

# End of Life Care for People with Developmental Disabilities

## Philosophy and Recommendations

For many years, advocates have been demanding equal access, as well as equal rights for people with disabilities. This has resulted in numerous improvements and opportunities for individuals, including the right to plan their own lives, choose their own supports, and live their lives with dignity and respect. The emphasis has been on the similarities, not the differences, with the choices and opportunities afforded other people in our communities. No longer are institutional placements considered an acceptable alternative for individuals with developmental disabilities who need supports. Increasingly, the services are provided under Home and Community Based waivers, which vary in each state, but are all focused on community based services and natural supports. Over the years, ICF-MR facilities have also downsized with the current trend being small group homes of 4 to 6 people. These trends, along with others such as mainstream education, public policy changes and fair housing enforcement, have begun to ensure that people with developmental disabilities have the same rights to community living and participation. As with society in general, people with developmental disabilities are aging, and facing many of the same choices regarding retirement and living options that are faced by each of us. The life expectancy of an individual with developmental disabilities is within 5 years of a non-disabled person, based on current demographics. We have been discussing this issue for several years; assisting people with retirement and health care needs, and now have begun to discuss end of life care planning and options for people with developmental disabilities, that mirror the options available to the general public.

Realistically, we must recognize and strive to overcome the barriers that exist to end of life planning for people with developmental disabilities, before moving on to best practices and choices. End of life decision making is not a single event that occurs when faced with a critical illness, but, rather, an on-going series of choices, based on life experiences, family and friends support systems, as well as health issues. Our philosophy is that individuals with developmental disabilities should be allowed and encouraged to articulate these choices, throughout the course of their lives, so that their wishes can be respected.

We recognize that individuals with developmental disabilities face some unique barriers to end of life choices. First of all, they are often in a dependent condition, where others, including well meaning family members and guardians, are making decisions on behalf of the individual. This brings a whole range of legal and ethical issues to the decisions surrounding end of life care, particularly in the legal and health care arenas. Add to this barrier, the confusing maze of regulations that accompany the support system often accessed by people with developmental disabilities, and the problems become even more paramount.

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Many people with developmental disabilities receive services and supports through the Medicaid system, both for acute care and for on-going services. Each state has developed its own set of rules and regulations regarding person centered planning and legal guardianship options, in addition to “death reviews” and critical incident reporting processes. While we all recognize the rights of individuals with developmental disabilities to exercise choice regarding end of life care, we have often failed to provide individuals and their families with the training and support they need to make these choices. Additionally, we have failed to educate the health care community, at times the general public, regarding the differences in facing a terminal illness and living with a chronic disability. Several advocacy groups are, with good reason, expressing a growing concern with discussions of end of life care that preclude the use of life sustaining technology that many individuals with severe disabilities use every day. These often heated discussions regarding “futile care” are becoming more common in health care settings across the country as people struggle to make decisions for others, whose right to choice may not be respected.

Given these issues, it is even more important that we recognize planning for end of life care as an on-going activity in a person’s life, that begins well in advance of a terminal illness. Educating individuals about death, and the rituals accompanying death may be an appropriate place to begin in the natural process of everyday life. In addition to creating educational opportunities to discuss the cycle of life in all of nature, we must not deprive individuals of the opportunity to participate in the rituals of death, such as attending the funeral of a loved one, or visiting a cemetery where a relative is buried, or planning a part of a memorial service for a beloved friend. Teaching skills associated with comforting, recognizing disenfranchised grief and providing opportunities to discuss choices are also some of the first steps in the planning process. End of life care decisions may change with the passage of time, based on an individual’s life experience, therefore allowing opportunities to discuss these decisions within the context of natural experiences is the best way to begin planning end of life choices.

We believe that the full range of choices available in a community should also be available for people with developmental disabilities. Services such as hospice, home health, family support, health care and spiritual comfort should be available to individuals with developmental disabilities, regardless of where they live. The right to die at home should include supportive living residences and group homes that often provide services to people with developmental disabilities. This means that Medicaid funding must be flexible to support changing needs for a person with a terminal illness, direct support professionals and other staff must receive the training and support they need to provide end of life care and state and federal Medicaid regulations must treat death as a natural occurrence, rather than a critical incident. While these issues may seem individually, and collectively, overwhelming, much progress has been made in communities across the country to increase funding flexibility and to support choice in end of life treatment. Several states have developed protocols pertaining to their Medicaid regulations that treat anticipated death differently than unanticipated death in regulations and investigations. This separate process relieves caregivers of the trauma of investigation and treats death with the dignity and respect it deserves.

Health care providers must receive education in pain management for people with developmental disabilities, particularly as it pertains to end of life care. Family members and staff must communicate with physicians and other health care providers regarding an

individual's pain, especially when the person is not able to fully communicate to their health care provider. Hospice providers, while willing to provide services, may need training in the particular needs of a person with developmental disabilities and an understanding of the regulations governing Medicaid services, if the person they are serving is receiving services. Several years ago, CMS wrote a letter of clarification concerning ICF-MR regulations and made it clear that hospice services could be delivered in ICF facilities. Unfortunately, states have not uniformly interpreted this letter and barriers to this service delivery still remain.

Perhaps the biggest barriers to end of life care choices for people with developmental disabilities, particularly those with mental retardation, is in the legal arena. Conflicting laws and regulations concerning guardianship, informed consent, DNRs (do not resuscitate orders) and related health care decisions are fraught with barriers for individual choice. Planning for end of life care must begin with an understanding of state law and the individual's capacity to give consent. Several projects, conducted by bio-ethicists around the country are researching ways to support and teach choice. Building on the things we learn in these projects, we recognize that teaching individuals about choosing a health care proxy or making choices about advance directives is a lengthy process that must be carefully explained. With the same attitude of individual choice, guardians must endeavor to reflect the choice(s) of their family member or ward when making end of life care decisions. Encouraging guardians to make decisions in advance of a critical incident is paramount to sound decision-making.

Decisions must be made with a pro-disability attitude. We must be clear in our advocacy for individuals with developmental disabilities that each person has the right to life, despite the level of their disability. Every person has the right to choose curative care, even in the face of a dismal prognosis. The right to high-quality palliative care should also be fully extended to individuals with developmental disabilities who choose this end of life treatment option. Healthcare providers must recognize and value the difference between disability management and prolonging the end of life. We believe that people with developmental disabilities must have access to the full range of end of life care options that we want for all our citizens. Working together, in a pro-disability movement, we can insure that our system of care, including long term and acute care options, fully support an individual's choice.

In summary we offer the following observations and recommendations:

- Discussions regarding end of life care should not be a formalized one-time event, but rather part of a natural discussion that takes place over time. Opportunities for learning should be maximized and individuals with developmental disabilities should be allowed to participate in their culture's rituals around death, including funerals, remembrances and other activities that occur during the natural course of one's lifetime.
- Training should be provided for legal guardians who are not family members as well as for family members, who may be asked to make decisions regarding end of life care for a person with developmental disabilities. This training should include information about choices available to the general public such as hospice, pain management, and treatment options. Legal needs such as advance directives, guardianship paperwork and related issues should also be discussed.

- Advocating for a full range of end of life care choices for people with developmental disabilities, including hospice, pain management, organ donation, the right to have decisions legally recognized, and the option to change their mind regarding their end of life care wishes
- Healthcare providers must respect the rights of the person with developmental disabilities to receive the full range of medical options available. People with developmental disabilities must have their pain recognized and treated.
- The Medicaid system must allow the flexibility for a person to exercise their choices regarding end of life care. Funding must support the use of hospice or related services within the person's normal living environment. Confusing, conflicting regulations must be eliminated and natural deaths must be treated with dignity and respect, rather than suspicions and investigation.
- The legal system must recognize the choices of people with developmental disabilities and/or their guardians.

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