



Nothing about us without us!

To the National Quality Forum's Person-Centered Planning Panelists,

Thank you for committing your time and expertise to improving the quality of person-centered planning for people with disabilities of all ages. [As you are aware](#), we have expressed concerns regarding the limited representation of people with disabilities on the NQF panel. 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. We are profoundly concerned by the overall 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. There is also a notable lack of self-advocates with mental health disabilities. We are writing you today to ask for your assistance in rectifying this situation.

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, including the critical discussion on developing performance measures for it. 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. In solidarity with our community, we ask that you withhold your participation in future panel discussions until more disabled panelists with a diverse range of experience are added. Specifically, we believe that at least 1 in 3 panelists should be people with disabilities, half of whom should be individuals with intellectual or developmental disabilities with expertise in the self-advocacy movement.

We deeply respect your work and critical insights into the topic of person-centered planning, and we are relying on you to use your influence to do what is right: acknowledge this oversight and fight for a solution. Until the disability community is fully represented on your panel, it is impossible for progress to be made. By choosing not to participate as a panelist until we achieve this goal, you can help us illustrate this point to the individuals who can make these changes. As people with disabilities, we know all too well what it is like to have our voices silenced. Please join us by withholding your voices in solidarity until ACL ensures our entire community is heard.

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  
Center for Public Representation  
National Consumer Voice for Quality Long Term Care  
National Health Law Program