



LAURA KELLY, Governor • KATHY KECK, Chairperson • STEVE GIEBER, Executive Director

*“To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities”*

Feb 12, 2020

Re: HB 2550, Neutral testimony, (written only)

Chairman Carpenter and Members of the Social Services Budget Committee,

My name is Craig Knutson, policy analyst for the Kansas Council on Developmental Disabilities. Thank you for the opportunity to speak with you today about HB 2550.

The Council values the full participation of people with disabilities in all aspects of community life through the provision of person-centered supports. We believe that high quality support requires all professionals to follow the individual path suggested by the unique gifts, preferences, and needs of each person they support, and to walk in partnership with the person, and those who love him or her, toward a life of opportunity, well-being, freedom, and contribution.

If we, as a state, are to ensure a high quality of life for all Kansans, we must make sure that there is an adequate funding of the service system to provide quality services for Kansans of all abilities. As part of its founding mission to help ensure adequate systems capacity, the Council has long advocated for appropriate funding of services. Let us be clear: the system *is* underfunded given our current approach to supports and services. However, simply believing that additional dollars will solve the problem is wishful thinking. The Council, as part of its founding mission, also advocates for Systems Change. As written, this money is earmarked to pay providers for people currently served.

We have an opportunity to fundamentally change the types of supports and services offered increasing outcomes that lead to a good life, and at the same time serve those who are on the waiting list. There isn't likely to be a single solution, but rather, a coordinated, multipronged approach is needed. Other conferees today will talk about some of those solutions.

Today, I would like to talk with you about why they Council believes that, unless addressed, this problem will only continue to grow. Often, when we talk about supports and services for people with (I/DD) within the context of policy, we think that we are talking about how these supports and services impact all people with I/DD. The harsh reality is that our policy discussions really target only a small percentage of Kansans with I/DD.



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When we talk about supports and services for people with I/DD, our focus is on the roughly 9,000 Kansans who receive some type of waiver services and another roughly 4,000 Kansans on the waiting list for waiver services. What we don't talk about is how this is only a small percentage of Kansans with I/DD. By definition, intellectual and developmental disability has a rate of prevalence of 1.58% of the general population. That means, in Kansas, with a population of 2.919M people, it is estimated that there are over 46,000 Kansans with I/DD. In other words, there are about 33,000 Kansans with I/DD that our current service system don't know about, who, in all likelihood, require some type of support during their lifetimes. Many, if not most, of these folks are currently supported by family members who provide support at no cost to the state.

What we are seeing, however, is a shift in demographics. As many of these family member caregivers age, not only are they not able to continue to provide support for their family members, but oftentimes age into a need for care themselves. Of the roughly 33,000 Kansans with I/DD that are not currently known to the system, it is estimated that approximately 18% of them have a caregiver aged 60 or over meaning that close to 6,000 Kansans who are not currently known to the system, potentially, may soon need some type of support that the state is currently not equipped to handle under our current models of supports and services.

Simply put: serving those on the waiting list, and any significant percentage of those Kansans with I/DD who are not currently known to the system will need to be accounted for when calculating the true costs of this bill. We have an opportunity with this bill to fundamentally transform how we support all people with I/DD who need services, including those on the waiting list.

Simply doing the same thing over and over again and expecting different results is what led us to this situation. We need to be creative in our solutions. We must rethink how we support people across all ages and all disabilities. We must ensure that we have adequate systems capacity and be innovative in our systems change to address this crisis head on.

Thank you for your time, and I am available for any questions at your convenience.

Craig Knutson  
Policy Analyst  
Kansas Council on Developmental Disabilities  
900 SW Jackson #569  
Topeka, KS 66612  
785.296.1980

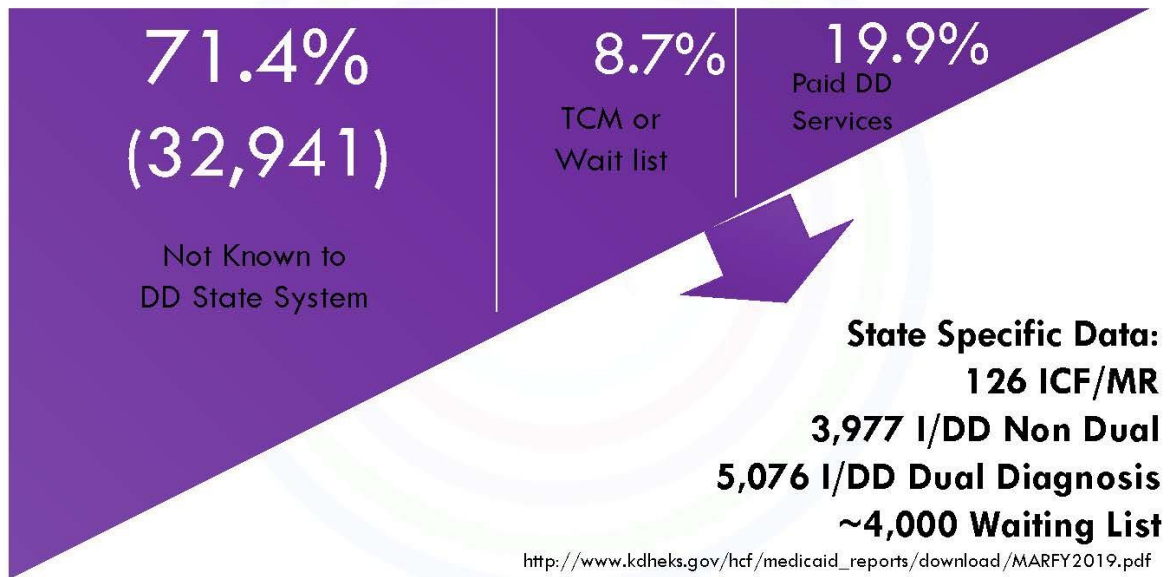


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## Kansans with DD

46,120 estimated Kansans with Developmental Disabilities\*



\*Based on 1.58% prevalence of 2.919 million citizens, US Census (2015)



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