ADRC of Wisconsin

Milwaukee County Aging and Disability Resource Center Governing Board

2018

Consumer Listening Session Report

DHHS Department of Health & Human Services

MILWAUKEE COUNTY
Department on Aging

Table of Contents

1. Introduction

2. Background
    a. Purpose/objective
    b. Context
    c. Accessibility/Diversity
    d. Planning
    e. Public Notice
    f. Format and Materials

3. Findings:
    a. ARC/DRC Specific
    b. Long Term Care System
    c. Quality of Life: Further Discussion Needed

4. Recommendations

5. Conclusion/Next Steps

6. Appendices:
    a. 2016 ADRC Recommendations to DHS
    b. Transcript of Letter to Aging and Disability Resource Board of Milwaukee County
    c. 2018 Consumer Listening Session Comments

Introduction

Aging and Disability Resource Centers are authorized under **s. 46.283 of the Wisconsin Statutes** and subject to the requirements contained in **Chapter DHS 10 of the Wisconsin Administrative Code**

The ADRC Governing Board was established to assist the support the Aging and Disability Resource Center in fulfilling its mission. The state contract assigns many duties to the governing board, four of which include:

- gather information about possible unmet needs of the ADRC's target populations for long term care and other services;
- report findings and recommendations to the ADRC Director, local officials, the Department, and other interested parties as appropriate;
- collaborate with other advocacy groups;
- provide well-advertised opportunities for public participation in the board's information gathering activities.

The 2018 ADRC Governing Board consumer listening sessions fulfill its duty to gather information through public participation.

Acknowledgments

The ADRC Governing Board would like to thank all the consumers that participated and shared their experiences. We also acknowledge the following people and organizations that made these listening sessions meaningful.

ADRC Governing Board members: Dan Lococo (Chair), Mary Neubauer (Vice-Chair), Pat Bruce, Rosemary Crump, Pastor Luci Hunter-Gaynor, Richard Zimmerman, Michelle Martini, Debra Jupka, Marilyn Lange. ADRC Governing Board Facilitator, Ann McCullough McKaig.

Department of Aging/Aging Resource Center and Disability Resource Center Staff: Karin Bachman, Kathryn Sprague, Bekki Schmitt, Brad Schlosser, Byron Rachow, Tamara Carr, Evelyn Vasquez, Randy Mueller, Ryan Bamberg, Hope Lloyd, Holly Davis, Priscilla Beadle.

Wisconsin State Department of Health Services: Christine See, Angela Moran,

Community Partners: Wilson Park Senior Center, Washington Park Senior Center, Wauwatosa Public Library, Family Caregiver Support Network, WI Women's Council: Christine Lydbury-

Women and Caregiving project, Milwaukee County Office of Disabilities, United Community Center.

The IRIS consulting agencies (ICA's) and managed care organizations (MCO's): Advocates 4U, Community Care Family Care, Partnership and PACE; First Person; iCare- Partnership; IRIS Connections; My Choice Family Care, and TMG.

Interpreters: Thank you to our sign language and Spanish interpreters who made it possible for all to participate.

Background

The ADRC governing body hosted another round of listening sessions in 2018 and compiled the direct comments of consumers, providers, caregivers, staff and state level administrators (See Appendices A and B). The objectives for the 2018 sessions were to obtain consumer, care partner and provider input regarding the ADRC services and note whether the overall experience and concerns with the publicly funded long term care system has changed significantly from 2016 (See Appendix C).

The governing board approved a plan to host three listening sessions in different areas of the county, two in the afternoon and one in the evening. The format included a brief overview of the services provided by the ADRC, a semi-facilitated discussion of consumer experiences and response to specific questions and needs of those in attendance. Informational materials about the Aging and Disabilities Resource Centers were available at the events. Index cards were available for written comments; however, none were received. ADRC staff were available to offer guidance to consumers who had questions about long term care services. Board members engaged in the discussion as well so that the sessions resembled more of a community conversation than a traditional listening session or public hearing. The response to this approach was positive.

Accessibility/Diversity: The governing board felt strongly that the listening sessions reflect and welcome diversity. They made the following suggestions: use language and promotion that values all participants regardless of color, background, religion or sexual identity, seek input on issues that are of concern to different groups of the larger community of consumers, ask board members, staff, community partners, participants can offer input on diversity and inclusion issues particular to these topics: transportation, LGBT, housing, racial justice, stigma, support network needs, immigration, language barriers, feeling welcomed/included in ADRC/LTC service system.

Planning was coordinated by a facilitator based on direction from the governing board, staff and community partners.

Public notice was given through community partners, social media, staff, email and flyers. The listening sessions were publicly noticed according to law through the Milwaukee County Clerk's Office.

Listening session participants reflected a mix of consumers, care providers, community organizations and staff. Attendees agreed on the types of support, problems and challenges that exist. Consumers could describe the experience with the ADRC from the "outside in". Customers described positive experiences with ARC and DRC Human Service Workers. Sometimes there is a wait for the initial contact due to number of requests for eligibility screens.

Once enrolled in the publicly funded Long Term Care system through a managed care organization (MCO) or IRIS consulting agency (ICA or IRIS), consumers report difficulties finding and retaining personal care services and transportation to participate in community activities and attend needed appointments. Consumers reported feeling confused about how to add or change services based on changing needs. Parents are a big part of an adult child's support network. When aging decreases the parent's ability to provide support, transition plans are needed and parents described feeling worried about the future supports for their children.

Staff and providers described the issues from the "inside out". Providers concur that there is a shortage of trained personal care workers and almost no availability of back up caregivers. They also observe that personal care workers have challenges accepting shifts if they rely on public transportation: service does not reach underserved areas and the travel time is not reimbursed, cutting into the time they can bill for service. The current professional market creates a challenge for the ADRC to find and retain experienced staff.

In the case of the session held at Washington Park Senior Center, the unexpected outcome was that there were no consumers present due to lack of attendance. The staff, state representatives and providers took the opportunity to engage in discussion of current ADRC and consumer needs with the board members who were present. No action was taken and the content of that discussion is included in Appendix A.

Comments indicated that outreach and education about resources are still needed in the community. Consumers say they have friends who do not know they can get help to stay independent and they don't report problems.

Findings

Milwaukee County Aging and Disability Resource Center (ADRC):
The consensus of participants was that the assistance provided by the Milwaukee County ADRC is very important and helpful. The comments reflected two challenges that are sometimes reported about accessing ADRC services: the amount of time it takes to get enrolled in services due to the numbers of requests for service, and a lack of awareness in the community about the ADRC and what it offers. The staff and board members agreed that more resources to provide outreach and retain trained staff would reduce these challenges.

Staff participated in the listening sessions to answer questions from participants and share their experiences in the field. They acknowledged that they receive a number of calls from loved ones who are concerned about someone in need of services. Staff are able to review services available and the steps to take to enroll a loved one in publicly funded long term care services. A staff person reported that when ADRC workers visit a consumer's home, the worker may encounter individuals with acute mental health needs that require a temporary protective order so that the consumer can stabilize and enroll in long term care services. Workers are prepared to respond to complicated situations, and the level of complexity impacts the amount of time it takes to respond to each request for service.

Staff and consumers discussed coordination between long term care providers (MCO's and ICA's) and ADRC staff. The ADRC staff have regular contact with all the MCO's and ICA's to coordinate the service delivery issues associated with the publicly funded long term care system. Once a consumer is enrolled in managed care or IRIS, the ADRC staff is unable to track how smoothly the transition to services goes for that consumer. If a consumer chooses an IRIS program, there is a span of time between referral and contact with the IRIS consultant that the consumer has to manage without a service plan. It was acknowledged that consumers still have trouble understanding the transition from the ADRC enrollment services to long term care with a particular model and provider. Consumers would like more assistance understanding the difference between the models, organizations and agencies that provide long term care. It is noted that this was the top issue for consumers in the 2016 listening sessions, and was mentioned again in 2018.

Consumers expressed confusion over how to change programs or add services. ADRC staff explained disenrollment counseling which is the process through which a consumer can change programs. The feedback was that "disenrollment counseling" is a confusing term that may interfere with consumers understanding that they can ask for assistance to change programs or add services. Since "disenrollment counseling" is a state defined process, the ADRC is not at liberty to consider renaming it.

One parent asked that ADRC service be accessible via email or website because many adults who on the spectrum of Autism do not feel comfortable talking on the phone but will use email.

One participant signed her request that staff and consumers who sign be placed together in residential settings to decrease isolation that people with severe hearing loss suffer. She brought a letter about the initiatives that address this concern (Appendix B).

<u>Long Term Care System (LTC):</u>
Comments about providers and models were limited. One person with limited sight reported problems with getting large print formatted plans and transit tickets from her IRIS care consultant. Another person felt that her friend didn't receive proper

care because her speech was difficult to understand due to her disability. Some people said that they had seen friends in self-directed service plans decline and need more services, but the consumer wouldn't tell the consultant and the friends couldn't help due to HIPAA.

Consumers were asked if they can report concerns to supervisors for follow-up. The response was that there is a way to share feedback with supervisors, but it doesn't "feel" as if that feedback is acted upon. Some people commented that consumers are sometimes afraid to report problems because they fear they may lose care services altogether. They said they feel as if providers label consumers as a "complainer" or "problem client" if the consumer asks for too much or expresses a concern.

Challenges with Caregivers:

Almost every participant reported a frustration with the shortage of skilled caregivers, the non-existence of back up caregivers and the high turnover of personal care workers. The discussion indicated that home-based personal care is not regulated the same way as nursing home care, so it may be hard for consumers to get the level of skill needed in their home. Participants said this issue threatens independent living.

One person described how exhausting it is to keep training new personal care workers. It takes so long that he misses out on activities and work while training a new worker. Some workers have had physical limitations that prevent them from performing all the care needed. Some care workers don't last longer than a week. In self-directed care, family members serve as care workers- might mean uncompensated, unreliable or untrained service. Finally, several consumers reported that there is a high "no show" rate for back-up caregivers.

This matter was of such great concern among the participants that the group began discussing factors that contribute to these unacceptable circumstances. Since consumers need to manage their benefits closely, they can only afford to hire caregivers for the amount of care needed. Anything less than four hours of care at a time is not practical for a worker - travel time and low wages make it impossible to make a living. If workers rely on public transportation, they cannot get to the residences due to route availability or make it in between consumers on time.

Staff acknowledged that the certification and training requirements for caregivers has been reduced and that personal care workers are not regulated at all. There seems to be very little that can be done to ensure the quality of home-based care that consumers can expect. Based on consumer comments, some strategies to address this issue might include advocating for personal care workers to receive more training, higher wages, reimbursement for travel, four hour shift minimums (which include the travel time) and team support.

Isolation:

Many of the comments reflected this type of feeling. Consumers reported wanting to participate in activities outside the home beyond medical appointment and treatment. They emphasized that they need personal care and transportation services to do that. When they don't have care and transportation, they can't get out of bed, let alone their residence and this contributes to isolation.

People who are hearing impaired experience isolation when there are not staff and other residents who can sign and communicate with them. Communication needs to be readily available for all people in residential facilities.

People with disabilities would also like access to fitness centers so they can exercise in the community.

One person identified a shortage of support groups for family, caregivers and grief due to the loss of a long-term caregiver.

Special Considerations for Ethnic Communities:

In ethnic communities, elders and people with disabilities experience increased isolation because they are not aware of services and experience language and cultural barriers. One person described how she is a contact person within her community. This person tries to keep track of resources, so she can encourage people in her community to use them. Transportation is a very big barrier for these elders, as well. They may live with an adult child in a place that does not have public transportation or they don't know how to use it.

Spanish-speaking consumers who go to the United Community Center (UCC) described how participating in those programs have improved their lives. The UCC offers a "one-stop shop" for services and consumers find that really helpful and supportive. Having staff and peers that speak the same language is very important.

Transportation:

Consumers consistently reported that they often arrive late to their appointments, work and activities due to long routes to pick up other consumers. There is no way for a consumer to know how long it will take them to arrive at their destination. This means they need to build in extra time which reduces the number of places they can go in a week.

One person said they flipped over in a van because they were not secured correctly and that some drivers do not know how to accommodate a wheelchair if it is a smaller, private, transit company. One parent teaches adults with disabilities how to drive to reduce their dependency on transit services. She would like there to be more ways for people with disabilities to learn how to drive.

Recommendations

- *Decreasing Wait List for ARC Service*: Support the ARC staff to develop and implement strategies to retain staff and decrease wait list.
- *Increasing Awareness of ADRC Services*: Advocate for resources to fund and staff outreach activities as needed.

- *Culturally Specific Outreach*: Review outreach strategies to ensure ADRC staff can be responsive to specific needs within communities of culture and color.

- *Decreasing Isolation for People Who Speak Sign Language*: Advocate for residential and rehab communities that have staff who speak sign on every shift, and residents who speak sign living near each other.

- *Addressing Phone Aversion*: Support staff to explore access to service for people who are phone averse.

- *Confusion About Long Term Care Models*: Continue to work with Department of Human Services to develop consumer centered guides to choosing a publicly funded long term care model and provider.

- *Confusion About Disenrollment Counseling*: Explore possibility of renaming that service.

- *Collaboration and Coordination with Publicly Funded Long Term Care Providers*: Reach out to the advisory boards of managed care organizations and independent care agencies to collaborate on evaluating outcomes of referrals and enrollments.

- *Caregiver Issues*: The challenges with finding and keeping caregivers is a complex issue that needs further study to identify strategies for improvement. The ADRC board can choose to adopt this issue as a priority for study and collaboration.

- *Transportation Issues:* The shortage or inefficiency of transportation services contributes to isolation and compromises an individual's health and wellbeing. Collaborate with transportation advocates to ensure availability of safe, responsive and affordable transit.

- *Diversify Feedback Channels*: Consumers can encounter the same difficulties with transportation and personal care when trying to attend listening sessions as with other appointments, work and activities. Explore other channels for consumer input to ensure ongoing feedback is available to providers and policy makers when they need to consider design and delivery of services.

Conclusion and Next Steps

The purpose of self-directed care is to support the independence of long term care consumers in the least restrictive environment by customizing services to the individual. When consumers can access these services, they experience a higher quality of life. When they can't access the services, they seem to be essentially "institutionalized" in their residence or their health can decline to the point of needing hospitalization. These are not new insights but remain as key points to emphasize that access to services is important but the quality of those services is, perhaps, even more important.

The people who attended the listening sessions expressed appreciation for the opportunity to share experiences with other consumer, staff, board members and advocates. The staff representatives from various organizations and government entities expressed interest in collaborating to make more information available to people who need it.

The ADRC Governing Board will share this report and recommendations with the County Executive and Board of Supervisors, the Wisconsin Department of Human Services and the Managed Care Organizations and Independent Care Agencies. They will also use the report as the basis for adopting priorities and objectives for the upcoming year.

Appendix A

2018 ADRC Listening Session Comments and Discussion

Note: This document contains direct comments and points of discussion from the consumer perspective.

All sessions followed the format: Dan welcomed the group, board members and staff made introductions and gave program overviews, then the session was opened to comments and questions.

In the case of the session held at Washington Park Senior Center, the unexpected outcome was that there were no consumers present due to lack of attendance. The staff, state representatives and providers took the opportunity to engage in discussion of current needs with the board members present. No action was taken.

9/18/18- Wauwatosa Library- 12 people
Board Members in Attendance: Dan Lococo, Mary Neubauer, Pat Bruce, Richard Zimmerman, Debra Jupka.
Staff in Attendance: Karin Bachman, Kathryn Sprague, Bekki Schmitt, Brad Schloesser, Byron Rachow, Tamara Carr, Evelyn Vasquez.

Barry: I live in assisted living. I have several disabilities. I do volunteer work at Public Museum. I go to St. Ann's for programs. I get services through Family Care. I need to work on telling people I need help so I can take care of problems' right away. My doctors don't believe me when I say everything is okay. I can get to Froedtert in 3 min. At St. Ann's there is a nurse who I check in for my health problems and I know what to do if I start to have a seizure. I trust the staff at apartments and they trust me. At the museum I notify security if I am having a seizure.

A woman asked: What does assisted living offer in regards to long term care? Response: it depends on the person. If a person is eligible for LTC, and you choose a provider, they will give a case manager to guide you to services and residential services might be one of those things.

How are ARC and DRC funded? if you needed more funding for something new would you go to County Board for more funding? Kate explained time reporting for Medicaid for State and Fed $$.

Problems with IRIS; I can't read my plan I need the print bigger and the worker won't do it. I am sight impaired. Transportation sheets for van tickets are too small to read. MAKE LARGER PRINT FORMAT

I had a friend who had a stroke and died while the caregiver was on respite. The IRIS plan for back up didn't work- no one came.

IRIS - finding back up caregivers is so hard. We can't find them. My experience is that the good caregivers get promoted and don't do care work anymore.

People who have difficulty speaking cannot be understood by the caregivers and can't get help to be independent.

Caregiver reports: PCW's need 4 hr shifts to take a shift or it's not worth it, $8-10/hr is not an incentive, some people only need 2 hrs.

Concern: Certification education requirements have been cut for PCW's. PCWs = Personal Care Workers. There are no requirements for PCW's. CNAs = Certified Nursing Assistants. Educational requirements have been reduced to become a CNA.

PCW's: Wage is part, but benefits like mileage. Taking public transportation to shifts is not practical. Caregivers have families to get home to and caregivers get calls from family that need them home too. Caregivers have multiple jobs to make ends meet.
Suggested starting PCW's at lower wage, if they stay, they get a raise after a couple of weeks. Many PCW's leave within a week. Offer increases to encourage cares to stay. Cares need team building and motivating. Person works with Bucks, offer perks, meals, prize cards for good work, cares need on-going support. Cares need a way of getting training from someone other than consumer. Consumers have to keep training with high turnover.

Hiring autism therapists- we got young eager college students who wanted to be the therapist. We offered home care hours in addition, but they wouldn't do that work. Even though they were already at the home. No future for home health aids- bad perception. We need to change that. Many cares have physical limitations that interfere with giving care. young people are in better health but they don't want to do the work.

Is there a way to give feedback to employers about the caregivers>? yes there is a way, but it doesn't feel like it is listened to. feels like the company offers to provides back up cares but then it doesn't work out. We have used 3 agencies and they have never had a back up.

Board comment- In summary: training of cares, the hiring and training for back up cares, screening -is it good enough? think outside the box about recruiting, maintaining and growing.

I was involved in a situation where the PCW stole money, it seemed like they didn't screen her.
She took a break outside the house and didn't come back.

Transportation- Transit Plus- I had so many problems I ended up on the board. I flipped in the van bc I wasn't secured correctly. Late- the vans got me places late. I used to tell them an hour earlier in order to get there on time. Currently I am using a smaller company but many drivers cannot handle wheelchair vans.

What was your Transit Plus board experience like? I have only been on the board a short time. I noticed that blind people asked for braille on their cards- transit Plus said yes. Asked for training ride for blind people and TP provided that.

Sometimes people w disabilities are raised to be compliant so they aren't used to advocating. I think people could learn how to advocate, suggest solutions or tell about problems. How to follow chain of command. Problems go unnoticed bc consumers assume there is oversight but there isn't. Consumers with disabilities= the disability prevents them from taking action on a problem. I suggest getting to know disabled people well and they will tell you about problems. Agencies don't get to know "us" = each consumer/people with disabilities. I am more than a checkbox. I don't meet the definition of the disability and I don't feel like they get to know about that. adjust to me.

Please introduce yourself and tell us why you came:
Jennifer, works for Luther Manor- came to listen. Transportation - I hear complaints- lack of transportation

Suzanne Home Care WI- caregiver- hears same problems

Dianna from IRIS 4u- came to listen. Recommended talking to supervisor if consultant doesn't understand what you need.

Phil Haddix- experience advocating for sons and others. Listening. We have issues that have led us to the hearing officers/courts and we try to share the issues we have so that others who have similar issues can feel heard and help.

Kevin Fech- IRIS- here to listen

Bliss Personal Care agency- listening

Sadie - 2 kids on spectrum , WI Aspergers Empowerment- leader of that group- older teens, young adults. Came bc no family support, will need care help. IRIS consultant has been awesome. We have had long term cares, we don't know about the future- continuity of care is my biggest worry. What happens when I die? Who will be the #1 for my kids who will always need help?

Chris and Stephanie- 24 yo son with disabilities- came to listen. Has IRIS, have moved providers once. Person is great but not sure if self-direct is enough help. at 18-19 it worked well- at 24 he doesn't have a lot of options, need job coach, employment opportunities. Don't know how to tap into the allowance, son asserting independence and need someone else to direct. more help so maybe the IRIS program isn't right at this point.
Life Navigators open house- they can't use them while we are in IRIS??

Pat Bruce- is there a support group for IRIS users?
LN has support group, part of My Choice family care.

Disenrollment counseling can help talk through needs and what programs line up to needs.
Suggested: TMG IRIS open house is a great place to meet providers.

Mary- My Choice family care- part of new project to offer small listening sessions and meet with families to talk through needs. Maybe we need to do more outreach and connecting families.
I have a long time friendship with a person with Downs- LTC is important.

Jeff : Care Patrol- service that helps seniors find safe assisted living, in home care, most are private pay but need to refer many people who can't private pay and refers to ARC/DRC and LTC benefits. The biggest thing people need is direction and the ARC does a lot to help.

Laurie parent of 2, and has a terminal illness- facing the future and reviewing options. Heading People First MKE- needs a meeting space, focusing on teaching advocacy skills and lobbying. Voting rights, driving to polls. Teaching people to drive. If someone driving has a stroke - you might need to take the wheel for safety. I get the best info from other parents. Most disabilities have a support group- the meetings I learn a lot don't always agree, but it's a place to start things. Autism- we didn't know anyone with Autism when he was diagnosed, now they are adults and we are scrambling to create things. Job coaches is an issue.

Michael- use a chair, frequent user.

Alice- here bc i want to learn about components. trying to help friend get over issues need to learn more.

Difficulty with guardian issues in court- everybody says that someone else can help.

Phone aversion- many people on the spectrum would prefer to communicate via email. Can county website accommodate that function? Social media messaging or forums?

Wilson Park Senior Center 9/19/18 Listening Session- 30 people; Spanish and Sign interpreters present. Each comment was translated in 3 languages.
Board members: Dan Lococo, Pat Bruce, Mary Neubauer, Richard Zimmerman, Rosemary Crump
Staff in attendance: Karin Bachman, Kathryn Sprague, Randy Mueller, Evelyn Vasquez, Ryan Banbury, Hope Lloyd

Arvilla signed her story. I am profoundly deaf and can hear nothing. I do not need extra services at this time but will. there are deaf people who need services. we met with reps in madison to talk about what deaf people need in rehab services and nursing homes. some facilities have a dedicated wing- that is good like being surrounded by people who can speak the same language. We want MKE to provide a nursing home and rehab services for deaf people to have providers who can speak sign/ and other consumers who can speak sign. communication needs to be readily available for all people in facilities. instead of 1-2 people who visit me- it is unfortunate way to live without communication. That is the way many deaf people live. I hope you come to me with questions about communication.

** 92 yo Spanish speaking woman thanked Arvilla for being here and working on this issue- great job!

Katie - Family Care helps me. I've got therapy, cleaning for house, friends, social. Barriers- there are people who want the help them too so the people that come in to do the testing - some are really good, some need more help to do the job getting the services for the consumer

IRIS- know people who have done well in IRIS but are too old for it and the friends see that the person needs more help but they can't call IRIS because of HIPPA- changing programs is hard and some people don't know how to do it. want a support group for caregivers loss. - when a caregiver dies, leaves, when a client dies the caregiver grieves- I couldn't find a support group.

(Karin Bachman explained disenrollment.)

Darryl- caregiver from Celeste Care- son is paralyzed, wife is disabled, 2 months we called adac and has had only one call back. Has not gotten assessment for 2 months- hasn't gotten enrolled. Karin asked him to give name and number to contact tomorrow.

Nealy- former staff at DRC. open communication with case workers. barriers with transportation issues. vans are out there serving, but listen to individual need. Having to depend on vans is hard- late, maybe they need more money, more communication with van drivers. Care partners need more flexibility to help the individuals. what helps is public speaking hear your voice. family care- doesn't help individuals to get a membership for YMCA to exercise. I want to go to a gym and exercise.
Katie- good point- we don't have a place to go exercise

Please introduce yourself and tell us why you came today:

MA- represent indian/asian community senior community, i am retired social worker. many people do not call resource centers they call me. i never knew wilson center was here. i am here to learn more, seniors are sitting around, they are able to go places, transportation is an issue, want to learn contact people to work with.

Andres- UCC goes for lunch to interact with people, he needs help with health insurance pain in legs

Lilya- UCC- if I need to call ADRC how can I do that? Needed brochure- Evelyn explained how to call.

Linda work at UCC as social worker. ARC and Department on Aging will visit UCC and explain programs. I share information with clients.

Anacia- from Mexico- UCC

Estelle- UCC- she didn't go because she didn't know about it, now she does there's a lot of activities- 92 and does exercise.

Umberto- UCC- really happy with services

Really happy with UCC

Roberto- UCC- really happy with UCC

UCC- sewing group- sell dresses for little girls

Victoria- likes UCC- has transportation and has fitness through UCC

UCC- Nico- 3 months since coming to US. No price to put on this program. Thank you for all of us.

D- UCC brought the group today- coordinates the program- wanted to get out and do something different and learn about other centers, services.

Richard Zimmerman asked if there are seniors in the group that know of people who are disabled and need services? She has neighbors that are elderly that need help- she will talk today.

Services COORD for assisted living at Lake Dr. Please do a listening session at UCC. Why aren't more people here today?

Arvilla asked what is UCC- Explained United Community Center at 730 W. Washington Ave

Judy - retired, volunteers in several programs, wants to stay current on services.

Lynn caregiver state agency- preparing for listening sessions around the state - wanted to hear what people had to say and how we organized it. Christine Lydbury from Wisconsin Women's Policy.

Kevin- IRIS consultant here to listen

Arthur -mother-in-law need services- here to learn. Tug of war between siblings whether she needs more services than family support. Pat referred him to Family Caregiver program. and Dept on Aging an do it, too. Family meetings can be a way to make progress.
Another person agreed that some people don't believe in services- that is a problem.

9/20/18 Washington Park- No consumers attended.
Board members: Dan Lococo, Mary Neubauer, Pat Bruce, Pastor Gaynor.
Staff included: Dept of Aging- Holly, ARC- Kate, DRC- Priscilla Beetle, DHS Christine See, DHS Moran, Randy Mueller-ARC, Wi Women's Council Christine Lydbury- Women and Caregiving project (Family Caregivers, informal, unpaid.), Kevin Fech- IRIS, Mary Claire Carlson- My Choice, Amos Besan - DRC

Note: Dan invited staff to have a discussion about issues they see and would like to address from their perspective.

What is important from your perspective?
Kevin- I am hearing the caregiver shortage impacts people the most. What can we do about it?
Pat- there was a grant a few years back that was designed to address that issue by funding training. No one was familiar with that grant- no discussion.
Pastor asked - is there training for care workers?
Kate- 2 groups of care providers- trained and untrained. Untrained is personal cares and cleaning. third group is paid cash, family makes arrangements themselves. CNA's provide care after being trained. Supportive Home care is one level of care- sometimes they are family members. Personal care requires training.
Strategies for Quality improvement - forum of agencies who hire care workers, - quality and then lack of care at all. Best practice /regulation.

Lack of care- cost issues, number of professionals is lower than number in need.
An example of a 60 yo woman with Downs, has had 3 care workers over her whole life. The stability is an outcome of good wage.
Invite legislators staff to address Medicaid reimbursement rates?
Lobby group for care workers- name? reps finance, training- argued against higher training hours
Caregiver Alliance?
Kevin: there is no training for home care-
Holly- it is a customer service angle- agencies can be expected to train around customer service. employee development.
Mary N- shared a story of an agency scheduling a worker when they are needed, but sending them when they are not needed so consumer will let them go. No flexibility from agency- customer service, customer centered.
Workers are not paid for travel costs or time.
Christine: Teaming up with students to meet demand for early shifts and evening shifts.
The pay is the issue. Start with legislators.
Pat- work on promoting the profession with high school students who are looking to leave high school and be job ready.
Retention is an issue with these programs- the pay is so low for CNA's that the students cannot make enough to live on while they are trying to get into nursing program.
Look at state funds for technical college as a leverage point.
If you train more, pay more, there isn't federal dollar to fund all those workers
Pat: Phyllis Brostoff?

Dan: since we have this group- how do you hear what consumers need and gaps that exist?
ARC- calls for help for loved ones- family visits note issues with cares. Concerned friends and family.
DRC- get calls from doctors, nurses for patients that need help. Customers don't realize how much work it is to hire their own workers- IRIS. Some people use informal cares- paying family members for home care. There is no training required, and a family member might not show up because they don't take it seriously. When a personal relationship turns to a paid relationship- the expectation changes and some of those relationships end.
Many family care workers get paid for 2 hrs of care but provide 4.
PCW agencies: Holly asked how do the agencies evaluate the staff? Many customers won't complain for fear of receiving no care or being labelled a complainer.
Kate- licensure motivation- if there is no licensure, there's no mechanism of accountability.
Caregiver Registry.
High demand in need has resulted in fast increase in more jobs- not regulated so there's a quality gap.

Nursing Homes are regulated and that addresses- home based services do not receive those resources
We are seeing people in family homes requiring super skilled care who used to be in nursing homes.
Nursing homes are now super skilled care of Medicare and short term.
The complaints in home based services are very dangerous.
Priscilla- DRC workers are finding that people with disabilities also have mental health needs. That requires a protective service referral in addition- and a review of the facility by DHS.
Why is that person living in community? Why is she not taking medication? Why don't caregivers know that her behavior is not healthy and normal and safe?
Pat asked if ARC has a waitlist. Kate: yes, it is a violation of state contract, we are abiding by guidelines and doing the best we can with our staffing levels. 3-4 wks wait for enrollment assessment.

Holly- identifying aggressive strategies to reduce waiting list and strategic planning to address with redesign.
Christine See- The state works with centers in resolving violations. looking at staff turnover. State is looking at supportive strategies to address challenges through funding reallocation review- current dynamic is that funding is stagnant and need is increasing
Hire train and replace when they leave for higher paying position at MCO/Waukesha
DRC- wait list = unknown, using OT to keep up with calls and assigning cases.
Dan stated that the board needs to know that number
Pat - 1/3 of all people will end up calling 911 before they receive assessment.

What did you take away?
We are understaffed to meet the need. We are taking steps to change to meet need.
Staff turnover- can't meet need if we are always training, recruiting. We are good at what we do we can't compete with salary.
continued open conversation of the gap in resources and need
what more can my state position do to help local need
operations and staff wage- set benchmarks to incentivize hiring faster to fill vacancies faster.
The things we can control we need to control.
state help? get comparable data from other counties, wages, flexibility, have board elevate the concerns to the elected officials to make it relevant and connections.
WWC recommends elevating the concerns to advocate to legislators- build awareness and sense of urgency. need training and continuing training for caregivers of adult children with disabilities. Forward planning issue for aging parents of adult children. How do we hold agencies accountable to maintain/improve quality of care?
being fully staffed in access unit of ARC is the biggest impact on moving through the enrollment process. Medicaid drives the process, some things can change somethings can't, filling the vacancies is #1.
Elected officials- focus on holding them accountable. People live longer, they need care for that longer life.

Appendix B

Transcript of Letter to the Aging and Disability Resource Center Governing Board of Milwaukee County

My name is Arvilla Rank. I have lived in Greenfield for the past eleven years plus in Milwaukee for 23 years before 1989. I am profoundly Deaf. At this time I do not need special services for myself. Ian here to speak for people who do need some special services and for any future services I may need.

I am sure you are already regularly using interpreters for the Deaf when you meet with Deaf Clients to facilitate in communication.

The most effective services to Deaf people can be provided by Direct Services, staff who themselves sign fluently. There are a variety of professionals who do have good communication skills in Milwaukee County.

Recently some of us met with some representatives of Milwaukee County and our state legislators to discuss the need for a Rehabilitation Center/Assisted Living Program/nursing home to have a "wing" dedicated to Deaf persons and with staff with appropriate communication skills. Several Large cities already have this type of program, i.e. New England near Boaton, Philadelphia, Iowa, Ohio. I know that some of them are privately owned. If Milwaukee County cannot do this, could you encourage a private facility? Being in a place where communication is readily available and being able to communicate with other patients is very important to mental and physical health. I pray I never need to be in one of these facilities but if I do I want other people I can communicate with around me. I have often visited older Deaf people where I and one or tow other persons were the only visitors they saw and communicated with easily, and these visit were only once a week or even every two weeks. Some people had dementia but I always felt it was worse because of no communication.

Thank you,
Arvilla Rank, (contact information)
September 19, 2018

Appendix C

2016 ADRC Governing Board Recommendations to DHS

Recommendations to DHS following Consumer Forums

- **Consumer Decision-Making**

Each organization contracting with DHS share information re: direct care staff retention, direct care staff pay, 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 is an online message board, creation of a report card for consumers to use or hosting consumer networking forums. We believe this type of sharing is valuable to consumers in their decision-making.

- **Functional Screens**

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. 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.

- **Shifting the Burden from Consumers**

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 agency to complete its work on their timetable. If an IRIS consumer has round-the-clock care needs requiring multiple care providers who may need to occasionally exceed the 40 hour 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.

- **Shortage Caregivers**

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