December 6, 2022

Response from the CCD DD, Autism and Family Support Task Force

These comments are submitted on behalf of the CCD DD, Autism and Family Support Task Force. The mission of the task force is to advocate for federal public policies that directly relate to individuals with developmental disabilities, autism spectrum disorders, family supports and the prevention of child abuse and neglect. These include, but are not limited to, the Developmental Disabilities Act, Autism CARES Act, Lifespan Respite Care Act, and National Child Abuse Prevention and Treatment Act.

2022 National Strategy to Support Family Caregivers

https://acl.gov/CaregiverStrategy

Questions for Narrative

1. **Which component of the strategy are you addressing with your comment?**
   a. **The 2022 National Strategy to Support Family Caregivers narrative**
2. **If you have additional comments on any aspect of the Strategy, please provide them below. (500 Characters)**
   a. We note that the Advisory Council discussed terminology such as "caregiver" versus "supporting families." We agree with the use of "supporting families." Care denotes a medical model that does not lend itself to supporting independence, dignity, and self-determination.

Questions for: Global comment for all four components

Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?

1.) The strategy correctly highlights the dire situation of the direct care workforce. Moving forward, the Advisory Councils should focus on how to develop a ready and well-qualified direct care workforce through better pay and working conditions, training, and improved career pathways.

2.) The Advisory Councils should focus on how Medicaid Home and Community-Based Services (HCBS) can help support caregivers.

3.) We acknowledge that caregivers should be a part of the care team but we would urge the Advisory Councils to highlight the care recipient should be at the center and is the ultimate decisionmaker.

Are there issues that are not covered in this component that should be addressed in future updates?

Accountability and transparency are critical as the National Strategy is being updated. We recommend that agencies working to implement federal actions are given the opportunity to provide updates to the public prior to the release of the updated strategy.

Questions for Federal Actions

3. **Which component of the strategy are you addressing with your comment?**
    a. **Federal Actions**
4. **Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward? (1500 Characters)**
    a. Assist all states in adopting the federal Lifespan Respite Care Program as a model to build statewide coordinated systems of caregiving and respite services for family caregivers caring for persons of any age or condition. Lifespan Respite grantees have demonstrated how to provide family and person-centered services; assist families in paying for care through self-directed voucher programs; developed innovative volunteer and faith-based models; built diverse coalitions; recruited and trained respite workers; and improved access to information and support through no wrong door systems.
    b. Make permanent eligibility, setting and provider flexibilities approved for Medicaid waiver HCBS under COVID-19 and provide emergency and ongoing respite that can accommodate those with behavioral, emotional, and mental health needs.
    c. Provide increased funding for IDEA's Parent Training and Information Centers, and HRSA's Family-to-Family Health Information Centers; creating a navigator program for family caregivers of adults with IDD who are not served under these existing programs.
    d. Make a dedicated FMAP increase for Medicaid HCBS permanent to build on the one year of funding included in the American Rescue Plan. An ongoing stream of additional federal funding, as outlined in the Better Care Better Jobs Act, is necessary to ensure that states have the fiscal certainty to actually expand access to and eligibility for services, including supports to families

5. **Are there issues that are not covered in this component that should be addressed in future updates? (1500 Characters)**
    a. Increased investments in publicly-funded-supports for people who live with family members must continue. Public policy should also focus on reducing waiting lists for people with IDD living with family members.
    b. Provide funding to assist in providing and using Augmentative and Alternative Communication, or AAC. This is crucial for the nonspeaking population in their communication with caregivers and others.
    c. Provide guidance as states implement HCBS Settings Rule and build person-centered planning with caregiver

   d. Expand the capacity of the SSA offices to decrease waiting times.
   e. Require the Office of Management and Budget to revise the Standard Occupational Classification (SOC) system to create a distinct classification for DSPs.
   f. Reauthorize and strengthen supporting families under Title II of the DD Act and authorize funding for each state and accountability to measure outcomes
   g. Authorize funding for parent training modeled after the successful Partners in Policymaking program
   h. Encourage CMS, PCORI, and NIDLRR to fund research and demonstration pilot programs. NIDLRR should also fund a family support center focused on the lifespan, not just elderly populations.
   i.

6. **If you have additional comments on any aspect of the Strategy, please provide them below. (500 Characters)**
   a. Accountability in implementation through transparency

Questions for State Plan

7. **Which component of the strategy are you addressing with your comment?**
   a. **Actions for States, Communities, and others** https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_ActionsSCO.pdf
8. **Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward? (1500 Characters)**
   a. An important component of the strategy is to encourage states to rebalance Medicaid spending to support caregivers in the community by adequately funding HCBS. It is critical that states support individuals with I/DD in communities. CCD values suggested actions such as requiring coverage of respite services, offering grants to develop adult day services, adopting self-directed models or vouchers that allow payment of direct care workers including family caregivers, and blending and braiding the funding sources to improve access to services.
   b. CCD stresses the importance of building capacity and providing training tracks and incentives to retain/recruit direct support providers, as the lack of DSPs is in a crisis.
   c. Another issue of importance is encouraging state agencies to compile an inventory of existing resources and programs for family caregivers. It also allows States to analyze current resources and programs to see what is missing.

    d. CCD agrees with the suggestion of incentivizing CBOs to train first responders and emergency department personnel to identify family caregivers during emergency situations and to ensure they have access to all necessary information.

9. **Are there issues that are not covered in this component that should be addressed in future updates? (1500 Characters)**
    a. An issue that is not covered is how to incentivize and track state implementation of the strategy. We suggest developing a mechanism to allow States to share with one another the different strategies they have implemented and track their impacts.
    b. Another issue not covered is supporting individuals and their families during crises and ensuring access to community-based mental health services and emergency respite and caregiver training. One strategy is for States is to establish a registry for real-time availability of community-based mental health services.
10. **If you have additional comments on any aspect of the Strategy, please provide them below. (500 Characters)**
    a. We appreciate the recommendation for researchers, students, or institutions to assess the effects on caregivers when individuals with disabilities, especially those with higher support needs, are integrated into the workforce through competitive, integrated employment practices. This is an issue many family caregivers face as their child with Autism transitions from school into the workforce.

PAID LEAVE COMMENTS

Questions

1. **Which component of the strategy are you addressing with your comment?**
    a. **The 2022 National Strategy to Support Family Caregivers narrative**
2. **Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward? (1500 Characters)**
    a. The Paid Leave Ad Hoc Task Force focused on paid leave policy and will focus our comments on that subject. We would urge the Advisory Councils to focus on the following three topics which overlap the goals that have already been identified: 1) Highlighting the importance of enacting a paid family and medical leave program that has a broad family definition and includes all workers. 2) Ensuring that caregivers are aware of the options available to them, including current leave options (including unpaid FMLA leave and state paid leave programs, paid sick days, flexible work hours, etc.) and other services (see the comments of the CCD LTSS Task Force). 3) Ensuring that federal agencies are sufficiently collecting

    data about caregivers (including racial equity, disability, LGBTQ etc.), funding and conducting research on the use and impact of paid leave programs, and highlighting the needs of caregivers. These three goals would focus on the progress we need to make, while also helping caregivers learn about and helping them to access the limited programs and services they can access now.

    b. We appreciate the mentions of paid leave through the narrative. In particular, we strongly support the call to action for lawmakers to pass a federal paid family and medical leave act. We also support the smaller outreach and engagement steps identified that would improve worker awareness of existing unpaid leave options.

3. **Are there issues that are not covered in this component that should be addressed in future updates? (1500 Characters)**
    a. We were disappointed to see that education on existing unpaid options is not comprehensively included throughout the strategy. It is equally important for CMS and HHS programs to educate caregivers on their currently available options as it is for not only ODEP and the Women's Bureau, but also all DOL to do so. Many caregivers are not aware of their rights or of options that may be available to them. Especially given the current direct care workforce crisis (as discussed in the narrative), ensuring that family caregivers know about and can utilize unpaid leave, sick days, state paid leave, and other programs should be a top priority for the Administration.
    b. We are particularly concerned that the Narrative only suggested a broader definition of "family" that includes grandparents and kin caregivers. While obviously it is important to include grandparents and other caregivers, it is equally important to include siblings, grandparents, aunts, uncles, cousins, nieces, nephews, grandchildren, and domestic partners and others related by blood or affinity. We would urge revisions to the report to make it clear that all these individuals must be included in an expanded family definition.
    c. We would also urge the Administration to ensure that data collection related to caregiving include not only demographic information, but information about gaps in the service system that result in great need for care (such as the number of hours of assessed need v. the hours actually staffed).