

**WINNEBAGO COUNTY
AGING & DISABILITY RESOURCE CENTER (ADRC)
PUBLIC FORUM MINUTES**

DATE: June 29, 2011

TIME: 2:30 p.m.

PLACE: Fox Valley Technical College, Oshkosh

ADRC Committee Members Present: Ginger Beuk, Janice Dibble, Diane Egan, Jef Hall, Debra Hogue, Donna Lohry, Mike Norton, Deb Pahl, Rob Paterson, and Tom Widener

ADRC Committee Members Absent: Ann Jungwirth and Jean Wollerman

ADRC Committee Staff Present: Mary Krueger, Mark Weisensel, Ron Duerkop and Dorothy De Grace

Jef Hall, vice-chair of the ADRC Committee opened the Public Forum at 2:30 p.m. by explaining that this meeting was requested by the state of Wisconsin for discussion on the progress of implementation of the Aging & Disability Resource Center (ADRC) as well as Family Care and IRIS (I Respect I Self-Direct). He explained that today we will be focusing on services that individuals may have received from these new programs which started in 2010 for the elderly and disabled adults in Winnebago County. Jef explained that the ADRC is a place where anyone can obtain information and assistance for enrollment and options counseling, and where initial benefit eligibility is determined for IRIS and Family Care. The IRIS program is offered through the Wisconsin Department of Health Services. A consultant helps you prepare your own support and service plan, and you will have an individual budget to help meet your goals. A financial service agency handles the accounting and pays your service bills. Jef said a person must meet eligibility criteria in order to receive services through the Lakeland Care District (also known as Family Care) where a case manager and nurse join you on your team. The goals of Family Care are to provide better access to services, more choice in services, and better quality services in a cost-effective manner. Comments from today about how well these programs are fulfilling the promise of long-term care reform will be shared with the Wisconsin Department of Health Services.

Following are six questions that have been provided by the state for discussion and comments by participants at today's meeting:

1. How have you or your relative or friend benefitted from participation in one of Wisconsin's long-term care programs in the past year?

Family Care —

- My mother's care has not changed—she is able to receive the same services at Sterling House as before. I noticed we no longer have to pay for certain personal items for her, which resulted in a cost savings from her limited out-of-pocket funds. The care team she is assigned is very helpful, especially the excellent nursing supervision of her health care.
- As a parent/guardian of an adult with special needs, I have found the Family Care system to be a total failure. Instead of meeting their goals of access, choice, quality, and cost-effectiveness, I have found roadblocks, dead ends, confusion, waiting lists, and more expense. Since Family Care came into our lives, things have dramatically changed. I do not feel that Lakeland, from upper management down to the case workers, is looking out for my son's best interests. It seems the "bottom line" comes first.

Other –

- Is there any mechanism we could use to communicate with other counties? Because the more communication we have the more we can learn and grow as a group.

2. What suggestions do you have for the state Department of Health Services for ways to improve the delivery of any of these programs?**ADRC –**

- Her mom has dementia, and she was told she had to “practically run her out of her money” while in a CBRF and potentially move her to a nursing home; then through the nursing home relocation program she could conceivably move her back to the CBRF. This daughter doesn’t understand why she has to move her mom from a facility that is costing \$5,000 a month into a facility that is going to cost the system \$10,000 a month. She said she was told she could probably do a two-month bed hold at the current facility, which would then be a \$20,000 cost. The move would disrupt her mom’s life, which is currently stable.
- His wife has Alzheimer’s and is currently in an assisted living facility. When a person is satisfied that the care of service is as good as anybody can get in an assisted living place, he fails to see the reason why the person needs to be relocated into a totally strange facility at more cost for an unknown length of time until she can be relocated back.
- They were promised (before the start-up of these programs) that the wait list would be eliminated in three years, and now we have 18 year olds who are graduating and being put on a wait list. She knows a family that is using their SSI check to pay a provider to let their disabled daughter go to work so she can feel like she is accomplishing something and feels good about herself. The wait list is getting longer and longer, and the only way off is for an emergency situation or if somebody moves out of state or if somebody dies.

Family Care –

- It is important to promote workers from within, as the more familiar with a program the more steps and money saved.
- Why is there such a broad difference in services and the amount that is paid for the services between IRIS and Lakeland when it is all supposed to be governed by the state to meet the needs and services of the people who need them?
- Lakeland Care District is only authorizing individuals to use doctors that are located in the Oshkosh area. Many of the doctors are not familiar with treating people with handicaps. I saw three different doctors until I found one that knew more about Cerebral Palsy. I feel that individuals who have no family members to stand by them don’t get the things they need through Lakeland Care District. I have asked for a different case manager and nurse, and it changes for awhile but goes back to the way it was before. They don’t consider that my body is changing from when I was 20 years old, and I need to use the wheelchair more. I feel that Lakeland Care District is going to take away my independence and put me in a group home or nursing home. They aren’t working as a team with me, and they’re not listening to what my needs are.

IRIS –

- Her mother-in-law is in the IRIS program, and it would be nice to know if there are other participants in the IRIS program that live near her so they could share the support person who might be looking for a few more work hours.

Other –

- He's been through the DVR program four or five times, and they tell you about jobs that anybody can do. When I go through a temp service, I get the best jobs. The DVR should go back to doing it the way they did in the past—they would go to companies and help people find jobs. Now they tell the people where there is a job available and that they should go apply for it.

3. What services, living arrangements or other supports are not available in your community that you consider important?**Family Care –**

- There is clearly not enough staff in the facility where her mom is. CBRF's are allowed to operate on a 1 to 20 ratio, which she finds outrageous when you need a two-person transfer, for example. She has difficulty with the wages that our caregivers are receiving and the quality of care due to the lack of staff. The people at Park View, for example, tend to stay in positions longer because they are receiving benefits. The problem begins with the caregivers and how they are treated. There is high turnover and inconsistency of care.
- I use day care from 7:30 a.m. until 4:15 p.m., and some days I could use a longer time. Also, I think meetings could be attended if there was a longer day care. It's a much needed service and it has served us well.
- His impression seems to be that Lakeland Care District and Clarity Care are somewhat privatized off of the county, and it's more about making money for the executives than it is about taking care of people. All we hear is that the state is out of money, but yet we see \$150,000 salaries going to the CEO's. He was really pleased with the county before, and he'd go back to the county system any day. He feels that in Family Care there is no communication even from one building to another regarding service. His son would like to see things, but he doesn't get to do them because he hears they don't have the staff, or they have to go to bed early, etc. The facilities aren't clean, and he wants to know when something will be done instead of seeing lots of people in offices.
- She has a guardianship contract with the county. She said there are good workers at Lakeland, but she needs better communication with some of them as to what they are doing with her clients. Her other issue is the same as it was with the county—transportation. Neither she nor Lakeland nor the assisted living facility knows where the transportation responsibility lies. She said a letter came out this week from Lakeland indicating that they are now looking into the transportation concerns.
- Lakeland doesn't want the transportation expense; therefore, people don't get to do the things they normally would do. Lakeland says they'll pay for trips to the store or doctor appointments, but not to other social events.

- There have been several incidents where my son's access to providers has been very limited or totally shut off. There is very little, if any choice of providers. If the providers are not "approved" or "signed on" with Lakeland, then we can no longer use them. In some cases, that means we need to travel to Appleton or Fond du Lac for care we used to get here in Oshkosh.

IRIS –

- She thinks this area has awesome services to provide for our individuals with disabilities; however, one area that is lacking greatly is job development. We have coaches and the DVR, but we need somebody to develop jobs in business specifically for individuals with disabilities— jobs that would meet the desires and ambitions of each individual.
- He feels a lot of people are burned out; luckily he has a great support system. He offers the capability to advocate for certain issues and needs of people.

Other –

- She thinks that as a community we treat the disabled and elderly in a good fashion, but frankly we were doing a better job when it was being run by the county where they knew our wants and needs. Now they put our care at the state level and they don't know us. We've made it too much of a broad-spectrum. It's no longer about the people; it's too much about the numbers. She realizes we have to consider the numbers, but they need to step down here and meet the people who are getting the services and the people who care about them.
- 4. As families and individuals struggle with the economic issues of the day, what problems are most challenging for you as a participant in Family Care (or another program) and what is challenging for your family or other caregivers?**
- The hardest thing to deal with right now is that we are constantly trying to cut back budgets. She understands that; but we are cutting budgets on human lives, which makes it difficult to keep staff. As a provider she hasn't given any of her employees a raise in seven years. Any increase in money she gets must go for the increase in expenses. The state needs to look at the money getting to the direct support givers, and not the people that are overseeing them.
 - She has concerns about economic issues: the functional screen is done annually, and if everyone is doing their job in the first place, the care plan should be what the person needs. According to this year's functional screen, money is being taken away. It's already been determined that a person is getting what he/she needs, and now some of it is being taken away. We are already being cost-effective, but we have to do it on less money. What is determining one year getting so much less than the year before, and is that a trend that will continue? If so, how are we expected to meet these budgets?
 - I think the day-to-day care of my husband who has different needs is the most difficult. A day care for a break or assisted living for respite is necessary and appreciated.

5. What services of the Aging & Disability Resource Centers have been most beneficial? What suggestions do you have for improvement of any service at the ADRC?

- When I was moving my mom here from out of state, the person at the ADRC directed her to what she needed to do and the steps she needed to take. She was very grateful that we were there for her.
- I would like to know how far along I am on the wait list for services.
- When she called the ADRC she received wonderful care. The person came to her home and gave her definitive information as to where to go for help. She commends the ADRC in Winnebago County.
- Her son was covered under the county plan, and now he is under Family Care. She investigated getting services through IRIS and found there is no money available from there. She wonders why there is this discrepancy in how much money he could get from Lakeland as opposed to how much from IRIS, since it's all state money. When she contacted the ADRC for an allocation adjustment, the functional screen showed that the money he could get decreased. She had been told that the functional screen was not to be used as a rate setting tool, but it seems as though that is what's happening. Lakeland has hired someone to do the functional screen that has never seen the member and therefore doesn't understand the behavior, attitudes, abilities, etc. of each person. She wonders how this can determine what the person can or can't do or how a dollar amount can be put on that.
- The person at the ADRC did the foot work for me to find an assisted living place while I work or have respite. She gave me phone numbers, contacts and availability. She was very helpful.
- She feels the questions asked for the functional screen need to be more person-specific rather than so black and white. If a person is asked if he can cook, the answer is considered "yes" even though he might only be able to cook in a lower capacity.
- The initial meeting was so important to give me hope that I wouldn't stay overwhelmed forever. Things were organized in my notebook when we finished and I was able to move on with knowing where to call and who to call for help.
- It amazes me that some families don't know about the ADRC, when all of a sudden their disabled child turns 18 and will need services. It seems we could do a better job reaching those families way before that point.

6. As the state and federal governments struggle with meeting the funding needs of programs for elders and adults with disabilities, do you have any recommendations about how to "stretch" the public dollar to serve more people or serve people better?

- There is a different point system and different charge for services in the various facilities. She's wondering if there could be a standardized set of questions that come up with the dollar amount so people aren't getting "railroaded," such as being offered a higher care service for a private pay individual, even though it's not needed. She would like to know what IRIS would pay for the same service.

- Coordination to avoid duplication. The fewer moves for people with mental illness the better. Also, changes are hard—consider all areas of their life before a change.
- It's hard to find jobs for some of these people. He suggested we have a dorm set-up for disabled individuals where they could do whatever they are able, such as cooking, housekeeping, etc. If they are capable, then they could go out into the community to work.
- She thanked the committee for having this opportunity to have face-to-face discussion and collaborate on some better solutions. She's had to find a place for her mother who has Alzheimer's. She found out about the ADRC wait list by accident and was told her options are limited because of the limited available funding. She was told that the best way to expedite any kind of funding for her needs would be to have her mother placed in a nursing home for 90 days and then tap into the relocation benefit. Her mother doesn't need nursing home care and does very well in assisted living. She would hate to disrupt the continuity that she is getting in this current facility just so she can gain the system. If we could get rid of some of the red tape, it would free up a lot of resources to put them where they're really needed.
- A small way to stretch the dollar is to do away with the requirement of a monthly prior authorization for every client. The paperwork adds up administratively. In the past when the county did the program, it was required every six months or up to a year
- She said that Lakeside Packaging is a godsend for most of the disabled people. They find work for them; they learn skills; they make friends; they learn good morals; etc. She suggested we could broaden that outreach with more funds. It would be a positive thing for the disabled and the community.
- I think a lot of us can only rely on what we read in the newspaper about the dilemma coming out of Madison. So many people don't know what is going on. He reads in the paper that they've cut so much more of the Medicaid program and then there's a freeze, but nobody knows what the freeze is.
- Quality of care is questionable. Group homes are having their budgets slashed to the point where, in some instances, safety is becoming an issue because they are understaffed. If they don't sign on with Lakeland, they will have no consumers and will be forced to close. They sacrifice daily to care for the special needs population, and they are being treated very poorly by Lakeland and the Family Care system. Instead of giving their employees raises and benefits, Lakeland should give these providers a living wage.
- He suggested a way to stretch some dollars for the Medicaid system. He said when the Family Cares were piloted they put in the provision that Family Care Districts had to provide certain mental health services to their recipients and not have it be a card paying system. No one has been able to explain to him why certain mental health services are the responsibility of the districts or the non-profits to pay and which ones are paid through the regular Medicaid card. His recommendation is to remove the responsibility of the districts or non-profits in paying for any mental health services and go back to the old way where the consumer presents the card to providers of mental health services. The provider would then bill the state, and the state would reimburse them directly. That way the providers could still keep the dollars they're getting right now and offer more services.

- Jef Hall, vice-chair of the ADRC Committee, explained that there are currently 320 people on the wait list for all Family Care services and IRIS. During the last administration we were told that the wait list would go away after three years. Under the new budget, the number of people we are serving in Family Care and IRIS is static right now. About 1200 people are currently receiving Family Care or IRIS in Winnebago County. We average about 26 people per month being added to the wait list; three residents are removed from the wait list due to attrition; and nine are removed from Family Care due to attrition. We cannot increase the number of people we are serving, so over the next two years the wait list will get a little bigger. However, we can add people to Family Care service through a nursing home placement. Statewide there are 400 emergency placements that the state can guarantee through Family Care. If one of the slots was approved for us and we lost a Family Care member due to attrition, that slot would go back to the state. The only way we get people off the wait list is through attrition; if a person no longer qualifies economically; or if someone ends up in jail.
- Donna Lohry, chairperson of the ADRC Committee, thanked everyone for coming today. She said she is insulted that the state would ask the consumers for suggestions on how the dollar can be stretched (see question #6). She appreciates the people who did have suggestions. She asked the participants at today's forum to keep the committee informed of any problems they see.

Jef Hall closed the public forum at 4:30 p.m.

Recorded by:

Dorothy De Grace, Secretary
Winnebago County Department of Human Services