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Office of the Assistant Secretary for Planning and Evaluation  
Strategic Planning Team  
Department of Health and Human Services  
200 Independence Ave. S.W.  
Room 415F  
Washington, D.C. 20201

**VIA ELECTRONIC MAIL – [HHSPlan@hhs.gov](mailto:HHSPlan@hhs.gov)**

**Attn: Strategic Plan Comments**

Thank you for the opportunity to comment in response to the draft HHS strategic plan for FY 2018 to 2022. The National Disability Rights Network (hereinafter “NDRN”) is the non-profit membership association of Protection and Advocacy (P&A) agencies that are located in all 50 States, the District of Columbia, Puerto Rico, and the United States Territories. There is also a P&A affiliated with the Native American Consortium which includes the Hopi, Navajo and San Juan Southern Paiute Nations in the Four Corners region of the Southwest. P&A agencies are authorized under various federal statutes to provide legal representation and related advocacy services, and to investigate abuse and neglect of individuals with disabilities in a variety of settings. The P&A Network comprises the nation’s largest provider of legally-based advocacy services for persons with disabilities.

The HHS strategic plan will have powerful implications for individuals with disabilities. We are pleased to see that the plan recognizes the importance of community integration, person centered and directed services, supported housing and employment, school inclusion, protection from abuse and neglect, and the need to end discrimination on the basis of disability.

As an overarching comment we encourage HHS to continue strong enforcement of the 2014 Home and Community Based Services (HCBS) settings rule, including the high standards for assuring that no presumptively institutional setting receives Secretary approval unless all elements of the rule are met for every individual in the setting. As more and more people have chosen to live in the community rather than in institutions over the last several decades, state HCBS systems have greatly expanded. The HCBS Settings Rule reflects the best practices that states have developed and the services they are working to expand.

The Rule ensures the accountability of HCBS dollars. Prior to the Rule establishing minimum standards, federal Medicaid dollars earmarked for HCBS frequently went to settings that were virtually indistinguishable from institutions (even though institutional settings are eligible for their own separate funding streams). The Rule is flexible to allow various types of settings that meet minimum standards. It neither sets size limits for settings nor prohibits disability-specific settings (like group homes). Instead any HCBS setting must satisfy basic standards and protections around autonomy, access to food and visitors, and opportunities to engage with the broader community. As a product of thousands of public comments reflecting a wide range of perspectives gathered over more than five years of a robust rulemaking process, the Rule is another important step in the movement towards full inclusion of people with disabilities, consistent with bipartisan federal laws like the Americans with Disabilities Act.

We further applaud, HHS' commitment to protecting individual rights and addressing abuse and neglect. Since P&A agencies are authorized under numerous federal statutes to protect people with the whole range of disabilities from abuse and neglect, we are acutely aware that these protections must be available in all settings where individuals with disabilities receive services. We urge HHS to clarify its commitment to protecting individual rights and addressing abuse and neglect in all settings where individuals with disabilities receive services, not just in traditional health care settings.

We equally applaud HHS' commitment to *“improving access to recovery support for people with serious mental illness and substance use disorders through [financing of]peer-based supports and services], broad adoption of evidence-based supported housing, supported employment, and supported education programs and [E]nsur[ing] that individual rights are protected including addressing abuse and neglect, parity, Olmstead, Americans with Disabilities Act, and other protections.”* HHS has a vital role in strengthening and developing high-performing long-term services and supports systems that promote competitive integrated employment, scattered site individualized housing, and person-centered and directed services in the most integrated settings appropriate, as required by the U.S. Supreme Court in the *Olmstead v. L.C.* decision.

Our final general comment is that federal and state Medicaid funding for community-based supports and services is quite limited and the majority of states have long waiting lists for access to these programs. We urge HHS not to allow limited Medicaid funds for community services to be given to programs that restrict activities and services beyond what federal and state law require. This document contains several “strategies” that will remove barriers to use of programs with religious beliefs or moral convictions. This causes us concern because some provider organizations with religious beliefs or moral convictions institute rules in their programs that restrict access to otherwise lawful activities that an individual with a disability might chose to engage. For example, a

religious-based group home operator may have a rule that an individual cannot have a guest of the opposite sex in their bedroom or cannot have alcohol on the premise. Such rules are incompatible with consumer choice and empowerment and serve to further limit choice of services that are already too slim.

Below are our comments and recommendations to clarify and strengthen HHS' strategies in these and other areas of importance to people with disabilities.

**151: Support availability of preventive health services such as screenings, immunizations, and vaccinations by healthcare providers and community partners**

- We encourage HHS to continue to provide education and information about the Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) program to state Medicaid agencies, medical providers, parents and family members, and to fully enforce its requirements. EPSDT is a highly effective and cost efficient preventative health care program. EPSDT is critical for the millions of children with special health care needs and disabilities who depend on Medicaid for their health care and long-term services and supports.

Unfortunately, our members, the P&As, find that State Medicaid agencies do not always have effective procedures for informing all Medicaid-eligible persons in the state who are under age 21 of the availability of EPSDT. This includes effectively informing families and children with disabilities and providing appointment scheduling and transportation assistance (as required by 42 C.F.R. § 441.56).

**162-163: Build out and broaden models that allow beneficiaries the option of controlling more of their healthcare dollars.**

- This goal is of importance to people with disabilities. We encourage continued HHS support of Medicaid programs that allow for consumer-directed options.

**184-185: Modify payments to achieve greater site neutrality and facilitate appropriate settings, including community settings, of care at a lower cost**

- We encourage HHS support for payment incentives for community based services and supports for individuals with disabilities rather than institutionalization. Decades of research has documented that when people with disabilities and seniors live in integrated community settings their overall quality of life is assessed to be better than when they live in institutions<sup>1</sup>. Research also finds that Community-based services for people with disabilities cost less and is

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<sup>1</sup> Kim, Larson, and Larkin, [Behavioral outcomes of deinstitutionalization for people with intellectual disabilities: A review of studies conducted between 1980 and 1999.](#) Policy Research Brief, University of Minnesota, Institute on Community Integration (1999).

more cost efficient than institutional care. <sup>2</sup> For example, the National Council on Disability, published a study looking at costs and found that in 2009, the average annual expenditure for state institutions was \$188,318 dollars, compared to an average of \$ 42,486 for Medicaid-funded HCBS. The study found that even when taking into account the complex factors that accompany transition from institutions to community settings, the states they studied (Kansas, Maryland and Massachusetts) still saved money by closing institutions<sup>3</sup>.

**199-201: Partner with states, community organizations, and the private and nonprofit sectors to educate Americans about their health insurance coverage options and how they can identify the best plan for themselves, and to provide information on how Americans can access and use their benefits**

- We encourage renewed and expanded federal support for the marketplace navigator and assister programs. These programs were essential for people with disabilities who often have cognitive or language barriers that can make understanding enrollment options and enrolling in Medicaid or marketplace programs more difficult.

**220: Improve patient safety and prevent adverse events such as healthcare-associated infections and medication harms across the healthcare system.**

We appreciate HHS' recognition of the need to improve the use of public health and health care data. We suggest that HHS also specifically mention the need to include the **collection** of health and health care data. We can only use the data that actually is collected and currently, demographic data is often not collected universally or pursuant to standardized categories. We urge HHS to include a bullet addressing the collection of health and health care data as follows:

- ***Improve collection of health and health care data by race, ethnicity, language, sex, gender identity, sexual orientation, age and disability. Race, disability and ethnicity data should be disaggregated. Health and health care data should be collected pursuant to recommendations made by the Institutes of Medicine.***

**242-243: Develop new payment and service delivery models that speed the adoption of best practices.**

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<sup>2</sup> *The Costs of Deinstitutionalization*, National Council on Disability (NCD) available at: <https://www.ncd.gov/publications/2012/DIToolkit/Costs/inDetail>. (December 2012).

<sup>3</sup> *The Costs of Deinstitutionalization*, "costs in detail" section.

- We encourage HHS support for payment incentives for community based services and supports for individuals with disabilities rather than institutionalization, as required by the U.S. Supreme Court in the 1999 *Olmstead v L.C. and E.W.* decision. Decades of research has documented that when people with disabilities and seniors live in integrated community settings their overall quality of life is assessed to be better than when they live in institutions<sup>4</sup>. Research also finds that Community-based services for people with disabilities cost less and is more cost efficient than institutional care. <sup>5</sup>

#### **249: Expand opportunities for Medicare and Medicaid alternative payment models to incentivize value-based care options**

- We recommend that if HHS uses financial incentives, those incentives should be focused on improving outcomes and not to reducing costs. While we support innovations to promote the provision of high-quality care, it has been our experience that alternative payment models can be implemented in such a way that they create incentives to stint on needed care or avoid costlier patients. People with disabilities are at especially high risk of harm from these incentives.

Tying incentives to cost-reduction incentivizes the reduction of all care, including *needed* care. Finally, new models of care also must not abrogate the existing protections for enrollees such as requirements for due process, reasonable promptness, amount/duration/scope, etc. That is, any alternative payment model must still abide by the existing requirements of Medicaid and Medicare without unduly restricting beneficiaries' access to guaranteed services and protections.

We appreciate HHS' recognition that preventive services should be available in community-based settings. We believe additional services should also be available in community based settings, particularly home and community based services (HCBS) provided through Medicaid. We thus recommend amending the relevant bullet as follows:

251: Help beneficiaries access ~~preventive~~ **all** care in community-based settings, while encouraging innovation and competition through use of performance-based payment.

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<sup>4</sup> Kim, Larson, and Larkin, [Behavioral outcomes of deinstitutionalization for people with intellectual disabilities: A review of studies conducted between 1980 and 1999](#). *Policy Research Brief*, University of Minnesota, Institute on Community Integration (1999).

<sup>5</sup> *The Costs of Deinstitutionalization*, National Council on Disability (NCD) available at: <https://www.ncd.gov/publications/2012/DIToolkit/Costs/inDetail>. (December 2012).

**273-274: Implement a collaborative model of behavioral health and primary care, that is team-driven, population-focused, measurement-guided, and evidence-based.**

- HHS should ensure that collaborative approaches are coupled with an explicit commitment to expanding and integrating essential community-based behavioral health support services. Essential community-based services include, but are not limited to, Peer Support Services, Assertive Community Treatment, Mobile Crisis Intervention, and various other intensive community-based services.

We recommend the following changes in light of these comments:

- Line 273-274: Implement a collaborative model, **integrating** behavioral health, primary care, and **community-based support services**, that is team-driven, population-focused, **person-centered**, measurement-guided, and evidence-based.

**294: Increase available information in cultural- and health literacy-appropriate levels, and in alternate formats, — such as in languages other than English, to improve access to health information.**

- We recommend that to the extent HHS recognizes the need for providing materials in non-English languages that it also recognize the need for providing materials in formats that will be accessible to individuals with disabilities who have communication needs. This would include large print format and audio or video recordings for those who cannot access written materials. We recommend amending the relevant bullet as follows:

Line 294: Increase available information in cultural- and health literacy-appropriate levels, and in alternate formats, — such as in languages other than English, **large print, or audio and video versions** — to improve access to health information

**353: Design healthcare options that are responsive to consumer demands, while removing barriers for faith-based and other community-based providers.**

We are concerned that this section fails to mention other federal civil rights laws and Executive Orders which are relevant to providing healthcare options that are responsive to consumer demands. These include Executive Order 13166, Title VI of the Civil

Rights Act of 1964, Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, the Age Discrimination Act, and Section 1557 of the Affordable Care Act. All of these laws must be fully implemented and enforced by HHS to ensure that HHS' programs and activities, and those it supports with federal funds, are responsive to consumer demands. We thus recommend adding the following bullet:

- ***Vigorously enforce laws, regulations and other authorities, especially Title VI of the Civil Rights Act of 1964, Executive Order 13166, Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, the Age Discrimination Act, and Section 1557 of the Affordable Care Act***
- **We also recommend editing line 353 as follows:** Design healthcare options that are responsive to consumer demands, while removing barriers for faith-based and other community-based providers, **as long as these organizations and providers put no rules in place that are more restrictive than otherwise required by state and federal law.**

Federal and state Medicaid funding for community-based supports and services are quite limited and the majority of states have long waiting lists for these programs. We urge HHS not to allow limited federal funds be given to a program that restricts lawful activities.

It has been our experience that some provider organizations with religious beliefs or moral convictions institute rules in their community-based settings or programs that restrict access to otherwise lawful activities that an individual with a disability might chose to engage. For example, a religious-based group home operator may have a rule that an individual cannot have a guest of the opposite sex in their bedroom or cannot have alcohol on the premise. For an adult with a disability having someone of the opposite sex in their room or drinking alcohol on the premise would be lawful, but for the group home operator rules.

#### **Objective 1.4: Strengthen and expand the healthcare workforce to meet America's diverse needs**

- We strongly support this objective and all of the strategies mentioned in this section, except we recommend changing lines 435-436, as recommended below:

435-436: "Remove ~~any~~ barriers to, and promote, full participation in the health care workforce persons and/or organizations with religious beliefs or moral convictions

Or

435-436: "Remove ~~any~~ barriers to, and promote, full participation in the health care workforce persons and/or organizations with religious beliefs or moral

convictions **as long as these persons and/or organizations put no rules in place that are more restrictive than otherwise required by state and federal law.**

Federal and state Medicaid funding for community-based supports and services are quite limited and the majority of states have long waiting lists for these programs. We urge HHS not to allow limited federal funds be given to a program that restricts lawful activities.

It has been our experience that some provider organizations with religious beliefs or moral convictions institute rules in their community-based settings or programs that restrict access to otherwise lawful activities that an individual with a disability might chose to engage. For example, a religious-based group home operator may have a rule that an individual cannot have a guest of the opposite sex in their bedroom or cannot have alcohol on the premise. For an adult with a disability having someone of the opposite sex in their room or drinking alcohol on the premise would be lawful, but for the group home operator rules.

**497: Encourage providers to communicate effectively with patients, families, and caregivers by offering tools and resources to assist discussions centered around care and healthier living**

- We support the information in this section but recommend that HHS include additional information about legal requirements regarding effective communication. The third bullet (line 497) **encourages** providers to communicate effectively with patients, family and caregivers (emphasis added). However, a number of civil rights statutes – including Title VI of the Civil Rights Act, Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act – provide actual requirements for effective communication. It should be part of HHS’ plan to ensure that providers subject to these laws do more than “encourage” effective communication. We thus recommend rewriting that bullet as follows:

497: ~~Encourage~~ **Ensure** providers **comply with federal civil rights requirements** to communicate effectively with patients, families, and caregivers by offering tools and resources to assist discussions centered around care and healthier living.

**507: Partner with private organizations, including faith-based and community organizations, to develop and implement programs that enable people to make healthy life choices**

- We recommend the following edits:

Partner with private organizations, including faith-based and community organizations, to develop and implement programs that enable people to make ***individually elected*** healthy life choices

**542: Support patient, consumer, and caregiver involvement in care planning, to ensure that care is person-centered, responding to the needs and wishes of those being serviced, including their religious or conscience needs and wishes.**

- We support the goal of patient, consumer, and caregiver involvement in care planning and urge HHS to include support for advance directive for behavioral health care as part of this strategy. When individuals are in a mental health crisis it is hard for them to be fully involved in the care planning process, mental health advance directives support HHS's goal of consumer involvement in the planning process by enabling their wishes to be heard even in a type of health crisis.

We also encourage HHS to include education of guardians with medical decision making power to be part of this strategy. Guardians often have no or very little information about the importance, value, and sometimes right, of the patient or consumer to be involved in the care planning process. Medical professionals also often lack information about the authority of the guardian to make health care related decisions for the patient or consumer. This can easily lead to physicians allowing guardians, who may not have the authority to make health care decisions on behalf of the patient, inappropriately giving the guardian the exclusive right to decide the care plan.

We recommend the following edits:

Support patient, consumer, and caregiver involvement in care planning, ***including, provision of information about guardians and health care decision making and use of advance health care directives and advance directives for behavioral health care***, to ensure that care is provided in a **non-discriminatory, person-centered manner, and responds** responding to ***all*** the needs and wishes of those being served., ~~including their religious or conscience needs and wishes.~~

**609: Expand the peer provider workforce by working with states to increase the training, certification, financing, and supervision of peers.**

- We recommend the following edits:

Expand ***and improve the quality and effectiveness of*** the peer provider workforce by working with states to increase the training, certification, financing, and supervision of peers.

**694: Engage individuals and communities, including through faith-based and community organizations, to provide social and community recovery support**

- We recommend the following edits:

Engage individuals and communities, including through faith-based, ***harm reduction,*** and community organizations, to provide ***evidence-based, non-judgmental*** social and community recovery support

**654: Expand prevention, screening, and early identification of serious mental illness and substance use disorders. And**

**658: Educate and empower individuals and communities, including through partnerships with faith-based and community organizations, to recognize the signs of serious mental illness and substance use disorders, to encourage screening and identification of such problems.**

- We support strategies 654 and 658 with the following edits:

Educate and empower individuals and communities, including through partnerships with faith-based and community organizations, to recognize the signs of serious mental illness and substance use disorders, to encourage screening and identification of such problems, ***and to ensure that individuals who are screened and/or identified are promptly referred to available, accessible community-based services and supports to address identified needs, without limitation based upon the provider or organizations religious or moral beliefs.***

**664-665: Promote healthy development, including social and emotional development, in young children to avoid behavioral problems and promote school readiness and learning.**

- We strongly support this goal and appreciate HHS recognition of the connection between health and school readiness and learning. We recommend this strategy be edited, as follows:

Promote healthy development, including social and emotional development in young children, **and community-wide initiatives to reduce exposure to trauma and adverse childhood experiences**, to avoid behavioral problems and promote school readiness, learning, and **long-term behavioral health**.

**692-693: Support broad adoption of evidence-based supported housing, supported employment, and supported education programs.**

- We support this strategy and its recognition of the preference for community-based services and supports that the majority of people with disabilities have made clear they want for decades. HHS has a crucial role in enhancing these programs. This HHS strategy can be made even more effective by promoting all forms of competitive integrated employment, community integrated housing, and making clear HHS support for inclusive education. We urge it be edited as follows:

692-693: Support broad adoption of ~~evidence-based~~ supported **community-based** housing, supported **competitive, community-based** employment, **mobile crisis services, assertive community treatment**, and supported, **inclusive** education programs, **and specialty children's services such as intensive home based services, intensive care coordination and therapeutic foster care**.

**696-697: Ensure that individual rights are protected including addressing abuse and neglect parity, Olmstead, Americans with Disabilities Act, and other protections.**

- NDRN strongly supports this goal and HHS' commitment to protecting individual rights, preventing abuse and neglect, and enforcing the ADA, the ADA integration mandate, and other protections. As part of this HHS commitment to enforcing the ADA and the Olmstead decision, we urge HHS to continue strong enforcement of the 2014 HCBS settings rule. The rule helps states comply with the ADA integration mandate.

We urge HHS to continue the high standards for assuring that no presumptively institutional setting receives Secretary approval unless all elements of the rule are met for every individual in the setting. As more and more people have chosen to live in the community rather than in institutions over the last several decades, state HCBS systems have greatly expanded. The HCBS Settings Rule reflects the best practices that states have developed and the services they are working to expand.

The Rule ensures the accountability of HCBS dollars. Prior to the Rule establishing minimum standards, federal Medicaid dollars earmarked for HCBS frequently went to settings that were virtually indistinguishable from institutions (even though institutional settings are eligible for their own separate funding streams). The Rule is flexible to allow various types of settings that meet minimum standards. It neither sets size limits for settings nor prohibits disability-specific settings (like group homes). Instead any HCBS setting must satisfy basic standards and protections around autonomy, access to food and visitors, and opportunities to engage with the broader community. As a product of thousands of public comments reflecting a wide range of perspectives gathered over more than five years of a robust rulemaking process, the Rule is another important step in the movement towards full inclusion of people with disabilities, consistent with Olmstead decision.

We also recommend that HHS explicitly state its commitment to compliance with and, if appropriate, enforcement of section 504 of the Rehabilitation Act and section 1557 of the Affordable Care Act, by naming them specifically.

Additionally, we recommend that HHS to make clear that its programs are committed to addressing abuse and neglect in all settings where individuals with disabilities receive services, not just in traditional health care settings. For example, our members, the nationwide network of P&A agencies, established by federal law and administered through ACL, AIDD and SAMHSA to monitor, investigate, and advocate to prevent abuse and neglect of individuals with disabilities, are permitted access to a broad swath of facilities, including juvenile detention facilities, foster care, homeless shelters, and jails and prisons, for the purposes of addressing abuse, neglect and rights violations. HHS' strategies should ensure HHS' commitment to protecting the rights of individuals is employed in all settings where individuals with disabilities are present.

We recommend the following edits:

696-697: Ensure that individual rights are protected including addressing abuse and neglect ***in facilities and programs that render care, supports, or services to individuals with disabilities; mental health parity, access to services and supports in the most integrated setting as required by Olmstead's integration mandate, the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act,*** and other protections.

**708-709: Promote the health and independence of older adults with or at risk for behavioral health conditions (i.e., mental illness, substance use disorders, suicide) through improved collaboration with federal and non-federal stakeholders.**

- We support this goal and recommend the following edits:

Promote the health and independence of older adults with or at risk for behavioral health conditions (i.e., mental illness, substance use disorders, suicide) through improved collaboration with federal and non-federal stakeholders ***and through increasing access to and availability of home and community-based long-term supports and services that provide full support to allow individuals to live and fully participate in integrated settings.***

**718: Improve adoption and continued refinement of evidence-based practices for mental illness, medication assisted treatment for opioid use disorder, and effective use of psychotherapy and antidepressant medication for depression.**

- We recommend the following edits:

Improve adoption and continued refinement of ~~selected~~ evidence-based practices for ~~serious~~ mental illness, medication assisted treatment for opioid use disorder, and effective use of psychotherapy and antidepressant medication for depression

**762-766: Provide expertise and tools to state and local governments, health systems and facilities, and other organizations, including faith-based and community organizations, to strengthen their capabilities to provide continuous, safe, and effective health care, public health services, and/or social services during emergencies and through the recovery period, including when such care**

**or services may need to be delivered in alternate settings or by alternate mechanisms.**

and

**786-788: Ensure that the needs of disadvantaged and at-risk populations are met in emergencies, through effective integration of traditionally underserved populations into planning, response, and recovery efforts.**

- Protection from abuse and neglect must be built into emergency planning. People with disabilities and older adults too often bear the brunt of poor disaster planning, and may need additional assistance to safely survive emergencies. For example, when Hurricane Irma was approaching Florida, officials announced their intent to use mental health commitment laws to involuntarily hold homeless individuals in psychiatric hospitals until the storm passed. While all individuals should be able to seek shelter, use of force is not the solution, particularly when serving the needs of individuals with psychiatric disabilities. Instead, we hope that HHS prioritizes strategies involving incorporating the input of people with psychiatric disabilities in the long-term planning for natural disaster evacuation efforts, maximizing communication via trusted channels and institutions, and offering low-barrier shelters to assist with evacuation.

We recommend the following changes to incorporate these considerations into HHS' strategies:

762: Provide expertise and tools to state and local governments, health systems and facilities, and other organizations, including faith-based and community organizations, to strengthen their capabilities to provide continuous, safe, **culturally competent, accessible, non-discriminatory** and effective health care, public health services, and/or social services during emergencies and through the recovery period, including when such care or services may need to be delivered in alternate settings or by alternate mechanisms.

786: Ensure that the needs of disadvantaged and at-risk populations are met in emergencies, through effective integration of traditionally underserved populations into planning, response, and recovery efforts, **and by creating and implementing plans to ensure that the needs of individuals with limited income, limited mobility, or special health needs are met during emergencies.**

**822: Increase capacity of emergency responders, healthcare and human services providers, and public health professionals to address needs of at-risk individuals in disaster and public health emergency preparedness, response, mitigation, and recovery.**

- We support this goal and urge HHS to support training and resources to ensure that emergency responders and professionals deployed in an emergency, with funding or backing from HHS, understand and are able to meet the needs of **individuals with any type of disability.**

**Objective 3.1: Encourage self-sufficiency and personal responsibility, and eliminate barriers to economic opportunity**

- We object to HHS' characterization throughout this objective of a lack of "personal responsibility" as the barrier to employment for returning citizens, without acknowledgement of discriminatory hiring practices, disability and/or trauma and restrictive conditions of release as major reasons for unemployment. Reentry support should be a long-term investment that addresses both structural and individual barriers to work.

878 should be edited as follows:

Increase access to comprehensive services (i.e., health, behavioral health, student loans, public assistance, and public housing) through ~~short-term, transitional~~ public welfare services and partnerships with other federal agencies and faith-based and community organizations, help formerly incarcerated individuals ~~develop habits of personal responsibility, including obtaining and maintaining~~ **health and social service supports that assist in gaining meaningful** employment, reconnecting with their children and families, paying child support, and avoiding recidivism.

**896 - 907: Invest in evidence-informed practices that enable adults, unemployed noncustodial parents, youth, and individuals with disabilities to prepare for, acquire, and sustain employment to enhance economic self-sufficiency and well-being for themselves and their families**

- **Provide assistive technology equipment to people with disabilities allowing them more self-sufficiency and eliminating barriers to their economic opportunity**
- **Working with faith-based and community organizations to advance independence and economic self-sufficiency of individuals and populations facing economic and social challenges through education, leadership opportunities, protection of rights, training, and capacity building**

- **Increase the number of employed people with disabilities by encouraging and assisting integration into the greater community's workforce**

We strongly support these goals and recommend the following edits:

Invest in ~~evidence-informed~~ practices that enable adults, unemployed noncustodial parents, youth, and individuals with disabilities to prepare for, acquire, and sustain **competitive, integrated** employment to enhance **independence, community integration, self-determination**, economic self-sufficiency and well-being for themselves and their families

- Provide assistive technology **devices, equipment, and related services** ~~equipment~~ to people with disabilities **to facilitate** ~~allowing them more~~ **independence**, self-sufficiency, **self-determination, community integration** and **eliminate** ~~ing~~ barriers to their economic opportunity
- Working with faith-based and community organizations to advance independence, **community integration, self-determination** and economic self-sufficiency of individuals and populations facing economic, **health** and social challenges through education, **employment**, leadership opportunities, protection of rights, training, and capacity building
- Increase the number of ~~employed~~ people with disabilities **engaged in competitive integrated employment** by **supporting compliance with and enforcement of the Americans with Disabilities Act, the Workforce Innovation and Opportunity Act, Section 504 of the Rehabilitation Act, and the Individuals with Disabilities Education Act; and** ~~encouraging and assisting~~ **supporting competitive, integrated employment in** ~~integration into~~ the greater community's workforce.

**984: Promote healthy development in young children to avoid behavioral challenges, promote school readiness and learning, and offer parents of young children access to evidence-based, culturally-appropriate parenting education and supports**

- We support this goal and note that parents with disabilities have a long history of discrimination in parental rights that continues today<sup>6</sup>. We recommend that HHS support the recommendations of the National Council on Disabilities in its 2012 publication *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*, among them to gather effective data on parents with disabilities and their families and fund research on parents with disabilities and their families. We further recommend that HHS educate states, providers and parents about the requirements of the Medicaid EPSDT program; support

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<sup>6</sup> See, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*, National Council on Disability, February 34, 2017 at <https://ncd.gov/publications/2012/Sep272012>

programs that enhance compliance with the EPSDT and CHIP programs; and promote coordination between the requirements of Medicaid and the Individuals with Disabilities Education Act.

We also recommend the following edits:

Promote healthy development in young children to **diagnosis, treat, prevent and ameliorate** behavioral challenges, promote school readiness and learning, and offer parents of young children, **including those with mental illness and/or intellectual and developmental disabilities**, access to evidence-based, culturally-appropriate, **non-discriminatory** parenting education and supports.

**1020: Support faith-based and community organizations to promote strong, healthy family formation and maintenance through programs that combine marriage and relationship education services with efforts to address participation barriers, economic stability, and needs of their participants.**

- We urge that HHS programs specifically include “addressing discrimination” as a priority in this strategy. Discrimination on the basis of disability in the area of marriage formation is a long-standing, common problem in America. HHS programs can very effectively reduce incidents of disability discrimination in this area. One example of HHS’s recent very helpful efforts in this area is HHS’s publication of requirements for accessible medical equipment in medical offices. This guidance and its enforcement will go a long way to ensuring that woman with disabilities are able to receive full gynecological exams on an accessible exam table. Unfortunately, there are many areas of continued disability discrimination related to family formation, among them: discrimination in adoption, child custody, lack of information provision from medical professionals, about sexuality, marriage and childbirth, and non-consensual sterilization.

We recommend the following edits:

Support faith-based and community organizations to promote strong, healthy family formation and maintenance through programs that combine ~~marriage~~ **and relationship** education services with efforts to address participation barriers **and discrimination**, economic stability, and needs of their participants.

**1067: Develop age- and dementia-friendly livable communities to improve quality of life for older adults, families, caregivers, people with disabilities, and the larger community**

- We support the development of additional community settings for seniors and people with disabilities. However, we would oppose HHS support for development of disability-only or disability-specific settings, which CMS has recognized in its technical “Guidance on Settings that have the Effect of Isolating Individuals Receiving HCBS from the Broader Community, as “likely to Isolate” people with disabilities and be “presumptively institutional”. HHS support of institutional settings would be counter to our nation’s movement toward expansion of community based settings for individuals with disabilities and seniors, and the ADA Integration mandate.

We urge HHS to make clear that if these disability-specific settings are funded with HCBS dollars they must comply with the 2014 HCBS settings rule, including following the December 16, 2017, CMS [“Guidance concerning Medicaid Beneficiaries in HCBS who Exhibit Unsafe Wandering or Exit-Seeking Behavior”](#).

We recommend the following edits:

Develop age- and dementia-friendly **community integrated housing options** ~~livable communities to improve~~ **promote, independence, community integration, self-determination and** quality of life for older adults, families, caregivers, **and** people with disabilities. ~~and the larger community~~

**1069: Promote independence of older adults and people with disabilities through improved federal collaboration, including with faith-based and community organizations, to ensure opportunities to live and receive services the community.**

- We recommend the follow edits:

Promote independence of older adults and people with disabilities through improved federal collaboration, including with faith-based and community organizations, to ensure opportunities to live, **be employed** and receive services in *their own homes and communities, in the most integrated setting appropriate to their needs, including integrated opportunities for active community participation in all areas of life.* ~~community~~

**1072: Foster culture change through inclusion and accessibility for children and adults with disabilities and older adults by removing physical and other barriers**

- We recommend the following edits:

Foster culture change through inclusion and accessibility for children and adults with disabilities and older adults **by robust implementation and enforcement**

***of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act.*** ~~and removing physical and other barriers~~

**1074: Ensure programs for people with disabilities and older adults help protect them from all forms of abuse, including physical, mental, emotional, and financial abuse, and help ensure their ability to exercise their rights to make choices, contribute to their communities, and live independently.**

- We strongly support this goal and recommend the following edits:

Ensure programs for people with disabilities and older adults help protect them from all forms of abuse and neglect, including physical, mental, emotional, and financial , and help ensure their ability to exercise their rights to **self-determination**, ~~to make choices~~, **to contribute to their communities, be competitively employed**, and live independently ***in integrated settings, and in a way that facilitates the greatest opportunities for active community participation in all areas of life.***

**1083: Pursue initiatives and programs to provide support to older adults, people with disabilities, and their families and caregivers as individuals move between institution settings, and home.**

- We strongly support HHS strategies to help individuals move from institutions to the most appropriate integrated settings, with supports. We are concerned that the wording of this strategy does not reflect our Nation’s commitment to true community integration as mandated in the ADA. By using the term “move between” instead of “transition” might suggest that at some points, community-based services and supports will not be sufficient and individuals will have to move between settings. This has not been our experience.

It has been our experience that the Medicaid Act if properly administered and fully enforced allows for a sufficient range of community-based services and supports to allow even individuals with the highest care needs and most medically complex disabilities to live safely in the community throughout their lifespan. If we find that that an individual is moving between community and long-term care institutional settings it means that his or her individual service plan needs to be re-evaluated and adjusted, but that services can be made available in community settings. In fact, some Courts have found that the most medically

fragile individuals can be better cared for in the community with supports than in a nursing facility, where 24 hour one-to-one supervision is often not available.

We also suggest not only using the word “home” but also referring to community settings. Although HHS likely wrote the word “home” with the intent to refer to anywhere a person makes his or her home. The continued stigma of people with disabilities being “dependent” could lead some individuals to limit the meaning of the word to “family” home. By using home and community based setting, instead, it makes clear HHS’ intent to supports a variety of community-based living options for people with disabilities and seniors.

We recommend the following edits:

Pursue initiatives and programs to provide support ~~to~~ **and enable** older adults, people with disabilities, and their families and caregivers ***to remain in their homes and communities; and to transition from*** ~~as individuals move between~~ institutional settings, ~~and home~~ ***to the most integrated community settings with appropriate supports and services.***

**1101: Assist states in strengthening and developing high-performing long-term services and supports systems that focus on the person, provide streamlined access, and empower individuals to participate in community living.**

- We support this goal and recommend the following edits:

Assist states in strengthening and developing high-performing long-term services and supports systems **that provide person-centered, person-directed services** ~~focus on the person, provide~~ streamlined access, and empower individuals ~~to participate in community living~~ ***to live and work in the most integrated setting appropriate to their needs, with supports that allow full participation in all aspects of community life.***

**1119: Include culturally appropriate, person- and family-centered care planning in federal social and healthcare services for older adults and persons with disabilities to protect individual choice and address a person’s current and future economic resources, including advanced care planning needs.**

- As mentioned earlier in these comments, we urge HHS programs to include education of guardians with medical decision making authority, and education of medical professional about guardianship authorities and how to appropriately

determine any limitations of a guardians authority to be involved in medical decision making.

Medical professionals also often lack information about the authority of guardians to make health care related decisions for a patient or consumer. This can easily lead to physicians allowing guardians, who may not have the authority to make health care decisions on behalf of the patient, inappropriately giving the guardian the exclusive right to decide the care plan.

We recommend the following edits:

Include culturally appropriate, person- and family-centered care planning in federal social and healthcare services for older adults and persons with disabilities to protect individual choice and address a person's current and future economic resources, including advanced care planning needs. **Educate providers about the role and possible limitations of guardians to be involved in the health care decision making process; and promote the use of supported decision-making and other alternatives to guardianship that maximize individual autonomy and choice**

Thank you for your consideration of these comments. Should you have any questions, please do not hesitate to contact Elizabeth Priaulx, Senior Disability Legal Specialist at [Elizabeth.Priaulx@ndrn.org](mailto:Elizabeth.Priaulx@ndrn.org) or 202-408-9514 x113.

Sincerely,



Curt Decker  
Executive Director