

**DEVELOPMENTAL DISABILITIES COUNCIL OF CONTRA COSTA COUNTY
BOARD OF DIRECTORS MEETING
February 27, 2013**

Board and Liaison Members Present: Suzanne Anthony, Chair (presiding), Stephanie Chapralis, Vice Chair, Craig Rose, Ange Burnett, Ella Liggins, Karen Lingenfelter, Jim Burton, Erin Rogers, Heidi Spaulding, Josh Sullivan, Ken Talken, Joanne Nakamura, Heather Hackett, Dan Denis, Vi Ibarra, Will Sanford, Peggy Black, John Rodriguez, Staff.

Board Members Excused: Nickole Bouslog, Krista Loomis, Stephanie Meakin, Carl Tolentino, Barbara Sheehy, Diana Thomas, Caroline Ortiz, Kimberly Williams, Pamela Perls, Penny Musante, and Rocio Smith.

Guests: Ron Usac, Area Board 5; Carol Anne McCrary, Contra Costa ARC; Victoria Greenleaf, RCEB; Pam Thomas, RCEB; Melanie Fowler, Las Trampas, Inc., Ralph Supper, California Autism Foundation; Emlyn Struthers, representing Senator Mark DeSaulnier.

Welcome and Introductions-Suzanne Anthony, Chair

The meeting was called to order at 10:06 a.m. and introductions were made around the room.

- The January 2013 meeting minutes were unanimously approved (M/Craig Rose; S/Heather Hackett), with no corrections.
- There were no additions to the agenda.

Nominating Committee-Craig Rose

Ken Talken reviewed Peggy Black's qualifications as a potential Board member. She was nominated to the Board (M/Craig Rose; S/Heather Hackett) and was unanimously approved and welcomed.

Presentation: Fetal Alcohol Spectrum Disorders (FASD):

Presenter: Peggy Black, M.A.

Peggy used a PowerPoint presentation for "An Overview of the Disorder [FASD] and Applications for Working with Individuals on this Spectrum."

A distinction was made between Fetal Alcohol Syndrome (includes distinctive facial characteristics) and Fetal Alcohol Spectrum Disorders. 80% of people with FASD have normal to above intelligence, as the disorder is primarily an invisible physical disability (brain damage). It is common in 1 out of 100 births.

Highlights of the presentation:

- A "safe" amount of alcohol to drink during pregnancy is not known;
- Binge drinking is the most dangerous, as toxicity from alcohol to a developing fetus is worse than cocaine, heroin and meth combined;
- Developing cells are starved of oxygen and fail to grow, causing damage to various regions of the brain (and other organs).

Peggy described various "Red Flags" that may point to FASD:

- Poor social skills, but very outgoing;
- Very affectionate (unlike people with Autism);
- Atypical or a scattered profile on cognitive testing;

- Multiple mental health diagnoses;
- Highly inconsistent mastery of skills;
- Mother was reported to have used drugs during pregnancy;
- Failure to make progress with traditional treatment approaches;
- Adaptive functioning much lower than what a normal IQ would predict;
- Expressive language is higher than receptive language;
- Person is or has been in foster care or was adopted.

Diagnosis involves an assessment of 10 brain domains. There is no diagnostic team in the Bay Area, with the closest being in San Diego or Portland, Oregon. FASD, so far, has not been included in training for physicians, and other professionals. As a result, it is often misdiagnosed as Autism Spectrum Disorders, Bipolar Disorders, ADHD and others.

Signs of permanent brain damage may include:

- Memory problems;
- Inconsistent performance;
- Ability to repeat instructions, but inability to put them into action;
- Impulsiveness, disorganized, hyperactive;
- Inability to understand consequences;
- Sensory overload;
- Sleep disorders;
- Difficulty with transitions, and other symptoms.

Results of misdiagnosis may involve:

- Fatigue, tantrums and frustration;
- Aggression, rage;
- Substance abuse;
- Trouble with the law; jail;
- High rate of dropping out of school;
- Homelessness;
- Inability to hold a job;
- Inability to live and function independently (in spite of a normal IQ).

Peggy mentioned several good models of services for adults with FASD in Canada, with people needing an “external brain” (external support and structure). Traditional behavioral approaches do not work for people with FASD, and making adaptations to the environment and developing systems of support are critical for success (interdependence, not independence).

FASD is not recognized as a disability by SSI and due to normal IQ, a person is not eligible for Regional Center services.

When working with adults with FASD, consider:

- Sensory overload may be a factor;
- Give one direction at a time;
- This is a physical disability and a lifetime disability that needs accommodation;
- Structure and routine are helpful;
- “show me, don’t tell me”;
- Transitions may be difficult---need preparation;
- Do not punish, based on brain damage; a slower auditory pace may be needed;
- Trusting relationships are helpful;
- Visual cues may be needed (example: at work may need a “no cell phone use” picture for a reminder);
- Star charts don’t work;

- Think younger in your expectations (even though IQ is normal).

Peggy described the University of Washington as the “mother ship” of FASD research. While the information is available, she expressed frustration in that physicians and other health professionals are not trained about it. There is also a stigma attached to the parents with addiction problems and children with FASD often have addiction problems themselves. It is a real challenge to get the correct diagnosis and treatment for FASD.

Peggy was thanked for a very enlightening presentation. Peggy passed out a flyer about an upcoming speaker, Diane Malbin, MSW, in Oakland on May 24th, entitled, “FASD and Intervention”. Registration is at www.nofas-ca.org/home.htm or contact Amber at fasdiva@gmail.com or Peggy at fasdca@gmail.com

Report from Jim Burton:

Jim stated that there were not a lot of new announcements regarding the State Budget. However, there were several trailer bills that will make changes to the Lanterman Act including:

- Regional Centers contributing to co-pays that people are charged for ABA services through their own health plan----there seems to be a lot of confusion around this;
- Removing the sunset date for an annual family fee for services (\$150-\$200), which would make the fee permanent;
- Revising the process for a judicial commitment, if a person is a danger to self or others---
-Jim felt this needs to be looked at more carefully;
- Redefinition of conflict of interest for Regional Center Board members. Jim felt the language of this trailer bill needs revising, as it may severely restrict who can serve on a Regional Center Board and maybe especially difficult to implement in smaller communities.

All trailer bill language is posted on www.dds.ca.gov: Select the “Budget” tab on the right.

A budget hearing is scheduled for March 7th at 9:30 a.m., with Senator DeSaulnier serving on this committee. It is expected that there will be a lot of discussion about the concerns at Sonoma Developmental Center (safety issues). Jim reported that Harold Pitchford came out of retirement as an Interim Executive Director to help with stabilizing SDC, while active recruiting for a permanent Executive Director is occurring.

Jim also indicated that there are currently 15 or more bills in the legislature related to Autism.

At the federal level, it is not clear the direct impact of the sequestration to our service system. It is expected that education will be hit hard with cuts and it will definitely impact California’s economic recovery.

Regional Center of the East Bay has a \$23 million insufficiency of allocation and this number is holding steady. The State has not allocated all State funds at this time. The 3% increase to RCEB is resulting in new nurses being hired and 8 new case managers coming on board soon. Jim felt they were making progress in rebuilding their staff.

ARCA is sponsoring a “Grass Roots Day” in Sacramento on March 6th.

Committee Reports:

Legislative Committee: Josh Sullivan and the CAC were congratulated for an “incredible” and “outstanding” Town Hall Meeting presentation. It was agreed that it was the best one yet, completely led by consumers and families with a huge impact on the legislators and their representatives.

Will Sanford stated that there is an avalanche of at least 25 bills that have been introduced and the East Bay Legislative Committee will tackle them next week. Of note is SB946 (ABA services under private insurance) and SB391 (creating a trust fund for low-income housing). In addition, the Employment First legislation has been re-introduced.

Transition Committee: The Transition Task Force meets the 3rd Thursday of each month in the RCEB conference room and hosts interesting speakers.

The West County Transition and Special Education Resource Fair will be held April 27th at the Vista Hills Education in Richmond. There will be free entertainment, many vendors and free door prizes-----fun for the whole family!

Stephanie Chapralis and John Rodriguez both wrote letters to Joe Ovick regarding the absence of a Transition Specialist for the County Office of Education and received no response. We discussed our next steps, including calls from Senator DeSaulnier's office, the 32nd District PTA and our local County Supervisors.

Future Meetings:

- March 27th: Impact of the Affordable Care Act (ACA)
- April 24th: Advocacy: Preserving Choice (at a West County location)

Announcements:

- Will Sanford announced an Open House for Futures Explored's new Film and Media Workshop facility: March 20th, 10 am – Noon @ 2021 Las Positas Court, #147, Livermore, CA 94551 (925) 456-0255, everyone is welcome!
- John asked for 3-4 volunteers to assist with the selection of award winners for our annual banquet. The banquet will be held at the Embassy Suites in Pleasant Hill, near the BART station for easy access. It will be held during the 1st week of June and Joey Travolta is confirmed as our featured speaker.
- Senator DeSaulnier is hosting 5 upcoming events: March 16th is an Open House; there will be 4 local Town Hall Meetings on the State Budget on March 13, 14, 19, 20. John will e-mail the announcement with details of times and locations.
- Jim Burton imparted sad news of the passing of a long-time advocate for our service system, Tamara Lowery, who died at age 47.

The meeting was adjourned at 11:55 a.m.

**Our next meeting will be March 27, 2013 at:
RCEB Conference Room
2151 Salvio Street, 3rd Floor
Concord, CA
Topic: Affordable Care Act**

Respectfully submitted electronically by,

Carol Anne McCrory
Contra Costa ARC