



Milwaukee County Aging & Disability Resource Center Governing Board

To: Carrie Molke, Director, Bureau of Aging and Disability Resources, DHS
Curtis Cunningham, Deputy Administrator, Division of Long Term Care, DHS

From: Jenice Burrell, Vice-Chairperson *Jenice Burrell*

Date: December 7, 2016

Re: Summary Report with Recommendations from Milwaukee County Consumer Forums on Long-Term Care

On behalf of the Milwaukee County Aging & Disability Resource Center Governing Board, thank you again for sending staff representatives to our two Consumer Forums held October 19th at IndependenceFirst and October 20th at the Washington Park Senior Center. We all learned a tremendous amount from the forums, both in terms of what is working well and where areas of improvement are needed. We appreciated your presence there as well.

Attached you will find two documents for your review and consideration: a Summary of the Consumer Comments (including written comments received through November 15th) and our Recommendations to DHS, based upon these comments. Both documents were approved at our Governing Board meeting on December 6, 2016.

We would welcome your written comments to be presented at the next meeting of our Governing Board, scheduled for **Tuesday, February 7th, 2017**. The meeting will take place from 10:00 am - noon at St. Ann's Center - Bucyrus Campus (2450 W. North Ave.). Please confirm that you or your staff representatives are able to attend and speak to the recommendations.

If you have any questions or require additional information, please contact Board Consultant Sue Kelley (414) 961-7262 or sue@suekelleyconsulting.com



Milwaukee County Aging & Disability Resource Center Governing Board

Recommendations to DHS following Consumer Forums

1. Consumer Decision-Making

Our long-term care programs are based upon choice and self-direction. While we value these principles, it is sometimes difficult for consumers to make choices with limited information. In order to address consumers' needs for additional information to guide their decision-making, we recommend that

- Each organization contracting with DHS share information re: direct care staff retention, direct care staff pay, the availability of transportation, additional training provided by the organization, and any specialty areas the organization might have. This data should be included with the information currently provided by the ADRC.
- DHS develop a consumer-to-consumer feedback sharing mechanism(s). Whether it's an online message board, creation of a report card for consumers to use, or hosting consumer networking forums, we believe that this type of sharing is valuable to consumers in their decision-making.

2. Functional Screens

We heard many concerns about the screening process and the screen results. In terms of administering the screen, we recommend that

- The functional screen is administered with a care partner present, as the norm. Consumers should be made aware that this is the expectation.
- In advance of the screening, consumers should be informed in writing of the types of things the assessment covers, in order to know what to expect.
- Screeners should emphasize that responses be geared toward a consumer's "worst days" as well as how they are doing the day of the screening.

In the interest of transparency, we also recommend that

- Each consumer receives a copy of his/her screen results.

- Each consumer receives contact information to share concerns they may have regarding their screen results.

3. Shifting the Burden from Consumers

In many cases, DHS policies and procedures serve as barriers to consumers having their needs met in a timely manner, particularly in the IRIS program. Whether it's a delay with an Iris Consulting Agency approving a new employee, a requirement that a consumer obtains multiple estimates for a wheelchair ramp, or finding employees for round-the-clock care needs while following the 40 hour work week policy, the burden falls on the older and/or disabled consumer.

We recommend that

- DHS allows more flexibility in IRIS and Family Care to enable consumers to meet exceptional needs. This would require that contracting organizations be granted more authority to make provisional decisions in order to expedite processes that prevent the timely delivery of care. As an example, we think it is reasonable to expect that an IRIS Consulting Agency can review and approve a new employee applicant within three weeks. If it takes longer, the employee should be provisionally approved so that the consumer has continuity of care, rather than having the consumer wait for the agency to complete its work on their timetable. Similarly, if an IRIS consumer has round-the-clock care needs requiring multiple care providers who may need to occasionally exceed the 40 hr. work week, there should be a quick approval process for this. If this situation occurs on a consistent basis, the agency should help to identify potential employees to assist, rather than leaving the consumer in the position of finding caregivers when demand exceeds supply.

We also recognize that consumers of long-term care programs are already facing a shortage of available direct caregivers, and that this need will increase with the aging of the population. We therefore recommend that

- DHS leads an initiative to increase the labor pool of direct caregivers and increase the retention of these workers.

ADRC Governing Board Consumer Forums 10/19 & 10/20/16 **Summary of Comments**

(includes additional comments submitted in writing through 11/15/16)

IRIS

- Approval of employees by Iris Consultant (IC) is slow - took one consumer 3 months to get approval from iLife to hire someone, although all the correct paperwork was submitted.
- Some policies are burdensome. Consumer is required to get 3 separate bids to build a wheelchair ramp (difficult to find contractors). The need is immediate but she cannot get all of the bids required.
- Employees who provide care need training, transportation.
- Policies seem to conflict with saving money at times. Example of hiring an agency for \$30/hour instead of paying the family \$13/hour. Another example involved paying an agency for transportation rather than reimbursing a family member at a lower rate.
- Budgets have been reduced, thereby limiting options and flexibility, which were the founding principles. Example of consumer being approved for 40 hours/week of personal care although her needs are far greater.
- IRIS Program has become far less flexible and far more bureaucratic. It has evolved from self-directed to overly directed by Wisconsin DHS and TMG.
- Great variance in IRIS Consultants. Example of consumer who asked for a wheelchair ramp but the first Consultant stated they do not address the exterior of the home in their assessment and budget. The most recent Consultant has been very responsive to their needs.
- Consumer reports that "Iris has been the best thing to happen to me...", citing the ability to feel safe in her home because she is able to hire personal care workers that she chooses using her own networks of friends and work connections. She has had the same IRIS Consultant since the beginning, which may explain why the program has worked so well.
- Concern about IRIS's Self-Direction feature starting to erode - why has DHS increased the number of nursing visits when the consumer is medically stable? Seems wasteful if it's done more than once per year.
- Concern about what happens following a hospitalization for surgery. Service hours did not increase although needs did. Instead of paying for a nursing visit, more service hours would have been a better use of resources.
- Consumer has had a positive experience with the program, "TMG has been wonderful; my consultant has been fabulous; everyone I have spoken to from management, to RN's as well. Including networking events for participants and professionals together have all been wonderful.
- Not having the same screener results in different screen results.

IRIS 40 hour work week policy for employees

- It has caused many problems for consumers, because 1) it's already difficult to find reliable employees; 2) it's another hurdle for consumers in juggling the schedules of so many people - in one consumer's case, there are 12 caregivers involved; 3) it's particularly difficult to find employees for night/weekend hours.
- Particularly burdensome for consumers with 24/7 care needs.
- IC agencies do not have a good understanding of the exceptions to this policy
- Employees with children sometimes need to bring them along. Their children's needs limits their ability to work. This leaves the consumer in a bad situation.
- State DHS needs to do a better job of communicating with consumers since there is so much confusion around this policy.

Resource Centers

- Consumer was told by Resource Center staff that they should sign up for IRIS to avoid the cost share in Family Care
- Not enough information is provided to distinguish between IRIS and Family Care Self-Direction.
- Could there be a website that has consumer comments about their experiences with providers so that new people can check it before they make an enrollment decision?
- Could there be something like a Better Business Bureau rating for these programs? Some type of report card that we could help develop?
- Provider has had positive experiences calling the ARC and the DRC in terms of answering questions and identifying resources.
- Uncertain about whether use of Resource Centers is limited to people based upon income
- Would like to have additional Resource Center location in neighborhoods - example of the consumer who attends the West Allis Senior Center
- Consumers don't know that they have a right to have someone else present when the functional screen is administered
- Disability Resource Center staff have been extremely helpful in advocating for a consumer with dementia when My Choice was unable to recognize his needs related to Frontal Temporal Dementia.
- Many consumers expressed confusion about the use of the functional screen in determining services, both initially and when re-done on an annual basis. Clarification is needed re: the relationship of the screen results to the consumer's budget and level of services.
- Consumers should be provided copies of their functional screen results. It is currently very difficult to get an organization to provide this.

Family Care

- Limits on Durable Medical Equipment budgets are driving people to IRIS

- Consumer was denied service too many times so switched to IRIS, which has been better
- There's a big difference between what consumer thinks is needed and what the case manager thinks is needed.
- Case managers need to be sensitive to LGBT consumers and the importance of including their care partners in the functional screen as well as the care planning
- People don't know what to do when they need more services than they are getting.
- Consumer reports that the program has worked well for her and that she appreciates her case manager.
- Case managers need education, compassion, and training in building a dementia-capable system. They do not recognize the unique needs of people with dementia, nor do they incorporate the caregiver in the assessment. Example of a case manager not approving transportation for the caregiver to accompany the consumer, although the consumer's dementia requires that someone stay with him or he becomes agitated.
- How are care partners supposed to identify the lead Dementia staff in each MCO?
- Recent decision by My Choice Family Care to end their contract with MCFI presents a challenge to 500 consumers well-served by MCFI. They will lose continuity of care. This is especially difficult for people who do not have anyone else in their lives - their MCFI team has dedicated themselves to people in need and this team may be the only support system the consumer has. MCFI is known as the organization who took on hard-to-serve consumers when no other would.
- My Choice Family Care is creating a conflict of interest by establishing its own Care Management Unit (CMU). What prevents them from promoting their CMU over others? What safeguards are in place to ensure their CMU is held to the same standards as other CMUs? As an example of the lack of integrity on the part of My Choice Family Care: they recruited a nurse from MCFI to serve as their new program manager and she in turn is offering MCFI employees a \$7k signing bonus to work for My Choice Family Care's internal CMU.

Unmet Needs

- Developing employment opportunities for people with Asperger's Syndrome. Example of the successful program developed at Froedtert.
- Transportation needed for employees to reach consumers who are not on a bus line. More bus routes.
- A system of ensuring that people with mental health needs receive their medications when their worker is unable to get there (not necessarily someone who is enrolled in Family Care or IRIS)
- More paid caregivers are needed.
- More guardians are needed.