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The National Association of State Directors of Developmental Disabilities Services (NASDDDS)

Respectfully Submits the Following Response to Centers for Medicare & Medicaid Services 42 CFR Part 440 [CMS–2404–NC] RIN 0938–ZB33 Medicaid Program; Request for Information (RFI): Federal Government Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services AGENCY: Centers for Medicare & Medicaid Services (CMS), HHS. ACTION: Request for information

Introduction

NASDDDS appreciates the opportunity to provide comment on the aforementioned RFI. NASDDDS members are the state agencies serving individuals with intellectual and developmental disabilities (I/DD) in each of the 50 states and the District of Columbia. Our members work in partnership with the State Medicaid Agencies to operate Medicaid long term supports and services for individuals with I/DD totaling approximately $42 billion annually, or nearly 30% of the total Medicaid LTSS expenditures nationally.

CMS will likely receive many comments in response to this RFI from a wide array of stakeholders. NASDDDS, as the membership organization of state agencies with key funding and operational responsibilities for these programs, respectfully requests that state agencies with funding and oversight responsibilities be given significant weight in the consideration of the comments received. States, as CMS' partners in the funding and management of the Medicaid program, should have a partnership role in shaping and designing programmatic improvements.

NASDDDS applauds CMS' identification of key, pressing issues requiring deliberation and is grateful for the opportunity to provide input.

General Comments

All of the topical areas identified within this RFI are essential to the continued efficacy of providing supports and services nationally to individuals with disabilities and individuals who are aging. Below, NASDDDS provides specific responses to the questions posed within the RFI, however, we also identified some cross-cutting considerations applicable to each of the areas:

- **Commitment to person-centered systems of support**

  - One of the most promising evolutions in LTSS during the past few years has been the Federal commitment to person-centered services. In consideration of each of these categories (and others), NASDDDS encourages CMS to demonstrate a steadfast commitment and ongoing technical support to enable LTSS systems to truly emerge as person-centered systems, keeping the individuals served and their families as the focal point. Such a focus will serve to further objectives related to quality, program integrity and overall system design and capacity.
- **Importance of the State/Federal Partnership**
  - States are key partners in the funding, oversight and operation of the Medicaid program. We encourage CMS to commit, in the deliberation on each of these elements and others, to utilize the partnership to jointly design solutions. Historical partnership efforts have resulted in long-standing and effective policies and products, particularly in the area of LTSS, and we would encourage a continued dedication to the proactive joint development of policies and solutions.
- **Effective and Efficient business practices**
  - Any effort to modernize the manner in which LTSS are designed, operated, and overseen should be governed by a commitment to effective processes that enable the deployment of limited human and financial resources to the important design, operations and oversight duties, removing where possible burdensome paper processes that may not add value to the individuals served.

Response to RFI Questions

A. What are the additional reforms that CMS can take to accelerate the progress of access to HCBS and achieve an appropriate balance of HCBS and institutional services in the Medicaid LTSS system to meet the needs and preferences of beneficiaries?

Since the early 1990s, State I/DD systems have been "balanced", in that the majority of the services provided to individuals with I/DD nationally are provided in home and community based settings. However, impediments remain, more so in some states than others, in fully achieving the appropriate balance of community versus institutional benefits. While significantly more obvious for individuals who are aging and individuals with physical disabilities, the structural barriers to HCBS continue to present challenges to state I/DD systems nationally.

While the benefit for intermediate care facilities for individuals with intellectual disabilities (ICF/ID) is an optional state plan benefit, all states must continue to offer it in their state plan in order to have an alternative to it in a 1915(c) waiver (still the predominant vehicle for community based LTSS nationally).

Utilizing current statutory authorities to further the priority of a better aligned LTSS system would be a welcomed development and NASDDDS submits the following items for consideration:

Programmatic and Clinical Eligibility

NASDDDS would encourage CMS to inform states of the opportunities under 1115 demonstrations to set needs-based functional eligibility less stringent than the institutional level of care. While this is already allowed in the 1915(i), state uptake of the opportunity has been hampered by the inability for states to have a controlled growth strategy to enable thoughtful change management and sufficient financial and system capacity development.

NASDDDS does support the concept of permitting a state to offer institutional care only to the extent individuals cannot be served with an appropriate amount of HCBS services in their own homes or other alternative community settings. However, such options should include sufficient flexibility to enable states to design policies and processes that are sensible for the individuals they serve (including the opportunity to target such approaches to certain populations/ages and subpopulations) and that do not become laden with burdensome bureaucratic process.

In both of these scenarios, NASDDDS would encourage the inclusion of procedural safeguards, including the right to a Medicaid fair hearing, to assure the level of HCBS support to such individuals is commensurate with their needs

NASDDDS also would encourage an alignment of the practices for level of care determination procedures across all authorities. Within the 1915(k), states may waive the annual recertification requirement for individuals if it is determined that there is no reasonable expectation of improvement or significant change in the participant's condition because of the severity of a chronic condition or the degree of impairment of functional capacity. This flexibility should be extended to all HCBS authorities, enabling a consistent approach that reduces both administrative burden and a potential area of stress for individuals with lifelong support needs and their families.

Financial Eligibility

Changes such as those noted above have both the promise and the challenge of tipping the institutional bias within the service array of Medicaid. However, there are still financial eligibility provisions that could hinder progress toward greater access to HCBS. Any policy developments, within an 1115 or otherwise, should consider opportunities to mitigate those biases, but must, as noted above, provide for state opportunity to manage the implementation and growth to incentivize state uptake.

One example for CMS consideration is to permit the state under an 1115 to establish a community-based Medically Needy Income level (MNIL). Currently, individuals spending down to Medicaid eligibility must spend down to the MNIL established within the state. These income levels were historically based upon a presumption that the individual lived in an institution, meaning that the MNIL is very minimal. This current MNIL construct essentially prevents an individual from moving to or returning to a community setting because there would be insufficient resources for the individual to live.

Ideally, states could craft multiple programs or consolidate multiple programs across disability or other target groups, in a manner that adheres to applicable laws (ADA, etc.). This aspect of the benefit would permit states to design tailored benefit packages for individuals with similar support needs.

And, as is often already customary within some 1115s, CMS should continue to permit states to offer eligibility akin to that permissible at 42 CFR 435.217 to individuals not enrolled in a 1915(c) waiver. This would be particularly helpful for states that have proceeded in developing 1915(k), the Community First Choice Option, as the current construct of eligibility creates administrative barriers for individuals who require enrollment in a 1915(c) waiver for eligibility purposes.

Importantly, the manner in which these groups or these adjustments to current practice are treated in the calculation of budget neutrality will impact state election. CMS should ensure that budget neutrality policies do not unnecessarily hinder state opportunities in this regard.

Enrollment strategies to enable controlled growth

States have limited financial and human resources. Any opportunities made available under existing statutory authorities should be structured to enable incremental growth toward the overall objective. Options that require either an accelerated ramp-up or that require the establishment of a de facto dual system (of services, eligibility, payment, etc.) will present insurmountable challenges to state uptake.

In the development of these options, CMS should highlight states strategies that can be utilized for measured, thoughtful and meaningful growth.

Person-Centered Planning and Service Delivery

As noted above, CMS' emphasis on person-centered planning and service delivery should be a pillar of any LTSS program design. NASDDDS encourages a strong partnership with states to provide more guidance on expectations related to person-centered planning and service delivery to ensure a continued focus on individuals, but not an unnecessary focus on paper processes.

Service Design and Offerings

NASDDDS encourages a continued permissibility to offer the full array of HCBS currently available in 1915(c) and 1915(i) in an 1115, including an emphasis on the importance of employment supports in enabling individuals to gain and maintain employment.

While room and board will remain a prohibited cost, CMS recognition of and strategies to address housing barriers is essential, including those supports available to help individuals establish and maintain community residences.

Opportunities for self-direction should be available in any service system, with sufficient state infrastructure to support individuals and to ensure strong program integrity.

Administrative Claiming

NASDDDS recommends that CMS, either through the 1115 demonstration if necessary or by other means, clarify that higher match is available for quality activities for HCBS (if provided by an external quality review entity). In both fee for service and managed care delivery systems, states should have sufficient resources available to them to provide robust quality oversight and performance improvement.

Furthermore, for those services provided under an 1115, evaluation construction should focus on meaningful individual and system-level outcomes.

Meaningful and Reasonable Transparency and Stakeholder Engagement

NASDDDS is appreciative of CMS' increased focus on transparency and meaningful stakeholder engagement, but fear that some of the recent processes (and the concomitant complexity of the waiver and related documents) may be contributing to a public input fatigue in some states, deterring meaningful conversation.

NASDDDS recommends the establishment of minimum expectations for stakeholder engagement to achieve the purpose of public input. These should include the following elements, but be sufficiently understandable and operationally feasible:

- Posting of summary documents, publicizing location (web or physical) of full technical documents
- Public input sessions – with volume and medium informed by the action or the contents of the action
- Summary of comments and dispensation of them in the final documents

Financing Considerations

As noted above, any opportunities made available within current statutory authorities must recognize the financial obligations of the states, permitting reasonable timeframes and flexibilities in program design to encourage, not dissuade, state election.

Administrative Simplification

In establishing opportunities for a revised approach to LTSS, it is essential that it include thorough yet streamlined CMS review, approval and oversight processes that focus on outcomes.

Recent practices resulting in increased state paperwork burden has impeded progress and increased costs in some instances without adding value to the individuals served. NASDDDS would encourage the development of CMS review and approval process that is more focused on performance and outcomes rather than process adherence.

CMS review could emphasize expectations for state systemic alignment with the objectives of the program with particular focus areas such as:

- Simplification for individuals and families
- Supporting families
- Promoting employment
- Financing considerations
- Stabilization of housing* (recognizing that CMS does not pay for housing, but needed supports can be essential in the maintenance of community residences).

CMS should ensure that the available sub-regulatory guidance is updated to ensure maximum consistency across authorities, reduces potential areas of contradiction and reflects the most current policy developments. This would include an update to Version 3.5 of the Instructions and Technical Guide.

B. What actions can CMS take, independently, or in partnership with states and stakeholders, to ensure quality of HCBS and beneficiary health and safety?

It has been nearly 15 years since there was a national impetus to redesign HCBS quality and CMS oversight of HCBS programs. The evolution of a data-based review process has strengthened state ability to utilize data in the ensuring that their processes are working within their programs. However, it would now be a good time to revisit these approaches to ensure a focus on meaningful systemic quality outcomes for HCBS (not just process and compliance). Any efforts must require, at a minimum, health/safety/freedom from abuse, neglect and exploitation, but should also support and encourage a broader focus on individual and system-level outcomes.

While these efforts must be careful to not hinder individual autonomy and choice, there is a state and federal obligation to make sure there are systems in place to identify and fix issues that compromise health and well-being.

We would strongly recommend the convening of a workgroup with state partners (including State Medicaid agencies and those agencies who operate HCBS programs) to develop core elements (and definitions) of abuse, neglect and exploitation (and other potential critical elements), similar to the core service definitions. This will provide a key framework for CMS expectations but enable some state-specific considerations.

A modernized approach to quality will allow CMS to draw upon recent national efforts related to outcome measurement. It must recognize, however, the structural undergirding that is essential to support a true approach to quality:

- Comprehensive robust infrastructure that sets the state on a path to high quality:
    - Case management;
    - Person-centered planning;
    - Incident management structures; and
    - System and Outcome Data and information systems.

With regard to structures for health and welfare, we do believe there are key constructs that each state must have in place and operational:

The state has a real time critical incident reporting system that---

- Clearly defines critical incidents resulting in harm, injury or death of Medicaid HCBS beneficiaries or circumstances that put a beneficiary at risk of harm, injury or death
- Reports such incidents to a centralized place outside of Medicaid HCBS providers for review and possible investigation
- Assures that provider staff down to the direct care level are regularly trained to use the incident reporting system and does periodic fidelity testing to double check
- Has consistent statewide criteria to triage such incidents by level of severity and defines response times for review and possible investigation according to severity levels
- Results in incident review and investigation findings along with specific mitigation action steps to prevent future similar incidents
- Is rolled up into a periodic trend analysis by provider to identify potential systemic issues, and is used in licensing or other program review of providers

The state has a system to report, investigate, and mitigate abuse and neglect of Medicaid beneficiaries that----

- Clearly defines abuse and neglect by levels of severity
- By statute or Medicaid policy requires mandatory reporting of all cases of abuse and neglect by medical practitioners, clinicians, professionals, state and local government officials, and Medicaid provider staff, including direct care staff, along with regular training on mandatory reporting duties
- Reports abuse and neglect to an authority operating 24/7
- Establishes response times for starting an investigation and initiating immediate protective proceedings based on the level of severity and standardizes these response times statewide

The state has a system to report, investigate, and mitigate abuse and neglect of Medicaid beneficiaries that----

- Assures an adequate number of trained protective service staff to meet required response times
- Concludes every substantiated investigation with a mitigation plan to prevent further abuse to the victim or other potential victims in close proximity

- Does fidelity reviews to test reporting patterns, response times and mitigation plans
- Conducts trend analysis of abuse/neglect cases to ascertain systemic issues and uses such analyses in licensing and other program reviews
- Has clear criteria to determine which cases are referred for criminal investigations and prosecution, including a clear agreement with the state Medicaid fraud unit

The state has a mortality review system that---

- Requires reporting of all unexpected deaths
- Conducts a preliminary review to determine any suspicious or unusual circumstances
- Conducts a full investigation when suspicious circumstances are present, including interviews with all relevant staff and a review of primary care and hospital records and autopsy reports by reviewers trained to review such records
- Concludes investigations by determining if abuse or neglect occurred, including a mitigation plan if anyone else in proximity of the deceased may also be at risk, and makes appropriate referrals to examining boards if any medical malfeasance is determined
- Does a trend analysis of unexpected deaths to detect any systemic problems and includes such analyses in any licensing or other program reviews

There are additional key considerations that CMS must undertake in order to assure strong quality efforts:

- Need to finance IT that supports meaningful data to inform quality efforts
- Need to finance personnel with sufficient quality expertise (not compliance orientation)
- Importance of resisting the temptation to impose survey and certification/conditions of participation model that does not work for in-home/community-based supports and may serve to undermine individualchoice and autonomy

CMS should reduce focus on counting and process and should instead focus on individual and system level performance outcomes (leveraging learning from quality in managed care service delivery systems). The current measures in the HCBS waivers, aimed at demonstrating compliance with statutory assurances, are primarily focused on measuring process rather than outcomes or true systems improvement. Recognizing that CMS must attend to minimum compliance, we might suggest a small standard set of standardized compliance measures that address the minimum statutory requirements. However, we would recommend that CMS, in partnership with the State government agencies who operate HCBS programs, identify a framework for actual performance measures that states can design to measure meaningful system outcomes, similar to those measures included in the National Core Indicators (in use in 46 states and the District of Columbia) and National Core Indicators for Aging and Disability. These are aggregated individual outcomes that provide a systemic view. States must be able to identify individual outcomes as well as systemic performance.

The quality framework designed in the development of HCBS waiver application (in 2003-2006) may be a good place to begin the discussion, recognizing that it must be updated to reflect current quality bodies of knowledge.

In terms of other steps CMS may consider, we would encourage exploration of opportunities to provide financial resources for data and IT to support quality efforts to enable states to design. In addition, we support efforts to ensure that state ability to access enhanced FMAP for IT systems for eligibility, enrollment and claiming systems is more streamlined for states to obtain, particularly for pieces critical in LTSS. Furthermore, given the importance of ensuring the health and welfare of individuals served in HCBS, CMS should consider an interpretation that enables enhanced FMAP for critical IT infrastructure facilitating incident management, mortality review, and broad quality oversight.

Such efforts would be aided by making technical assistance available from the CMS Regional Offices to assist states in the preparation of required document submissions.

In addition, the 1915(c) waivers have a high level of scrutiny on compliance and minimum standards. We would recommend that CMS work to move away from the minimum compliance orientation and to move to a more standard outcome-oriented focus on performance improvements. This could be done in a consistent manner across the various state plan and waiver authorities.

CMS should partner with states in the identification of necessary expertise and technical assistance in the formal quality body of knowledge to ensure a sound performance management structure.

C. What program integrity safeguards should states have in place to ensure beneficiary safety and reduce fraud, waste, and abuse in HCBS?

States share the Federal concern regarding ensuring the safety of individuals served, as well as with the prevention of fraud, waste and abuse, and continue to be actively engaged in developing strategies to address these issues.

For abuse, neglect and exploitation, as well as for fraud waste and abuse concerns, a multi-layered approach is essential to ensure that everyone involved in the service system understands their role and responsibility in relationship to keeping individuals safe and being strong stewards of taxpayer dollars.

Education is a key component for both of these broad issue areas, including protocols to assist individuals in making strong judgements related to these areas. For issues related to fraud, waste and abuse, we believe that CMS, CMS Program Integrity personnel and state Medicaid and operating agencies should collectively identify an array of strategies for state use. These should include:

Strategies for Prevention
Strategies for Detection
Strategies for Response to identified issues

Transcending all of these elements is a necessary ability to collect data and identify trends in order to inform performance improvement and prevent future instances of fraud, waste and abuse.

As noted above, we believe there are key elements to strong state systems to prevent abuse, neglect and exploitation, including functional systems for incident management and investigation, and other elements.

Importantly for both of these areas, it is important that CMS work with states to identify best practices for working relationships and information sharing across program personnel, program integrity personnel, law enforcement and others critical to keep individuals and resources safe.

Standard Federal Requirements

NASDDDS does not believe that minimum Federal standards is a key component in furthering program integrity, and may have unintended consequences of driving up costs without adding value in the efforts to prevent fraud, waste and abuse. Furthermore, this approach may serve to undermine individual autonomy and choice. NASDDDS recommends a partnership approach that includes states, providers and individuals served and their families in identifying strong practices for prevention. All of the key HCBS stakeholders have a vested interest in stemming any such fraud, waste and abuse, and together we can develop solutions that neither add cost and burden nor compromise individual autonomy and choice.

Worker Registries

States may wish to pursue this as a voluntary option, but registries should not be a prerequisite to employment (either in self-direction or traditionally furnished services). A mandatory approach to a registry has a number of issues for state consideration:

- Invokes employment relationship between state and potential home care workers.
- May preclude individuals' ability to freely choose otherwise qualified individuals from providing services.
- May introduce a costly endeavor to build and maintain within the state.

Instead, a worker registry could be an approach a state could pursue to improve linkages between individuals who need services and those who can provide them.

In relation to the remaining questions in this area, we believe that states should be able to demonstrate to CMS that they have system-level mechanisms to ensure that workers providing supports meet minimum qualifications, including eligibility to participate in federally-funded programs. States should retain discretion on certain matters, including process and approach to criminal background investigations. With regard to individual employee/attendant identifiers, NASDDDS believes that the burden of this proposed solution would far outweigh the potential benefits. Instead, states should be able to describe their own data capabilities and approaches to auditing that sufficiently demonstrates that they can ensure claims paid were for authorized, appropriate services provided to eligible individuals by qualified personnel.

As noted above, NASDDDS would strongly recommend a joint state/federal effort to identify an array of best practices from which states and their partners in the operation of the HCBS/PCS programs can draw to ensure strong program integrity. This effort should include an overview of the broad federal expectations, and continued effort to inform all

levels of the system in their role and responsibility in the stewardship of federal and state dollars.

D. What specific steps could CMS take to strengthen the HCBS home care workforce?

NASDDDS recommends the consideration of strategies that emulate the national health service corps' (HRSA.gov) capacity building efforts for direct support workforce. This program provides capacity development incentives (in the form of loan repayments) for certain clinical personnel to provide services in underserved areas. A comparable program may be advisable to incentivize capacity development in the home care workforce.

In addition, HCBS has lagged in utilizing technology as a solution to provide support to individuals. We recommend a state/federal effort to identify strong and/or emerging practices that can be leveraged in home and community based service settings to increase better utilization of technology.

Importantly, however, NASDDDS recognizes the perilous shortage of workers, both presently and in the foreseeable future. We encourage CMS to work closely with states to devise workable, sustainable solutions to attract greater numbers of individuals to this field. This should include acknowledgement of the support beneficiaries get through friends and family without bureaucratizing those relationships. CMS should consider how support of peer to peer and family to family networks can be available as a funded HCBS service and/or incorporated into administrative support of HCBS programs. We do not believe that significant federal intervention into state rate-setting efforts is the solution, however. States must have the flexibility to design state-specific (and sometimes population-specific) solutions that work within their specific context(s). Interventions such as those posed in the RFI may have significant and unintended consequences related to overall program sustainability, employee/employer relationships, and questions of federalism.

As noted elsewhere in this response, we believe that, in the partnership set forth by Title XIX, CMS and its state partners must together ascertain strong practices and guidelines for state consideration and adherence, but not prescriptive solutions that may inadvertently hamper the state innovation that has been a hallmark of the Medicaid program since 1965.