Participants: Tom Fiorentino, Mary Ann Langton, Robin Wood, Sheldon Toubman, Karyl Lee Hall, Kevin Brophy, Siobhan Morgan, Dawn Lambert, Patricia Richardson, Mark Schaefer, Maggie Ewald, Michelle Jordan, Robin, Judy Stein, Marie Porter, P-something, Julie Peters, Stephanie Burnham, Alyssa Harrington, John Freedman

Notes

The group discussed the purpose of the design group. Several participants had thought the purpose was to discuss payment models and voiced concern with the bundled payment model options that the Task Force recommended, including:

- Capitation did not work for Medicaid. The FFS system in Medicaid is working much better than the capitated system.
- Many of the capabilities being proposed such as telemedicine and Community Health Workers are already reimbursed under FFS.
- There is a crisis in home care and people with disabilities do not have access to needed services. Changing payment models in the midst of this fraught environment will not solve the problem but make it worse.
- The capabilities should define the payment model, not the other way around.
- People with disabilities are being consulted too late in the process of development payment model options.

The group discussed that the purpose of the design group was to discuss how primary care can better serve people who have disabilities through enhanced care delivery capabilities, rather than the payment model. Several participants expressed difficulty divorcing the capabilities discussion from the payment model options.

Several participants discussed how the current payment and care delivery system is fragmented and broken and does not work for people who have disabilities. The people that they work with who have disabilities do not get the same level of care as people who do not, care is not equitable, and there are huge gaps in preventive care. Not all participants agreed. They expressed that this group being involved in this discussion was an opportunity to define ways to make care better and more equitable for people who have disabilities. The group agreed that everyone had this goal, but there were questions about how to get there. Some participants felt a bundled payment model would not do anything to improve the system and would instead make it worse.

The group discussed how to define “disabilities”. Some participants noted that it is difficult to define services without a defined population. Others felt that having specific definition contributed to the fragmentation of the system – the point should be to include everyone rather than requiring people to meet certain qualifications to be eligible for certain services, which is part of the current problem.

After more discussion, the group agreed to make recommendations about care delivery capabilities to improve primary care for people with disabilities, with the explicit provision that this group’s
recommendations in no way support an endorsement of the payment model options under consideration for the Primary Care Modernization initiative.

The group discussed opportunities to improve primary care for people with disabilities, including:

- There is a lack of knowledge in primary care about how to work with people who have disabilities.
- People with disabilities often travel long distances to see specialists who understand their condition. Being able to access these specialists via telemedicine would go a long way. A successful, out-of-state telemedicine consultation for patients with Prader-Willi syndrome was given as an example.
- Issues go beyond just access – people with disabilities do not receive the same quality of care as people who do not have disabilities.
- Primary care for people with disabilities should be person-centered. There are measures of shared decision-making that can help measure whether care is person-centered.
- The patient and their circle of support (e.g. families, caregivers, designees, etc.) should be at the center of the care team.
- If there are practices that specialize in care for people with disabilities, they should be accessible via public transportation such as bus lines. Consider incentives to have these practices in certain areas.
- People with disabilities may use subspecialists as their primary care providers depending on their needs at the time. Consider fluidity in who the primary care provider is at any given time.
- Restrictions in eligibility for home care when people return to the community from facility settings are affecting access to these very needed services. Consider waiving eligibility requirements for home care.

The group discussed having a four hour meeting on December 7th to continue defining the primary care capabilities for people who have disabilities.