



PARENT HOSPITAL ASSOCIATION SONOMA DEVELOPMENTAL CENTER

# THE ELDRIDGE GAZETTE

*Embracing a future of possibilities*



OCTOBER 2018 ISSUE

P.O. BOX 237, ELDRIDGE, CA 95431  
[www.parenthospitalassociation.org](http://www.parenthospitalassociation.org)

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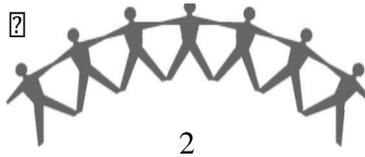
KATHLEEN MILLER  
CO-PRESIDENT'S MESSAGE  
OCTOBER 2018

Marking the End

Last night I dreamt I was walking through the center. It was different, the faces were not the same faces, but it was clearly the place and it was downsizing and in a state of confusion. I feel the following poem summarizes my feeling:

The bustle in the house  
The morning after death  
Is solemnest of industries

The sweeping up of the heart  
And putting love away  
We shall not want to use  
Until eternity

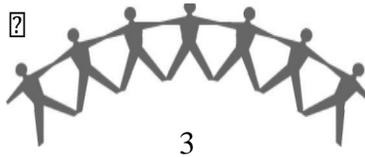


The closing of Sonoma Developmental Center is a kind of death.

Most residents have moved on from Sonoma Developmental center (SDC) and are settled in their new homes. Many wonder why we should keep looking back to SDC now that only a few residents remain. They wonder why they should continue to attend PHA and pay dues to an organization that no longer represents SDC residents or maybe their family member. As a response to those folks I am citing the reasons I continue to remain involved with both PHA and others who supported our residents.

- 1- The SDC campus remains of critical importance to folks in Sonoma Valley. Whatever happens on the campus will impact them. They welcomed SDC residents for decades and now I want to support their efforts to have a voice in what happens on the SDC site. I also feel strongly that the history of the site needs to be honored. The cemetery needs improvements. Camp Via should be restored and used by the young, both able or disabled, to experience the beauty of that natural setting. None of that happens without strong community engagement. We are a part of that community.
- 2- Now that we are a part of the larger community system, we are subject to the same issues as the rest of the disabled community. Dental care remains a major issue for many and health care is uneven with some enjoying good quality care and others forced to take whatever they can get. These are issues that require strong continued advocacy. Without united family voices, I see no one able to push the system of care for the most disabled beyond where it is today. There even exists a real chance of back sliding in the face of tight future budgets.
- 3- The safety net is not safe. Providers are being pushed to take clients who are they not ready to handle or are inappropriate for community homes. These clients can place both staff and the others living in the homes at risk and leads to rapid turnover of staff. In some cases families are being pushed to continue providing care for disabled family members who pose a threat to other family members. Mental health services for dual diagnosis are very limited and often inappropriate. The role of the state continues to be diminished and often seems to only include that of making up new rules and restrictions and doling out the money.

The main reason for our continued advocacy, however, is the diminished role of the state. They function now more like the federal government. We are looking at a system of care where the state appears to play an increasingly diminished role where they create policy and they use the power of the dollar to enforce that policy. They hold occasional meetings soliciting community input, but it is unclear how much of that input is utilized. This places pressure on Regional Centers, providers, and families to pick up the slack. In some cases this is appropriate and has worked to put the IDD population closer to their family support and their community. In some cases smaller homes fit the needs of the individuals with disabilities. However, one size does not



fit all! The current system appears to be uneven and full of holes. We need to stick around to help pick up the inevitable slack.

***Karen Moen, PHA Co-President***  
***Message:***

As Sonoma Developmental Center closes, we all face a future that is vastly different than what we have known in the past. We are still in a period of transition from the familiar state hospital/developmental center system of care to that of a myriad of community-based service systems that look and feel different from what we have been accustomed to for so many years.

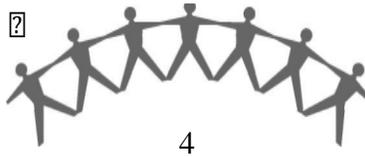
As we begin this new journey, I urge us all to not only remain involved in the lives of our loved ones and but also involved with the service providers and regional centers responsible for the ongoing support and care of our sons, daughters, brothers, sisters, aunts, uncles, and friends.

So many of our members were not only actively engaged in PHA while it was based at SDC, but were also active in unit parent groups throughout the years. These activities brought us strength and, for some of us, proved to be sources of information and good advice. Some of my fondest memories are of the annual Malone fund-raising efforts lead by Norma Burdick who saw to it that we raised a enough money each year that we were able support a variety of unit activities and field trips and even purchase a van for unit use. Those were truly remarkable times.

But now, we move our focus from activities at SDC to new activities with new people in new places. Like many of you, I struggle with how I now make any impact that will result in even better and more comprehensive systems of care for my daughter and for all the other men and women leaving SDC.

Being action oriented, I'm sharing the short-list I've come up with for involvement in the future. I hope you will join me so together we can continue the work begun so long ago at SDC. Weekly I remind myself that I pledge:

1. To remain an active member of PHA/Family Advocates United;
2. To find out when my local regional center holds its board meetings and attend those meetings whenever possible--just showing up does have an impact. (For information visit <https://www.dds.ca.gov/RC/RCLookup.cfm> for a directory of counties with a link to the regional center serving each of those counties. Once you go to the website for your regional center, look for "Board of Directors Meetings."); and
3. To find out what services exist for all Individuals with Developmental Disabilities (IDD) in my county and let PHA/Family Advocates United know where service gaps may exist--together we can then continue to work on issues regionally and statewide.



I look forward to the continued involvement of us all in this organization which has served us well throughout the years.

Karen Moen, Co-President, PHA/Family Advocates United

## **PHA GENERAL MEETING MINUTES SEPTEMBER 8, 2018**

The meeting was called to order at 10:03 AM The meeting was being held at Hanna Boys Center..

The executive directors of Golden Gate, East Bay, and North Bay regional centers were guest speakers.

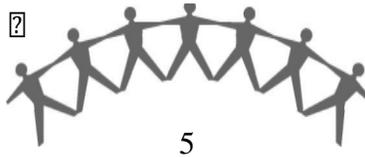
The minutes from the May meeting were approved. Kathleen said that there will be four general membership meetings a year in the future. On November 10 the focus will be on health care including dental care and mental health care. Some areas have better services than others.

The next issue of the Gazette will not be mailed. There are some volunteers who will mail newsletters to those who need to have one mailed to them. The Gazette will be on the PHA website. The web address is [parenthospitalassociation.org](http://parenthospitalassociation.org). If PHA members see an interesting article they can suggest that it be posted on the website.

There are going to be several events to commemorate the closing of SDC. SDC has been unique even among developmental centers. There has been a connection with the local community. On October 31 the last Halloween parade will be held at SDC. It will start at 10:30 am. Former clients are being invited back to participate or just come and watch the parade. We will be hosting a lunch for staff and former staff after the parade to thank them for all the hard work they have done and are doing for our loved ones. The theme for the events is Protecting What We Love. On November 3 there will be an event at Hanna Boys Center in the auditorium and patio area. That will be at 3 to 5 pm and will feature the family photographs taken by Christian Pease. There will be refreshments. If you wish to attend this event you will need to register. An email will be sent out with details how to register.

Kathleen introduced Tracy from the Glen Ellen Forum. That group is working to support maintaining open space. They have an online petition to the governor to appeal to keep open space and to have a local voice in what happens to the SDC land. PHA has worked to 1) protect residents 2) protect staff and 3) protect open space. The Glen Ellen Forum has also been working to preserve the history of the area. PHA has also drafted a letter and sent it to local legislators.

Tracy said she would be leaving information on how we can contact the governor to have local input on what happens to the SDC land. At this point about 2500 people have signed a petition for preserving open space and for having local control of the area. You can go online at [eldridgeforall.org](http://eldridgeforall.org) to get information on actions you can take to support the effort to maintain open space. You can also google "Glen Ellen Forum" and under SDC Transition in the right column click on the link to sign the petition. The Glen Ellen Forum has been working to preserve the history including the SDC cemetery.



PHA would like to see Camp Via renovated so it can be used again in the future for our folks.

The program with the directors of the regional centers came next. The theme is the vision for the future and barriers that are faced.

The directors introduced themselves: Gabriel Rogin from North Bay Regional Center, Eric Zigman from Golden Gate Regional Center, Lisa Kleinbub from Regional Center of the East Bay.

Gabriel said that North Bay covers Napa, Sonoma and Solano counties. Eric Zigman said that Golden Gate covers San Mateo, San Francisco, and Marin counties. Lisa Kleinbub said East Bay covers Contra Costa and Alameda counties.

She shared some of the vision for East Bay. They have looked at having an inclusive community. They want their people to feel comfortable in their community. They serve about 21,000 individuals with IDD (Intellectual and Developmental Disabilities). They serve people from being in their own home, to being in homes with support, and to being in a group home or residential home of some sort. They have not placed anyone in a developmental center for several years unless they have had severe and challenging behaviors.

One of the problems in the community has been how to serve those with complex medical needs or behavior needs. As we have moved toward the closure of Sonoma they have had the opportunity to increase the resources and create new resources in the community. They want to make sure the services can meet people's needs.

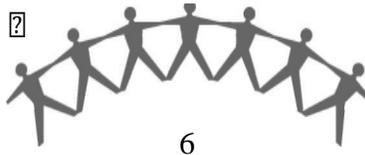
There is a lot of opportunity for families to continue to be involved. They have Developmental Disability Councils which were formed after JFK had efforts around intellectual disabilities in the 1960s. They were formed across the country. They are housed in public health. People can participate in them and share their ideas. They have board meetings every fourth Monday (most months). Families attend the East Bay board meetings and can share ideas.

Kathleen said she was not aware of any spiritual care being offered for SDC movers to East Bay. Lisa said that when they looked at spiritual care that there were a number of avenues where that exists already. Both the Catholic and Muslim communities have program to serve individuals with developmental disabilities. They also work with individuals to identify the religious practice they want to be involved in. Lisa said it would be hard to have a central area for spiritual services and want to try to have those services provided where the people live. Kathleen said there is a lot of data showing that developmental center movers do not have much opportunity to get spiritual services. Lisa said that as people move that spiritual needs can be included in the plan.

Eric Zigman from GGRC said that the three counties included in GGRC are the three most expensive counties in the state which does create challenges for them. Eric had a role in the Agnews closure process. The relationship in that closure was difficult. Eventually it did improve with various activities such as teas. He was impressed with how collaborative the SDC families were and how productive those meetings were.

All of the regional centers are funded by state and federal funds. All are 503c nonprofit organizations.

The GGRC board ratified a strategic three year plan at the end of June. That plan has four areas.



1) Housing and home support. This includes the actual housing as well as the support staff in those homes.

2) Community engagement and education. One aspect of this is working with the community to be more welcoming and understanding. This includes getting more medical people to understand our people. The other aspect of this goal is to try to make the regional centers more “navigable” and understandable for families. He thinks the work will move more and more to have better community awareness and have better partnerships.

3) Investing in staff. The relationship of the person being serviced with the person serving them is very important. We have to invest in staff at GGRC and also in the homes. We want to reduce turnover. Consistency of staff is very important. With the enriched funding that has been given for those moving from the developmental centers, the situations our loved ones are in are a demonstration of how we can serve the other 300,000 people in the regional center system.

4) Agility and impact. The non-profit status allows them to meet needs in more creative ways as opposed to a government agency.

Eric said the two things families can help the regional centers most with are 1) the rates for provider agencies and 2) how the regional centers are funded operationally. It is always families who have protected the Lanterman Act over several decades. There is a rate study going on now for all the provider agencies. We need advocacy in the legislature to support rates. The report will come out in 2019. There is a need to connect the cost of services with the rates the state provides. The regional centers need a way to pay staff more competitively.

Gabriel has worked at several regional centers. The vision is really in the Lanterman Act. Make sure people thrive in their community and are able to live the life they want to live.

When he got to North Bay Regional Center, he realized that North Bay has not always done a good job of collaborating with their partners. He has made working collaboratively his number one priority. They are working with SDC now. They have prioritized bringing former SDC staff into their system to make sure all that knowledge is not lost. There are former SDC staff working at the federally qualified health clinic in Santa Rosa.

Providing spiritual care is on their list. North Bay is working with the chaplain at SDC to be able to provide spiritual care for those moving from SDC.

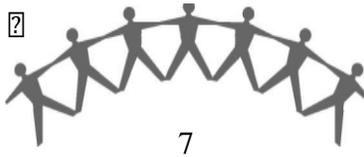
There are barriers in the community at large. Resources that are available for those moving out of SDC are extraordinary. They have had almost unprecedented support from the Department of Developmental Services to pay the rates they need to pay for those moving out of SDC. The providers they are working with now for the DC closure are in a separate category. The rates for those in the community (not including dc movers) need to be reformed.

Housing is expensive in their area. North Bay developed 29 homes to accommodate those moving from SDC into their area.

The clinic was opened in Santa Rosa to serve people like those moving from SDC. They are close to getting oral sedation for dental at that clinic.

They are working to improve how they work with others such as the Spanish-speaking community.

Start-up funding had been frozen, but now some money has been released for start-ups. They need to work on crisis prevention.



A question is that there is funding for our loved ones now, but for how long? Eric said that the state has maintained community placement planning funding for 14 years so far for those who moved from Agnews. He said that this funding is really just adequate funding.

Models have been developed which show what can be done and these have set the bar higher.

Health rates are an issue. The federal government is now realizing that serving those with IDD is an issue and that rates may need to be higher for those people.

The discussion was opening to the audience for questions.

Molly asked where those who go into crisis will be able to go in the future. In the past people were often able to go to a developmental center, but those are being closed.

The answers: There is hope that there will be less need for the safety net because of all the planning that has been done. North Bay has a crisis team that goes into homes to help if someone is starting to go into crisis. There are crisis beds. Northern Star will remain open on SDC until the two crisis centers in Vacaville are ready. The state is creating crisis homes. The regional centers work together to help support each other.

GGRC is developing a crisis center with San Andreas. The enhanced behavior support homes are going to make a difference.

Kathleen said that some psych facilities are reluctant to take regional center clients. They are not part of the regional center, but part of the back-up system. Having local psych facilities is critical. This is something she would like to see everyone work on.

Lisa said she would like to see legislation proposed that every county mental health facility have some special people working there who know how to work with people who are dually diagnosed with IDD as well as a mental health disorder. GGRC started a mental health clinic in San Mateo and East Bay has established one based on the GGRC model. There needs to be training for young psychiatrists to work with those who are dually diagnosed.

A mother asked about rent subsidies for her son who is with GGRC. Eric said there is a way to get a rent subsidy, but there are qualifications needed to get it. He would talk with the mother later.

Brien asked the directors to identify some of the things that they are proud of in their area.

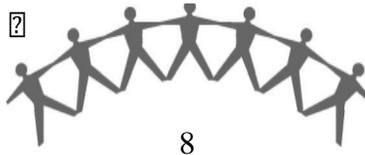
Lisa said she was proud to have the mental health facility up and running. She is proud of the work being done to support diverse communities (Spanish and Asian).

Eric said there is increased incentives for employment. There is now paid internship for some of their clients.

Gabriel said they are redeveloping the board. They have formed a legislative committee. They are working on increasing housing capacity. They can go to city council meetings. They are looking at a pilot of self-determination for how money is spent.

Tom asked about when and where North Bay board meetings are. He said it is hard to find that information. He also said the nearest dentist for his son will be in Sacramento and asked if there was a way to have it closer.

Gabriel said that North Bay needs to be better at letting people know where they meet and when. They do rotate the location. The next meeting will be on October 3 at 5 pm at SDC. Gabriel said that sedation dentistry is a great need. Rates and hospital privileges are a problem. However, if your loved one needs it, it will be provided.



Kathleen said that people need to get outside. At SDC they can get outside every day. Camp Via was a camp for our folks for decades. We need to get it included in the state park.

Lisa said that East Bay has Camp Arroyo which serves a variety of people including those with autism.

Steve said that GGRC has done a good job for his sister. His sister attended a picnic with her day program and it was phenomenal. When his sister was in a home before (20 years ago) the services were not very good. The training is much better than before.

Karen thanked Eric for the help moving her daughter. She said there are different things available in different communities that could be established in each regional center. She said regional centers share ideas for employment opportunities. How do you work together to take these to Sacramento?

Eric said there are 21 regional centers. They meet together with 21 others on a regular basis. All regional centers would like to have a FQHC like the one in Santa Rosa. They are always paying attention to what one regional center has and their regional center does not have. We have a flexible system, so it allows a regional center to develop a new resource and then maybe share it later and get it elsewhere.

In East Bay they have a legislative coalition. They have some forums to share efforts. For the cities it is mostly housing issues. The regional centers may need to be more involved with the state parks to provide opportunity for their clients.

In GGRC there is a service provider advisory committee. They have a subcommittee which took legislators around to see places serving GGRC clients.

Don't understand your own power. Legislators know families are sincere. If families get together three things they want and then coordinate with the regional centers, we could go to the legislature with those.

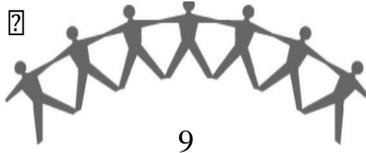
Alex said it is important to get Camp Via back in operation. Gabriel said that for the population served by the regional centers that having the opportunity to be outdoors is even more meaningful than for others.

Are we looking at a two-tier future? Those coming from the DCs and those who were not there?

Some who were not in a DC have been moved to places designed for DC movers.

Now we have to stand up and have rates increased so everyone can have their needs met. Supported living services rates are not always adequate. Kathleen said that we want people to join us and we can advocated for you. Karen said that it is one thing for regional centers or vendors to ask for more money, but what really makes a difference is families talking with legislators.

The meeting was adjourned at 12:08.



## **Save the Date**

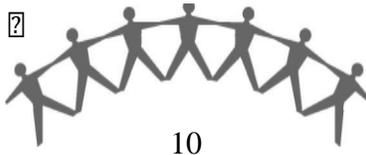
October 27 -Town of Glen Ellen becomes living gallery with photographs of last SDC residents in large banners posted around town! Be sure to pay a visit.

November 3 - Event at Hanna Boys Center to mark the closure of SDC

November 10 - PHA meeting at Hanna Boys Center at 10:00AM. The issues of health and dental care will be major topics

March 2019 - The second Saturday will be the annual legislative meeting at Hanna Boys Center. Place it on your calendar now

**A reminder that it is time to renew your **membership** at year's end. The membership form is on the following page. Thank you!**



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# PHA MEMBERSHIP FORM

For membership January 1–December 31, 2019

Make checks payable to : *PHA*

**MAIL DUES AND DONATIONS TO:**

**Beverly Austin  
PHA (Parent Hospital Association)  
2683-17th Avenue  
San Francisco, CA 94116**

Check which type of membership below.

MEMBERSHIP DUES:  \$25.00 Individual

\$30.00 Family (individuals with same address)

If donation included, please indicate the donation amount here: \$ \_\_\_\_\_

**PROVIDE THE FOLLOWING INFORMATION FOR PHA (*Please Print Clearly*)**

Name: \_\_\_\_\_

Address: \_\_\_\_\_ (Street)  
\_\_\_\_\_ (City/State/Zip)

Check here if this is a new address since 2017

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Would you consider being on the PHA Board: Yes  No

Would you consider being on a PHA Committee: Yes  No

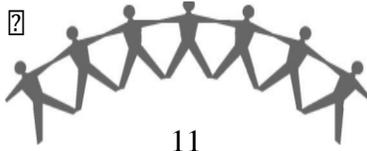
*Please check all that apply:*

Family Member

Conservator

Former SDC Staff

Other: \_\_\_\_\_



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