**Arc of Iowa Annual Meeting Agenda and Notes**

August 20, 2016

Welcome | Doug welcomed participants to the meeting. He introduced himself, and introductions continued around the room:

* Jeremy Beavers; President of The Arc of Mason City
* Steve Beavers; Board member of Arc, of Mason City
* Tricia Crane; Executive Director of The Arc of Story County
* Susan Teas; Board Member of the Arc of Iowa and the Arc of Story County
* Alice Philips; Board Member of the Arc of Iowa and the Arc of Mason City
* Cheryl Keller from Ankeny, has a child with special needs
* Delaine Petersen; Board Member of the Arc of Iowa from Cedar Rapids and has two children with special needs, who became involved with Arc through her children.
* Paula Connolly; and son Aaron of the ASK Resource Center
* Cindy Smothers from Cedar Rapids, has a 32 year old son with disabilities. She has been on the board of directors for Arc of East Central and past president.
* Donna Bachman; Board Member of the Arc of Iowa from Carroll.
* Legislator, Lisa Heddens; The State of Iowa

EXECUTIVE REPORT | Doug shared information about the MAAC (Medicaid Advisory Committee) meeting that he attended this past week. The printed report indicated that 97% of ‘clean’ claims have been processed in a timely manner.

He asked pointed question(s) about actual Medicaid payment and what the papers are reporting, with no answer.

This committee has 60 members, Arc of Iowa is one. The recent rule change has provided for 10 members who are family members, and they have a voting block. Doug indicated that at this time the committee is not a change agent but more of community listening post. Meetings in the past were poorly attended, but in the past year have become more organized. The chairperson will always be the Director of Public Health.

Doug asked for input from the group about issues for regional groups. Cheryl indicated that she does not have an Arc to go to for advocacy. She and Cindy talked about schools not communicating well about the Arc; most information is online and schools are concerned about privacy and litigation. Cheryl said that she would like to be able to easily find services; and that it would have to be difficult for the younger parents and not knowing what to ask for or look for.

Doug talked about history of Arc starting from frustrated parents who networked and started the Arc and fought for services. Over time it has become more complacent, and services are available in places but not consistent across the state.

As funds do not come through for providers of care, there will more need for people to be more involved to advocate. Cindy talked about the changes in rules that are making it hard for smaller care provider organizations to operate, more rigid in order to get reimbursed.

Paula shared about working with Hispanic population, who are unaware of what services are available and they also have a culture that does not share about the disability within their family network.

Doug talked about finding a new vision for Arc, so that people get to know each other across the state, and share what they are doing and have done, so that everyone can benefit from others’ knowledge. Doug believes that there is a two year window to build the Arc groups in Iowa, so that Arc can continue to exist and continue to advocate. We need to help them know how to find and pull together young parents to be part of The Arc. There is need to support rural areas as services are not available either because of payment being denied for services or services providers leaving the profession from lack of reimbursement, we will need to ‘lawyer up.’

ABLE-Act: can set up funds for a child, and state cannot take the money as long as child is alive.

Doug encouraged the Board to see a new vision for the state chapter:

* Build a stronger network between regional/local Arcs, to share information to help each other
* Strengthen the leadership and responsibilities of self-advocates across the State and bring them to the table
	+ Initiatives like the Heartland Self Advocacy Network (four states working together: Kansas, Missouri, Nebraska, and Iowa) have begun to bring consumers forward through Community Listening Sessions, Social Media Sites, a webinar on the History of Disabilities in Iowa and National Training to teach consumers how to be advocates. The group has made a few small changes but the efforts are growing. This year they plan to support the Fuel Assistance Bill to support Iowa’s with physical disabilities receiving assistance for pumping gas.
	+ They have also partnered with Iowa Disability And Aging Advocates Network (IDAAAN);
	+ And created the Voice of Iowa Disability Facebook page.

LUNCH | Meeting reconvened at 12:50 PM

LEGISLATIVE UPDATE |

Lisa Heddens; The State of Iowa Representative was introduced. She is also a parent of a child with disabilities.

She spoke about the change-over to managed care. Medicaid is made up of 21% persons with disabilities and older adults, but they utilize the largest portion (80%) of the Medicaid money [which makes persons with disabilities a target for cuts and additional management]. Managed care meetings are being held to listen to consumers across the State. On August 29, the Legislature Rules Oversight Committee is meeting and hosting listening sessions to better understand the needs of those on Medicaid Managed Care. Presentations planned include the private companies that manage care and the Dept of Human Services. No consumers were going to be included, but Lisa has plans to include consumers. Both Senators and House members are present. This meeting is a live steaming event.

From local service providers, complaints include non-payment, no payment at the correct rate, having to get loan/credit to pay workers, 64% say they will reduce services because of high cost of administrative costs.

Lisa explained that data needs to be collected in order to know what is working and what is not working, so that changes can be made as needed. Other states that use managed care brought the change on more gradually than Iowa has done, so learning to do business differently has been more difficult for Iowa. Lisa feels that her job at this time is to monitor. It will take time to know what is working vs not working. When legislature convenes in January, discussion will occur on possible changes. The Administrative Rules and Regulations Committee is important, as rules are necessary in order to know how to implement the intent of the legislation.

Lisa indicated that a personal presence at the capital is needed when the issues and legislation around disabilities is on the agenda. Paula Connely agreed; she also reported that lack of information about how to lobby makes people/groups stay away. We should be contacting our legislator once a month about the issues of Arc, or of disabilities. Talking about what works, what doesn’t work, and how or why this is an issue for you/what you want them to consider.

Discussion about why CCO (Consumer Choice Options) is getting paid/payment for providers while other entities are not able to get their claims approved. Delaine suggested that we help the smaller Arcs in Iowa become ISB (Independent Service Broker) so that they can manage their own services.

Lisa shared her business cards with the group before leaving for another appointment.

Doug asked Paula Connolly, from the ASK Resource Center, to talk to the group. She became involved after her daughter was born with disabilities. She was given a list of phone numbers to call and ask for assistance. She was unable to find what she needed and wanted to involved in combining the service information. Parent Training Information group in Iowa had lost its funding and so Paula’s small group decided to replace that group. After being accepted as a PTI center within ASK, Paula also applied for and received a grant for health education center. Paula, through ASK, has been involved in helping to get waiver programs started with Julie Beckett. All of her work is based on grant $, so it depends what gets funded.

Paula wrote a 3-part newsletter about managed care to explain it consumers, which has been shared across the nation. ASK began to post articles about managed care, so that consumers could learn about it and be able to work with the change, and call people to action to help it be implemented as best as possible.

Remember that you have a voice, and make sure that voice is used to make the choice of who is in office, no matter what the election.

She also talked briefly about block grants and the push make Medicaid $ in a block grant. There is also talk about making Medicaid a per capita basis, where Iowa will not do well. Also talk about making Medicaid $ spent by disability.

Meeting adjourned at 2:30, after Delaine drew for door prizes