**MASSACHUSETTS RARE DISEASE ADVISORY COUNCIL (RDAC)**

Thursday, September 21, 2023, 9:00-11:00 AM

Meeting Minutes

*Approved 11.16.23*

**Dr. Dylan Tierney welcomed all the meeting.**

He began by introducing two new members to the council.

**Gail Ryan**, PharmD who will be replacing Dr. Michael Sherman and completing his term. He also introduced **Yue Huang,** Senior Analyst for Research and Cost Trends at the Massachusetts Health Policy Commission, who will be replacing Celia Segel and completing her term.

**D. Tierney conducted roll call to establish a quorum**

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| --- | --- | --- |
|  | **Council Member** | **Present** |
| 1 | Charlotte M. Boney, M.D | NO |
| 2 |  Janis Creedon  | NO |
| 3 | Lisa Deck  | X |
| 4 | Andrew A. Dwyer, PhD, FNP-BC, FNAP, FAAN | X |
| 5 | Senator Paul R Feeney (Maya Robinovitz) | X |
| 6 |  Julie D. Gortze, RN  | X |
| 7 | Guadalupe Hayes-Mota, MBA, MS, MPA  | X |
| 8 | Lena Joseph, RN, CPN | X |
| 9 | Representative Hannah Kane (Kerry Shea) | X |
| 10 | Andrew A. Lane, MD, PhD | X |
| 11 | Representative Jay Livingstone  | X |
| 12 |  Jeff R. Livingstone, PhD | NO |
| 13 | Diane Lucente, MS, LCGC | X |
| 14 | Alexsandra B. Mahady  | X |
| 15 | Jenn McNary | X |
| 16 | David T. Miller, MD, PhD | X |
| 17 | Tai Pasquini, PhD, MPA (Sen. Bruce Tarr)  | NO |
| 18 | Shivang Patel, Pharm.D.  | X |
| 19 | Asma Rashid, MS, CGC  | X |
| 20 | Michele Rhee, MBA, MPH | NO |
| 21 | Robert E. Schultz, MBA | NO |
| 22 | Yue Huang | X |
| 23 | Gail Ryan, PharmD | X |
| 24 | Glenda E. Thomas  | X |
| 25 | Ryan Thompson, MD, MPH | X |
| 26 | Dylan Tierney, MD, MPH | X |
| 27 | Ann Wessel, MS, RD, LDN  | X |
| 28 |  Ross Zafonte, DO | NO |

Quorum established. The meeting was called to order at 9:11am

**D Tierney** asked if all received the minutes from the last meeting on July 20th, 2023? He then asked if there were any corrections or edits. No response. He then asked for a motion to accept the minutes as presented.

**D Miller** made a motion to accept the minutes from 7.20.23 meeting.

**L Deck** seconded.

Roll Call vote was taken by **D. Tierney**

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| --- | --- | --- |
|  | **Council Member** | **Approved** |
| 1 | Charlotte M. Boney, M.D | NA |
| 2 |  Janis Creedon  | NA |
| 3 | Lisa Deck  | Yes |
| 4 | Andrew A. Dwyer, PhD, FNP-BC, FNAP, FAAN | Yes |
| 5 | Senator Paul R Feeney (Maya Robinovitz) | Yes |
| 6 |  Julie D. Gortze, RN  | Yes |
| 7 | Guadalupe Hayes-Mota, MBA, MS, MPA  | Yes |
| 8 | Lena Joseph, RN, CPN | Yes |
| 9 | Representative Hannah Kane (Kerry Shea) | NA |
| 10 | Andrew A. Lane, MD, PhD | Yes |
| 11 | Representative Jay Livingstone  | Yes |
| 12 |  Jeff R. Livingstone, PhD | NA |
| 13 | Diane Lucente, MS, LCGC | Yes |
| 14 | Alexsandra B. Mahady  | Yes |
| 15 | Jenn McNary | Yes |
| 16 | David T. Miller, MD, PhD | Yes |
| 17 | Tai Pasquini, PhD, MPA (Sen. Bruce Tarr)  | NA |
| 18 | Shivang Patel, Pharm.D.  | Yes |
| 19 | Asma Rashid, MS, CGC  | Yes |
| 20 | Michele Rhee, MBA, MPH | NA |
| 21 | Robert E. Schultz, MBA | NA |
| 22 | Yue Huang | abstained |
| 23 | Gail Ryan, PharmD | abstained |
| 24 | Glenda E. Thomas  | Yes |
| 25 | Ryan Thompson, MD, MPH | Yes |
| 26 | Dylan Tierney, MD, MPH | Yes |
| 27 | Ann Wessel, MS, RD, LDN  | Yes |
| 28 |  Ross Zafonte, DO | NA |

**Dr. Tierney** spoke to the group about the agenda stating that we usually have a speaker with a rare disease but today we would be having a speaker to help us understand some of the challenges of accessing social supports and resources for those with a rare disease. He introduced, **Pamela Chamorro, MSW, LICSW** the Director of Social Services as Boston Children’s Hospital (BCH) where she provides leadership to over 200 Masters level clinicians located throughout the hospital's inpatient, ambulatory and satellite locations.

Pam thanked the council for having her and offered to help in any way needed going forward. She began by stating that access to social supports and services is priority for BCH. She stated that the hospital has recently made the social determinants of health a priority for BCH. The hospital realizes that providing this kind of support to their patients and families will be necessary for their patients to be successful in their treatment plans. We need to understand what the families are facing and partner with them to support their primary and secondary providers. BCH is a tertiary facility and many families are not from the area so providing support for the social determinants of health needs to be a critical part of our treatment plan. There are social workers throughout the hospital system but there is a lot of inequity. Getting access to social work services is the first step but all patients in the hospital do not get access to social services. We have case managers who help with durable medical equipment, but social work is needed to help with social supports.

The most frequently needed resources include meals, transportation, parking, gas, time of work, and childcare, and other needs often cannot always be addressed.

Health literacy is the other critical issue. There are huge gaps in health literacy among patients and families. For patients with a rare disease, it becomes a much bigger problem. Most rare diseases involve unique terms and descriptions. We need to do a better job at improving health literacy among all, especially for those with a rare disease.

We have to realize that when patients and families come to BCH their house is usually “on fire” (not literally but it’s a synonym for the situation) Our job at the social work department at BCH is to provide a hose to put out the fire. This is often very challenging and frustrating for our staff.

**D Tierney** thanked Pam for her thoughtful words and asked How patients access social services at BCH.

**P Chamarro** stated that having access to social services gives greater access to social services and supports but not everyone gets access to social services. She added that some departments like Cystic Fibrosis, Sickle Cell, and Primary Care all have access to social services because they fund a position. A department needs to fund the position of a social worker in order to have access to social service. We know this creates inequities and we are working on it but this is the way it is now. One example is the genetics department which sees a lot of rare disease patients, they do not have access to social work services.

**J McNary** asked about transitional care. What resources are available for those that age out of BCH care and move to adult care?

**P Chamarro** stated that transitional care has been identified as a challenge. We acknowledge that we do not do this well. We do have a program that supports transitional care called the Bridges Program but it continues to be a challenge. As for home care, we need to do better. In January, there will be a new requirement by the Joint Commission to reduce health care disparities. These requirements will have new elements of performance to address health care disparities.

We also have workforce issues. We need to increase the pipeline for this workforce. We need to think of creative ways to encourage people to go into this field.

**G Thomas** asked what BCH does when the patient or family doesn’t speak English as their primary language. She continued by stating that giving a resource phone number is great but what if the message on the other end of the line is in English? Then what?

**P Chamarro** stated that she sees language and cultural integration is critical to the future of healthcare at BCH.

**G Ryan** asked where the resources come from.

**P Chamarro** stated that we often refer clients and families to 211. She added that BCH is privileged to have a philanthropic fund that can be used for extenuating circumstances. Other hospitals often do not have this type of fund.

**G Ryan** followed up by saying that the payer side sees social determinants of health as an issue also.

**Y Huang** asked how social work was reimbursed.

**P Chamarro** stated that most social workers were employees of the hospital and they did not get involed with billing issues.

**D Tierney** thanked Pam for her thoughtful conversation and said that this conversation continues to remind us about equity in healthcare. He added that this was a good reminder for all of us and that as we look toward the next speaker, we need to think about the social services and resources that will be most impactful for those with a rare disease. He then introduced **Barbara L’Italien,** the Executive Director of the Disability Law Center.He added that Barbara has served as a State Representative and a State Senator and is well-versed in the legislative processes. He stated that she was also the author of the Autism Report from the Autism Commission, which was quite instrumental is changing laws and policies for those with Autism. He stated that she was here to talk with us about things to consider as we look toward writing our annual report, including recommendations to the governor, state legislature, and state agencies.

**B L’Italien** began by thanking the RDAC for asking her to speak. She started by saying that she was elected to the House of Representatives in 2003. She was the mother of an autistic son and knew that she wanted to make a difference in the lives of those with Autism. She began by cultivating relationships in the legislature. It took almost seven years to do the groundwork. As a legislator, she was able to write the enabling legislation for the Autism Commission. She knew that she wanted to engage as many government agencies as possible, and she wanted to make sure that the work of the commission included all ages and all levels of the spectrum.

She stated that she thought this work would take about a year, but it took three years. In the end, they were able to bring fourteen government agencies and four legislators to the table.

It was also an emerging time for Autism. There were so many people interested in the work we were doing. We created subcommittees to engage as many people as possible. This was a time when we could only meet in person. The RDAC has the advantage of meeting by ZOOM, so it may be a great opportunity to get more people interested in your work.

She then stated that discussions with state agencies was key. The commission wanted to hear from the agencies about what they could do to help with each specific issue that was identified. She felt that it was very important to give some solutions to the problems and not just state the problems and needs in the report.

She stated that the biggest accomplishment of the commission was getting medical coverage for Autism. At the time, behavioral health interventions were not covered. Families were going bankrupt trying to provide care for their Autistic children.

Building on this success, the commission was able to come up with thirteen recommendations. Each recommendation had a least one action item. We divided our recommendations into 3 buckets.

Short term, meaning it would take at least two years to implement.

Mid-range, meaning it would take up to five years to implement.

Long range, meaning it would take up to ten years because it required substantial financial investment or structural changes to the environment.

At the beginning, we first looked at prevalence. That was the starting point. We engaged the public and got as much feedback as we could from them.

Next we developed recommendations by priority. Each recommendation included the state agency that we thought could help in the solution.

We developed a grid, <https://www.mass.gov/doc/autism-commission-report-2013/download>

that consisted of the priority, the recommendation, the entity(ies) required for the solution, what was actually required for implementation, the legislation that was or to be filed, that line item in the state budget, and the timeline for implementation (short, mid, long) with the dates.

Realizing the timing of all this was critical. There was penned up demand of change. There was a rise in Autism advocacy and the growth of Autism Speaks. There was an enormous amount of grassroots efforts underway. It really was the perfect storm.

The work of the commission ended with the sunset clause and the work still goes on but it’s very different now. We were able to make a lot of changes but there are still more to be done.

The report was released in 2013 and although much of the report has resulted in change, there is still work to be done. Eight of the thirteen recommendations have been implemented. The senate president and house speaker were critical in the success of this implementation.

She stated that it was a pleasure being part of this movement and she knows that the work resulted in some genuine improvements in the lives of those with Autism and their families.

She thanked the RDAC for asking her to speak and asked if there were any questions.

**G Ryan** thanked the speaker and asked how medical care for those with Autism has changed from then until now.

**B L’Italien** answered by saying that it mostly affected behavioral health billing. The language evolved around “medically necessary.” State agencies rebelled, saying that this would “break the bank.” The commission created a “hotline” to get input from the public about their insurance coverages for medically necessary behavioral health services. She then embarked on many discussions with the insurance world to negotiate coverages for these medically necessary services. Realizing we needed data to support our work, we were able to access state agencies to do cost analysis. Those analyses revealed that paying for this type of services would not break the bank and in fact once implemented, it did not.

**A Dwyer** thanked Barbara for her work and time to speak with the council. He then asked how the RDAC should think about what state agencies to engage. How do we know which agencies we need to get involved.

**B L’Italien** stated that it was a collective effort for the Autism Commission and it will most likely be a collective effort for the RDAC. She stated that she would think that at least the Department of Developmental Services (DDS), Department of Public Health, (DPH), and MassHealth would definitely be involved but we should maybe consider other agencies like Labor and Workforce Development (LWD). When the Autism group met, they knew they wanted to address the lifespan so they also engaged, Elder Services, the Department of Mental Health (DMH), Department of Elementary and Secondary Education (DESE), Massachusetts Rehabilitation Commission (MRC), DMH and DDS. During the discussions, DMH didn’t think they should be involved. Mostly because they didn’t understand Autism. They didn’t’ think they knew anything about Autism. There were many tensions between DMH and DDS but working together was critical to the success of implementation.

**J McNary** stated that although the RDAC is in its infancy, is planning on following this path so that is encouraging. She asked for advice on how to prioritize the recommendations of the RDAC. How does the RDAC figure out which recommendations will have the greatest impact?

**B L’Italien** answered by saying that it is not easy. With so many people involved it is hard to figure out the highest priority. The decided to select the recommendations that were most important to the people. We identified thirteen. Then we looked at feasibility of implementation. What was the effort to implement the recommendation? With my legislative lens I was able to provide insight into the effort to implement. She said she would recommend having some public sessions to gain input from the public. She also recommended no more than ten recommendations.

**A Rashid** added that she was a geneticist and wanted Barbara to know that she has seen an impact on the laws that have been implemented. She stated that the work of the commission has made a difference.

**D Tierney then** asked if there were any other questions or comments. No response so he thanked Barbara for her thoughtful presentation. He stated that it gave us much to think about and set a high bar for the RDAC. He then proceeded to discuss the next item on the agenda.

**The VIRTUAL TOWN HALL date has been set for SATURDAY, OCTOBER 21ST.** He stated that the RDAC wants to create a forum to gather information from the public. We decided on virtual for many reasons, but mostly, it would hopefully make it easier for people to participate. The purpose of this session is to gather information about who the stakeholders are and to better understand the resources available and not available for those with a rare disease living in Massachusetts. He stated that although we have some more work to do on the logistics, we have a tentative agenda. The session would begin with some opening remarks (maybe from a legislator) followed by a summary of the RDAC and its work to date. Followed by public input. The two questions that will help us gather the information we need are;

* What resources are working well?
* What resources are not working or not available?

We are thinking that we would give everyone about 3 minutes to give their response to these questions. We were thinking that we would have a registration that included their testimony (answer to these questions). This way, we can query the responses and try to get the most diverse types of responses. He also added thathe spoke with the DPH communications team about how to market our event and they suggested using our website. We should put all information about the event on our website and drive everyone there. He asked if there were any questions.

**G Thomas** asked when the registrations would be ready. She added that she would not be able to attend as she would be attending another rare disease conference.

**J Gortze** added that there was a Rare New England event that day also.

**J McNary** added that we would need to let people know that they could submit testimony without be present.

**D Tierney** asked if we should change the date as there were a few conflicting events that same day. He asked if the following Saturday was better (October 28, 2023)

**Several people responded in chat stating that the 28th was a better day.**

**D Tierney** stated that he would check with the IT team to see if we could change the date to 10.28.23 and get back to all asap.

He stated that we should move on to the next item on the agenda. Workgroup 1. He handed the meeting to D Miller, chair of workgroup 1.

**D Miller** stated that all received the final version of the prevalence paper. After incorporating the edits and comments received, the white paper has been finalized. He stated that he would like to give a special thank you to the primary authors of the paper before asking for a motion to approved the paper so that it could be distributed and included in our annual report.

He thanked **T Pasquini** for he leadership and heavy lifting in the writing of this report. He also thanked **A Dwyer**, **A Lane,** and **D Tierney** for the work to finalize the paper. He then asked for a motion to approve the paper as presented.

**A Dwyer** made a motion to vote on the paper. **J McNary** seconded.

**D Tierney** conducted a roll call vote to approve the prevalence paper as presented.

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|  | **Council Member** | **Accept** |
| 1 | Charlotte M. Boney, M.D | NA |
| 2 |  Janis Creedon  | NA |
| 3 | Lisa Deck  | NA |
| 4 | Andrew A. Dwyer, PhD, FNP-BC, FNAP, FAAN | X |
| 5 | Senator Paul R Feeney | X |
| 6 |  Julie D. Gortze, RN  | X |
| 7 | Guadalupe Hayes-Mota, MBA, MS, MPA  | X |
| 8 | Lena Joseph, RN, CPN | X |
| 9 | Representative Hannah Kane  | NA |
| 10 | Andrew A. Lane, MD, PhD | X |
| 11 | Representative Jay Livingstone  | X |
| 12 |  Jeff R. Livingstone, PhD | NA |
| 13 | Diane Lucente, MS, LCGC | X |
| 14 | Alexsandra B. Mahady  | X |
| 15 | Jenn McNary | X |
| 16 | David T. Miller, MD, PhD | X |
| 17 | Tai Pasquini, PhD, MPA (Sen. Bruce Tarr)  | NA |
| 18 | Shivang Patel, Pharm.D.  | X |
| 19 | Asma Rashid, MS, CGC  | X |
| 20 | Michele Rhee, MBA, MPH | NA |
| 21 | Robert E. Schultz, MBA | NA |
| 22 | Yue Huang | X |
| 23 | Gail Ryan, PharmD | X |
| 24 | Glenda E. Thomas  | X |
| 25 | Ryan Thompson, MD, MPH | X |
| 26 | Dylan Tierney, MD, MPH | X |
| 27 | Ann Wessel, MS, RD, LDN  | X |
| 28 |  Ross Zafonte, DO | NA |

**D Tierney** then called on Workgroups 2 & 3 for an update on their survey tool.

**J McNary, W2 Chair,** added that all should have received the final version of the survey tool [tinyurl.com/RDACMA](https://urldefense.com/v3/__http%3A/tinyurl.com/RDACMA__;!!CPANwP4y!Rg3q-Fgw5eZdrJpKyQ946uv2FQB_oqXY_I3bBA0Lo3yaMMY6t8bNzgr4d6VgH2v6kHrX4_O6h-V6fTL_8GupjF7pBftKya8$)

She thanked **Shivang Patel** for all his work on this survey tool. He has done most of the heavy lifting. She reiterated that the purpose of the survey was too gather information on who we need to engage with and gather as much information as we can about the resources that are available and the resources that are in greatest need. She asked if the group was ok to move forward an send out the survey?

**G Hayes-Mota** asked what we were doing about other languages.

**J McNary** stated that the workgroup discussed this but didn’t know how to proceed. No one knew how to get the survey translated. She then asked the council if anyone knew how to get the survey translated or had any other thoughts on gathering information from those who do not speak English as a primary language.

**G Hayes-Mota** stated that he would be happy to translate the survey into Spanish.

**G Thomas** then asked about analyzing the responses. She asked how we would deal with responses in another language.

**G Hayes-Mota** added that this could be an issue.

**S Patel** added that the tool he used to develop the survey had an option to translate. He could select the language for translation and the program would do the translation.

**J McNary** thought that was a great idea and added that we could launch the survey now rather than wait for another meeting. Time is precious. She suggested starting in English and then updating in Spanish later.

**S Patel** added that he could do that at any time but would have to inactivate the link while working on it. He suggested adding the new languages in the middle of the night for the least disruption.

**J Gortze** added that in the past, RNE has not had good luck gathering information by survey tools. She wasn’t sure how good of a response we would get.

**A Dwyer** added in the chat that the 4 top languages in Massachusetts are English, Spanish, Portuguese, and Chinese.

**Y Huang** offered to translate it into Chinese.

**D Tierney** asked if all were ok to move forward with this plan:

Launch the current survey in English and follow up as soon as possible with Spanish, Portuguese, and Chinese versions. All agreed.

He then stated that it was 11:00, and was there was a motion to adjourn.

D Miller made a motion to adjourn

A Dwyer seconded

D Tierney adjourned the meeting at 11:02 after stating that the next **FULL COUNCIL MEETING was on November 16th, 2023, 9:00 am – 11:00 am**

**Workgroup 2 & 3 update – Jen McNary, W2 Chair**

**Discussion of Final Survey Tool, marketing, and outreach**

**10:50 – 10:55 ANNOUNCEMENTS**

Discuss town hall if time permits.

**NEXT FULL COUNCIL MEETING: September 21st, 2023, 9:00 am – 11:00 am**

Ask for a motion to adjourn.

Repeat the name of the person who makes the motion and the person who makes the second.

Ask all if they agree to adjourn.

**Adjourn** – State time meeting is adjourned for the minutes.