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End-of-Life Care Policies for People With an Intellectual Disability

Issues and Strategies

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It is estimated that more than 650,000 individuals with intellectual disabilities live with caregivers who are 60 or more years old. As they age, they face end-of-life issues in relation to their caregivers, as well as their own health care needs. This article examines some of the major issues concerning end-of-life care for people with an intellectual disability, presents findings of a recent national survey on end-of-life care vis-à-vis the policy implications, and describes some of the emerging strategies and innovations designed to promote improved end-of-life care.

In 1991, the coordinator of a community services unit at a Family Services agency received a call from the case manager of an Association for Retarded Citizens’ residence. The case manager requested consultation on how to support five residents of a group home for six older adults who had lived together for 10 years. One of the residents, a popular man in his 60s, had died a few days before. The residential staff was apprehensive about how to support the surviving residents. They were asking the case manager, “What do we do? What do we say? How do we talk about this with the other residents?” They were also concerned about possible reactions of residents to the future admission of another resident, about the residents’ withdrawal from activities, and about behavior changes.

The social worker receiving the call was so pleased that the agency had sought consultation that she readily agreed to provide the service. Shortly thereafter, however, she discovered that there were few references, guidelines, or resources on providing bereavement support to older people with an intellectual disability (ID), and even fewer references about support to staff or family at the end of life for older people with an ID (Barbera, Pitch & Howell, 1989; Deutsch, 1985; Emerson, 1977; Kloeppe & Hollins, 1989; Lavin, 1989; McDaniel, 1989). The paucity of the literature in this area contrasted sharply with the burgeoning literature on the general population’s dying and death, which addressed the needs, tasks, and rights of the terminally ill person and how palliative care could effectively assess, care for, support, and assist diverse dying persons. Bereavement and mourning, widowhood, special needs of children, and general issues of survivorship were also discussed in articles on theory, research, practice, and education about dying and death. There were abundant research and resources on education about dying and death for professionals, volunteers, families, and the general public. Where policy was concerned, supportive medical, legal, and financial policies had been formulated, implemented, and evaluated since the inception of the hospice movement, and additional federal legislation was in progress. In short, the consultant in this situation found herself extrapolating from the available literature on dying and death for the general population to the special needs of the population with an ID.

Fortunately, more articles and resources on end-of-life care for older people with an ID have appeared in the last decade, and the issue receives relatively greater recognition in terms of its ethical, legal, psychosocial, and policy implications (Blanck, Kirschner & Bienen, 1997; Botsford, 2000a, 2000b; Friedman, 1998; Fauro & Grimes, 1994; Harper & Wadsworth, 1993; Hedger & Smith, 1993; Kauffman, 1994; Luchterhand, 1998; Service, Lavoie & Herlihy, 1999; Wadsworth & Harper, 1991; Yanok & Beifus, 1993). Even now, however, research, interventions, best practices, and policies on end-of-life (EOL) care for older people with an ID remain neglected points on the continuum of issues for this population. In addition, although a life-cycle perspective is now applied in research about and practice with individuals with IDs, aging and the end of life continue to be not only the last but also the least studied stages of life.

In response to this gap, the goals of this article are threefold: to examine some of the major issues concerning EOL care for people with an ID, to present the findings of a recent national survey on EOL care vis-à-vis the policy implications for people with an intellectual disability, and to describe some of emerging innovations and developments in EOL care programs and policies that may serve to promote improved EOL care for this population.
Two approaches are employed in this discussion about EOL care policy for people with an ID. The first of these is a system perspective, which allows consideration of national as well as state, local, and agency factors that influence EOL care. The second is attention to the social construction of disability, consisting of the social meanings attributed both to disability and to individuals who are defined as having an intellectual disability. Concerning the terms mental retardation, cognitive disability, and intellectual disability, we have chosen to use the term intellectual disability (ID), while recognizing that there are other legal, professional, cultural, and social definitions and that the various terms are not necessarily synonymous.

**Historical Background**

Analysis of EOL care as a social policy for people with an ID begins with review of the history and effect of prior social policies on individuals with a developmental disability. U.S. social policies concerning people with an ID have historically used various medical, psychological, physical, and behavioral criteria and definitions for the manifest purpose of determining eligibility for services, benefits, and a range of interventions, which have included segregation in institutions, involuntary sterilization, and withholding of medical treatment for newborns and infants with a developmental disability (Edgerton, 1967; Frank, 2000; Groce, 1997; Linton, 1998; Morris, 1991; Pernick, 1996; Trent, 1994). These criteria and definitions, and in particular those associated with the medical model, have pathologized the behaviors, physical and cognitive characteristics, and morality of individuals with an ID—with the effect of marginalizing them socially and economically. Within the context of this history, there are formidable social, legal, ethical, medical, and ideological issues surrounding both EOL care and developmental disabilities in general. These issues also contribute to the intensity of the conflicts and ambiguities surrounding EOL care policy for individuals with an ID (McClimens, 2003).

Other major factors to be considered in the analysis of policy are the existing political and economic relationships of the stakeholders in the policy. These relationships are largely determined by the social constructions of disability, and as policy making is a political process, the political status of people with an ID is also implied by the social constructions. Stakeholders in social policies generally have competing or conflicting interests, particularly concerning definitions of who qualifies for services—in this case, who qualifies as "mentally retarded," "cognitively disabled," or "intellectually disabled," and who controls decisions about eligibility, access, and reimbursement for services believed to be appropriate for the population. Groups with a stake or investment in how disability is defined include not only individuals with an ID and their families, whose very lives are affected, but also the government that provides financing for benefits and services, as well as the various providers and their organizations who are reimbursed for such services as medical, rehabilitation, educational, residential, and vocational services.

Albrecht has compared five different models or social constructions of disability that are helpful in considering the implications of these constructions for the power relationships of the stakeholders in social policies concerning people with a developmental disability (Albrecht, 1992, pp. 85–86). Within the medical model, for example, the physician retains decision-making control, particularly if the host setting is a medical one. Providers from other settings, such as rehabilitative settings, may advocate for patient participation and assume that as rehabilitation professionals with essential knowledge and expertise, they also have a decision-making role. The individual with an ID and the family bring their own wishes, preferences, perceptions, values, and expectations to this process as well. However, the role of the individual with an ID is that of a patient who follows doctor’s orders. In terms of political status, this “sick role” bestows no power.

Providing another example of the implications of a social construction for social policy, Carder (1987) has described how the dying and death of a person with an ID was dealt with in institutional settings; for example, by the sudden removal and disappearance of a resident, with no explanations offered to other residents and no opportunities for their questions, farewells, expressions of grief, bereavement, or mourning. The professional consensus at the time was that people with an ID were incapable of understanding dying and death and that they would quickly forget the person who had died. The implications of this policy were that people with an ID had no right to information, to dying or death with dignity, to participate in the funeral rites of the general society, or to be acknowledged as valued people in life or death. Nor was it unusual for information to be withheld from them, frequently at family members’ request, about the deaths of family members, even parents and siblings. The rationalization for this policy was the belief that people with an ID should be protected because they were incapable of coping with such realities as death. Curiously, it was believed that they could cope with such unreality as their parents or other family members’ sudden, interminable absence from their lives because of “illness” or a really “long trip”—not uncommon explanations of such disappearances.


With funding from the Robert Wood Johnson Foundation, research conducted in several states to assess the effect of these policies has confirmed that individuals are being en-
couraged to choose service providers, develop individualized budgets for their supports, manage more of their care choices, and pursue personal goals. The studies have also documented positive outcomes in terms of the benefits of self-determination and choice in support services (Johnson, 2001). The Robert Wood Johnson Foundation also funded community-state partnerships to improve end-of-life care. These grants were designed to support the work of state-based task forces to identify and implement changes in policy and practice designed to improve EOL care. One of these grantees, the Midwest Bioethics Center, has addressed issues in EOL care for people with an ID; the outcomes from this project will be discussed in a later section.

**Issues in End-of-Life Care Policy for People With an ID**

In conjunction with Medicare, Medicaid is the primary public source of funding for services for individuals with developmental disabilities (Hanson, Neuman, Dutwin, & Kasper, 2003). Like many citizens dependent on Medicaid for health-care insurance, people with developmental disabilities frequently confront obstacles in obtaining medical and dental services in terms of accessibility, availability, timeliness, quality, and comprehensiveness (Neri, & Kroll, 2003; Scheer, Kroll, Neri, & Beatty, 2003). A decreasing number of physicians who accept Medicaid, an ever-changing formulary of medications covered by Medicaid, and the scarcity or lack of medical specialists who are available or willing to provide services to people with disabilities are factors that contribute to inadequate medical care (Hanson et al., 2003, 564).

In addition, although physicians may be more willing to prescribe pain medications for palliative care than for other care, they are still reluctant to prescribe to individuals who may not be able to communicate their pain and comfort level verbally or in terms of traditional assessment tools. In the confusing array and arrangements of physicians, specialists, pharmacies, and other health-care providers, people are also often unable to effectively advocate for their health-care needs (National Institute on Disability and Rehabilitation Research, 2003). Families, including aging parents, are sometimes available to provide advocacy, or advocacy may be allocated to direct support professionals.

At a recent forum sponsored by the Administration on Developmental Disabilities, in Washington, DC, representatives of the National Association of State Developmental Disability Directors and the Human Services Research Institute reported the findings of a quality assurance survey using core health indicators in seven states (National Core Indicators Phase IV, 2002). Health care was identified as the overarching issue for improving and ensuring the quality of life for people with an ID. A persistent theme of the findings was lack of medical oversight and problems that individuals encountered as they attempted to access generic, community-based health services. The survey also found that physicians were unaccustomed to working with individuals who might not verbalize symptoms, and that support staff who accompanied individuals to their medical visits were frequently untrained in observing and communicating signs and symptoms of an individual’s health-care needs, whether related to illness or to disability.

Not all states have hospice care as a Medicaid-covered service, which effectively prevents a person with an ID from accessing hospice care unless he or she also receives Medicare benefits. It has been estimated that more than 433,799 people with developmental disabilities live in Medicaid-supported programs or receive in-home supports (Braddock, 1999). Of these, more than 290,000 receive services in Home and Community Based Services waiver programs. Although the Home and Community Based Services program is more flexible than the Intermediate Care Facility–Mental Retardation program, there are still policy issues regarding EOL care options.

At the federal level, the Centers for Medicare and Medicaid Services have endorsed the use of hospice care in Intermediate Care Facility–Mental Retardation and Home and Community Based Services waiver programs. However, each state has developed its own policies and procedures, which may or may not include shared Medicaid payments for the service provider and the hospice agency. This complexity adds to the confusion surrounding EOL care, and the inadequacy of the payment structure sometimes forces hospice care to be delayed or denied. Many states do not have a flexible payment system to allow an individual’s needs to be reassessed or to allow additional or different health-care services to be provided as the person’s needs change. All of these factors converge to influence the type of care a person may be able to access at the end of his or her life.

For example, a person may have been living in a group home for more than 20 years when he or she is diagnosed with a terminal illness that requires nursing support. Hospice services can be accessed for nursing care; however, the group home provider may be unable to change the person’s service plan to add additional staff members to provide the daily supports. The payment system for services does not allow for a reassessment of the individual’s needs or increased funding for additional supports, particularly direct nursing supports. Providers are increasingly concerned with the individual’s care under these circumstances, as well as the liabilities that may result from attempting to provide care for an individual without adequate medical oversight. In this event, without the additional supports that the individual requires, the agency operating the group home may move the individual to a nursing home for EOL care.

Nowhere has the complexity of EOL care for people with developmental disabilities been more complicated than in the legal arena. Competency, always an issue in health-care decisions, becomes an even more complex issue for people with an ID (Flower, 1994; Friedman, 1998; Martin, Emmanuel, & Singer, 2000; von Guten, Ferris, & Emmanuel, 2000). The question of informed consent for a person with an intellectual disability is
particularly problematic at a time of crisis. Although a person’s competency is assumed by the courts and service providers in the absence of a legal guardian for an individual, health-care providers are reluctant to proceed with treatment, and are certainly reluctant to withhold it, without a legal determination of competency in the case of persons with an ID (Friedman, 1998). Given the risk of coercion by authority figures, the issue of undue influence from doctors, health-care workers, social workers, family, guardians/conservators, and friends further complicates legal determination of competence to make life decisions (Flower, 1994). As in the institutional era, with its paradigm of incompetence, even individuals with mild cognitive disability may have their competency to make decisions questioned by health-care providers. In addition, many people with a disability may be presumed to be characterized by “global incompetence,” when in fact they are quite able to communicate and make personal life-and-death decisions. Some individuals with an intellectual disability may also be able to make and communicate their preferences and decisions within the context of their relationships with family, other informal or formal caregivers, or other significant relationships.

In some cases, family members may be unable to obtain guardianship in a timely fashion and may, as a result, be denied the right to make legally binding decisions despite their long-term support of their relative. Family members, especially older parents, may not acknowledge the need for guardianship and, on the basis of their past experiences with health care, assume that they will be able to make decisions for their loved one. Imagine their surprise when confronted by physicians who refuse to acknowledge their decisions or input. In fact, many disability service providers have also been surprised when hospitals refused to recognize DNRs (do-not-resuscitate orders) and advance directives signed by a person with an ID whom the provider considered competent to make such decisions (King, 2002).

At a recent presentation at a Qualified Mental Retardation Professionals conference, three vastly different responses were reported when giving signed DNRs to hospitals in various areas of the country (King, 2002). One hospital accepted the DNR with no questions. One hospital simply refused to accept it, and the attending physician in the emergency room would not write a DNR order. The third hospital referred it to their Ethics Committee for review. Both lack of consistency and lack of flexibility can result in health-care providers’ rejecting the competence and capacity of a person with ID to make such decisions. As a result, their wishes and decisions about the end of their lives are often not respected or honored.

Even in states in which public guardianship programs exist, there has been little training for advocates and guardians about EOL care. For example, public guardians may state that their responsibilities “end at death.” They consequently do not view decisions about wills, burials, funeral arrangements, autopsies, and related issues as their responsibility. At a recent meeting regarding supports for an 89-year-old woman who was living in a community-based Medicaid waiver home and receiving an array of support services, the publicly appointed guardian stated that she was unwilling to sign advance directives and would only consider them “when the need arose.” The guardian did not see the necessity to engage the individual in EOL care discussions despite her advanced age. As a result, the older woman was denied the opportunity to make choices about her EOL care, to state her preferences for burial or funeral arrangements, or to formalize advance directives.

Although no one relishes such discussions, more people are recognizing the need to purchase “pre-need” funeral arrangements, put in place living wills that clearly state EOL care preferences, and communicate with families regarding wishes. We are even putting our choices about organ donations on our driver’s license and other documents to ensure that our wishes are known and respected. The general population is indeed reluctant to have these uncomfortable conversations, and there are complexities of interpretation and implementation of the policies “in the streets” (Stowe & Turnbull, 2001). The policies for making and communicating their wishes, however, are “in the books.” For an individual with an ID, this is not the case.

Weighing in on this issue also are self-advocacy groups, such as Not Dead Yet, who are outspoken in their opposition to the effect of prejudicial social attitudes on the quality of life and death of individuals with a disability (Singer, 1994). Where EOL care policy is concerned, these groups have pointed out how devaluing attitudes, such as the belief that living with a disability is a fate worse than death, may encourage the withdrawal of treatment or the physician-assisted suicide of a person with a disability in the guise of promoting the “right to die” or “death with dignity” (Johnson, 2003; The Resistance, undated; Taylor, 2000).

**Current Status of EOL Care**

Key questions for research about EOL care for older people with an ID are, “What are the barriers to people with IDs choosing how they wish to be cared for at the end of their lives?” and “To what extent do existing medical and legal policies acknowledge and promote the rights and needs of older people with an ID where EOL care is concerned?”

A recently completed national survey of organizations providing services to older adults with ID provided some findings relevant to answering these questions (Botsford, in press).

To explore the status of EOL care for older adults with an ID, The Volunteers of America, Inc., surveyed administrators of 500 organizations, 32% (160) of whom responded, and all of whom provided services to older adults with ID (Botsford, in press). Some of the major findings from the study were

1. In testing differences among the ratings administrators gave to the current need, priority, and resource allocations for EOL care in their or-
organization, their mean ratings of the current need for EOL care was found to be significantly higher than the means of the administrators’ ratings of either the organizational priority of EOL care or the organizational allocation of resources for EOL care.

2. Only 43% of the administrators indicated that EOL care training was available for their staff, and only 12% included information on EOL care in annual staff orientations.

3. Administrators identified their primary administrative problems in providing EOL care as regulations about levels of care, approval of waivers for additional equipment or staffing, reimbursement issues, regulatory/reimbursement pressure to fill residential beds quickly, and concerns about agency liability. The difficulty of obtaining approval of waivers and reimbursement issues were identified by more than 70% of the administrators.

4. Where community networks were concerned, administrators identified gaps in services, problems in care coordination, community providers’ lack of education about people with an ID, and the reluctance of other providers to serve consumers.

5. Chief among administrators’ concerns about staff providing EOL care was the unavailability of direct care staff and nursing and medical staff (79%). They also indicated that staff members were concerned about their liability (58%), their lack of training in EOL issues (72%), and how to respond to families (62%).

An example of the staff’s concern about their liability in providing EOL care is the process of “death reviews” by state Medicaid offices. Because of regulations regarding abuse and neglect as well as other state regulations, deaths in programs for people with developmental disabilities are often treated as investigative events, even when death from natural causes has been anticipated. In several states, for example, all deaths of “class members,” individuals who have moved to community-based services from institutions, are investigated and reviewed by numerous state officials. The actions of staff members, including direct support staff, case managers, and nurses, are reviewed and questioned by a committee of state regulators, including medical personnel (usually a physician and a nurse, as well as others), regardless of the individual’s diagnosis or the circumstances surrounding his or her death (i.e., hospice care). Such processes increase the apprehensions of staff members providing EOL care.

The findings of the study underscored the need for providers to train and educate caregivers, including medical and palliative care providers, in EOL care. Cross training of caregivers was indicated, in that health and palliative care workers would benefit from training to meet the needs of persons with an ID, whereas people caring for people with an ID would benefit from training in provision of palliative and EOL care. In addition, the study identified obstacles presented by agency, state, and national systems, such as approval of waivers; adequate funding for staff—particularly medical staff; dysfunctional regulations, such as the indiscriminant “death reviews”; and reimbursement regulations that hampered timely provision of hospice care.

Emerging Strategies and Innovations for Improving EOL Care

Development of Guidelines for Decision Making

Guidelines for health-care decision making, including EOL care decisions for people with a developmental disability, have been developed by several organizations (Blanck, Kirschner, & Beiner, 1996; Friedman, 1998; Kapp, 1990, 1991; Midwest Bioethics Center, 1996; G. Stein, personal communication, March 24, 2003). As discussed previously, advance directives and informed consent depend on definitions of capacity to make and communicate choices. However, in the cases of people with Alzheimer’s or other dementias, mental illness, and people with an ID, the assessment of capacity is complex and problematic. New assessment tools promise to give these populations greater input into their care by allowing assessment of “decision-specific capacity,” “assisted capacity,” “in-context capacity.” Other tools to assess EOL wishes and preferences concerning surrogates and guardians are also being developed.

The identification and management of pain is a cornerstone of palliative care. For this reason, there is a need to work within the medical community to develop protocols for pain expression and thereby affect pain management for individuals with an ID who are terminally ill. Developing assessments useful for pain identification would greatly enhance EOL care for people with an ID. An important contribution that these guidelines and new assessment tools can make is to provide a springboard for policy discussions, for “stakeholders” to communicate and negotiate about definitions, concepts, tools, measures, and systemic changes involved. The guidelines represent a critical staging point in the evolution of policy development.

An Umbrella of Developmental Disability, Hospice, and Aging Services With Overarching Policies, and Programs

Across the country there are numerous examples of developmental disability service systems and aging service systems forming coalitions (Ansello & Google, 2000). These systems have historically had little dialogue, but they are all dealing with aging consumers whose needs increasingly affect both service systems (Braddock, 1999). For years, providers of aging
services excluded older people with developmental disabilities, and although this continues to be the norm, more providers are including seniors with disabilities within their traditional services. By forming closer linkages, the aging system and the developmental disability system address the needs of aging caregivers, of aging individuals with developmental disabilities, and of older people dealing with EOL issues. At this point, some advocates for older people and for people with a disability are converging to address the need for structural reforms, to reduce or eliminate barriers, and to increase program responsiveness (Kennedy, 2002).

Similarly, some hospice providers are expanding services to include individuals who previously lived in state institutions and who transitioned to community settings. As aging individuals and individuals with extensive medical needs have left the institutions, health-care providers, including hospice services, have begun to integrate these individuals into community-based services. Training, planning sessions, and medical advocacy provided by developmental disability service systems and designed to help individuals transition into generic supports have enabled some individuals to remain in their community-based homes to the end of their lives.

Some of the issues in establishing linkage between hospices and providers of services for people with an ID are access, coverage, and benefits from one provider system to another. Formal interagency agreements at the community and regional levels are steps in mezzo-policy development. For example, in some cases, providers are developing community networks of services by means of memoranda of understanding, in addition to intensive cross training of staff members. In effect, through collaboration, these networks are incrementally expanding the capacity of the systems to provide more individualized and appropriate EOL services.

**Education, Training, and Consultation**

In 1998, a New York State interdisciplinary task force consisting of representatives from public and private organizations developed a monograph and curriculum on EOL care for staff members working with older people with an ID (Botsford & Force, 2004b). The task force included interdisciplinary representatives from the New York State Office of Mental Retardation and Developmental Disabilities, hospices, private organizations providing residential and other services to people with an ID, and Marist College. The task force produced the monograph, a supporting resource manual, and a 1-day training seminar on EOL care for providers, family members, and consumers. After piloting the training program, the task force subsequently received funding from the New York State Office of Mental Retardation and Developmental Disabilities, the New York State Developmental Disabilities Planning Council, and the New York State Association for Retarded Citizens, Inc., to implement and evaluate the curriculum by conducting staff development and training in EOL care throughout the state. In response to announcements of the availability of the monograph, requests for copies were received from all over the world, including Australia, Denmark, England, New Zealand, and India. The monograph subsequently went into a second printing and was translated into Spanish. These responses were clear indications of the widespread need for such information.

Largely because of the efforts of a state task force in New Jersey, a 5-day course on EOL and palliative care is now required in New Jersey for all state guardians of people with disabilities, which includes 30 social workers and caseworkers. The task force is currently engaged in commenting on proposed EOL regulations that were recently published by the New Jersey State Division of Developmental Disabilities. In addition, a New Jersey Ethics Network established by the task force makes ethics consultation available to health-care professionals, families, guardians, advocates, and people with a developmental disability (G. Stein, personal communication, March 24, 2003).

Several training curricula for helping adults with an ID understand dying, death, loss, and advance directives have also been developed (Hedger & Smith, 1993; Sterns, Kennedy & Sed, 2000; Yanok & Beifus, 1993). The Midwest Bioethics Center and the Institute for Human Development at the University of Missouri at Kansas City have developed a group process model for helping individual participants, family members, and friends to think through stressful EOL scenarios and attitudes toward life-sustaining treatment and other EOL issues, including completion of advance directives (Midwest Bioethics Center, undated). These programs may enhance the capacity of people with an ID to participate in decision making about their EOL care and also to demonstrate the limitations of traditional mental status assessments.

Where professional education is concerned, numerous professional organizations have demonstrated a commitment to improving EOL care for the general population and to raising the standards of education and practice of practitioners in nursing, hospice care, medicine, social work, psychology, clergy, public health, and law. In addition, there are hospice organizations, foundations, and professional organizations dedicated to promoting improved EOL care. To date, however, the special needs of older adults with an ID at the end of life have not been specifically addressed by most human services professions. For this reason, the development and integration of curricula and ongoing training resources for professional education about EOL care for older adults with an ID is a priority. Given the availability of resources and curricula for education about EOL care for people with an ID, inclusion of such material in existing curricula on EOL care for physicians, nurses, social workers, hospice workers, clergy, and other professionals would promote wider awareness and knowledge about the need of this special population for community-based professionals.

Person-centered planning is the accepted modality for developing service plans for individuals with an ID in the Medicaid system. Training for caseworkers on how to initiate...
planning for EOL care would increase the likelihood of individuals with IDs and their families actually expressing their desires and preferences for EOL care, funeral arrangements, burial plans, and other related topics that are frequently omitted from person-centered planning sessions.

**State-Level Policy Innovations**

The state of Oklahoma recently drafted a policy on EOL care for people with an ID who receive services in Medicaid-funded programs (OAC 340:100-5-262). The policy statement reads, “The Developmental Disability Services Department (DDSD) affirms life and regards dying as a normal process which should neither be hastened nor prolonged. DDSD encourages individuals to fully exercise their rights and make decisions about end of life issues that allow them to live with dignity and comfort.” In addition, Oklahoma developed rules that apply to the use of hospice, case management responsibilities, nursing care, and death review policies for individuals who are receiving EOL care in supported living settings: “Rules in this section apply to DDSD staff and to service providers who are contracted, licensed, or funded through the Home and Community-Based Waiver or DDSD state funds to persons who have been certified by a physician to be terminally ill. A person is considered to be terminally ill if he or she has a medical prognosis of life expectancy of six months or less if the illness runs its natural course” (OAC 340:100-5-26).

This policy reflects integration at a state level among the state’s departments of mental retardation and aging, as well as with provider groups, family members, and other concerned parties in the state of Oklahoma. Although the policy is too recently on the books and on the streets to be evaluated for its effect on the quality of EOL care, it is indicative of state-level policy innovations in EOL care for people with an ID (Stowe & Turnbull, 2001).

**National Initiatives**

In the fall of 2001, Volunteers of America, Inc., a national provider of human services, received a grant from the Administration on Developmental Disabilities, with matching funding from the Project on Death in America of the Open Society Institute, to lead a national initiative to improve EOL care for people with an ID. The 3-year project, Last Passages, is a demonstration project designed to help redefine dying and death from being a “critical incident” to being the natural end of the life cycle.

Through the National Association of State Developmental Disability Directors, the Last Passages project conducted a national survey, findings of which were reported earlier, to identify policies, programs, and quality assurance practices that acknowledge the rights of individuals with an ID who have a terminal illness. The project replicated the successful New York State training model in Oklahoma and disseminates information via a Web site (http://www.albany.edu/ ss/w/research/ endoflife.html) and is hosting a national planning conference for professionals, providers, families, and consumers around the country.

**National Policy Developments**

Senate Bill 2857, a bill “to amend titles XVIII and XIX of the Social Security Act to improve the requirements regarding advance directives in order to ensure that an individual’s health care decisions are complied with, and for other purposes,” was introduced into the Senate in August 2002 and referred to the Committee on Finance (S. 2857). Also known as the Advance Planning and Compassionate Care Act of 2002, the bill would develop standards and measures to assess EOL care, study implementation of a national uniform policy on advance directives, focus on improving policies related to the use of advance directives, provide a national information hotline for EOL decision making and hospice care, and provide for demonstration projects for innovative and new approaches to EOL care for Medicare and Medicaid beneficiaries. It would also establish a 15-member EOL care advisory board but did not explicitly require representation of people with a developmental disability. With effective advocacy, coalition building, and lobbying, this bill could promote the access, availability, and quality of EOL care for people with an ID at a national level.

**Conclusion**

Policy developments in EOL care for people with an ID are emerging at the micro, mezzo and macro levels. As these policies continue to evolve incrementally, the ethical, legal, medical, and multisystem dimensions of EOL care for people with an ID continue to create strains and tensions that challenge people, programs, and providers at agency, state, and national levels. These characteristics of the process are not unique to policy development in the area of EOL care for people with an ID.

EOL care for people with an ID has been affected by the structural and systemic shifts to community-based services, by social policies establishing civil rights for people with developmental disabilities, and in response to these policies, by agencies’ development and adaptation of policies and programs that recognize such civil rights as self-determination, inclusion, participation, equity, and autonomy.

Some of the barriers to access, availability, equity, and quality of EOL care for people with an ID reflect broader problems with the national health-care system. Among these problems are the increasing shortage of nurses and medical personnel, continuing shortage of medical personnel specializing in care of people with developmental disabilities, cost-containment efforts, strategies for rationing health care, and the complex, fragmented regulations and financing of health care in the United States. Where legal barriers are concerned, key issues are criteria for informed consent, capacity, and competence, with their implications for civil rights and decision making about EOL care.
Negative perceptions about people with a developmental disability and about aging, dying, and death continue to present barriers that require continued public education as well as focused instruction for professionals and service providers in the community (i.e., in hospitals and hospices, and for public health and other providers). The benefit of education concerning advance directives and EOL issues for people with an ID and their families has been demonstrated.

Although closer integration of aging, developmental disability, and hospice-care systems expands the capacity of the systems to be more responsive to needs, it also requires greater flexibility in service delivery, regulations, and financing. As a result, these systems are simultaneously struggling with the need for both flexibility and uniformity, or at least consistency, in such areas as standards for care, coordination of services, and reimbursement.

Evaluation and diffusion of the outcomes of state- and foundation-sponsored demonstration programs are likely to promote improved EOL care. In addition, national initiatives are aiding in diffusion of policy innovations, in part by facilitating interstate communication among policy-making officials in state developmental disability service organizations. The recent proposal of a bill for a national policy on EOL care may provide an opportunity for advocates to ensure that the concerns and needs of people with an ID are included.

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