

ACTION ITEMS FOR UNDERSERVED POPULATIONS SUBCOMMITTEE

I. Access to Palliative and End of Life Care

Racial Minorities

This subcommittee acknowledges possible reasons why minority communities access end of life care at far lower rates than their white counterparts:

Culturally, Latinos, African Americans and Asian Americans may have different attitudes and approaches to end of life of care. Also, African Americans may be particularly distrustful of the health care system because of past injustices perpetrated against them.

Economically, Maryland's poorest communities are disproportionately nonwhite. Because of financial constraints, some of these communities may not be able to fully survey and take advantage of their end of life care options.

Legally, many nonwhite immigrants are a mobile population without relatives and greencards. Many do not speak English well and are unaware of their rights to medical benefits.

In its initial step, the Council should embark upon an investigatory phase to gauge accurately the obstacles these groups face in accessing end of life care in Maryland. Once data gathering is complete, the Council should offer a detailed set of recommendations to address the state's shortcomings.

Children

We are concerned that inadequate attention has been paid to pediatric palliative and end of life care services. Most terminally ill children die in institutions because physicians are particularly reluctant to forgo curative therapies in favor of hospice services. Hospitals, in particular, offer a unique set of challenges because of the dearth of in-patient palliative care services to manage pain and because they are often insufficiently staffed to provide for the care needs of terminally ill children.

This subcommittee recognizes that although reimbursement is available for expensive hi-tech treatments for children, many insurers do not provide the same coverage for pediatric palliative care services. This Council should explore alternative reimbursement mechanisms for this type of care. Additionally, we believe the Council should look at ways to fund more nurses trained in providing palliative and end of life care services to children.

Dementia Patients

Because dementia patients have difficulty in expressing pain, they often do not receive proper management of their symptoms. To our knowledge no set of procedures exists to deal with this challenge and the Council should work on developing guidelines.

Also, we recommend that the Council assess how costs for hospice care of nursing home patients, who disproportionately suffer from dementia, are reimbursed and offer recommendations to help make the system more efficient and responsive to their needs.

Wards of the State

The State has the responsibility to provide end of life care to certain populations- prisoners, the mentally ill, the developmentally disabled, and foster children among others- in its custody. The Council should examine if policies and systems of accountability currently in place are adequate.

This subcommittee has particular questions about terminally ill children in foster care such as the process by which decisions are made when biological parents are incapable of doing so and when the state should seek guardianship. The Council should help navigate these difficult issues.

II. Tailoring Advanced Care Planning

Forms and Related Materials

The Council should ensure that the populations noted above have access to documents that are user-friendly and in the language with which they are most familiar.

Having the Conversation

Similarly, in establishing guidelines for advance care planning, the Council should be sensitive to the cultural concerns of different communities and the needs of certain populations.

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