



ACQ JUNE 11, 2020 ZOOM MEETING MINUTES

MEMBERS PRESENT

Veronica Chavez-Neuman, Lily Martinez, Catherine Salazar, Patrick Anaya, Virginia Lynch, Christine Barden, Stevie Bass, Lisa Blue, Daniel Ekman, Joyce Munoz, Allyson Rhatigan, Sandy Skaar, Jerry Bartley, Walt Benson, Kathleen Cates, Dan De Paula, Gabriela Ramos, Tracy Perry, Angelique Tafoya, Sandra Woodward, Laura Matthews

MEMBERS ABSENT

April Spaulding, Mark Taylor

WELCOME

Patrick Anaya, Past ACQ Co-Chair, welcomed members and guests to the meeting. ACQ members and guests introduced themselves. Marc Kolman thanked Patrick Anaya and Lecie McNees for continuing to support the ACQ and the ACQ Executive Committee until new Co-Chairs could be elected.

ELECTION of ACQ CO-CHAIRS

Letters of interest and resumes were emailed along with the meeting agenda. ***MOTION: Patrick Anaya asked for a motion to approve Daniel Ekman and Lisa Blue as ACQ Co-Chairs. Joyce Munoz seconded the motion. There were no objections and three abstentions. The motion passed.***

COVID-19 UPDATE/DIRECTOR'S UPDATE

Scott Doan thanked everyone for their continued participation and adherence to DDSD directives. Dealing with the COVID-19 pandemic and protecting the safety of all has been difficult for clients, families, guardians, service providers and DDSD. We have been under stay at home orders since March 16, 2020. The Governor has announced Phase 1 reopening plans. DDSD is maintaining the stay at home orders to protect individuals with developmental disabilities because of their underlying medical issues. The mortality rate in New Mexico is much higher and alarming for these individuals. DDSD is working to find the right balance in providing services while still keeping everyone safe. Last Friday, June 5th, DDSD held listening session with 60 participants. This first session focused on stakeholder input on how to get back to person-centered planning in a COVID world. Another session will be held on June 15th. We hope to see a vaccine available in the next 12 to 18 months.

Community day services are going to look different. DDSD will continue with some in-home day services because this has worked well for some individuals. It has not worked

well for others. We will be going back out in the community in smaller groups. Technology will be a larger, improved part of our service system. Individuals can attend clubs and event virtually. There will be a hybrid model of in-home, community and virtual services. We are working to get case managers, guardians, families and therapists back into homes. We are looking at small group day programs with an occupancy of 1 to 1 or 1 to 3.

Almost 4000 direct support staff were tested for COVID in May. DDSD would like input on the following:

- Should individuals in services be tested? Individuals have a right to refuse the testing.
- How should DDSD comply with court orders to go to the home?
- Should case managers and therapists be tested before going into homes?
- What should be the DDSD guidance on masks? Some of our individuals may not be able to tolerate wearing a mask.

DDSD will be developing a guidance document. The above questions are important and not easy to address. The June 5th listening session included discussion on DDSD services and the waivers. DDSD will issue guidance for all waivers.

Comments/Questions:

- Christy Barden – Medically Fragile does not have the same issues as the other waivers. Families and individuals are used to being at home and know how to prevent infection. Our processes are different. We have not had any individuals test positive.

Scott Doan – Thanked Christy for the helpful input. Would like to know the Medically Fragile processes so we can learn from and incorporate the infection control processes in our other services.

- Stevie Bass – Asked if the 40-hour time limit could be adjusted. Her daughter's team can only work up to 40 hours and she is running out of hours. Stevie has been exposed and is self-isolating so she cannot fill in the other hours her daughter will need.

Scott Doan – Not aware of any discussion regarding the 40-hour limit. Scott will take this issue back to the Mi Via program manager to consider options.

- Allyson Rhatigan – As a parent of a child with a developmental disability who has several medical issues, I would like to see the data you shared on the higher mortality rates for this population. The CDC general reports do not contain similar data.

Scott Doan – Our sample size is small. The SGF program has had no positive tests. The Mi Via Program has had one individual test positive and this person is doing well. 16 individuals in the DD Waiver Program have tested positive and 5 individuals have passed away. This is a 31% mortality rate. In NM, there is a 3.9 to 4% mortality rate in the general population. This is why we are working to move forward safely.

- Allyson Rhatigan – How do we safely access health care such as urine collection and blood draws for the individuals in our system who have underlying health conditions?

Scott Doan – We need surveillance testing and clear guidance on how to provide individual therapy services safely. For example, physician practices are requiring everyone to wear masks. Patients have to wait in the parking lot until their appointment time and someone comes out to get them.

- Stevie Bass – My daughter requires 24/7 care. She has 5 caregivers and me. My daughter's home is clean and she is not exposed to anyone but us. We are all using clear safety precautions to maintain her health. She has adapted well to the stay at home orders even though she is no longer going to her 5 jobs. She walks outdoors daily and we are putting in a garden. Her care team developed a complex schedule for her that includes yoga, painting, etc. to keep her physically and mentally stimulated. In several ways she is doing better than she was before COVID. There is concern about individuals not having person centered planning but we are doing well with her. She is not suffering and she has a rich life. We live in Taos and there is a lot of open space to walk in. My main concern is running out of hours for her care team.

Scott Doan – Thanked Stevie for the update and stated he was glad to hear her daughter has such a great support system. He understands the 40-hour limitation and will discuss this with Jennifer Rodriguez.

- Gabriela Ramos– What does hybrid services mean?

Scott Doan – Hybrid services means more flexibility within our services. Some services will be in the community, some in the home, some virtual, some in a small group. There will be flexibility with group size and service location to support safety.

- Kathleen Cates – Grateful to listen and participate in the listening session on June 5th. Likes the hybrid plan as we will need to reinvent service options. Life ROOTS is doing online support and interaction. Concern about the day program retainer rate. A day program in the Metro region has closed permanently. Day programs will not be able to continue or they will be so small it will take months to get back into full service. Day programs need a subsidy. Our budgets are being approved right now and difficult to know what our budgets will be.

Scott Doan – Aware of the June 30th retainer payment deadline. These are very difficult times for all of us. The special session next week may impact DDSD funding and we

can't move forward until we know if there are budget cuts. We don't have any details on what DDS can expect from the special session.

Melanie Buenviaje– DDS has to follow CMS requirements on retainer payments.

- Angelique Tafoya – The retainer payment was not just for day hab. We also need to talk about direct services and all programs.

Scott Doan – DDS directives impact all providers. DDS is working to make good decisions.

- Angelique Tafoya –Thanked Scott Doan for his timely responses to provider questions and concerns.
- Kathy Salazar – Asked about the impact of retainer payments ending for the Mi Via Program. It took a long time to receive guidance on how to bill for Mi Via services. We need specific guidance regarding each service. A service matrix of what providers can do and when they can do it would be helpful. Please include Medically Fragile Program directives. Parents of medically fragile children have been self-isolating for years. Some programs will have to let employees go.

Scott Doan – Thanked Kathy and stated he wrote down her comments. Scott will add a line about medically fragile services in Memo 21. The challenge is to figure out how many kids in the medically fragile program have been tested.

- Christy Barden thanked Iris Clevenger and Melanie Buenviaje on their quick response to question regarding how to continue medically fragile care.
- Patrick Anaya – Asked if the plan is to test before reopening Day Hab?

Scott Doan – No final decision has been made. DOH is considering ongoing surveillance testing such as providers testing a percentage of their staff each week. DDS has to follow the Governor's and the DOH Secretary's mandates but we want feedback.

- Angelique Tafoya –Memo 19 has a telehealth component. Who has to have telehealth and what is the intention? It seems like telehealth is geared for agency run homes.

Scott Doan – The directive is for individuals in supportive living, family living, DD Waiver, etc. for DD waiver so all individuals have access to the Internet. The Internet is becoming a basic utility for all of us. The memo did address areas in New Mexico where the Internet is not available.

- Angelique Tafoya –There are so many different family living situations and there is going to be resistance. Some families are not interested in telehealth. Why make this a requirement if a family does not want to use it and they don't want to pay for Internet service?

Scott Doan – Please continue to advocate by discussing the pros and cons of Internet services with families. The decision can be made on a case by case basis. If there is an exception, follow the exception request process. You can't use the decision consultation form.

- Christy Barden – MCOs are a huge resource for needed supplies and for sheltering at home. Their staff come to our service plan meetings.

Scott Doan - Don't forget about care coordinators.

DDPC UPDATE

Daniel Ekman – We are working on a 5-year plan. We developed a paper and online community survey to obtain input to help develop the goals for the plan.

SUPPORTS WAIVER UPDATE

Jennifer Roth and Victoria Herrera reported. The Supports Waiver is on track for July 1. Thanks for the interest, ideas and work that have gone into the development of the Supports Waiver. A draft of the Supports Waiver standards is on the DDSD website. We are processing providers. In a couple of weeks, there will be targeted outreach for some services that have additional needs such as vehicle modification. We will provide live remote onboarding at the end of June and during the first part of July. Frequent operation meetings will be held. We are offering online courses and accessible modules.

Victoria Herrera – Thanked DOH for their collaborative work with HSD on the Waiver application.

- Angelique Tafoya – Asked if CARF accreditation is a requirement for the Supports Waiver.

Jennifer Roth – CARF is a requirement in our standards. Agencies have 18 months to achieve accreditation. Provider agencies will be notified by July 1 if they were accepted. We will be reviewing the CARF accreditation requirement.

- Sandy Skaar – Asked when people will be notified of their selection to the waiver.

Jennifer Roth – We are waiting on final approval from CMS. We will start mailing letters on July 1.

- Tracy Perry – Asked if everyone on the Support Waiver wait list will have a case manager.

Jennifer Roth – Case management is available once a person is on the Supports Waiver. We will be sending out 2,000 Supports Waiver offers in the first year. The community benefit portion is accessed through Centennial Care.

Melanie Buenviaje – We are working to enroll people into community benefits. HSD will work with DOH on a joint letter that will be mailed closer to July to everyone who will be offered the Supports Waiver. The letter will specify how community benefits compare to the Supports Waiver.

- Cathy Salazar – Asked how will child pend status will be handled.

Jennifer Roth – If an individual is on the DD Waiver wait list, then the individual is eligible for the Supports Waiver. If the individual is in child pend status, then the individual is not eligible for the Support Waiver.

- Cathy Salazar – Need a clear answer on the age when scores are accepted.

Jennifer Roth – Will find out and let Cathy know.

MORTALITY REVIEW COMMITTEE

Daniel Lucero and Dr. Ronald Voorhees reported using a PowerPoint presentation. The Mortality Review Committee (MRC) Annual Reports for SFY 2018 and SFY 2019 were emailed prior to the meeting. DDS reviews participant deaths in the following DOH funded programs: DD Waiver, Medically Fragile Waiver, Mi Via Waiver, FIT, and State General Fund. The Supports Waiver will be added to the mortality review process.

The goal of mortality review is to effect system change by improving the provision of care, reducing morbidity and mortality, and promoting the provision of competent and caring services and supports. Mortality review is not an investigation to find blame. It is a learning opportunity for those who provided services and supports for the person in order to improve supports and services for others. It is also an opportunity to reflect and honor the individual who died.

The mortality review process is as follows:

- DDS staff requests and collects information;
- Service and other care providers supply electronic records related to the person's health;
- Mortality Review Committee Nurse Coordinator reviews, summarizes and distributes information to the committee;
- Mortality Review Committee reviews case, identifies issues and makes recommendations at the individual, provider and system level.

Physicians review the deaths of Jackson Class members. 2/3 of deaths are people on the traditional DD Waiver. In 2018, the committee reviewed 55 deaths. In 2019, the committee reviewed 39 deaths.

The committee wants to learn if actions could have been taken to prevent the death, provide more effective treatment, or provide a better quality of life. The four big questions that are asked are:

- Was there a better way to recognize the issue?
- Was there a better way to plan?
- Was there a better way to act?
- Was there a better way to communicate?

Overall findings identified by the committee can be at the provider or the system level. A mortality review may also contain commendation for exemplary care by the provider.

Comments/Questions:

- Lisa Blue - Our son is an adult. It is a challenge to go from a pediatrician to a physician who treats adults. It took us 2 years to find a doctor who would treat my son like an adult. I am doing my dissertation on this issue. Families as Faculty helps 3rd year medical students learn about individuals with disabilities.
- Cathy Salazar – Medical students don't always realize why they go through the Families as Faculty program. We need to help medical students understand that disability will be part of their practice no matter what their area of expertise is. Disability is part of life. Families as Faculty consists of a stable group of families whose children have a wide range of disabilities. We only utilize families in the Metro area. Medical students participate in a 30-minute orientation, a 2-hour visit with a family, and a 90- minute wrap-up.
- Lisa Blue – Our son is non-verbal. Medical students are focused on passing their boards. It is a systemic problem because there is nothing in the boards about disability. Some people with disabilities who are in their 40s are still going to their pediatrician. It is a big problem when they need emergency care.
- Cathy Salazar – Our adopted daughter went through the mortality review process. As her parents, we were sad but grateful to have the information to help us understand why and how she died.
- Allyson Rhatigan – Asked what can parents do to help their children if they contract COVID.

Dr. Voorhees – We don't have a vaccine yet so the key is prevention for this very vulnerable population. Prevention includes staying home, wearing masks, social distancing, and staff not working when they are ill. Reopening has to be very carefully implemented.

Scott Doan – Agreed with Dr. Voorhees. NM has reached out nationally to other states to find out what they have learned and are doing differently to prevent COVID deaths.

Daniel Lucero – The Mortality Review Committee will meet to discuss COVID deaths and develop systemic recommendations that will be shared with stakeholders.

Amira Rasheed – Asked about the membership of the Mortality Review Committee. Does the committee have any parents, advocates, or self-advocates?

Daniel Lucero – The committee does not currently have any individuals from the community. The Jackson settlement stipulates the membership and guests. There is a representative from the Governor’s Commission on Disability.

Dr. Voorhees – We presented to the ACQ to obtain input from outside the mortality review process.

- Christy Barden – Who sends the letter out about the mortality review? When a child dies, a form letter from DHI goes to CYFD and to the family. Our office is copied on this letter. Families are concerned that they have been reported to CYFD. There is no reason to send this letter to families. Iris Clevenger has tried to address this issue. Medically fragile children typically don’t ever get better.

Daniel Lucero – Was not aware of the issue and will follow-up with DHI. He doesn’t know the reporting requirements to CYFD. He will research and get back to Christy.

- Cathy Salazar – Her family was reported to CYFD when her daughter died. She died of injuries she sustained when she was 4 months of age which was before we adopted her.
- Dr. Voorhees – DHI investigates and a letter is sent to the provider and guardian. The mortality review committee does not issue a letter to providers and guardians.

Daniel Lucero would like ACQ feedback on the following open recommendations:

- In FY2019, as noted also for FY2018, aspiration-related causes continue to be a significant cause of death reviewed by the Mortality Review Committee
 - Health alert related to aspiration and dementia to be revised and reissued.
 - Pneumonia project suspended due to other priorities.
 - What other actions are needed?
- Recommendation to improve the quality, coordination and communication of health care, including working with the MCOs to improve medical care for persons with I/DD. Suggestions?
- The current Decision Consultation process needs modification to ensure that adequate processes are in place that promote appropriate decision-making. Suggestions?

The Mortality Review Committee was established to be a driver of systemic change. The committee found the Decision Consultation Form did not provide adequate information. The form has draft changes. The form will come back to the ACQ for input. Daniel also requested ACQ feedback on the Annual Reports.

- Gabriella Ramos - Case managers complete the Decision Consultation Form. We are not medical people and there is only so much information we can provide. Complicated medical situations are difficult.

Daniel Lucero - Will take Gabriella's comment back to the committee.

SUBCOMMITTEE REPORTS

Policy and Quality – Chris Futey reported. The committee met yesterday and focused on reopening face to face training. Abuse, neglect and exploitation training is discussed in today's memo. The training goes on line today. It is more user friendly. Advocate videos will be utilized in DD Waiver training. All training videos are being reviewed and updated. This has been a great process. DDSD is requiring individual specific training of providers. DDSD core trainings are available. Once we reopen face to face training, we need to know how many participants should be trained to allow for social distancing and should everyone wears masks. There is a request for DDSD to develop online capacity for all training. Other states do complete online training. We are looking at a blended approach with some of the training face to face and some online. ISP meetings have improved when conducted over the web and there is an increase in family participation using web meetings. ISP checklist is used to identify when an ISP can be face to face. The Training Unit will continue to speak with internal and external stakeholders on the reopening plan.

Medically Fragile Family Advisory Board - Lori Stewart reported. The Family Advisory Board will have Jennifer Bartz apply to become an ACQ member. Once Jennifer is an ACQ member, she will provide reports. The Family Advisory Board meets monthly for 2 hours. Membership includes representatives from HSD, DDSD, MCOs, families, APS, etc. Since we have started using Zoom for our meetings, we have increased participation from other areas of the state. The Medically Fragile Waiver amendment has gone out for public comment. We are waiting on CMS approval. Medically fragile individuals are mostly served by home health aides. The current hourly rate is \$16.32 and it will go up to \$30.00 an hour. The Medically Fragile waiver expires on July 1, 2021 and renewal is in process. We will send the notice out for tribal comment in August and for public comment in September.

Employment & Community Inclusion – Casey Stone-Romero reported. The committee has not met. We need an ACQ Co-Chair. We have had inconsistent participation at many of our subcommittee meetings and we need guidance from the ACQ.

Comments/Questions regarding the Employment & Community Inclusion Committee:

- Stevie Bass – Our daughter is very involved in her employment. We need answers to questions such as: How do you find the jobs? What should a job coach ad in the newspaper look like? How do you organize the job responses and meet with the right candidates?

Casey will bring Stevie's questions back to the committee.

Patrick Anaya asked the ACQ who is interested in joining the committee.

Amira Rasheed would like to join. Casey typed her contact information in the chat box.

PUBLIC COMMENT:

Wendy Corry - Thanked DDSD for the advocacy partners group discussion on reopening. Appreciate DDSD's collaboration with providers.

Scott Doan – Thanked providers for working in partnership with DDSD.

Lourdes Vizcarra – Fully supports a separate line for the Medically Fragile Waiver. Asked if retainer payments will be made for the Medically Fragile Waiver. All physicians need training for working with individuals with intellectual and developmental disabilities.

Scott Doan – There are no plans for retainer payments for the Medically Fragile Waiver. DDSD is waiting on the results of the special session. Scott revised Memo 20 so there is a line about testing and a line for the Medically Fragile Program.

MOTION: Patrick Anaya made a motion to adjourn the meeting. Lisa Blue seconded the motion. There were no objections or abstentions. The meeting was adjourned at 12:50 pm.