



WAITING IN WISCONSIN

A bulletin about the disability waiting list in Wisconsin written by Gerry Born
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WHERE DO WE GO FROM HERE ?

On November 1, 2003 I had the opportunity to provide the closing presentation at The Arc-Wisconsin Disability Association's conference in Prairie du Chien on this topic representing the Wisconsin Council on Developmental Disabilities. On the previous day Dennis Harkins provided an inspiring presentation on how far we have come since the first group home opened in Prairie du Chien in 1972. He presented this history interweaving the lives of the eight people who were placed in 1972. He had to state near the end of his presentation that stagnation has been the description of the DD service system during the last ten years. This is emphasized in the current biennial budget for the State of Wisconsin. After thousands upon thousands of advocacy hours, there are almost no new funds for people on waiting lists and very limited increases for disability services. After nearly six years of trying to address waiting list issues with very limited success, it is really necessary to ask the question, "Where do we go from here?"

The answer is complicated, and there may be many opinions. Some of the ideas included in my Arc presentation are the following:

- With the recent Supreme Court Decision on campaign finance reform, we must make an all out effort for this in Wisconsin to make it possible for disability advocacy efforts to be on an equal footing with other legislative advocacy and lobbying efforts.
- Government priorities need to change. We must work to have disability funding and services become a much higher priority. If government can spend \$89 billion it does not have for the Iraq initiative, it must be a matter of priorities, not money.
- We need to renew our efforts to build up the grassroots advocacy effort and then use the network relentlessly in 2005-07 budget efforts.
- Real long-term care reform may ultimately be the answer. More about this below.
- We must help to make sure all people interested in disability issues vote and seek information from those running for office on their positions about disability services.

Besides the usual methods in trying to influence the legislature and the administration to improve disability services, some disability advocates are now seriously considering some type of waiting list lawsuit. It is felt by some that this may be the only way the State of Wisconsin

will ever respond to the growing needs for services for people with disabilities. In any case, some new strategies are needed to get our message across.

LONG TERM CARE REFORM

Since the last edition of this bulletin, many changes in the Department of Health and Family Services' (DHFS) long-term care reform proposal have occurred. No longer are they proposing a demonstration waiver for five years that seeks federal participation in the demonstration. Now DHFS is proposing a series of waiver modifications to current home and community services (COP-Waiver and CIP) and several new waivers. They are proposing to add personal care to the COP and CIP waivers and amend the current Family Care waiver to allow expansion. They are also proposing a waiver to include mental health recipients who are in nursing homes, a new Family Care-like waiver to do Pre-Family Care, and a Personal Care (Independence Plus) waiver that would move personal care from the Medical Assistance (MA) card to being a waiver service through the county.

These are very major proposals. Advocacy groups have had meetings with DHFS officials to discuss these proposals, and it is clear that many of them are not fully developed but are only in the concept stage at this point. A couple of the critical proposals are Pre-Family Care and personal care. Pre-Family Care will expand a Family Care-like program to additional counties. It would be much like Family Care but might not include all long-term care services packaged in the rate. Likely, institutional care would not be included. This would allow an orderly expansion of Family Care over the next five years so that at that time most of the state would be included. Funding for this effort is needed, and as counties or groups of counties begin, Pre-Family Care may not be an entitlement, but I think we can all be assured that as this program unfolds, DHFS will work hard to ultimately make it an entitlement. In fact, the Family Care waiver requires it to ultimately be an entitlement. The role of counties, this entitlement question, new funding to address waiting lists, and how regional the program needs to go are questions and issues that need to be addressed. At the same time, DHFS deserves credit as it strives to improve access to long-term care services for people with disabilities and the elderly.

The personal care changes are included with the move to more managed long-term care and are also an effort to bring a program that is rapidly growing into some level of more limited growth. Under the proposal if a person were on a waiver, personal care would be provided under the waiver. If a person were not on a waiver, the person would get personal care through the county, not through the MA card. Management for the program would come from the county. Combining personal care with the waivers makes much sense if the entitlement is maintained. Providing it as a stand alone service through the counties may be a good idea, but there are many questions. It is still unclear how the entitlement would work or how the funding would flow. It is clearly still a work in progress; there will be much opportunity for input.

The ultimate entitlement to long-term care services through a program like Family Care may be the only hope of having the needed expansion of services for people with disabilities. The four Family Care counties providing services for people with disabilities have no waiting lists,

and most people seem quite satisfied with the program. The strategy to address waiting lists may have to change to one that emphasizes working with DHFS for a long-term care reform initiative that is satisfactory to the disability community. Stay tuned.

The next update will be near the end of January or in February. From January 5 to 19, 2004 I will be on vacation.

Happy Holidays and have a great New Year!

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