

**AGING & DISABILITY RESOURCE CENTER (ADRC)  
OF  
DANE COUNTY**

**Public Listening Sessions on May 1, May 29 and May 31, 2019  
about consumer and family experiences with the ADRC, Partnership, Family Care and IRIS  
in Dane County**

**Submitted to Department of Health Services  
June 26, 2019**

**EXECUTIVE SUMMARY**

On May 1 at 10:00 a.m., May 29 at 5:30 p.m. and May 31, 2019 at 10:00 a.m. the Aging & Disability Resource Center (ADRC) Board of Dane County held public listening sessions as part of the ADRC Board duties. These public information gathering sessions were advertised to the public via the ADRC website, various email list services, printed fliers and advertisements in the local newspapers. The advertised discussion topics were: Tell us about your experiences with the ADRC, Partnership, Family Care and IRIS and identified unmet needs for older adults and people with disabilities in Dane County.

Overall, approximately 100 people attended the three sessions. A total of 10 people spoke at the listening sessions and 14 people submitted written comments via email. Some of the main issues/concerns and comments expressed centered around the following topics:

- The ADRC was universally praised for their professionalism and ability to help anyone who contacts them. The ADRC office is seen as a great place to come when you need to get help and learn how to navigate the adult long-term care system.
- A small sample of IRIS participants showed that most people who chose IRIS are reasonably satisfied with their services.
- Reduced transportation service is causing more isolation of individuals' social and church-going time. Para-transit services are being denied to residents who reside in Monona, on routes that were previously covered, as they are right on the border with Madison. Concern was expressed about reduced transportation services having a negative effect on Dane County's very high employment rate of individuals with disabilities.
- MCO's are squeezed by the State's deliberate cuts to the capitated rate. Recently, reduced services by up to 60% in reimbursement for services by a Dane County MCO caused lots of confusion for families and clients. Most of these families/clients opted to move on to either another MCO or switch to the IRIS program in order to keep their current level of services and their same providers. This situation caused many hardships for the families and clients involved. More transparency is needed regarding rate setting and Dane County labor costs must be factored in to the rates.
- People with disabilities were institutionalized on an emergency basis for 148 total nights from January through April of this year. This number surpasses the combined totals for 2017 and 2018. These in-patient costs are expensive and greater efforts to prevent emergency detention in the first place would better serve the individuals along with the budget of the MCOs.

- Fragmentation of the current system makes it easy to “pass-the-buck” when issues arise. There is no local control and accountability and there is little opportunity for community discussion about the current Family Care/IRIS systems.
- Clients and family members report an overwhelming support of Support Brokers and for providing increased time for the brokers included in their individual budgets.
- Getting reimbursed for Durable Medical Equipment (DME) is problematic because of new “red tape”. Examples of this include:
  1. a person with a "hospital bed", who has had it and needed it for years. Bed breaks. Cannot be repaired. Request after request is made for a new bed. There is no info on what the issue is. it took about 6 months to get the bed, and all the time it was broken put the person supported at risk. And staff. why did it take that long? What was the care team doing? We don't know.
  2. Someone with c-pap, cough assist, nebulizer and shaker vest: MCO does not use the vendor that has supplied for years under card services. Their vendors say they can't provide the needed items (the "supplies" part of equation). Weeks go by; supplies are out, no new vendor in place, repeated requests to get the items needed. We ended up buying them on line so she had them. eventually they got a vendor, who still took a long time to get the right items.
  3. > Someone needs a lift; did not previously need one. MCO wanted us to use the housemate's lift, which was not the correct type, and minimally would require her own sling. Vendor is not in Dane County. Item does not come. we call the vendor; they say they don't supply to Dane County. Go back to the care team who says yes they will. Eventually they show up, a few days later, with a sling that does not work. Eventually, with ongoing requests and verification from PT and doc that a different lift was needed, they approved it, and then it still took MONTHS to get the lift. By then the person could no longer bare weight and can't use the standing lift.

### **PUBLIC TESTIMONY COMMENTS**

The ADRC public hearing on May 1, 2019, was conducted in Cross Plains, WI at the Northwest Dane Senior Center. There were approximately 20 people in attendance, including two representatives from the state Department of Human Services (DHS). One set of parents provided testimony. The parents' main concern:

- Make sure that appropriate training is provided to caregivers and providers caring for their son with I/DD.
- The parents were also highly supportive of the Support Broker concept as they are getting older and not able to keep up on things like when they were younger. They had been accustomed to their son's Support Broker under the former Dane County waiver program.

The ADRC board then conducted a discussion about ADRC issues/concerns. Highlights were:

- A representative of one of the providers in Dane County talked of her concern when one of the MCOs reduction of as much as 60% in reimbursement for services. The representative stated that they could not provide continuing services to clients at such a reduced rate.
- A representative from UW School of Nursing reported that they were very impressed with the ADRC services for individuals with Alzheimer’s and the training provided to individual families and employers.
- A social worker was pleased with mobile assistance.
- A representative from a SSI Managed Care provider wanted to become familiar with resources to him for one of his clients.

The ADRC public hearing on May 29, 2019, was conducted in Madison, WI at the Alliant Energy Center. There were approximately 60 people in attendance, including one representative from the state DHS. Eight people signed up to provide testimony. Highlights of that testimony are as follows:

- A parent was complimentary of her contacts with the ADRC staff.
- One commenter who is an IRIS provider, voiced an issue that IRIS consultants are not consistent with their potential solutions for individuals’ issues/concerns. To whom do people make their appeals in such cases?
- One organization, LOV-Dane, provided information about a survey of IRIS recipients. With a return rate of 10.5%, the survey results indicted 92% of respondents stated their services were going O.K. or better than expected. However, other survey results indicated:
  - a variety of problems with Fiscal Employment Agencies (FEA),
  - IRIS budgets are too low to cover desired parts of their plan,
  - denial of requested services for certain kids such as WIN Nurse, Support Broker, one-of-a-kind service),
  - a little over 25% of respondents reported that they are not receiving an adequate level of services (i.e. this includes a number of people who are receiving fewer hours of support broker time than they requested),
  - and a variety of problems associated with transportation.
 Overall, the LOV-Dane survey indicated that reaction to IRIS after one year in Dane County was encouraging.
- Another commenter expressed her disappointment about a lack of transportation services.
- A commenter from the Dane County Developmental Disabilities Coalition expressed the following issues/concerns:
  - Inadequate funding threatens the stability of the managed care system as well as the health, safety, and community inclusion for people with disabilities.
  - Positive outcomes for people with disabilities are threatened without improvements to Family Care and IRIS (positive outcomes such as more people living in the community and more community employment)
  - Programs are removed from local control and accountability.
  - The consequences are real. For example: from January through April of 2019, people with disabilities were institutionalized on an emergency basis for a total of 148 days. That number surpasses the totals in 2017 and 2018 **combined**. These emergency institutionalizations cost money which the County taxpayers are primarily on the hook for--divert public safety resources and extract a big human cost.

- The inability in the managed care system to be nimble during crises. Discharges from institutions delayed because of contracting and provider network issues. Unawareness of, or delay in engaging, local prevention resources.
- Heartening to see that Dane County was awarded a one-time grant from DHS to confront this increase within the managed care system. MCOs must engage providers and county experts from the get-go when it comes to challenging behaviors. The DD Coalition stands ready to be an engaged partner in this work.
- Another commenter expressed the need for Support Brokers from conversations with some 45 parent members of her local group. Some parents are timid than others and really need to have more hours from a Support Broker. Commenter also stated that she heard from these same parents that the IRIS consultants are not consistent in their interpretations and decision-making.
- A commenter from the supportive housing provider side said that she was very pleased with the communication with the ADRC manager and ADRC staff. Gathering information at the right time is critical. Durable Medical Equipment (DME) requests are difficult to expedite. Transportation services need to be discussed.
- One set of parents said that continuous changing of MCOs and/or changing providers is a disruption for a person with a disability and their families.
- A commenter expressed the need for quality control in the IRIS program.

The ADRC public hearing on May 31, 2019, was conducted in De Forest, WI at the Community Center. There were approximately 20 people in attendance, including two representatives from the state DHS, a state representative who is a contract coordinator and one state representative who works with Quality Control.

One parent signed up to provide testimony. Highlights of that testimony are as follows:

- She stated the continuous need for a Support Broker with adequate number of hours.
- She no longer has the support needed to care for her child.
- She claims that decisions are coming from the state from those who do not know her child.
- She can't find another provider agency because other agencies do not have the support staff.
- Her child is so much more than the Functional Screen (provides for screening).
- There is a need for training more caregivers.
- Provide enough funding to pay caregivers commensurate for caregiving duties.
- There is no accountability for the IRIS Consultants.
- IRIS consultants acting as "gate-keepers" more than anything else.
- The ADRC board then conducted a discussion about ADRC issues/concerns with those in attendance. Highlights were:
  - One commenter asked that the conversation about paying caregivers adequately be moved up within the total scheme of things. Other comments in this area followed:
    - One commenter advised contacting your state representative.
    - Another commenter stated that many caregivers have more than one job, sometimes 2 or 3.
    - Another commenter stated that we need to train more caregivers.

- One commenter stated that the pay is lower for caregivers due to “the culture.”
- One IRIS provider, who is also a Guardian for a client, stated that very little direction is given (to her as a Guardian).
- Another commenter advised that we should expand awareness and perhaps request that the ADRC convene discussions around workforce expansion.
- One commenter says to involve employers more.
- Another commenter stated that Attic Angel pays their caregivers \$15/hour but they still struggle to get applicants.
- Another commenter advised to be engaging- publicize more, get on the News (Neil Heinen), get DD Coalition more involved, Better Business Bureau, Social Media, Day Care Agencies, parents of kids, aging parents.
- Another commenter advised to educate on how to be an advocate
- Another said to get our stories in newsletter (ADRC newsletter and others)
- Another commenter advised getting the Long-Term Care Workforce more advertising (i.e. note on the ADRC website, plus add other resources to the web site).
- Commenter from AAA mentioned contacting the National Family Caregiver Support Program for potential grant money. A grant has already been given to the Waisman Center here in Madison.
- Rock County is planning a caregiver conference in 2020

## **WRITTEN TESTIMONY**

- A person writes that she has found the ADRC to be a valuable resource. States that the staff is helpful and well informed as to the intricacies of public benefits and she would not be able to duplicate the services provided by the ADRC. This person points out that there are gaps in service for those seniors and persons with disabilities who need personal care. There is also a need for additional rent subsidies as many seniors do not have funds to pay for those services. This person states, “it seems evident to me that providing more at-home care to seniors and people with disabilities is way more cost effective than institutional care (not to mention more desirable in many other ways).” This writer goes on to say that a well-funded program to provide such assistance would be a great thing plus it would be a great way to provide jobs to low-skilled workers, provided the pay is high enough to sustain the necessary travel.
- A parent writes that: My child has Down Syndrome and lives in a very nice group home. We need funding to keep staff from leaving for better paying jobs. People with disabilities need structure and consistency in order to avoid behavior problems.
- A worker employed in the community shared information about the shortcomings in services for the people and fears that we are getting away from person-centered care and moving to a model that puts budgets first.

This person goes on to say that 3 of the 4 people currently supported have IRIS. I have found that though I have had a better experience with IRIS over family care, there are still a fair amount of issues we have experienced. Firstly, the people I support who have IRIS have not been approved for any other medical transportation aside from MTM. MTM has been horrendous to work with, oftentimes it even takes 45 minutes to set up a ride by phone. Someone I support has missed 5 appointments and has been late to several others because MTM either neglected to pick him up, picked him up too late, or attempted to pick him up at the wrong address. On a few occasions, they have scheduled the ride through mad city mobility, who sent the ride back to MTM because they were full, and MTM never rescheduled the ride or contacted me that the ride would be different. This has been extremely hard for the person I support who has a lot of anxiety about medical appointments and is also trying to cope with his recent decline that leaves him unable to get in and out of cars unless they are able to transport him in his wheel chair. To combat this, the person I support has had to pay for metro tickets out of pocket for medical appointments because using MTM gives him too much anxiety.

I have also had a hard time with getting IC's to follow through with requests. Someone I support requested that their nutritional shakes be covered by IRIS because they were not covered by Medicare and he cannot afford the expensive shakes out of pocket. The IC told me that IRIS will not cover ensure, but another person on my caseload does have IRIS and does get their ensure covered by their support budget. Additionally, I find that most times there is a general lack of response by the IC'S assigned to the people I support. I do not feel like they have the best interest of the people supported in mind and that in general, they do not take the necessary time to get to know the person. I feel like they are focused on the financial impact, not on the well-being of the person supported. I have not heard from 2 of the three Iris consultants in months, not even to check in or to respond to update emails I provided them.

Piggy backing off of that, the ICA made a billing mistake that cost someone I support several hundred dollars. I had to contact them an excessive amount of times and even get my director to contact them before they agreed to reimburse him. Even then, after promising to pay him, he was not reimbursed for months after. The IC was very hands off while trying to get this sorted out.

IC's seem to come and go very quickly. Only one person I support has had the same IC since they were enrolled in IRIS, and someone I support has had 3 in one year. I feel like this contributes to the IRIS consultant not having enough information or rapport to truly advocate for and support the consumer. Overall, I think that there is a lot of inconstancies in IRIS and with various IC's. It is my hope and wish that everyone on the team for someone supported really takes the time to understand not only what their needs are, but who they are as a person. Understanding that is the best way to make sure the people we support have their needs met and can live healthy, happy, fulfilled lives. I do not feel like the current model of IRIS (or family care) supports this.

Family care has been even more problematic for me and the people I support. One MCO has been especially awful. I was supporting a fella who really needed some mental health intervention and more general support in his life. This MCO was no help with this. They were very financial-based and did not seem to understand that people can't always be molded into categories. People's lives are unpredictable of course, but can be drastically improved if their teams work together to find appropriate interventions for folks and if everyone on their team is working to understand what the person actually needs and not just how to fulfil a goal. This

MCO was very goal centered and really focused on the cheapest way to make sure that basic needs were met.

Another MCO was also difficult to work with a majority of the time. Though they did try to keep in contact more than other agencies, they were also very, very budget centered and not helpful in crisis. In August, the flooding in Madison had caused someone I support to be homeless for over a month because their building was so damaged. This MCO did nothing to ensure that the person was safe and had what he needed. They never offered emergency assistance for the months' worth of accessible hotel bills which was a huge burden for him.

For another person I support, they rushed through the assessments and I felt as though the person I support could have used more support from their care Wisconsin budget than she received. If the screen would have been done properly and with care, outcomes for this person would have been much better.

This MCO was also not respectful of appropriate communication. I had asked the care manager to please schedule meetings with me instead of the person supported, so I could foreshadow the visit for her. The care manager neglected to do this and visited the person without enough warning multiple times. It caused the supported person a lot of stress and anxiety which caused a ripple effect in her cares for the day.

I want to thank you for taking the time to read this email. I know that no system can be perfect, but I do feel like we owe it to the people we support to improve things for them. Not everything with these programs is negative, but I fear that we are getting away from person centered care and moving to a module that puts budgets first and neglects to truly understand the person we support as an individual with more to them than the amount of money it takes to get there very most basic needs met.

- This person sent in testimony that was given to the Joint Finance Committee during recent budget hearings.

There is a Crisis in Caregiving for the Developmental Residential facilities for Developmentally Disabled, almost all of which are supported by public funding under Medicaid waiver programs, employ Direct Support Professionals to care for their residents. The State provided reimbursement rate is currently about \$10.50 per hour, which has not been increased in 10 years. Average wages in most industries have increased about 30% in that time. These non-profit facilities that care for disabled persons cannot retain a competent workforce at that reimbursement rate, and many around the country are simply going out of business. In 2017 the situation was described as a national crisis in the Report to the President on America's Direct Support Workforce Crisis. That crisis has gotten worse in the past 2 years.

The Joint Finance Committee has conducted public hearings around the state concerning Assembly Bill 56/Senate Bill 59. The language in AB56/SB59 requires "DHS to increase rates paid for direct care to agencies that provide personal care services." I recommend you consider language that would require funding provided by the Legislature be passed directly through the agencies that manage personal care, including the Managed Care Organizations, to the actual providers who employ the Direct Support Professionals.

Those bills also provide for an increase of 1.5 percent for staff who perform direct care. That's about a 15 cent an hour raise after 10 years. Such a negligible increase is not only an insult to these dedicated individuals, but it does not seriously address the crisis. If the residential facilities end up having to go out of business because they cannot hire staff to care for their residents, the state and the country will have an even more serious crisis.

I urge you to provide a 15 percent increase in the reimbursement rate to providers of those services.

- Another written testimony centered around the IRIS program.

We thought that after the first budget if nothing changed it would be somewhat automatic. The State decreased the home care by several thousand dollars and our IC said they did not know why but it was happening to many participants. She submitted an amendment and it was approved. We were informed the whole budget was approved. Now we are told we have to justify two items again. The first is for broker services and the second is for personal trainer services. The broker has been a valuable team member from the beginning. During the transition she came up with ideas the IC had no knowledge they existed. The IC's haven't provided service provider names. Without the brokers knowledge we would be lost in finding the providers our ward needs. Guardians cannot be expected to know all of this information and it is unreasonable to have rules like this. She helps settle disputes with providers and the ongoing transition to his current home. The ICs are not allowed to help in some areas because of either state or company rules and are quick to let us know this. We wanted the broker to file MA and Food Share paperwork in addition to the other services. I discussed with the state's IRIS expert and he had no idea that the county was filing this for all participants. We went to an owner of an ICA and they stated that at the next meeting with the state she was going to bring this up. The state is again saying that it is the responsibility of the guardian. We have asked for the Admin Code Rule or Statute that states this to no avail. We've been informed they allow this for other counties. The rules state guardians can hire professionals but the state has imposed a broker denial for Dane County. We fought for these services in year one, it is unreasonable to have to fight for services needed every year and to have unrealistic state provided funding budgets that do not even provide for the basic service without having to file an amendment by our IC.

The person we care for needs to do strengthening exercises for posture and stability. He is not capable of doing them safely alone and the state says that the house staff should do it at home. According to the state, house staff need to have full medical, physical therapy, occupational therapy and whatever other expertise they decide on a whim. They have this one size fits all mentality. Our person has one staff member at the house to take care of him and his two roommates. It is not reasonable to think that a person that needs to be watched and helped to exercise can "learn" how to do them when they are incapable or have staff with no PT, OT or Trainer experience to take over the safe supervision of exercising while taking care of all the roommates.

We requested a "Fair Hearing". We asked for the evidence the state had and were never provided it. We were told they could send it to us one day before the hearing. We did not have the hearing because our Ombudsman stated they spoke with the judge and he said we needed to accept a compromise or go to a hearing which we would lose. Not exactly what I would call "Fair", We accepted the compromise because of this. The state later gave us the entire broker budget because of all the problems with the first ICA. Now we are expected to have to fight for these services again. Why?



The ADRC was helpful in getting us our first choice of ICA and transitioning to a new ICA when the first one did not work out. The ICAs were so overwhelmed because of the state's underestimation of IRIS participants that they could not keep up. Our first IC did not return emails or phone calls all while the state was sending letters telling us to communicate with the IC. We even got a letter after we went with a new IC and the budget was finally approved.

The state was ill prepared for the transition in Dane County and is trying to force clients into Family Care in my opinion, by making IRIS harder than necessary.

- This testimony is from a parent who has a child who is non-verbal and is enrolled in IRIS.

My child is non-verbal and now in the IRIS plan. He has an excellent IRIS Consultant, who has put together a really good plan for him, but we are all still learning and do not always think of everything at the time of the annual plan meeting. Sometimes some small event is not covered, i.e. additional rides which may be needed and were not accounted for in the original plan. If the amendments are submitted before the plan is finalized, this is not usually an issue. If these need to be added after the fact, this takes a bit more work.

My child's residential provider and work provider have made this transition a positive experience. He needs assistance for many tasks so having a good residential provider to make that happen is most helpful. He is fortunate to have a work provider who helps him stay focused. I believe having a good work provider is in the disabled individual's best interest. Employers are not able to provide this resource and having a work provider is truly a valuable asset.

For the most part, the transportation provider has done a really good job getting him to his various work sites. In the beginning, this was a little sporadic because they were not always sure where at the location they needed to be to pick Paul up. When they take Paul home from work, they call the caregiver to make sure Paul is inside and someone is home.

Regarding the IRIS plan, you basically have to think of everything from the residential provider, to the work provider and transportation provider so that everything is well planned out in advance. Currently, the residential provider employs a caregiver who lives in the home so Paul is very fortunate.

The ADRC was very helpful when my son transitioned from Family Care to IRIS. If I have questions pertaining to IRIS, I could call them but now I contact the IRIS Consultant as she can help me figure out what my son needs, but the ADRC is always there if I need them.

- **The unmet needs now and in the immediate future:**

The biggest issue is lack of good caregivers which seems to be a growing problem across the board. I hear many parents state that they are not able to find good caregivers. Most residential agencies train their staff "caregivers", and if the individual is with an agency, they are responsible for the backup plan.

For those parents who need to hire their own staff, there is not a suitable backup plan. Most parents or siblings work and are not able to step in if someone does not show up. This is a problem that needs a solution because many disabled individuals are non-verbal or are not able to do certain day to day tasks on their own. Part of the problem, may be having a low pay rate for this type of work and the other may be that the economy is good right now so people are applying for other jobs.

I do not know how this problem can be resolved but this is certainly something that needs quite a bit of thought as the disabled and older adult population is growing.

Currently, there is no list for individuals looking for roommates which Family Care used to provide. When someone leaves a residence, it is very difficult to find out who is looking for a roommate.

Right now, the IRIS plan is working for my son. If the funding changes for disabled individuals, this would have a very significant impact for Paul and many others. Thank you for taking the time to read my comments.

- This person writes about their family's rocky past year experience.

It has been a rocky road this past year! I had to switch IRIS agencies. With one of them, they started us, not the month agreed to. The head of this IRIS agency refused to submit a budget amendment even after they had all the supporting data. It is difficult to access necessary agencies, when they have no availability, ie dialectical brain & no other options. Truly miss Dane County efficient use of resources!

- This person writes about her experiences from the perspective of being an elderly person with autism.

She feels that she was inappropriately placed in the service system under a healthcare system that treats schizophrenia and bipolar disorder and clinical depression, thereby locking her out of the support system of people with developmental disabilities. She claims to have been locked out of medical treatment for the service of comorbid illnesses. Having been enrolled in the Care WI Partnership program, she writes about her negative experiences. Due to budget cuts to Care WI, her services were either changed or cut and those changes got worse due to more budget cuts. She complains of case management being done essentially by telephone versus in person. Real help from her case manager was overturned by people at Care WI that had never even seen her. This writer goes on to say that she knows that there is better service "out there" because she volunteers for an agency that supports people with developmental disabilities. This person claims that there is only one agency that Care WI contracts with that supports people with developmental disabilities. However, that agency had a very high turnover rate and the staff had to cancel appointments, often at the last minute. This person claims to have been in three homecare agencies and that she didn't leave them, they left her. She has had difficulty staying in apartments but finally found friends at the YWCA. This person has a need for a specialized hospital bed and has had trouble accessing a new bed, but finally, this bed arrived. She did however, lost some of her medications and tried to get them replaced through her pharmacy. But the pharmacy called her and stated that Care WI refused to pay for replacement of medications no matter what. She did find one improvement with Care WI in 2018 and that involved Care WI had email access to the case managers and nurses for the first time. She has also had trouble getting a walker from Care WI. The one she uses now came from loan closet. She says that the medical care equipment companies that Care WI contracts with want to play games.

This person's most recent difficulty is that she finally moved into a group home and was told that she could begin work at Catholic Charities Day Center. Then, after she was moved in, she was told no Day Center because the home that she moved to was an Adult Family Home.

Now, this person is self-employed as a street musician but is having problems paying for transportation to/from downtown Madison. Taxi Cabs are prohibitively expensive. She recently got accepted for Para Transit. Right now, this person is in trouble because she got a bill from Care WI stating that she ran up over \$4000 in debt that she hadn't reimbursed for 5 months of room and board at a group home. She says the truth is, she is really struggling with the housing crisis that exists here in Madison.

- Another person writes about the overall budget under IRIS

I guess I was under the impression that our budget would contain everything that we needed. I was wrong. I found out that a portion of our expenses must be paid by our son. Two examples are as follows: A) Every summer our son goes to a summer camp. In conversations with camp personnel, they want nothing to do with IRIS. B) We are also sign up with UCP for respite care. There have been emergencies where we must hire our neighbor for Respite. When this occurs, we pay for Respite and not from our IRIS budget.

When we signed up for IRIS a year ago it was a disaster. If I recall there were 3-4 Agencies we could pick from. The agency we wanted was already filled. Thus, we could not use that one. Another Agency was for profit agency which I did not want. We were forced to sign up with another agency that was not originally in Dane county. I did have a conversation with the agency that could take no more clients. I asked if we could be added to a waiting list. The Director said no as the State of Wisconsin does not allow it. I remember asking how they can plan for the future if they do not know how many clients they might add in future years. The only comment was, it is difficult.

- This person writes about the inconsistencies of IRIS Consultants.

Thank you for inviting feedback. I am the guardian for 2 disabled young adults both involved in the IRIS program.

ADRC was very informative, helpful & flexible in the initial transition process.

Different IRIS organizations and ICAs were intentionally selected, and the experiences have been different. I agree with other speakers (I observed the Madison Hearing) that there were few options available - and choices disappeared on an almost daily basis. I was also told in some conversations that I had no choice and the organization would be doing the matching.

The role of the IC has been uniquely defined by the differing organizations - one clearly describes the role as limited to paper shuffling, and other is more actively involved in knowing the client and acknowledgeable about the actual care and support needs.

Both IC were knowledgeable about the budget process, although it was obviously a learning process with many "1 more form...signature..." events.

The timing and number of forms to be updated needs to be streamlined (one signature with initials for different components?), with a focus on signer being informed what, if any, changes in the form has occurred.

Within 8 months of the transition to IRIS, the young adult received 30-day notice of being dropped from a vocational support organization that had provided supportive employment for the past 9 years (30 hrs of support/week). The information provided was that it was no longer fiscally possible to support a client with complex support needs. Because the employment sites were through the agency (shared with other clients), the paid employment was also lost. When ADRC was contacted to inquire how alternative supports might be identified, there was no direction beyond suggesting asking Avenues if they might play a role - however the budget for Avenues was designed to solely help with financial advice. A budget amendment to allow access to this unanticipated service adjustment through a support broker service (unlikely to be accepted) cannot be processed to deal with a "30-day notice". As others at the Hearing stated, there is no known "recourse when there's a problem", or for dealing with "contracting challenges". Where (if not a broker-type service) will information and transition process be reasonably available to have any hope of "changing" providers or services?

In one situation there has never been full staffing in place since the transition to IRIS. As others have shared, there is the challenge about what is a living wage for support personnel in the Madison/Dane County related to the cost of living. Although I have not experienced an emergency institutionalization over the past year, and was sorry to hear how the rates of this support mechanism have risen over the past year.

I also agree with the comment "big mystery around the codes for billing". I have submitted forms for one pay period and had them accepted, only to have them not be processed the next time despite still receiving the same "auto-response" that they had been received.

- This person writes about the need for several changes/additions.

There is a need for...

- More adult day care centers, ideally offering home-like settings, hours from 7:00 a.m. to 7:00 p.m., and services such as bathing and hair-washing.
- Specific criteria for what is required to be provided by CBRFs offering memory care.
- A requirement that CBRFs offering memory care accept people who are two-person transfers (i.e., people who are unable to assist in their transfer out of a wheelchair). Or, at least, that directories of CBRFs indicate whether those facilities accept people who are two-person transfers.
- A website like YELP that provides reviews by consumers of assisted living and nursing home facilities.
- More funding for quality assurance monitoring of assisted living and nursing home facilities. (Consider moving that function from the State to the County.)
- Planning for the growing number of older people who have no children or whose few children live at a distance.

- This person writes about her disappointment in how things have changed for the worse under Family Care/IRIS system.

I was not able to attend the public hearing held at the AEC with regard to the above subject. I would still like to voice my concerns. As the mother of an adult in the system, I am very concerned for my child's well being. I am less than happy with Family Care at this moment due to their lack of involvement/help/follow through. They started out seeming as though they were going to be very helpful and advocate for my son, then suddenly ... crickets. No word from anyone, then when I finally did hear from someone, I'm told there's been a staff change, then a little bit of assistance picked back up, then ... crickets again. Another staff change apparently, as well as apparent contract negotiations with FC and one of the organizations. I've been told multiple times "she's out of town" or "I just got back" ...

I'm very disappointed at how things have changed, seemingly for the worse, coinciding with the switch over to FC/IRIS.

- This person is concerned about who advocates for her and the health needs of her husband.

Thanks, maybe this exists but I would like to see a monthly newsletter for aging folks!

- (1) What Medicare covers? Yes, there is a website and pamphlet, but they need translation for people.
- (2) Why balance and strength are contributing to longevity; how do you get it? ( yoga, tai chi, gardening) yoga has restored much of my strength and flexibility
- (3) Who advocates for me and how do I advocate for myself?

As I said at the forum or hearing, I feel rather informed and empowered (now) but there is so much I didn't know until I acquired/ grew some cancer cells and I met several advocates and made friends in yoga. In between the confusion and acquisition, I was pretty lost and confused and improvising important decisions.

I would do this with others because knowledge really is power and connection, and doing Yoga and writing poems isn't enough now.

Part of this is about people like my husband who are healthy/ athletic but have minimal D coverage, not sure as issues arise what to do. I thought there are other brothers and sisters in aging with issues that can be complicated and new.

Also, thanks for the chance to express my sincere appreciation for direction.

## **RECOMMENDATIONS**

- The State needs to promote and encourage person-centered relationships throughout the Family Care and IRIS system.
- The State needs to look at the issue of caregiving for seniors and people with disabilities. Specifically, the shortage of and the lack of qualified caregivers and the issue of lower pay for

caregivers needs to be prioritized, discussed and a plan of action developed and implemented as soon as possible.

- The State needs to work with Dane County on providing financial support for flexible solutions to the existing transportation system.
- The State needs to continue to monitor and provide the necessary funding to implement and continue a quality long-term managed care system. Provide adequate funding for Family Care and IRIS so that the MCOs do not have to suffer rate cuts and thus disrupt the consumer, families and providers by passing those rate cuts on to providers and consumers.
- The State needs to monitor quality assurance and contract negotiations for Family Care and IRIS contracts in order to remove the fragmentation of the system and insure consistency of decision-making and the provision of services.