

May 2, 2019
URGENT

Re: Person Centered Planning Committee and National Quality Forum

Administrator Lance Robertson
Administration for Community Living
Department of Health and Human Services
330 C Street SW
Washington, D.C. 20201

Dear Administrator Robertson,

We are writing to express our disappointment with the current status of the Person Centered Planning and Practice Committee (PCPPC) convened by the National Quality Forum, and to request your immediate action.

The roster of the PCPPC members has a number of well-respected and competent professionals; however, it includes no individuals with intellectual disabilities or psychiatric diagnoses, who represent a large number of the individuals directly affected by the committee's work. Several of the organizations and individuals who signed onto this letter submitted comments in response to the roster about this lack of representation, and the responses indicated that this will not be changed. This is unacceptable!

The responses received stated, "We have captured proponents for underrepresented populations within the Committee. Because of size constraints, not all voices can be directly represented." This is antithetical to the entire concept of person-centered planning. Person centered planning requires that people with disabilities are at the center of, *and active participants in*, their plans. This comment is deeply troubling and calls into question the legitimacy of the panel itself. A panel which sees no issue with excluding the individuals most likely to have person-centered plans, and most likely to have directly relevant lived experience, is not a legitimate body to develop any sort of metrics with regard to person-centered planning.

Further, the responses suggested that these individuals should participate in web meetings and other opportunities open to the public - the first of which is scheduled for tomorrow, which is less than one week from the response date. They did not provide adequate lead time nor any information on accommodations for participation, which all but guarantees many of those not represented on the committee will not be able to participate in the web meeting. This is both disingenuous and in violation of the ADA's requirements for public accommodations.

ACL's mission states that "All Americans – including people with disabilities, and older adults, - should be able to live at home with the supports they need, participating in communities that value their contributions."

This mission only can be supported when the person with the disability, or who is older, is at the true center of their individualized person centered planning process and "at the table" designing the process and its training. In view of these major concerns and the critical importance of this work on Person Centered Planning, we request that you postpone the Friday May 3, 2019 PCPPC meeting and delay any further work until the issue of committee membership has been rectified. To that end, we request that you meet with representatives from the cross-disability community to determine the appropriate process for moving forward and reopening the nomination process to ensure adequate representation on the Committee. These representatives should include: Self Advocates Becoming Empowered (SABE), the Autistic Self Advocacy Network (ASAN), the National Coalition for Mental Health Recovery, the Bazelon Center for Mental Health Law, the American Association of Retired People (AARP), the Brain Injury Association of America (BIAA), and the National Council on Independent Living (NCIL).

Thank you for your immediate attention to this letter.

Signed,

ORGANIZATIONS:

Access Living: Amber Smock, Director of Advocacy

ADAPT of Chicago: Cal Montgomery, Organizer

ADAPT of Georgia: Zan Thornton, Rev Butch Brosman, Co-Chairs

ADAPT of Kansas: Mike Oxford, Organizer
ADAPT of Metro DC: Laura Halvorson, Organizer
ADAPT of Montana: Marsha Katz
ADAPT of Texas: Bob Kafka, Organizer
ADAPT of Washington: Janine Bertram Kemp, Organizer
American Association of People with Disabilities: Helena Berger, President
and CEO
Autistic Self Advocacy Network (ASAN): Julia Bascom, Executive Director
Bloom's Connect: Sheryl Grossman, Founder/Facilitator
Boston Center for Independent Living: Bill Henning, Director
Center for Independence, Lakewood, WA: Pat Kosier, Director
Center for Public Representation: Alison Barkoff, Director of Advocacy
Colorado Cross-Disability Coalition: Julie Reiskin, Executive Director
Council on Quality and Leadership: May Kay Rizzolo, CEO, CQL
DAYBREAK4DEAF, S.V. Thornton
Disability Policy Consortium of Massachusetts: Charlie Carr, Legislative
Liasion
Disability Rights Education & Defense Fund: Susan Henderson, Executive
Director
Disabled Queers In Action (DQIA): Elisabeth Huhn, Co-Founder
HIGH IMPACT: Allan I. Bergman, CEO
Liberty Resources: Nancy Salandra, Director of Independent Living
Services
National Council on Independent Living: Kelly Buckland, Executive Director
National Council on Independent Living—Emergency Planning
Subcommittee: Todd Holloway, Chair
National Organization of Nurses with Disabilities (NOND): Eileen Quinn, Co-
Director
National Rehabilitation Association: Fredric K. Schroeder, Ph.D., Executive
Director
Not Dead Yet: Diane Coleman, President/CEO
Partnership for Inclusive Disaster Strategies: Marcie Roth, CEO
Personal Attendant Coalition of Texas: Cathy Cranston, Organizer
Portlight Strategies, Inc.: Paul Timmons, Jr., Director
Starkloff Disability Institute: Colleen Kelly Starkloff, Founder/CEO
TASH, Inc: Ruthie-Marie Beckwith, Executive Director
Topeka Independent Living Resource Center: Ami Hyten, JD, Executive
Director

Reverend Butch Brosman: Georgia, individual signer

Cc: Bob Williams, Independent Living Administrator, ACL
Shawn Terrell, Health Insurance Specialist, ACL
Ralph Lollar, Director of LTSS, CMS