeholder engagement with federal partners to obtain meaningful input into the planning and implementation of states’ Medicaid managed care programs. This allowed NCD to zoom in on rural issues as part of its focus on the rollout of managed care.
* In July 2015, NCD convened a congressional forum on youth with disabilities who receive social security benefits, with youth with disabilities speaking for themselves of their own experiences, against the backdrop of ongoing policy discussions of reforms to the nation’s Social Security system.
* In September 2015, NCD convened a twitter chat with mental health advocates on the critical issues within proposed mental health reform. The area of mental health policy is an important one given the current focus on the Hill, and NCD used this twitter chat to help inform its upcoming 2016 Mental Health in postsecondary education project.
* In September 2015 NCD convened a twitter chat on people with disabilities and disaster preparedness, response, and recovery. This built on previous policy work.
* Throughout FY2015 NCD engaged more broadly with the cross-civil rights community, meeting and engaging with groups including but not limited to AIDS Drug Assistance Programs, the Leadership Conference for Civil Rights, MALDEF, the Lawyers Committee for Civil Rights, and the National Juvenile Justice Network.
* Internationally, NCD has hosted delegations from Turkey, Jamaica, Liberia, China, Romania, Chile, Honduras, Dominican Republic, Morocco, Nepal, Mongolia; Laos, Sri Lanka, Venezuela, Argentina, Vietnam, Azerbaijan, Bangladesh and Gambia to discuss NCD’s role and responsibilities. There was a follow up visit from a previous Japanese delegation with the Executive Director, Policy Director and Policy Analyst to specifically dig into the issues around the rights of parents with disabilities.

**FY2016 – Planned Activities**

FY16 planned activities largely build on the work of FY15 with a few exceptions:

* NCD plans to host a White House Forum on Parenting with a Disability. Similar to the White House conferences on bullying, Hispanic policy, and lesbian, gay, bisexual and transgender (LGBT) Americans, the Council plans to host a conference – the first of its kind – to attempt to answer several questions of prominent concern such as: what actions have been taken on the state and federal level to address discrimination against parents with disabilities and their children – what are the barriers and facilitators; what promising practices and/or state initiatives have been implemented to support parents with disabilities and their children since the release of NCD’s report; and what progress has been made on NCD’s report recommendations and what more needs to be done to advance and promote the rights of parents with disabilities and their children.
* NCD will convene a listening session on police violence and disability with the disability and broader civil rights communities. This is in response to a request from the White House to weigh in on this issue as it impacts people with disabilities.
* NCD will work with the White House Domestic Policy Council to convene a discussion with the disability community and key representatives of CMS, HUD, and DOJ about the legacy of the Olmstead decision and the work still remaining.
* NCD will convene three mini “town halls” at the November board meeting – one on mental health services in higher education; one on direct care workforce challenges; and one on emerging technology.
* NCD will be convening a high-level congressional policy briefing regarding the Council’s recommendations for mental health reform and to elevate the experiences and voices of people with psychiatric disabilities.
* NCD will continue to convene congressional policy briefings on our latest report on Social Security reform and work with key staff in both the House and Senate to inform reform proposals.
* NCD will convene Twitter chats for moms with disabilities and dads with disabilities tied to Mother’s Day and Father’s Day (after the success of similar activities in FY15)
* NCD anticipates visits from additional foreign delegations in FY16.

**FY2017 – Objectives**

FY17 objectives tied to engagement will largely be determined by the policy work being undertaken and the guidance NCD gets from key stakeholders.

***Roundtables and Congressional Forums/Briefings/Papers -*** NCD has made use of its statutory authority to receive testimony by hosting congressional forums on the topics of the federal budget, voting, social security reform and parenting rights. In FY17, the Council intends to continue utilizing this authority to host at least one congressional forum, likely tied to the topic of one of its recent reports, taking into consideration the interests of NCD’s stakeholders and the focus of Congress at the time. In addition or alternatively, NCD may choose to host a roundtable, briefing, or issue a white paper taking into consideration the interests of NCD’s stakeholders and the focus of Congress at the time. Finally, following on the release of the agency’s 2016 *Progress Report* focused on technological innovation, NCD will likely pursue an innovative event that will highlight the report’s findings and recommendations.

***Infographics***

NCD has recently made several technological upgrades, including purchase of in-house graphics software and hardware. Once staff are trained on these items, NCD’s hope is to begin producing occasional policy infographics to help distill policy data and recommendations into a supplementary user-friendly format to accompany policy reports and also stand on their own through dissemination through social media channels, including a possible agency Instagram account.

| **Strategic Objective #2** | **Policy Development & Collaboration –** Address stakeholder concerns and priorities by advancing specific, practice policy solutions and encouraging collaboration. |
| --- | --- |

Following feedback from key stakeholders, starting in 2016, NCD has decided to focus the projects of a given year around a core theme. The key theme for 2016 is civil rights and for 2017 is employment. While issues come up that demand NCD’s immediate attention and as a result, the agency may pivot or find a way to reallocate time and resources to the given situation, it is our hope that this will assist the agency in continuing to build on its robust body of work.

Conversations in 2014 led the Council to examine the actual structure of its policy reports and how to make them more useful to our many constituents. 2015 saw the vast majority of reports scaled down in size and include model legislation. NCD also developed its first issue brief in 2015, focusing on the Higher Education Opportunity Act.

**FY2015 – Results**

In 2015, NCD released *Securing the Social Contract: Reforming Social Security’s Disability Benefits System*, a report examining complex policy in two benefit programs linked to key aspects of the ADA—Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Recommendations focused primarily on decoupling health care benefits and cash benefits eligibility, providing wrap-around health benefits, further examination, planning, and gradual phase-in of a revised disability definition for benefits eligibility, management proficiency, early intervention, improved federal collaboration efforts, ways to boost work incentives, evidence-based practices addressing youth and people with mental health needs among vulnerable groups, and state supplemental systems. Current budget debates in Congress and with the President have highlighted that our nation faces a number of daunting fiscal challenges. According to the 2011 Social Security Trustees’ Report, the Social Security Disability Insurance Trust Fund is scheduled to become exhausted in 2016. Because of increasing numbers of claims due to the economic situation and concerns with potential work disincentives facing both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) recipients, these programs have been highlighted as in need of reform by policymakers.

In FY2015, NCD has convened multiple hill briefings on this topic and has found support for our recommendations by both House and Senate offices as well as politically diverse policy think tanks.

***School to Prison Pipeline***

In FY 2015, NCD decided to take a look back its 2003 report, [*Addressing the Needs of Youth with Disabilities in the Juvenile Justice System: The Current Status of Evidence-Based Research*](http://www.ncd.gov/publications/2003/May12003). In the last year, a number of different efforts have been going on around the country looking at best practices in reforming the juvenile justice system to improve outcomes for all young people.

With the tremendous body of work tied to this subject area already, the Council did not need to reinvent the wheel nor engage in a deep dive about the state of the state. NCD worked with the Disability Rights Defense Fund, the HSC Foundation, the Civil Rights Project at UCLA and others to develop *Breaking the School to Prison Pipeline for Youth with Disabilities.* This report was intended to build off of the great work of the recent report developed by the Council of State Governments and be used as a tool to establish a foundation for more focused discussion, tied specifically to potential upcoming reauthorizations of IDEA and ESEA.

***Education Issue Briefs In Light of Reauthorizations of ESEA and HEA***

Given the priorities in Congress of completing the reauthorizations of both the Elementary and Secondary Education Act (ESEA) and the Higher Education Act (HEA) in the coming session, NCD provided policy principles and recommendations to both House and Senate committees working on reauthorization, to promote education equality and high expectations for students with disabilities as well as consider professional development programs and strategies to support teachers to meet the needs of students with disabilities.

***CMS Regional Office Stakeholder Meetings*** – This project was a follow-up to our Medicaid Managed Care report and facilitated NCD, local stakeholder and CMS Regional Office staff conversations to promote greater dialogue and contact between key decision-makers in CMS' Regional Office system and the disability community regarding Managed Care waiver applications and dual eligible demonstration proposals. In FY 15, NCD held four additional regional forums with HHS regional offices regarding Medicaid managed care and the review of state 1115 and 1915(b)(c) waiver applications, dual eligible demonstration proposals and relevant Medicaid waiver or state plan amendments.

***Transportation Update: Where We’ve Gone and What We Know –*** Investing in independence necessarily involves investing in transportation. People with disabilities cannot work if they cannot get to the workplace.

In 2005**,** NCD released a comprehensive transportation report addressing access to ground transportation for people with disabilities: [*The Current State of Transportation for People with Disabilities in the United States*](http://www.ncd.gov/publications/2005/06132005). In FY 2015, NCD looked at progress made since 2005 and examined the recommendations made by NCD in the 2005 report to identify which recommendations have and have not been addressed successfully, and identified what barriers remain for people with disabilities in accessing transportation, including rural transportation. Particular emphasis is being placed on transportation issues for people with disabilities in rural and outlying urban areas; and inner city transit issues – subways, buses, taxis and issues regarding “silo” transit systems such as para-transit.

***Self-Driving Cars: Mapping Access to a Technology Solution***- In 2004 NCD issued a report, *Design for Inclusion*, aimed at educating designers and manufacturers about the way electronic and information technology (E&IT) intersects with the needs of individuals with disabilities, and how designing with access in mind can significantly increase the size of targeted markets for E&IT. In 2011, NCD took the next step in recognizing the transformative power of technology and innovation, and examined the importance of social media and other information technologies in connecting people to job opportunities in report *The Power of Digital Inclusion*. The latest innovations in technology are now upon us through the use of autonomous vehicles. Released in 2015, *Self-Driving Cars: Mapping Access to a Technology Revolution* explores the emerging revolution in automobile technology and the promise it holds for people with disabilities, as well as the obstacles the disability community faces to realizing that promise. The report examined the current state of the technology, current approaches to regulation, and potential technological and policy barriers to full use by people with disabilities, and provides recommendations for preventing or eliminating those barriers, including model legislative language.

Although experts in the field across all sectors, whether government or industry, agree that self-driving cars will evolve through many stages, the fully autonomous vehicles needed by many people with disabilities are most likely to appear on our roads sometime between 2020 and 2035. Yet the disability community knows better than anyone how being involved in planning from day one is critical to a successfully accessible product, regardless of how many years in the future it lies. The recommendations set forth in this report are intended to ensure people with disabilities benefit from and realize the freedom of fully autonomous vehicles. The recommendations addressed AV accessibility; funding for research; uniformity of requirements across the 50 states that address non-discrimination, privacy, and ethics; financing; and inclusion of disability access in future hearing testimony.

***Home and Community-Based Services: Creating Systems for Success at Home, at Work, and in the Community*** Over the last several years, considerable energy and effort has been focused on the topic of expanding Home and Community Based Services (HCBS) for people with disabilities and older adults. Studies have shown that community services are less expensive than institutional care and making such a shift could potentially save Medicaid millions of dollars annually. Additionally, efforts by the Department of Justice’s Civil Rights Division to enforce the Supreme Court’s 1999 *Olmstead v. L.C.* decision have also helped to further the shift towards community services. Despite this significant progress in terms of state willingness to invest in community support infrastructure, considerable tensions remain as to how to define and assess the quality of HCBS.

In this report, NCD reviews the research on outcomes since Olmstead, and finds that strong trends indicate that smaller, more dispersed and individualized community settings further integration and positive outcomes for individuals with disabilities. Specifically, greater individual choice, satisfaction, housing stability, and higher levels of adaptive behavior and community participation are associated with living in residential settings of smaller size. This research tends to support the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services (HHS/CMS) decision to promulgate final regulations impacting all Medicaid Home and Community Based Services authorities which establish that only settings of limited size and with certain characteristics will be entitled to receive Federal Financial Participation under the various Medicaid HCBS authorities. However, this national policy shift in favor of integrated supports and services presents a number of challenges to the state agencies and providers that have been furnishing supports prior to the implementation of these regulations. The research compiled in this report can help guide state policy makers, service providers, people with disabilities and their advocates in a collaborative effort to align support systems with the Olmstead decision and the requirements of the HCBS regulations.

***ADA@25 Scorecard*** *--* In our work to revise the format of the Annual Progress report to make it more user-friendly for our varied stakeholders, including Members of Congress and their staff, in 2015, NCD produced, with the assistance of a contractor and local stakeholders, a five state examination of progress made in implementing the goals of the ADA in the past 25 years. The Council convened a stakeholder group of national disability stakeholders to determine objective metrics to measure implementation and compliance with the ADA.  Additionally state stakeholders were asked to identify targets and goals to be achieved by the 30th ADA Anniversary to measure continuing and future implementation efforts. These metrics will be utilized by the Council in meeting our statutory obligation to inform the President and Congress about annual progress.

**Police Violence and the Disability Community--** As in the case with NCD’s work on the civil rights of parents with disabilities, from time to time issues arise from the grassroots that the Council is asked to weigh in on. This has been the case as it relates to police violence against people with disabilities. Being mindful that a majority of police interactions with the disability community end positively, the Council knows that law enforcement struggles with how to engage with the broader community, as this is an issue that goes beyond mental health. In this past year NCD participated in a series of meeting of the White House Task Force on 21st century policing and meetings with the COPS office at the U.S Department of Justice and the Domestic Policy Council to offer guidance on data collection, community engagement, and accountability measures.

**2015 Policy Outcomes**

* A legislator in the state of Massachusetts introduced legislation based on NCD’s model legislation from the 2012 *Rocking the Cradle report*.
* The State of Maryland issued racial profiling legislation that was inclusive of disability as one of the protected categories.
* The U. S. Department of Justice's Civil Rights Division together with the U. S. Department of Health and Human Services' Office of Civil Rights and Administration for Children and Families issued joint technical assistance about the applicability of Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act to the administration of child welfare programs, activities, and services. (As per NCD’s 2012 *Rocking the Cradle* report)
* As recommended in NCD’s Principles and Recommendations for ESEA reauthorization the 1% cap on students taking alternative assessments remain in Every Student Succeeds Act reauthorization.
* The Department of Health and Human Services and the U.S. Department of Education included access issues tied to parents with disabilities in their guidance on early childhood education centers following a briefing with NCD’s Executive Director and Attorney Advisors.
* NCD provided extensive technical assistance to Senators Wyden, Casey, and Grassley in the development of bipartisan legislation called the Transition to Independence Act that would incentivize states to invest in supported employments.
* As NCD has consistently recommended, Senator Brown proposed legislation to raise the asset limit under SSI.
* In the aftermath of national tragedies, NCD has consistently cautioned against the expansion of the categories of individuals prohibited from owning firearms to include individuals on the SSA rep payee database. In FY15 Representative Sam Johnson proposed legislation that would prohibit the use of this data in this way. NCD provided technical assistance to the House Homeland Security Committee’s Integrated Public Alert Warning System (IPAWS) legislation.
* Following extensive communications and a 2014 forum on Accessible Currency NCD hosted with the Government Accountability Office, the Bureau of Engraving and Printing and the Department of Treasury announced that upcoming twenty dollar bills will be brailed.
* As a result of NCD’s report*Transportation Update: Where We’ve Gone and What We Know* the Department of Justice held a workshop using NCD’s report for line staff at DOJ; DREDF held a briefing at the Access Board on our recommendations; and DOT Secretary Foxx highlighted NCD on his blog noting “No matter what mode of transportation people use, they need a simple way to contact us so we can hear their concerns. **Thanks to a recommendation from the National Council on Disability,** I have directed senior leadership here to develop a DOT-wide system for travelers to submit their concerns about accessibility on sidewalks, buses, trains, and planes.”

**FY2016-Planned Activities**

***Affordable Care Act--***NCD will release a series of reports on the Affordable Care Act. The purpose of the research will be to analyze the impact of the Affordable Care Act (ACA) on people with disabilities . ACA is one of the most significant pieces of domestic legislation enacted since the 1960s. ACA’s changes to the country’s health care system will affect millions of Americans, with a disproportionate impact on people with disabilities. Without question, many provisions of ACA will result in significant improvements in health care access for people with disabilities. On the other hand, as they implement ACA’s favorable provisions, federal and state policymakers may not use approaches calculated to achieve the maximum possible gains for people with disabilities. Moreover, ACA’s new initiatives create new dangers.

The decisions of federal and state policymakers as well as private sector entities (such as insurers and providers) will greatly shape the fate of people with disabilities under ACA. ACA implementation is at a critical point, a time to take stock of what has already happened and to identify the future choices that will most significantly affect people with disabilities.

***Forum on Police Violence and the Disability Community***

NCD will build on its’ ongoing advising of the White House Task Force on 21st century policing by pulling together a meeting of the disability community, broader civil rights colleagues, and law enforcement organizations to talk about how to improve the engagement between these communities. Our goal is to host a forum in collaboration with the office of the Assistant Commissioner for Training with the NYPD and colleagues with the COPS office and the White House to discuss what a reform agenda should look like, specifically as it relates to data collection, community engagement, and training. NCD expects this to build off of previous work on juvenile justice reform, and the 2016 report on issues facing people with mental health disabilities in post-secondary education.

***Self-Driving Cars: Mapping Access to a Technology Solution***

To follow up on the 2015 report, *Self-Driving Cars: Mapping Access to a Technology Revolution*, NCD will engage in discussions with partners in private industry including Google, Mercedes Benz, and others to talk about the accessibility issues tied to people with disabilities accessing this exciting technology. The Council will also be continuing to engage the National Highway Transportation Safety Administration and the relevant hill offices on the opportunities to be gained by making this technology accessible for people with disabilities.

***Reforming Private Health Insurance to be Consistent with the Goals of the ADA --*** The current focus on health reform, community living, and enforcement of the Supreme Court decision in Olmstead v. L.C.[[1]](#endnote-1) primarily focuses on public health benefits, Medicaid, in particular. However, little attention is being paid to the extent to which private health insurers structure health benefits in ways that interfere with an individual’s right to live in the community. Private health policies often contain exclusions or restrictions on the types of services most needed by people with disabilities, and have an institutional bias – covering services if an individual lives in a nursing home or rehabilitation facility, but not covering the services in the individual’s home. Many private insurance plans do not adequately cover rehabilitation and habilitation services and devices; and mental health and substance use disorders, including behavioral health treatment.

According to the Institute of Medicine,[[2]](#endnote-2) habilitation, mental health, substance abuse and behavioral services have largely been left to the public sector to provide and fund at taxpayers’ expense. For example, many private plans fail to cover, or place unrealistic restrictions on, durable medical equipment and limit prosthetic limbs to one per lifetime. In addition, many private plans only cover therapies to the extent that they result in progress toward recovery – thereby discriminating against people with permanent disabilities who need therapies to maintain functioning or prevent deterioration of functioning, such as people with cerebral palsy, multiple sclerosis, or people who need psychiatric rehabilitation. Most private plans do not cover hearing aids or low vision aids and avoids covering services for children with autism or intellectual disabilities through use of a definition of “medical necessity” that applies only to restoration of function.

Such benefit limitations have a disproportionate detrimental effect on people with disabilities that go far beyond a negative impact on health. The impact is so extreme that many people with disabilities cannot work because employer-sponsored health insurance is inadequate compared with the benefits they can receive from Medicaid. Private insurance limitations and exclusions force some people who would rather be at home into more costly institutions; placing further strain on cash strapped public programs. This is in direct contravention to the Americans with Disabilities Act, the Olmstead decision and generally-accepted principles of community living and inclusion. The private insurance market is in need of significant reforms if people with disabilities are to participate equally in private health insurance. The purpose of this potential project is to analyze the policies of the 20 largest private health insurers and document the contract provisions that are inconsistent with the goals of the ADA, the Olmstead decision and the Administration on Community Living (ACL) initiatives. Furthermore, the analysis could include specifics such as spotlighting the practices of the private insurance market that have the intent or effect of discriminating against individuals with disabilities.

***English Language Learners and the Individuals with Disabilities Education Act***

Research indicates that students of color with limited use of English sometimes get mislabeled as disabled rather than receive appropriate services as English Language Learners. However, there are students who are both students with disabilities and English Language Learners. The purpose of this project would be to look into what are the challenges facing this population and what are the barriers in accessing programs and services that could meet their needs, and what (if any) best practices exist in ensuring their academic, social, and occupational success. This would also look at how Centers for Independent Living, Protection and Advocacy Organizations, and Parent Training and Information Centers engage with families of children with disabilities who also have limited English proficiency. This project would include formal recommendations for inclusion in upcoming reauthorizations of IDEA and ESEA.

***Reimagining the Annual Report to Progress—The State of the Disability Union***

As a follow up to the 2015 Annual Report to Congress, NCD will roll out a series of state-focused fact sheets that individuals with disabilities, state and local organizations and members of Congress can utilize when looking at ways to improve access to programs and services for individuals with disabilities. This fulfills NCD’s goal of reimaging its Progress Report to increase its value to the general public while at the same time highlighting groundbreaking work the Council is engaging in to improve the lives of people with disabilities. Based on feedback from the disability community, we’ve started rethinking how to better market this report as a “State of the Disability Union” to better align the content with relevant branding.

***Social Media Dialogue on Voting***

With 2016 being an election year, and building off of NCD’s existing body of work tied to the voting rights of people with disabilities, the Council will host three social media dialogues tied to ongoing physical barriers, attitudes, technological gaps, legislative hurdles, and polling place practices encountered by voters with disabilities.

***Congressional Forums***

NCD has made use of its statutory authority to receive testimony by hosting congressional forums on the topics of the federal budget, voting, and parenting rights. In FY16, the Council will use this authority to host at least one congressional forum, likely tied to the topic of one of its recent reports, taking into consideration the interests of NCD’s stakeholders and the focus of Congress at the time.

***White House Forum on Parenting with a Disability –*** As mentioned earlier, the Council continues to receive significant interest from Federal and State legislators, community based organizations (disability and non-disability), and the general public about its work on the Civil Rights of Parents with Disabilities. NCD will convene a forum on this topic-- to provide a venue for the necessary key stakeholders (parents with disabilities, federal agencies, advocates, members of Congress and their staff, service providers, and researchers) to convene and begin focusing the necessary attention this issue so rightly deserves. The conference will address several questions of prominent concern such as: what actions have been taken on the state and federal level to address discrimination against parents with disabilities and their children – what are the barriers and facilitators; what promising practices and/or state initiatives have been implemented to support parents with disabilities and their children since the release of NCD’s report; and what progress has been made on NCD’s report recommendations and what more needs to be done to advance and promote the rights of parents with disabilities and their children. In addition, the conference will break the report out into key topics including, but not limited to child custody, foster care and adoption. The Council will also be working with colleagues from the National Council on Independent Living and the Christopher and Dana Reeve Foundation on the release of a “know your rights” toolkit, for parents with disabilities, to be released at the Forum.

**FY2017-Objectives**

The employment of people with disabilities remains staggeringly low. The focus for FY17’s policy work will be on employment, and will potentially include the following policy areas:

***The Accessibility of Emerging Technologies*** In our 2011 Digital Inclusion report, we noted the nexus between accessible digital technology and social media on the employment of people with disabilities and NCD first proposed the development of a technology bill of rights in its 2011 Annual Progress Report. We recommended Congress enact a comprehensive bill for people with disabilities to clearly establish that manufacturers create accessible user interfaces for all products; authorize the U.S. Access Board to establish uniform technology access standards; and provide for effective enforcement mechanisms. NCD wants to build on this recommendation in FY17 and undertake a “futures study” on the impact of inclusively designed digital technologies for people with disabilities. This would be a vision paper applying the futures studies approach to outline strategies to foster an inclusive, digitally driven futures for people with disabilities.

***Workforce Investment and Opportunity Act (WIOA)***  – WIOA will have been in place for three years in 2017. NCD plans to develop a series of briefs regarding the full implementation of the employment provisions WIOA.

***Implementation of Section 503 -*** Section 503 of the Rehabilitation Act of 1973, as amended, prohibits federal contractors and subcontractors from discriminating in employment against individuals with disabilities, and requires these employers to take affirmative action to recruit, hire, promote, and retain people with disabilities. The new rule strengthens the affirmative action provisions of the regulations to aid contractors in their efforts to recruit and hire people with disabilities, and improve job opportunities. The new rule also makes changes to the nondiscrimination provisions of the regulations to bring them into compliance with the ADA Amendments Act of 2008. The new Section 503 regulations became effective on March 24, 2014. NCD would like to assess the implementation of Section 503 on its three year anniversary.

***Progress Report* –** NCD will issue its statutorily required annual progress report, but will focus its efforts on addressing employment issues.

**Outside of the specific employment context, NCD will continue its other areas of focus in the following ways:**

***Guardianship –*** Despite reforms that gained traction in the 1980’s which provided some procedural protections to individuals facing guardianship, including due process requirements, the right to legal representation and the possibility of limited guardianship, somewhere between 1.5 million and 3 million adults are under guardianship, in approximately 90% of those cases the guardianship is plenary (all legal rights removed) and in too many cases the reality is that the fundamental and basic right to make decisions for oneself is removed “with all the procedural rigor of processing a traffic ticket.” Article 12 of the CRPD says that the right of legal capacity shall be enjoyed equally by all persons, without regard to disability. Countries that have signed the CRPD must revamp their guardianship laws to provide alternatives to guardianship such as supported decision-making, which provides support to individuals whose cognitive, intellectual or mental health disabilities impair their ability to make decisions without removing the right to make decisions altogether. Even if the U.S. signs the CRPD, the principles of Federalism will prevent these state guardianship laws from being impacted by this international treaty. Guardianship represents a threat to the individual rights of persons with disabilities and undermines the goals of the ADA and Olmstead. Furthermore, there is growing evidence that individuals under guardianship are frequently the victims of abuse, neglect and exploitation by the very guardians appointed to “protect” them. Finally, individuals under guardianship are often subjected to overly restrictive placements that violate the spirit of Olmstead. The Council will undertake a rigorous study of adult guardianship and develop principles that will guide reform as it has done in other areas such as the recent groundbreaking report on parenting.

***Civil Rights of Parents with Disabilities–*** NCD will continue its focus on the parenting rights of people with disabilities, zooming in on specific communities within what we categorize as “parents” who are often not actively included in the discussion of parenting rights, i.e Fathers with disabilities; Native Americans/American Indians with Disabilities; Grandparents with disabilities.

***Mental Health and Higher Education* –** building on NCD’s previous higher education work in FY16, NCD will develop a report on sexual assault on campuses/violence against students on campuses.

***Foreign Policy* –** Five years will have passed since NCD’s last report regarding foreign assistance and ten years since its 2007 foreign policy and disability report. NCD will review which recommendations from its foreign policy portfolio remain outstanding in 2017, and develop a roadmap for implementation of the remaining recommendations.

**APPENDIX A-**

**NATIONAL COUNCIL ON DISABILITY BUDGET**

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| **DESCRIPTION** | **FY 2016 Appropriation** | **FY 2017 Request****(1.3% COLA)** |
| **BUDGET TOTAL** | **3,250,000** | **3,468,000** |
| **PERSONNEL** | 2,005,802 | 2,075,000 |
| **TRAVEL** | 132,500 | 172,000 |
| **RENT, UTILITIES AND COMMUNICATIONS** | 289,436 | 294,500 |
| **PROGRAM, RESEARCH AND PRINTING** | 335,587 | 386,100 |
| **TRAINING AND PROFESSIONAL ASSOCIATIONS** | 8,500 | 12,500 |
| **AUDIT** | 30,000 | 30,000 |
| **PAYROLL, ACCOUNTING AND HR SERVICES** | 125,475 | 128,000 |
| **SUPPORT CONTRACT SERVICES** | 195,600 | 210,000 |
| **INFORMATION TECHNOLOGY**  | 10,500 | 30,500 |
| **PAYMENTS TO FEDERAL AGENCIES** | 44,200 | 46,000 |
| **SUPPLIES, SUBSCRIPTIONS AND MATERIALS** | 72,400 | 83,400 |

**APPENDIX B- COST DISCUSSION**

The Council is requesting a total budget authority in FY 2017 of $**3,468,000**. In FY 2016, the Council was provided with $3,250,000.

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| **PERSONNEL**FY 2016 $2,005,802FY 2017 $2,075,000 |  | For FY 2017, NCD’s budget request supports 9 Council members and 13 staff (FTEs). The 13 FTEs consist of an Executive Director and 12 permanent staff. NCD was not fully staffed in FY2016. Obtaining and maintaining full time Federal staff is critical to fulfillment of the agencies mission. Our FY2017 budget request included funds for the following:* 1.3% COLA and associated benefits
* Increased transit subsidy

Benefits have been calculated based on our experience with the benefit packages employees have chosen in the past.  |
| **TRAVEL**FY 2016 $ 132,500FY 2017 $ 172,000 |  | The largest portion of our travel budget is devoted to the cost of fulfilling NCD’s authorizing statute to conduct public meetings no less than four times each year. All Council members and staff are reimbursed in accordance with travel federal per diem regulations. As a respected advisor in the disability community, NCD will coordinate forums and release reports on disability topics. NCD occasionally extends invitations to subject matter experts and consultants in the disability community to travel to meetings and events to speak on issues affecting the disability community. Expenses related to the invitational travel include airfare, lodging, per diem and accommodation requests. Budget constraints prohibited the council from conducting four in person meetings outside the DC area in FY2016. Inadequate funding will continue to reduce our outreach to the disability community. |
| **RENT, UTILITIES AND COMMUNICATIONS**FY 2016 $ 289,436FY 2017 $ 294,500 |  | NCD currently leases space from the General Services Administration. Our lease expires August 21, 2021. In addition to the cost of leasing office space, NCD utilizes a number of communication methods in order to facilitate work of and between NCD members and staff, as well as to engage with stakeholders. NCD continues to monitor cost savings opportunities in these areas. |
| **PROGRAM, RESEARCH AND PRINTING**FY 2016 $ 335,587FY 2017 $ 386,100 |  | With constrained resources, NCD targets contractual services where funding is needed the most. NCD’s priorities are established by appointed Council members who represent the disability community. The Council members compile comments from the community and stakeholders throughout the year and determine projects based upon the goals and objectives outlined in NCD’s strategic plan. Policy reports, working groups, white papers and projects may at times enlist the support of outside individuals and groups who possess topical expertise not available on NCD’s staff or Council. Any reduction in funding directly impacts NCD’s ability to conduct program activities.  |
| **AUDIT**FY 2016 $ 30,000FY 2017 $ 30,000 |  | As a small agency, NCD works with GSA to solicit a vendor to complete an unbiased annual audit of our internal operations. The annual audit reviews the Council's internal control over financial reporting as a basis for compliance with the Office of Management and Budget (OMB) audit guidance for the purpose of expressing an opinion on financial statements. |

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| **PAYROLL, ACCOUNTING AND HR SERVICES**FY 2016 $ 125,475FY 2017 $ 128,000 |  | As a small agency, NCD secures outside support to complete payroll, accounting, human resource services and legal consultation. This process reduces cost to NCD and assists in fulfilling federal requirements. NCD is authorized by statute to contract with the General Services Administration (GSA) Commissions and Boards (CABS) and Office of the Chief Financial Officer (OCFO) for accounting, payroll and financial reporting.  |
| **SUPPORT CONTRACT SERVICES**FY 2016 $ 195,600FY 2017 $ 210,000 |  | Many of the staff and Council members are people with disabilities. NCD provides accommodations for employees with disabilities during work hours and at NCD meetings and events as requested. Absent a budget increase, NCD must cover these costs by reducing policy work or restricting public meetings to the DC area. To provide ongoing continuity in the NCD office and to fulfill gaps in staff NCD utilized the services of contract support services in FY2016 to fulfill the agencies mission.  |
| **INFORMATION TECHNOLOGY** FY 2016 $ 10,500FY 2017 $ 30,500 |  | As a small agency, NCD secures outside support to agencies IT needs. NCD anticipates increased expenses in FY2017 to address FISMA compliance and upgrade existing equipment.  |
| **PAYMENTS TO FEDERAL AGENCIES**FY 2016 $ 44,200FY 2017 $ 46,000 |  | As a small agency, NCD secures interagency agreements with outside support to complete technical functions such as job postings, procurement and security services. This process provides NCD with expertise per subject matter and reduces cost to NCD and assists in fulfilling federal requirements.  |
| **SUPPLIES, SUBSCRIPTIONS AND MATERIALS**FY 2016 $ 72,400FY 2017 $ 83,400 |  | NCD utilizes professional periodicals, subscriptions to technical publications and services to achieve its mission and serve the public and disability community. These resources are essential for NCD operations. As a small agency NCD has a very small budget for office supplies, furniture and general supplies. |

**APPENDIX C- OUTREACH AND TECHNICAL ASSISTANCE DATA**

The total number of individuals who “like” NCD’s Facebook page has more than doubled from 9,000 in 2014 to over 22,015 as of September 1, 2015.  Similarly, NCD’s Twitter account from which we host “live” tweets of disability-focused legislative hearings and briefings, and coordinate discussions among stakeholders and constituents has increased its followers by nearly 2000 in the last year to total 6,840 in September 2015.

NCD remains recognized by the disability community as a leader in utilizing social media to engage with stakeholders with our active Facebook and Twitter accounts. NCD staff continued to “live tweet” many disability policy events and hearings on Capitol Hill and the White House to bring information from these Washington, DC based events, which were neither webcast nor available for teleconference participation, to far wider audiences beyond the beltway.

Reflecting changes to how people prefer to receive information via ever-changing distribution methods, NCD continues to utilize its traditional email distribution listserv for constituents who favor this method of information delivery. Approximately 3,000 subscribers receive regular policy and activities updates from the agency in this way.

Finally, in keeping with NCD’s strategic plan goal to leverage media more aggressively to help brand NCD and help frame national conversations on disability, NCD Members and staff were highlighted in numerous state, local, national and international media pieces on a broad range of topics.

Highlights of NCD’s media placement in FY15 include:

• In November 2014, NCD’s Public Affairs Specialist was interviewed by USA TODAY about the possible effect of the election results on the 57 million Americans with Disabilities. USA TODAY is the third largest newspaper in the United States with a daily circulation of 1,674,306.  A historical overview of elected officials with disabilities was a secondary focus of the article.

• NCD’s Attorney Advisor was quoted by the Associated Press on February 7 about parenting with a disability. Stories published and republished by the AP are distributed to more than 1,700 newspapers, and more than 5,000 television and radio broadcasters. The AP operates 243 news bureaus in 120 countries.  NBC’s THE TODAY SHOW also referenced NCD’s report and published details of the issue on their website including an interview with NCD in March 2015. That month, the flagship morning news program averaged 5 million viewers daily.

• NCD’s Quarterly Meeting hosted by Pittsburgh, PA in May 2015 led to six articles before, during and after our visit in the Pittsburgh Post-Gazette (circulation: 173,160 Daily; 317,439 Sunday) covering a wide range of topics including the impact of the Americans with Disabilities Act, local employment initiatives, coverage of our panels and discussions, and an editorial penned by former Attorney General Richard Thornburgh as a result of NCD’s visit there.

• An article co-authored by NCD’s Public Affairs Specialist in May 2014 titled “How Misunderstanding Disability Leads to Police Violence” continued to be used as source material for subsequent articles and OpEds in the Washington Post, the British Broadcasting Company, and the Daily Beast. The article was also submitted as a supporting document for proposed legislation under consideration by the Alaska State Legislature in 2015.

These activities, in combination with regular and numerous in-office meetings, including with international delegations, demonstrate that NCD has maintained a large impact, relative to its size. NCD continues to make strides in being a national voice of the disability community, reflective of the community’s wide range of disability types, geography, age, and cultural diversity.

NCD’s official agency website is a library of over thirty years of disability policy research spanning the wide range of topic matters that impact the lives of people with disabilities. Since NCD’s foray into social media outreach three years ago, we have seen an impressive increase in the number of people connecting with our body of policy work through social media activity driving individuals to our website.

In FY13, we had approximately 288,000 unique visitors to the website. In 2014, we had approximately 40% more visitors, at approximately 400,000 unique visitors. As a testament to the efficacy of our outreach efforts, with a month to go before the end of the 2015 fiscal year, we have already surpassed the total from last year at the same point in time by over 175,000 unique visitors, another 49% increase in visitors over FY14; and an 87% increase over FY13. The three most commonly viewed reports in FY15 were evidence to the diversity of NCD’s stakeholders, the breadth of our mission, and the relevance of our reports, years after their release – *The Current State of Health Care for People with Disabilities* (2009)*; Effective Emergency Management: Making Improvements for Communities and People with Disabilities* (2009);and *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* (2012).

**Meetings, Conferences and Other Speaking Engagements** – NCD received numerous invitations this past year to speak at state, national and international conferences and other events and makes good use of the opportunities it accepts by sharing its latest policy findings and recommendations with hundreds of attendees at each event.. These extend beyond NCD report releases and hearings and often lead NCD to beneficial new working relationships. FY 15 highlights include:

* Following up on the success initiated in 2013, NCD continued hosting public forums on issues related to Medicaid Managed Care (MMC). In the last year, NCD conducted three additional MMC forums. On December 12, 2014, NCD conducted a MMC forum at Liberty Resources (Independent Living Center) in Philadelphia, PA, on February 12 a MMC forum was conducted in Baton Rouge, Louisiana. On June 15, a forum was conducted in Austin, TX and on July 7, 2015, NCD returned to Topeka, KS where the forums began generating print and broadcast media. The most recent MMC forum was conducted in Madison, WI on August 31.
* On May 27, 2015 Executive Director Rebecca Cokley presented at the National Conference for Race & Ethnicity in American Higher Education (NCORE) titled “What is 21st Century Policing?” addressing the interplay between disability, racial disparities in American society and the current culture of policing in the United States building on the success we initiated last year by the article NCD co-authored on the topic of police violence and disability for THE ATLANTIC.
* On April 11, 2015 NCD Executive Director Rebecca Cokley presented at the first-ever disability-themed event at the National Conference of the National Action Network in NYC at a panel called “Disability at the Intersections of Justice: Fighting for the Rights of All Description.” The event was live-streamed and tweeted live by NCD staff to extend the information beyond the location and the event itself.
* In ongoing cross-agency collaboration, in the last year NCD has maintained a regular presence in posts to Disability.gov’s blog including the topics of ending the School to Prison Pipeline, Transportation Barriers and Access, Home and Community Based Services, and recommendations on how to improve Social Security disability benefit programs.
* Throughput the year, NCD staff member and author of the *Rocking the Cradle* report, Attorney Advisor Robyn Powell, continued to present at numerous academic, legal, and policy events on the topic of ensuring the rights of parents with disabilities and their children. For example, in January 2015, Robyn presented in New Mexico at the Children’s Law Institute conference as well as to the National Council on Independent Living’s Civil Rights subcommittee.
1. Olmstead v. L.C., 527 U.S. 581 (1999). [↑](#endnote-ref-1)
2. Institute of Medicine, “Essential Health Benefits: Balancing Coverage and Cost” p. 108, (Oct. 2011).

 Institute of Medicine, “Essential Health Benefits: Balancing Coverage and Cost,” p. 131. [↑](#endnote-ref-2)