

Center for Development and Disability
Consumer Advisory Board Meeting Minutes
Wednesday, October 13, 2004, 1:00 - 4:00pm



Participants: Lee Bussolini, Randy Costales, Cindy Gillen, Alan Greenfeld, Judy Greenfeld, Jeffrey Griffith, Karin Fulford, Bill Hedrick, Tony Husted, Judy Liddell, Marilyn Martinez, Cate McClain, Mette Pedersen, Jon Peterson, Larry Strickland, Ivie Vigil, Rick Warden

Guests: Tony Grossman (LEND), Judi Ferdinand (LEND)

1. Welcome:

CDD Director, Dr. Cate McClain, welcomed new and returning CAB members to the meeting.

2. What's Something Important That Has Happened in Your Life Since We Last Met?

Each meeting participant introduced themselves and shared important personal and professional happenings.

3. What Will Happen at This Meeting:

Judy Liddell reviewed agenda items. (See enclosed agenda)

4. Medically Fragile Case Management Program and Other CDD News:

Dr. McClain, Judy Liddell and Mette Pedersen shared the following CDD up-dates:

- Medically Fragile Case Management Program still in critical condition. Program is currently providing case management services, despite large cut backs due to increasing deficit and inadequate State funding. Advocacy letter from CDD CAB members received by Governor Richardson and referenced in on-going negotiations with Salud programs (Loveless, Molina, Presbyterian) and State Secretaries. Positive response is expected at policy briefing to State legislator. Program staff is no longer able to provide technical assistance to the state around these issues or assist in the Waiver re-write as they have in the past.
- LINC (CDD Library) received the 2004 Blue Ribbon award from the US National Commission on Libraries and Information Science. This award recognizes LINC's outstanding efforts and impact on providing accurate, effective consumer health information; increasing awareness, outreach and training to a wide-range of individuals on consumer health related issues.
- Project Pueblo Connections received a 5 year implementation grant from the US Health and Human Services Department to continue its partnership with 5 Sandoval Pueblos, Inc. to develop infrastructure and family resources to identify and serve persons with disabilities in pueblo communities.

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- Bureau of Indian Affairs (BIA)/Office of Indian Education Programs will fund the CDD to conduct a feasibility study for collection and interpretation of student test score data across BIA funded schools in 23 states.
- BIA/Office of Indian Education Programs is also funding the CDD to develop 3 early childhood projects including the National Native American Early Childhood conference to be held in Albuquerque, November 8,9,10. Participants are expected from 60 tribes nationwide. In addition, 2 college credit courses will be developed and piloted in the Southwest for Native American educators working with young children and families. Courses will focus on early childhood special education and working with parents. For more information go to: <http://cdd.unm.edu/ec/oiep/>
- Dr. Craig Ramey, of Georgetown University, will conduct a policy and research seminar with key researchers and policy makers in New Mexico on November 8th. The discussion will focus on Native American early childhood issues.
- Project SELF (Supports for Early Learning Foundations: <http://self.unm.edu/>) provides cost efficient online training to address issues with self-regulation in infants and toddlers. The US Office of Special Education Programs funds this new project.

5. Early Childhood and Specialized Personnel Development Division Family Involvement (ECSPDD)

Mette Pedersen, ECSPDD Director, presented information on how ECSPDD involves parents and families to guide and participate in past and current activities. Mette asked for CAB member input on how ECSPDD can increase and better their methods to involve families in their BIA/Navajo Nation project. (See enclosed handout packet)

Question 1: What is your best thinking about engaging parents on the Navajo Nation?

CAB Members gave the following suggestions:

- Understanding cultural background
- Use Chapter Houses as avenues for communication and support
- STEPS to Success conference in Farmington
- Smaller conferences and more of them
- Explore distance learning such as TV links between Tuba City, AZ, Northern Arizona University in Flagstaff and Chapter Houses
- Use someone from within the Community/Chapter House to increase trust in the Chapter House
- Navajo Nation partnerships with parent coordinators
- Address transportation and childcare issues to make involvement possible
- Prevention and cultural appropriateness
 - Images
 - Disability perception
 - Get input
 - Blessing of spiritual leaders
- Sub-contracting - Navajo Nation/Diné Division of Education
 - Local leadership

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Question II: How can non-traditional Native American families best be served?

CAB Members gave the following suggestions:

- Follow the "*Families as Faculty*" model used at San Juan College in Farmington
 - meet with families with children with disabilities
- Educate educators regarding substance abuse, recovery, etc.
 - stigma associated with substance abuse
 - need for basic education
- Wrap around support for kids and parents
 - look at centralized services
- Train staff as service coordinators
- Sensitivity of educators regarding privacy, culture, and information
- Mentors who can help others
 - Who can find these mentors?
- Include fathers of children with disabilities, everyday fathers
 - How to reach, educate, include?
- Tribal leader participation
 - address with caution
- Navajo court system
 - educating judges, etc.

6. CDD's Strategic Planning

CAB members gave the following input to help guide CDD's strategic planning for the upcoming years.

State Issues

- New head of Special Education
 - Hope to continue working with schools
- Concept of Federal Law
 - Just because it is a law doesn't mean it will happen
 - Personal experience
 - Pull money where non-compliant
- New LTSD director is a parent of a child with a disability
 - Less compartmentalization of people - see whole person
 - On-going advocacy
- New Secretary of Health had a sibling with a disability
- New Secretary of Aging
- Governor's initiative about hiring people with disabilities
 - Dr. Eaton's office interested
 - Develop job alternatives
- More technical assistance needed to schools
 - Advocate for state technical assistance employees to be regionally assigned
- Potential of Family, Infant, Toddler program moving to Children, Youth and Families Department
- Robert Wood Johnson Grant to kick start self-direction

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- 211 National Information hotline almost ready for use
- On-going direct support staff turnover
 - Need for direct support
- Growing population of aging individuals
 - Cross training needed to address aging issues
- Redesign of Behavioral Health
 - Schools still don't understand behavioral health needs/services
 - Principals/administrators often not supportive

Federal Issues

- IDEA (Individuals with Disabilities Education Act) not supportive of behavioral health issues
 - Reauthorization up in the air regarding outcome
 - May be dismantled
- Marriage penalty for people with SSI/SSDI
 - Lose benefits if own property
- Outcome of national elections
- Medicaid/Medicare changes
- Section 8 services cut

7. CDD Annual Campaign

Larry Strickland, CDD Development Officer, introduced the CDD's new annual giving campaign. Larry explained how CDD employees are the first to give and how their contributions to the organization are used as leverage to encourage and entice outside financial interest. CAB members were asked for input into this process.

CAB members brought-up the following questions and comments:

- Q: Will private and/or public contributions affect efforts for federal funding?
A: Private and/or public contributions can strengthen funding efforts by providing proof to federal agencies of the community support and identification for needed services.
- Most popular opinion expressed was accountability and to distribute reporting of outcomes from private and/or public contributions. People want to see how their contributions are used and how they impact the community.

Adjournment

Cultural Issues and Disability

[Ran out of time to address this agenda item during meeting.]

The leadership division is planning to submit a proposal in December 2004 with the main goal of developing a series of web-based modules in the area of cultural competency. The

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target audience will be health care workers and educators. These modules will provide information that will hopefully lead to more positive approaches when delivering health care services. The vision of this project is to increase access to health care to many people who now feel uncomfortable when receiving health care services because of cultural differences.

Request: CAB members interested in reading parts of the proposal are invited to review and provide their input before the middle of December 2004. Readers will need to respond quickly at the time input is requested.

This project is a national effort with five other University Centers for Excellence. If funded, the project will be housed here at the CDD.

Contact Carolyn Richardson if you would like to participate or if you have any questions or comments: (505) 272-3022; CRichardson@salud.unm.edu

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