CCD
CONSORTIUM FOR CITIZENS WITH DISABILITIES

July 30, 2021

Frank Pallone, Jr.
Chairman
House Committee on Energy and Commerce

Patty Murray
Chair
Senate Committee on Health Education Labor & Pensions

Dear Chairman Pallone and Chair Murray:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) write in response to your request for information on design considerations for legislation to develop a public health insurance option. CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. Thank you for the opportunity to comment. Over the past several years, we have developed principles for health care reform and for the inclusion of long-term services and supports in health care reform that are attached for your reference and will guide our responses to your request.

1) Questions 1, 2, and 7

We take no position on the particular approach that Congress should take in creating a public option. We believe that many of the proposals that exist, such as Medicare for America, Medicaid Buy-In, Medicare-Plus Buy-In or a Marketplace plan public option, could provide comprehensive and affordable coverage for people with disabilities. We believe that the Committees have identified the correct problems to consider, and thought it would be helpful for the Committees to be aware of issues that we currently experience that a public option could address. We believe a public option would be a step in the right direction, if structured correctly and in accordance with our principles as follows.

A primary goal of creating a new public option should be to improve all forms of health coverage. Congress must take into consideration how a public option would interact with other forms of coverage, especially our existing public coverage through Medicaid and Medicare. In particular, steps should be taken to ensure that necessary improvements are made to Medicare and Medicaid so those who remain enrolled in those programs, many of whom are people with disabilities, are not left behind. It is particularly critical that the public option and any other efforts to fill the coverage gap will not undermine Medicaid expansion or other pathways for people with disabilities to access Medicaid.

A new public option must make progress towards reducing health disparities and achieving health equity. It is not enough to improve health on average; it must produce meaningful results across populations and subgroups. That also means that the option must collect and report performance data disaggregated by key demographic categories, including disability, to establish a baseline and trajectories for health disparities. The public option should include mechanisms to implement innovations targeted at reducing disparities over time. Among other policies needed to improve health equity for people with disabilities, the new option should have prohibitions on discriminatory benefit design, including cost-sharing structures that disproportionately impact people with disabilities and shut low-income people out of care. The legislation should prohibit the new system from using Quality-Adjusted Life Years, Disability-Adjusted Life Years, and other comparative and cost-effectiveness measures which devalue the lives, experiences, and perspectives of people with disabilities.

Services must also be physically and programmatically accessible to people with disabilities. This means that navigating the program must be simple and understandable. Sufficient, well-funded assistance must be available free of charge to help consumers with enrollment, coverage issues, and appeals.

Any new health insurance option, including a public option, must ensure adequate access to health care providers and services. If the public health insurance option uses health plans and networks, there must be strong oversight of network adequacy, including cultural competence, languages spoken, and accessibility of providers and medical equipment. Robust access to accessible telehealth services should also be included. Expansion of telehealth, including audio-only and text-based services, as a supplement to in-person and other service modalities during the public health emergency has helped many people with disabilities access care more routinely and conveniently. It has also improved access to specialists for people living in medically underserved areas as well as for people with more rare health conditions. It is critical, however, that network advocacy oversight and provider payment ensure telehealth not replace access to in-person services. Similarly, while critical, exceptions and appeals processes are not a substitute for robust coverage and networks. The Part D appeals process is famously difficult to navigate. Research shows high rates of approval of treatment and services upon appeal, suggesting that denials occur when treatments are appropriate and appeals reward those who have the ability and resources to navigate the system.

2) Questions 3 and 5

Our principles make it clear that health care coverage must be affordable for all people, including those who have higher than average health costs. Ensuring that premiums are affordable is necessary, but insufficient to ensure affordable access to care. Deductibles and other cost-sharing must *also* be affordable. Premiums and out-of-pocket costs should be nominal or non-existent for low-income populations. First dollar coverage helps people with disabilities who need access to care and treatment on a routine basis have predictable and affordable co-pays. Deductibles and out-of-pocket caps should also be limited based on household income, recognize that people with disabilities often have higher than average out of pocket medical expenses, and ensure the public option is not catastrophic-only coverage.

We urge the Committees to pursue cost-control mechanisms other than utilization management. Utilization management, such as prior authorization or step therapy, disproportionately impacts people with disabilities and chronic conditions who frequently need high-cost, high-intensity care and do not have lower-cost alternatives. Many states eased or eliminated prior authorization during COVID-19, and this did not dramatically increase health care usage. Policymakers should analyze data from this experience and reconsider the frequent application of prior authorization as a barrier to needed services, rather than a tool to improve care quality.

3) Question 4

Most people with disabilities rely heavily on health coverage because of their disabilities or chronic conditions. To be accessible to them, any new coverage must be not only affordable, but *comprehensive*.

In order to be comprehensive, we believe that any coverage expansion must include coverage of Home and Community Based Services (HCBS). Currently almost exclusively available via the Medicaid program, access to HCBS is substantially limited, with hundreds of thousands of people on waiting lists, relying on unpaid caregivers, or going with their basic needs unmet. Lack of access to HCBS in other health coverage traps people with disabilities or chronic conditions in poverty because they must rely on Medicaid. We were delighted when Chairman Pallone proposed expanding access to HCBS in Medicare[1] and we believe that any new public option must also cover HCBS. As part of a new public option, this coverage would not replace existing Medicaid HCBS coverage, but would allow the newly eligible population, which would include those in the Social Security Disability Insurance waiting period and who live in non-Medicaid expansion states, to access the services they need. The HCBS benefit within the public option should be robust, ensuring that people with disabilities have other affordable, comprehensive coverage options besides Medicaid. Since most of the enrollees within a public option are unlikely to require HCBS, the public option represents a unique risk pool that should be effective in constraining costs.

In addition, a public option that effectively addresses comprehensive and affordable access to health care must include prescription drug reforms. Americans continue to struggle to afford their prescription drugs, including in Medicare, Marketplace coverage, and employer coverage. We urge Congress to find ways to reduce prescription drug costs across the system that do not rely on limiting patient access. The primary mechanism to lower prescription drug costs in non-Medicaid coverage is through negotiations that result in restrictive formularies, high cost-

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[1] http://c-c-d.org/fichiers/CCD-Comments-on-Pallone-LTC-Discusion-Draft.pdf

sharing, and utilization management. These practices may result in lower prescription drug costs for health plans, but hurt people who need high cost prescriptions by limiting their access. Further, these price negotiations between manufacturers and payers often do not result in lower out-of-pocket costs for those taking the medications, who still pay cost-sharing, like deductible and coinsurance, off of list price. In general, we urge Congress to find ways to reduce prescription drug costs that do not rely on limiting patient access.

If the public health insurance option uses essential health benefits (EHB) as a standard, we urge Congress to improve the EHB standard for prescription drugs, which currently only provides one drug per class. Congress should consider using the Medicare standard of two drugs per class plus additional coverage for protected classes, or the Medicaid standard, which guarantees coverage with required rebates from manufacturers.

4) Question 8

Finally, the primary purpose of a new public health insurance system should be to expand comprehensive, affordable coverage. Any further aims, such as delivery system reforms, should be thoughtful, limited, and designed to improve access to care. Congress should avoid reforms that hurt people with disabilities in the name of improving health. For example, the Affordable Care Act included provisions supporting “wellness programs”, exempting these programs from prohibitions on medical underwriting and allowing employers and health plans to discriminate against people with disabilities by charging higher premiums if enrollees did not complete required wellness activities or meet health metrics. Since 2010, research has shown that these programs do not improve health or control costs. Congress should avoid similar provisions that seek to control health care costs by discriminating against people with disabilities or chronic health conditions.

We would be happy to discuss any of these issues in more detail, especially once you have settled on a structure for the new system, about how to ensure that the coverage works for people with disabilities. Please contact Natalie Kean (nkean@justiceinaging.org) with questions or to arrange a meeting.

Sincerely,
American Academy of Physical Medicine & Rehabilitation
American Association on Health and Disability
American Council of the Blind
American Dance Therapy Association
American Music Therapy Association
American Network of Community Options & Resources (ANCOR)
American Therapeutic Recreation Association
Autistic Self Advocacy Network
Brain Injury Association of America
Disability Rights Education and Defense Fund (DREDF)
Epilepsy Foundation

Justice in Aging
Lakeshore Foundation
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Disability Rights Network (NDRN)
National Health Law Program
The Arc of the United States

Attachments:
CCD Disability Principles for Health Care Reform
CCD Disability Principles for Inclusion of Long Term Service and Supports (LTSS)

CONSORTIUM FOR CITIZENS
WITH DISABILITIES

CCD Disability Principles for Health Care Reform

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. As we begin a new Congress, the Consortium for Citizens with Disabilities (CCD) Health Task Force issues these updated principles for health care reform efforts.

For the disability community, access to health care is not only a matter of life and death, but a matter of liberty and civil rights. The experience of people with disabilities is a **litmus test** for how well a health care system addresses the needs of all people living in the United States. If a health care system provides comprehensive, high-quality care to individuals with disabilities and chronic health conditions, then it will likely also serve the needs of the broader population.

Specifically, the CCD Health Task Force will use the following 7 principles to guide its assessment of health care reform proposals from a disability perspective: **Comprehensiveness, Affordability, Non-Discrimination, Community First, Simplicity and Enforceability, Implementation and Transitions, and Accountability and Reporting**. These principles build on principles around inclusion of long-term services and supports (LTSS) in health reform produced by the CCD LTSS Task Force.

PRINCIPLES

Comprehensiveness – Comprehensive coverage must be available to all people across all types of health insurance coverage.

- Health care reform efforts should preserve the services provided by existing baseline coverage.
- There should be a mandated, comprehensive, federal benefit package that is available to everyone.
- Health care reform efforts should fill in key benefit gaps in existing programs such as Medicaid, Medicare, and the Affordable Care Act’s health insurance marketplaces. This would include ensuring all coverage includes access to vision, hearing, and adult dental services, as well as EPSDT services for children at all income levels and Non-Emergency Medical Transportation for low-income individuals. Reform efforts should not leave out certain categories of services, like LTSS, that are currently provided almost exclusively via public health insurance programs with restricted eligibility.

- Service categories with chronic and long-standing provider shortages, such as home health care, or with providers who are frequently outside the coverage system, such as in behavioral health and habilitation and rehabilitation, should receive extra attention and investment to improve and ensure network adequacy.
- Health care reform efforts should ensure that health care professionals receive training and experience working with people with disabilities.

Affordability: Health care coverage must be affordable for all people, including those who have higher than average health care costs:

- The burden of premiums, out-of-pocket expenses and cost-sharing requirements for participants should be non-existent for low-income populations. Any cost sharing must provide protections for low-income individuals, people with disabilities, and those with chronic conditions, and ensure affordability for people of all incomes in public and private programs.
- Cost sharing is a blunt and largely ineffective tool for improving efficient use of health care dollars, as most health care decisions and costs, particularly those for people with disabilities, are driven by health care providers.
- Cost sharing places a disproportionate and discriminatory burden on people with disabilities and chronic health needs.
- Cost sharing also creates a major barrier to care, especially for low-income people.
- Reforms should emphasize transparency in relation to pricing, provider availability, cost sharing, service availability, grievance and appeals, and all other elements of health coverage.

Non-Discrimination: People with disabilities of all ages and their families must have all their health needs met as they participate in the nation's health care system. While disability affects people of all races, ethnicities, genders, languages, sexual orientations, and gender identities, disability does not occur uniformly among communities. These differences must be taken into account to ensure equitable reform efforts. A reformed health care system must be physically and programmatically accessible and must:

- Ensure that all health coverage adequately meets the needs of people with disabilities and chronic conditions. People with disabilities must not be forced to remain in poverty in order to access needed services and supports.
- Strive towards health equity and reduce disparities. It is not enough for the health care system to produce improved results “on average;” it must produce meaningful results across populations and subpopulations. In addition to reducing existing health disparities, it must chart a course for their elimination.
- Continue prohibitions on discriminatory health care benefit designs that would exclude or have a disparate impact on specific populations with higher health care costs or of minority status. This includes cost-sharing structures that disproportionately and discriminatorily affect people with disabilities and others who have higher health care needs or require uncommon services or treatments.

- Prohibit using Quality-Adjusted Life Years, Disability-Adjusted Life Years, and other comparative-effectiveness measures which devalue the lives, experiences, and perspectives of people with disabilities and chronic health conditions.
- Ensure that people with disabilities can move anywhere in the country without experiencing a disruption in access to comprehensive, accessible, high-quality health care services and/or long term supports and services.

Community First: Adults and children with disabilities often need long-term services and supports to live good lives and age with dignity in the community. Community living is a civil right. Unfortunately, the history of institutionalization has left much of our health care system with an institutional bias. Health care reform efforts should:

- Include and expand home and community-based services (HCBS) in any health reform efforts.
- Build on decades of progress to ensure people have access to HCBS by mandating access to HCBS and eliminating institutional bias.
- Enable friends and family to provide services and supports for friends and family members with disabilities of any age in the community, while not assuming or compelling the provision of these services in place of formal services.
- Ensure that all people with disabilities of all ages are able to receive services in settings that are truly community-based.
- The CCD Long Term Services and Supports Task Force has developed detailed principles for the inclusion of LTSS in health reform efforts, which can be accessed here.

Simplicity and Enforceability: In any health care system, services must be physically and programmatically accessible and people must be able to enforce their rights:

- Minimize administrative complexity for individuals and families receiving health care services.
- Have mechanisms to ensure sufficient provider capacity, particularly for community-based services for people with disabilities, chronic conditions, and complex medical and behavioral health needs.
- Hold health care providers and payers accountable for making and maintaining settings that are physically and programmatically accessible.
- Include accessible and direct processes for individuals to address issues with their care and services and appeal adverse coverage determinations. Create ombudspersons, consumer advisory councils, and other mechanisms for people with disabilities to provide feedback and address systemic issues.
- Avoid placing a heavy complaint burden on individuals who may be experiencing health crises or are otherwise disincentivized from bringing enforcement actions against needed care providers.
- Provide access to the courts so that individuals can ensure that these protections are enforced.

Implementation and Transitions: In any health care systems transformation, the implementation of new systems and transition from old to new will be challenging for people with disabilities or chronic conditions who need consistent and constant access to health care. Any reform efforts should ensure that the implementation and transition period:

- Maximizes continuity of care through emphasizing smooth transitions between care settings; a seamless continuum between health care services, behavioral health, rehabilitation, and long-term services and supports for people with disabilities and chronic illnesses; and minimizing disruptions during coverage transitions.
- Increases the capacity of the health care system to address the critical or unforeseen issues that arise during periods of transition, such as shifting from one type of coverage to another, from pediatric care to adult care, or from one eligibility pathway to another in the same program.
- Ensures continuity of and continued access to specialty providers;
- Includes a phase-in or transition period adequate to ensure continuity of care for people with disabilities and chronic health conditions.

Accountability and Reporting: A crucial aspect of health care reform efforts should be robust quality metrics and reporting. The collection and reporting of quality metrics should include standards for physical and programmatic accessibility that are embedded within quality care standards and monitoring that is already taking place among various health care entities and should be:

- Transparent, timely, and accessible for health plan enrollees, potential health plan enrollees, advocates and researchers;
- Comprehensive, including alternative mechanisms, like ombudspersons, to address quality problems in real time.
- Increasing use of and reliance on more person-centered outcomes to augment existing medical model measures or assessments of functioning;
- Subject to sufficient oversight, enforcement, and advocacy to ensure quality of life and improve quality of care in all settings;
- Adequately funded and sufficient to support quality care, including sufficient training, protections, and compensation for the workforce.

CCD will analyze health care reform proposals based on how well they meet these principles and serve people with disabilities and chronic conditions.

Signatories as of March 27, 2019:

Allies for Independence
American Academy of Physical Medicine & Rehabilitation
American Association of People with Disabilities
American Association on Health and Disability
American Diabetes Association
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Network of Community Options and Resources
American Occupational Therapy Association
American Physical Therapy Association

American Therapeutic Recreation Association
Association of University Centers on Disabilities
Autism Society of America
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
Center for Public Representation
Disability Rights Education and Defense Fund
Epilepsy Foundation
Family Voices
Justice in Aging
Lutheran Services in America-Disability Network
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Disability Rights Network
National Health Law Program
Paralyzed Veterans of America
Special Needs Alliance
The Arc of the United States
United Spinal Association

Attachment

CCD

CONSORTIUM FOR CITIZENS
WITH DISABILITIES

CCD Disability Principles for Inclusion of Long Term Service and Supports (LTSS) in Universal Health Care

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. This document lays out principles regarding long term services and supports (LTSS) that the undersigned members of CCD believe must be incorporated into any universal or “For All” health care system in the United States. This document complements the CCD Disability Principles for Health Care Reform, available at http://www.c-c-d.org/fichiers/CCD-Health-TF-Principles_3-27-19.pdf.

For the disability community, access to health care is not only a matter of life and death, but also a matter of liberty and civil rights. People with disabilities of all ages need access to the ***right*** kinds of health care services and supports to ensure that they can live in the community and have lives and jobs like everyone else--otherwise, people can be and are trapped in institutional settings away from family, friends, jobs, and other fundamental aspects of life. Long-term services and supports (LTSS) refer to the daily living supports that people with disabilities and older adults need. LTSS includes home and community-based services (HCBS), which are the overwhelming preference of service delivery for the disability community and older adults. Expanding access to HCBS has been the focus of the disability community’s advocacy for the past fifty years and there remains much progress to be made.

There is extremely limited access to LTSS in private insurance or Medicare, and few families have the means to pay for these daily services on an ongoing basis, much less for the decades or lifetime that people with disabilities often need these services. This has left Medicaid as the main payer of LTSS. But Medicaid disadvantages HCBS because it has an “institutional bias” that mandates states to cover most institutional services while making coverage of HCBS optional. States can and do cap access to HCBS, creating waitlists or other restrictions to access, which the disability community strongly opposes. These waitlists and restrictions force many people with disabilities and older adults to rely on unpaid family caregivers and other programs that ensure access to housing, nutrition, work supports, and other basic needs, if available. Inability to access needed services and supports can also lead to job loss, unnecessary interactions with the criminal justice system, homelessness, or greatly diminished health and function. For those who can access services, Medicaid’s strict eligibility criteria trap people with disabilities and older adults in poverty to obtain services, hindering the economic opportunities and ability to save for their families’ future or for their own retirement. The state-federal partnership that underpins Medicaid also means that there is substantial state variation in access to LTSS and even greater variation in access to HCBS.

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The Affordable Care Act began to establish a federal floor of covered services, which includes mandated access to some of the critical services people with disabilities and older adults need including rehabilitation, habilitation, prescription drugs, and behavioral health services. A universal or “for all” health care system **must** continue this progress by establishing and **guaranteeing access** to a standard benefit package that includes LTSS in all health insurance. Any new system must also preserve the decades of progress that provides protections for people with disabilities, including the Early and Periodic Screening, Diagnostic and Treatment mandate and other consumer protections.

We urge all proposals to incorporate the following principles:

True Universal Health Care - All individuals must be included in any new universal system, especially people with disabilities, older adults, and others with high health care needs.

- Health coverage should be accessible in an equitable way without discriminating on the basis of race, color, national origin, sex, gender identity, sexual orientation, age, or disability.
- This must include universal eligibility for all people, without income or asset limits that require people to impoverish themselves to access needed services.
- The health care system itself must be accessible for people with disabilities, older adults and others with high health care needs.
- There cannot be a separate system for access to LTSS, and access to LTSS cannot be pre-conditioned on institutional levels of need.
- Any LTSS assessment process, including eligibility and allocation assessments, should be done in a consistent, uniform and transparent way, capturing all individuals with disabilities (including, specifically, people with developmental and mental health disabilities who are often omitted in such assessments).

Comprehensive Coverage of All Services - Any new universal system must include LTSS as part of the universal service package.

- Any new system should focus not only on access to traditional health care services, but also on LTSS and social determinants of health, creating a social model of health care instead of the traditional medical model.
- All care and services should also be consumer-focused and directed. Services should be as expansive as possible, flexible, consumer-driven, person-centered and tailored to the individual’s needs and preferences.
- Any system must recognize and support the central role family caregivers play in planning for and providing LTSS. It should include strategies to support caregivers who are otherwise employed to help maintain their financial security. A system should assess the needs of family caregivers and provide information, training, counseling, respite and other supports to address their needs. The program **must not** compel informal supports in lieu of developing a viable system of LTSS.

Community First Care - Any new universal system must eliminate institutional bias and instead incentivize **Community First**, maintaining and advancing the decades of progress of the disability community to ensure access to HCBS.

- This will also prevent the loss of progress in states that have done more to expand access to HCBS for people with disabilities and older adults.
- This should also preserve and build upon the clear definition of HCBS created by the HCBS settings rule and ensure that all people with disabilities of all ages are able to receive services in settings that are truly community-based.

Coordinated Care and Programs - Any new universal health care system must thoughtfully incorporate and work with current and future social and economic support services. Health care services, including LTSS, should be seamlessly integrated with other service systems and payment and services should be aligned to promote optimal care and service delivery.

- There must also be investment in care coordination, which can be especially important for people with disabilities and older adults who have challenges navigating complex systems.
- In particular, any new system must include and invest seriously in explanation of the new system and outreach and engagement with all populations, but specifically marginalized populations including people with disabilities, low-income older adults and individuals with limited English proficiency.

Inclusive Quality Metrics and Reporting - Any new universal health care system should have robust quality metrics and reporting, with transparency for advocates and researchers. These metrics must be focused on person-centered outcomes, instead of exclusively focusing on medical model measures or assessments of functioning.

- Outcomes measures should be person-centered, reflecting how well an individual is supported in leading a self-determined life, and should include measures of beneficiary experience and satisfaction measures instead of simply relying on medical measures or functional assessments.
- Quality assessment must include sufficient oversight, enforcement, and advocacy programs to ensure quality of life and improve quality of care in all settings.
- Quality metrics must also include examination of funding and if it is sufficient to support quality care, including sufficient training, protections, and compensation for the LTSS workforce.

Sincerely,

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American Association on Intellectual and Developmental Disabilities
American Dance Therapy Association
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National Disability Rights Network
National Health Law Program
National Respite Coalition
Paralyzed Veterans of America
Partnership for Inclusive Disaster Strategies
Special Needs Alliance
TASH
The Arc of the United States
United Spinal Association

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