

Representative Morrell, Mr. Hall, Ms. Smith and members of the Long Term Care Work Group,

I am Joanne O'Neill and I work for the Arc of King County as Coordinator of Parent Training and Assist. Coordinator of the King County Parent Coalition. I also have taught the Medicaid Personal Care Parent Provider training since it's inception in 1998 and helped the Arc of WA create the current training that is now used for MPC Parent Providers. I am a nurse with a specialty in Rehabilitative nursing but most importantly I am a parent of two adult children with developmental disabilities. Today, I am representing the parent coalitions listed on the POSITION STATEMENT which I have provided to the committee.

Thank you for allowing me to speak with you today. I was very concerned at the possibility that you would not hear our statement since I am representing PARENT PROVIDERS. 67% of the people with developmental disabilities live with their families. Additionally some of the folks who have moved out of their family home continue to have parents as primary or part times care providers. Within Developmental Disabilities this would make parent providers the largest group of Individual Providers in the state.

I have a position statement from statewide Parent Coalitions for Developmental Disabilities. We feel this statement is important and is supported by statewide parent coalitions which represents thousands of families across our state. In order to sign on to this position statement Parent Coalition Coordinators contacted their boards and/or rapid response teams to get a consensus. Most supported this statement totally. Some had concerns that we were too restrictive in the description in the number of hours that an "Intermittent provider" could work per year in order to fall into that category. They wanted more hours allowed.

The curriculum information for parent providers is, I believe

provided to you in the form of a matrix. Here are some of the points that we feel are important to us. The Fundamentals of Care Giving is not an appropriate curriculum for our families. I repeat: The Fundamentals of Care Giving is NOT an appropriate curriculum for our families, nor our sons and daughters. Please remember these families have been providing care for their sons or daughters for 18 years before being required to go for “training”. They could “train the trainers” in how to care for **their** adult child. Many have manuals that they have created for the use by someone other than a family member when this need arises. We support continuing the 6-hour parent provider training with additional specialized training as voluntary.

Some of the areas that parents need and would like more information and training on are:

- some need help with challenging behaviors.
- others need additional help with communication issues and supports.
- employment supports and how to use MPC for Activities of Daily Living on the job.
- assistance in fully understanding the new DDD assessment including the CARE assessment;
- SSA, MPC Program rules and other public benefits that our sons and daughters are entitled to.

In addition, our families need and request the following information:

- Wills, Special Needs Trusts, Guardianship; Social Skills, and recreational opportunities;
- successful integration into their community;
- housing needs;
- employment opportunities, funding sources, and the Division of Voc. Rehab;

Families all over our state need all this information.

Our population's issues are not "end of Life" issues. Our families' issues and needs are life-long and are habilitation needs. While many of our sons and daughters may need to be "cared **for**", we are also teaching them to care for themselves. Developmental Disabilities is about LIFELONG learning. It is about teaching people to become as independent as possible. Parents hope to work themselves out of a job whenever possible.

Another one of our **worries, and** it is one that personally keeps me awake at night, is that the cost of this "one size fits all" training proposal will bankrupt the system, and in order for the state to pay it's share they will significantly narrow eligibility **or** that they will cut MPC all together. MPC is an **Optional** state program. Some other states have made draconian cuts to their Medicaid programs. The result of this could/would be that families who are currently able to keep their loved one home or in the community would be forced to move their sons or daughters to a more restrictive environment such as our institutions, at a much greater cost to society – not to say anything about the emotional toll this would take on the person with the developmental disability and their family.

It makes good sense to provide parents with relevant training options – not the 140 or 80 hours, or the 12 hour continuing ed. or the MENTORING that has been proposed. All of this is a waste of our time and government money.

We, as families, strongly support training and benefits for those who choose this as a career path. It is important for everyone here to understand that the vast majority of our families want to care **only** for their adult son or daughter. Families provide far more care than they are paid for saving the government enormous amounts of money.

Please consider the person with the developmental disability and their family's needs before you create another industry (training) built on the backs of our people.

Respectfully submitted,

August 29, 2007

Joanne O'Neill, R.N.

Representing today, the Statewide Parent Coalitions for  
Developmental Disabilities.

The Arc of Washington State - Parent Trainer of Parent Providers  
of Medicaid Personal Care

The Arc of King County, King County Parent Training and King  
County Parent Coalition for Developmental Disabilities;