AAPD
American Association of People with Disabilities

CCD
Consortium for Citizens with Disabilities

January 28, 2021

Xavier Becerra
Secretary-Designate
U.S. Department of Health and Human Services

Dear Secretary-Designate Becerra:

Thank you for meeting with our organizations to discuss the disability community's priorities for the Biden Administration. Our nation is currently home to more than 61 million people with disabilities, and this number grows every day. The disability community is incredibly diverse in both identity and experience. Disability is most prevalent in women and in Black, Indigenous, and people of color. People with disabilities experience poverty at disproportionate rates. For these reasons, and so many others, it is critical that the entire Department of Health and Human Services understand that the disability community is a core constituency that all of its agencies must work to prioritize and serve. The Department of Health and Human Services plays a key role in the advancement and protection of people with disabilities' civil rights and the ability of disabled people to live in their communities, receive affordable, quality medical care, and engage in activities of daily living. The COVID-19 pandemic has had dire consequences for people with disabilities. Two thirds of all coronavirus deaths have been people with disabilities and staff in congregate settings. As we have seen in coronavirus data more broadly, congregate settings that primarily house residents of color, no matter their location, size, or government rating, have experienced deaths due to COVID at two to three times the rate as congregate settings that primarily housed white residents[1].

For people with disabilities who have survived so far, COVID-19 has disrupted every aspect of their lives -- from loss of employment, to being unable to access necessary care and supports, to a lack of access to personal protective equipment. These

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[1] "The Striking Racial Divide in How Covid-19 Has Hit Nursing Homes." New York Times. (September 2020). Available at [Covid-19 and Nursing Homes: A Striking Racial Divide - The New York Times (nytimes.com)](nytimes.com).

problems, and many others, were anticipated by the disability community as soon as the first COVID diagnosis occurred in the United States. For the past eleven months our organizations and others have engaged in coordinated advocacy to ensure critical needs of disabled people, our families, and our service providers were addressed in coronavirus relief packages. Despite this great effort, our needs have been largely ignored by Congress. Further, while the coronavirus pandemic would pose significant challenges to any administration, many of the difficulties faced during COVID-19 have been caused by a lack of leadership and responsiveness of the previous administration when addressing the pandemic and the needs of disabled people. This pattern of behavior is not unique to the COVID-19 pandemic period, but rather reflective of the posture the Trump Administration often took for the past four years, during which the lives and rights of disabled people were all too frequently under attack. Our organizations have come together to submit a number of urgent recommendations to save lives, change the trends for COVID-19, and continue to advance civil rights and community integration for all.

1. Saving the Lives of Individuals with Disabilities during COVID-19

- **<u>Protecting the lives of people in institutional and congregate settings and transitioning people out of these settings</u>.** People with disabilities and older adults face a particularly high risk of contracting COVID-19 and of experiencing complications and death if exposed.[2] This risk has been elevated by the severe outbreaks in institutional and congregate settings across the country. There is an urgent need for a coordinated national strategy to ensure the safety of individuals in all institutional and congregate settings, including not just nursing homes but also intermediate care facilities for people with intellectual and developmental disabilities, psychiatric hospitals, assisted living facilities, board and care homes, and other congregate settings. The few regulations and guidance documents issued to date have largely focused on nursing homes, but an effective national COVID-19 strategy must address individuals in all types of congregate settings.

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[2] A recent study showed that people with intellectual disabilities and autism die at rates up to 2 to 2.5 times higher than the death rates of others who contract COVID-19, and that they contract the virus at a higher rate. Joseph Shapiro, “COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities,” *National Public Radio* (June 9, 2020; 5:00 AM), https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili. People with intellectual and developmental disabilities (IDD) experience a higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes. Margaret Turk, Scott Landes, Margaret Formica, and Katherine Goss, “Intellectual and Developmental Disability and COVID-19 Case-Fatality Trends: TriNetX Analysis,” *Disability and Health Journal* epub ahead of print (May 24, 2020), https://www.sciencedirect.com/science/article/pii/S1936657420300674.

An essential aspect of ensuring the safety of individuals in congregate settings is reducing the number of people admitted into and remaining in institutional and congregate settings. Despite the rampant outbreaks of COVID-19 in these settings, transitions to the community have slowed or stopped in most places due to challenges faced by community systems. A coordinated strategy involving HHS, HUD, FEMA, and DOJ is needed to help states transition and divert people with disabilities from these settings. Sufficiently reducing the census of these settings would afford many the opportunity to live in safer community settings and make physical distancing possible for those remaining in congregate settings. CMS must also end pandemic-related waivers of the PASRR screening and review process that prevents inappropriate admissions to nursing facilities. Finally, it is urgent that HHS support dedicated funding in the next COVID-19 relief package for home and community-based services (HCBS) to enable transition and diversion from congregate facilities. Such funding is necessary to address the new challenges community service systems face due to COVID-19 and to ensure that state budget shortfalls do not result in cuts to HCBS services precisely when those services are needed most.

- **Ensuring accessibility and equity in the distribution of coronavirus vaccines.** While speeding up distribution of COVID-19 vaccines is rightly a priority of the Biden-Harris Administration, it is critical that accessibility and equity issues not be overlooked. The success of vaccine distribution efforts requires that both the information and the means of distribution be accessible. Information regarding the vaccines should be provided in alternative formats including plain language, screen-reader accessible formats, and other alternative formats, in sign language and in non-English languages spoken in the US. Furthermore, vaccine sites must be accessible to disabled people. This means requiring states to make reasonable modifications to address the needs of people with disabilities, such as establishing mobile and home vaccination programs, providing no-cost transportation, ensuring that support personnel (such as interpreters and personal aides) for people with disabilities are also vaccinated, and ensuring physical and communication barriers do not exist either at or within vaccination sites. Lastly, to ensure accessibility, the vaccines must be widely available not only through regular sources of care and public health agencies, but also through non-traditional sources as necessary to reach underserved populations that face barriers in accessing care.

We urge you to consider the principles for vaccine allocation released by CCD in October 2020 in making decisions concerning vaccine distribution.[3] As states work through their vaccine prioritization, we also request that the Administration recognize the particular vulnerability of those people with disabilities who receive Medicaid home and community-based services, a majority of whom have multiple health conditions, many of whom are people of color, and who require assistance with activities of daily living which means they cannot isolate themselves.

- **Ensuring non-discrimination in health care delivery.** The COVID-19 pandemic led many states to either develop or update Crisis Standards of Care plans to address questions regarding the rationing of medical care in anticipation of potential shortages. Many of these plans explicitly exclude or deprioritize people with disabilities and older adults from life-saving treatment and use criteria that disproportionately harm Black, Indigenous, and people of color (BIPOC). The work HHS OCR has done thus far – issuing a March 28, 2020 bulletin that makes clear that disability rights laws apply during this public health emergency and working with several states to revise their crisis standards of care to comply with federal civil rights laws – has been critical to efforts to prevent discrimination in medical rationing. However, we believe that more must be done and that OCR should continue prioritizing its work in this area. It is critical that OCR issue additional guidance or emergency regulations providing more detail to covered entities about their legal obligations, to promptly resolve pending and new complaints, and to work with DOJ on litigation in instances where covered entities will not voluntarily engage in resolution.

  Further, we strongly support proceeding with the rulemaking process that has been initiated at HHS to address discrimination in HHS-funded programs and activities, including with respect to crisis standards of care, organ transplantation, health care value assessment methodologies (i.e. quality-adjusted life years and similar metrics), and other related topics. We encourage prioritization of those regulations, which would provide important safeguards against disability-based discrimination in health care services. For crisis standards of care, we urge HHS to issue guidance before regulations are finalized, due to the urgent need for such guidance as soon as possible while COVID-19 continues to spread.

- **Expanding Data Collection.** COVID-19 has highlighted the longstanding systemic inequities in our healthcare system for BIPOC, including people with disabilities, who have contracted COVID-19 and been hospitalized at higher

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[3] COVID-19 Vaccine Allocation Principles, Consortium for Citizens with Disabilities (Oct. 2020), available at http://www.c-c-d.org/fichiers/CCD-Vaccine-Allocation-Principles-October-2020.pdf.

rates.[4] We urge HHS to require the collection of data with stratification of reporting by key demographic groups, including disability status, age, sex, sexual orientation, gender identity, race, ethnicity, primary language, residential setting, and treatment setting. Having this data, and examining how the demographics intersect, will enable HHS to better identify compounding disparities in access to and quality of care, services and supports. This attention to data is desperately needed both immediately to ensure that the COVID-19 response is addressing the needs of the disability community and all people, and longer term to move forward on building more equitable systems for delivering health care and long-term services and supports.

- **Ensuring equity in access to HCBS**. As we advance our goals of increasing access to home and community based services for people with disabilities of all ages, we must ensure that equity is front and center. We know that inequities exist in access to and quality of HCBS that harm BIPOC. For example, we know residential facilities with Black and Latino/a residents are experiencing more COVID outbreaks and deaths compared to facilities whose residents are predominantly white. Therefore, both immediately and long-term, we are asking HHS to focus on helping people of color with disabilities to transition out of institutions to the community and, equally important, on developing targeted diversion strategies.

  However, much more work needs to be done to identify HCBS inequities and tangible solutions. We encourage CMS, ACL and OCR to work collaboratively to identify racial and other inequities in HCBS, with a particular focus on how poverty, English proficiency, gender and gender identity, and sexual orientation can compound racial and ethnic disparities for individuals with disabilities. We look forward to working together to develop strategies for addressing these inequities, including requiring states to develop equity plans for their HCBS programs, providing TA and funding for outreach to communities of color and the providers that serve them, and collaborating with the U.S. Department of Housing and Urban Development (HUD) regarding targeting affordable, integrated, accessible housing to people transitioning from, or at risk of entering, institutions.

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[4] See, e.g., Kaiser Family Foundation "Racial Disparities in COVID-19: Key Findings from Available Data and Analysis" (Aug. 17, 2020), available at https://www.kff.org/racial-equity-and-health-policy/issue-brief/racialdisparities-covid-19-key-findings-available-data-analysis/.

2. Reversing Harmful Healthcare-related Policies

- **The Affordable Care Act.** Administrative changes designed to undermine access to comprehensive, affordable health coverage accelerated during the last four years. The ACA has largely weathered these attacks and has never been more popular. We recommend several urgent actions to rebuild the ACA's foundation and strengthen access to coverage for all U.S. residents, including millions of people with disabilities.

  First, we urge you to reverse the prior administration's policies that undermined access to Marketplace coverage. For example, in 2018, CMS extended the definition of short-term, limited-duration health plans from 3 to 12 months. These limited coverage plans, which need not comply with key ACA protections, divert people from comprehensive Marketplace coverage and expose them to serious financial and health risks. A Congressional inquiry found that these plans added over 600,000 new enrollees -- a 27% increase -- in the year after the change was finalized. The CBO projected the change would also increase premiums for full Marketplace coverage. Reversing this rule, and the related rule on association health plans, would strengthen access to comprehensive coverage for people with disabilities.

  We also encourage you to bolster access to Marketplace navigators and other resources that help inform consumers about Marketplace coverage and how to select the best plans for their needs. The prior administration slashed navigator funding and offered guidance reinterpreting section 1332 of the ACA to allow states to effectively eliminate the principal of a one-stop web-based Marketplace for health insurance. One of the last acts of the prior administration was to codify this guidance into regulations. We ask that the new administration take advantage of the regulatory freeze to reverse this rule, which we believe is inconsistent with the statute, and revoke approval for Georgia's 1332 waiver, which allows the state to effectively eliminate its Marketplace. The new administration should reestablish clear regulations that reinforce all the statutory guardrails for 1332 waivers in the spirit of the ACA's vision of expanding access to universal, comprehensive, affordable coverage.

  The Trump administration also weakened the ACA's Essential Health Benefits regulations by creating a race to the bottom for state EHBs and by allowing more substitutions, among other things. We urge HHS to not only reverse these changes, but to strengthen the federal role in defining EHBs, particularly in the categories most crucial for people with disabilities, such as prescription drug coverage, mental health, and rehabilitative and habilitative services.

Finally, we urge HHS to rapidly reverse the prior administration's weakening of civil rights protections. The 2020 regulations implementing Section 1557 of the ACA rewrote a long-standing interpretation of sex stereotyping, excluding LGBTQ+ individuals from protection. While several courts have already found that part of the rule inconsistent with the Supreme Court's ruling in *Bostock v. Clayton County* and enjoined it, other parts of the Section 1557 final rule remain in place. This includes provisions drastically limiting the ability to challenge discrimination in health benefit design and removing the notice, tagline, and effective communication requirements that help people with disabilities and people with limited English Proficiency access health and due process information. Swift action to restore and strengthen these ACA protections through rulemaking will signal the new administration's commitment to equity and civil rights.

- **Medicaid.** For four years, the Trump administration pursued administrative avenues to make it harder for people to access and maintain Medicaid coverage. These administrative approaches, many of which center on Section 1115 authority, have caused substantial harm to low-income individuals and families. For example, in Arkansas, over 18,000 adults lost Medicaid after the State temporarily implemented a CMS-approved work requirement in its expansion program.

  Lower courts vacated the Section 1115 waiver approvals that allowed Arkansas and New Hampshire to impose work requirements, but the Supreme Court took up those cases in the fall. The government's opening brief is due on Jan. 19. The Biden administration must make clear immediately that it will no longer allow states to impose work requirements or other inappropriate uses of 1115. Immediate steps should include:

    - Rescinding the 2018 guidance letter that announced the new policy allowing states to impose work requirements
    - Denying all pending 1115 applications to implement work requirements, including those from AR and NH
    - Initiating the process of terminating work requirement waivers in states with approved waivers;

  - Informing DOJ that HHS has changed its position on work requirements, no longer wishes to defend the previously issued approvals, and does not want the Supreme Court to issue a decision on the merits.

We also ask that the administration rescind the harmful 2020 CMS guidance that encouraged states to apply for Medicaid block grants and inform Tennessee that its recent aggregate cap approval will be withdrawn. In addition, as noted below in Section 3, we ask that the administration rescind CMS guidance documents concerning Section 1115 waivers permitting coverage of services for individuals in mental health and substance use "institutions for mental diseases" (IMDs) and stop approving new IMD waivers.

Another pressing action is to pull back the Trump administration's recent reinterpretation of the COVID Maintenance of Effort requirement that protects eligibility and access to services for Medicaid enrollees during the public health emergency. This reinterpretation, which allows states to cut Medicaid services and still receive an enhanced federal match, is not consistent with the Families First statute and may lead to serious access barriers for people with disabilities as state legislatures begin their sessions this month looking to resolve budget shortfalls with Medicaid cuts.

- **Public charge rule.** We support your ongoing efforts to address the Trump administration's harmful regulation redefining what it means to be a public charge. Disability organizations filed amicus briefs in numerous court cases challenging the rule, including the litigation you brought as California's attorney general. Though numerous courts found that the public charge rule violates Section 504, the rule remains in effect. In addition to encouraging your swift action to revamp this rule, we ask that any new rulemaking not simply return to the inadequate 1999 guidance in place prior to the Trump administration's rule. Rather, it must better align with the principles of *Olmstead*. We ask you to involve numerous HHS entities, including CMS, ACL, and DOJ Civil Rights Division, to give their input on fixing the public charge rule.

3. Community Inclusion and Disability Rights

- **Strengthening Enforcement and Implementation of the HCBS Settings Rule**. The HCBS Settings Rule, finalized by the Obama administration in 2014, was originally slated for implementation in 2019. The effective date is now 2023. Medicaid pays for long-term services and supports for people with disabilities in both institutions and in the community; this regulation was designed to clearly define the differences between Medicaid institutional services and Home and Community-Based Services (HCBS). Prior to the rule, states and service providers often received funding for HCBS waivers but provided those services only in group homes, sheltered workshops, and other congregate settings with heavily institutional characteristics. As a result, people with disabilities who preferred to receive HCBS would either leave institutions or spend years on waiting lists, only to receive services that were theoretically in the community but in reality were virtually identical to the institutional services they had already opted out of. These quasi-institutional settings received payments not from Medicaid's existing funding stream for institutional services, but from the much more limited pot of Medicaid HCBS waiver dollars. The Settings Rule establishes basic standards to address that problem and ensure that services receiving HCBS funding are genuinely HCBS.

But the Trump Administration has in many ways abandoned the Rule, undermining implementation, issuing guidance to weaken the Rule, and postponing the effective date until 2023. Given the way COVID-19 has devastated congregate settings for people with disabilities, HHS’s investment in the Settings Rule is more important than ever before. We request HHS act swiftly to put real resources, priority, and urgency towards this Rule and work with states to make sure they are ready for full implementation in 2023. People with disabilities, service providers, and state systems all regard this as an urgent priority, but it will take strong federal leadership to ensure that the rule is fully implemented and that people with disabilities receiving HCBS are truly integrated into their communities, have real alternatives to congregate settings, and receive good quality services.

- **Delaying Electronic Visit Verification Enforcement and Implementation**. In contrast, we urge you to ensure that the Centers for Medicare and Medicaid Services (CMS) delays the implementation of electronic visit verification (EVV) requirements set forth in the 20th Century Cures Act until after the COVID-19 pandemic ends. States will begin facing penalties for non-compliance with these requirements beginning on January 1, 2021. These penalties could not come at a more dangerous time, when state Medicaid systems need more – not less – resources to help people receiving services stay safe during the COVID-19 pandemic. The pandemic has significantly interfered with state capacity to implement the new system required by the Cures Act. While we understand the impetus for quality control that prompted the EVV requirements, focusing on their implementation during this time – and financially penalizing states that have had to redirect efforts away from EVV implementation during the pandemic -- would take away vital staff time and resources from ensuring the health and survival of people with disabilities during this pandemic. Moreover, the pandemic's effect on the economy has strained state resources, and further impacting states' Medicaid Home and Community-Based Services (HCBS) budgets by assessing these penalties will harm the people who rely on these services. Therefore, we strongly recommend that EVV implementation and enforcement be delayed to the maximum extent possible. Following this delay, HHS and CMS leadership should meet with representatives from the disability community to discuss concerns relating to privacy and EVV implementation more broadly, and identify best practices for states.

- **Aligning HHS Mental Health Policy with the Justice Department's Civil Rights Enforcement for People with Psychiatric Disabilities**. The Trump Administration shifted the focus of SAMHSA and CMS away from the longstanding commitment to promoting expansion of proven community-based, recovery-oriented services such as supported housing, mobile crisis, supported employment, peer support, intensive case management, and coordinated mobile teams. It instead focused a great deal of effort on promoting the expansion of institutional care and involuntary treatment. The Biden Administration must refocus mental health policy on addressing the dramatic gaps in voluntary, community-based mental health services across the country. Expanding these services, which prevent institutionalization and incarceration and enable timely discharges from institutions, would reduce the need for institutional beds, afford individuals better lives, promote compliance with the Americans with Disabilities Act and the *Olmstead* decision, and align HHS mental health policy with the Justice Department's civil rights enforcement efforts seeking to expand these services and end overreliance on institutional care.

  In particular, CMS encouraged states to apply for waivers of Medicaid's "institutions for mental diseases" rule while giving short shrift to expansion of the community services needed to prevent institutionalization and to discharge individuals from institutions in a timely manner. CMS's guidance encouraging these waivers is inconsistent with the Medicaid demonstration waiver authority. Moreover, these waivers have exacerbated overreliance on institutional care at the expense of community services, undermining compliance with *Olmstead* and the Justice Department's efforts to enforce it. CMS' guidance documents on this issue should be rescinded and no new demonstration waivers granted for services in IMDs.

In addition, SAMHSA should discontinue its efforts to promote the expansion of involuntary outpatient commitment (sometimes labelled “assisted outpatient treatment”), when studies have consistently shown that court orders have no impact on outpatient treatment outcomes. Finally, the Office for Civil Rights should withdraw its proposed rule to weaken HIPAA privacy protections with specific emphasis on people with serious mental illness and substance use disorders. The proposed rule is unnecessary and would undermine the effectiveness of treatment by discouraging individuals from speaking candidly to mental health professionals.

The Biden HHS should also encourage and provide help to state and local governments to implement strategies for diverting calls to 911 and police to mental health responders where appropriate, with the goals of linking individuals with voluntary community-based services and avoiding needless arrest and incarceration as well as tragic deaths. These services must also meet the needs of communities of color. Further, HHS should assist states with strategies to permit Medicaid payments for community service providers engaging incarcerated individuals to ensure successful reentry into the community. These steps are important elements of efforts to address the racism in our mental health and criminal justice systems resulting in the vast over-representation of people of color in police encounters and in jails and prisons. Finally, the Administration must also make the concerns and voices of those individuals who receive mental health services central to Administration policy. Their perspectives were largely dismissed during the past Administration.

- **Increasing the focus of the Administration for Community Living on people with disabilities**. The Administration for Community Living (ACL) was created by the Obama administration with the primary charge of advocating for community living for people with disabilities and older adults across the federal government. A major focus of the Obama-era ACL was on building bridges between the aging and disability communities and ensuring that the two administrations housed within ACL held shared goals and could work together smoothly. Unfortunately, the Trump administration has replaced that approach with a single-minded focus on aging and older adults, to the near-total exclusion of people with disabilities. A prime example of this has been ACL’s work regarding COVID-19; while ACL advocated vigorously with the Secretary to put in place protections for older adults living in nursing facilities, no such efforts took place to advocate for people with disabilities in other, equally deadly congregate settings, despite repeated urging from stakeholders. ACL should act immediately to rectify this dangerous error; more broadly, it should take concrete steps to ensure it is equally prioritizing both the disability and aging communities in all aspects of its work, particularly given the wide overlap between the two. ACL underwent a reorganization under the Trump Administration which demoted all of the disability programs and elevated the aging programs; this reorganization should be dismantled and these programs should be brought to parity. It is imperative that ACL return to the core of its mission: aggressively promoting community living for all people with disabilities, of all ages, including those with the most significant disabilities. The leadership of ACL should meet with leading disability organizations in the first 100 days to discuss a new vision and more equitable structure for ACL.

- **Working with Congress on legislation to strengthen HCBS and its workforce and addressing Medicaid's institutional bias**. Longer term, there remains much work to be done to increase access to HCBS, strengthen the direct care workforce, and address Medicaid's institutional bias. The Biden Administration should support legislative strategies to increase parity among states, address direct care worker wages, eliminate the institutional bias and address the waiting list for these services. In addition to federal legislation, there remains a major need for HHS leadership on these issues, with over 90% of aging adults wanting to age in place, people with disabilities spending years on waiting lists for HCBS, and the warehousing of people with disabilities in institutions or other large congregate settings still prevalent. We urge the Secretary to meet with disability rights organizations within the first 100 days to discuss potential steps HHS could take to address this crisis, regardless of Congressional action.

- **Ensuring access to rehabilitation services, mobility devices and assistive technologies.** Finally, the ability of people with disabilities to live independently in the community requires access to appropriate rehabilitation services and access to mobility devices and assistive technologies under Medicare, Medicaid and private payers. We urge you to ensure that both COVID-19 survivors and non-COVID individuals with disabilities and chronic conditions have access to the rehabilitation services that meet their needs. We also urge you to approve the pending Medicare National Coverage Determination (NCD) Request for Reconsideration of seat elevation and standing systems in power wheelchairs to enhance the ability of people with mobility impairments to fully function and live independently.

Our organizations appreciated the opportunity to speak with you about these recommendations and the further opportunity to provide follow-up documentation. Given your work in Congress, your work in the California state government, including your recent leadership creating a Disability Bureau in the California Department of Justice, we look forward to your confirmation as Secretary of Health and Human Services. We look forward to regular and continued engagement from all agencies within HHS in order to work together to save the lives of people with disabilities, reverse harmful healthcare related policies, and to advance community inclusion and disability rights will not only benefit the disability community but will benefit all Americans.

Sincerely,

American Association of People with Disabilities
ANCOR
The Arc of the United States
Association of University Centers on Disability
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
Justice in Aging
Little Lobbyists
National Association of the Deaf
National Association of State Directors of Developmental Disabilities Services
National Council on Independent Living
National Disability Rights Network
New York Association of Psychiatric Rehabilitation Services, Inc.
Partnership for Improved Patient Care
Partnership for Inclusive Disaster Strategies
United Spinal Association