



November 11, 2009

Comments to the Assembly Committee on Long Term Care and Aging

Dear Assemblypersons,

We would like to present comments and concerns to provide an additional perspective about the expansion of Family Care in Wisconsin, as you consider the testimony of the limited invited guests at your November 12, 2009, hearing.

Our Involvement with Wisconsin's Long Term Care Reform

Arc - Winnebago County Disability Association, located in Oshkosh, has been following and been involved in the implementation of Family Care across the state and in Winnebago County. Staff and volunteers have participated on planning committees for the forming of Lakeland Care District (comprised of Fond du Lac, Manitowoc and Winnebago Counties). We have organized numerous community forums and workshops to help individuals and families grasp the concepts, the new language and what changes they might anticipate, along with the options they have available to them. We have been asked to speak to many community groups and committees to provide our perspective. In these efforts we have maintained a careful balance of learning and providing solid, factual information and expressing our concerns about the potential impacts of the new system. In May of 2009, I was appointed to the newly forming Lakeland Care District governing board as an advocate to represent members being served.

We do not share the viewpoint of those you will hear from and those who have contacted you that Family Care will provide positive results in our community for individuals with disabilities and the elderly, and their families. In fact, we worked hard (unsuccessfully) to slow down the rollover of Winnebago County into Family Care expansion. We could see that:

- results of expansion had not yet been analyzed;
- that expansion was taking place too rapidly for the Department of Health Services (DHS) to stay on top of it;
- that quality controls were limited;
- that it was underfunded and undercapitalized;
- that information was too carefully controlled and not straightforward;
- that potential members were not being told of all their options and rights at the times they were making decisions;
- that appeals processes were inadequate and intimidating;
- that access to independent advocacy was (and still is) nonexistent or insufficient; and
- that input into expansion efforts from the constituency who would be most affected was not available in any meaningful, nontoken way.

We have been raising these concerns early and often. Due to extreme political pressure to expand Family Care, our concerns have been largely ignored.



Quality

Quality reports provided to DHS never include the impacts on service providers, the impacts of the disruption of services to families, or the loss of choice as a result of the loss of small service providers. Quality surveys to Family Care members can be skewed toward the positive.

Eliminating Waiting Lists

Here is how Family Care eliminates waiting lists: it simply does not allow them. That's it. There is no magic formula, no added resource. If the waiting lists were the problem to be solved, the implementation of such a rule would simply have forced counties to create efficiencies that would have resulted in elimination of waiting lists.

Saving Money

Family Care does have cost efficiencies. This is done in a few ways. The most notable is by reducing services and supports to cover only very basic needs. The second, and never discussed, is the “nickel and diming” of providers. By driving down reimbursement rates (often referred to as “bringing care under management”), providers are forced to pay less and less in wages to an already under-populated, underpaid profession. Increased administrative costs drive out small service providers and allow the economies of scale enjoyed by large providers to flourish. The results of low rates and high costs are fewer choices for consumers and a reduction in the quality of direct care staff, with staggeringly high turnover rates (which can have a disastrous affect on the people being served).

In creating the actuarial formula for determining capitated rates, financial results of the five pilot counties were used. This information did not take into account the additional costs of expansion. At the last Wisconsin Long Term Care Council (November 3, 2009), several Managed Care Organizations undergoing expansion testified about the costs of capacity building and “bringing care under management,” which are resulting in current year anticipated deficits of \$5 million to \$9 million dollars per Managed Care Organization (MCO).

It is becoming increasingly clear that, at least during expansion, the capitated rates are insufficient to cover the costs of:

- Administering a fully functioning managed care organization, including facilities and staffing costs, along with claims management, IT and other logistics;
- Providing adequate care for individuals with disabilities and the elderly;
- Eliminating existing waiting lists;
- Serving additional qualified applicants (the “out of the woodwork effect” because people are now entitled to receive services);
- Building provider capacity in the area, while reimbursing adequately;
- Building a risk reserve.

Appeals and Grievances

An element of Long Term Care Reform that has been touted is its A&G processes. There are two avenues:



1. An appeal to the MCO through its own process (an individual has already been denied a service after expressing their view that it is needed; it seems nonproductive to make a request to the same entity that gave the denial);
2. An appeal to the State of Wisconsin, through an Administrative Law Judge.

Families worry about making an appeal directly to the MCO because they are concerned that doing so may result in a loss of services (some form of retaliation). Whether or not this fear is based in reality, it is a fear we have heard expressed numerous times and is the reason few families complain. A “member advocate” is available through the MCO, but is perceived by families as an extension of the MCO, sometimes rightly so. Families rarely appeal to the state because it is an intimidating process for most families who are just trying to get by and get the services they feel their family members need. A local appeals process is needed that is quick, fair, independent and easy to access.

Independent Advocacy

Disability Rights Wisconsin has won the contract to administer a program for advocates. Fortunately, during the past budget cycle, the Wisconsin legislature increased the ratio of advocates from 1 advocate per every 3,500 members to 1 advocate per every 2,500 members. We are grateful for the efforts to make that happen. However, we see advocates only in Milwaukee, Madison and Rice Lake. As a large population base expanding into Family Care in the greater Fox Valley area, we are not aware of any immediate plans for an advocate to serve this area. The number of potential members in the three counties served by the Lakeland Care District alone would justify a single advocate through the DRW advocacy program. We wonder what happened to the prescribed ratio.

Piecemeal Unfolding

The expansion of Family Care has been unfolding in a piecemeal fashion. As issues arise, such as the higher than anticipated costs, new elements are added and the rules are constantly changing. An example of this is the development of the Franchise Model for Family Care. In continuing efforts to create efficiencies, DHS is working on a franchise model that will take advantage of economies of scale to provide some of the structural/administrative needs for MCOs. Specifically, DHS is moving toward one or two vendors that will operate claims processing. Another path is creating a statewide IT system that MCOs can buy into. It appears, though, that none of this will be mandated. We question whether MCOs will take advantage of the new systems, given the investments they have made in developing regionalized systems that work for them.

Lack of Meaningful Stakeholder Involvement

There is no formal process for a citizen to appeal, provide input, file grievances, or express concerns with the decision and policy making process that gave rise to Family Care and expansion efforts. Decisions are made before people learn of them and there have been no means to challenge decisions or the methods of implementation.

We have seen people with disabilities, the elderly, family members and advocates invited to planning committees. Because we (Arc - Winnebago County Disability Association) are advocates, our participation in local planning committees is listed as “stakeholder involvement.” Our input, though, has been mostly ignored. Our suggestions and questions do not result in any changes to policy or practice. At times



Lakeland Care District personnel have listed the community forums that were organized by Arc - Winnebago County Disability Association as their own to demonstrate their efforts to include stakeholders. The irony is that we organized the forums because Lakeland Care District personnel were NOT providing information to stakeholders, and had no intention of doing so until after our county had voted to form the district.

Legislators have told us that they do not hear anything about Long Term Care Reform from their constituencies—positive or negative. Their assumption seems to be that they would be receiving a clear message if people were having problems. Unfortunately, this is an erroneous assumption. Individuals with disabilities and the elderly, and their families, tend not to be involved in political processes for many reasons:

- Some individuals with disabilities and the elderly can't because of communication, transportation and other barriers to participation;
- Family members are often unable to participate in the political process because they are caretaking or can't find someone to care for their loved one to get some time away;
- Stakeholders receive information too late to provide input or feedback;
- The policy, finance and impact issues are complex and difficult to digest—individuals and families have a hard time not only understanding them, but applying them to their own situations;
- Individuals with disabilities, the elderly, and family members frequently feel that they shouldn't complain because they should simply be grateful for what they do get (and they are grateful), or they fear losing what they have. They do not want to "make waves."

Must Work

DHS and interested parties have pushed Long Term Care Reform in such a way that it must work and leaves no room for failure. Long Term Care Reform has completely eliminated communities' ability to manage long term care services on their own by thoroughly dismantling existing systems. As noted in the November 4, 2009, letter from Arc-Wisconsin Disability Association to Representative Peggy Krusick, Family Care can only work by increasing funding or by cutting costs. The primary method used so far is cutting costs, and this appears to be done at the expense of quality and intensity of care for people with disabilities and the elderly.

Please take our statements into consideration as you listen to your invited speakers. We are available as an independent voice representing people with developmental and their families to provide further input or to answer any questions you may have. We can be reached at 920-236-9230 or lea@arcwinnebago.com.

Sincerely,

Lea Kitz
Executive Director