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Centers for Medicare and Medicaid Services (CMS)
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Baltimore, MD 21244

Submitted electronically to: HCBSMeasuresRFI@cms.hhs.gov

Autistic Self Advocacy Network Regarding Request for Information: Recommended Measure Set for Medicaid-Funded Home and Community-Based Services (HCBS)

The Autistic Self Advocacy Network (ASAN)¹ - a 501(c)(3) nonprofit disability rights and advocacy organization by and for autistic people ourselves - appreciates this opportunity to provide information and perspectives to CMS which will inform the development of effective quality measures for home and community-based services (HCBS). ASAN has a longstanding commitment to effective services which place the needs of HCBS consumers - people with disabilities - first and foremost. ASAN supports CMS' development of draft HCBS quality measures as a critical first step towards this goal.

ASAN is nonetheless concerned that this RFI drastically under-prioritizes one of if not *the* most important metric for determining the quality of HCBS - the degree to which beneficiaries retain choice and control over their own lives. Instead, the RFI prioritizes the *appearance of* choice and control. For example, the "Choice and Control" subdomain - despite being one of the most important subdomains - contains primarily² simple situation specific measures, such as whether a beneficiary can "eat meals when they want to" or "furnish and decorate their room however they want to."³ These measures, while they are important, are limited in scope and do not remotely cover the entirety of the complex process of determining whether a beneficiary has self-determination in their daily life and the ability to make choices for themselves, without coercion. Some of the best measures

¹ For more information on ASAN, visit our website at: <https://autisticadvocacy.org/>.

² While a few more complex measures in the "Choice and Control" subdomain exist, such as "percentage of people who say they were able to choose the services they get as part of their service plan," they are fewer in number. The questions that are ultimately used are also dependent upon the survey instrument adopted by the state, such as the National Core Indicators or HCBS CAHPS survey.

³ Centers for Medicare and Medicaid Services, *Request for Information: Recommended Measure Set for Medicaid-Funded Home and Community-Based Services* at 25-26 (2020), available at: <https://www.medicare.gov/medicaid/quality-of-care/quality-improvement-initiatives/measuring-and-improving-quality-home-and-community-based-services-hcbs/index.html> [hereinafter "RFI"].

proposed for the “Choice and Control” subdomain are listed, without justification, as only ready for later implementation, such as “Percent of respondents who indicate being able to make personal choices to the extent that they desire.”⁴ By contrast, the “Holistic Health and Functioning,” “Workforce,” and “Community Inclusion” subdomains contain more detailed questions, such as the “Workforce” subdomain’s “NCI-AD-10: Percentage of people whose support staff do things the way they want them done,” or the “Community Inclusion” subdomain’s “NCI-AD-1: Percentage of people who are as active in their community as they would like to be” in its extended set.⁵ ASAN strongly encourages CMS to prioritize measure development for the “Choice and Control” subdomain more highly than it does in this RFI.

We are also concerned that the measures in both the “Choice and Control” and “Person-Centered Planning and Service Coordination” subdomains are not sufficiently comprehensive, at times appear to apply to only a subset of beneficiaries utilizing HCBS, and that the most important measures in each are often placed in the optional extended set of measures rather than in the vital base set.⁶ ASAN urges CMS to place increased emphasis on the development of those measures that center beneficiary self-reported perspectives on their own services and to put the ability to decide what action is taken at any point in their life - instead of access to a small number of limited “choices” at scheduled intervals - at the forefront of what is evaluated.

Additionally, ASAN urges CMS to create a plain-language version of this RFI. The RFI is written using complex language that is only accessible to a person with considerable expertise in the field of HCBS and LTSS. Moreover, the proposed draft measures include specific references to quality measure sets developed at earlier points in time (for example, “MLTSS-3: LTSS Shared Care Plan with Primary Care Practitioner” or the HCBS CAHPS “Choosing the Services That Matter to You Composite Measure (Q 56, 57)”) with no explanation of what questions are included in these measures or what subjects they relate to.⁷ Most people with cognitive disabilities, particularly people with intellectual and developmental disabilities (IDD), would find it nearly impossible to read and understand this RFI, even though it pertains to the future development of quality measures for services they themselves may be receiving. People with cognitive disabilities are, as consumers of HCBS, among the most important stakeholders that this RFI must serve. Quality measures made without the input of the beneficiaries they support are presumptively invalid. ASAN

⁴ RFI at 25.

⁵ RFI at 25, 26, 27, 29, 34.

⁶ RFI at 23-24.

⁷ See RFI at 12; *CAHPS Home and Community Based Services Survey*, Centers for Medicare and Medicaid Services, <https://www.medicare.gov/medicaid/quality-of-care/quality-of-care-performance-measurement/cahps-home-and-community-based-services-survey/index.html> (last visited Oct. 13, 2020).

therefore recommends that CMS consult with skilled plain language translators in order to create a version of the RFI that is no higher than a 6th grade reading level.

This RFI asks respondents to answer specific questions related to the development of HCBS quality measures, as well as questions concerning its draft framework. ASAN's responses to the questions most pertinent to its constituents are below.

Question: Which domains in the NQF report are most important to address through the recommended measure set?

ASAN recommends that the base measure set be revised to focus more extensively on the "Choice and Control" and the "Person-Centered Planning and Coordination" domains, and that these domains be revised to include a greater diversity of measures that better reflect the beneficiary's actual control and participation, rather than measures that simply evaluate whether the beneficiary can do one activity or another.⁸ These two domains focus on the beneficiary experience and beneficiary control over the direction and focus of their own HCBS services - and therefore, their own lives. All other aspects of the HCBS service system and delivery should be subordinate to, and designed to effectuate, person-centered service provision and the beneficiary's own life goals. Even if high-quality services are delivered in the community and outside of an institution, the services are still functionally institutional if the beneficiary lacks meaningful personal control over them. In this situation, institutions would simply have been moved from inside buildings to outside buildings, and HCBS would serve no purpose. ASAN also recommends that CMS add additional measures to the "Community Choice and Inclusion" base set and extended set.⁹

According to the final 2016 report, the Choice and Control domain should contain measures that help define "the level to which individuals who use HCBS, on their own or with support, make life choices, choose their services and supports, and control how those services and supports are delivered."¹⁰ The Choice and Control domain is among the most vital for the purposes of evaluating whether HCBS are implemented in service to those they support, rather than to the person's family or service providers. Nonetheless the "Choice and Control" subdomain, rather than being prioritized, contains only the same number of measures as several other domains (10-14).

⁸ National Quality Forum, HHSM-500-2012-00009I, Task Order HHSM-500-T0014, Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement 17-21 (Sept. 2016)[hereinafter "National Quality Forum"]; RFI at 22-25.

⁹ RFI at 25-27.

¹⁰ National Quality Forum at 19.

Additionally, the measures listed as both being a part of the base set and that will soon be ready for implementation only partially achieve the subdomain's goals, leaving important aspects of the subdomain unmeasured. Most of the HCBS quality measures listed under the Choice and Control domain, as derived from existing survey instruments, contain questions on whether the person can decide on their "daily schedule," decide either how to spend their free time or whether they want to get together with friends or family, and questions on whether or not a person can decide what services they get.¹¹ The problem with these measures is that they are asking discrete questions about whether the beneficiary can do specific things, rather than whether a particular beneficiary actually *has* control over their lives. For example, a person might have the ability to choose whether they go out that day or stay at home - and therefore have the ability to "decide" their "daily schedule" (a component of the Everyday Choice Scale Composite Measure) - while still having no ability to decide in the moment that they want to go to bed 15 minutes late, spontaneously change plans, or watch a TV show their support person finds annoying. The person might be able to "decide" when and what to have for lunch without being able to change their mind, make choices at any time during the day rather than at some specific time, make "unhealthy" choices, or decide how that lunch is prepared and by whom. A person may have the ability to visit friends and family that their service providers are aware of, but nonetheless may have a limited ability to visit new friends or friends not approved of by their service provider. ASAN recommends that the HCBS quality measures, instead of measuring a person's ability to perform discrete and limited actions, must additionally and more importantly evaluate whether the person can act as they *choose* to at any given moment, with the service provider acting as support. If a person cannot do this, they are essentially in an institution consisting solely of themselves, rather than acting as a free and independent member of the community.

The few measures which do address these aspects of choice and control more directly are constrained by the very structure of the RFI's assumptions. For example, the RFI appears to state that if a state is taking part in the National Core Indicators - Aging and Disabilities (NCI-AD) survey, the measure "NCI-AD-10: Percentage of people whose support staff do things the way they want them done" will be used during initial implementation.¹² Although this question addresses a key component of choice and control, there is no comparable question in other sets¹³ and it is not mentioned in the "Choice and Control"

¹¹ RFI at 23-25; *CAHPS Home and Community Based Services Survey*, Centers for Medicare and Medicaid Services, <https://www.medicare.gov/medicaid/quality-of-care/quality-of-care-performance-measurement/cahps-home-and-community-based-services-survey/index.html> (last visited Oct. 13, 2020).

¹² RFI at 13.

¹³ The closest measures in the "Choice and Control" subsection and/or other subdomains are either not ready for initial implementation (such as the "Percent of respondents indicating being able to direct their services and supports as they desire" measure) or relate to control over *type of services* rather than whether the person can control, at the individual level, how those services are performed.

domain section. A person who can control whether or not their support provider does a task for them (or whether the support provider instead prompts them to do it in specific ways) and how the support provider does it has *more* control than a person who decides only whether or not they will go out that day. Troublingly, by allowing states to elect which survey instruments are used, without ensuring the same key factors are repeated across tools, this measure is in effect limited solely to the population that happens to be in a state (and disability subgroup) taking part in NCI, while other beneficiaries are deprived of its value. Other similarly vital measures - such as the percentage of those who were able to vote, the percentage of those “who are as active in their community as they would like to be,” and the percentage of those whose case managers have talked to them about services that might meet their needs - are included only in the extended sets of various domains, and even then are only made available to states utilizing the tools they derive from. These or substantially similar measures should be prioritized and made available for the measurement of HCBS received by *all* beneficiaries, potentially by developing revised versions of the relevant survey instruments.

The “Person-Centered Planning and Coordination” domain, similarly, is intended to be focused on “the individual’s goals, needs, preferences, and values,” according to the 2016 report. It is designed to evaluate the degree to which the person-centered planning process is directed by the person themselves and results in an implementable plan that improves the person’s life. Nonetheless the section pertaining to Person-centered planning and Coordination contains (in the base set) only the most limited and opaque measures of the person’s involvement in the development of their plan, such as whether the plan includes “things that are important to you,” or whether their case manager “asks what they want.”¹⁴ Only the extended set, which contains measures which are optional, measures the percentage of people “involved in making decisions about their service plan.”¹⁵ Without this measure or a similar measure present, the degree to which person-centered planning is person-centered in the first place is not being measured, and therefore the quality measures are made toothless. We strongly recommend that the base measure set for this domain be revised to include a broader variety of questions that capture the beneficiary’s degree of involvement in the development of their own plan, and that questions that pertain to beneficiary involvement be included in the base set ready for initial implementation.

Additionally, ASAN recommends that CMS broaden the number of measures included in the base “Community Choice and Inclusion” set. The current base set includes, to its detriment, only measures that pertain to the ability to get transportation out into the

¹⁴ RFI at 20-21.

¹⁵ RFI at 21.

broader community.¹⁶ Only the extended, optional measure set would examine a beneficiary's ability to interact with the things and people in the community they desire to interact with, and their ability to receive additional services and supports to do so. Measures examining employment are only mentioned as measures for later implementation.¹⁷

The RFI's apparently limited understanding of measures related to community inclusion is troubling. Community inclusion refers to far more than the mere ability to *enter* the community. Community inclusion is a complex idea that involves the degree to which a person is connected with both a community's members and its institutions. The ability to walk and enjoy the sights and sounds of the community at will, interact with local businesses, and pursue one's interests are all part of community inclusion. Establishing mutually rewarding relationships with community members and organizations - as well as making friends and visiting family - are also parts of community living, as is the ability to impact and change one's community and make use of its resources. It may additionally concern access to competitive, integrated employment in the community, as employment facilitates relationships, myriad opportunities for community participation, and access to money and services important for community inclusion. The "Community Inclusion" section's base set should encompass *all* of these ideas, rather than the mere act of traveling into the community. We recommend that all recommended extended set measures be moved into the base set.

We also note that several measures in other domains are essential for assessing community inclusion, including CAHPS HCBS Q 56, 57: Choosing the Services That Matter to You Composite Measure,¹⁸ and NCI 50: The percentage of people who say they were able to choose the services they get as part of their service plan.¹⁹ We recommend that these or similar measures be moved to the Community Inclusion domain.

Question: Are there other measures that should be included in the base set or the extended set?

ASAN recommends that CMS include three additional types of measures in the base set:

(1) measures which evaluate the degree to which a person possesses control over day-to-day, moment-to-moment living, rather than solely measures pertaining to specific activities;

¹⁶ RFI at 26.

¹⁷ *Id.*

¹⁸ RFI at 20-21.

¹⁹ RFI at 23-24.

(2) measures which determine the amount of control the person has over the direction of their person-centered planning meetings and the content of their service plans; and

(3) additional community-integration measures which determine the extent to which the person is meaningfully included in significant aspects of the lives of all people.

Recommended new measures falling under the first category would include but would not be limited to more measures similar to “NCI-AD-10: Percentage of people whose support staff do things the way they want them done,” such as: additional measures across categories which evaluate the extent to which an individual can control the manner of work performed by their support person in depth (such as determining whether the support person performs the skill themselves or teaches the disabled person the skill), additional measures across categories that evaluate the extent to which an individual can make new friends and go to see friends their support person does not like, the percentage of people who have the ability to reject or change the day’s plans or activities at any time, how comfortable a person is disagreeing with their support worker (and what the outcome of that disagreement would be); how comfortable a person is telling their support worker to stop or change how they are doing something; and, with respect to an indicator of poor service quality, the percentage of people whose service providers, within the last three months, refused to comply with a specific request of the person. These and similar measures would address aspects of daily living or future planning that all people should have the right to engage in themselves, and that HCBS should facilitate.

Recommended new measures falling under the second category would include but would not be limited to: the percentage of people who consistently attend all person-centered planning meetings, the percentage of people who act as their own facilitators during person-centered planning, the percentage of people who have chosen their own facilitators, the percentage of people provided with accessible documentation of what was discussed at the meeting, the percentage of people who are able to change service providers at will during person-centered planning process (including the agency providing services and not solely support staff), the percentage of people who receive services in accordance with new goals listed in their person-centered plan within one month, and the percentage of people who are demonstrably able to request a new service or support based on their specific goals and desires. These measures would help address whether or not a person controls, facilitates, or otherwise is able to direct the person-centered planning process, as well as whether that process leads to a true change in services. Additionally, measures currently included under other extended sets which reference the person’s case manager or the ability to file complaints concerning services should be moved into the

Person-Centered Planning and Coordination domain. These must rightly be considered part of the person-centered planning process.

Recommended new measures for the third category are: measures which evaluate the extent to which a person can go out to purchase things they need or that interest them, measures which evaluate whether a person is able to marry and form families in the manner that they wish to, additional measures concerning the availability of affordable disability-accessible housing, measures concerning whether the person has the means to pursue their educational and/or vocational goals, and measures that determine the extent to which the person feels that they are included in community events. ASAN also recommends measures that evaluate with more specificity the degree of control the person has over *significant* decisions, such as those concerning medical care, finances, personal and sexual relationships, moving and housing, and others. Current measures primarily refer to choice of work and employment and are rarely included within the base set.

ASAN additionally recommends that CMS require states to stratify data produced from these measures according to race, ethnicity, disability, age, sexual orientation, gender identity, status as an English language learner and/or primary language other than English, type of residence (such as whether the resident lives in their own home or in a group home), and whether that residence is located in an urban or rural community.

Health equity, including the rectification of service provision inequities among people with disabilities ourselves, is essential to any federal quality enhancement effort, including in home and community-based services. Although people with disabilities all suffer the impact of ableism, people with disabilities receiving HCBS are a highly diverse group that often experiences racism, sexism, and homophobia as well. Structural oppression further marginalizes beneficiaries and make community-based services even less accessible to them. LGBTQ people receiving Medicaid funded-HCBS for example, particularly trans people, are threatened by proposed rules and regulations which propose to exclude them from the populations protected by federal anti-discrimination law.²⁰

ASAN therefore proposes that data from each measure be disaggregated by the above categories - and, wherever possible, cross-tabulated to account for those who experience multiple marginalizations. Currently, the proposed measure set only suggests that states *should* attempt to stratify the data, along with one measure which evaluates whether non-English speakers receive information in their preferred language.²¹ This is not

²⁰ *ASAN Opposes Unjust Changes to ACA Regulations*, Autistic Self Advocacy Network (Jun. 12, 2020), <https://autisticadvocacy.org/2020/06/asan-opposes-unjust-changes-to-aca-regulations/>.

²¹ RFI at 16.

nearly sufficient. Clear data showing health inequities in the HCBS system is critical for improving the overall quality of HCBS services nationwide.

We recommend that CMS review and refine the HCBS measure set annually using a process that prioritizes the voices of people with disabilities who use HCBS. We additionally recommend that this review evaluate the degree to which, and how, the measure set is working to improve the lives and community integration of HCBS beneficiaries.

An annual review would mirror the review of adult and child core measures, which is especially important given the ongoing measure development in HCBS. The review process must include plain language materials accessible by users of HCBS themselves, including users with intellectual and developmental disabilities (I/DD), and in-depth consultation with beneficiary stakeholders.

ASAN will continue to work with CMS and other disability rights organizations in order to ensure that HCBS quality is measured by the freedom possessed by HCBS beneficiaries and the degree to which we can live normal lives in the community. For more information on ASAN's positions with respect to HCBS please contact Kelly Israel, our Policy Analyst, at kisrael@autisticadvocacy.org.