

## Palliative and Hospice Care for Persons with Disabilities

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Palliative care and hospice care seek to provide comfort and relief to individuals with chronic or terminal illnesses and their families. Discussions about these health care options may be challenging and emotionally charged for individuals with long-term disabilities, especially for those who have faced difficult health crises in the past. Understanding the differences between palliative and hospice care, as well as understanding the historical fears within the disability community around end-of-life care, can help providers navigate such discussions with participants.

While both palliative care and hospice care focus on quality of life for participants, there are also key differences. Palliative care is specialized medical care focused on providing relief from physical suffering for people living with serious illnesses. Palliative care is appropriate for participants in all stages of a disease, not only those who are terminally ill, and may involve the use of life-prolonging medications. Hospice care, on the other hand, provides support and care for participants and their families in the last phases of a life-limiting illness. The focus of hospice care is on making terminally ill participants comfortable for the end of life, and it does not involve the use of life-prolonging medications.

To understand the fears many participants with disabilities may have about palliative and hospice care, it is important to understand this population's unique perspectives and the historical context that have led to their general fears and mistrust. Those with severe disabilities may have been told by health professionals that they will never regain functional ability and are therefore unable to live a full and meaningful life. Furthermore, the medical industry's historical view of persons with disabilities through the lens of a diagnosis or a "broken body" has added to participants' fears and suspicions of being viewed as only a diagnosis, and creates a greater challenge to discussions of palliative or hospice care.

Given this context, it is important to adopt strategies that introduce participants to palliative or hospice care in a way that mitigates these fears. A strong, trusting relationship between participants, providers, and care partners is essential when engaging in difficult conversations about these care options. Providers initiating the conversation should be sensitive to participant concerns and should actively listen to their fears. Encouraging staff to build relationships with participants helps improve their understanding of the lived experience of having a disability, which in turn can inform the nature, type, and amount of services that may be most appropriate. Developing rapport and a trusting relationship with the participant prior to the need to discuss palliative and hospice care is critical. By adopting these strategies, providers can create treatment plans that take into account the participant's experiences and health goals, and help alleviate their fear.

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