



## 60 YEARS OF PIONEERS... AND WE'RE JUST GETTING STARTED

November 4, 2009

Representative Peggy Krusick  
Wisconsin State Assembly  
P.O. Box 8952  
Madison, WI 53708

Dear Rep. Krusick:

The Arc-Wisconsin Disability Association is Wisconsin's oldest and largest developmental disability advocacy membership association. We have 7,000 members served through 28 local and regional chapters. Over the past several years, our organization has given well over 100 presentations on Family Care to legislators, state staff, county staff, provider organizations, parents, guardians and people with developmental disabilities. We have a wealth of expertise and experience in nearly every facet of Family Care. Given that our organization was not invited to provide oral testimony at the November 12<sup>th</sup> hearing of the Assembly Committee on Aging and Long-Term Care, I am providing written testimony that includes just a few things our members have learned and experienced related to Family Care.

When our organization began our educational efforts related to Family Care many years ago, we made sure to stress that we support, and continue to support, the concepts of Family Care: choice, access, quality and cost-effectiveness. As an organization, we also continue to support the expansion of Family Care.

While we have supported the concepts and expansion of Family Care, we continue to have significant concerns. Several years ago, our three primary concerns about Family Care were: insufficient funding for the program, lack of independent advocacy and a lack of emphasis on self-directed services. As you know, funding continues to be a primary concern. When the expansion of Family Care was announced a few years ago, the "mantra" was that everyone currently being served would continue to be served, all of the people on waiting lists would be served and all of the new people (based on demographics) that would be eligible for Family Care would be served *and all of these people would be served for the same amount of money being spent at that time*. Our warning at that time was that the only way to make the promises of Family Care work would be to invest in the program through more funding or to reduce service levels to people in the program. From what people across the state share with me, there is little of the former and plenty of the latter. The lack of adequate funding impacts every Family Care "player" – the managed care organizations, the providers and, most importantly, the Family Care members.

The second concern that we had, and continue to have, is the lack of independent advocacy within Family Care. We were worried that Family Care participants would have no place to go "outside of the system" if they had a concern or grievance. Our gratitude goes to the Governor, you and your legislative colleagues for approving a system and funding for independent advocacy.

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Disability Rights Wisconsin is effectively providing independent advocacy for individuals within Family Care. However, additional support for provider and system advocacy is required. Providers in Family Care have no such independent advocate should they have a concern or grievance with a Family Care managed care organization. Where can a provider go when a managed care organization comes to them with a new contract that includes a 30-50% cut in funding with the expectation that the provider continues to provide the same level of services?

The third concern that we continue to have is the lack of emphasis on self-directed services. Very few Family Care members know that they can self-direct a significant portion of their service budget. There has been little effort to let people know about this option. With the growth of IRIS, the self-directed service waiver option, there has been even less effort to share information about the option of self-direction within Family Care.

I share these concerns not just from the perspective of a staff member of Wisconsin's oldest and largest developmental disability advocacy membership organization. I also serve as a legal guardian for several adults with developmental disabilities around the state, including several that have transitioned from traditional waiver programs to Family Care. I have personally experienced the frustration of being given very little information about Family Care, being given no information about self-directed services within Family Care and having to work with providers on ways to "absorb" a 30-50% cut in funding for a person whom I serve as guardian.

Based on all of my experience, the primary issue is the lack of adequate funding for Family Care. Many Arc members were deeply involved in regional Family Care planning efforts. There was a significant amount of discussion and collaboration among all of the planning entities in a region. However, once implementation came around and entities realized there was insufficient funding, there seemed to be an "everyone for themselves" approach and mentality. The level of collaboration that was evident in the planning processes no longer existed. This lack of collaboration now seems to have been "systematized" into Family Care. Whenever I ask what I think is a basic question, nobody seems to know the answer or where to direct me to find the answer.

In closing, I want to again stress that The Arc-Wisconsin Disability Association continues to support the concepts of Family Care. This program has the potential to effectively serve a great number of people. All of the concerns we have are implementation issues. While any program of the magnitude of Family Care will have some implementation issues, there seem to be a great number of very serious and ongoing issues related to implementation. The Arc-Wisconsin Disability Association is willing and able to work to bring about the level of collaboration that will help minimize the number and severity of implementation issues related to Family Care.

Thank you for your consideration.

Sincerely,

*Jim Hoegemeier*

Jim Hoegemeier  
Executive Director