



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

Health Reform Recommendation No. 3:

***CCD Supports Comparative Effectiveness Research
with Proper Protections to Ensure Continued Access to Devices and
Services for People with Disabilities and Chronic Conditions***

The Consortium for Citizens with Disabilities (CCD) believes that comparative effectiveness research is, and should continue to be, an important tool in helping patients and providers distinguish between the effectiveness of both existing and emerging treatment options. Having better evidence to support the clinical effectiveness of a wide range of health care interventions has the potential to lead to improvements in the quality of care and could potentially maximize the impact of the health care dollars spent in this country.

CCD, a coalition of national disability-related organizations, urges caution, however, to pursue comparative effectiveness research in a manner that does not lead to inappropriate restrictions in coverage of and access to assistive devices, therapies, treatments, medications, and long term services and supports for people with disabilities and chronic illnesses.

Many of the assistive devices, technologies, and therapies used by persons with disabilities to be functional and live independent and fulfilling lives have widespread application and are generally accepted by physicians and other health care professionals. Because many of these devices and technologies do not have to undergo the rigors of FDA review, the formal evidence base for such treatments may be less developed than other areas of health care.

With respect to all devices, therapies, and medications, it is important to recognize that disability conditions vary widely in severity and complexity. There are often multiple comorbid conditions in play and many disabilities are low prevalence, making specific and meaningful clinical effectiveness studies challenging to pursue. Ethical questions and other factors often make double-blind clinical trials in this area non-viable. Even well-grounded research on the general

population can be easily misapplied to the disability and chronic illness populations, especially persons with intellectual, behavioral and cognitive disabilities.

In fact there are many potential applications of comparative effectiveness research to areas other than acute care medicine such as long term services and supports for these populations. It is critical that the outcomes of such research are not misapplied or used to broadly establish coverage rules that trump an individual's circumstances and specific needs.

For these reasons, the CCD believes that comparative effectiveness research is not a substitute for the clinical judgment of the physician or health care professional in consultation with the patient. In the absence of double-blind clinical studies, due consideration should be given to reliable observational studies and consensus medical opinion, along with the clinical judgment of the health care professional. This is particularly important for people with complex, disabling, or chronic conditions.

Comparative effectiveness research is very important and has the potential to bring down health care costs over time by improving the quality of care. CCD supports the pursuit of comparative effectiveness research as long as there are meaningful protections to prevent inappropriate restrictions in coverage of and access to health care and long term services and supports for people with disabilities and chronic conditions.

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