

Person-Centered Planning and Practice Proposed Roster with Public Comments and NQF Responses

Lavina Tomer, Chair

Organization: Southern Arizona Senior Pride

Comment

Hello, Senior Pride serves the LGBTQI+ community in Southern Arizona. My comment: It is critical that there is one or more professionals and advocates who are inclusive and are committed to diversity on the panel. Does your anti-discrimination clause include sexual identity and gender identity or expression? I would like to see someone on the panel who will speak to minority communities: their experiences, needs, compounded aging issues and lack of services. I would include people of color, different languages, sexual and gender minorities, immigrants and refugees. Thanks for the opportunity to comment.

Received: Monday, April 15, 2019

NQF Response

Thank you for your comment, during its selection process NQF took into consideration a wide range of perspectives when assembling the Committee with special consideration towards individuals that represent often marginalized groups and those individuals that have experience with cultural competency. There are several Committee members that meet these requirements. Because of the constraints on Committee size, we cannot accommodate all minority voices directly on the Committee, but welcome all to attend the meetings and offer their insights during the public comment period of the calls. There will also be opportunities to make comments on draft versions of the Committee's reports.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Mary Lee Fay, Executive Director

Organization: National Association of State Directors of Developmental Disabilities Services (NASDDDS)

Comment

Thank you for posting the proposed roster for the Person-Centered Planning and Practice Committee. We appreciate that this roster has not yet been finalized, as we believe you inadvertently omitted an essential stakeholder set from this group. Individuals with intellectual and developmental disabilities comprise a significant group of individuals receiving LTSS in this country. The state systems that provide essential supports to them manage more than 1/3 of our nation's LTSS budget. It is imperative that I/DD systems and the individuals they support have representation in these critical discussions. Therefore, we respectfully request that you reconsider the application for Mary Lou Bourne, Director of Quality for the National Association for State Directors for Developmental Disabilities Services (NASDDDS) to be on NQF

Person Centered Planning and Practice work group. We find given the scope of LTSS for people with I/DD across the nation is so large that this is a significant gap in your representation. Ms. Bourne has the capacity to represent the state I/DD programs through her association work and has one of the most extensive resumes nationally on person centered planning, person-centered thinking and person-centered systems, making her an ideal applicant for this group. Please reconsider your decision.

Received: Monday, April 15, 2019

NQF Response

Thank you for your comment. NQF received a record number of applicants for the Committee. During its selection process NQF took into consideration a wide range of perspectives when assembling the Committee with special consideration towards individuals with I/DD that received HCBS LTSS services. We appreciate your concern about I/DD state system representation. We believe that our roster has sufficient representation of state's providing I/DD services but encourage individuals that were not selected for the Committee to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Leslie Feinberg, Organizer/ Peer Facilitator

Organization: Supporting Our Youth & Adults Network (SOYAN)

Comment

In the time I've known Amber Decker I have seen her skills at peer facilitating and research expand. Amber is a conscientious daughter to her mother with serious mental illness as well as a staunch advocate for her son with autism. Additionally, as a parent advocate with serious roots in the metropolitan NYC sphere of educational and OPWDD-policy issues, Amber shines. Amber is always willing to take on a task that benefits the advocacy interest and paves the way for new opportunities to engage families in our shared community. The intersection of family life on the dynamics of supports can only be understood by a person with lived experience. Amber Decker embodies all that and more! The presence of a family member on this panel addressing Person-Centered Planning shines a light on the importance of engaging the people the services are intended to support. I applaud the committee's inclusion of Amber Decker and support the important work of the committee. Thank you for your time!

Received: Monday, April 15, 2019

NQF Response

Thank you for your comment of support for Ms. Decker. During the selection process NQF took into consideration a wide range of perspectives and wanted to ensure representation of family members, advocates, and peer supports.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Valdeko Kreil, NHA, Administrator

Organization: Utuqqanaat Inaat

Comment

Good afternoon, I wanted to inquire whether there is still time to be considered as a panelist? If so, please let me know what information you would need from me. Thanks in advance.

Received: Monday, April 15, 2019

NQF Response

Unfortunately the 30-day nominations period for the Committee is closed. We encourage you to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Thank you,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Marsha Katz

Organization: ADAPT,

University of Montana Rural Institute, retired

Social Security Advisory Board, retired

Comment

Hi, I notice a lack of someone with an intellectual disability and someone with a mental health disability on the roster. Hoping you will fix this so there is at least token representation, and then please assure they have any any needed accommodations, and that plain language is used.

#NothingAboutUsWithoutUs #RepresentationMatters

Received: Monday, April 15, 2019

NQF Response

Thank you for your comment. We felt very strongly that the voices from the community, including those with intellectual disability and mental illness, needed to be adequately represented on the panel. We have individuals who receive home and community based services represented, as well as those who have extensive experience working with and designing programs to empower those with intellectual and behavior health challenges. NQF did not receive nominations for individuals that self-identified as intellectually impaired or having mental illness. Because we actively seek a balanced and representative broad range of perspectives, we invite additional voices to be heard. We encourage public participation

during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Respectfully,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Jim Lenker

Organization: Not mentioned

Comment

Dear PC Planning Team, I reviewed the proposed roster, and it looks very strong. My biggest recommendation would be to consider adding at least one physical therapist and one occupational therapist to the roster. Both professions are involved as service providers throughout the lifespans of people with disabilities -- early intervention, school-based therapy, transition plans, vocational placement, adult inpatient and outpatient rehab, home care, and skilled nursing. In addition, both are involved with a spectrum of disability populations: developmental disabilities (e.g., cerebral palsy, learning disability, autism spectrum disorder), acquired physical disability (e.g., head trauma, spinal cord injury, cumulative trauma, arthritis), progressive conditions (e.g., multiple sclerosis, ALS, muscular dystrophy, dementia), mental health difficulties, and cancer. In all of the above cases, the perspectives of both disciplines would be helpful in supporting the needs for person-centered planning, as well as the action steps that would foster making PCP a reality.

Received: Monday, April 15, 2019

NQF Response

Thank you for your comment. NQF received a record number of applicants for the Committee, including a wide range of professionals and professional societies that provide care to individuals in this community. Unfortunately we are not able to include them all directly into the committee. We agree that occupational therapists and physical therapists provide critical services for individuals with disabilities, especially those receiving home and community based services. Because we actively seek a balanced and representative broad range of perspectives, we invite additional voices to be heard. We encourage public participation during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Respectfully,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Susan Hershman

Organization: Child Development Specialist

Comment

Dear All, I highly recommend Amber Decker to be a member of the Person Center Planning panel. She is an outstanding parent and family advocate in the NY Metropolitan area. She is passionate about making a difference in the lives of people with developmental disabilities. It is vitally important to have a family member on this panel. Amber is conscientious and extremely hardworking. As a parent and a professional, I believe that Amber Decker would be an asset to this panel.

Received: Monday, April 15, 2019

NQF Response

Thank you for your comment of support for Ms. Decker. During its selection process NQF took into consideration a wide range of perspectives and wanted to ensure representation of family members, advocates, and peer supports.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Charlene San Nicolas

Organization: Guam Department of Public Health and Social Services

Comment

Good afternoon- For the Person-Centered Planning and Practice Committee- Inquiring if there will be any representatives from the U.S. Territory in the Pacific to broaden the Person- Centered Planning and Practice most especially within the Medicaid arena. And if not how will the multi-stakeholder approach to address person-centered planning practice as part of the long-term services and supports systems be supported from. This is being brought up as the public comment is up through April 26 at 6pm ET.

Received: Monday, April 15, 2019

NQF Response

Thank you for your comment. NQF received a record number of applicants for the Committee. During its selection process NQF took into consideration a wide range of perspectives including the seating of individuals with experience implementing person-centered practices within communities with varied cultural backgrounds. Because we actively seek a balanced and representative broad range of perspectives, we invite additional voices to be heard. We encourage you to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Cal Montgomery

Organization: Not mentioned

Comment

Hello, I am writing in response to the proposed PCP Planning roster. I am deeply disappointed in this list. At the center of the person-centered planning process we are supposed to find the people with disabilities whose lives are most affected. For LTSS, we are talking primarily about 3 categories of people: people with physical disabilities, people with intellectual and developmental disabilities, and people with psychiatric diagnoses. These separate groups have been the foundation of four distinct submovements of the disability rights movement, each with its own history, analyses and goals: the independent living movement, the self-advocacy movement, the consumer/survivor/ex-patient movement of which the peer/consumer movement are the primary representatives of those seeking LTSS, and the self-advocacy movement. Although all of these movements encompass significant diversity, their origins are still clear today in terms of who (diagnostically and in terms of institutional systems) is primarily represented and whose historic analyses and goals are at the forefront. Given that, I would expect to see clear representation of all of the three major groups involved, including: * participants in the independent living movement who have physical disabilities, including at least one who has lived in a nursing home, * participants in the peer/consumer movement, including at least one who has struggled to access care and one who has struggled to avoid "care", * participants in the neurodiversity movement, including at least one who is nonspeaking, * at least one older adult who was nondisabled most of their life and aged into needing LTSS, * significant diversity along a number of lines, certainly including but not limited to racial and gender diversity, * A real commitment to providing full inclusion to all of these participants. What I am seeing is a lot of "experts" who certainly bring a lot to the table but who should not be at the center of this process, plus representation from the independent living movement. This is not enough. This is about disabled people; we should be there in full array. Although I do not know the leaders in all of these submovements and therefore cannot offer you a full list of names, I recommend that you begin with people like Tia Nelis (TASH), James Meadours (Texas Advocates), Liz Weintraub (AUCD), and Julia Bascom (ASAN) and their counterparts elsewhere in the movement to begin the process of making a list of potential recruits. If you want to talk about centering us, you must begin by centering us. Thank you.

Received: Tuesday, April 16, 2019

NQF Response

Thank you for your comment. We agree that individuals directly from the community are critical to include in this effort, and we have actively included patient self-advocates directly in the committee. Unfortunately, none of the individuals that you recommended were nominated or self-nominated to the committee. This does not preclude their voice from being heard. Because we actively seek a balanced and representative broad range of perspectives. We encourage public participation during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period.

Respectfully,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Zan Thornton

Organization: Georgia ADAPT

Comment

Thanks Cal. Great suggestions which I hope they will follow-up and correct their lack of intersectionality and diversity.

Received: Tuesday, April 16, 2019

NQF Response

Thank you for your comment.

Sent: Monday, April 29, 2019

Penny Shaw, PhD

Organization: Aging and Disability Advocate

Comment

Yvonne, Let me first tell you about Nora Super. In her partial bio in the paragraph below, you will see that she was in charge of the White House Conference on Aging 2015, including regional meetings. At the request of Elizabeth Warren I was invited to the invitation-only WHCoA Boston regional meeting. I fast forward to the final "event" of the meeting, an open-mike presentation where those of us in the "audience" could speak on whatever we wanted. Much to the surprise of Nora, and the others gathered, I said the following - a paraphrase - Nora [I addressed her directly as she was there] - Can you explain to me why all the speakers have been government officials and service providers? Can you explain to me why representatives of so many important stakeholder groups were not invited? I mentioned the following - representatives of advocacy groups like the National Consumer Voice for Quality Long-Term Care, journalists specializing in aging issues like Kay Lazar of the Boston Globe. I asked Nora why the director of the Disability Law Center here in Boston wasn't invited to provide insights on the intersection of disability and aging. Several people came up to me after I spoke to thank for for contronting Nora, and the way our government operates with a limited view of how policy should be made. I was most struck - by a man who I didn't know - who came up and tapped me on the shoulder, and thanked me for speaking up. He introduced himself as Phillip C. Marshall, the grandson of Brooke Astor who forthrightly accused his father of elder abuse and financial exploitation of his grandmother. He offered to send me a copy of the book he'd written, but I told him I'd already read it! Phillip is someone who's a real advocate on behalf of the "elderly". Hopefully, he saw me as a strong advocate as well. The people not on the NQF roster - and essential to any genuine success of this endeavor - are the user/experts, those with lived experiences of the daily challenges of getting person-centered care. The next paragraph which defines user/experts, I copied and pasted from the website of the Institute for Human Centered Design Boston - actually the global center of... - where I am one of their user/experts. "A user/expert is a person

who has developed expertise by means of their lived experience in dealing with the challenges of the environment due to a physical, sensory or cognitive functional limitation. IHCD has an established database of user/experts who range from adolescents to people in their '80s. The only expertise you need is the willingness to share your honest experience when evaluating a place, product, technology or service. Participants help review the usability and accessibility of physical environments as well as products, services and new technologies." I repeat that I do not see any user/experts on the roster. I therefore say to the NQF - and I am known for being blunt and proud to be so - that the roster I received is yet another example of our government at work, not representative of all the stakeholders at all.

Penny. Nora Super bio [in part] - "Prior to joining the Milken Institute, Nora held several key leadership roles in the public and private sectors. Most recently, she served as the Chief of Program and Services at the National Association of Area Agencies on Aging (n4a). In 2014, Nora was appointed by President Obama as Executive Director of the White House Conference on Aging, where she received wide recognition for her nationwide efforts to improve the quality of life of older Americans. In 2015, Nora was recognized as one of America's top 50 "Influencers in Aging" by PBS Next Avenue and was the Honoree for Outstanding Service to Medicare Beneficiaries by the Medicare Rights Center. She has also held leadership roles at the U.S. Department of Health and Human Services, AARP, and Kaiser Permanente. "

Received: Tuesday, April 16, 2019

NQF Response

Thank you very much for your comment. NQF agrees with your sentiment that voices from the community need to be directly integrated into this Committee, and that the reports that emerge need to reflect the perspectives of patients within the community setting. There are patient self-advocates who have been direct recipients of home and community based services who are included in this Committee. NQF is a non-profit organization committed to improving the quality of care that patients received nationwide; we are not a government organization. Our process allows direct comments from members of the public during the Committee's deliberations. We encourage comments from the public to point out any omissions or errors that stem from misalignment with community perspective during both Committee meetings, as well as within the resulting reports.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Mary Somoza

Organization: Advocate for children and adults with disabilities

Comment

I am writing to express my delight that you have invited Amber Decker to your distinguished panel. Especially as she is a parent of a child with a disability and a member of our large organization of parents helping parents in self direction in New York State. Amber is a dedicated advocated, tireless, full of energy and knowledge from that famous school of "hard knocks". Life. She is a star amongst our parents, and you will be well served having her on board. Thank You.

Received: Tuesday, April 16, 2019

NQF Response

Thank you for your comment of support for Ms. Decker. During our selection process NQF took into consideration a wide range of perspectives and wanted to ensure representation of family members, advocates, and peer supports.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Jordan Scheff, Commissioner

Organization: Department of Development Services

Comment

Dear Sir/Madam: I am Jordan Scheff, Commissioner for the CT Department of Developmental Services. I appreciate the effort you are about to undertake with the Person Centered Planning and Practice Committee. As a state director for services to people with Intellectual and Developmental Disabilities, I can attest to the time and review I and my colleagues give to this topic. However, in reviewing the roster, I am very concerned with the absence of representation of state systems for people with I/DD on your panel. I am a member of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) which represents the state I/DD agencies in all 50 states and the District of Columbia, supporting more than 1 million individuals with intellectual and developmental disabilities and their families. I am writing today to encourage you to reconsider the composition of the Person-Centered Planning and Practice Committee. I respectfully request that you add Mary Lou Bourne, NASDDDS' Director of Quality to this roster. Ms. Bourne has unparalleled expertise in the field of person-centered practices and state systems. Ms. Bourne was asked to provide technical assistance and consultation in person centered planning and practice to federal staff at both CMS and ACL, and was invited to present information at the launch of the Office of the National Coordinator for electronic LTSS documentation. It is essential that I/DD systems responsible for overseeing and funding such a significant portion of LTSS in this country, have representation on this important panel. We look forward to NQF's addition of Ms. Bourne to this committee and to its ongoing work. In addition, as a state director, I would strongly encourage you to also consider adding members who have lived experience with intellectual and/or developmental disabilities. Individuals with disabilities have the greatest stake in how our systems implement and measure person-centeredness, and have real experience from the direct results of our success. The advocates with intellectual disability I work with directly use the following phrase when working at our state legislature: "Nothing about us, without us". Given the huge extent to which our services comprise a large percentage of federal spending on LTSS, I ask you again to reconsider. It is imperative that individuals supported in our systems have a voice in this discussion. Thank you.

Received: Wednesday, April 17, 2019

NQF Response

Thank you for your comment. NQF received a record number of applicants for the Committee. During its selection process NQF took into consideration a wide range of perspectives when assembling the Committee with special consideration towards individuals with I/DD that received HCBS LTSS services. We appreciate your concern about I/DD state system representation. We believe that our roster has sufficient representation of state's providing I/DD services but encourage individuals that were not selected for the Committee to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Melissa Crawford, Person Centered Practice & Service Equity Coordinator

Organization: Office of Developmental Disabilities Services

Comment

Thank you for the opportunity to provide public comment on the proposed roster for the Person Centered Planning panel. Currently you have an abundance of knowledge and expertise with the proposed members of the panel that can establish definitions, core competencies, and necessary systems characteristics. I also noticed that the purpose of the group is also to provide considerations, recommendations and guidance to enhance the success of person-centered planning and coordination at the state level for long-term services and supports systems (LTSS). There are a couple of concerns that the National Quality Forum and Administration for Community Living may want to consider prior to confirming the current panel members, as listed below:

- Please consider additional members that identify as self-advocates that can share their experience of services and how policy impacts them regarding person centered practices and services across LTSS services.
- The current membership of the panel has only one person of color in the panel, which without mindfulness in the process, that lack of diversity of membership will create bias towards communities of color and other intersectional minority groups across the country that access LTSS services. Please consider expanding membership to those leaders who also identify as a person of color, as well as other minority groups. This also include those who speak other languages other than English or communicate not using words that could share their diverse lived experiences in the recommendations for systems change in LTSS services.
- Additionally, the current proposal of members are all high level professionals in the field, and while they all may have experience in direct service work, it would be helpful to consider members of the panel that are currently doing day to day work with people receiving services. Their input would be eye opening to consider when considering policy, procedure and systems change, as they could share where recommendations on a federal level could create gaps in applicability in day to day work. Please feel free to reach out if you have any question about these public comments. Thank you.

Received: Wednesday, April 17, 2019

NQF Response

Thank you for your comment. We agree that individuals directly from the community are critical to include in this effort, and we have actively included self-advocate patients and care givers directly in the committee. Because we actively seek a balanced and representative broad range of perspectives, we invite additional voices to be heard. We encourage public participation during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period.

Respectfully,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Lee Grossman, Administrator

Organization: Developmental Disabilities Section, Behavioral Health Division

Wyoming Department of Health

Comment

Dear Sir/Madam: I am Lee Grossman and I serve as the Developmental Disabilities Section Administrator for the State of Wyoming. I appreciate the effort you are about to undertake with the Person Centered Planning and Practice Committee. As a state administrator for services to people with Intellectual and Developmental Disabilities, I can attest to the time and review I and my colleagues give to this topic. However, in reviewing the roster, I am concerned with the absence of representation of state systems for people with I/DD on your panel. I am a member of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) which represents the state I/DD agencies in all 50 states and the District of Columbia, supporting more than 1 million individuals with intellectual and developmental disabilities and their families. I am writing today to encourage you to reconsider the composition of the Person-Centered Planning and Practice Committee. I respectfully request that you add Mary Lou Bourne, NASDDDS' Director of Quality to this roster. Ms. Bourne has unparalleled expertise in the field of person-centered practices and state systems. Ms. Bourne was asked to provide technical assistance and consultation in person centered planning and practice to federal staff at both CMS and ACL, and was invited to present information at the launch of the Office of the National Coordinator for electronic LTSS documentation. It is essential that I/DD systems responsible for overseeing and funding such a significant portion of LTSS in this country, have representation on this important panel. We look forward to NQF's addition of Ms. Bourne to this committee and to its ongoing work. Best regards.

Received: Wednesday, April 17, 2019

NQF Response

Thank you for your comment. NQF received a record number of applicants for the Committee. During its selection process NQF took into consideration a wide range of perspectives when assembling the Committee with special consideration towards individuals with I/DD that received HCBS LTSS services. We appreciate your concern about I/DD state system representation. We believe that our roster has sufficient representation of state's providing I/DD services but encourage individuals that were not

selected for the Committee to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Jane Chinelo

Organization: Not mentioned

Comment

In an assisted living where i work as a supervisor in Atlanta Georgia, Patient Center Care was introduced over 7 months ago to care givers; now care partners offering care to seniors. So far, it has provided more bonding and quality of services towards the seniors. Lesson learned from this new transformation showed that care partners now understands senior's needs more specific to them and their families to better offer good services.

Received: Wednesday, April 17, 2019

NQF Response

Thank you for your comment. We encourage you to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Sent: No date

Pamela Bruce, Social Service Advocate 3, Lead Worker

Organization: Division of Aging/Adult Protective Services

Georgia Department of Human Services

Comment

Good afternoon. I hate that I missed the dead line for this but how do I become apart of this in the future? Thanks.

Received: Wednesday, April 17, 2019

NQF Response

Thank you for your comment. We encourage you to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Sent: Monday, April 29, 2019

Amber Decker

Organization: Special Needs Parent/ Caregiver and Advocate)

Comment

Dear PCP Planning NQF, The name of this panel is the "Person-Centered planning" panel and yet there are no caregivers or parents listed who have direct experience and that is disappointing. I was nominated but for unspecific, unknown reasons am not being appointed. That said your panel roster (excluding Amber Decker myself) and appointment speaks volumes about your process and shows a failure to include caregivers and parents as valuable panel members in any capacity. The only one who comes close is "Maggie Winston" since she is the only self-advocate however you have no parent representation. Children and those with guardians also have a right to person-centered planning, I look forward to seeing further opportunities for parents in your process but do not expect to see any as we have been left out of these discussions to date. Sincerely.

Received: Thursday, April 18, 2019

NQF Response

[ALREADY REPLIED] Firstly, apologies for the confusion that seems to have arisen. You have been selected to be seated on the Committee and we are waiting until the end of the public commenting period to officialize the roster from "proposed" to the actual Committee.

Additionally, though not always listed in the bios on the proposed roster, numerous individuals who join you as Committee members included being patients, patient advocates, or caregivers in their initial nominations submission.

If you have any additional questions, or would like to discuss anything further we'd be happy to schedule a call with you.

Thank you,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Alex Bartolic, Director-Disability Services

Organization: Minnesota Department of Human Services

Comment

I am the director of Disability Services at the Minnesota Department of Human Services. I am excited about the possibility of the effort you are about to undertake with the Person Centered Planning and Practice Committee. As a state director for long term services and supports for people with disabilities, including people with intellectual and developmental disabilities, autism, physical disabilities, brain injury, mental illness, chronic health conditions and HIV/AIDS, and working in close collaboration with our Aging and Adult Services Division, I am continuously seeking ways to align our system policies, regulations, funding, processes and evaluation with person centered practices. This is not only a topic of intense interest in our state, but one we engage in nationally. As I reviewed the roster for the Person Centered Planning and Practice

Committee, I was struck by who was on there, and who was missing. Particularly lacking was representation of state systems for people with I/DD. I am asking that you reconsider the composition of the committee, and include Mary Lou Bourne, NASDDDS' Director of Quality to this roster. I am a member of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) which represents the state I/DD agencies in all 50 states and the District of Columbia, supporting more than 1 million individuals with intellectual and developmental disabilities and their families. Mary Lou Bourne would bring unique experience and representation of state systems striving to improve person centered practices. Mary Lou Bourne's unparalleled expertise in the field of person-centered practices and state systems has been a great resource for Minnesota and states across the country. She has been engaged with us in Minnesota as we create systems change across populations to further person centered practices. I can attest to her unique expertise in developing systems to further person centered practices. Ms. Bourne has been asked to provide technical assistance and consultation in person centered planning and practice to federal staff at both CMS and ACL, and was invited to present information at the launch of the Office of the National Coordinator for electronic LTSS documentation. It is essential that I/DD systems responsible for overseeing and funding such a significant portion of LTSS in this country, have representation on this important panel. We look forward to NQF's addition of Ms. Bourne to this committee and to its ongoing work. In addition, I strongly encourage you to also consider adding members who have lived experience with intellectual and/or developmental disabilities. Individuals with disabilities have the greatest stake in how our systems implement and measure person-centeredness, and have real experience from the direct results of our success. It is imperative that individuals supported in our systems have a voice in this discussion. Thank you for your consideration of my request to assure balanced representation on this important endeavor by including Mary Lou Bourne and persons with lived experiences. Regards.

Received: Thursday, April 18, 2019

NQF Response

Thank you for your comment. NQF received a record number of applicants for the Committee. During its selection process NQF took into consideration a wide range of perspectives when assembling the Committee with special consideration towards individuals with I/DD that received HCBS LTSS services. We appreciate your concern about I/DD state system representation. We believe that our roster has sufficient representation of state's providing I/DD services but encourage individuals that were not selected for the Committee to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Kimberly Lackey, Director of Public Policy and Advocacy

Organization: Paraquad

Comment

Hello, I am writing in response to the proposed PCP Planning roster. I have some concerns with this list that I would like to share on behalf of Paraquad. At the center of the person-centered planning process we are supposed to find the people with disabilities whose lives are most affected. For LTSS, we are talking primarily about 3 categories of people: people with physical disabilities, people with intellectual and developmental disabilities, and people with psychiatric diagnoses. These separate groups have been the foundation of four distinct submovements of the disability rights movement, each with its own history, analyses and goals: the independent living movement, the self-advocacy movement, the consumer/survivor/ex-patient movement of which the peer/consumer movement are the primary representatives of those seeking LTSS, and the self-advocacy movement. Although all of these movements encompass significant diversity, their origins are still clear today in terms of who (diagnostically and in terms of institutional systems) is primarily represented and whose historic analyses and goals are at the forefront. Given that, I would hope to see clear representation of all of the three major groups involved, including: * participants in the independent living movement who have physical disabilities, including at least one who has lived in a nursing home. * participants in the self-advocacy movement who have intellectual disabilities, including at least one who has lived in an ICF or CILA home. * participants in the peer/consumer movement, including at least one who has struggled to access care and one who has struggled to avoid "care". * participants in the neurodiversity movement, including at least one who is nonspeaking. * at least one older adult who was nondisabled most of their life and aged into needing LTSS. * significant diversity along a number of lines, certainly including but not limited to racial and gender. This current roster seems to consist of the majority of professional/experts. Paraquad strongly feels that there should be additional representation from the disability community, one self-advocacy is simply not enough. Sincerely.

Received: Friday, April 19, 2019

NQF Response

Thank you for your comment. We agree that individuals directly from the community are critical to include in this effort, and we have actively included patient self-advocates directly in the committee. Because we actively seek a balanced and representative broad range of perspectives, we invite additional voices to be heard. We encourage public participation during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period.

Respectfully,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

KaraLe Causey, Board Chair

Organization: Pioneer Network

Comment

Dear National Quality Forum: Thank you for the opportunity to respond to the proposed roster for the Person-Centered Planning & Practice Committee. We are presenting comments as a coalition of four national organizations in the aging sector that all share a foundational mission based on person-centered philosophy and practices. Our organizations have pioneered and serve as leaders in the national movement to transform aging support and services to person-centered practices. The work the proposed committee members are undertaking is important as the federal government, states and private-sector organizations use the National Quality Forum's endorsed measures. Thus, the composition of the proposed roster is significant. As such, we are greatly concerned about the proposed roster. We recommend the following:

Inclusion of an Older Adult and Individuals Living with Dementia and Disabilities: Person-centered care is predicated on the voices of those receiving care and support being at the table. It does not appear there are older adults using long-term services or supports, individuals living with a disability, nor any individuals living with dementia selected to serve on the committee. First-person experiences and perspectives are essential and valuable.

Increased Representation from the Aging Services Sector: It appears that 50% of the proposed roster are individuals who represent the disability sector, 28% are individuals who represent clinical, managed care, and state and health insurers, and 22% are individuals who represent the aging sector. Given the United States is experiencing an unprecedented growth in the aging (e.g. 65 and older) population that is projected to double by 2050 due to the aging of baby boomers (U.S. Census Bureau, "An Aging Nation," 2014), the low percentage of aging services representation is troubling.

Representation of Individuals with Dementia Expertise: During the last five years of life, the total health care expenditure for people with dementia is more than a quarter-million dollars per person, some 57 percent greater than costs associated with death from other diseases, including cancer and heart disease (<https://www.nih.gov/news-events/news-releases/health-care-costs-dementia-found-greater-any-other-disease>). The costs are extraordinarily high because dementia is widely misunderstood by the medical community. The roster lacks expertise in dementia – both from a living with the condition perspective as well as from an informed person-centered service provider perspective. To resolve the concerns stated above, we recommend the inclusion of two individuals who have already submitted applications - Peter Reed, MPH, PhD and Penny Cook, MSW. Both individuals are highly qualified in the aging arena, have extensive knowledge and expertise about person-centered practices, and work with individuals living with dementia. We also recommend including an individual living with dementia and an older adult currently receiving supportive services. Our organizations would be pleased to provide recommendations for these two positions. Finally, recent calls by Sen. Charles Grassley and Centers for Medicare & Medicaid Services Administrator Seema Verma to strengthen oversight, enhance enforcement, and improve care in the nation's nursing homes, presumably in response to the recent report from the Government Accountability Office (GAO), bring to light the fact that society as a whole devalues older adults, which points to the need—now more than ever—for models of care that illustrate hope, promise, and better quality care, all of which mitigates the risk of abuse and neglect. These are the kinds of models that are uniquely represented in this coalition. The importance of the work being undertaken by this Committee is too significant and important to err in the composition of the voices and perspectives that will inform the process. We appreciate the opportunity to express our concerns to you and provide recommendations to ensure a balanced and well-informed roster.

Received: Thursday, April 25, 2019

NQF Response

Thank you for your recommendations. NQF feels that we have sufficient representation from Committee members who have intimate familiarity with issues related to person-centered planning within aging and dementia. If either of the individuals that you mentioned are interested in participating as members of the public, they are very welcome, and will have opportunities to comment during the public comment period of our meetings, as well as to provide feedback on both the interim and final reports.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Marguerite McLaughlin, Sr Program Administrator

Organization: Healthcentric Advisors

Comment

Colleagues: Though I appreciate the fine choice of professionals who have made it to the roster, I strongly endorse Penny Cooke, President of the Pioneer Network to join the ranks of PCP planning group. Her vast experience, keen ability to find solutions, deep understanding of PCP and enormous professional network will serve to guide NQF and its work in a powerful direction. Include her and reap the benefits of this remarkable professionals expertise.

Received: Thursday, April 25, 2019

NQF Response

Thank you for your recommendation. With the record response that we had to our call for nominations for this Committee, many talented individuals were not able to be accommodated directly. While Penny was not one of those selected, we would invite her participation as a member of the public during the committee calls, and would very much welcome her review and comment on the interim and final reports.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Camille Dobson, Deputy Executive Director

Organization: National Association of States United for Aging and Disabilities (NASUAD)

Comment

To Whom It May Concern:

We are pleased that Pearl Barnett, our Director of Operations, was selected for the Person-Centered Planning and Practice Committee. We believe she will ably articulate the perspective of our state members on this most important topic. As you know, Medicaid is the largest single payer for long-term

services and supports in the country, and states, as the local administrators of Medicaid LTSS programs, are the front lines for policy development and program implementation.

Given the large role that states play, we were most concerned that other significant state constituencies are not represented on the committee. We specifically call out the absence of representation from the state Developmental Disabilities directors. Person-centered planning and practices have their roots in the DD community, and it is imperative that the state perspective be shared. While we appreciate that there are other experts in the DD space on the proposed roster, none of those individuals have the breadth and depth of experience as Mary Lou Bourne, who was nominated by our sister association, the National Association of State Directors of Developmental Disability Services. In fact, we were surprised to see four managed care plans represented rather than a key state advocate.

We urge you to reconsider your initial decision and add Mary Lou to the committee roster. Sincerely,

Received: Friday, April 26, 2019

NQF Response

Thank you for your comment. We look forward to working with Pearl. NQF received a record number of applicants for the Committee. During its selection process NQF took into consideration a wide range of perspectives when assembling the Committee with special consideration towards individuals with I/DD that received HCBS LTSS services. We appreciate your concern about I/DD state system representation. We believe that our roster has sufficient representation of state's providing I/DD services but encourage individuals that were not selected for the Committee to participate during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Kelly Israel, Policy Analyst

Organization: Autistic Self Advocacy Network

Comment

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

Received: Friday, April 26, 2019

NQF Response

Thank you for your comment. We agree that individuals directly from the community are critical to include in this effort, and we have actively included patient self-advocates directly in the committee. We unfortunately did not note any self-advocates from some of the communities mentioned in your comment self-identified within our applicant pool, and none of the individuals that you suggested have been nominated or self-nominated. We have captured proponents for underrepresented populations within the Committee. Because of size constraints, not all voices can be directly represented. We actively seek a balanced and representative broad range of perspectives, and we invite additional voices to be heard. We encourage public participation during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period.

Sent: Monday, April 29, 2019

Angel Miles

Organization: Not mentioned

Comment

Established in 1980, Access Living is a non-profit, Chicago-based disability rights and service organization that provides individualized, peer-based services for people with disabilities. We would like to first thank CMS, ACL and the NQF for their commitment to work together to establish systems change influenced by Person Centered Planning principles and practice. Second, we do have some strong recommendations for changes to the Person Centered Planning proposed roster.

As one of the first Centers for Independent Living in the nation, championing legislation and providing services that enables Home and Community Based Services (HCBS) Long Term Services and Supports (LTSS) have long been a core component of Access Living's work. Our organization was part of the initial start-up of the Illinois Home Services Program in the early 1980s, and we have supported consumers who participate in a range of Medicaid HCBS and LTSS. As part of our organizational philosophy, we adhere to the disability rights principle "Nothing About Us Without Us;" and we are committed to maintaining that at least 51% of our employees identify as persons with disabilities, several of whom also use HCBS and would not otherwise be able to work. In addition, through our contributions to the Ligas, Williams, and Colbert consent decrees in Illinois, we have supported the development and enforcement of litigation related to the Olmstead Supreme Court decision. Hence, based on our advocacy and experience in working directly with people with disabilities as peers, we would like to raise the following concerns about the current panel of experts nominated for the CMS and ACL Person-Centered Planning and Practice Committee.

We are concerned that the current panelist makeup does not reflect the original values, characteristics, or intent of Person Centered Planning, because there are no self-advocates with

intellectual disabilities included. For us, this is cause for great concern. Access Living contends that this panel cannot produce through policy what it lacks itself in composition. To stay true to the Person Centered Planning Principles, the panel itself must also include a significant number of people with a variety of disabilities who have participated in person centered planning and/or have other person centered planning expertise. Self-advocates are valued for their experiential expertise, whereas “patient” is a term that prioritizes the knowledge of medical experts. The call for panelist request feedback from patients but not self-advocates. This must change.

Next, we urge that the panel include representation from those in the psychiatric survivor movement. This group has long been seriously overlooked as a source of expertise in Person Centered Planning. Moreover, around a third of people with intellectual/developmental disabilities, with whom Person Centered Planning was first used, have a dual diagnosis of also a mental health disability. Many who have dual diagnoses have many lessons to share from the experience of being institutionalized. The voices of psychiatric survivors are necessary to ensure a full table.

We are also concerned that the proposed roster is lacking in racial, ethnic, sexuality and cross disability diversity. In regards to gender, it is unclear that the roster includes people who are transgender or nonbinary. Attention to cultural competency and intersectional implications of health policies and practice is imperative to insure that structures of inequality are accounted for and not reproduced in Person Centered related policy and practice. How does race, class, gender, sexuality, language, type and severity of disability etc. impact the Person Centered Planning needs of people with disabilities? The current roster of panelists does not reflect a diverse composition of panelists with personal and professional expertise that could contribute to meaningful responses to this question.

In closing, we recognize that this panel’s guidance has the potential to contribute to much needed systems change that could impact millions of Americans with disabilities. Once the vital strategic input of this panel is put in place, it will be difficult to shift. Hence, for this panel to accurately and effectively meet its objectives, it is imperative that the people and community who developed the concept of Person Centered Planning, and are invested in its practice every day, be reflected in those who are teaching and informing CMS how it should be implemented. It is not acceptable that self-advocates with intellectual disabilities, leaders in psychiatric survivor work, and professionals with intersectional competency, were not invited to the table. Given these issues, we request that CMS and ACL extend the call for panelists so that more members of the disability community have an opportunity to nominate panelists that we believe will best inform your overall agenda for further integrating Person Centered Planning in CMS and ACL. Anything less is co-optation of the ideas of members of the disability community and rhetoric that will not result in the intended meaningful, effective and accurate structural change so strongly needed.

Received: Friday, April 26, 2019

NQF Response

Thank you for your comment. We felt very strongly that the voices from the community, including those with intellectual disability and mental illness, needed to be adequately represented on the panel. We have individuals who receive home and community based services represented, as well as those who have extensive experience working with and designing programs to empower those with intellectual and behavior health challenges. NQF did not receive nominations for individuals that self-identified as

intellectually impaired or having mental illness. Because we actively seek a balanced and representative broad range of perspectives, we invite additional voices to be heard. We encourage public participation during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period. All information on the project and web meeting information can be found on the NQF website.

Respectfully,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019

Lindsay Baran, Policy Analyst

Organization: The National Council on Independent Living

Comment

I write today in response to the proposed Person Centered Planning (PCP) Roster released on April 15, on behalf of the National Council on Independent Living (NCIL). NCIL is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. NCIL represents thousands of individuals with disabilities and organizations including Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other organizations that advocate for the human and civil rights of people with disabilities throughout the US.

Person Centered Planning is intended to give disabled people more control and input into their service provision. As PCP applies to the provision of long term services and supports (LTSS) for people with all disabilities, a stakeholder panel that will establish key components of person centered planning and coordination must be reflective of the full range of individuals who will be affected by these new processes and the NQF project.

The PCP Panel as it stands is not acceptable. To truly reflect the full range of stakeholders and the people at the core of person-centered planning, the PCP Panel must include cross-disability membership. The Panel must be modified to include people with intellectual and developmental disabilities (I/DD) and people with psychiatric diagnoses.

Again, PCP is intended to increase the control disabled people have over their lives and services. Disabled people have a long history of control being taken away from them, and people with I/DD and psychiatric diagnoses in particular often face additional disproportionate barriers to control over their lives and long term services and supports. Representation on this panel by individuals with IDD and psychiatric diagnoses who can speak to these barriers and facilitators to person-centeredness is critical.

I would also like to note that while PCP ensures that disabled peoples' needs and preferences are centered, the Independent Living Movement is guided by consumer direction and consumer control. Consumer direction ensures that disabled people are in control of their services, from what's offered to how they're delivered to who provides them; consumer control is the guiding principle that people with disabilities are the best experts of their own needs, and with regards to CILs that means power and authority is vested in people with disabilities. I mention this here because these terms have increasingly been used interchangeably, and while they share the goal of increasing the control disabled people have

over the services they receive, they are quite different and must not be conflated. Person centered planning is not, and must not be, a replacement for consumer direction.

Thank you for the opportunity to submit these comments.

Sincerely,

Kelly Buckland

Received: Friday, April 26, 2019

NQF Response

Thank you for your comment. We agree that individuals directly from the community are critical to include in this effort, and we have actively included patient self-advocates directly in the committee. We unfortunately did not note any self-advocates from some of the communities mentioned in your comment self-identified within our applicant pool. We have captured proponents for underrepresented populations within the Committee. Because of size constraints, not all voices can be directly represented. Because we actively seek a balanced and representative broad range of perspectives, we invite additional voices to be heard. We encourage public participation during the web meetings, all of which have dedicated opportunities for public comment, as well as to provide comments on the interim and final reports when they are posted for a 30-day comment period.

Sent: Monday, April 29, 2019

Ralph Warren Jr, PhD

Organization: Not mentioned

Comment

Hello I am writing a recommendation for Amber Decker Senior Family Peer Advocate, self-employed New York, New York

I hope that she becomes one of the people chosen for the final Person-centered planning and practices panel.

Amber is an excellent choice based on her years of tireless and effective advocacy for multiple populations of people receiving Medicaid Long Term Services and Supports in NY. She has assisted her parent in obtaining and sustaining behavioral health services and assisted her son in a similar manner with I/DD services.

I have known Amber for a few years now and I have participated with her in several formal and informal advocacy groups and efforts. These settings and activities include: family advocate groups for self-directed services in OPWDD services, quarterly advocate meetings with CMS staff and NY state agency staff, Medicaid Matters New York (MMNY), a state-wide Medicaid advocacy coalition, and in other coalitions . She has grown and taken on new perspectives along the way. And in significant ways, Amber ,has become more effective over the past year in facilitating meetings and work groups and helped others who get overwhelmed and frustrated to channel their energies in positive ways.

Amber is very knowledagble about person centered planning practices in adult services. I do not know her work directly in the educational system/child services. It is clear though looking through the proposed panel membership that greater inclusion of experienced, productive and positive family

advocates is needed. Amber is such a person, and she has accomplished a great deal for people with disabilities in NY.

More family/self-advocates are needed to provide balance and shape analysis and recommendations at a national level regarding systems change at state and local levels. The lived experience and practical problems of individuals and families can be easily passed over and misunderstood when family/individual advocates are not official full members of national standards panels.

I look forward to hearing about the progress of your work and hope you reach out for periodic feedback on how states implement assessment, service planning, and program evaluations. This is particularly needed because generic person centered planning must not lose the depth of needs assessment, professional practice and direct support services unique to disability groups (I/DD, TBI, elderly, etc.). I write and provide this recommendation from a personal and professional perspective. I have professional education and work experience in research/evaluation of disability services, and I use and depend on long-term services for people with developmental disabilities. Respectfully.

Received: Friday, April 26, 2019

NQF Response

Thank you for your comment of support for Ms. Decker. During the selection process NQF took into consideration a wide range of perspectives and wanted to ensure representation of family members, advocates, and peer supports.

Sincerely,

Person-Centered Planning and Practice Team

Sent: Monday, April 29, 2019