



September 30, 2016

Ms. Vikki Wachino  
Deputy Administrator and Director  
Center for Medicaid and CHIP Services  
U.S. Department of Health and Human Services  
7500 Security Boulevard  
Baltimore, MD 21244

Dear Ms. Wachino:

I am writing to provide comments on the Oregon Health Plan Extension. Since its founding, the Partnership to Improve Patient Care (PIPC) has been at the forefront of patient-centeredness in comparative effectiveness research (CER) – both its generation at the Patient-Centered Outcomes Research Institute (PCORI), and its translation into patient care. Having driven the concept of patient-centeredness in the conduct of research, PIPC looks forward to bringing the voices of patients, people with disabilities, and their families to the discussion of how to advance patient-centered principles throughout an evolving health care system.

As the Chairman of PIPC and having a disability myself, I am particularly sensitive to the implications of state health policy on children with disabilities. It is my history with epilepsy that led me to author the Americans with Disabilities Act, to continue my advocacy for people with disabilities, and to lead PIPC. I am proud to see services for autism being recognized as vital for so many families in the work of policymakers and some political candidates. We have come a long way.

Therefore, I am extremely concerned about the potential implications of the proposal to extend the Oregon Health Plan as currently drafted. As chair of PIPC, I have made it my ministry that patients and people with disabilities must have a meaningful voice in the development of health policies, particularly in the discussion about what constitutes “value” in health care. Yet, what I have learned from the families of autistic children in Oregon is that they are not at the table and their perspectives of valued services for their children are not being taken into consideration.

As I understand there are two critical issues. First is the waiver from EPSDT that allows Oregon to restrict coverage to only services on a prioritized list, as opposed to following the statute’s requirement to cover “all medically necessary diagnostic and treatment services.” I have been very vocal, along with all my colleagues representing people with disabilities, about my concerns with the use of measures of cost effectiveness and particularly quality-adjusted-life-years (QALYs) to determine value. It has been our experience that these types of measures of value often conclude that we are not worth it, that our lives are not valuable. As a result, we are denied access to needed health care. In this case, Oregon’s policies are withholding access to medically necessary care for needy children, which is most egregious.

Second, I am concerned about representation of patients and people with disabilities on the Health Evidence Review Commission (HERC) that develops the prioritized list of healthcare services. According to the waiver application, HERC is supposed to include “two health consumers.” I am told that qualified “health consumer” applicants were rejected, and therefore no “health consumers” serve on the HERC. I support the definition being proposed by advocates, stating that the HERC membership clause in Oregon’s section 1115(a) waiver should be clarified to specify that the “Health Consumers” must actually be bonafide consumer representatives who are either (a) Medicaid recipients, or the parents or guardians of Medicaid recipients; or (b) representatives of non-profit advocacy organizations representing the needs of Medicaid consumers. Without genuine representation of patients and people with disabilities, it will be impossible to accurately determine the implications of payment and coverage decisions on outcomes that matter to impacted patients, people with disabilities and their families.

Instead of policies that reinforce the old paternalistic system of health care and work against personalized medicine and the Precision Medicine Initiative, policymakers should focus on delivery reforms that activate and engage patients and people with disabilities and support shared decision-making between patients, people with disabilities and their providers. We believe that solutions that center on patients and people with disabilities are the best approach to improving overall health care efficiency and quality. CMS should require states like Oregon to engage patients, people with disabilities and their families, providers and other stakeholders in the creation of a health system that puts patients and people with disabilities at the center. Let’s work together toward patient-centered solutions.

Sincerely,



Tony Coelho  
Chairman, Partnership to Improve Patient Care