

March 10, 2015

> Capitol hearing presentation...Lilly's story

> Co-chairs and members of the committee, I am Becki Moore from Redmond Oregon.

> My husband and I were born and raised in Central Oregon and have been blessed with three amazing daughters who keep us on our toes!

> Our youngest daughter Lilly has Rett Syndrome...a rare and randomly occurring Neurological syndrome affecting every aspect of development. Lilly no longer can walk, talk, or use her hands in a meaningful way, yet Lilly is very intelligent understands everything going on and being said around her. Lilly is a typical 4 Year old who loves to watch Disney movies, go to the park, and joke with her friends at school.

> When Lilly was first diagnosed it was devastating because by that time she had regressed and lost everything. The Early Intervention specialists were there to help us pick up the pieces. One member of the team would visit each week on alternating schedules whether it was physical, occupational, or speech therapy, someone was there to give a hug, warm smile, and then listen. They listened to what Lilly's needs were and then came up with a plan using all of the tools in their toolbox to help our family keep moving forward and supporting Lilly's development...and they provided a lifeline to other services and families. They helped us see beyond Lilly's diagnosis and helped us learn how to make life work within our "new normal".

> The people who are on the front lines serving our neediest population have been doing more with less for a very long time. At the current funding levels it's really only covering the increase in caseloads, with little being done to increase services back to per-recession levels.

> Home visits are only one aspect of what these professionals do and we are so grateful to have had the opportunity to work with all of them. I can't help but think that the impact could have been larger though had Lilly have been able to see each specialty once per week or more.

> Birth to 5 years is the most important time developmentally...it is critical that we fund these programs and support our most vulnerable and needy group to a level that is going to be therapeutic and yield a positive outcome for children and families!

> Please increase funding for EI/ECSC services.

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