



State Council on Developmental Disabilities



STATE OF CALIFORNIA
Gavin Newsom, Governor

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January 30, 2023

RE: Developmental Disabilities Council State Plan
OMB Control Number: 0985-0029; Doc. Number 2022-26077

To Whom It May Concern:

Thank you for the opportunity to provide comments on this issue. On behalf of the California State Council on Developmental Disabilities (SCDD), we urge you to thoroughly review the data collection process for State Plans.

The Federal Register announcement requests public comments on the proposed collection of information, especially regarding the four categories below. SCDD's response to each part follows:

(1) Whether the proposed collection of information is necessary for the proper performance of ACL's functions, including whether the information will have practical utility

Increased demographic data does have value in the creation and implementation of State Plans. The data could help find and serve commonly underrepresented communities, and closing gaps is always the goal of any State Plan. SCDD notes, however, that some of the required data points might not match or correlate directly one-to-one to demographic data collected or reported through federal and state sources. Additionally, with socio-economic political dynamics, some of these data points are difficult to collect and even asking will result in people not attending SCDD events. It is also possible that some of the topical narrative questions may not directly link to any actual State Plan goals. As with any increase in required demographic survey information, once multiplied by the number of surveys conducted, this increases staff time on compiling and analyzing the data. SCDD urges restraint as feasible on questions that do not directly correlate to any State Plan goal versus collecting data just for collection's sake and flexibility where data collection can result in barriers providing ACL-funded activities under the SCDD State Plan.

(2) The accuracy of ACL's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used to determine burden estimates

The announcement suggests that an average amount of time spent on the State Plan is 367 hours. As expected from the most populous state, SCDD expects a significant amount of time will be spent on the State Plan in the coming years, perhaps an order of magnitude larger than the federal estimate. In the last State Plan period, SCDD received approximately 6,500 responses, half of which were digital and

"The Council advocates, promotes & implements policies and practices that achieve self-determination, independence, productivity & inclusion in all aspects of community life for Californians with developmental disabilities and their families."

half via hard (paper) copies. Compiling and analyzing this data requires months of work of several SCDD staff members - significantly more time than reflected in the ACL estimate.

Of course, California has the largest number of survey reports, and reviews. But the increased number scales faster than one would expect, given just a larger population. This makes the total average across states and territories an unreliable indicator of the required hours for larger-population states spending significantly larger amounts of time on research, analysis and development of the State Plan.

Further, although no state received a full passing review for its State Plan, California's State Plan received feedback with only minor formatting edits, with no major requested changes. For California, the entire time spent finalizing the State Plan was approximately two years, which included translation of the statewide survey, proposed State Plan and public comment survey into 16 languages for maximum outreach, and repeated review by community-based cultural and linguistic focus groups for accuracy and relevancy. The additional time required to edit, review, and build surveys on the Qualtrics platform also requires more staff time to ensure California's State Plan and its development process meet federal requirements. In short, the process of developing a State Plan that is useful, accurate and relevant requires significantly more time than the estimate assumes.

SCDD urges federal officials to consider a sense of proportionality in reporting requirements as compared to the relatively small amount of federal funds received by Councils.

(3) Ways to enhance the quality, utility, and clarity of the information to be collected

The utility of the information collected is significant, as discussed in point (1). However, SCDD would encourage further collection of qualitative information (i.e., stories from individuals), rather than a focus on such raw, unwieldy data. In addition, while the intent of the Executive Orders to achieve equity and equality for LGBTQI individuals is vital, invasive or highly personal demographic questions often elicit very low response rates. Survey respondents question as to why these questions are being asked at all, and if they are needed for the individual to obtain the services that they need. Each further question unrelated to the specific needs of the individual creates further mistrust with the interviewer or public survey process and adds an even greater time and work burden in adding new information into the State Plan.

(4) Ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques when appropriate, and other forms of information technology

While ACL is well aware of challenges with the Verity system it is worth documenting the experience at this point in time as it relates to minimizing burden. The Verity system makes uploading mass amounts of quantitative and qualitative/narrative data difficult, given its formatting issues. Graphs, tables, web addresses, and even some symbols and characters all are difficult or impossible to enter into the system, requiring narratives that strain available character limits. Staff spends significant time trying to get data to fit into the system. A more accessible, data-relevant and user-friendly platform

would significantly lessen problems associated with information collection and reporting. If there were some ability to copy and paste respondent narratives directly into the system without these Verity limitations, that would aid data reporting. A standardized form for uploading quantitative data sets (i.e., a .csv file or Excel spreadsheet) would also lessen the time burden, as opposed to entering data one cell at a time.

Thank you for the opportunity to comment on Developmental Disabilities Council data collection, reporting and State Plan development process.

Sincerely,

A handwritten signature in blue ink, appearing to be 'A. Carruthers', with a stylized flourish at the end.

Aaron Carruthers
Executive Director
California State Council on Developmental Disabilities