



April 17, 2019

Senator Testin
Senate Committee on Health and Human Services
Wisconsin State Capitol, Rm 131 S
Madison, WI 53707

Representative Sanfelippo
Chair, Assembly Committee on Health
Wisconsin State Capitol, RM 314N
Madison, WI 53708

Dear Senator Testin, Rep. Sanfelippo and Committee members:

The Wisconsin Board for People with Developmental Disabilities (BPDD) thanks the committee for the opportunity to provide testimony in support of Assembly Bill 24 and Senate Bill 26.

Step therapy requirements have detrimentally impacted people with intellectual and developmental disabilities (I/DD), especially those that have neurological disorders including epilepsy and other conditions that may result in seizures. Finding the right combination of medications and other techniques, including dietary changes or surgery, to manage symptoms often involves a time-consuming process of trial and error. Even small variations to medications or protocols may lead to loss of control over seizures.

Many people with epilepsy have described seizure control going awry when switching to generics or even between generic drugs. While the active ingredients are the same, any deviation of active or inactive ingredients can prove destabilizing for people whose seizure control is tenuous.

We recently heard from one parent who spent many years trying dozens of medications to control the hundreds of seizures their daughter was having each day. They found one drug that worked and had successfully controlled their daughter's seizures for many years when their HMO decided they wanted to switch to a generic version. In this case, the neurologist intervened, and the HMO respected the medical opinion that any variation would have devastating effects so that the patient could continue on the brand name drug that had already proven to be effective.

Step therapy also impacts people with I/DD who may be on multiple medications. The interaction between multiple drugs can be a delicate balance and changes to any one drug may trigger changes in control of symptoms, management of reoccurring or chronic conditions, and overall well being of the individual. Individuals do respond to the same medication differently.

Deciding what drug(s) and protocol are best able to manage the patient's health and quality of life should be between doctor and patient; it should not be determined by an insurer.

BPDD is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with developmental disabilities (more about BPDD https://wi-bpdd.org/wp-content/uploads/2018/08/Legislative_Overview_BPDD.pdf).

Our role is to seek continuous improvement across all systems—education, transportation, health care, employment, etc.—that touch the lives of people with disabilities. Our work requires us to have a long-term vision of public policy that not only sees current systems as they are, but how these systems could be made better for current and future generations of people with disabilities.

Thank you for your consideration,

A handwritten signature in cursive script that reads "Beth Swedeen". The signature is written in black ink on a white background.

Beth Swedeen, Executive Director
Wisconsin Board for People with Developmental Disabilities