

I'm Lyn Redwood and I am a holdover from the previous committee.

In preparation for our meeting today I went back over minutes from previous meetings and watched some of the online videos.

The one that stood out the most was last April, when representatives from both the Obama administration and the Secretary's office attended the meeting as part of autism awareness month.

In response to comments and concerns made by members of the committee they agreed that we were "not doing enough", that we "needed to redouble our efforts" and that we should look at what we have learned the past 4 years and ask how we can do better moving forward with the reauthorization of the committee.

One of the things I have learned is that despite all the efforts of the IACC, very little has actually been accomplished that directly translates into reducing the burden of autism for families or has resulted in improvements in the health and quality of life for those individuals with the disorder.

The prevalence of autism continues to skyrocket and families are collapsing due to the financial and personal burdens that a diagnosis of autism creates. Dr. Insel stated during the April 2011 meeting that using the word "crisis" is not an overstatement and that we don't have the answers.

In the information we received for this meeting is a document that outlines the charge of this committee. We serve in an advisory capacity, create and update the strategic plan and summary of advances, monitor all federal activities regarding autism and report back to the Secretary. We are not tasked with establishing public policy or implementing research or service programs.

Last year we sent two letters to the Secretary regarding wandering and elopement and the unnecessary use of seclusion and restraint for individuals with autism, both of which have resulted in tragic consequences. Both letters included specific recommendations for addressing our concerns, including policy recommendations, but our concerns have yet to be fully addressed.

According to the National Autism Association, since September of 2011, there have been total of 194 reported incidents of wandering with 17 deaths. The most recent was last week when 5 year old Jeremiah Conn drowned in a rainwater retention pond near his home.

So I have learned the past 4 years that we desperately need an agency within HHS that is solely dedicated to the unmet needs of the autism community that CAN establish public policy and implement necessary programs to address these urgent issues that face our community on a daily basis.

In 2008, Barack Obama issued a campaign pledge to “appoint a Federal ASD coordinator to ensure that ASD receives the recognition and priority it deserves from the federal government.” The Coordinator would be tasked with eliminating bureaucratic obstacles that may be delaying the implementation of important ASD measures and to “ensure that all federal ASD dollars are spent in a manner that prioritizes results”. We desperately need that to happen.

We also need an Office of ASD Research under the NIH Director modeled after the Office of AIDS Research to fortify the activities of the IACC and to implement necessary policies to effectively respond to this urgent health emergency.

The Office would be responsible for annual comprehensive trans-NIH planning, budgeting, portfolio assessments, establishing scientific priorities and ensuring that research dollars are invested in the highest priority areas of scientific opportunity and are aligned with the vision, mission and values of the Strategic Plan for Autism Research as directed by the Combating Autism Act.

Dr. Insel stated during the April meeting that we needed a better way to think about autism in an effort to be more efficient and effective. The appointment of a federal ASD coordinator and the establishment of an Office of ASD under the Director are opportunities to do better moving forward in an effort to get the answers families so desperately need.

