



November 9, 2015

The Honorable Charles E. Grassley
125 Hart Senate Office Building
Washington, DC 20510

Dear Senator Grassley:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) are writing to express our support for the intent of the Transition to Independence Act (S. 1604) and suggest some language and other feedback to further strengthen the goal of decreasing segregated employment and increasing competitive, integrated employment for people with disabilities. CCD is a coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of the approximately 57 million children and adults with disabilities in all aspects of society.

The undersigned organizations are very supportive of the goal of ensuring that millions of Americans with disabilities have access to integrated employment options and the opportunities to live and work as equals among their peers. We believe that the incentives-based approach of the Transition to Independence Act could be effective in ensuring that states are achieving its benchmarks and expectations. In addition, we make recommendations in the comments below to protect access to Medicaid home and community-based services as people transition out of segregated settings. Failing to retain access to needed supports such as personal attendants and more could jeopardize the success of the demonstration and threaten people's independence.

In order to better realize the intent of Transition to Independence, we submit the following specific feedback aimed at strengthening the proposed legislation.

General

The undersigned organizations believe that, given the strong evidence base that exists in favor of community integration and integrated employment outcomes, this demonstration should be made available to any state that is willing to meet the minimum eligibility requirements, rather than only ten initial states.

In addition, we recommend adding initial funding for selected states to build workforce capacity and retrain current direct support workers to better assist people with disabilities in transitioning to

competitive integrated, employment and integrated day services. We suggest that states be required to reinvest the bonus payments back into increasing integrated employment and integrated day outcomes for people with disabilities.

Medicaid Buy-In

We suggest replacing the current Medicaid Buy In (MBI) requirements contained in Section 2(b)(2)(A) and (B) that in order to be eligible for the demonstration the participating state must have a MBI with income limits of no less than 400% of FPL and at least \$20,000 in resources with a preference for participation rather than a requirement. We believe these requirements might severely restrict which states could participate (currently only 6 states have MBI programs that meet both of those requirements) and that states are not likely to participate if they would need to expand their MBI programs to do so. It also seems unlikely that states will offer MBI eligibility requirements for demonstration participants that are significantly more generous than their overall MBI programs (if that is even an option for states under the demonstration). As such, we urge you to change those requirements to a preference for award of demonstration participation rather than an eligibility requirement.

We also suggest that the Secretary be required to give preference to states that offer home and community based services, including employment based services and supports, to their MBI participants. Currently, states have the option to offer HCBS to people eligible under their MBI programs but not many do.

Recommended Language:

Sec. 2 (b)(1) Minimum Standards –

(2) PREFERENCE GIVEN TO CERTAIN STATES FOR DEMONSTRATION PARTICIPATION.—The Secretary shall give preference in selecting states to participate in the demonstration to states that have Medicaid Buy-In programs that meet the following requirements —

- (A) an assets or resources test for participation by an individual in the Transition to Independence Medicaid Buy-In Option that is not less than \$20,000;
- (B) an income requirement for for participation by an individual in the Transition to Independence Medicaid Buy-In Option that is at least up to 400 percent of the Federal poverty line;
- (C) offer home and community based services, including employment based services and supports, in the Medicaid Buy In program; AND
- (D) establish such other requirements for an individual’s participation in the Transition to Independence Medicaid Buy-In Option as the Secretary shall specify.

Potential Barriers to Implementation Relating to Interaction with Other Federal Programs

There are many unknown issues that may arise as this program is implemented. For instance, many CCD organizations have taken the position that determining eligibility for public programs is an essential governmental activity and should not be privatized. Requiring states to use independent contractors to determine who is potentially eligible to participate in the demonstration programs is a concern because

the legislation does not describe who these independent contractors might be, what qualification they must have, and what standards they would use to determine potential eligibility. The undersigned organizations recommend that the requirement that participating states use independent contractor be deleted.

However, we recognize that one of the goals of this language appears to be creating an eligibility pathway to the Medicaid Buy-In demonstration for people who are not Supplemental Security Income (SSI) beneficiaries or for people who have been determined eligible for disability insurance benefits under Title II of the Social Security Act. We recommend replacing the current language with a requirement that the state describe the specific eligibility criteria, beyond the income and asset requirements, that it will use to determine potential eligibility and the alternative eligibility process it will create and/or use for non-Social Security and SSI beneficiaries.

We recommend that there be a process whereby the Secretary identifies potential issues that may arise and that those concerns are included in the application process so that each state must identify how they will address the concerns.

Recommended Language:

Implementation Process in the Application Requirements –

The Secretary shall:

1. Identify the potential barriers to successful implementation that may arise, including but not limited to:
 - a. Eligibility review and criteria
 - b. State regulations on service delivery
 - c. Timeliness of eligibility determination
2. Include a request to outline how states would address the identified issues in the application process

Participating states shall submit a description of the eligibility criteria the state will use including the process it will use to determine potential eligibility for non-Social Security and SSI beneficiaries.

Person-Centered Planning

The undersigned organizations recommend adding an application requirement for the state to participate that describes the person centered planning process the state intends to use with demonstration participants. The person-centered planning requirements of the final rule, Medicaid Program: State Plan Home and Community-Based Services, 5 year Period for Waivers, Provider Payment Reassignment and Home and Community –Based Setting Requirement for Community First Choice and Home and Community –Based Services Waivers at this time does not explicitly refer to Medicaid demonstration programs pursuant to Section 1115 of the Social Security Act or other Medicaid demonstration authority. However, we urge that states be required to provide a description that is consistent with Section 441.301 of the final rule, which describes the person centered planning process needed for waiver and state plan home and community based programs.

Recommended Language:

Sec. 2 (c)(2)(G) Application Requirements - A description of the person centered planning process that the state intends to use with demonstration participants.

Rule of Construction (Requirements for Meeting Mandatory Benchmarks)

The undersigned organizations recommend that the language regarding the Rule of Construction be renamed Requirements for Meeting Mandatory Benchmarks and be altered to more accurately depict the intended outcomes. Renaming the requirement clarifies that it is a statutory requirement and not an interpretation of other language.

Recommended Language:

Sec. 2 (f)(3)(ii)(III) Requirements for Meeting Mandatory Benchmarks ~~*Rule of Construction*~~ – A working-age individual with a disability shall be deemed as counting towards a percentage reduction for purposes of this clause if the individual is

- a) employed in a competitive, integrated employment setting for at least 10 hours a week on average over a 120-day period during the year involved or
- b) receiving integrated day services that reach the level of care required in the individual’s person-centered plan or
- c) a combination of both (a) and (b);

enabling the individual to achieve, if desired, a comparable level of benefit as before the change in placement. The State must report aggregate data to the Secretary on the outcome of all individuals transitioning out of congregate settings being counted towards fulfillment of this benchmark.

Termination of Vocational Rehabilitation Funding

The undersigned organizations have questions regarding the “criteria” referenced in Sec. 2 (f)(4)(C). Is this criteria for constituting a segregated setting or criteria for terminating vocational rehabilitation funding? What are some elements of the criteria that you think might be established? Finally, does the Secretary of HHS have the authority to terminate Vocational Rehabilitation funding? If so, where is that authority granted?

Nature of Disability Language

The undersigned organizations recommend replacing the language about “the location and nature of employment is determined by the individual’s disability” to better clarify the legislative intent.

Recommended Language:

Sec. 2 (h)(4)(C) Exclusions – Such term does not include segregated enclaves, segregated mobile work crews or other employment scenarios where an individual is placed based solely on his or her disability.

Integrated Day Services

The undersigned organizations recommend taking this section out of the definitions sections and moving it to the section that describes standards a state must meet in order to meet the benchmarks. In other words, instead of defining integrated day, we suggest you recast this part of the bill as a set of standards for day services through which it can be determined that a particular set of day services are “integrated”, for the purposes of determining whether a state has met benchmarks for bonus payments only.

The term integrated day services means services that assist individuals with disabilities to develop a sense of identity and a feeling of belonging that comes from actively participating in the daily life of their communities. The goals are for individuals with disabilities to:

- Be supported in their efforts to actively participate in the diverse range of experiences that characterize community life.
- Not be segregated or denied the right to participate in any community activity solely on the basis of disability.
- Be familiar with their communities.
- Use the same community resources as others do, not depending on “special” services just for people with disabilities.

Recommended Language:

Integrated day habilitation services are provided outside disability specific programs or facilities and in settings that support the full access of individuals with disabilities to the greater community to the same degree as individuals not receiving services that are provided consistent with all of the following:

- a) Each individual receiving such services has an individually tailored schedule that is directly related to and reflects the individual's specific interests and goals.
- b) Activities take place on an individual basis or in small groups of individuals who choose to be served together.
- c) The majority of time spent receiving such services takes place within the broader community rather than within a single-site, fixed site, or center-based program for individuals with disabilities, regardless of the program size.
- d) The services are provided consistent with the requirements of section 441.710 of title 42, Code of Federal Regulations.

Providing Medicaid Beneficiaries Access to Premium Subsidies and Cost-Sharing in the ACA

The undersigned organizations are supportive of ensuring that people with disabilities have access to as many insurances options as possible to meet their health care needs. However, the organizations believe that statutory authority already exists for states to provide premium assistance for individuals in the Medicaid program. We therefore recommend that the ACA provisions be deleted from the bill. See the CMS frequently asked questions document about how states can provide premium assistance under

current law, which can be accessed here: <http://medicaid.gov/Federal-Policy-Guidance/Downloads/FAQ-03-29-13-Premium-Assistance.pdf>.

Stakeholder Involvement and Transparency

The undersigned organizations recommend adding language about transparency and the role of self-advocates. We believe the best recent model for transparent public engagement would be the regulations governing the comment process for § 1115 demonstration projects. This approach includes a 30-day comment period at the state level, a requirement for at least two public hearings and the posting of a detailed draft plan on the state website, and a requirement that the state include a response to public comments collected (along with a description of whether it incorporated these changes) in the draft it submits to CMS. In addition, stakeholders have another 30-day comment period at the federal level for the revised draft. CMS posts all these documents in a single place on its website, which makes it easier to track when new § 1115 proposals are up for federal review.

Self-advocate engagement should be a critical part of this process. In the context of other proposals to move people out of sheltered workshops and into integrated employment, inadequate direct outreach to self-advocates has resulted in their underrepresentation in the comments process. Self-advocates may face barriers to attending town hall meetings, especially if those meetings are not in accessible venues served by accessible public transportation. Self-advocates may also face barriers to commenting if the state fails to provide information on the demonstration project in plain language, or if the state posts the notice on the state web site without conducting additional outreach to the specific population targeted in the demonstration. In these situations, self-advocates may receive information about the proposal only through their service providers. Any comment process should therefore involve a concrete, practical outreach plan for self-advocates.

Evaluation

The undersigned organizations fully support the data collection requirement in the bill and recommends that CMS be given the authority and funding to evaluate the results of the demonstration in the participating states. States will be collecting and submitting data which should help stakeholders understand what is happening in the demonstration states but the bill should go further and require evaluation of the data and outcomes. The evaluation should include identification of best practices, evaluation of who received services and the outcomes, and other information that would be useful to other states seeking to increase competitive integrated employment.

Recommended Language:

Below is a modified version of the research and evaluation provisions for the Money Follows the Person Demonstration which is a model for this demonstration.

g) Research and Evaluation.—

(1) In general.—The Secretary, directly or through grant or contract, shall provide for research on, and a national evaluation of, the program under this section, including assistance to the Secretary in preparing

the final report required under paragraph (2). The evaluation shall include an analysis of the characteristics and outcomes of the individuals participating in the demonstration and the best practices developed to achieve the goals of the demonstration.

(2) Final report.—The Secretary shall make a final report to the President and Congress, not later than (enter date), reflecting the evaluation described in paragraph (1) and providing findings and conclusions on the conduct and effectiveness of Medicaid Buy In demonstration program.

(3) Funding.— Not more than \$1,100,000 per year shall be available to the Secretary to carry out this subsection.

Conclusion

We thank you for your longtime support for the disability community and your current efforts to decrease segregated day settings and increase competitive, integrated work and non-work activities. The undersigned organizations appreciate the opportunity to engage in constructive dialogue with your office to further strengthen the goals of this proposed legislation. If you have any questions regarding our comments or would like any further clarification/explanation of any recommendations contained in this letter, please contact Sarah Meek, Chair of the CCD Transition to Independence Ad-Hoc Workgroup, at smeek@lutheranservices.org.

Sincerely,

Association of University Centers on Disability
Autism Speaks
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Easter Seals
Goodwill Industries International
Jewish Federations of North America
Lutheran Services in America Disability Network
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Council on Independent Living
National Disability Institute
National Disability Rights Network
National Down Syndrome Congress
National Down Syndrome Society
The Arc of the United States
United Spinal Association