

To: Chair Gelser Blouin and Members of the Senate Human Services, Mental Health, and Recovery Committee:

Remembering Kathryn Weit

January 31, 2022

There have been a handful of individuals in my life who have had a great impact on me, and Kathryn Weit is one of those people. I first met Kathryn almost 20 years ago when she was doing the Blueprint Project, came to Grants Pass with a couple of other women, and wanted to hear about my life, my son Ian, and my experiences navigating the developmental disabilities system. I didn't really understand what the Blueprint Project was about, but for me, it was about having a lifeline thrown my way in a time of desperation. It was about meeting Kathryn.

Kathryn was the first mom I met whose son had disabilities similar to Ian's, so I looked to her to see how she had navigated her way through certain things and also as a glimpse into my own future. Colin was 10 years older than Ian, so she was 10 years ahead of me on the path. At that point, our family still had a few years before Ian would turn 18 and transition out of children's services, but I was already worrying about what his life would look like and dreading what I was hearing from the service system. Would he be able to stay in our community around the people who loved him, or, because we were in a rural community, was he going to have to take a "bed" anywhere around the state when one became available? Would the loving caregivers who had been with us for many years and were highly trained be able to continue working with him, or would an agency be unwilling to hire them, assuming we could even find an agency willing to serve him? These were a few of the many impossible choices that our family was having to look at. In 2003, when Kathryn took me to Colin's home that first time and showed me what she and George were setting up for him, I was completely blown away by their vision. It was such an ideal set-up and my heart was eased just seeing it. I dared to feel inspired that perhaps we could do something similar for our Ian.

I faced so many hard decisions and had so many big questions over the years we knew each other, and she was not only able to guide me and soothe my worried

heart, but she was able to inspire me with her approach. What a gift she was! It was through talking with her that I learned for the first time that I was not alone and that there were other parents around the state who were not only struggling to figure out how to survive this unusual life we were given, but who were also learning how to rise up and get their child's needs met through awareness, education, and advocacy.

In 2004, with Kathryn's enthusiastic encouragement, I went through Partners in Policymaking and also became a member of the Oregon Council on Developmental Disabilities. While I was on the Council, we started producing a magazine called *Oregon Perspectives*. As our committee began to talk about the direction we wanted the magazine to go and how we hoped to accomplish our goals, we focused on the importance of story-telling. Kathryn said one thing that I will always remember: "When you know someone's story," she said, "you can't help but care about them."

Wow!!! When you hear someone's story and begin to care about them, they become individuals and not just "consumers" or someone on your "caseload." It changes how you govern; it changes the laws you make; it changes how you teach your classrooms; it changes how you raise your children. And when that realization dawns, things change for the better, for everyone.

With her simple words, everything opened up for me. I knew it was true but hadn't yet put it into words: My family's story had value. What we were going through needed to be shared. Kathryn's statement opened my mind to the power of each of our stories and why it is so important to tell them. Why our legislators need to hear our stories, on both the state and federal levels. Why our teachers, medical professionals, and therapists need to hear our stories. Why our friends and community members need to learn about our lives. Through Kathryn, I learned how to tell my family's story without being afraid.

Another thing I took to heart was how even though most people with developmental disabilities can work or be integrated into regular classrooms for at least part of their day, reality is that there are those for whom this inclusion is not possible, even with adaptations, modifications, and extra support. My Ian is one of

these people, and I learned that it is alright and even critical to speak to the truth and the reality of who he is. In fact, though he himself cannot speak or even understand some of the simplest things, it is important and essential that people like Ian have a voice. I would have given anything if he could have been integrated more into the school system, the work force, and the community, but he is who he is, and my role in his life has been to advocate for what HE needs and not just settle for someone else's idea of what those needs might be. Kathryn's open-hearted vision, wisdom, encouragement, and willingness to share helped me find my voice, so that I could give my son his voice.

Since I live in Southern Oregon, I was not able to see Kathryn as often as I wanted to or needed to. However, whenever I came to Salem or even to Eugene, she always made time for me. There were even a couple of times when I was able to help her with something she was trying to figure out for Colin.

I remain ever grateful for each thing Kathryn brought to my attention; each concept she helped me understand; each time she was willing to listen and offer an idea that might be helpful; and each little bit of hope she gave to me. I will remember her kindness, her wonderful sense of humor, and the interest she expressed in how I was doing. We could laugh together at some of our common experiences, and that was incredibly helpful for us both. The loss of Kathryn is huge in my world. I wish I could tell her just one more time how grateful I am that she has been a part of my life and how important she still is to me.

Mar Goodman
Cave Junction, OR