

CENTER FOR DEVELOPMENT & DISABILITY CONSUMER ADVISORY BOARD

MEETING MINUTES

October 22, 2014 11:00 AM – 2:00 PM

Attendees:

CAB Community Members: Cynthia Berkheimer, Self Advocate; Randy Costales, ARC of New Mexico; Jeff Griffith, Self-Advocate; Iris Clevenger, DDS; Wendy Corry, DDS, Judy Greenfeld, Family Member; Lisa Rossignol, Family Member, Lily Martinez, Disability Rights of NM, Family Member; Marilyn Martinez, Self-Advocate and CAB Co-Chair; Jon Peterson, Self Advocate

CDD CAB Members: Marcia Moriarta, Psy.D., CDD Director and ECHSF Division Director; Tanya Baker-McCue, FCPD Division Director and CAB Co-Chair; Christina Barden, MF Division Director; Tony Cahill, DHP Division Director; Dan Wenz, CDDTS Division Director; Rhonda Bofman; FCPD Operations Manager/Facilitator/Recorder.

- Meeting called to order:** Tanya Baker-McCue opened by asking attendees to introduce themselves and describe their field of work/how they came to be affiliated with the CAB. She then introduced the new CDD Director, Marcia Moriarta. Marcia spoke at length about the responsibility of stepping into Cate McClain's shoes; about the tremendous growth the CDD had experienced in recent years; and about how the CAB could have more of a voice—both at the local level and with the national AUCD network.. She also spoke of the upcoming national meeting at AUCD, where new CAB member, Lisa Rossignol, was accepted to present on the NM Disability Story Project as well as a poster presentation on Family as Faculty research. The CDD is supporting Lisa's expenses as a CAB member and Family Leader to travel to the conference. Marcia then thanked Cate McClain for her service and dedication to the CDD and informed the Members about Cate's new role as Interim CDD Medical Director during the leadership transition period.
- Marcia opened the floor to questions anyone may have about her new role as CDD Director or anything else that may concern the CAB:**
 - **Jeff Griffith:** What would the impact be if all UCEDD's across the US were no longer in existence?
 - Marcia: Impact would be devastating. Systems could collapse given all the holes that still exist in the infrastructure of supports for the disabled.
 - **Marcia (to Members at large):** How do you think it would impact each of you?
 - (Some general comments from members about how supports have improved a lot, thanks in large part to the work of the CDD, but that more remains to be done.)
 - **Tanya (responding to member comments):** The CDD is often the organization asked to provide necessary services. The CAB is the forum designed for the

purpose of allowing members the opportunity to give us input. We will be looking for more opportunities to reach out for input.

3. **Floor opened to Marilyn Martinez to report on her advocacy work:** Marilyn spoke about her experience presenting at the Southwest Conference on Disabilities, where she gave a 40 minute presentation on her cause: *Marriage Without Penalty*. She read a letter that captured her testimony before the New Mexico Legislative Sub-Committee on Disabilities. The gist of that letter was “Persons with disabilities should be able to marry without fear of losing vital public assistance – particularly Supplemental Security Income (SSI), which imposes a reduction in benefits, effectively a penalty, on those who marry.” (A copy of the draft was distributed to members and attached)

- **Tanya Baker-McCue:** “This is a very important issue that tends to be overlooked by those not affected. The general public is probably not aware of what is happening here.”
- **Randy Costales:** “This is a tremendous letter and effort on Marilyn’s part. She has worked 14 years on it and has obtained 600 signatures. This should be taken to the national level.” He then offered to help Marilyn push it forward to D.C.
- **Jeff Griffith:** “The only thing I would suggest is that you should probably remove the reference to people marrying people of opposite sex.”
- **Christy Barden:** Expressed her appreciation to Marilyn for her efforts. “Parents of Medically Fragile children have actually divorced in order to avoid such penalties.”
- **Wendy Corry:** Suggested the language regarding Lesbian, Gay, Bisexual and Transgender (LGBT) be changed to read “marriage with their partner”.
- **Paula (Marilyn’s helper):** “Another memorial will be drafted about the issue in 2015.”
- **Lily Martinez:** This could be a Civil Rights issue.

Marilyn closed her remarks by saying that the Sub-Committee had endorsed the letter, and she will go to Santa Fe again to lobby for legislation to eliminate the marriage penalty.

- **Tanya Baker-McCue:** Thanked Marilyn for all her efforts and offered any additional support that CDD might be able to provide to help move this forward.

4. **Floor was opened to Lisa Rossignol to report on her research project “A History of Disability in New Mexico from 1940 to Present”.** She recounted her efforts to record individual accounts at a Summit she had attended, and how various groups there had separated themselves into “silos”, making it somewhat difficult to collect interviews. Lisa then also recounted some anecdotal stories she had already received and her interactions with the AUCD about her research, which they have been very supportive of; particularly the new Director, Andy Imperato. AUCD is aware of the CDD’s support of the project as well. Lisa will present about her research at the National AUCD Conference this year.

- **Tanya:** Remarked about how she has enjoyed watching Lisa work through the process and how it’s helping her bring new ideas forward about how we can better serve our constituency.

- **Marcia:** Remarked that she has also met Andy Imparato and really appreciated what he can potentially bring to the UCEDD's to help their CAB's illuminate the issues.
- **Lisa:** One of the big silos is class structures within the communities of persons with disabilities. Her research partner is a documentarian, who is getting interviewees talk more about the issues directly related to disability and less about personal interest stories that may not be of interest to others.
- **Marcia:** Remarked that it may be more difficult to reach people on an emotional level without some of those personal interest stories.

This line of discussion continued at some length, after which Marcia thanked Lisa for her voice and for pushing the envelope for change.

5. **Floor opened to Christy Barden:** Christy remarked that she had to leave early, but wanted to get the word out to everyone that the Medically Fragile Waiver is up for renewal. Hopefully, it won't be carved out of Centennial Care.

12:30 – 1:00 Break for Lunch

6. **Marcia reopened with remarks about her future vision for the CDD CAB:** She remarked that she had not done formal strategic planning until now, but felt that the CAB should be drawn into that process within six months to a year. She encouraged Members to broaden their thinking as opposed to just reporting. She then asked “How can we do more to get your input and ideas and actually implement them? Meaningful discussion that informs all would be the goal to aspire to. Sometimes we move too fast. We do not have to do everything tomorrow.”
 - **Tanya:** For me, the CAB is an integral and meaningful forum, as well as a valuable resource we may be able to cultivate. We can learn about issues from the variety of constituencies represented. We could do a better job of identifying those issues, and tap into more resources that could effectively help with them. Part of the current strategic planning within the CDD, is that the Aligning Group is now called the Senior Leadership Team. We are working with our state agency and community providers to help increase meaningful job opportunities for persons with disabilities. We've gotten input from families during that process but we could also tap into the CAB for developing some best practice ideas. There are a lot of ways in which CAB members can help us improve everything we do.
 - **Randy Costales:** Please clarify your strategic planning process as it relates to the CAB. How often do we do that and is the CAB really required? We all have enough meetings to go to. Are you getting consumer input from other directions?
 - **Tanya:** Yes, we usually hold 2 to 3 CAB meetings per year. A case in point of how the CAB can be a valuable resource is that by input from Marilyn (Martinez), we learned that we needed to choose a location for the CDD that was on a bus route. Both Marilyn and Lisa provided input today that was very informative and valuable.
 - **Lisa:** More discussion of different advocacy groups—and how they were negatively impacted by the “silo” problem. She then suggested we invite members

of each of these bodies to join the CAB. Also suggested inviting experts in other areas, such as insurance, to be guest speakers.

- **Jeff:** My sense is you guys have too many decisions for the CAB to make. Do we have the time or expertise to be involved in everything? Perhaps selective targeting of issues would be better for meetings.
- **Lily:** I would much prefer this kind of format for future meetings, even though learning about what the CDD is doing is always interesting.
- **Marilyn:** We need more issues that affect our everyday lives to discuss in future meetings. We have felt left out in the past. We want to be able to relate and be able to engage in the items under discussion.
- **Tanya:** In deference to that, we will table the reports from the directors. There are other ways we can disseminate that information.

7. **Closing Remarks - Tanya:** Thank-you to everyone who attended. All input will be taken very seriously and met with new directions—humbled, inspired and passionate responses. Also, if you think of other ideas on your way home that you would like to share, please e-mail them to me at TBaker-McCue@salud.unm.edu.

The next CAB meeting will be in a few months, at which time we will implement some of the new ideas that have been brought forward.

8. **Upcoming Events:** We will not be having the Craft Fair around the holidays this year as we have done in the past. However, we will be having a CDD Holiday Open House on Friday, December 12th, from 2:00 p.m. to 5:00 p.m. It will be formatted like a progressive meal, where you can go from floor to floor, and it will be come-and-go at your convenience.

- **Lisa:** Can you incorporate a sort of scavenger hunt on each floor with a relatively nice prize for the winners?
- **Jeff:** Also, can you put up informational placards at each department that would educate people about CDD programs as they move about?

(Both ideas were liked by Marcia and Tanya.)

Also, Autism and Other Developmental Disabilities Division is having its annual Giving Thanks Luncheon. For a donation, people can come and try several home-made soups and pies. This will be held on Monday, November 15th, from 11:00 to 1:00 in the Conference areas. This year, donations will go to support a child to attend Camp Rising Sun. (Marcia clarified that donations are optional.)

Lastly, we hope to hold a flu shot clinic as we have done for the last five years. The tentative date is November 17th, but we will have to confirm.

Final questions or comments were requested. With none forthcoming, meeting was adjourned.

Next meeting: Spring 2015 (TBA)