

My name is Raymond (Ray) Gerke. I live in Perry, Iowa.

Thank you for allowing me to speak to you today. I am honored to be here to share my story with you in order to help you understand the importance of supporting home and community based services.

I received a diagnosis of cerebral palsy when I was an infant. At that time, my parents were given the choice – take me home and raise me like any other child, or place me in an institution. They chose to take me home.

My early years were filled with family vacations, road trips with my Dad in his truck, and games, rivalry and love between me and my siblings and cousins. When I was eight, my parents were told that I needed more intense therapy services than what I could get in my home community. They were told the best thing they could do for me would be to place me in a facility where I could get physical, occupational and speech therapy.

So, all of a sudden, I found myself in a town two hours from my home – alone without understanding why. I was totally unprepared for this strange setting. Instead of my family and friends, I found myself sharing my life with 97 other individuals with disabilities. Some of those strangers became my friends, but no one could replace what I left at home.

Because I did not understand, I cried for those first two days, and then many days off and on for the two years I lived there full-time. After those first two years, I returned to my home during the school year, and spent summers back in the facility.

It took three years to learn the system – to know what to expect and be able to handle things without those childhood tears. For example, I learned independence. We were not allowed visitors as they might upset us. I learned not to trust people. In a congregate setting, the young kids gets teased and bullied by the more experienced. Kids take things from each other, and worse, if adults see something they like, those things also often come up missing.

In that same setting, my experience included having to go along with demands of an authority figure who had power to make my life miserable – even when that authority figure's demands included misusing my body to meet his personal desires.

I got all the intense therapy I needed – but at what cost?

When the professionals decided that the therapy had gone as far as it could, I returned to my family home. That experience – though over four decades ago – has had lasting impact on my life and my perspectives.

Today I live with my wife, who also has Cerebral Palsy, in a home we own. I work full-time. I drive myself to work and wherever else I need to go. I have many, many friends,

some who have a disability, some who do not. I live a full life – a life that I direct myself with supports.

I also carry with me each and every day the burden of knowing that the threat of institutionalization is as real for me today as it ever has been. If I lost the funding sources that provide me the ability to maintain my life as it is, my salary could not cover the costs of having staff to assist me with getting ready for work, preparing my meals, or getting me into bed at night.

Without that support, I'd have few options but to return to a setting much like the facility I knew those early years. I would then no longer be directing a few select personal assistants to assist me with the choices I make on how I like to live, and I would also no longer have the independence I know today. My life would lack privacy. When I lose choice, independence and privacy, I also lose my dignity and I lose my freedom.

In order for me to maintain my life in the community, and to provide other people of all ages who live with disabilities today the same opportunity, I ask you to:

- Eliminate the institutional bias in Medicaid by requiring states to include community based personal assistance services in their Medicaid plans. Individuals who qualify for Medicaid should automatically be eligible for community services—not just services delivered in institutional settings as in current law.
- Provide financial incentives for states to help individuals transition from institutions to community settings. Because community settings are typically less costly, this benefits not only the individual but also the federal and state treasuries.
- Assist states in developing and implementing a strategy to “re-balance” their long term care systems so that there are more cost-effective choices between institutional and community options.
- Provide financial support and create incentives for states to develop quality community-based supports and services, including support to help states find ways to recruit, train, and retain direct support workers.
- Offer respect to the people whose lives are affected by disability policy decisions by not just listening to them, but by having them be a part of the decision-making itself.

Today, I am an active advocate for all people with disabilities. I serve on many boards and committees, two of which strongly apply to this topic:

- I am a member of Iowa's Olmstead Real Choice Consumer Task Force. We are working to effectively implement the Olmstead decision in Iowa. This includes advocating for the policies I just stated as well as working with the Iowa Department of Human Services to take advantage of CMS's new progressive policy of self-direction, which promotes community living and affords individuals more choice and control over the services they receive.

- I also serve as the co-president (self advocate representative) for the National Coalition on Self-Determination, Inc. – the only national coalition that has both parents and consumers working together on issues.

The work of both of these groups focuses on “real choices” –

- The freedom to live the way you want – to self-direct your life
- To be able to purchase the services you need to support you in your life
- To live a life with dignity
- To have the freedom to make new friends and participate in your community, and
- To support your right to vote

Again, I urge you to pass legislation that will incorporate the policies I have mentioned today that help people like me have all the right resources exist in the community for me to participate fully as an American citizen. Your decisions are important to the lives of many, many people who like me, live under a threat that should not be present.

Thank you very much for your time and attention to improving access to Medicaid Home and Community Based Services.