

The Health Council of Marin

Minutes of Regular Meeting: Tuesday, May 22, 2018

Marin General Hospital

250 Bon Air Road, Larkspur Room

Greenbrae, CA 94904

Members Present: Barbara Wientjes (President), Constance Barker, Allan Blau, Sandy Ross, Claudia Schimmer, Derice Seid Tao

Members Absent: Bridget Gleason, Jennifer Rienks

Guests: Esther Blau (Marin Medical Reserve Corps), Suzanne Blau (parent of ASD young adult), Ingrid Lin (Golden Gate Regional Center), Sheraden Nicholau (Regional Manager – Bay Area Office of State Council on Developmental Disabilities), Jeremiah Oakes (Integrated Community Services), Jade Schoenhoeft (parent of ASD child), Loretta Rogers (Secretary)

Handouts: *Agenda, An Introduction to Needs and Gaps in Health Care Systems for Patients with Autism, Community Reports on Autism 2018, Exploring Health Disparities among People with Intellectual and Developmental Disabilities*

1. **Call to Order:** At 7:40 pm, President Wientjes called the meeting to order.
2. **Welcome and Introductions:** President Barbara Wientjes welcomed all attendees and all attendees introduced themselves.
3. **Public Comment Time:** None.
4. **Swearing in of the new HCM member and returning members.** Loretta Rogers, a deputy county clerk, swore in the new HCM member, Claudia Schimmer, and returning members, Barbara Wientjes and Constance Barker.
5. **Approval of the minutes of the April 24, 2018, meeting:** Connie Barker asked that the minutes be amended to show that her absence on April 24th was excused. With this amendment, Derice Seid Tao moved that the minutes be approved. Connie Barker seconded the motion. The motion passed unanimously.
6. **Urgent Addition to the Agenda.** Sandy Ross informed the HCM that the Board of Supervisors has the right to sunset any of its advisory boards and commissions. The HCM needs to request of the Board of Supervisors that its sunset date be extended another four years.
 1. Sandy Ross moved that the HCM request this extended sunset date. Claudia Schimmer seconded the motion. The motion passed unanimously.
 2. Sandy Ross moved that the following request be sent to the Board of Supervisors: “Health Council of Marin wishes to have its sunset date extended for another four years as per the May 16, 2018, memo from Josh Swedenberg, and therefore added to the resolution the CAO is drafting for the Board of Supervisors.” Claudia Schimmer seconded the motion. The motion passed unanimously.
7. **Presentation on Autism by Sheraden Nicholau, Regional Manager – Bay Area Office of State Council on Developmental Disabilities, and Ingrid Lin, Director for Clinical Services – Golden Gate Regional Center.**
 1. Alan Blau introduced the presenters and thanked them for coming.
 2. Sheraden Nicholau stated that the **Golden Gate Regional Center (GGRC)** is one of 21 such centers around the state. It was founded in the 1960’s by a group of families that came together to advocate for people with developmental disabilities. In the 1970’s, its mission was expanded to include autism. Its purpose is to provide services and support to individuals with developmental disabilities. Their goal is to move people out of institutions and into communities.

3. The **California State Council on Developmental Disabilities (CSCDD)** is founded by state and federal law. Its purpose is to provide support and services to individuals with developmental disabilities. They serve San Francisco, Marin and San Mateo counties. Among its activities are (1) advocacy for funding, research; (2) capacity-building; (3) discerning gaps in the system and pushing for legislation, changes in policy, etc. at all levels; (4) doing surveys regarding the quality of services and satisfaction of patients; (5) other.
 4. **Sources of data on autism:** Sheraden then provided a list of websites that are good sources of data, trends and research regarding autism. She also provided a list of websites that are good sources of anecdotal evidence.
 5. **Needs and gaps:** Patients and providers have identified the following needs and gaps: (1) Individuals and families report difficulty accessing care and services, including dental, mental health, reproductive health and care-giver services. (2) Providers report not having enough resources, ASD-specific contacts and education to meet needs (3) access to care and services as a critical issue. (4) Screen and early identification are critical and not all providers are attuned to this diagnosis. (5) More needs to be done regarding abuse prevention and support for housing.
 6. **Opportunities to make an impact:** Sheraden reviewed ways that HCM members and members of the public can make an impact to address these needs and gaps: (1) Organize / Attend community forums to provide information and feedback. (2) Include awareness of I/DD when addressing disparity reduction strategies or organizing / participating in policy discussions, negotiations for MOUs, etc.
 7. **Definition:** Ingrid Lin reviewed the DSM-5 criteria for diagnosing autism spectrum disorder.
 8. **Statistics for Marin County:** Ingrid reported that the latest CDC estimates for the prevalence of autism is 1:50 or around 1.7%. For Marin County, this is estimated to be around 4,423 individuals. GGRC is currently serving 208 individuals and special education enrollment is 315. Therefore, it seems likely that many individuals are not getting the treatment they need.
 9. **Lanterman Developmental Disabilities Services Act:** Ingrid reviewed the criteria for being eligible for services under the Lanterman Act. It was clear that many individuals who meet those criteria are not getting services. She also went over various recent legislation which provides for mental health, behavioral health etc. for autism.
 10. **Personal stories:** Jeremiah Oakes, Suzanne Blau and Jade Schoenhoefst each briefly told their personal experiences as a person with autism or the parent of an autistic child.
 11. **Q&A:** Claudia Schimmer stated that a problem is that most of the providers who specialize in autism are located in San Francisco. There are few such providers in Marin County. Also, housing costs and the cost of living generally are so high here that caregivers can no longer afford to live here making them hard to acquire for people who need their services. Alan Blau asked which county in California might act as a model for others. Sheraden said San Mateo was the closest thing to a model. Barbara Wientjes asked how the HCM could help. Sheraden said that they could lobby and monitor the new California Assembly Select Committee on I/DD. Also, Sheraden and Ingrid will send Allan Blau a list of things the HCM could do to assist. He will share the list with the other HCM members.
8. **Electronic Visit Verification (EVV) for Home Health Care Workers and HR620 ADA Education and Reform Act of 2017:** Connie Barker explained that EVV was added to the 21st Century CURES Act of 2016 as a way of making the new law “revenue neutral.” It was thought that by implementing EVV, fraud would be eliminated, and with the resulting savings off-setting the new expense. Many clients and caregivers have objected. There appears to be bipartisan support for correcting the problem. The legislator who sponsored the legislation declared that EVV was never intended to apply to consumer-directed services; however, the law specifically states a roll-out date for these services as opposed to the one for agency services. A bill is now being introduced to move the roll-out date for consumer-directed services to 2020. California has devised a workable plan as they have listened to users. The privacy issue has been addressed by have three options for location for provision of services: home, community, both. At the

- California level, we have gotten everything we wanted, but there is some fear that the federal regulations would exclude the California model. The goal is to have parity between the agency and consumer-directed sides. Connie will continue to follow and keep the HCM updated.
9. **Topic for next month's meeting:** Allan Blau will investigate acquiring a speaker for the next meeting to speak further about autism. Barbara Wientjes will contact Jennifer Rienks regarding a speaker to address suicide prevention. Connie Barker will investigate setting up a speaker regarding the Disability Integration Act.
 10. **HCM member reports and announcements:** Connie Barker stated that she noticed that Marin Community Clinics has installed dispensers with unscented soap in their bathrooms. Claudia Schimmer provided an update on RxSafe Marin activities.
 11. **Adjournment:** The meeting adjourned at 9:13 pm. The next meeting will be on Tuesday, June 26, 2018, from 7:00 to 9:00 pm at Marin General Hospital in the Larkspur Room