

HB 1359 Caregiver/Advisory Board Testimony  
by Gail Person, SPRN, HN-BC.

Thank you committee chair Lee and the Human Services committee members for this opportunity to appear today. I am here to speak for HB 1359. I am Gail Pederson from Valley City, District 24. I am a Special Practice Registered Nurse in Holistic Nursing and a Board Certified Holistic Nurse. My scope of practice includes cannabis education and consultation. Since the true implementation of the program started after the last legislative session, problems have arisen which were not visibly apparent until implementation. Problems with the caregiver aspect of the medical cannabis program became evident quite rapidly. Some of our most vulnerable citizens were restricted from participating in the program. That is pediatrics, disabled adults and the elderly, particularly those in communal living settings.

Through the ACNA, I am on a national long term care (LTC) working group for cannabis access/legislation for LTC facilities. The elderly are the largest growing group utilizing cannabis as medicine. What this working group comes down to, besides setting up a research project with cannabis and dementia, is finding a work around to federal regulations restricting organizations who receive federal funds from allowing cannabis in their facility. This includes organizations for most any major health system. The developmentally delayed/adult disabled population is personally important to me since I have a 30 yo son in this category. I am also on the Board of Directors for the organization he is connected to, The Open Door Center in Valley City.

The current, 1 primary caregiver (which was amended to 3 and that I requested be amended to 5 as presented, is inadequate for someone needing 24/7/365 days a year coverage. They cannot, because of disability, age or institutionalization are unable to use the product on their own. As a nursing supervisor for many years, understanding staffing patterns and the number of people needed has made this an important issue. Continuity of care cannot be realized without these changes.

The situations I will tell you about are personal. They represent flaws in the program.

My sister in Law Sam suffered from difficult to control seizures after being hit by a car when she was 11. She was on every new seizure medication that came out as she aged. She was never seizure free. The horrendous side effects she endured from the medications, from having to have her gums carved down, to liver complications, they never did control her seizures. She had many “scary spells” throughout the day. She was a zombie because of her medication. She died a little over a year ago at the age of 60. We had talked to her neurologist about using cannabis, but never pursued it because of her living in a group home setting and the restrictions we faced. She was not being treated as a normal citizen.

Matt is 35 years old and has Cerebral palsy. He lives in his own apartment with the help of caregivers who are not able to give him his cannabis product. Matt got his card early in the program, but because of the difficulty of a single caregiver providing for him, it was inconsistent in finding him a solution for his spasms, nausea and anxiety. He let his card lapse without really being able to see if cannabis worked for him. Matt does not have the rights of a healthy, mobile North Dakotan.

Jonathan's is a young man who lives in a group home setting. His neurologist recommended that his parents/guardians try CBD. It worked! He slept on the days they saw him and were able to give it to him. His mother's testimony will hopefully be heard today.

Ronnie and Alexa. You are aware of them as Alexa was instrumental in adding Autism Spectrum Disorder to our list of conditions last session and spoke on our pediatrics measure this session. I received the North Dakota Legendary Nurse award for Advocacy in 2019, nominated by Alexa. She had to wait for Ronnies bus to give him his afternoon dose and missed presenting me the award by 10 minutes. They are not being treated as a normal citizens.

I also want to tell you, the pediatric solution that was suddenly created before the legislative period did not work for him. His behaviors increased quite dramatically. They are at a dead end again. An increase in unproven psychotropic meds are their reality as he ages.

Also of concern is the background check for the extra caregivers. It is a financial hardship for anyone. Primary guardians who are initiating the applications should be able to designate who the other caregivers should

be, with the same registration/attestation that is laid out in HB 1213.

I agree with the formation of the advisory board under 19-24.1-38, but I would like to have at least two patients represented or several more “at large” positions. The limitation of 1 patient is not realistic. The Advisory board is currently filled with those who were active in implementation. It is now time to shift to a patient centered group that is concerned with the functionality, transparency and consumer safety of our program. This should include tracking of complaints by card holders and quality control not just adverse reactions.

Thank you to those representatives that have heard the need for more participation of patients. It is time to take care of all of our citizens equally and removed the criminality of this plant. I leave with you the 6th and final basic principle from the NCSBN guidelines. I have paraphrased adding legislator instead of nurse, constituent instead of patient.

“In addition to ethical responsibilities under the legislator’s jurisdictional law. The legislator shall approach the constituent without judgement regarding their choice of treatment or preferences in managing pain or other distressing symptoms. Awareness of one’s own beliefs and attitudes about any therapeutic intervention is vital, as you are expected to provide care for your constituents without personal judgment.”

Thank you for considering this change. I will stand for questions.