



Nothing about us without us!

April 26, 2019

Administration for Community Living (ACL)

VIA ELECTRONIC MAIL – pcplanning@qualityforum.org

Autistic Self Advocacy Network Re: Proposed Roster for Person-Centered Planning Panel

The Autistic Self Advocacy Network¹ appreciates the opportunity to provide comments on the proposed roster for the Person-Centered Planning Panel. ASAN is firmly committed to improving the quality of person-centered planning and is pleased that both the Administration for Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS) are collaborating towards the development of performance measures for it. However, ASAN is extremely concerned about the woefully limited representation of people with disabilities on the panel itself. Only one person on the panel is listed as a self-advocate, and none of the proposed panelists have an intellectual disability.

Long term services and supports *must* be constructed, informed, and delivered with the in-depth involvement of those they are designed to serve - people with disabilities. ASAN is pleased that ACL and CMS have crafted a roster of individuals who have significant expertise in the field. An effective stakeholder panel is critical to the success of this project. However, the vast majority of the panelists (although some work in the Independent Living field) have either a service provider or medical background. Only one person on the panel is listed as a self-advocate, and none of the proposed panelists have an intellectual disability. This is a glaring and unacceptable oversight given the number of long term services and supports (LTSS) beneficiaries with intellectual disabilities. Additionally, as far as we are aware, no one on the proposed roster has a mental health disability.

Failing to include the individuals most likely to *use* person-centered planning is contrary to the goals of person-centered planning. It severely limits the kinds of improvements that the panel can possibly make, and amounts to holding meetings About Us, Without Us. These serious deficiencies are not present because experts do not exist. The following is a list of

¹ The Autistic Self Advocacy Network (ASAN), a 501(c)(3), non-profit organization, is the nation's leading self-advocacy organization by and for autistic people ourselves. For more information on ASAN, you can visit our website at: <http://www.autisticadvocacy.org>.

expert stakeholders with intellectual disabilities who are highly qualified to serve on the panel:

(1) **Tia Nelis**, the Director of Policy and Advocacy at TASH and founder of People First of Illinois;

(2) **Liz Weintraub**, Senior Advocacy Specialist at the Association of University Centers on Disabilities (AUCD), disability policy expert, and nationally recognized public speaker;

(3) **Julie Petty**, President of the Board of Directors of Disability Rights Arkansas, Disability Specialist at Partners for Inclusive Communities, past President of SABE from 2006-2009, and previous Chair of the President's Committee for People with Intellectual Disabilities;

(3) **Ivanova Smith**, Advocate Faculty at the University of Washington Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program, Young Professional Board Member at the Arc of King County, and previous Self Advocacy Coordinator and Chair of Self Advocates in Leadership (SAIL);

(4) **Max Barrows**, Green Mountain Self Advocates Outreach Director and previous White House "Champion of Change," who provides technical assistance to self-advocacy groups and peer support groups throughout the state of Vermont;

(5) **Ricardo Thornton**, Vice Chairperson of the D.C. Developmental Disabilities Council, former member of the President's Committee for People with Intellectual Disabilities (PCPID), Member of Project ACTION!, survivor of the infamous Forest Haven institution, nationally recognized deinstitutionalization advocate and disability rights expert, and Special Olympics athlete;

(6) **Bernard Baker**, President of Self Advocates Becoming Empowered (SABE), President of People First of Georgia, and Georgia Advocacy Office Board of Directors member.

ASAN therefore urges CMS and ACL to appoint multiple stakeholders with intellectual disabilities - including individuals who receive home and community based services (HCBS) and/or LTSS and participate in the person-centered planning process. We also urge ACL and CMS to specifically recruit stakeholders of color, stakeholders who are LGBTQ, and stakeholders with mental health disabilities. To do otherwise would call into question the legitimacy of the panel itself and undermine its critical mission.

For more information on ASAN's positions with respect to self-advocacy and representation of people with disabilities in matters that concern us, please contact Samantha Crane, our Director of Legal and Public Policy, at scrane@autisticadvocacy.org.