



PARENT HOSPITAL ASSOCIATION SONOMA DEVELOPMENTAL CENTER

THE ELDRIDGE GAZETTE

Embracing a future of possibilities



FEBRUARY 2018 ISSUE

P.O. BOX 237, ELDRIDGE, CA 95431
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CO-PRESIDENTS' MESSAGE

From Kathleen Miller, PHA Co-President

IS SDC STILL SAFE?

Sonoma Developmental Center is in the last year of closure. Experienced staff are now leaving as soon as they can finalize their exit plans. This is expected. We all know that the last year before closure is the most dangerous one at the developmental centers. During the Lanterman closure we heard reports of problems ranging from staff overtime, unit supervisors included in the counts, and others including wildlife causing problems on the campus. In view of that it is time to review how things are going at SDC.

Some norms do appear to be eroding. When clients returned to SDC after the fires three units were collapsed. Clients were shifted with very little planning in place. This may have been needed because some buildings were unusable due to smoke. What is more difficult to understand is that families were not notified and discovered the moves through phone calls or visits on their own. This not only violated the long standing SDC policy requiring family notification, but it also violated years of norms of how unit closures happened over the years.



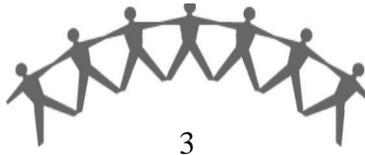
This erosion of norms is not the only one. Some problems seemed to be the result of the fires and their aftermath. Clients did not have adequate clothing on hand, the TV s no longer worked because the cable connections were lost. Classes or day schedules were disrupted and did not resume right away. We want to acknowledge the efforts of staff to correct many of these problems. The last information I had was that day schedules were taking place, the TVs were back online and clients now have socks and underwear.

Equally troubling are reports the SRP and regional centers are warning families that SDC is no longer safe with staff leaving. They say these things in order to pressure families into rapid placements. This is especially concerning for those of us who do not have a home in place for our family member and may not for some time. It is more or less the same issue that took place during the fires while during the Dixon days there were 40 placements. We were being reassured Dixon was safe while some were told SDC residents were not safe and needed to be placed rapidly-even in homes that were different from the ones they had planned on having their SDC loved ones move to.

There is no denying, however, that some residents are paying a high price for the loss of committed staff and the many changes. A number of ICF residents have had their behavior deteriorate. One resident that had been stable until recently put his hand through a window. Even North Star, which has seen staff transfers, has had difficulty. A resident from North Star with challenging behaviors who had made gains, has more recently begun to return to severe acting out behaviors. These changes in resident's behaviors are merely the symptoms. I worry about what they are trying to say with their deteriorating behavior and what they are feeling that leads to it.

The most troubling sign of problems at SDC however, is the death data. We have never been able to determine how many die in community homes once they leave developmental centers. A review of the recent risk assessment reveals that the outside agency that tracks the deaths of developmental center movers has made improvements for the first time in tracking these deaths so that we may be able to determine this in the future. PHA has been collecting information on deaths that occur while clients remain at SDC. For years, decades actually, the death rate was about 3%. About 3% of SDC residents died in any given year. In recent years the percentage of deaths has been creeping up. This is to be expected as clients age and the numbers of remaining residents is smaller. What is not expected however is a large increase from one year to the next. This happened with the NF residents at SDC last year 2017. (See the data cited below)

2011 overall 3.49%
2012 overall 3.05%
2013 overall 4.3%
2014 overall 3.3%
2015 overall 3.4%
2016 overall 3.55%
2017 overall 6.6%



There were two additional deaths during the fire where clients were placed in community settings and where they died within days of placement. If these two deaths are included the death rate for 2017 goes over 7%!

The fires cannot be entirely blamed for the higher rate as there were months before the fires when there were more deaths than the fire month.

We were told that all these deaths were expected. I do not know what that means. The truth is that many of our very fragile clients have defied expectations by living longer than expected and some of those who died were not the most fragile. We were told that none of the deaths were due to staff error. Administration is not on the units and may not be aware when mistakes are made and norms are eroded. The truth is that one small error with an NF client can have tragic consequences.

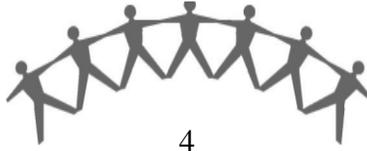
We do not know why the deaths have increased. We do not know why ICF clients have begun acting out. Nor are we interested in assigning blame. What is alarming is that when we first pointed out the increase in deaths what we heard were excuses and not concern and a determination to discover why the deaths are happening at such an increased rate. PHA has since spoken with DDS and requested that DDS get an outside agency to review the deaths. PHA also requested they place additional nurses to observe and train new staff on the NF units as needed to keep the residents safe. DDS has promised to follow up on these requests. The main take away is that all of us who have family remaining at SDC must be vigilant. If you see something that concerns you or affects your family member speak out. The last year of a closure things are changing, staff are leaving, and norms are eroding. This is not a time to be shy. Being respectful is always good, and being grateful is a must for our dedicated staff and always makes sense but...

IF YOU SEE SOMETHING, SAY SOMETHING!

CO-PRESIDENT'S MESSAGE
By Karen Moen, PHA Co-President

SDC and Client Safety and Stability

Like all family members and conservators, I am concerned when I see what appears to be a very worrisome spike in death numbers. As we already know, many of our family members and loved ones are medically and behaviorally fragile. All the questions that have been raised at meetings and in telephone calls to Board members are important for PHA, SDC management and DDS leadership to discuss openly and in the spirit of achieving the best results for our family members whether they reside in NF or ICF units.

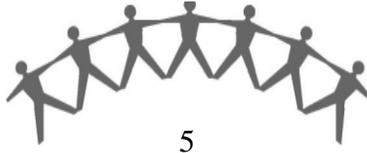


During a meeting between representatives of DDS and PHA Board members on January 12, 2018, we went through the mortality data. Without infringing on client confidentiality, DDS indicated that all the deaths had been subject to a thorough external and internal review and nothing suspicious was noted during the reviews. However, DDS offered to assign nurse consultants from DDS to come to SDC to work on the NF units to review existing procedures and the daily care requirements of the NF clients. This was done in an effort to alleviate family concerns and to ensure that the NF clients continue to receive the appropriate level of care while waiting for transition to community homes. These consultants have now been on site for approximately three weeks.

This is a stressful time for us all. Kathleen Miller's message raises concerns related to all the changes at SDC in recent months including not one but two evacuations, the return to SDC, and the subsequent consolidations of several units. In addition, we are now starting to see many of the long term staff leave SDC as they are offered positions with other state agencies that ensures they will be able to continue to care for their own families. There is little we can do about people choosing what is best for their professional future, retirement, and for their own families. But we can hope that as many as possible will be able to stay at SDC until the final units are closed. As we know, familiar staff and careful cross-training are what is required for any successful transition especially a transition to new communities and homes.

On a personal note, I would like to say that in midst of all this change, I have been very appreciative of care given to my daughter who started exhibiting signs of extreme PTSD before Thanksgiving. Thanks to the doctors, nurses, therapists, and direct care staff she has received care that is helping her work through what many of us saw as a most unexpected crisis. How much the closure activities and familiar staff leaving or being reassigned to other units impacted her behavioral crisis, we will never know. I am pleased to note, however, that, while she isn't "out of the woods yet" and is needing to be prepared for a move to a community group home in late spring, she is better than she was. This is due to the staff and physicians working with her even during the holidays, to SDC management assigning extra staff to her ICF unit to help deal with her crisis and to help ensure that her peers had the support they needed. There was no hesitation in making certain that resources were available to help her stabilize during a major crisis that is not yet over.

I remain hopeful that we can all continue to count on SDC management and DDS leadership to do all that they can do to help our family members remain safe at SDC and transition to the community smoothly. If you have any questions, including questions about what or what didn't move with your family member to the community (personalized wheel chairs, etc.) or questions about the process underway as more of our family members move away from SDC, do not hesitate to contact members of the PHA Board or the staff at SDC. By working together, we can help our family members achieve a transition that prepares them for life in their new homes.



PHA GENERAL MEETING MINUTES JANUARY 13, 2018

The meeting was called to order at 10:05 am. The minutes from November 2017 were approved.

Kathleen has those present introduce themselves.

The topic for today is “What happens when there is a disaster in the community?”

The next meeting will be on March 10. We will be honoring those who have supported us through the years. Advocacy is not over.

In May we will meet in groups again to discuss the future of PHA again.

The health clinic in Santa Rosa is going forward.

Administrative report by Aleana Carreon.

There are 166 residents at SDC today. 58 are in nursing and 108 are in intermediate care. There are also 5 people in the crisis center. They have had 4 placements so far in January and expect to have 14 more placements by the end of the month.

An emergency information line has been created. The number is 1-707-938-6900.

A welcome back (from Dixon fairgrounds after the fire) party was held on January 5.

The night shift had food delivered and had their celebration on January 9.

The Black and White Ball is being held in the gym on February 7 from 6:30 pm to 8:30 pm.

Kathleen said that the exodus of experienced staff is happening. The number of deaths in 2017 was much higher than in 2016. It is not sure what the death rates are in the community. At SDC there were 9 deaths in the nursing units in 2016 and 19 deaths in those units in 2017. There is concern about this increase. The response was that many of those who died were on hospice. Whenever there is a death there is an investigation. The deaths in 2017 were expected. SDC is probably hanging on to some of the sicker patients who will have a harder time transitioning into the community.

The California Health Alert Network tracks health issues and is now looking at flu and hepatitis cases. No residences at SDC are on restriction at this time. Two residents has influenza A, but have recovered. There are many new staff at SDC.

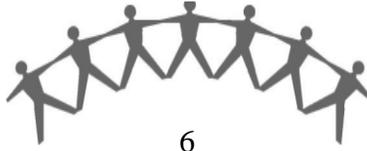
Kathleen asked if memorials were still being held at SDC. Aleana said they are still being held.

The vacancy rate for staff has been stable. It was commented that of the 25 staff at Malone, 22 are long-term staff.

End administrative report.

Kathleen asked those who were here from DDS (included John Doyle) to address three items: 1) Proposed California budget for DDS 2) Tour last Monday at SDC 3) What happens to people like those at SDC when a disaster occurs in the community?

John Doyle said that the budget proposal was released last Wednesday, January 10. DDS will have 7.3 billion dollars. 6.9 billion is for the community. 376 million is for developmental centers. SDC is still scheduled to close at the end of December 2018. They have approval from the Medicare for coverage for those at Porterville through December 31, 2018. There were 537



residents of developmental centers on June 30, 2017. They expect to have 361 residents as of June 30, 2019 which includes Porterville.

On Monday the governor's office of emergency services, some county representatives and others toured SDC to consider options for SDC after it is closed. DGS is the landlord of the property now. DDS is a tenant here. They are considering using some land for temporary housing because people were displaced by the fires last October.

DDS has the main concern for the health and safety of the residents and staff here now. If individuals are placed in temporary housing here, do we separate them from those who are residents here now? The Department of General Services has the final say on what will happen to the land here. State agencies such as universities have first claim on using the land.

Keeping this facility running in warm shut-down costs 8-10 million dollars a year.

The contractor who was here to look at the buildings was almost done with the report when the fires struck in October. It is expected that the report will be completed by sometime in February.

Karen expressed concern about the possibility of housing students and others on the land and said that when the present residents are still here, those who might be moving onto the land should have background checks.

Kathleen said that the buildings here don't seem in good enough condition for temporary housing. Also is this possibly going to lead to more permanent housing?

John said that state surplus land is for state use. DGS takes over the land. Then they see if other state agencies want to use the land. For example Lanterman land was taken over by the state university system. The governor has made a commitment to the community here as well about the use of the land.

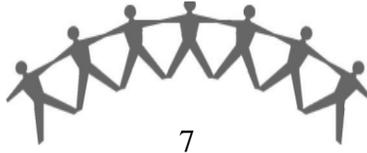
The topic of "What happens in the community in an emergency?" was next.

The state's role is to oversee what is happening. DDS is to be kept apprised by the regional centers. The governor's office is concerned that residents at developmental centers are fragile. Much assistance was given to the SDC residents when they were evacuated to the Dixon fairgrounds in October. DDS has the Everbridge notification system to connect with regional centers and others during an emergency.

A representative from Alta California Regional Center said that many were evacuated to the Yolo county fairgrounds when the Oroville Dam evacuations were ordered. Every care home has a plan of what is to be done in an emergency. 300 were in care homes or supported living in the area affected by the Oroville Dam emergency. Notification goes out by the Everbridge system. If the message goes out and a home (or in some cases an individual) does not respond back, then they arrange to check with that home to make sure that those people are safe. For example the Highway Patrol went to homes. Many homes had evacuated before the landline message was sent out. They said they need to update with cell phone numbers.

East Bay Regional Center; There were some disasters in the 1980s and 1990s, but they have not had any recently. Both Alameda and Contra Costa counties have extensive plans for disasters.

How are people's needs met in a shelter? Each shelter has a needs assessment team. This may include moving some people to hospitals. Most service providers are connected with the community. Most homes have a generator.



They rely on DDS to help out with those who are living alone (like those in supported living).

North Bay Regional Center: Their number one role is to support vendors and clients. During the fire in October when the Everbridge system was used 98% reported back in the first day and by the second day 100% were accounted for. Each home posts an evacuation plan in the home. It includes who does what tasks (such as who turns off the gas). The regional center has 2 satellite phones and can communicate with the state (DDS and office of emergency services).

They figured out where the people went and community care licensing and others came out to check what was needed.

Karen asked how medical prescriptions were made available. (This answer was to be given later in the meeting.)

Kathleen mentioned that putting medically fragile people together in a large facility is maybe not as safe for them.

A representative from Alta California Regional Center said that many providers have other homes and can move people to those homes in an emergency.

A vendor for some North Bay Regional Center homes said that there was an enhanced behavior support home that had the Courtyard and the Marriott as evacuation locations, but both of those locations were in danger. They were headed for Sonoma, but could not get through. They coordinated with Golden Gate Regional Center to move the residents to San Bruno during the disaster.

Homes have medications supply for a minimum of 30 days in a locked box. They also have an attending psychiatrist who can write prescriptions if necessary.

There are emergency packs in the vans with client files locked in the vans.

Tom Chesterman asked if people are moved in an emergency, will family be notified. The answer was yes that family would be notified after the move and people are in safe locations.

There was a comment that maybe there should be one place to evacuate that is close and another that is farther away.

Staff in the homes have a backpack with the information and supplies needed. They have a radio to get updates and an emergency cell phone to use. There is a communication tree.

One group of homes wound up arranging to stay at a day program in South San Francisco during the fire. They had one van for each of the three homes and one extra van, so they were able to move the 14 clients in the 4 vans to South San Francisco. They were able to get some extra beds moved to the site and the site had showers and lifts.

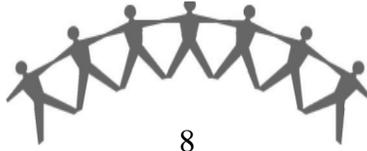
Evacuation sites for the general public are not equipped for the medically fragile.

The fire marshal knows where people are who need extra help when there is an emergency evacuation or similar event.

Residential care facilities have the same plans as medically fragile homes.

Providers who have more than one home may be better situated to accommodate an emergency.

Molly said that evacuation to public shelters does not work very well for some people such as the medically fragile and those with severe behavior problems.



The state's role is critical in an emergency. Providers can need help with getting special equipment moved such as hospital beds.

Not all phone take a group text. Land lines are important when there is a disaster since cell phone towers may be down.

The meeting was adjourned at noon.

Save the Date

WHEN: March 10, 2018 at 10 am to Noon

WHERE: New location at SDC -Sifford building

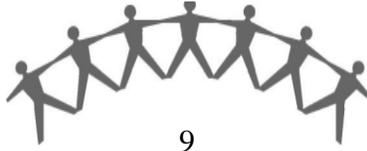
WHO: Local legislators and community partners will join us

WHY: This meeting will be a milestone meeting where we can thank some who have helped us during the closure. It will also be the last PHA meeting held on the SDC grounds. -Please join us on March 10th!

Membership renewal time

We have attached the membership form on the following page for your convenience.

Thank you for your continued support!



Parent Hospital Association
Sonoma Developmental Center

MEMBERSHIP FORM

For membership for January 1, 2018 –December 31, 2018

PLEASE CLEARLY PRINT INFORMATION

Make checks out to “parent hospital association” or PHA

MAIL DUES AND DONATIONS TO:

Beverly Austin

Parent Hospital Association

2683-17th Avenue

San Francisco, CA 94116

Check which type of membership below.

MEMBERSHIP DUES: _____ \$25.00 Individual

_____ \$30.00 Family (at same address)

If you are also including a donation, please put the amount here: _____

For family membership, please give names of the additional family members living at the same address on the bottom of this form.

PROVIDE THE FOLLOWING INFORMATION FOR PHA FILES.

Your Name: _____

Your Address: _____

Phone No. _____ Email: _____

Would you consider being on the PHA Board: Yes: __ No: __

Would you consider being on a PHA Committee: Yes: __ No: __

Please check which applies:

Family or conservator of a current resident of SDC _____

Family of a former resident of SDC _____

Friend of SDC (no family members at SDC) _____

If you have a family currently at SDC, please fill in the information below.

Your Family Member’s Name at SDC: _____

Unit at SDC where your family member lives _____

Relationship to Family Member: ()Parent ()Sister ()Brother ()Conservator
()Relative ()Friend ()Other

If you are joining as a family membership, please list any additional family members at the same address not already listed in the above address information.



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