

2022 National Strategy to Support Family Caregivers Comments

Comments for Narrative

Which component of the strategy are you addressing with your comment?

- The 2022 National Strategy to Support Family Caregivers narrative

If you have additional comments on any aspect of the Strategy, please provide them below.

- 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.

Global comment for All Components

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

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

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.

Comments for Federal Action

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

- 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.

- 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.
- 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.
- 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
- Reauthorize and strengthen supporting families under Title II of the DD Act and authorize funding for each state and accountability to measure outcomes
- Authorize funding for parent training modeled after the successful Partners in Policymaking program
- 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.

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

- 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.
- 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.
- Provide guidance as states implement HCBS Settings Rule and build person-centered planning with caregiver
- Expand the capacity of the SSA offices to decrease waiting times.
- Require the Office of Management and Budget to revise the Standard Occupational Classification (SOC) system to create a distinct classification for DSPs.



If you have additional comments on any aspect of the Strategy, please provide them below.

- Accountability in implementation through transparency

Comments for State Plan

Which component of the strategy are you addressing with your comment?

- Actions for States, Communities, and others

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

- 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. We value 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. We stress the importance of building capacity and providing training tracks and incentives to retain/recruit direct support providers, as the lack of DSPs is at a crisis. Another issue of importance to our affiliates is encouraging state agencies to compile an inventory of existing resources and programs for family caregivers. The value of the Autism Society is to connect individuals with resources and this would be a great support in doing so. It also allows States to analyze current resources and programs to see what is missing. We also value the suggestion of incentivizing CBOs to train first responders and emergency department personnel to identify family caregivers during emergency situations and ensure they have access to all necessary information. Many of our affiliates provide training to first responders on how to interact with individuals with autism, and identifying caregivers is a critical aspect to ensure safe interactions.

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

- An issue that is not covered is how we can incentivize and track state implementation of the strategy. It would be ideal to have a mechanism to allow States to share with one another the different strategies they have implemented and track their impacts.
- Another issue that is 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. A great strategy for States is to establish a registry for real-time availability of mental health services.



If you have additional comments on any aspect of the Strategy, please provide them below.

- 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.