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

**Workgroup 3 Subcommittee Meeting**

Monday, June 5th, 2023

10:00 AM – 11:00 PM

**Meeting Minutes – Approved August 7, 2023**

**REMOTE MEETING:**

https://us06web.zoom.us/j/86192819030?pwd=UE9SVVg5ZTViY3BmRGoyT3VGWWUzUT09

**Welcome**

**L Joseph (chair)** welcomed all to the meeting at 10:05.

**L Joseph** then conducted Roll Call for attendance.

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| **Workgroup member** | **Present** |
| **Lena Joseph** | **X** |
| **Glenda Thomas** | **X** |
| **Shivang Patel** | **X** |
| **Jenn McNary** | **X** |
| **Charlotte Boney** | **X** |
| **Hannah Kane** | **X** |
| **Robert Schultz** | **-** |
| **Asma Rashid** | **X** |
| **Paul Feeney** | **X** |

**Also in attendance, D. Tierney.** Chair of the RDAC.

**L Joseph** then asked if all received the minutes from the last workgroup meeting on April 3rd. All responded affirmatively. She then asked if anyone had any edits or revisions. No one responded. So she asked for a motion to conduct a roll call vote to accept the minutes as presented.

**Rep Kane** made a motion. **G Thomas** seconded the motion.

**Roll call** vote was conducted by **L Joseph**

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| **Workgroup member** | **Approved** |
| **Lena Joseph** | **X** |
| **Glenda Thomas** | **X** |
| **Shivang Patel** | **X** |
| **Jenn McNary** | **X** |
| **Charlotte Boney** | **X** |
| **Hannah Kane** | **X** |
| **Robert Schultz** | **-** |
| **Asma Rashid** | **X** |
| **Paul Feeney** | **X** |

**L Joseph** stated that the minutes were approved as presented. She then asked **S Patel** if he was able to share his progress on the survey tool as he was the primary creator of the tool.

**S Patel** shared his screen with the group and walked through the survey as completed so far. He stated that Workgroup 2 and Workgroup 3 have worked together to create a single survey to accomplish the data-gathering goals of both groups. He created the survey based on the questions presented to him by workgroups 2 and 3 chairs.

He walked through the survey tool, explaining that there were 2 sections. Section one was related to the questions from workgroup 3, and section two would address the questions from workgroup 2. He asked if the explanation for each survey was ok

**J McNary** asked if there could be another question added to survey 2. She asked if there could be a section for comment under the resource section so the participant could add information about how useful or not the resource was.

**G Thomas** asked how we planned to get the survey out. How would we get people to complete the survey, and who would we send it to?

**L Joseph** suggested that we create an introductory paragraph to explain the survey and we could include that with the link to the survey.

**G Thomas** stated that she thinks it is important for people to know why they should complete the survey. She suggested reaching out to NORD and other advocacy groups to see if they would send the survey to their lists.

**L Joseph** asked if we should send it to only local organizations or to national ones also.

**D Tierney** added that as the group reviews the data that comes back from the survey, someone may need to sort it by local and national information.

**L Joseph** stated that the group hasn’t really discussed how they would organize and update the information. If we collect all this information, we know that it needs ongoing updating.

**D Tierney** asked what the end goal was for the group. What is the outcome the group is looking for? He also stated that it was possible for the workgroup to come back with a recommendation that the state form an office of rare disease, and that office would be responsible for maintaining and updating the list of stakeholders and resources for the rare disease community.

**J McNary** added that she knows this is a daunting task. She received a resource directory URL for a person that lists and maintains resources in Massachusetts for those who are disabled. She stated that she tried using the list last week, and several of the resources were either not available or the information was not correct. The person maintaining this list does it regularly, so we know this is a lot of work.

As a parent looking for resources, it’s often more frustrating to get hope that there is a resource only to find out it isn’t available or the information is inaccurate.

**L Joseph** agreed that this would be very frustrating for patients and families.

**J McNary** stated that she also thought that we could prioritize the resources to identify the ones that are in the greatest need.

**D Tierney** added that it would be important to know the resources that were in greatest need. He also thought that it would be important to get information from the public about this. How do we hear from the public about the needs that are not available or difficult to access.

**J McNary** asked if we should ask a question to the survey that asked about the greatest need? For example, it is housing, personal care, etc.

**D Tierney** added that this may be important to understand the needs of the rare community in Massachusetts.

**G Thomas** asked if we should ask about legislative bills affecting some of these resources so that the RDAC can review them.

**J McNary** added that she just met with a legislator about some legislation related to resources, which would be important for us to consider.

**L Joseph** asked the group if they thought about a timeline for getting this survey out and collecting the responses. Should we give people at least a month or two so we get more responses?

**Rep Kane** suggested that a shorter timeline may be better. Sometimes when you give people too much time, they put it aside and then forget about it. Should we put it out to the workgroups for feedback and then send it to the full council for beta testing before we send it out to the general public?

**G Thomas** asked how we would get it out. Who are we sending it to?

**L Joseph** stated that she thought that we might need to rely on word of mouth or ask advocacy groups to send it to their membership.

**G Thomas** recommended that we start working on a distribution list. Maybe we could contact NORD and Every Life Foundation to see if they will send it out.

**S Patel** added that we could use social media to get the word out too. We could create a QR code that links to the survey. We could create a flyer for hospitals and other social networking groups. The flyer would have a QR code so people could link directly to the survey. He also thought that the group could work on a distribution list in google docs.

He then asked how he would get feedback on edits to the survey. He asked if the introduction needed to be modified. Should the title of the survey tool be worded differently? If people want to complete both surveys, I can add a thank you at the end with some language that asks them to complete the other survey.

**G Thomas** asked how people can respond with information on different resources. Under resource type, can we add all?

**S Patel** stated that he could add all to the list.

**L Joseph** asked if anyone had any additional thoughts about the survey tool.

**G Thomas** asked if the group could review the survey before finalizing it. And where should we send comments?

**L Joseph** stated that Mary Lou would send the survey to both workgroups for feedback before finalizing.

**G Thomas** asked about the timeline. What is the timeline for feedback?

**L Joseph** stated that the timeline should be as follows:

1. Send the survey tool to both workgroups, asking for feedback by June 23rd
2. Jen and Lena will draft an introduction paragraph that will go out with the survey link
3. Jen and Lena will review the feedback from their workgroup and get any edits or revisions to Shivang by June 30th.
4. Shivang will make edits and finalize the survey by July 13th
5. Mary Lou will send the final survey tool to the full council on July 17th.
6. The full council will beta test the survey.

**A Rashid** asked if the Google doc with the stakeholder list was still available to the group.

**L Joseph** stated that it was. People could add to this list, and we could use it as our distribution list for the survey. That way, we know if it has already been sent to a group, hospital etc.

She then stated that we were at the end of our meeting. Was there anyone to make a motion to adjourn?

**Rep Kane** made a motion to adjourn. **G Thomas** seconded the motion

All agreed to adjourn.

**L Joseph** adjourned the meeting at 11:00 am