



## Testimony to the Administration on Developmental Disabilities December 6, 2010

Thank you for inviting us to present this testimony.

I am Dr. Denver Fox, the parent of two children with profound disabilities, Andy, born with profound developmental disabilities and Tim, paralyzed from the shoulders down on his 21<sup>st</sup> birthday. Andy now lives successfully in a Host Home and Tim is a Stanford Law School graduate and he and his wife are noted attorneys - having achieved a record ADA accessibility settlement with Kmart and successfully settling with Burger King – both in the millions of dollars. They continue their accessibility efforts with other major corporations.

I am also the founder and coordinator of NOEWAIT, the National Organization to End the Waitlists and PAD-CO, Parents of Adults with Disabilities in Colorado.

I am struck that there are meetings, conferences, hearings, articles and the like about services to individuals with developmental disabilities – and they all consistently ignore over 370,000 individuals who receive no services because they are on waitlists. Additionally, they never approach the issue of portability of services between states. No matter whether it is the request for testimony for these hearings, an Arc national conference, AAIDD, TASH or similar alphabet organizations, the issue of services to those hundreds of thousands of individuals waiting and waiting for critical services and held prisoner in their own states is simply swept under the rug.

Yet, there are some folks who are attempting to solve the problems of waitlists and portability – NOEWAIT has identified 31 states with some sort of waitlist campaign – including efforts by Developmental Disability Councils, Protection and Advocacy organizations, state Arcs, a variety of coalitions and through litigation.. Some are highly organized with major efforts, others just getting started or needing organizational help. We have recently developed a directory listing these state efforts, which I am leaving with you.

The one commonality amongst these 31 state efforts is that the states do not communicate with each other. No state really knows what other states are doing, their successes and failures, their strategies and tactics. Nor have the states jointly developed a national strategy - such as to reverse priorities and make Home and Community Based services the default Medicaid service and institutional care the waiver service. Likewise, there have not been strategies developed on the critical issue of allowing individuals with developmental disabilities and their families to move from state to state and retain critical services..

NOEWAIT's plea is for support by the Administration on Developmental Disabilities for a national conference and methods of communication amongst these states. NOEWAIT is ready and willing to take the leadership role in this opportunity to provide services and portability to over 370,000 individuals waiting and waiting and waiting and those receiving services who are prisoners in their own states.

We need your help. Contact [Noewait@noewait.net](mailto:Noewait@noewait.net). Web page <http://www.noewait.net/>

**NO WAIT, NO BOUNDARIES**  
*Services when we need them, where we need them*