

Madam Chair, Madam Vice Chair, esteemed members of the committee,

It is my honor to introduce you to Senate Bill 19-215, a bill to request funding for meals for the PEP (Parents Encouraging Parents) Conference. Because of new Federal regulations the funding for communal meals was cut. This resulted in significant changes to the program which undermine its efficacy. Senate Bill 19-215 asks for \$ 68,000 in state funds to purchase meals which will allow continuation of the program in its original format. Senate Bill 19-215 also create a mechanism to ensure that the legislature will be informed of further changes to the integrity of the program and decide if it is worthy of continued funding and support.

PEP was an innovative program by the Colorado Department of Education that changed my life as the parent of a child with disabilities. And I am not exaggerating. It really changed my life and maybe you can blame PEP for me growing up to become a state legislator!

PEP was a free weekend program for parents of children with disabilities that was held quarterly. Parents were given the opportunity to go to a hotel without their children and spend a weekend with seasoned parents of children with disabilities and with education, health care and disability law experts while they learned about their children's rights as Americans living with disabilities in the US. Even more important than the legal knowledge that was shared by the experts was the ability to spend quality time with other parents who were sharing your lived experience.

People always say that there is "no book" on how to raise a child with significant disabilities; for my family PEP was that book. I cannot over emphasize to you how affirming it was to speak with other parents (without our children present) and share our deepest fears and hopes in an environment of understanding. While at the same time having experts present to ask questions of and ensure you were doing all that you could for your child. Because of PEP my daughter's educational path changed completely. And the parents I met at PEP, several of whom you will hear from today, became lifelong friends who I continue to turn to in low moments of family life for affirmation and support.

PEP provided lodging, meals, experts, and access to seasoned parents who share your life experience. Parents paid their own transportation and arranged for care of their special family during the weekend. I am embarrassed to admit I have no idea how much the program cost the state. No matter the cost, I and many of my dearest friends, can tell you that it completely changes the lives of families parenting children with disabilities.

The folks who told me about PEP being undermined said it had to do with the federal government not allowing payment for communal meals. I would urge you to use state funds for this program. It is invaluable.

Today you will hear from other people whose lives were changed because of PEP. I ask that you pass Senate Bill 19-215 to provide the same opportunity for future families coping with disability.

There are two amendments that have been drafted. Yesterday I received L001 which reflects input by the Board of Education. Many of their requests are reasonable. Unfortunately, several of their requested changes would codify current changes and allow further undermining of PEP. I urge you to reject that amendment.

Last night I incorporated many of the changes requested by the Board into L002. However, I retained those portions which make PEP PEP and ask that you instead adopt this amendment.

I appreciate your time and attention and am happy to answer any questions either now or after you hear testimony from others in my PEP family.

Respectfully,

Irene Aguilar  
Mother of Amelia Milagro Bost  
On behalf of La Familia Bost-Aguilar

