Coalition for Mental Health Reform

December 1, 2016

Sen. Mitch McConnell
Majority Leader, US Senate
317 Russell Senate Office Building
Washington DC 20510

Sen. Harry Reid
Minority Leader, US Senate
522 Hart Senate Office Building
Washington DC 20510

Re: Concerns with H.R. 34, the “21st Century Cures Act”

Dear Majority Leader McConnell and Minority Leader Reid:

The Coalition for Mental Health Reform is made up of organizations that work to promote equal opportunities for individuals with psychiatric disabilities in all aspects of life, including health care, housing, community living, employment, and education. We also believe that the voices of people with psychiatric disabilities must be an important part of mental health reform. The organizations in this coalition work closely with and some are led by people with psychiatric disabilities.

As a coalition we worked to make sure that many harmful provisions in H.R. 2646, the Helping Families in Mental Health Crisis Act, now incorporated into the 21st Century Cures Act, were removed and/or edited.

We continue to be concerned with portions of H.R. 2646, addressed in our prior correspondence, that also appear in the 21st Century Cures Act. We believe provisions of the bill threaten independent living for people with psychiatric and other disabilities. We would particularly like to highlight our concern about Section 12006.

Electronic visit verification system threatens the independence of older Americans and of people with disabilities.

The requirement for Electronic Visit Verification (EVV) systems is based on outdated and erroneous assumptions. First, the systems assume that people with disabilities and seniors who use attendant services are homebound because most systems use a home (“land line”) phone to verify that an attendant has arrived or finished a shift. Today, attendant service users receive services and supports throughout the community and use cell phones which can be shared. EVVs also purport that electronic systems are more effective than other forms of visit documentation. These systems have been demonstrated to be less secure and less effective in prosecuting fraud than non-electronic systems which provide transparency, require multiple sign-offs and have verified signatures. Finally, these systems rely on
predetermined schedules which are not used in consumer directed attendant programs.

Additionally, the systems will impact the independence and privacy rights of people with disabilities by imposing a *de facto* homebound requirement on Medicaid attendant service users, preventing the disabled individual from monitoring submitted hours, and in some cases providing geo-tracking data to the government on the movements of disabled people. Finally, states that require EVV may be found to be joint employers of attendants and liable for overtime payments.

The EVV requirement will require people with disabilities needing services to remain in their homes, instead of going to work or to stores or to see friends, relatives or doctors – in short all the activities of a full life. The majority of laws affecting people with disabilities passed in the last half century recognize the importance of independence. They recognize that providing community services, rather than services in institutional settings, is not only a recognition of our rights under the Americans with Disabilities Act to be integrated in the community, but also that such community integration generally comes at a decreased cost to government. Most significantly, this was affirmed by the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999).

Section 12006 would require states to implement EVV systems rather than to verify personal care and home health care through other methods. **We oppose the EVV requirement because it is harmful to individuals with disabilities, ineffective at addressing fraud and has the potential to increase state liability.** We urge the Senate to remove Section 12006. If it is imperative to include a requirement to verify personal care and home health services, a requirement for states to address fraud in those services by a system at least as effective as an EVV system could do so consistently with the life needs of people with disabilities receiving services.

We look forward to the opportunity to work with Congress to address these concerns and to assist with the passage of a mental health reform law. Please contact Lindsay Baran, National Council on Independent Living, Lindsay@ncil.org, (202) 207-0334 (voice) with any questions or concerns.

Sincerely,

**American Civil Liberties Union**

**Autistic Self Advocacy Network**

**National Coalition for Mental Health Recovery**

**National Council on Independent Living**

**National Disability Rights Network**

**New York Association of Psychiatric Rehabilitation Services**