

## Proposal Spiritual Care during Transition

The Lanterman Act specifies that the men and women in developmental centers have a right to worship and for this reason Jewish, Catholic, Protestant and chaplains work at SDC. When the Lanterman Act was written, mainstream American culture religiously identified itself by membership in one of the three above religious traditions, and religious attendance was considered to be synonymous with spiritual growth. Individuals who resided at SDC were religiously identified by the preferences of the family and had the opportunity to attend services according to their religious tradition.

Today our religious culture is much more diverse because of variations in ethnicity or culture, access to information on the internet, and a lack of need to attend mainstream religious services. New generations of adults have not been religiously initiated and many people seek spiritual teachers or practices outside of mainstream religions. The idea of being “spiritual” rather than “religious” is a well-accepted notion in our culture. State prisons are court mandated to recognize, accept, and serve this plurality of religious choices among prisoners. The right to worship has become much more individual since the time of the Lanterman Act.

This presents a new challenge to those responsible to provide worship for the developmentally disabled. How is the right to worship to be understood for the men and women who will be transitioning out of SDC into a pluralistic and diverse religious culture? How is spiritual care to be provided for persons who may not speak or cognitively process but who nevertheless have a strong spiritual thirst because the spiritual is something they can process? How does a planning group identify the potential for spiritual healing and growth for individuals transitioning out of SDC and then identify interventions which will enable that individual to thrive in their new life? We believe that professional chaplaincy offers a proven and effective solution to these questions because spiritual assessment and spiritual care are exactly what professional chaplains are trained to provide.

We are very happy to hear that there are church communities that warmly welcome persons with developmental disabilities and that some caregivers take individuals to worship at church. This is obviously an optimum arrangement to enable individuals to exercise their right to worship. Nevertheless I am realistic enough to know that not all individuals transitioning out of SDC have the behavior skills to be fully accepted in an outside church community, that not all church communities truly embrace persons with developmental disabilities by including their participation in the service, and that many ministerial leaders would be at loss to interact one to one with a person who is developmentally disabled.

The development of professional chaplaincy and the rigors of training for it as well as the research that is being done to support the value of the work of chaplains causes us to write this document. We want to broaden the concept of “the right to worship” to include “the right to spiritual care by qualified professional chaplains.” Just as it is assumed that hospice chaplains offer necessary care to the dying and their families, that veterans receive spiritual care in hospitals and homes, and that both public and private hospitals offer spiritual care to the sick, it should equally be assumed that persons with developmental disabilities have special needs in exercising their right to worship.

Many of the men and women we serve are profoundly spiritual people with the capacity to deeply move us. There are also some who are spiritually sick. Small group visits in the

cottages make a difference because these visits are tailored to each group. More than 10% of the population of SDC attends Sunday services and many more would benefit if not for mobility and transportation issues. The people who attend the Sunday “church” service at SDC do not respond or pray with their cognitive minds. They don’t identify with dogmatic explanations and they have a very short tolerance for spoken words. They are much more people of the heart who respond to body language, story, images and music expressed in a manner that enables as many as possible to understand. We cannot quantify the blessings received by the men and women we serve, yet we have observed persons expressing spiritual issues of remorse, anger at God, grief, or anxiety as well as joyful bliss, peaceful calm and a sense of purpose or self-esteem.

Professional chaplains today are endorsed by their religious leadership, study in seminary or its equivalent, and take additional training in health care settings. Some are also board certified. While chaplains are formed to minister within their specific faith tradition, additional training emphasizes providing interfaith spiritual care. Chaplains are trained to be available to everyone according to the other’s personal spiritual needs and perspective.

Spiritual care in hospices, with veterans, and in hospitals includes:

- Assessing patient and family for signs of spiritual and moral distress
- Discovering a patient’s self-understanding or “story” of their situation
- Identifying coping skills and sources of support
- Listening to spiritual and often emotional concerns including
  - powerlessness,
  - feeling isolated,
  - grieving and loss,
  - coping with change,
  - crises, or loss of faith
  - family concerns,
  - the need for forgiveness and/or reconciliation with others,
  - estrangement issues with one’s religious tradition,
  - ethical decision making,
  - support during emergent crises and death
- Charting assessments, interventions, results, and recommendations.

Patients are referred to outside religious leadership when appropriate. Prayers and blessings are prayed and sometimes rituals are performed. Staff are supported as well. In addition chaplains may organize and educate volunteers and sit on bioethics and palliative care committees as well as be on call for emergency or crises situations.

Research is clear that chronically ill persons who have a spiritual practice and or belong to a religious community of some kind fare much better over the long course of their illness. They tolerate more pain, heal faster with fewer complications, and are less likely to be repeatedly hospitalized. The men and women who currently live at SDC live with multiple levels of disability and declining states of health. Their need for spiritual care may be more acute than persons with chronic illness who are not burdened with cognitive disability. We believe that spiritual care can greatly enhance the transition of persons from SDC to the community, provide them with a means of processing change, and encourage an optimum new life.

Chaplain ministry at SDC currently includes:

Providing Sunday “Church”

The Catholic chaplain provides two Sunday services: one in the nursing side and one in the ICF side. In previous years, the Catholic service at 1:30 Sunday afternoon was “Church” for everyone who wanted to attend. It is a Catholic communion service, using the Catholic liturgical year (Advent, Christmas, Lent, Easter) according to the Catholic chaplain’s job description, but the Protestant chaplain shares preaching and other planning for the services. All are welcome. There is no discussion about who believes what. The service is designed for maximum participation from everyone with preaching through slide imaging and musical support. This service includes a joyful noise. Persons who would not be tolerated in outside community churches are welcome here.

#### Providing Jewish Holy Day Celebrations

Jewish holy days are also celebrated by the Jewish chaplain and collaborating staff. The Protestant chaplain currently lights Shabbat candles on Friday evenings in one of the cottages.

#### Providing Spiritual Enrichment

All three chaplains combined visit all but two cottages for spiritual enrichment. They use music, movement, story and prayer as well as personal interaction to offer soul enrichment and growth to the men and women who choose to attend. The cottage small group services emphasize personal dignity, encouragement for spiritual growth, prayers, and blessings, according to the style of each chaplain’s respective religious traditions. The small group setting enables each individual to be seen, but does not put anyone on the spot to talk or interact. Each person takes in what they take in and all are enriched. Over time, chaplains become familiar and personal relationships have grown with both individuals and staff.

The Sunday services, Jewish holy day services, and weekly small group services are repetitive encounters with the men and women who reside at SDC, enabling them to grow spiritually and in their capacity to worship as well as to cope with the stresses of their lives. Counting weekly, bi-weekly and monthly services by all three chaplains, we encounter 700-800 individuals a month to provide spiritual enrichment. Failure to provide continuing spiritual support in the community may be experienced keenly as loss. Furthermore most of the men and women who live at SDC do not have the words to ask for what they need spiritually.

Providing a 15 minute training during the Person Centered Planning training at new employee orientation. This presentation reflects on the spiritual nature of those we serve and distinguishes between the personal religious sensibility of staff and the spiritual needs and rights of the men and women who live here. We offer a definition of “spiritual” which embraces all people of all faiths, and explain the necessity to respect what is sacred for everyone. We explain the role of chaplains and what chaplains can do for staff. Finally, we offer a short film meditation on the spirituality of being alive on earth which again is sensitive to all faith traditions. The best caregivers for the developmentally disabled are those who are both professionally competent and spiritually aware because the developmentally disabled are very spiritually aware (non-verbally) themselves.

The Catholic chaplain serves on both the Bioethics Committee and the Palliative Care Committee.

Both the Protestant chaplain and the Catholic chaplain collaborate with staff and family to provide memorials or celebrations of life for the men and women who have lived here. We offer support to grieving family and staff and have on occasion provide memorials for staff persons.

We contact priests or local clergy/ministerial leadership when needed and can also collaborate with local clergy for celebrations of life.

We visit people who are in the hospital.

When invited, we visit persons at Northern Star

We counsel staff

The Catholic and the Protestant chaplains are members of the Sonoma Valley Ministerial Association, an interfaith community organization focused on building understanding and communication with local clergy and religious leadership, and to provide both events and community service.

Our Proposal:

We propose that there be traveling chaplains who visit individual homes to check in with the developmentally disabled persons living in the community, first as part of transitioning out of SDC, then as needed for others who may benefit. These chaplains can be contracted through the Community State Staff Program or other organization, either centrally, or regionally, to do the following:

1. Be present to men and women in their home or activity site.
2. Assess persons for signs of spiritual distress and provide interventions as needed.
3. Provide spiritual enrichment according to the home and the needs of the individuals.
4. Educate and support staff at the home sites when needed.
5. Provide memorials and grief support when needed
6. Support bioethical decision making and/or sit on palliative care committees
7. Educate volunteers if need be
8. Continue to provide Sunday church services which are tailored to the needs of people who might not be readily accepted in community churches.
9. Provide spiritual support for families
10. Collaborate with local clergy when needed.

Professional state employed chaplains are required to keep up to date on certification and continuing education. As the transition proceeds and the population of SDC drops, chaplains could begin to spend one day a week visiting those who have moved out. Over time, they would transform their ministry to care for developmentally disabled persons in the community.

Respectfully Submitted,

Rabbi Ira S. Book, Jewish Chaplain

Noelani Sheckler-Smith BCC, Catholic Chaplain

Rev. Kathy Speas, M.S.W., M.Div., Protestant Chaplain