

## **Needed: Non Crisis Comprehensive Services**

My name is Carla Cudmore. I'm from Polk County. My daughter Calin, is 21 years old, but functions at the level of a one year old. She cannot walk or talk, cannot feed herself or use a restroom, requires extensive lifting and has limited use of her arms. Calin has grand mal seizures, and cannot be left alone. We love her dearly but she requires a great deal of time, patience and strength. We hope she will live with us for a long, long time. But we worry, how long will we be able to care for her?

Calin "graduates" from high school in just one month. She will go on to a day program 4 hours a day. We are very thankful for that, but, there are still many hours left in each day and week, and Calin must be cared for, each and every one of them. That is our job, her Dad and I. But... we need to work, we will wear out and we will die. The lifting, the lack of sleep, the stress, and depression. Parents of disabled children age faster than our counterparts.

My husband and I are also part of the now famous, "sandwich generation". We still have kids at home and up until a month ago, we were also the sole care givers for my blind mother with dementia.

What will happen to our daughter, when we can no longer care for her? The State of Oregon requires we make, the most important decision, in our daughter's life, when we are at our most vulnerable, during a crisis. When our crisis occurs, if our city or our county has no suitable beds available, Calin could be placed anywhere in the state. Crisis management does not work, and in my view, is not fiscally sound.

The system must change and provide access to comprehensive services without crisis. Parents and care givers must be allowed to work together and plan with the state and counties to transition our children into 24-hour care. By planning comprehensive services, parents and the "system" can be innovative. Innovative ideas can help retain private insurance, keep parents involved with their child, maintain family and community ties and even combine family resources with those of the government to stretch valuable dollars.

There are many of us, the baby boomers with our severely disabled adult children at home. But, we need help. The State of Oregon and the Department of Human Services must plan for a non-crisis, truly comprehensive approach for adults with developmental disabilities who require 24-hour a day, 7-day a week care.

Thank you

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