

Dear Co-Chairs Senator Steiner Hayward and Representative Rayfield, and all members of the Ways and Means Human Services Subcommittee,

We write in support of funding developmental disability services, which have made such a critical difference for our family.

Our son, Rhys Morgan-Krebs, is now 8 years old. He is a bright spark, a highly affectionate child full of laughter and curiosity who loves music and dance. On first meeting Rhys, you would instantly recognize that he is not neuro-typical. Rhys has a noticeable language delay, he moves his body in a very unique way, and he displays several comforting repetitive body movements. You would know Rhys has special needs – but you would also instantly like him. Rhys is charming, eager to please and rapidly becomes a favorite among teachers and therapists.

When Rhys was 19 months old and failing to meet developmental milestones such as walking, Rhys was diagnosed with the rare genetic disorder Williams Syndrome. Moderate autism and Celiac disease have since been added to the constellation of Rhys's challenges.

Rhys's health care is primarily covered by Susannah's employer-provided health insurance, Kaiser Permanente, but Rhys also qualifies for Medicaid in case of need – and children with Williams Syndrome often experience significant heart issues, so high quality medical care is of the utmost importance. Rhys is under the care of Doernbecher Children's Hospital to monitor his heart, which is exhibiting increasing issues but thankfully has not required surgery. Rhys currently receives 11+ hours of Applied Behavioral Analysis (ABA) therapy each week through Kaiser.

Rhys has received case management, early intervention and supportive services through Multnomah County. We especially benefit from Respite Care, which uses Medicaid dollars to provide care for Rhys, who needs careful supervision. Rhys is also under the care of Portland Public Schools; he is in second grade in a Communication-Behavioral-Academic (CBA) classroom at Alameda Elementary School, where he also participates in general education classrooms.

Both of us, Rhys' mothers, are highly competent professional women. Jocelyn is a Professor of Biology at the University of Alaska Anchorage. Susannah is CEO of Oregon Food Bank. Even with our combined intelligence and education, we have desperately needed and greatly appreciated every ounce of support from disability professionals to navigate the system and secure supports for Rhys. We feel for other families raising children with special needs who may not have the resources available to us, and for whom disability support services are absolutely critical for their children to receive the support they need to thrive.

From our personal experience we can assure you that having a child like Rhys is a great joy – and a great challenge. It is both appropriate and important that the State of Oregon continue to support families like ours so that the parents can be useful and active citizens and most importantly, so that our children have every possible opportunity to live full and successful lives.

Sincerely,  
Jocelyn Krebs and Susannah Morgan

and Rhys Morgan-Krebs:

