

MEDICALLY FRAGILE CASE MANAGEMENT PROGRAM
 FAB (Family Advisory Board) – Tuesday, November 5, 2024 1730 - 1830

AGENDA

| Agenda Items | Notes/Comments |
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| Zoom Link – Click here Meeting ID: 577 324 8303 Passcode: 888300 | |
| <p>MEETING ITEMS</p> <p>WelcomeVail</p> <p>Welcome Amira Rasheed, ADA Coordinator, Civil Rights Advocate, AG’s office</p> <p>Welcome Emily Fletcher, Child Life Specialist, Kids’ Resilience Garden, www.krqnm.com</p> | <p>Attendees: Amira Rasheed, Emily Fletcher, Caroline Enos, Melissa Brashear, Kirstin Horne, Laura Violante, Rebekah Deane, Linda Tabar, Christina Garcia, Vail Woodard, Ann Marie Parmenter</p> <p>-Amira, she works with the Civil Rights Division with the Attorney General’s office. Any complaints or issues can be sent to her office. Dedicated email - arasheed@nm DOJ.gov and work phone is (505) 717-3584 and work cell phone number is (505) 269-3570. The website is https://nm DOJ.gov. She is very active in the waiver programs as well and can help with applications. She is available for any ADA issues in the community.</p> <p>-Emily, she was a full-time mom prior to becoming a child life specialist she was a big advocate for her children. She is a certified child life specialist and she recently opened a private practice. She loves to help children and families with difficult situations. She is open to partner with other agencies. Child life is a field that seeks to support infants, children and teens along with their families as they face difficult circumstances. Traditionally this was in a hospital setting but there is a new movement to be in the community. Developmentally tailored diagnosis education, help with in-home procedures, medical play for patients or siblings, creative expression activities. She imagines there will be more as she better understands the needs of the medically fragile community. There is a link to her website that where suggestions and feedback can be offered. Ann Marie discusses that this is a good time that this service is discussed as the medically fragile renewal will be coming up again and possibly adding services. A question was asked about if</p> |

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Follow up on recent family events All

- Swap Meet in Farmington; Feeding, G-tube Zoom; Trunk or Treat

she can educate in schools to peers, Emily explains she has done this before and it has been helpful.

-Trunk or Treat, overall went well. 38 trunks were present, CDD Infontet, Subaru car club, CP parent association and several staff members and families. Lots of smiles and activities for the kids.

-Feeding/g-tube zoom, not a lot of participants but good information was shared. Information was added to the newsletter.

-Swap meet in Farmington, not a lot of participants but those involved were able to share supplies.

Planning for upcoming Family Engagement All

- Family Zoom Connections – Planning next few parent information sessions
 - Some ideas – fire safety presentation by ABQ Fire Marshal; Guardianship Family Panel Q&A
- Holiday Party in Albuquerque 12/7/24 2-5pm, need volunteers for set up, tear down and during event, families must RSVP, catering Olive Garden, families provide wrapped present for Santa to give to child during event

-Holiday party will be the next big family event, we do want families to participate and families will have to RSVP due to meals from Olive Garden. MFCMP will share what is needed for volunteers closer to the event.

-AMP spoke with the Fire Marshal regarding fire safety in the winter. Discussed a possible guardianship panel with parents that have gone through it. Rebekah offers that she would help with the panel. Laura offers that she has been interested in doing an equipment presentation. Two parents agree that an equipment presentation would be helpful.

-Caroline reports that she shared an ostomy support group.

-Kirstin and Rebekah discuss other issues that go along with guardianship such as SSI, ABLE accounts, savings account, etc.

-Parents are good with every other month FAB meetings and zoom presentations/connections on the off months.

-AMP asks about outside agencies attending the FAB. Kirstin feels like it is important that agencies that would be working directly with the child would be a good idea. She is unsure about MCO's state

FAB Planning for FY25 All

- Maintain every other month frequency? Handling non-family requests to attend?
- FAB updates at ACQ, next on is 12/12/24, FAB update about noon
- MFW Renewal input
- Recent parent concerns – denial of car seats by MCOs; increasing education of providers, including residents

Wrap Up Vail

ADDITIONAL IMPORTANT INFORMATION

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Next Meeting will be Tuesday, January 7, 2025 at 5:30 pm

agencies attending without a reason or agenda. Parents agree it could be helpful but they should be 'vetted' so families can be prepared for their attendance and what they would like to discuss. AMP would also like families to offer input on the agenda.

-AMP would like the FAB to think about the renewal, hot topics are: budget caps (DD waiver does not have budget caps and MF waiver does), and services that are not available because there are not providers. Kirstin discusses that the last renewal and addendums where they discussed services. Like massage. She would like to have state representatives come so FAB can ask questions. It would be nice to have some follow up and answers on things that have been approved but cannot be utilized. AMP is not sure if state reps would attend but Jen Rodriguez did state that she is open to hearing any concerns. It may be the best avenue to put it in writing as a whole from the FAB. Address it as we are addressing a new renewal what means are being taken to make this renewal look different.