



Disability Network

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Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attn: CMS-2296-P
Mail Stop C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

Re: File Code CMS-2296-P

Dear Sir or Madam:

The Lutheran Services in America Disability Network (LSA-DN) is writing to comment on the notice of proposed rulemaking that will change the regulations that implement Medicaid home and community-based services 1915(c) waivers. The notice was officially published for comment on April 15, 2011.

LSA-DN is a nationwide network of Lutheran social ministry organizations that serve the needs of people with intellectual and developmental disabilities (ID/DD) and related conditions. LSA-DN members provide support and services to thousands of people throughout the United States. Members share expertise in developing and providing innovative, high-quality individualized supports including habilitation, work readiness and employment, residential services, respite care, in-home services and independent living supports. LSA-DN is a part of Lutheran Services in America, a network that serves one in fifty Americans across the country.

LSA-DN believes that access to Medicaid funded home and community-based services (HCBS) must be increased. Through community-based supports and services, Medicaid empowers people with the ability to reach their full potential. LSA-DN supports regulatory changes that can help to improve access to these services and supports. We applaud CMS' efforts to define HCBS across its programs including the waiver programs. It is critical in these tough economic times to ensure that HCBS waiver services are being provided in the appropriate and accurately described community settings that guarantee persons with disabilities can live, work and prosper in the most integrated setting in the community. However, we caution CMS to make certain that

consumer choice as to where and how individuals receive services should take precedence over other priorities. We urge CMS to avoid unintended consequences of vague or too narrow language that would result in individuals having to move from their long time homes in the community or lose critical services. Finally, we want to emphasize the need to involve stakeholders in dialogue as CMS moves forward on working with states to implement final regulations.

441.301(b)(1)(iv)(B) - STATE OPTION TO CONSOLIDATE WAIVER GROUPS

LSA-DN supports in principle CMS' move to allow states to combine populations or groups under one waiver. This will allow flexibility in service provision, and coordination of needs in situations such as when both an adult child with a disability and her aging parents need similar services and supports. We want to encourage caution and clarity in several areas when moving forward:

Continued Access for Current Waiver Recipients - Although there are many positive aspects to the development of waivers based on activities of daily living rather than diagnosis, LSA-DN believes that removal of diagnosis based waiver target groups should not diminish funding for people with ID/DD to receive waiver based services. When states apply to combine waivers, steps must be made clear as to how at the state level the merging will occur and how the state will make certain no one loses a waiver slot that they currently have. In addition, to ensure ongoing equity, CMS should calculate and monitor the baseline combined funding for individual populations. Many states have robust ID/DD HCBS waiver services, which LSA-DN would want to see continued, even while states work to rebalance the HCBS system for the aging and physical disability populations.

Fairness in Addressing Waiting Lists - We encourage CMS to take steps to ensure fairness, transparency and access across diagnosis when states are dealing with those currently on waiting lists. States must be clear about the process for merging waiting lists, which must include a strong public input component, and be encouraged through the change in waivers to move more people off waiting lists and into services.

Evaluation of Appropriate Provider Rates - In addition to having concerns about the process of merging waiting lists and determining a fair and equitable way to serve across diagnosis categories, we also have to raise concerns about what will happen to current provider payment rates for specific services that now vary between populations under the divided waiver system. In creating one waiver for multiple populations, states need to consider the market value of the provision of certain services. We would hate to see the reimbursement rates for services be reduced to the lowest common denominator without consideration for ensuring continued access for consumers to a diversity of service providers. We recommend that CMS require that states review an analysis of current provider rates across waivers and the market rates of those services before making changes to or combining rates. States should also be required to have a very open and public comment process so that consumers, advocates, service providers and other stakeholders have a meaningful opportunity to provide input.

Population Specific Expertise & Coordination with External Supports - LSA-DN also wants to guarantee that the expertise of serving specific populations is not lost in the merging of

waivers at the state level. State Medicaid Directors do not always have the experience of working with the ID/DD community or administering long term services and supports. Therefore, we encourage CMS to ensure that state Directors of Developmental Disabilities maintain a strong role in the administration of waivers for the ID/DD community so that expertise and the ability to respond to disability specific needs are not lost. We suggest that there needs to be clarity about which office will assume the lead role, especially when the waiver addresses more than one target population. In addition, service providers who have historically worked with specific disability populations should be encouraged to utilize and share their disability specific expertise. Finally, CMS should forward the coordination of waiver services with services not usually under the waiver but still integral to people with disabilities such as supported employment.

441.301(b)(1)(i), (b)(1)(6), (b)(1)(iv) - PERSON-CENTERED PLANNING

LSA-DN commends CMS' emphasis on a person-centered planning process with a strong priority on the individual's desires and choices. To the extent possible, individuals receiving services should have a role in directing their services. We lift up the need to ensure that adequate funds are made available to provide appropriate service levels. We would ask that the following items be added to the regulation under the person-centered planning section:

- In Section 441.301(b)(1)(i)(B), add “consistent with Olmstead integration efforts”;
- In Section 441.301(b)(1)(iv)(A), add: “people chosen by the individual – including paid or nonpaid individuals.
- In Section 441.301(b)(1)(iv)(A)(2), following the statement “Provides necessary support to ensure that the individual has a meaningful role in directing the process” add “Individuals who are not able to lead the planning process themselves, their chosen representative is allowed to play an active role, while including the individual to the extent to which they can participate”;
- In Section 441.301(b)(1)(iv)(A)(3), add “occurs at times and locations convenient to people chosen by the individual and provides necessary accommodations due to distances traveled;
- After Section 441.301(b)(1)(i)(B)(5), regarding back-up strategies, include technologies such as remote monitoring and future technologies;
- In Section 441.301(b)(1)(i)(B)(12), add “in inappropriate or less integrated settings”;
- After Section 441.301(b)(1)(i)(B)(12), add “Include a budget adequate to cover the cost of services and supports laid out in the person-centered plan”;
- In Section 441.301(b)(1)(i)(B)(3), add to the list of types of individually identified goals “spiritual or religious needs”.

441.301(b)(1)(iv) - CHARACTERISTICS OF HCBS AND NON-HCBS SETTINGS

Prioritizing Consumer Choice - LSA-DN believes that services and supports that are individualized and encourage community inclusion will best meet an individual's needs. Providers of services and supports have a moral obligation to ensure community inclusion is a priority regardless of an individual's living arrangements. LSA-DN supports CMS in not limiting the number of participants in a setting as means of defining home and community. Home and community are defined differently for each individual. We believe that the consumer's choices should direct the person-centered plan, reflecting the individual's definition and view of community and community living.

Preventing the Misuse of HCBS Waiver Dollars - However, we understand the need to create parameters to respond to recent attempts by certain states to alter the names, but not the spirit of institutional campuses and buildings or build community housing on these campuses in order to access HCBS waiver dollars. These efforts ignore the intent of Olmstead, which is to ensure individuals live in the most integrated settings possible. We are happy to see that CMS is denying these efforts by states and encouraging instead a real transformation and move to integrated community living. We encourage CMS to specifically bar HCBS waiver dollars from going to any current or former state run publicly operated institution or campus. LSA-DN believes that state governments should not be in the business of providing HCBS services, but rather should support private nonprofit organizations to offer direct services and supports to individuals. Currently many states maintain a conflict of interest by administering Medicaid and paying themselves usually a higher rate to provide services to the detriment of the growth in HCBS. This conflict of interest must be eliminated.

Keeping People in Current Housing - The standards outlined in the current proposed rule raise concerns for LSA-DN in that they appear to significantly limit use of waiver services in housing that is disability specific. LSA-DN recommends that CMS specify that Housing and Urban Development buildings built under Section 811 be included as waiver approved community housing. With the passage of the Frank Melville Supporting Housing Act in December 2010, the 811 program is in the process of being transformed to embrace the move away from disability specific housing towards fully integrated housing situations for people with disabilities in the community. LSA-DN would protest the removal of individuals in current 811 housing from HCBS waiver services. In many cities such as San Francisco, 811 apartments are some of the few affordable, accessible housing for people with disabilities in the city. If waiver services can not be utilized in those buildings, it would force many people out of their current homes or risk losing supports. We believe that this 811 housing stock should not be lost by virtue of individuals with disabilities being unable to receive HCBS in their homes. We would encourage CMS to work with HUD to promote in current 811 buildings further community inclusion.

Supporting Housing Choice - In addition, we must remember that the consumer choice should be the primary determinant about where individuals receive HCBS waiver services. LSA-DN is concerned that there is ambiguity in the proposed regulations that might be read as eliminating group homes for individuals with ID/DD. We would oppose eliminating this option as consumers should have a range of housing options to choose from including roommate situations or group living. Therefore, we encourage CMS to support a variety of appropriate housing models for the provision of HCBS waiver services including group homes, host homes and other roommate housing situations as well as options to live alone.

Non-Residential HCBS Criteria - When considering the definition of HCBS as it relates to where services are provided, LSA-DN would remind CMS that some congregate service settings might be preferred by consumers or be most appropriate for consumers. For example, adult day programs can cut down on potential isolation issues facing the elderly aging in their own homes in the community. Congregate settings for the delivery of prevocational services might also be more appropriate than the delivery of services in the home. Although services provided in an integrated way in the community should be encouraged, we caution a move to requiring that all

HCBS waiver services be provided in a non-congregate setting resulting in the limiting of consumer choice. We ask for clarity from CMS around the nature and definition of appropriate work and service sites based on this proposed rule.

Clarifying “As Determined by the Secretary” - The proposed regulations leave a lot of ambiguity around the (B) “Has qualities of an institution, as determined by the Secretary”. We would like to see that area of the regulations flushed out to at least articulate the criteria that the Secretary will be using to identify qualities of an institution. Our concern is that this determination will not be clear and will change over time, making program and housing planning more challenging.

441.304(d) - WAIVER CHANGES AND PUBLIC INPUT

LSA-DN applauds CMS for defining “substantive changes” to waivers and adding clarity about when states need to include key stakeholders in conversation about changes to the waivers. We would emphasize that new proposed waivers should also require this level of stakeholder participation and transparency. To ensure changes to waivers or that the creation of new waivers reflect the primary goal of providing real choice and opportunity for people with disabilities of all ages, there must be a robust public input process developed. Consumers must have ample opportunity to participate in a meaningful way in that process. Transparency should also be the highest priority. Thus, LSA-DN encourages CMS to require states to do the following activities to ensure real input, participation and transparency:

- Notice of proposed changes to existing waivers or the creation of new waivers on the state website with minimum 45 days advertising, including a public notice on the website, newspaper, or list serve that provides what changes are to be made, if there are any adverse consequences and how the public can get involved;
- Opportunity on web and in stakeholder meetings to provide feedback on proposed waiver. Meetings should include consumers, service providers, advocates, families, and other stakeholders;
- Posting on the CMS website all active and pending states waivers;
- Submission by states of all public comments and the steps that states are taking to address those comments;

The process outlined above should be required when substantive changes to a waiver are requested or with the creation of a new waiver.

SUMMARY OF COMMENTS

In summary, here are number of the key issue areas LSA-DN would like to see addressed:

1. Consumer choice as to where an individual wants to live, receive services and work should be the primary driver of the development and the implementation of a person-centered service plan and the determination of housing possibilities and non-residential settings for services. We should be very careful when limiting an individual’s choice in these areas.
2. When combining waivers, states must address concerns and articulate their process around ensuring continued access to current waiver recipients, developing an equitable way to address those on waiting lists, maintaining adequate provider rates across populations and cultivating population specific expertise.

3. We encourage CMS to specifically bar HCBS waiver dollars from going to any current or former state run publicly operated institution or campus. LSA-DN believes that state governments should not be in the business of providing HCBS services, a conflict of interest, but rather should encourage non-governmental organizations to offer direct services and supports to individuals.
4. Stakeholder input and participation are critical to ensuring a strong waiver system. Transparency must be paramount as well as responsiveness to issues that are raised in the public input process.

LSA-DN member organizations have an extensive history of providing services and support to thousands of people with disabilities. As faith-based services providers, LSA-DN member organizations have unique perspectives and would appreciate any opportunity to work with CMS in the development of policy guidelines for states. As the HCBS system evolves and strengthens, we must remember that the primary goal for a successful service system needs to be strong mechanisms to ensure consumer choice and consumer direction of all long term services and supports.

Thank you for the opportunity to comment on the notice of proposed rulemaking. We value our public-private partnership with CMS in serving people with intellectual and developmental disabilities. We support the ongoing efforts toward improving the implementation and reach of services and support to enhance full inclusion and we are willing and eager participates in future dialogue to seek solutions to support these goals. If LSA-DN can be of further assistance, please contact me at mcooch@lutherservices.org or at (202) 626-7949.

Sincerely,



Meg Cooch
Director of Policy and Advocacy
Lutheran Services in America Disability Network