



Help provide a voice to stop the addition of the “Wandering” label to ICD-9-CM!

“Labels are for cans, not people.” T.J. Monroe, APSE Board member & Self Advocate

Background:

Last week, the ICD-9-CM Coordination and Maintenance Committee met to discuss the future of medical coding in the United States. The ICD-9-CM stands for the International Classification of Diseases, Ninth Revision, Clinical Modification, and is the US government's official system of assigning codes to medical diagnoses and procedures. The day before the meeting, the Centers for Disease Control and Prevention (CDC) posted for the first time information on the codes under consideration - including a new medical diagnosis for "wandering" related behavior in children and adults on the autism spectrum and with other developmental disabilities. If approved, this new coding promises to label hundreds of thousands of children with a "wandering" diagnoses that would make it easier for school districts and residential facilities to justify restraint and seclusion in the name of treatment. Furthermore, this diagnosis carries no clear definition and the CDC's proposal uses poor quality research to claim that it should apply to the majority of autistic children and those with other developmental and intellectual disabilities.

Issue:

The CDC's last minute proposal was made public only the day before the public hearing on these coding was scheduled to occur - well after the registration for people to give public comment had closed! Our only chance to have our voices be heard is to flood the written comment session before that deadline passes on April 1st. To do that, we need your help! Here's what you can do:

Action:

First, send an e-mail to CDC's co-chair of the ICD-9-CM Coordination and Maintenance Committee telling them to REJECT a medical label for "wandering"-related behavior. Her name is Donna Pickett and her e-mail is dfp4@cdc.gov. Remember, they have to hear from us by April 1st!

Talking points to help state the case that there should not be a medical coding label of “wandering”:

1. Labeling hundreds of thousands of children & adults with a "wandering" diagnosis will increase restraint and seclusion utilization unnecessarily in schools and homes. One of the consistent messages in last year's advocacy for federal legislation to stop restraint and seclusion in schools was that when schools plan to restrain students, they do restrain students - frequently with tragic results.
2. By labeling hundreds of thousands of school -aged children and adults with disabilities with a diagnosis of "wandering", CDC will encourage districts and adult service providers to plan for the use of restraint for these individuals in Individualized Education Plans (IEPs), school safety planning, and Individual Service Plans (ISPs). **This will limit the ability of people with this label to live, work, and recreate in their communities.**
3. By claiming that "wandering" is an unavoidable medical diagnosis instead of a behavioral response to specific circumstances, children and adults with little to no communication needs may lose one of their last ways of making family members, educators, and adult service providers aware of abusive or sensory overwhelming environments, or trying to leave a dangerous situation.
4. Far from making children with disabilities safer, this proposal will enable abuse "in the name of treatment" and make it harder for non-speaking students and adults to communicate problems to their families.
5. The "wandering" diagnosis lacks meaningful research support. There exists no research to classify "wandering" as a medical rather than a behavioral issue. This proposal is being pushed forward without meaningful research support.
6. The use of the "wandering" label on adults will enable abuse and restrict the civil rights of Americans with Disabilities. As children labeled with this diagnosis grow up, a "wandering" label could be used as a factor to justify guardianship - the stripping of legal capacity - in areas where it otherwise would not be deemed acceptable.
7. Advocates of a "wandering" label make the case that its usage would enable insurance coverage for tracking devices, whose use for adults would restrict freedom of movement and make it harder for individuals to flee abusive situations.
8. This diagnosis will increase the usage of more restrictive service-provision placements, like institutions and group homes, as a way of countering the "flight risk" that labeled individuals will be presumed to pose. **This label will make it harder for people to receive consideration for employment.**

As a member of APSE, please encourage them to reject the “wandering” medical label.

Remember, we only have till April 1st! Thank you for taking the time to weigh in and we appreciate your support as we continue the struggle against abuse and for our civil and human rights.