

TESTIMONY IN SUPPORT OF HOUSE BILL 1359 to increase the number of certified caregivers.

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Chairman Weisz and House Human Services Committee Members, my name is Sandy Smith. I am the parent of a son with severe autism. I am testifying in favor of House Bill 1359 with the proposed amendment that a registered qualifying patient may have no more than five registered designated caregivers. Only 2 of those 5 registered caregivers will have the ability to purchase product and will be designated as such on their application.

Our son was diagnosed with autism in 2002. He is now 18 years old and my husband (Dad) and I are his legal guardians. Our son was doing very well after having received extensive therapy for much of his life. However, our lives changed on July 4, 2018 when he had his first grand mal seizure. We now think about our lives as “before seizures and after seizures.” Our son was put on seizure medication which caused him to engage in very aggressive & dangerous behavior. We spent two years changing and adjusting medication only to see his behavior become even more dangerous. Our son is 6’1” and weighs 255 lbs. He is bigger than both me and my husband. Some of this behavior is listed below:

- Hitting parents, teachers, para professionals, therapists, direct support professionals, doctors, and dentist. The doctor got a bloody nose and the dentist’s glasses cut his face.
- Hitting parents and staff while driving in a vehicle requiring us to purchase a minivan with a third row seat to keep the driver safe.
- Loud screaming, yelling and destruction of property. Smashed TV’s, many holes punched in sheetrock, slamming drawers and doors until destroyed.
- Slamming hand on windows to the point we had to cover them with plexi-glass to keep him safe.
- Severe self-injurious behavior in the form of hitting his own head.

We were literally afraid of our own son. I was afraid to be home with him by myself and I could not let anyone else be alone with him either. I was aware of others trying medical marijuana to help with aggressive behavior. After more research my husband and I took several months to decide if we were going to try medical marijuana. It came down to the decision of whether we were going to be able to keep in at home with us anymore. We started in September 2020. Medical marijuana has been life changing for us. His behavior has improved significantly. We are no longer afraid of him. Teachers, therapists and others that work with him are reporting significant changes in behavior and cooperation. He is happier, more engaging and his language has even increased slightly. He tolerates haircuts and shaving with no problems. Most importantly he has not hit anyone since got on a therapeutic dose in early October.

Medical marijuana (we use tincture) is “medicine” to our son and he needs to take it like any other of his medicine on a regular schedule (every 4 hours) to keep him in a consistent regulated state. He has no idea what he is taking. To him is it just the same as taking any of the other antipsychotic medication that has not worked for him and caused significant amounts of weight gain.

I got my son certified for medical marijuana and I got certified as his caregiver. Our plan was to have at least his Dad also get certified when our son turns 19 in April so he could help me administer it to our son. I was devastated to learn that for some reason there can be one designated caregiver. This affects every aspect of my life. I can never be more than 4 hours away from our son. Families affected by

autism already lead an isolated life and not having other designated caregivers has made that even worse for me. I am on the clock at all times. It makes it very difficult work. It affects my ability to see my children and grandchildren. It affects my ability to help my Mom through her cancer battle. It affects my marriage and my mental health. I could not even spend more than 2 hours with my family at my dad's funeral in October (about 60 miles away) because I had to get back to town to administer our son's medicine. I cannot do this by myself anymore.

HB 1359 as it is written today would allow up to 3 designated caregivers. While I would sincerely appreciate more caregivers there are still significant limitations with only allowing 3. I have two older daughters and in addition to certifying my husband I would certify one of my daughters as the third caregiver because this third caregiver would have full caregiver rights and could purchase, possess and administer. I would not feel comfortable giving someone outside my family full caregiver rights. Thus, this still does not allow both me and my husband to attend school events, sporting events, church events or other family events together with both of my daughters and grandchildren because one of us will still have to stay behind to dose my son. I would feel comfortable with a caregiver that was outside my immediate family having just the ability to administer or dose my son. The proposed amendment addresses this issue. I urge you to recommend a do pass for HB 1359 with the amendment that a registered qualifying patient may have no more than five registered designated caregivers. Only 2 of those 5 registered caregivers will have the ability to purchase product and will be designated as such on their application.

I sincerely thank you for your time today.

Thank you,  
Sandy Smith  
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