

Family Information Session - Meeting Summary

June 27, 2015

10:00 AM to 2:00 PM

Wagner Building (Sonoma & Laurel Avenues)

Sonoma Developmental Center

15000 Arnold Drive

Eldridge, CA 95431

The purpose of this information session was to make Department of Developmental Services (DDS), Sonoma Developmental Center (SDC), and local Regional Centers (RC) staff available to receive family member input and answer any questions about the proposed closure of Sonoma Developmental Center. The meeting was scheduled as a start to the ongoing dialog and collaboration necessary to complete a comprehensive closure plan, reflective of the concerns of families, by the October 1, 2015 statutory deadline. A phone line was made available for parties unable to attend in person.

Welcome and Introductions

Karen Faria, Executive Director of SDC welcomed participants and started introductions. Representatives from DDS, SDC, the Sonoma Regional Project, Golden Gate Regional Center, North Bay Regional Center, Regional Center of the East Bay, Alta California Regional Center, San Andreas Regional Center introduced themselves. Far Northern Regional Center was represented on the phone.

Ms. Faria then made opening comments framing where we are today, acknowledging the difficulty of the changes presented by closure and affirmed everyone's commitment to work together for the best possible outcome for the individuals who live at SDC as they transition to the community. Ms. Faria then introduced John Doyle, the Chief Deputy Director of DDS.

Review of Budget Proposal

Mr. Doyle provided a quick review of the budget proposal and where things stand today with the budget being signed. In the budget, the state has made an initial investment of almost \$47 million (described as a "down payment") on developing the different types of homes and resources that will be needed for people moving from SDC. The budget also provides resources (about \$1.3 million each) to DDS and the Regional centers to coordinate the closure process.

He then explained that "budget trailer bills" are bills that have items needed to implement the Budget Act. The trailer bills also reflect the intent of what the Legislature may want to do in certain areas. This year, the Developmental Services trailer bill is Senate Bill 82 (a copy of the full text of the bill is available online

here: https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520160SB82).

Based on input from Sonoma's families, the Sonoma Coalition and other stakeholders, this bill makes some specific modifications to what's required under law in a closure plan.

Mr. Doyle then walked the group through the changes to Welfare and Institutions Code requirements for developmental center closure plans (found in Section 4474.1) that are pertinent to Sonoma. Changes made by the trailer bill (SB 82) include the following requirements:

- Consideration for the use of state staff (Sonoma employees contracted to work in the community) for mobile health and crisis teams in the community and the use of state staff in new state-operated models that may be developed as a component of the closure plan.
- DDS must confer with the county in which the Developmental Center (DC) is located and shall consider their recommendations for the use of DC property.
 - Mr. Doyle noted that DDS does not own the DC land, but is a tenant that is essentially renting the land from the Department of General Services (DGS) and that DGS is the state entity that controls what happens with state-owned property.
- Additional information on resident characteristics in the plan including, but not limited to, age, gender, ethnicity, family involvement, years of DC residency, developmental disability and other factors that will determine service and support needs.
 - The Legislature has made it clear, and the administration agrees, that it is very important to understand exactly who is transitioning to the community, what their service needs are and how we develop them.
- A description of stakeholder input, which must include local issues, concerns and recommendations regarding the proposed closure and alternative uses of DC property.
- A description of the unique and specialized services provided by the DC including, but not limited to: crisis facilities, health and dental clinics; and adaptive technology services.
 - The Northern STAR crisis unit was referenced as an example of a “place of last resort.”
- A description of how DDS will transition the clients’ rights advocacy contract provided at the DC into the community.
- A description of how the well-being of your loved ones will be monitored during and after their transition to the community. This is an issue critical to DDS, regional centers and all entities that monitor the transition process. How well people do once they have moved into the community is the most important thing, so it is going to be an area of significant focus.

Transition Process

Amy Wall, DDS, gave an overview of how the transition process will work. She referenced the Contact Information document distributed at sign-in that lists the dedicated web page, phone number and email address for the closure of SDC and made sure everyone who wanted a copy received one. (This document is available online at <http://www.dds.ca.gov/SonomaNews/index.cfm>) Participants were encouraged to contact DDS with any questions, concerns and/or input and comments for the closure report.

Ms. Wall then reviewed the comment process, clarifying that “comments” are any input people want to give DDS for consideration in the closure plan. Comments can be submitted in person at the upcoming public hearing on July 18, or submitted online, by email, or mailed to DDS by September 1, 2015.

Ms. Wall then moved to the review of the transition process starting with the principle that there is no “one size fits all” transition planning. Transitions are tailored to each individual and no two families are going to experience exactly the same transition process. Though individualized,

there are some common milestones that everyone has to achieve as they move through the transition process. The overview of the transition process focused on those major milestones.

She then referenced an additional handout that people could take home and review. Titled "Transition Guidelines," the document was developed for the closure of Lanterman Developmental Center, but provides a good overview of the big milestones in the transition process. These guidelines will likely be modified to be more Sonoma-specific by a Resident Transition Advisory Group (RTAG) that will be formed as we move forward in the closure process. The RTAG is made up of DC residents, parents and family members, regional centers, advocacy groups, and employees of the developmental center.

Consistent with the Lanterman Act and the values of collaboration and person centered planning, individualized transition plans will be developed for each person who lives at SDC. Each transition plan will be based on that person's needs and will be developed by the Interdisciplinary Team, (ID Team or IDT) to ensure all services and supports are in place at the time a person moves.

The transition process starts with the individual program plan (IPP) and continues as the ID Teams meet to identify each person's goals, objectives, services and supports they are going to need in the community. Comprehensive assessments are one of the many different assessments that inform the IPP process to help identify potential service options.

The men and women who live at SDC and their families will be provided with numerous opportunities to learn about different service options. There will be tours, open houses, photos, videos and provider fairs. SDC staff, RCs and DDS will all be working hard to make sure that people who live at SDC, their families and conservators have access to several different ways to learn about the variety of options available in the community.

After exploring what's out there, the next step is to look at some specific options. When the family and consumer identify a home they like, or think they're interested in, SDC sets up a "Meet & Greet." The SDC staff, through the Sonoma Regional Project, will be the people in charge of coordinating all of your transition activities, so they will help you set up a Meet & Greet, with the provider of the home you're interested in. The Meet & Greet is where the provider, staff, consumer and family come together to see if a specific option has the potential for a success. There is not a prescribed number of Meet & Greets that have to occur. Some people just have one and decide they like their first choice, while others have done 5, or even 12, Meet & Greets. It just depends on what you need to see to get to that specific option you're looking for.

If the Meet & Greet goes well and that's the specific option chosen to move forward with, then an initial Transition Planning Meeting (TPM) is held. This is the "kickoff" to the transition planning process where the ID Team comes together to start an individual transition plan, which is the document that formalizes the transition planning items discussed with the ID team. The TPM goes into the detail of what supports need to be in place at the home, what kind of transition activities need to occur and when they are expected to be done. Transition planning is a very dynamic and responsive process that evolves as the ID Team sees fit. There can be many TPMs, or just a couple, it really depends on what each person needs.

Included in the TPMs with the individual transition plan document, is a separate document, the individual health transition plan (IHTP). The IHTP identifies all of the healthcare-related needs required for transition and is developed with the SDC physicians and staff who know the individual the best.

A Transition Review Meeting (TRM) is held at the conclusion of the transition planning process. The TRM is an opportunity to ensure all parts of the transition plan and IHTP have been implemented effectively and where the move date is set. The TRM is held no less than 15 days before the planned move to provide the opportunity for any member of the ID Team to raise any issues they felt haven't been fully addressed through the transition planning process. The TRM allows for a fair hearing process for conservators or a *Richard S.* request if there's any objection from a member of the ID Team who is not a conservator.

After the TRM, a person moves. Then there is post-move monitoring where the RC and Regional Project do follow-up visits for a year after the move, which supplements ongoing visits and oversight by DDS, licensing and RC quality assurance processes.

Ms. Wall concluded her comments by acknowledging that a lot of information was shared, reminding people that the example Transition Guidelines handed out are just that, an example, which will be reviewed by Sonoma stakeholders for possible modifications. She then recommended people review the Transition Guidelines handout outside of the meeting, including the roles and responsibilities section that starts on page 6, and directed them to email or call with any questions that may come up as a result of their review. The Transition Guidelines handout is available online at <http://www.dds.ca.gov/LantermanNews/docs/TransitionGuidelines.pdf>.

At this point in the meeting, Ms. Faria introduced Mei Kung, the new Director of the Sonoma Regional Project, effective July 1, 2015. Ms. Kung's brother used to live at SDC. She helped him move into the community – at first very reluctantly. It was hard work and a little scary for her, but she made his transition work by being very involved. She has worked with most parts of the development services delivery system in her career. Her personal experience and passion will be a great benefit in her new role and she looks forward to getting to know everyone.

Questions and Comments from Participants

The meeting was opened to participants for questions. Ms. Faria acted as moderator. Regional Center representatives, SDC staff and DDS representatives were available to answer any questions applicable to their role(s). The questions and concerns discussed for the duration of the meeting by participants in the room, and on the phone, are summarized below.

- **Timeline**
 - How can a comprehensive closure plan be completed by October 1, 2015? There simply isn't enough time.
 - How does the legislative approval process for the plan work?
 - We're not there yet, the final structure of the plan is too vague.
 - The goal is for SDC to close by the end of 2018; however, individuals will not move until the services and supports that they need are available and ready in the community.
- **Meetings with the Regional Centers**
 - Smaller meetings with specific RCs would be helpful to families.
 - Some RCs have already started having meetings with families; other RCs are in the process of scheduling these meetings.
 - RCs want to have these conversations. Look for upcoming meetings and reach out to them if you have questions.
- **Funding**
 - Are homes and funding for services guaranteed in perpetuity?

- Many regional centers use nonprofit housing organizations to purchase homes so the home does stay in the system in perpetuity.
 - DDS, the Department of Finance, the Governor's office and legislators understand the resources necessary to make transitions successful and support people in the community on an ongoing basis.
 - The community needs more funding. Community providers are just hanging on, how can they deliver quality services?
 - The initial money in this year's budget is basically a "first installment." People know it will likely cost just as much to serve some individuals with significant medical or behavioral needs in the community as it does in the DC; the money is not the issue, it's about what services are most appropriate.
 - The Governor has convened a special session of the Legislature to address the sustainability of health services and funding, including services for people with developmental disabilities, with the intent to develop revenue sources that will sustain funding for these programs into the future.
- **Safety/Interactions with Law Enforcement**
 - Several individuals shared their fears of future interactions with community law enforcement personnel that may not be familiar with people with developmental disabilities or significant behaviors.
 - 911 services are not prepared to help people with developmental disabilities. Can there be some sort of back-up or support for 911?
 - North Bay Regional Center highlighted that they provide ongoing training with local law enforcement and fire departments to help them recognize the RC clients in the community and become familiar with them. Other RCs do this as well.
 - How do you protect people from abuse in the community?
 - How do you assure safety in the community, especially for individuals with sexual behaviors?
- **Open Space**
 - There are healing properties to SDC's open spaces.
 - Several people living at SDC walk a lot and need the freedom and open space they have at SDC.
 - Will individuals be able to have a big, roomy, beautiful natural place like SDC in the community? Freedom of movement is key for a lot of people.
- **Oversight in the Community**
 - Will DDS sustain their involvement and what oversight will be provided?
 - Yes, DDS has an ongoing responsibility to serve Californians with developmental disabilities and are just one level of oversight in the community.
 - Any adverse events need to be reported to family members as well as the RC and other official entities.
 - Details are needed on the type and frequency of oversight in the community, especially from licensing and the RCs.
 - Ongoing monitoring of community homes, including unannounced visits, is provided by the Department of Social Services (licensing), regional centers and DDS.
 - What kind of oversight is conducted to ensure financial stability of providers?

- Community providers over a certain level of income have to have an audit by a Certified Public Accountant every year which the RCs review.
 - Is assistance provided to homes for their paperwork and tax issues?
- **Family Support in the Community**
 - What's the equivalent to the Sonoma Parent Hospital Association in the community?
- **Transparency/Accountability/Lack of Data in the Community**
 - Mortality data for people who have moved out of a DC needs to be shared.
 - Data on incarcerations, medical incidents, restraints and other occurrences in the community should be available.
- **Medical Care in the Community**
 - Managed care and the availability of appropriate specialty physicians and services in health maintenance organization (HMO) networks is a big concern.
- **Community Homes**
 - Quality and continuity of care in the community are paramount. How do we achieve the level of care provided at SDC, or improve it, in the community?
 - We need to try and provide homes where friends can stay together.
 - Currently, the RC system is based on geography. It would make more sense to have a needs-based structure to address people with significant behaviors or other needs whose transitions would be better served based on their needs.
 - Resources need to be developed before placements occur.
 - How can you find out how long a home has been open and if the provider is stable?
- **Alternative uses of the SDC Property**
 - Considerable support for H. Belmont's plan to develop homes on SDC property was expressed.
 - Why can't we just revamp and rename SDC as a "community" so the federal government will fund it?
 - Dental and psychiatric care should remain at SDC in a clinic that won't close 1-year after SDC does
 - All of SDC's specialized services should be available after closure in a clinic (or clinics) on the campus, including the specialty shoe shop and wheelchair repair.
 - Getting specialized wheelchairs at all in the community was raised as a significant concern.
- **Lessons Learned**
 - Lessons learned from previous closures should be shared as well as how DDS is going to use lessons learned to improve transitions.
 - Problems and solutions from the Lanterman closure should be built on to benefit the SDC closure process.
- **Decision Making**
 - Who is the ultimate decision maker for residents? The regional center, DDS, the courts?
 - The transition process is driven by the ID Team, which includes conservators. The ID Team has the final say on what home an individual

should go to. Any member of the ID Team can appeal the transition if they feel something is not right.

- **Communication**

- Not everyone is on email. Hard copies of information in the mail will be necessary.
- Share some success stories from other closures.
- DDS needs to share some specific problems and the resulting solutions experienced in the Lanterman Closure.
 - Two examples were shared at the meeting. One where a new model of service for significant behaviors was adopted by a provider and a regional center to create a home that could serve an individual from Lanterman with significant behavioral challenges that didn't "fit" into any existing homes, and the other was where transitions were delayed because individuals' medical conditions changed the level of care they required, so more time was needed to build additional supports into the specialized medical homes the individuals were moving to.

- **Staff**

- State staff following individuals to community homes would be a very good thing.
- Many staff in the community make minimum wage and there is high turnover, how can people be assured their loved ones will receive the same quality, compassionate care in the community that they receive at SDC?
- How are staff in the community held accountable for wrongdoing?
- Do community staff receive training and have responsibilities as mandated reporters?
 - Yes, they do receive training and are mandated reporters.
- Are background checks done on community staff?

- **Consolidation of DCs**

- Can we achieve budget savings by consolidating the 3 remaining DCs into one?
 - The federal government has made it very clear that they will not fund congregate living.

A lot of important issues were raised by family members. Some questions were answered at the meeting, while remaining and others will be addressed in future communications and in the closure plan.

The PHA has their meeting scheduled for July 11, for families to come together a talk amongst themselves. There is a public hearing scheduled for July 18, 2015 from 10:00 a.m. to 5:00 p.m. in Sonoma¹ and more meetings like this one can be scheduled, if needed, to keep dialog going about the future of SDC and the men and women that live here.

The meeting concluded.

¹ The location was finalized after this meeting concluded. The public hearing will be at the Sonoma Valley High School Pavilion from 10:00 a.m. to 5:00 p.m. on Saturday, July 18, 2015.