Centers for Medicare & Medicaid Services Department of Health and Human Services
Attention: CMS-2296-P
P.O. Box 8016, Baltimore, MD 21244-1850

RE: opportunity to File Code CMS-22296-P

To Whom It May Concern:

Thank you for the comment on this proposed rule concerning the 1915c Home and Community Based Service (HCBS) waivers. The Centers for Medicare and Medicaid Services (CMS) should be commended for taking such important positions on items like what is considered home and community settings, requiring the use of person centered planning, and making the waiver process more transparent to interested stakeholders.

The National Disability Rights Network (NDRN) is the non-profit membership association for the federally mandated nation-wide Protection and Advocacy (P&A) and Client Assistance Programs (CAP). The P&A/CAP Network has special federal authorities to advocate for all people with disabilities by guarding against abuse or neglect; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems. NDRN promotes a society where people with disabilities have equality of opportunity and are able to participate fully in community life by exercising choice and self determination.

CMS has recently taken strong positions on what settings are home and community based in order to qualify for the use of 1915c waiver funding, and that continues in this regulation. By definitively stating what environments are not a home or community setting, CMS will help ensure that the intent behind HCBS waivers is fulfilled by providing services in the most integrated settings. Clarifying that building smaller homes on the grounds of institutions and creating disability specific housing complexes or communities are not considered home and community will help end recent troubling attempts to use 1915c waiver funds to create these inherently non-integrated settings.

The following are additional NDRN comments on the proposed rule.

Broad Level Comments:

We urge CMS to make all its rules requiring person-centered planning and definitions of HCBS consistent across all CMS waiver programs, not just 1915c waivers.

We urge CMS to clarify that these rules cover not just HCB settings but also HCB services covered under 1915c waivers, for example: pre-vocational services (like sheltered workshops) and adult day services.

If a state requests a grandfather period to convert their current 1915c waiver programs into one that meets these new rules, we urge CMS to grant these for as little a time period as possible. CMS should not grant unlimited waivers. We recommend a grandfather period of no longer than the end of the next waiver cycle or if the state is in the last 18 months of its existing waiver, than no longer than 18 months beyond the end of the current waiver cycle.

Subpart G: Section 441.301 Contents for the request of a waiver

We strongly support this entire section requiring person centered planning. The recognition that plans for a person with a disability should not be made without the involvement of the person has been increasing in recent years, and CMS recognizes this important trend in this regulation by requiring the use of person centered planning when developing the uses for HCBS waiver funds. The importance of having this concept fully recognized in the federal regulation cannot be understated and will hopefully lead to its use in a number of other programs.

In particular we appreciate (b)(1)(i)(A)5. Requiring inclusion of "strategies for solving conflict of disagreement within the process which includes conflict of interest concerns." It should be recognized that guardians or providers could have financial conflicts that unduly influence service choice. While they need not be excluded from the process, strategies must be available for eliminating or minimizing potential financial conflicts.

In (b)(1)(i)(A)(6) requiring the planning process to "offers choices regarding the services and supports they receive and from whom," we urge that this choice should be informed and not violate the ADA Title II as interpreted by the U.S. Supreme Court in Olmstead v L.C. and E.W. In order for choice to be informed, an individual must be provided information about existing HCBS services, as well as, services that could be made available or come available within the state 1915c waiver parameters.

We are firmly supportive of the requirement in (b)(1)(i)(B) to do "person-centered functional assessments" rather than diagnosis based assessments, in the person centered plan. This provision could be strengthened by requiring case managers who are independent of any provider. The use of "captive" case managers eliminates a significant check on inappropriate or inadequate services. Requiring independent case managers provides greater assurance that the individual goals and services will be appropriate and cost-effective and also will reduce actual or potential conflicts of interest.

We appreciate that (b)(1)(i)(B)(3) includes employment as an area to include in "Individually indentified goals." CMS recognizes that employment can be a vital component of community life. NDRN agrees, and recently issued a "Call to Action" to highlight the problem of the disability service systems failure to provide enough quality work for people with disabilities; relying instead on work in segregated environments with low wages.

In (b)(1)(i)(B)(4) we urge CMS to clarify that, while the individual service plan can reflect "unpaid services", these "unpaid services" must not be required. And "unpaid services" should not be required, as a reason for providing a lesser amount of Medicaid personal assistance than would have been offered under the waiver had these "unpaid services" not been available.

In (b)(1)(i)(B)(iv) and b)(1)(i)(B)(iv)(A) we commend CMS for definitively stating what environments are not a home or community setting. This will ensure that the intent behind HCBS waivers is fulfilled by providing services in truly integrated settings. On the other hand, CMS should **not** attempt to define what is HCBS. This approach would not be as flexible and would risk creating a definition that leaves out a setting that is in fact integrated. This risk would get greater over time, since societal attitudes about what services should be provided in the community are likely to change and expand over time.

The proposed 401.301(b)(1)(iv)(A)) could be strengthened by adding after "public institution" the words "or sharing common employees or management with a public institution." NDRN opposes any other changes to the wording in b)(1)(i)(B)(iv)(A). This provision as worded is vital in order to stop the current trend of states across the country building or attempting to build smaller homes on the grounds of institutions and obtain 1915c waiver funding for these settings. It will also halt state's attempts to create disability specific housing complexes or communities and claim 1915c waiver funds to create these inherently non-integrated settings to live and / or receive services.

NDRN is aware that some people may be submitting comments that propose striking the part of the provision stating "a housing complex designed specifically around a person's diagnosis or disability." We urge you not to strike his language. This language is vital to stopping the attempts of providers to create segregated residences for people with disabilities. NDRN is deeply opposed to any exception to this provision for residences designed specifically for individuals with Alzheimer's or dementia. There is nothing inherent about this diagnosis that means an individual should have fewer rights to, or desire for, integrated environments. Creating a special exception for a certain disability group based on current attitudes about their abilities is a dangerous precedent. It also does not reflect the fact that current ideas about disabilities shift overtime. These proposed rules should remain flexible and not designed around one specific disability group.

We support section (b)(1)(i)(iv)(B) proposing that HCBS funding be forbidden if a setting "has qualities of an institutional setting as determined by the Secretary." This is an important protection for recipients because it allows flexibility so that "institutional qualities" can change as do cultural norms defining community integration.

Subpart G: Section 441.302 State Assurances

NDRN supports the provisions in this section of the rule. We support the ability of a state to serve more than one target group under a single waiver. In addition to the assurances provided in 441.302(a)(4) and (5), we urge CMS to require that the cost neutrality calculation used in a combined waiver application be based on the target group with the highest estimated institutional cost. Without this requirement states may choose to base cost neutrality on the lowest cost target population, which could place high cost target groups at risk of institutionalization because the waiver cannot meet their service and support needs.

Subpart G: Section 441.304

NDRN strongly supports all provisions in this section. CMS has made some important improvements in the administration of the HCBS waivers through this regulation.

Please maintain the full list of "substantive changes" included in 441.304 (d)(1).

NDRN applauds the change in 441.304(d)(2). Not allowing a new waiver or substantive changes in an already existing waiver to take effect until the waiver has been approved by CMS will help ensure that the waivers fulfill the mandate of the HCBS waiver program. The rule may also save money prematurely spent to arrange for new or changed waiver services. And it can reduce confusion that Medicaid beneficiaries and providers experience when a proposed amendment is announced and later rescinded.

In addition, the new due process and transparency requirements will help interested stakeholders know about proposed waiver amendments before they are actually implemented. Further, it provides CMS a new opportunity to hear from individuals directly affected (beneficiaries and providers) about the likely impact of the proposed changes. Today, waiver amendments are often a secretive and closed process, offering ineffective strategies for Medicaid beneficiaries and their advocates to comment on, or plan for proposed amendments.

We applaud CMS for seeking input on new ways to ensure compliance with the provisions of the HCBS waiver. We recommend that CMS view the P&A Network as an official part of their panoply of new corrective strategies. P&As are established in every state and territory and already knowledgeable about

existing1915c waiver programs. P&As are trained in how to monitor disability service systems and how to design corrective action plans.

NDRN urges CMS to avoid use of a "moratorium on waiver placement" as a corrective strategy. Moratoriums are more likely to harm people with disabilities who seek limited HCBS options, than they are to harm states which may, indeed, like a moratorium because it is a means of reducing waiver program expenses.

Requirements for Assisted Living As Stated in the Preamble

We support CMS's intent to require assisted living facilities to have person centered and independent living standards in order to be covered under a 1915c waiver. In addition to these requirements we ask CMS to ensure appropriate due process regulations for individuals using HCBS funds while living in an assisted living facility.

We strongly support the requirements for residents to have separate kitchen, bath, living room, and bedroom. While it is true that many current waiver homes may not meet these standards, CMS should be setting standards that meet the goal of maximizing independence. Current waiver programs can be altered to become more person-centered and homelike. This is only likely to happen with definitive timeframes and the leadership of CMS.

Please maintain the obligation for a kitchen. The opportunity to make choices about what to eat and when to eat and to make meals is very often removed from individuals living in institutions. CMS is commended for viewing access to a kitchen as part of HCB settings. While some individuals might have disabilities that make access to a cooking unit dangerous, there are means to reduce this concern short of eliminating the requirement. Just one of many such possible examples can be found in the Texas 1915 (c) Medicaid waiver standards regarding assisted living facility apartments – that reads: "a kitchen area is an area equipped with a sink, refrigerator, cooking appliance … *The cooking appliance must be able to be* kitchen on conditions *removed or disconnected [*italics added*]."*

NDRN commends CMS for the many important improvements to the 1915c HCBS waiver program in these proposed rules, and we hope to see them when the final regulation is issued.