

**Draft Meeting Minutes
Rare Disease Committee
December 15, 2023, 2-4 pm**

Attendees: Ann Alley (electronic), Michael Busk (electronic)**, Michael Busk (electronic)**, Mindy Cameron (electronic) **, Guy Crowder, Wade Clapp**, (Aaron) Joel Feldman**, Julie Gries, Tara Jellison**, Kendra Harper (electronic), Meghan Leaird**(electronic), Kristi Linson (electronic), Laura McLinn**, Patric Mulligan, Lucy Paskus** (electronic), Satiago Schnell** (electronic) , Jodi Skiles (electronic)** , Robyn Spoon (electronic), Nancy Swigonski, Ty Sullivan**, Jake Torrie; Courtney (did not note her last name. Concerned citizen) **denotes voting privileges

Meeting minutes for the November meeting were approved. Meeting minutes from the October meeting were approved with requested revisions.

Bylaws were approved unanimously by voting members present. Meghann Leird abstained. (Dr. Schnell was not online at the time of voting.) In accordance with electronic policy, these were voted on by roll call.

Presentation from Dr. (Jeremy) Ty Sullivan on Indiana Medicaid. (Slides attached.) Medicaid is a state and federal partnership. Medicaid is 18% of the State budget and makes up 84% of the FSSA budget. FSSA division include:

- Aging
- Disability and Rehab services
- Disabilities
- Disability Determination Bureau
- Early Childhood and Out of School Learning
- Family Resources
- Indiana 211
- Medicaid
- Mental Health and Addiction

Around 2 million Hoosiers are enrolled in Medicaid which is about 20% of Indiana's population. Pathways is expected to go live in 2024 and will impact waivers. There was quite a bit of conversation about the waivers. There will be changes because of this. Waitlists were discussed. It is likely that the waitlist timelines are driven by timelines. Dr. Sullivan will ask internally about what increases the waiver timelines and why disability for specific conditions is not an automatic qualifier for Medicaid. The Medicaid waiver is fee for service/ "the good kind" of Medicaid.

Committee members believe that it would be helpful to explore to recommend automatic determinations based on commission.

Also, committee members mentioned how difficult the process is and wanted to discuss recommendations that could simplify the process and professional/parent education. Costs,

budgetary constraints and legislative considerations for proposing increases in coverage (i.e. budget years are only every other year) need to be considered. Committee members discussed that these are costly and would require additional funds.

It was requested that DDARS and Disability Determination be brought in to speak to the group. It was also requested that Medicaid as a secondary coverage be reviewed in another meeting.

Dr. Swigonski led the survey discussion. Dr. Swigonski was discussed the importance of finding "burning questions" that could be translated into policy and recommendations. (Dr. Swigonski's slides are attached.) The survey, even if the questions seem already known, it provides quantifiable information for stakeholders and legislators. Dr. Swigonski provided an overview of various Indiana "report cards" and other states had done in making recommendations. (i.e. research, genome sequencing, quality of life, delayed diagnosis, economic impact.)

At this time, the survey was specific to pediatric cancer with the intention of future survey expansion. It was discussed that there would be some items that were compatible across conditions. A request was made to circulate the survey beyond just Indiana hospitals since patients especially along the borders often travel to other states.

Some questions in the survey will be pediatric cancer specific but some will relate to commonalities across pediatric cancer and other rare disease. Committee members had quite a bit of discussion about whether or not to continue in this manner. It was discussed that rare disease includes adults as well. Again, the mission of the RDAC is expansive. This year it will survey around pediatric cancer, which has lifetime impact, but the committee will continue to cover other areas. Of note, being too broad makes it concrete policies and recommendations difficult to craft, recommend and fund.

Dr. Swigonski led a brainstorming session on questionnaire development on pediatric rare disease. A request was made to not "boil the ocean" in this survey. The committee will need to pare this questionnaire down after this generation. Members urged the group to consider timelines; legislative sessions; (and not discussed, staff support availability.) Rare disease is too big to address all at once and committees will need to focus on smaller parts of it. It was discussed that the questions generated could retained and even if weren't use it for this survey, that the RDAC might use in the future.

It was suggested that the group would also use Medicaid data to "mine" for additional information. Dr. Schnell mentioned that his team at Notre Dame could support analysis of this data and possibly the all payer data base.

The Committee wants to make recommendations about waivers. Group wants to recommend that Indiana is aligned with RUSP alignment. Group wants to further discuss copay accumulators and how we might ban that in the future. It was suggested that RDAC members be called for expert testimony DRPT (this is what Medicaid uses to determine coverage.)

Mindy Cameron wants to develop a policy recommendation for the committee to address copay accumulators and can coordinate this effort within the RDAC.

It was suggested that this group make a recommendation/or timeline to improve the ease of Medicaid enrollment especially for patients with rare diseases. Waivers, and the difficulties across the differing waiver processes, would be another issue that would be addressed. This may be especially pertinent to diverse populations who have other barriers. A recommendation stands to simplify the process—families need help to access the system. (Committee members notes that there have been, successful, efforts in the past to simplify Medicaid enrollment.)

A recommendation was made that this group support a resource/list/space to support access for families and individuals with rare disease. It is unclear who should be charged with this duty. The group should review what is already on 211 and see if that is a place to house this information. As part of this and other recommendations, the group wants to propose dollars to staff the RDAC committee.

By unanimous agreement, Laura McLinn was elected to serve on the Perinatal Genomics Committee within MCH. Update on the Genomics Committee will be added to the standing agenda. In accordance with electronic policies, this vote was taken by roll call from all attending members.

Partner sharing was tabled until the next meeting.

A teams site has been established for the RDAC.

Meeting adjourned at 440 pm.

Action items:

- Set up a presentation from DDARS. (Set for February 9)
- Set up a presentation from Aging. (Request has been made but not in time for January meeting.)
- Set up a presentation from Disability Determination Bureau. (Request has been made but not in time for January meeting.)
- Further discuss data mining at another meeting to pair it with qualitative data at a future meeting. (Dr. Schnell volunteered to provide support for data analysis if the data can be obtained.)
- Brainstorm a vision for the committee overall in addition to the survey work; how to communicate with legislators; and ongoing work outside the survey.
- Work on recommendations to make Indiana RUSP aligned and ban CoPay Accumulators.
- Bring in someone from 211 to assess how to add Rare Disease Resources/Discuss other ways to make resources and tools easily available for people with rare diseases.

- Three subcommittees have been established for now:
 - Survey
 - Copay accumulators
 - “Making it easier for Rare Disease Patient to enroll in Medicaid and have resources”/ 211 tab.

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