



Nothing about us without us!

Dear Assistant Secretary Robertson,

We are writing to you again in follow up to a coalition letter sent to you on May 2nd, 2019, as well as public comments submitted by ASAN on April 29th, 2019, regarding the composition of the National Quality Forum's (NQF) panel to set national quality standards on Person-Centered Planning. [As you know](#), we are profoundly concerned by the lack of self-advocate experts with intellectual and other cognitive disabilities--the people most likely to have highly relevant lived experience with person-centered planning--on the panel. This lack of representation threatens the legitimacy of the panel itself. Due to the seriousness of this issue, we are requesting that you work with CMS to cancel the contract with NQF and restart the process with a new contract which clearly outlines core considerations for panel composition, including the central role of self-advocate experts.

Of the 28 individuals on the panel, only 3 are individuals with disabilities, all of whom represent the Independent Living movement, and only one of whom has identified as having an intellectual disability. No self-advocates were included who are expert leaders in the self-advocacy movement for people with intellectual and developmental disabilities--the community most likely to have person-centered plans. There are no self-advocate experts from the mental health or aging communities. In order to embody the values of person-centered planning, it is imperative that people with disabilities be deeply involved in any discussion on this topic, *especially* the critical discussion on developing performance measures which will drive payment and policy. Any project that claims to focus on person-centered planning, yet does not center the voices of people with disabilities, violates the core principles of person-centered planning.

Any recommendations resulting from a panel with this fundamental flaw will therefore necessarily lack legitimacy. Indeed, we have already seen the inevitable consequences of this approach. Representatives from NQF responded to our concerns by referring to "patient self-advocates" and assured us that there are "proponents for underrepresented populations within the Committee," noting that "not all voices can be directly represented." During the meeting itself, one committee member argued that some individuals lacked the capacity to have goals. Each of these statements is offensive, betrays a basic lack of knowledge on the topic, and is contrary to the fundamental values of person-centered planning. Taken together, they are utterly disqualifying.

It is clear that the panel, as it is currently composed and staffed, will be unable to discharge its duties and deliver meaningful recommendations. It must be disbanded. A new contract must be written which corrects these fundamental problems and

ensures they won't happen again. The current panel must be reformed and expanded until at least one-third of its members are self-advocates with disabilities, including people with mental health disabilities and older adults, as well as disabled leaders of color. At least 50% of these self-advocates must be leaders with intellectual and developmental disabilities, including autism, who are experts on person-centered planning and leaders in the self-advocacy community. We the undersigned are happy to work with ACL and CMS to educate NQF staff regarding person-centered planning, accessible meetings, and supporting self-advocate leaders. There is no substitute, however, for the voices of people with lived experience. The work of the panel cannot move forward until this occurs.

The project before NQF represents an enormous opportunity to improve the quality, consistency, and usefulness of person-centered planning across the country. The quality of person-centered planning has a direct, tangible impact on the quality of life of people with disabilities and older adults. This project has the potential to change our lives. But the dangers of a panel which ultimately is not able to fully embody the principles of person-centered planning and produces flawed, regressive recommendations are equally profound. This is too important to get wrong. We urge you, in the spirit of person-centered planning, to heed the voices of the people at the center of this discussion--and require NQF to do the same.

With respect,

Autistic Self Advocacy Network
National Council on Independent Living
National Coalition for Mental Health Recovery
Self Advocates Becoming Empowered
Disability Rights Education and Defense Fund
Not Dead Yet
ADAPT Montana
Chicago ADAPT
Disability Policy Consortium of Massachusetts
Topeka Independent Living Resource Center, Inc.
Starkloff Disability Institute
Judith Heumann

In solidarity:

Justice in Aging
National Disability Rights Network
Center for Public Representation
American Therapeutic Recreation Association
National Consumer Voice for Quality Long Term Care
National Health Law Program