Advance Directive Advisory Committee
Meeting Summary
February 23, 2023, 9:00-11:00

Welcome and Introductions

The Advance Directive Advisory Committee (ADAC) invited members to introduce themselves. Because the ADAC has several new members, we invited all members to share their backgrounds and discuss why they serve on the ADAC.

Structure and Membership of the ADAC

- Woody English, the ADAC Chair, provided background on the Committee, its structure, and its membership.
  - The ADAC is in statute. The ADAC has flexibility to determine its governance structure, set the frequency of meetings, and determine its agendas and priorities, as long as it meets statutory requirements.
    - For planning purposes, the ADAC has a steering committee comprised of the chair (Woody English), the vice chair (Eriko Onishi), staff from the Oregon Health Authority (Charina Walker), and a consultant who supports the work (Diana Bianco). This group helps plan agendas and follow up on action items.
    - The goal is that the ADAC meets least four times a year, though the ADAC can hold additional meetings if they choose.
- There are 13 positions for the ADAC that are defined in the statute. Below are those positions and the members who currently fill each one.
  A. One member who represents primary health care providers
    - Eriko Onishi

  B. One member who represents hospitals
    - Jenn Hopping

  C. One member who is a clinical ethicist affiliated with a health care facility located in this state, or affiliated with a health care organization offering health care services in this state
    - John Holmes

  D. Two members who are health care providers with expertise in palliative or hospice care, one of whom is not employed by a hospital or other health care facility, a health care organization, or an insurer
    - Woody English
    - Barb Hansen

  E. One member who represents individuals with disabilities
    - John Merrick Russell

  F. One member who represents consumers of health care services
    - Bill Hamilton

  G. One member who represents the long-term care community
    - Megan Resetar

  H. One member with expertise advising or assisting consumers with end-of-life decisions
    - Christine Deckum Harrington

  I. One member from among members proposed by the Oregon State Bar who has extensive experience in elder law and advising individuals on how to execute an advance directive

- Christopher Hamilton

J. One member from among members proposed by the Oregon State Bar who has extensive experience in estate planning and advising individuals on how to make end-of-life decisions
    - Meredith Williamson

K. One member from among members proposed by the Oregon State Bar who has extensive experience in health law
    - Deborah de Quevedo

L. Long Term Care Ombudsman
    - Fred B. Steele, Jr.

History of the ADAC

Woody shared the history of the ADAC in Oregon.

- In the 1990s Oregon established its Advance Directive. Prior to that, people could use a document called "Directive to Physicians" which was not utilized as much as people had hoped.
    - The medical community wanted something solid, so the Oregon legislature responded by putting the Advance Directive into law.
    - The advantage was that the health care community rallied behind it.
    - The disadvantage is that it was locked in law and could not be changed.
- At about the same time that the Advance Directive was drafted, the POLST was created. The POLST was not locked in statute like the Advance Directive which allowed the POLST to be updated and adjusted more easily over time. Also, there has been funding for administration of the POLST, which has allowed the board to grow, change, make updates, and educate the public and providers. There is little funding to support the work of the ADAC.
    - As a result of the high awareness of POLST and low awareness of the Advance Directive, people thought that POLST was necessary for any advanced care decisions.
    - When Medicare started paying providers for conducting advanced care conversations and documenting them, some healthcare systems, looking for something easy to measure, used the POLST for this because it's documented in medical records. As a result, a lot of POLST forms were filled out inappropriately.
    - This encouraged people in the community to lobby the state legislature (for three years) to update the Advance Directive. The updated Advance Directive is written into statute and can only be changed/updated through legislation.
    - Legislation (ORS 127.532) established the Advance Directive Adoption Committee and tasked it with drafting a new form. That work was completed in 2020. The ADAC also created a User's Guide to accompany the form. Through SB 199, the legislature updated the form in the 2021 legislative session and passed legislation that included the updated form.
    - SB 199 also included the continuation of the committee, renaming it the Advance Directive Advisory Committee. The ADAC is required to review the form and recommend changes as needed at least once every four years.
        - Now that the form has been updated in statute, the ADAC is focused on educating the public and providers on the Advance Directive and receiving feedback and input from users of the Advance Directive (in legal and medical communities) that could be used for further updates in the future.

- A plain language expert looked at the Advance Directive closely to try to make it as accessible as possible. The ADAC then made its recommendation to the legislature for what should be in the Advance Directive, but the final decision was up to the legislature, and they made some changes to what had been recommended.
- The form submitted to the legislature was at a 6th grade reading level. After it passed through the legislature, some parts of it were up to a 9th grade reading level.

Discussion and questions

- ADAC members posed questions about the history and functioning of the ADAC, including the following:
    - Was there a discussion of using the uniform model act and having the current directive as an example or an optional form?
        - No.
    - A couple of years ago there was an idea of having an Advance Directive for dementia, but it didn't make its way through the legislature. Where is that idea now?
        - There has been some discussion of that, though it has not ever been a formal agenda item, and we haven't been involved with any groups advocating for that.
        - That is the kind of topic committee members can bring forward to be discussed as a committee It may be outside our scope, but all committee members are invited to bring topics for discussion.
    - How does the Advance Directive in the 1980's (before it was put into law) compare with the Advance Directive today?
        - The Advance Directive in the 1980's started as a "living will" and followed the format of a Last Will and Testament. Shortly thereafter, the document evolved from just instructions to include the appointment of a "power of attorney for health care," which we are now calling a "health care representative."
        - Now the focus is on supporting health care decision making, which involves a partnership between patient and health care providers.
        - The format of the Advance Directive today is a collaborative discussion talking about prognoses, options, various treatment plans for situations that are often different from any standard definition of what someone might be going through, and therefore requires a deeper understanding of an individual's values and wishes than just checking on a treatment plan which is what the original Advance Directive relied on.
        - The Advance Directive is in a period of transition from something that is very formal and legal format to something that is more fluid and involves engaging with a health care representative.
        - Our focus now is on supporting a health care representative to represent an individual when a care plan is being decided on.
    - Why was "extraordinary suffering" taken out of the new form?
        - We need to review notes from ADAC meetings to help with recollection of the discussion and rationale.
    - In the first four-year term of the ADAC it was easy to measure success because there was a new Advance Directive form that was put into statute. How will we measure the success of this four-year term?

        - The question about how we measure success is a good topic to put on the agenda for future discussion.
    - What changes did the legislature make after the committee provided its recommendations?
        - We will find out the specific change the legislature made and report back.

2023 Goals

We discussed goals for 2023.

- Education about the Advance Directive is a priority goal.
- We should discuss how we might measure success.
    - One way to measure success would be to find out how many people have completed an Advance Directive, but not sure if or how that could be done.
    - Each hospital may have data around how many of their patients have an Advance Directive. A requirement for hospitals to provide that data could be written into law.
    - The CDC does keep record of Advance Directive use per state. In 2018 in the West Coast (Oregon included), 27% had an Advance Directive and that was one of the lowest in the country. The West Coast has one of the highest POLST usage rates.
    - If there is something more recent than 2018, we might be able to get access to that CDC data. We could also as OHA to see if they could help get us that data.
    - We have a registry for POLST which makes it easier to collect those numbers and other West Coast states don't have that.
    - Data from hospitals won't show everyone who has an Advance Directive since there are people who have completed one, but it is not submitted to the hospital until they are admitted.
    - Could we have the POLST registry expanded to also include Advance Directives? That is something we could discuss and possibly recommend.
- Could we propose to legislature a law that would require clinics and hospitals to have an Advance Care Planning Coordinator?
    - We could discuss that and decide if we want to make that recommendation.
    - What about Care Navigators at colleges who could have conversations about long term care and Advance Directives with students?

March Education Event

- Bill Hamilton shared information about an information/education session the ADAC is holding in March in a conference room at the Oregon Health Authority. It will be a hybrid event.
- This will be a test session to see how it might work in the future for ADAC members to provide education to the public about the Advance Directive.
    - Will be held on March 23rd as a "lunch and learn."
    - OHA is providing information about this event to the public.
    - The format of the meeting will be factual.
    - There will also be a survey at the end for participants to help us improve the sessions in the future.
    - We would like ADAC members to attend and/or invite others to attend.
    - At next meeting we will report back about the session and feedback we received.

Public Comment

- Sister Veronica Schueler - Chancellor of Archdiocese of Portland
    - Excited to hear about efforts about education and appreciated the comment that the Advance Directive should be a life-long document.
    - Regarding the event in March, could some people from her congregation attend?
        - It is open to everyone. It is test session. There will be more in the future.
    - There is a form on the OHA website, which is also in statute, regarding the appointment of a personal representative. It isn't the official Advance Directive form. Can it still be used?
        - The ADAC will review it and discuss the form at a future meeting.

Future Discussion Topics and Action Items

Potential future agenda items for the ADAC

- How the ADAC will measure success moving forward
- Review of appointment of a personal representative form on OHA website
- Debrief of education session and planning for future sessions
- Advance Directive for people with dementia

Action Items

- OHA will check on data for Advance Directive use in Oregon.
- We will look at what changed from ADAC's submission of the form to what the legislature adopted.
- We will look at why "extraordinary suffering" was taken out of the form submitted to the legislature.