

DAY ONE PROJECT

Establishing the White House Council on
Disabilities to Address Modern Challenges
for the Disability Community

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Summary

Every American deserves to engage with the world on their own terms. But for the 61 million adults in the United States living with a disability,¹ challenges—including social isolation, the need for advanced assistive technologies, access to care, and economic security—abound. These challenges require a coordinated National Strategy on Disabilities.

To empower people with disabilities to engage with the world on their own terms, President Biden should establish a White House Council on Disabilities tasked with the mission of providing a federally coordinated approach to aligning federal policy, medical reimbursement, and research funding to address issues critical to people those living with disabilities. The goal of this Council would be to provide much-needed leadership and coordination among federal agencies and with external stakeholders, that enable the development of (and access to) the new knowledge and technologies necessary to better support Americans with disabilities of all types and further enrich connections to one another and our economy.

Challenge and Opportunity

July 26, 2020 marked the 30th anniversary of the Americans with Disabilities Act (ADA). This landmark piece of legislation aimed to “provide equality of opportunity, full participation, independent living, and economic self-sufficiency” for people with disabilities.² The ADA also drove positive change in Americans’ attitudes about disabilities by asserting that people with disabilities “should participate fully in all aspects of our communities and have opportunities to take risks, to succeed, and—yes—to fail.”³ While the ADA has addressed many of the major civil-rights challenges faced by those living with disabilities, more must be done to modernize the government’s approach to meeting the needs of people living with disabilities.

Over a quarter (61 million) of adult Americans live with a disability.^{4,5} The Centers for Disease Control and Prevention (CDC) reports that out of this group:

- 13.7% have a mobility disability, experiencing serious difficulty walking or climbing stairs.
- 10.8% have a cognition disability, experiencing serious difficulty concentrating, remembering or making decisions.
- 6.8% have an independent-living disability, experiencing difficulty doing errands alone.
- 5.9% are Deaf or have serious difficulty hearing.

¹ Okoro, C.A.; et al. (2016). Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States. *Morbidity and Mortality Weekly Report (MMWR)*, 67(32): 882–887. U.S. Centers for Disease Control and Prevention.

² 42 U.S. Code § 12101 – Findings and purpose, <https://www.law.comell.edu/uscode/text/42/12101>

³ National Council on Disability. (1997, reissued 2010). “Equality of Opportunity: The Making of the Americans with Disabilities Act.” Washington, D.C.

⁴ Okoro, C.A.; et al. (2016). Prevalence of Disabilities.

⁵ U.S. Centers for Disease Control and Prevention. (2020). “Disability Impacts All of Us.”

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- 4.6% have a vision disability, experiencing blindness or serious difficulty seeing even when wearing glasses.
- 3.6 percent have a self-care disability, experiencing difficulty dressing or bathing.

We the authors write from the perspective of people living with Amyotrophic Lateral Sclerosis (ALS), which creates physical and cognitive limitations for thousands of Americans each year and serves as a powerful example of many obstacles Americans with disabilities often face. ALS is just one of the countless conditions that make it challenging for Americans to engage with the world in the way that they want. Many of these challenges could be addressed through coordinated federal activities, investment, and programs for people with disabilities.

For example, those living with conditions such as muscular dystrophy, multiple sclerosis, Alzheimer's, and spina bifida, need new and improved technologies that provide better mobility, independence, and self-care—technologies such as lighter, nimbler wheelchairs. Today's power wheelchairs are heavy, bulky, and hard to transport on buses and planes. In fact, one airline recently proposed a policy that would preclude people who use heavy wheelchairs from flying on small regional jets.⁶ While the policy was reversed after activist involvement, the fact that it was proposed in the first place demonstrates some of the limitations of existing equipment and policy. Public and private investment in innovation that would make power wheelchairs lighter and more mobile would make it easier for people with certain mobility limitations to leave their homes and more fully engage with the world.

Directly related to the need for innovation is the need for modern payment and reimbursement policies that create affordable access to such technologies for people living with disabilities. New medical technologies are useless if people aren't able to access them. For example, Medicare only covers equipment primarily intended for in-home use. That means that Medicare will not reimburse for essential exterior home modifications such as wheelchair ramps. People with disabilities have the right to be outside. It is time for a commonsense approach to coverage for services and technology that empower Americans with disabilities to experience life on their terms. Another example is that Medicare will only cover equipment for a direct medical reason. This constraint precludes coverage for multi-use devices that can ease access challenges for people with disabilities, including tablet computers that can convert eye gaze to speech and other assistive technology devices.

It is time for a commonsense, open-minded approach to coverage for services and technologies that empower Americans with disabilities. Today's medical-reimbursement policies are outdated and problematically narrow in scope. These policies must be updated to recognize the broad potential of consumer technology and value of connectedness to wellness. Removing constraints on innovation and function in reimbursement policies will also encourage

⁶ Shapiro, J. (2020). "American Airlines Reverses Policy That Imposed Weight Limit On Wheelchairs." National Public Radio, November 23.

development of new and creative solutions to the diverse challenges facing those with disabilities.

Modern and coordinated research, development, and reimbursement policies are critical for tapping the enormous value that society would gain from enabling people with disabilities to engage the world more fluidly and consistently—including through employment. Just 36% of adults living with disabilities are employed.⁷ Addressing the challenges faced by people living with disabilities would help more of those people join the workforce, boosting the economy and productivity while enabling those with disabilities to live lives that are fuller and more financially secure.

Finally, there is a need to develop a data-centric approach to the evolution of policy over time to ensure that guidances, rules, and regulations are regularly updated to meet the needs of people living with disabilities based on data and the best information available. Are our policies having the impacts we need to help people with engage the world on their terms?

Plan of Action

Establishing the White House Council on Disabilities

The Biden campaign's *Plan for Full Participation and Equality for People with Disabilities* provides solid groundwork for ensuring that people with disabilities are included in policy and decision-making.⁸ Realizing the promise of this plan requires a coordinating executive body to ensure that government agencies are implementing synergistic policies and avoiding bureaucratic silos. The Biden-Harris Administration should establish a White House Council on Disabilities (WHCD), run through the Domestic Policy Council, as an action-oriented entity that complements—rather than replicates—the largely advisory work of the National Council on Disability.⁹ The WHCD's responsibilities would include:

- (1) **Coordinating federal activities and programs** for people with disabilities.
- (2) **Examining everyday challenges** facing those living with disabilities, identify opportunities for addressing those challenges, and set goals and timelines designed to increase engagement and stimulate innovation around disabilities.
- (3) **Revisiting the ADA** to see where improvements and updates need to be made.

The WHCD should be tasked with developing a National Strategy on Disabilities that lays out specific actions and forward-leaning public policies related to each of these workstreams that should be implemented over the next four years in order to improve quality of life for all people living with disabilities in the United States. As part of developing the strategy, the WHCD should

⁷ Hou, C.-Y. (2020). The Americans with Disabilities Act is turning 30. Here's what you should know. *The Hill*, January 2020.

⁸ See "The Biden Plan for Full Participation and Equality for People with Disabilities," Biden Harris Democrats, <https://joebiden.com/disabilities/>.

⁹ "About Us," National Council on Disability, (n.d.), <https://ncd.gov/about>.

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launch a robust public-engagement effort. For instance, the WHCD should organize forums that bring together private and public stakeholders to discuss common issues, and should host listening sessions to hear directly from people living with disabilities and their care partners.

The Biden campaign's *Plan for Full Participation and Equality for People with Disabilities* provides solid groundwork for ensuring that people with disabilities are included in policy and decision-making.¹⁰ However, a coordinating executive body is needed to ensure that government agencies are implementing complementary policies and avoiding bureaucratic silos, so that the promise of the President's campaign plan can be realized. This action-oriented effort would be complementary to the National Council on Disability, which is "an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities".¹¹ The Administration should build on this work and existing structures to ensure that the Biden plan can be implemented by appointing a Director of the WHCD to drive and oversee this effort.

The WHCD should also be tasked with establishing a comprehensive research agenda focused on addressing challenges faced by those living with disabilities that goes beyond the development of new technologies, and also improves social engagement and isolation common among people living with disabilities. The agenda should include research on:

- (1) Meeting **technology needs**, including those related to assistive technology and durable medical equipment (DME), communications technology and broadband access, transportation, and education.
- (2) Ensuring **affordable access** to and reimbursement for care, including by implementing new financing mechanisms, working with existing providers, and funding innovation.
- (3) Promoting **economic security** of those living with disabilities, including by expanding employment opportunities, implementing tax reforms, and changing social policies.

Priority areas and opportunities for action

Herein, we expand on three priority areas—and associated opportunities for action—that the WHCD could pursue. Each of these areas demonstrates the clear positive impacts that a WHCD could have on the lives of the millions living with disabilities across the United States.

Priority Area 1. Research and technology: innovation that empowers

People with disabilities use a variety of technologies to improve their lives. For mobility-challenged persons, for instance, key technologies include powered wheelchairs, special beds, and stair-lifts. But these products can be expensive and unwieldy, and no federal agency is specifically charged with driving innovation for the disabled community. In cases where

¹⁰ "The Biden Plan for Full Participation and Equality for People with Disabilities," Biden Harris Democrats, <https://joebiden.com/disabilities/>.

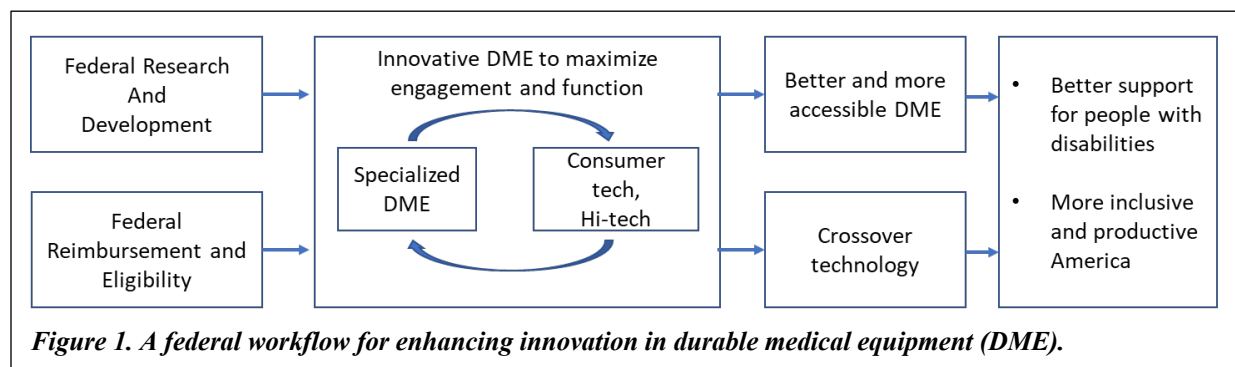
¹¹ "About Us," National Council on Disability, (n.d.), <https://ncd.gov/about>.

innovation has occurred, such as more compact ventilators or high mobility wheelchairs, Medicare’s focus on in-home use does not adequately consider the benefits of equipment that better supports travel and social engagement.

As part of the National Strategy on Disabilities, the WHCD should identify ways to improve and expand access to advanced technologies for people living with disabilities, such as:

- Providing federal incentives for development of cost-effective solutions to address the challenges that people with disabilities face.
- Development of a DARPA-like agency for Health (HARPA) to address the market failures that often limit innovation for people with disabilities.
- Providing much-needed coordination among federal agencies on a research and development agenda and an investment plan for diverse technologies to assist those living with disabilities.

The federal government could also establish clear and straightforward reimbursement pathways for advanced technologies. Better reimbursement policies create incentives for innovations and accelerate uptake of new technologies, thereby improving quality of life improvement for people living with disabilities. Durable Medical Equipment (DME) is a class of technologies that would especially benefit from modernized reimbursement policies. DME refers to non-disposable devices used at home to assist someone with a function. Examples of DME include wheelchairs, ventilators, crutches, and CPAP machines. As discussed previously existing reimbursement policies like in home use requirements tend to be rigid in the types of DME they cover, leading to disincentives to innovate in this space. The WHCD could coordinate a strategy for enhancing innovation in DME, as illustrated in Figure 1.



The first step is to ensure that research and development funding,¹² as well as federal insurance coverages for DME, enable innovation that maximize engagement and equipment function. The

¹² E.g., through a proposed Assistive Technology Innovation Fund and through existing funding from the National Science Foundation, the National Institutes of Health, the Department of Veterans Affairs, the Defense Advanced Research Projects Agency, and others.

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Centers for Medicare & Medicaid Services could sponsor an Innovation Pilot testing novel DME devices. The WHCD could ensure that federal initiatives such as this are coordinated and complementary. The second step is to encourage DME manufacturers to enhance collaborations with manufacturers of consumer technology (e.g., speech-to-text capabilities and auto-driving assistance) as well as with manufacturers of cutting-edge technology (e.g., brain-computer interfaces and exoskeletons). Innovation to support enhanced mobility, computer control, and other important functions for people with disabilities can in turn cross over to applications in broader consumer markets. The end result of these cycles of improvement will be better DME for people with disabilities as well as new products that benefit even those outside of the disabled community.

Priority Area 2. Communication and social engagement

The WHCD could establish an interagency agenda to develop and deliver science and technology that can reduce the isolation of Americans living with disabilities, and empower those Americans to engage with the world as they wish. Developing and implementing the science for this subset of Americans can not only result in fast improvements, but can also help develop strategies to address isolation and disengagement across America as a whole.

The impacts of social isolation have come into sharp focus during the COVID-19 pandemic. Yet people with disabilities face challenges of isolation every single day. Disabilities can make it difficult to communicate online, to speak on the phone, and/or to meet people in person. Investments need to be made to identify and deploy effective mechanisms for all people with disabilities to maintain social engagement and emotional wellness. The Biden campaign's call for a new Assistive Technology Innovation Fund, administered by the Department of Commerce, to sponsor public-private partnerships focused on increasing the independence of people living with disabilities is a great starting point. As with DME, innovations targeted at the disabled community will ultimately cross over into the broader consumer market to help address isolation and disengagement across America as a whole.

Improving access to broadband is fundamental to ensuring that people with disabilities have the means for social and economic engagement. Broadband also fulfills a medical need, providing better access to healthcare through avenues such as remote monitoring and telehealth. However, according to a Pew Research Center survey, “[d]isabled Americans are about three times as likely as those without a disability to say they never go online.”¹³ Adults with disabilities are also less likely to have broadband at home. President Biden's commitment to invest \$20 billion in rural broadband infrastructure, direct the federal government to support cities and towns that want to build municipally owned broadband networks, and increase funding for states to expand broadband will help communities tackle the digital divide. Broadband access alone is

¹³ Anderson, M.; Perrin, A. (2017). “Disabled Americans are less likely to use technology.” Pew Research Center, April 7.

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not sufficient to create social engagement, but ensuring equitable access is an important first step.

A next step is supporting research into how today's technologies and tools can be leveraged to better include and engage people living with disabilities. How can we best use broadband and internet-enabled platforms to promote social engagement? How can instrumental enablers of engagement like broadband and social media, accessible transportation, DME, and others be combined with behavioral and educational interventions, volunteer activities, and online communities to reduce social isolation? These are empirical questions that need study and demonstration, coupled with evidence-based policymaking, to drive a new era of inclusiveness for all people with disabilities. And if we as a nation can develop the science to address isolation for Americans with physical and communication challenges, we can use that same science to help reduce isolation for *all* Americans. This will lead to the more connected and inclusive nation President Biden has been calling for and that we all wish to see.

Finally, reducing social isolation and promoting engagement—as well as simply making it easier to get around one's community—for those with disabilities demands a concerted effort to address transportation challenges. While investing in better, nimbler DME is a start, new strategies and investments are also needed to improve the transportation infrastructure for the disabled community. Making it easier for people with disabilities to go out in the world makes it easier for them to take advantage of broader opportunities for employment, volunteering, and social engagement, leading to an increase in well-being for individuals and strengthening the overall fabric of our society.

Priority Area 3. Affordable access to care

People with disabilities often have more complex medical needs as well as greater difficulty obtaining quality care. The WHCD should draft forward-leaning access to care policies that agencies can implement, including policies related to telehealth, transportation to medical appointments, and others. Additionally, many forms of disabilities typically require specialized care, including care that sometimes cannot be provided within the person's home state. Accessing out-of-state care can be challenging, especially for people covered by Medicaid or CHIP. Even after a state Medicaid program or Medicaid Managed Care Organization (MCO) has already authorized out-of-state care, delays in accessing that care may follow. This is an area that the WHCD should examine and propose policy solutions or pilots to address.

People with disabilities often have more complex medical needs as well as greater difficulty obtaining quality care. Additionally, many forms of disabilities typically require specialized care, including care that sometimes cannot be provided within the person's home state. The WHCD should draft forward-leaning access to care policies that agencies can implement, including policies related to telehealth, transportation to medical appointments, and access to distant specialty services.

Conclusion

The Americans with Disabilities Act (ADA) is a laudable piece of civil-rights legislation. But this 30-year-old law certainly does not solve the many challenges encountered by Americans with disabilities today. ADA current rules are insufficient – three decades ago it was about getting people into places and securing legal protections, but we’re facing a different set of problems now like access to Broadband, self-driving cars, and telemedicine.

Now is the time to put into motion a coordinated federal effort to empower people with disabilities to engage with the world on their own terms. The problems are complex and require coordination of federal agencies and leadership from and within the White House. The Establishment of the WHCD could ensure that legislative policy fixes and agency implementation go hand in glove.

The Biden campaign’s *Plan for Full Participation and Equality for People with Disabilities* provides a solid foundation for ensuring that people with disabilities are well served by federal policy and decision-making.¹⁸ A coordinating body can bring the President’s vision to life and ensure that government agencies are implementing complementary policies and avoiding bureaucratic silos. A new White House Council on Disabilities (WHCD) can serve these functions.

Within 6 months of formation, the WHCD should develop and release a detailed National Strategy on Disabilities that covers topics such as innovation in technologies that enable those living with disabilities to engage with the world as they choose, ensuring affordable access to those technologies, and promoting economic security by expanding employment opportunities for those living with disabilities. These actions can and must be informed by the communities they affect. The WHCD should prioritize listening sessions with those living with disabilities and their care partners. It will also be important to bring together other key stakeholders from the disabilities community, including nonprofits, advocates, medical providers, payers, technologists, and others. By working together, we can do much to empower people with disabilities to live independently and to the fullest.



Frequently Asked Questions

Which federal agencies should be represented on the White House Council on Disabilities?

We recommend that the White House Council on Disabilities be led by the Domestic Policy Council and include representatives from the following agencies:

- Department of Education
- Department of Housing and Urban Development
- Department of Justice
- Department of Labor
- Department of Transportation
- Department of Veterans Affairs
- Administration for Community Living
- Consumer Financial Protection Bureau
- Defense Advanced Research Projects Agency
- Federal Trade Commission
- Food and Drug Administration
- Centers for Disease Control and Prevention
- Centers for Medicare and Medicaid Services
- National Council on Disability
- National Institutes of Health
- National Science Foundation
- Office of Science and Technology Policy
- Office of the Surgeon General
- Social Security Administration
- Substance Abuse and Mental Health Services Administration

How can the White House Council on Disabilities ensure that it is responding to the most pressing needs of those living with disabilities?

The WHCD should hold interactive listening sessions with people living with disabilities, as well as with caregivers of those living with disabilities. The WHCD should also use a data-driven approach to developing policies and priorities that address the most pressing needs of people living with disabilities and enable them live their lives on their terms.

Didn't the Americans with Disabilities Act ensure equality for people living with disabilities?

The ADA was a groundbreaking piece of civil-rights legislation. But while the ADA gave people living with disabilities the *right* to engage with the world on equal footing, it did not necessarily provide the *means*. A coordinated federal effort is needed to ensure that people with disabilities are empowered to engage comfortably, fully, and in the way that they choose.

About the Authors



Allison Martin, M.S. draws on over a decade of experience at the crossroads of health and government. As a Director at Faegre Drinker Consulting, she partners with organizations in the patient-advocacy and biomedical-science space to advance their missions through public policy, advocacy, and federal-government relations. Allison uses firsthand experience to help organizations and coalitions navigate the congressional landscape through planning and executing congressional advocacy campaigns as well as developing policy and legislative strategies. Allison also helps patient-advocacy groups and the pharmaceutical industry work with agency leaders on patient-focused drug-development activities, including creation and growth of public-private partnerships, the development of patient experience data, and facilitation of community-led drug-development guidances. Before her work as a consultant, Allison served as a senior healthcare fellow for U.S. Representative Phil Gingrey and as a staffer for U.S. Senator Lamar Alexander. Allison earned a Master of Science in Microbiology and Immunology from Georgetown University.



Michael Stebbins, Ph.D. is a geneticist and public-policy expert who served as the Assistant Director for Biotechnology in the Obama White House Office of Science and Technology Policy. He is currently the President of Science Advisors, a science and health consulting firm he founded in 2018 to provide science, technology, and public policy guidance to private companies, philanthropies, and non-profit organizations. He is also a Senior Fellow at the Federation of American Scientists. While at the White House, Dr. Stebbins' work led to large initiatives across the federal government to address antibiotic resistance, protect pollinators, improve veterans' mental health, increase access to federally funded scientific research publications and data, promote preferential purchasing of antibiotic-free meats, reform the regulatory system for biotechnology products, drive federal purchasing of bio-based products, and improve management of scientific collections. Dr. Stebbins previously served as the Vice President of Science and Technology for the Laura and John Arnold Foundation, science advisor to the Obama Presidential Campaign, and on the Obama White House Transition Team. He

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is the former director of biology policy for the Federation of American Scientists and worked for U.S. Senator Harry Reid and at the National Human Genome Research Institute. Before coming to Washington, he was a senior editor at Nature Genetics. Dr. Stebbins is on the Board of the Value in Cancer Care Consortium and chair of the Board for Vivli. He serves on the scientific advisory boards for Datavant and Amida Technology Solutions.



Neil Thakur, Ph.D. brings more than two decades of experience as a public-health expert to the fight against ALS. He serves as the Chief Mission Officer for The ALS Association, where he leads their research, care services, and advocacy programs. Before joining the Association, Dr. Thakur served in the National Institutes of Health (NIH) Office of the Director, making NIH research more impactful. He managed the world's largest policy to make biomedical research papers publicly accessible and co-chaired the White House task force that led to the requirement that all federal science agencies adopt similar policies. He also spent a year on detail to the U.S. Senate Special Committee on Aging, focusing on effective long-term health care. Prior to his time at NIH, Dr. Thakur was Assistant Director of Health Services Research and Development at the Department of Veterans Affairs. Dr. Thakur has received numerous federal awards, including the Secretary for Health and Human Services' award for Meritorious Service, the second-highest award that the Secretary can bestow. Dr. Thakur holds a Ph.D. in Health Policy from the Yale University School of Public Health and completed a National Institute of Mental Health (NIMH) postdoctoral fellowship in mental-health services research at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill.



About the Day One Project

The Day One Project is dedicated to democratizing the policymaking process by working with new and expert voices across the science and technology community to develop actionable policies that can improve the lives of all Americans. For more about the Day One Project, visit dayoneproject.org