**MassMATCH Advisory Council Meeting Minutes**

**December 21, 2016**

**Members in Attendance**: Tory Dixon, Robert Dias, Owen Doonan, Randi Sargent, Jae Spalding, Ann Shor, Susan LaSante, Jonathan O’Dell

**Members Not in Attendance:** Lisa Chiango, Les Cory, Peter Gefteas, Kevin Hatch, Karen Janowski, Maxine Knight, Linda Landry, Tom Mercier, Lee Nettles, Alexander Pooler, Paul Remy

**Program Staff in Attendance**: Kobena Bonney, Tanya Bombard

**Representatives from Provider Agencies**: Cathy Bly, Dan Mayo, Joan Cosentino, Leo Tonevski, Karen Langley, Chuck Smith,

Introduction and Communication Protocol: Ann Shor chaired the meeting until arrival of Jae Spalding. Ann asked everyone to use the microphone and identify themselves when they speak.

Discussion and Approval of Minutes: The September minutes were approved with no changes.

***Program Updates*:** Kobena Bonney

Kobena gave an update on the MassMATCH proposal to the Reeve Foundation. Only State AT Act programs like MassMATCH are eligible to apply. The challenge is to come up with innovative ideas towards increasing access to assistive technology to improve the lives of people with all kinds of paralysis.

The advisory council had previously set up a committee to discuss and come up with activities, projects, ideas that might be good to consider in preparation for the grant. The initial idea was an AT kit for newly paralyzed individuals to enable them to communicate (with family and the outside world) while in the hospital and when they leave - during the initial transition. The committee also thought it will be good to hold a couple of focus groups to meet people with paralysis, and hear about their thoughts and ideas.

MassMATCH held three focus groups in Boston, Worcester, and Pittsfield. The top two issues that came up were people being able to weigh themselves and knowing what condition their body is in to help prevent pressure sores and inform their future decisions. The proposal that was submitted were for getting accessible scales and pressure mapping technology.

Notification from the Reeve Foundation is expected in February and the release of funds in March. There is up to $75,000 for each State AT Act program applicant. Reeve Foundation expects to give out 4 or 5 grants this year.

MassMATCH put in for just about $75,000 for the MassMATCH Weight and Seating Independence Project. The project will serve Central and Western Massachusetts and will be housed at UCP Berkshire in Pittsfield as part of the MassMATCH AT regional Center. The project will purchase a number of transportable wheelchair accessible scales and also pressure mapping technology that anyone can borrow to use at home.

In addition, MassMATCH will purchase and locate four non-transportable wheelchair accessible scales at Independent Living Centers - AdLib in Pittsfield, Stavros in both their Amherst and Springfield offices, and Center for Living and Working in Worcester. Any interested individuals can go and use the scales on site to weigh themselves, or they could borrow a transportable scale from the ATRC.

Owen asked if there was much interest, or objectives to testing the needs and desires of different groups, like young children, teenagers, college kids, seniors.

Ann answered that there was no focus on a particular age. There will be three different sizes of pressure mapping systems, pediatric, medium adult size, and then at least one bariatric size. It can be borrowed and use in an office to test out a chair someone sit in at work, or anywhere else.

Randi asked if there were any qualifications or skills one needs or if an individual can do themselves and come up with a conclusion. Or does a professional have to do it?

Kobena answered, yes. There is some specialized knowledge needed, especially the interpretation of the data. Part of the project will involve working with Tom Mercier of DDS and a council member. Tom and his staff will work with the organization that makes the pressure maps to come up with a "How To Manual”. The manual will be given with the pressure map to help anyone do at least the initial mapping. Whatever decision is made afterwards will be up to the individual. They can take the data to a professional to interpret it and use it to advise them of what they need.

Ann stated Tom Mercier did feel confident that with guidance on how to use this system and read the results that it would be useful to the individual and not just a professional.

Karen stated she has been at two pressure mappings at Spaulding with physical therapists and that anyone can learn how to do this. She explain that you would be looking at a laptop screen, it will be a picture of the person's butt. The pressure is in different colors. The bright pink means no oxygen, greens and blues is a lot of oxygen. You lift the person up, adjust the cushion, bring it down and try again, with the goal of getting blue.

Jae stated she is excited that there is forward movement with pressure mapping tools for people who use wheelchairs. She would like to know if the Advisory Council can have a training to inform members on how the system works and see the document Tom Mercier is going to create before it is released so members can have input.

Kobena said part of the project will be training organized for staff of ATRC Pittsfield, and for others that are interested to learn. Folks that are interested should go to those trainings. He’ll let everyone know about those trainings.

Jae stated that the Advisory Council is losing members and one of the things that would be helpful is if this Council were able to get a training at the next meeting to see what allegedly we advised MRC to do. To see that training manual Tom Mercier's going to put out. But as a council it would be great for some of the lay people here to know that the next meeting, should that kind of tutorial be done by then. To make suggestions that could be talked about during the next meeting. The Reeves Foundation proposal has been a big part of what this council has done this year and it would be good for the members to be a part of it.

Ann responded that by the next meeting MassMATCH will know if the grant is awarded. Most likely we would not be ready yet to do any kind of a presentation for the March meeting. But absolutely we would welcome input from members that are interested in the manual that is being put together. Not sure if a full training on the use of this system can be done because that is a few hours long, but a demonstration, sure. It would be really interesting to see how it works. If MassMATCH is awarded the grant hopefully that can happen for the June meeting.

**ATRC RFR Kobena Bonney**

Kobena announced that the Request For Responses regarding the contracts to run the MassMATCH AT Regional Centers has been published. The deadline for responses is the end of January 2017. As part of the process, interested parties are able to submit any questions they have about the RFR or the work to be done to MRC. MRC will then publish the answers to those questions s on the same website where the responses have to be submitted.

The next step after the RFR has closed will be for MassMATCH staff to form a committee to review the submissions received and decide on the winner for each of the two locations. The plan is to award the new contracts effective April 2017. We plan to form a committee made up of MassMATCH program staff, a rep or two from MRC Vocational Rehab, and a rep or two from the advisory council.

The existing contract under which Easter Seals – MA and UCP Berkshire run the two ATRCs was for an initial 5 year period and renewed once for another 5 years. The new contract will be the same.

**FY16 Federal Annual Report**

Kobena announced that the official MassMATCH annual report for FY16 was submitted to the feds. Following past practice, we plan to have a user-friendly version produced for members and the general public.

Randi asked if the report is available online.

Kobena responded that it will be available on the CATADA website after a few months.

**REquipment Update**: Karen Langley

Gave data from July through November. There was 661 items reassigned, which surpassed the goal of 600 for the year. The types of devices that were reassigned are 236 community living devices, 71 education, 2 employment and 25 with no response. The largest age demographic is between the ages of 22 and 64 at 478 served. Over the age of 65 is 257. Below 21 is 92. Two thirds of what REquipment does is mobility devices, such as manual and power wheelchairs, scooters, etc. The numbers show that the male to female ratio is pretty close with serving just a little more of the female population. The number one request is manual wheelchairs, particularly transport chairs, second is shower chairs and third is power wheelchairs. In terms of disability, who is receiving devices, the number one is "other." People who haven't answered at 168. Arthritis is second at 79 people. The third was stroke at 37, and spinal cord injury at 36. During this period REquipment served 42 veterans. There has been 1,190 devices re‑assigned since April 2013. Valued at 2.16 million dollars. The program is doing a great job in 2.5 - 3 years.

Karen Langley recently took over the REquipment program and the first month‑and‑a‑half was to do a transfer of power, for Chuck and Roxy to learn the system, the folks from MRC, Tanya being the one was running the show with Elaine taking the calls and donations. Since then, REquipment has done 15 outreach activities, including exhibiting, presentations, something with DLC, the Boston Network cable show, and recently, on the Worcester cable TV show.

REquipment is taking on three new part time employees and they are all people with disabilities and those three people start right after January 1st.

There has also been various changes to the website. On the consumer intake, when a person identifies they want one particular device, race/ethnicity was added. To help see who is being served and what kind of outreach needs to be done. There is donor intake form online now. The number of statuses and responses they can see have been squished. Replacing the Mass. Hospital School logo because it’s now Pappas Rehabilitation Hospital for Children. There is three new methodologies that have started for the satisfaction survey. The first one is a postcard, it has four questions that relate to federal requirements. When the device is delivered, the person is given the postcard that has the number of their device on it. The second will be random sampling. Looking back at a three‑month period, do 10% of those who received a device and send them a much larger survey. The third is up on the website, there will be a satisfaction survey for donors and recipients. Come spring REquipment will be holding equipment drives, each of the reuse partners to host at least one. The first one will be with Spaulding Rehab Hospital in Cambridge, and the Cambridge Commission on Persons with Disabilities.

**UCP Berkshire:** Dan Mayo

ATRC Pittsfield has last quarter numbers in. Two loans and 28 demos in the last quarter. The next newsletter that everyone will be able to see will have a successful loan story. The nephew of someone who works with the center’s insurance company needed a speech communication device while his was being purchased through insurance, and the center was able to loan one to him. With the same app he was using, which is called Touch Chat, and the center had to extend the loan a few times. Luckily the ATRC was able to do that because there were no people looking for that device during that time period. So it was extended twice. The child was able to continue to use the device to improve his language skills. The family sent the ATRC staff a great thank you letter and that will be coming out with the MassMATCH newsletter so long as they get their permission.

**ATRC Boston:** Cathy Bly

From September to today. ATRC Boston have had 134 device loans. Mostly for assisting in decision‑making, done by family members and most of those loans were for devices in the speech and language area. 290 devices were loaned out. Out of those loans, 85 said that it would meet their needs out of 134 and 82% were highly satisfied with those loans. In the area of demonstrations, ATRC Boston had 23. The most popular were vision demonstrations and most were also involving individuals with disabilities. The majority of those demonstrations also met their needs and there was 100% highly satisfied rating. The center had 26 different outreach and public awareness activities; which included tours of the center, conferences, presentations, outreach and demonstrations.

**Stavros-** Tory Dixon

Stavros has posted on the REquipment site 25 pieces of equipment. Of that about 20 have gone out. One of the things is just trying to get the word out that they are looking for equipment to be donated because they have more people who need equipment than they have equipment. Stavros is asking their staff to get the word out, it’s in the newsletter and things like that. The biggest issue is not having enough of what people need.

Karen stated Tom Mercier will be sending out a mass mailing to all the Councils on Aging asking them to identify if they have any equipment that they are not using with the goal of getting them to donate equipment.

**Meeting purpose, duration and structure**: Kobena Bonney

In light of feedback from some of the members who are still here, and some who have left, this is something that needs to be revisited. The length of the meetings and the content. The question is, should the meetings be shorter? There are a few options to explore. One is to start the meeting at 1pm and go until 3pm. That is two solid hours of talk. Keep the meeting schedule at quarterly meetings. Meeting prep and refreshments could start at noon. Maybe include a ten or fifteen-minute break in between. Two hours should be enough time to talk about what’s on the agenda. That means also making choices about what is it that we do in the two hours.

Tory asked could the meeting be pushed back. 12:30 to 2:30. The later it is the longer it takes to get home.

Dan stated from his perspective coming from Pittsfield, if the meeting is four hours or two, it is a full day. It is a two‑hour drive from Pittsfield, so it is six hours if it is a two‑hour meeting or eight hours if it is four.

Ann suggested sending out a quick poll because not all the members were present.

Kobena said he’ll send something out to all members to ask for feedback.

Jae said one of the things under the bullet point in the agenda is the purpose of the meeting. That some people have expressed concerns about what the council does at the meetings. The amount of time it takes to carve out in the day members want it to be worthwhile. She stated that during her tenure as Chairperson that’s been something she has been trying to push, that members should look at what is being done here, why lay people should be invested. Jae suggested that part of the survey include what people want to do when at the meeting. What they are expecting from the meeting. How many lay people, people who are not currently representing an agency or organization that had to report today? Council members that have a disability or their child or someone that they are very close to has a disability. Can the survey include something that addresses that?

-Five people raised their hand out of fifteen-

## Owen suggested having flexibility on length of meeting depending on topics and demos.

Randi suggested program partners submit activity reports before meetings.

Jonathan expressed concern about ASL/CART providers accepting shorter jobs.

Dan expressed worries about elimination of long form discussion on any given topic.

Chuck suggested breaking meeting up into groups for providers to meet.

Kobena mentioned having Video Conferences at specific MRC locations

Jae suggested live conferences on social media and asked Owen to gather conferencing options and Jonathan to make sure it could be fully accessible.

**JONATHAN O’DELL did a PowerPoint presentation**

Jonathan stated that CART/ASL wouldn’t necessarily work for people who are deaf or hard of hearing. Because they may not be able to understand English. CART wouldn’t work for a Deaf person because every deaf person is a different individual with different needs. Then showed an example by yelling in Russian and asked if the members could understand what he was saying. Some people raised their hands stated they could hear him but couldn’t understand what he was saying. He stated that was the point he was trying to make, ASL is its own language and many people who learn it may not understand English. Jon explained how the ear works and how we hear and high frequency loss. On one of the slides was different types of hearing aids and he explain the difference between them.

Ann asked if he thought that other than the different sizes of the hearing aids, if the quality of them were comparable.

Jonathan talked about the capabilities of each and the pros and cons. He also told the story of Blue tooth and how it got its name. Jon explain another slide and what tele coil was and talked about cochlear implants. He also talked about how Bluetooth can route calls from a cell phone directly to a hearing device

Kobena asked if cochlear implants impacts speech.

Jonathan stated that it may be because he can hear the way things are pronounced now and some of the things that were mispronounced has been corrected, like the city of WORCESTER. He passed around and FM based system hearing device.

Kobena commented that he had been to Audio theater performances with audio descriptions and they provide an FM system as the performance is going on.

Jonathan mentioned the Regal cinema has Sony Caption Glasses. He also stated that text live is to replace TTY.

## Robert stated to Jon that he mentioned the phone, blue tooth and rerouting the call to the implant. Then asked if he has used it, or any of the listening in features in the iOS devices where you put the phone down on the table and it picks up conversations and reroutes it to the hearing aid or implant?

Jon talked about different types of listening devices that out there to use in those scenarios. He also talked about an app for cell phones called AVA and how even though it may have started with good intentions it is completely useless. Jon then finished the rest of the slides from his presentation.

***Working Group Subcommittees Updates***:

**Membership Committee:** Kobena Bonney

Kobena mentioned that four members will no longer be part of the advisory committee. They are Alcilio, Allan, Joy and Molly. He mentioned the committee will meet again to decide what to do for outreach to get more people to join. He would like more diversity in the group as well. Kobena also mentioned that the members should consider giving another one year extension to the other members whose terms may be expiring.

**Website Committee**: Kobena Bonney

Kobena asked everyone to feel free to participate in the website committee. The plan is to set up a meeting for that committee soon to discuss and review the things that are expected of New England Index to do. He stated that they are planning on rebuilding the website and expressed the need of the committee in the involvement on deciding what is to be done.

Ann mentioned she had two announcements about different grants that MassMATCH will be working on. One being a federal grant that MA received a five year grant to do focus work on young people who are transitioning to employment, called transition pathway services. It will be in three working parts of the state including three ILC’s, three VR offices and MassMATCH. They will be partnering together to make sure that the participants get all the information about AT and about MassMATCH programs. The second grant she mentioned is, MassMATCH will be getting a grant from the Executive Office of Elder Affairs.

## This is to provide two levels of training to people who are working in the no wrong door system, at Independent Living Centers, aging service access points, councils on aging, other service providers throughout Massachusetts. Basic level training on assistive technology, what it is, where you can get it, funding sources, and so forth. The more intensive training related to the tackle tool, which is a tool that is used to identify what sort of assistive technology somebody needs to help them transition from an institution into the community. This is a two‑year project to basically make sure that staff in the community organizations are very well aware of assistive technology resources.

The meeting adjourned at approximately 2:45 PM.