

Darla Chafin

LD 659

LD 659 An Act to Promote Seamless and Flexible Home and Community Support Across the Lifespan for Individuals with Intellectual and Developmental Disabilities or Autism

Neither for Nor Against

Senator Baldacci, Representative Meyer, and members of the Health and Human Services Committee:

My name is Darla Stimpson Chafin and I live in Augusta. I am the parent and guardian of a 55-year-old woman with special needs. She has lived at home, in a facility in El Paso, Texas, Pineland Center, and several group homes. Presently, she is a resident in a group home in Auburn where she has been since 2010. This is the longest placement she has had since Pineland and she considers it her home. And she also feels most proud to have me visit AND leave just like she suspects other adult families do. She tries to help her staff and to avoid falling and to continue walking. I am sure that many who have taken care of her in the past would be amazed. I am. And more importantly, she feels that she is part of a group that helps each other and all are equal. And although we had a complete change of staff during COVID, she got through the transfer without any serious falling accidents, illnesses, or depression. When she had COVID, staff arranged for her favorites to transfer with her in isolation and she was not upset as would be expected with the abrupt change in routine and placement. Because she does need close assistance to prevent accidents, she never had the opportunity to be part of a day program until this agency arranged for Cathy to come in early and help with preparations, then to stay for a short time with the group. She loved it. It was right for her. She was so happy to be with a group of peers. Due to staffing shortages, she is no longer able to do this. She also lost her swim program and horseback riding although efforts are being made to try to activate any of them.

Concerns with this LD:

Although this bill has wonderful ideas and improvements for many, it also has very vulnerable gaps. Frankly, the fact that it was not considered important enough to be a "major substantive rule," while stating it would include all services to this population within five years is a bit insulting. After dealing with this and similar systems for over fifty years, I was still startled to see this LD being classified as "routine technical." Not even in Texas would anyone have considered these issues routine and technical.

I suspect this may not only be due to any federal mandates but also the struggle to get changes completed before the next election. No matter the result of an election, it will be more difficult to correct mistakes made due to rushing for completion with a premature deadline. Careful development of such a system could be done, although possibly not completed. However, if careful and all inclusive work is done on this, it would be difficult to justify not completing it. And at the very least, defending continuing this effort to its completion would be much more palatable than eliminating appropriate services to members of this class through oversight.

In Section 2, under Relationships, a new waitlist is established. What happens if the group home is closed due to a lack of funding or staffing? I see no place for my daughter in the Lifespan program as it's developing. She uses a walking belt when away from a familiar area. On the other hand, she would never be accepted in a nursing home. She is too active and noisy until she withdraws so completely that she frightens those caring for her.

Though when current programs will close is broadly mentioned, there is no information on what will remain for those with the most complex needs, balancing health while avoiding boredom.

This is a complex and sensitive project. It is indeed "major substantive."

I'd love to see a successful, all-inclusive program. I just don't want us to do any more harm. In the last administration we had to ask for an important LD that would have had a serious impact on this population to be changed to Major Substantive. Is this happening because of a lack of knowledge about the impacted population or because the Legislature's load is overwhelming or prejudicial? That's a terrible word but usually it really is grounded in a lack of knowledge about those targeted, lack of money, and even an overwhelming work load. Ironically, finding the elusive solution to complicated problems often leads to a better program doing less damage and therefore less repair and frees up time as well.

Thank you for your consideration of this.

And feel free to contact me if you need further information or even a visit with my daughter.