

2023-25 September 2023 Human Services Committee Testimony September 28, 2023

RE: Testimony in Support of Proposal (*reference 2023 Session SB 820*)

Thank you, Chair Gelser-Blouin and members of the committee for allowing me to provide our family's experience. My name is Roberta Lincoln, and while I work for the State of Oregon, I am here as a private citizen. I am an adoptive parent of two special needs male children of color. Both of my sons are considered "Complex Cases" – because they experience Intellectual/Developmental Disabilities (I/DD), as well as medical, mental and behavioral health challenges.

My older son is autistic and suffers from Post Traumatic Stress Disorder (PTSD) due to trauma caused in school-settings. At times, over the past few years, he has had externalized, and significantly distressed, unsafe behaviors. Prior to COVID, we had Direct Support Professionals (DSP), which was extremely helpful for skill-building and emotional and behavioral regulation for both boys. However, during the isolation of COVID, without DSPs, these behaviors became unmanageable, and put our family at risk. More concerning were the behaviors where his life was at risk due to multiple suicide attempts.

We tried to obtain intensive in-home behavioral therapy, but these services were not available through the mental health (MH) systems. While we eventually found these through a community provider funded by a Child Welfare grant for adopted children, the waiting list was 6-9 months long. Escalated behaviors do not diminish, just because you are on a waiting list. If those intensive in-home services were available to us through the MH system, we would not have had to delay the vital in-home skill-building and crisis prevention services. However, because of the long wait, my son's behaviors escalated to crisis-mode, which led us numerous times to hospital emergency rooms, and sometimes multiple hospitals in one day. We were considering out-of-home placements for our son.

Our family's crisis hit the crescendo a year ago when he attempted suicide due to racism and discrimination at school. My son had a week-long stay in an emergency room, at a hospital which houses an in-patient youth psychiatric unit in the Portland area. We struggled to get an appropriate psychiatric unit placement, because of my son's developmental disabilities and the supports he required for the activities of daily living. They said they were not 'set-up for that level of care' in their adolescent unit. Thankfully, he was able to receive services in the children's unit for several weeks, where he thrived. Unfortunately, upon discharge, there were no supports, services or plans in place to maintain the progress he had made. There was no case manager, no care coordination, no referrals to specialists, and most critically, there was no mental health provider lined up to continue his care.

For 6-months, we unsuccessfully searched for a mental health provider for my son. It seemed impossible and we lost all hope. These were very dark times for our entire family -- we lived in crisis mode.

However, through a number of accidental and random phone calls to friends and families, we were connected with Oregon Health Authority's (OHA) - Behavioral Health Unit - and their "complex case management" staff. Having the assistance of skilled complex case managers made all the difference

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in the world because they worked alongside us, guiding us through the Systems of Care, and even removing barriers we had experienced for months, allowing my son to be successfully matched with the MH provider he required.

At that time, we obtained a DSP who was well suited for our son. His DSP has been providing skill-building and supporting emotional, behavioral and independence goals in our home, and the changes in his behaviors were remarkable. We were able to enroll him in a day-treatment program that uses Collaborative Problem Solving... and the progress since this point has been astonishing. It has been a solid year since we have had to involve emergency services.

As I have stated in testimony in support of the 9-8-8 Bill, our family is informed and well connected and yet during our major moments of crisis, we were unable to access the necessary support for our family. When families are in the throes of a crisis, trying to navigate the broken Systems of Care on our own, parents and care-givers are overwhelmed... and at times, paralyzed. When families lack the necessary mental and behavioral health supports and services, and are experiencing crisis, they are forced into making critical decisions quickly. If those supports and services were already in place, the crisis might never have happened. Lack of supports exacerbates the existing mental and behavioral health problems.

Trying to avert the need for emergency services and out-of-home placements is the goal. In order to succeed, families require supports and skill-building before emotional and behavioral challenges escalate to the point of requiring emergency services and alternative placements. **Providing the infrastructure -- like skilled complex case managers, MH and Behavioral Health supports and services such as in-home providers, and making those available to all families regardless of income limitations – EARLIER AND SOONER - is a necessary investment in Oregon’s youth, those with or without disabilities. It sends the message that every child, every parent, every person in Oregon matters!**

Thank you for allowing me the opportunity to speak with you today.

/s/ Roberta M. Lincoln
Parent