

# Center for Development and Disability Consumer Advisory Board Meeting Minutes

1:00-4:45, June 5, 2003



**Participants:** Christy Barden, Randy Costales, Alan Greenfeld, Judy Greenfeld, Johanne Guyton, Sam Howarth, Barbara Ibañez, Judy Liddell, Marilyn Martinez, Cate McClain, Evangeline McLuckie, Jon Peterson, Connie Pine-Bizzell, Carolyn Richardson, Cynthia Seyb, Phyllis Shingle, Jack Smith, Melody Smith, Judith Stevens, Cal Wright

## **Topic:**

1. **Welcome:** CDD Director, Cate McClain welcomed CAB members to the meeting.
2. **What Will Happen at This Meeting** Judy Stevens reviewed CAB member roles for each item of the agenda as well as items in each CAB member's folder (6/5/03 agenda, First Responders handout; Emergency Preparedness Coalition handout)
3. **What's Something Important That Has Happened in Your Life Since We Last Met?** Each member shared important personal and professional happenings.
4. **How CDD's Neurodevelopmental Division is Including People with Disabilities and Families** Karen (Cal) Wright received how the Neurodevelopmental Division is including... (see attached). Cab members asked the following questions and made these comments:
  - Have people with Autism attended trainings? (Jon P.) Yes, trainings are during day hours and we may have to adjust the training schedule to have more attend. (Cal)
  - Do people with Autism help to do trainings? (Jon P.) No. (Cal)
  - The "meet and greet" sessions are rewarding and positive. (Phyllis S.)
  - We have 9 different trainings scheduled for next year (2 of which will be meet and greet). (Cal)
  - What are some of the points that make (your son's) employment successful with SWAN? (Cal to Alan and Judy G.) The employer needs to have trained co-workers who are motivated and know how to work with the person. (Judy G.) Depending on the need level of person, a job coach may be needed for a time and then is faded out. (Alan G.)
  - Do the HMOs have Case Managers for people who have higher need for care? (Randy to Christy) Yes, it can be requested, there is a toll free number that is available. (Christy)
  - Do you have different parents or the same parents working with you? (Connie to Cal) Both. (Cal)
  - What are some outstanding issues for the CDD right now? (Randy to Cate)

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- There is an explosion of large numbers of people with Autism needing services resulting in a long waiting list for the Autism Clinic. The Autism Clinic is the only multi-disciplinary team in the state and many teachers aren't trained to address the issue. There is also the issue of who is going to pay for the recommended amount of services. Currently, diagnostics is not reimbursed and CDD offers it as free service. (Cate)
- Is there any entity in the state that is tracking the increase in certain type of disabilities? (Evangeline to Cate) Our population in New Mexico is small, so it's difficult to get federal funding to do studies about these issues. (Cate) There is a children's critical disease registry. Also, Carol Clericuzio, M.D. dysmorphologist can help. (Christy)
- Does Office of Sp. Ed. have info about types of disabilities and comparative data among other states? (Alan to Sam) Yes, some data. We have a culture to identify and segregate students 60% of the day or more. We are developing videos for capacity building and to influence policy-making. (Sam)

### **Open Discussion on Education**

- Issue of teacher support, proper modeling of inclusion and teacher support, lack of use of People-First language, the joy of inclusion, huge issue of resources in the state, individualized support with written plans of what to do. (Cynthia, Christy, Evangeline)
- Collaborative partnership with student, parent, schools and communities. Need for info for parents. Parent Panel. (Christy, Connie, Phyllis)
- Foster parent education and techniques for partnerships and professionals. Parent to parent, teacher-to-teacher, networking, mentoring (Evangeline, Judy G.)
- What is the CDD doing with Pre-School Networks? (Connie)
- Students who have graduated need to help train teachers. (Jon)
- Part C requires less restrictive environment; interactions with professionals needs to change; a shift in culture around expectations is needed. It's a social cultural issue in how we respond to the situation. Absolutely, in-service training is needed for teachers and administrators regarding a conceptual shift. Instead of starting with the most restrictive environment, we need to start with least restrictive environment. (Sam)
- We need a society that values people. Societal change is needed. (Johanne)
- Each person is unique and shouldn't be labeled. (Connie)
- Get multiple effective strategies happening to affect thinking (Sam).
- Celebrate successful situations and communicate it widely. (Connie, Sam)
- Recognize success in teachers through a video project and other avenues. (Sam)

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**5. How to Build and Strengthen Community for Better Lives and Emergency Preparedness**

Judy Liddell provided an overview of how the focus of emergency preparedness for people with disabilities came about at the CDD. The two handouts in the CAB packets were reviewed: 1) First Responders: Assisting People with Cognitive Disabilities developed by Judith Stevens (this is a draft, give comments to Judith by June 13, 2003 at: [jstevens@salud.unm.edu](mailto:jstevens@salud.unm.edu) or phone 272-1853); 2) Bay Area Emergency Preparedness Coalition For Seniors and People with Disabilities. Using these two handouts combined with personal experience, CAB members gave input and ideas into how to increase emergency preparedness based on these four questions:

- 1. What should a first responder know about people with disabilities?**
- 2. What organizations in your community could help first responders make sure that the needs of people with disabilities are met?**
- 3. What would be the best way to enlist their help?**
- 4. How do you let people with disabilities know about the emergency?**

These questions were applied to the following different emergency situations by CAB members partnered together:

1. **Health Emergency** (e.g. SARS – people have to be notified, aware of dangers, perhaps kept safe – quarantined)
2. **Environmental Emergency** (e.g. wild fire – people have to leave their homes, need special equipment, medications, etc.)
3. **Basic Service Emergency** (e.g. water supply is not safe to drink – people have to be notified, advised of what to do, respond to their own medical needs, etc.)

The following summary reflects the input received from the CAB member partner groups corresponding to the emergency situation:

<b>1. Health Emergency, e.g. SARS – People have to be notified, aware of dangers, perhaps kept safe (quarantined).</b>		
QUESTION	RESPONSE #1	RESPONSE #2
<b>1. What should a first responder know about people with disabilities?</b>	<ul style="list-style-type: none"> <li>▪ Medical condition</li> <li>▪ Look for identification (medical)</li> <li>▪ Quarantine</li> <li>▪ Be aware of needs of the individual and what they may need for long term</li> </ul>	<ul style="list-style-type: none"> <li>▪ Who they are</li> <li>▪ Where they are</li> <li>▪ How to communicate</li> <li>▪ What are the medical needs</li> <li>▪ Medically Fragile – notify ancillary SVCS keep CHUMS info on their person</li> </ul>

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<b>1. Health Emergency, e.g. SARS – People have to be notified, aware of dangers, perhaps kept safe (quarantined). (continued)</b>		
<b>QUESTION</b>	<b>RESPONSE #1</b>	<b>RESPONSE #2</b>
<b>2. What organizations in your community could help first responders make sure that the needs of people with disabilities are met?</b>	<ul style="list-style-type: none"> <li>▪ Public Health Office</li> <li>▪ Churches</li> <li>▪ Schools</li> <li>▪ Senior Centers</li> <li>▪ Employers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Salud programs</li> <li>▪ Preparedness - get families thinking</li> <li>▪ Churches and other community agencies that serve the particular person</li> <li>▪ Chapter houses</li> <li>▪ Neighbors</li> <li>▪ Schools</li> <li>▪ Public health office</li> </ul>
<b>3. What would be the best way to enlist their help?</b>	<ul style="list-style-type: none"> <li>▪ Training (when possible) to organizations</li> <li>▪ Designate outreach person for emergency</li> <li>▪ Make organizations aware of person with needs in the community</li> </ul>	<ul style="list-style-type: none"> <li>▪ Educate them about DD and other aspects of their condition and how to interact with that individual, explain their role as a community agency</li> </ul>
<b>4. How do you let people with disabilities know about the emergency?</b>	<ul style="list-style-type: none"> <li>▪ Communicate in any way - for understanding</li> <li>▪ Public announcements</li> <li>▪ Phone calls</li> <li>▪ Make sure all communication avenues are accessible - (disabilities are each individual – research needs to be done to decide how effective)</li> <li>▪ Medically fragile caretakers need to be aware</li> </ul>	<ul style="list-style-type: none"> <li>▪ Don't scare them - preparedness</li> <li>▪ Talk about emergencies frequently</li> <li>▪ Organize fire drills</li> <li>▪ Organize info and add new information - do reviews of different kinds of emergencies and what that means to them.</li> <li>▪ What does Quarantine mean? Some self-determination - how to participate in decisions – parents and clients</li> </ul>

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<b>2. Emergency in the environment, e.g. wild fire – people have to leave their homes, need special equipment, medications, etc.</b>	
QUESTION	RESPONSE #1
<b>1. What should a first responder know about people with disabilities?</b>	<ul style="list-style-type: none"> <li>▪ Know what equipment they use/need</li> <li>▪ How to talk to them</li> <li>▪ Organizations that can help them – services</li> <li>▪ Explain to people with disabilities what is going on – how long</li> <li>▪ More similar than different</li> <li>▪ Family/guardian info</li> </ul>
<b>2. What organizations in your community could help first responders make sure that the needs of people with disabilities are met?</b>	People First, Providers, ARC, CDD, churches, friends, PRO, Red Cross, MCH, shelters, PBDC, P&A, support groups
<b>3. What would be the best way to enlist their help?</b>	Ask, discussion groups, workshop, flyers, in-service
<b>4. How do you let people with disabilities know about the emergency?</b>	Radio and T.V. public announcements, Internet, flyers/info, use the organizations they are involved with, parents/staff, phone tree, First responders have one person specialized in disabilities, medical professionals, neighborhood networks, inform community how to help people with disabilities, educate families and self-advocates about informing EMS about their special needs

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<p><b>3. Emergency involving basic service, e.g. water supply is not safe to drink - people have to be notified, advised of what to do, respond to their own medical needs.</b></p>			
QUESTION	RESPONSE#1	RESPONSE #2	RESPONSE #3
<p><b>1. What should a first responder know about people with disabilities?</b></p>	<p>Location, Disability, What person does, Where family is / supporters, Where to get back-up supplies, whether help is needed, waivers for supplies, medical supply house, locations of generators, etc., car dealers/van loans</p>	<p>Police, fire, medical, advance training on how to communicate and how to reach them, check for special health needs, medical</p>	<p>They might have different methods of communication, know some strategies for communication such as: speak slowly, rudimentary sign, simple terms, etc.</p>
<p><b>2. What organizations in your community could help first responders make sure that the needs of people with disabilities are met?</b></p>	<p>BabyNet hotline, ARC, school, churches and religious affiliation, DVR, recreation groups, family support groups, P&amp;A, Red Cross, physicians, pharmacies, behavioral health support groups, rehabs, counselors</p>	<p>Civic groups: government employees, teachers, Red Cross, non-profits, shelters for homeless, urgent care centers, clinics/hospitals</p>	<p>Individuals with disabilities usually have people in their lives who support them e.g. family, friends, paid staff, church groups, advocacy organizations, parent groups, DD providers, case managers, schools, other volunteer groups</p>

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<p><b>3. Emergency involving basic service, e.g. water supply is not safe to drink - people have to be notified, advised of what to do, respond to their own medical needs. (continued)</b></p>			
QUESTION	RESPONSE#1	RESPONSE #2	RESPONSE #3
<p><b>3. What would be the best way to enlist their help?</b></p>	<p>Voluntary registration forms, initial personal contact, persons w/disabilities volunteer to train, community awareness weekend</p>	<p>Public service announcements - electronic and print</p>	<p>Remember that the responses from individuals with disabilities may be different or unusual e.g. hand flapping, ticks, seizures, panic attacks, etc., an example might be a young man who flaps his hands may appear threatening, please remain calm and attempt to reassure and calm the individual, plan ahead, awareness</p>
<p><b>4. How do you let people with disabilities know about the emergency?</b></p>	<p>Neighbor/partners, regular ways, air raid warning, let them know its over</p>	<p>Through natural supports i.e. - religion/friends, co-workers, teachers (get info to teachers), try to gather in public places, schools, churches</p>	<p>Individuals with disabilities may need more than just the information. They may need support in carrying out the instructions e.g. "Please show me where you keep your stored water? Let me show you how to boil your water correctly." May need help with medical needs, education</p>

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### **6. The New CAB Website**

CAB members provided the following input regarding the CAB website:

- Need availability to contribute ideas (if not able to attend upcoming meeting) online prior to meeting for all CAB members to review (i.e. discussion board)
- Change "Home" to "CAB Home" to avoid confusion with CDD Home
- Add to Member Profile: how long served on CAB, other boards and committees, resource information (willing to share with others based on experience and interest)
- Add to Welcome and Contact Us pages: If you are interested in serving on the CAB, contact us.
- Add an alphabetical listing of resource areas and CAB members to contact regarding that resource information
- Add a link titled: "Advisory Board" to the CDD Home Page side bar to link to the CAB web page
- Add a link titled: "Advisory Board" to the CDD People Page above "A to Z Directory"

### **7. Feedback About Today's Meeting**

CAB members shared the following feedback regarding the meeting:

#### **Liked about the meeting:**

- Having one area of the CDD highlighted in the meeting
- Open discussion on one topic (i.e. education)
- It was productive and was truly advisory

#### **Ideas for future meetings:**

- Prior to the meeting, let CAB know the meeting topic for open discussion
- Continued growth on mentoring other CAB members is needed
- Have different input (i.e. a consumer who went through the Autism Clinic sharing their experience with CAB)
- Go away from CAB meetings with recommendations to do something in our communities (i.e. assigned in the CAB minutes and posted on CAB website)
- Use CAB members to spread awareness about the CDD (i.e. broad message)
- Need more CAB involvement on the Strategic Direction Taskforces
- Email reminders to see CAB website for updates and information

*Minutes Prepared By:*

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**CDD Partnership Initiative**