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Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING FOR PEOPLE WITH INTELLECTUAL AND PHYSICAL DISABILITIES

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TABLE OF CONTENTS

I. INTRODUCTION.....	1
II. WHO ARE PERSONS WITH DISABILITIES?.....	2
III. DISABILITY COMMUNITY PERSPECTIVES.....	5
A. Advance Care Planning for People with Physical Disability.....	7
B. Advance Care Planning for People with Intellectual Disability.....	10
IV. GAPS AND BARRIERS.....	17
V. TRENDS	19

I. INTRODUCTION

The concerns, perspectives, and values of people with disabilities have often been overlooked in the extensive research, programs, and policies regarding advance directives, advance care planning and end-of-life care more generally. In spite of the limited programming and research, people with disabilities need to plan for times of serious illness in order to receive good end-of-life care and have their wishes respected. Following lengthy histories of societal abuse, neglect, and prejudice, advance care planning is necessary to assure that people with disabilities have access to necessary care, services, and supports, as well as inclusion in the societal dialogue about care near the end-of-life.

This paper describes the current status of advance directives and advance care planning in the disability community and identifies where gaps exist in policy, practice, and research. The aim is to better assure that the needs and issues of people with disabilities are considered and integrated into new policies designed to promote effective advance care planning. This report reviews professional literature, consumer materials, and Internet sites pertaining to advance care planning, surrogate decisionmaking, and end-of-life care for people with physical and intellectual disabilities.

II. WHO ARE PERSONS WITH DISABILITIES?

Although there is no general consensus as to who are people with disabilities, comparable definitions of disability have been developed for a range of clinical, policy, demographic, and research purposes. Asch and Mudrick have found agreement that people with disabilities:

- have a permanent or chronic physical or mental impairment or condition;
- the impairment or condition may differ in degree of severity;
- the impairment or condition may differ in degree of visibility to others; and
- the age of onset of the impairment or condition varies by individual.¹

Legal/policy definitions of disability have been developed in recent decades to protect individuals from discrimination in the most important components of American life -- employment, housing, and public accommodations that include schools and universities, settings for the delivery of health care and social services, business and commercial services, recreational/cultural programs, transportation, and telecommunications. Functional definitions of disability are provided by the Federal Rehabilitation Act of 1973 (for federal agencies) and the Americans with Disabilities Act (ADA) of 1990 (for state and local governments and private entities). Although the parameters of these definitions have been expanded and narrowed by various court decisions, in essence:

The term 'disability' means, with respect to an individual: (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such impairment; or (C) being regarded as having such an impairment.²

According to the U.S. Equal Employment Opportunity Commission, the ADA covers persons with impairments that:

Substantially limit major life activities such as seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working...[I]ndividual[s] with epilepsy, paralysis, HIV infection, AIDS, a substantial hearing or visual impairment, mental retardation, or a specific learning disability [are] covered.³

Furthermore, the Individuals with Disabilities Education Improvement Act of 2004, which applies to educational services for children requiring special instructional

¹ Asch, A & Mudrick, NR, "Disability," *Encyclopedia of Social Work*, 19th Edition (NASW: Washington, DC, 1995), 752-761.

² ADA of 1990, 42 USCA § 12102(2).

³ U.S. Equal Employment Opportunity Commission, "Americans with Disabilities Act, Questions and Answers." Downloaded on 4/3/07 from <http://www.usdoj.gov/crt/ada/q%26aeng02.htm>, citing its regulations.

methodologies, provides definitional guidance on the conditions that affect a “child with a disability.” These conditions include children who need special education and related services due to: “mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities.”⁴ This illustrative listing of conditions in children might be used to apply to individuals throughout the lifespan.

Professional and consumer literature may use the following terms to characterize people with disabilities:

- “Physical disability,” to describe orthopedic and mobility impairments, as well as sensory limitations such as vision and hearing, and speech impediments.
- “Developmental disability,” defined as a “severe, chronic disability...that: (i) is attributable to a mental or physical impairment or a combination of mental and physical impairments; (ii) is manifested before that individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in three or more...major life activit[ies].”⁵ More commonly, the term “developmental disability” is used to apply to people with intellectual disabilities as a result of mental retardation. In recent years, the terms “developmental” and “intellectual” disabilities are preferred as descriptive terms to “mental retardation.”⁶
- “Cognitive disability,” resulting from neurological impairment at any age. Such a disability may be early onset and also called an intellectual or developmental disability, or later onset due to traumatic injury (such as head trauma from automobile or other accidents) or medical condition (such as Alzheimer’s or Parkinson’s diseases).
- “Psychiatric disability” to describe long-lasting behavioral, mental health, or emotional conditions.
- Individuals may be “dually diagnosed;” in other words, have concurrent diagnoses or labels of multiple disabilities, such as intellectual and psychiatric disabilities.

The *2005 Disability Status Reports*, compiled by the Rehabilitation Research and Training Center on Disability Demographics and Statistics at Cornell University estimates that 7.8% of the United States population has a physical disability, defined as “a condition that substantially limits one or more basic physical activities such as

⁴ Individuals with Disabilities Education Improvement Act of 2004, 20 USC § 1401(3).

⁵ Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 USC § 15002(8)(A).

⁶ AAIDD, “*Mental Retardation is No More -- New Name is Intellectual and Developmental Disabilities.*”

Downloaded on 4/3/07 from http://www.aamr.org/About_AAIDD/MR_name_change.htm.

walking, climbing stairs, reaching, lifting, or carrying.”⁷ In addition, The Arc estimates that between 1% and 3% of Americans has an intellectual disability.⁸

Although a variety of definitions of disability are used, for the purposes of this paper, we are using the following definitions:

- “Intellectual disability” refers to people with cognitive limitations, primarily resulting from mental retardation, at varying degrees of severity (commonly diagnosed through IQ measures as mild, moderate, severe, or profound), with onset at birth or very early in life.
- “Physical disability” refers to individuals with irreversible, serious orthopedic and mobility impairments, such as spinal cord injury, paralysis, cerebral palsy, multiple sclerosis, muscular dystrophy, and congenital conditions. This paper focuses on physical disability acquired during childhood, adolescence, or as a younger adult, although these individuals may have limitations comparable to with those with chronic illness (such as heart disease, cancer, renal disease, or HIV) or age-related medical impairment (such as Alzheimer’s or Parkinson’s diseases). In addition, while individuals can have both physical and intellectual disabilities, the term “physical disability,” as used in this paper, does not include those with limited intellectual capacity. The purpose of this narrower definition is not to further “balkanize” people with disabilities, but to assure that the unique perspectives of this often overlooked community are appropriately addressed; there is substantial literature and discussion on advance care planning for people with chronic illness and age-related medical impairment.

⁷ Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC), *2005 Disability Status Reports* (Cornell University: Ithaca, NY, 2005). Downloaded on 8/23/07 from http://www.ilr.cornell.edu/edi/disabilitystatistics/StatusReports/2005-pdf/2005-StatusReports_US.pdf?CFID=23655795&CFTOKEN=23636838.

⁸ The Arc, *Introduction to Mental Retardation* (The Arc: Silver Spring, MD, 2004). Downloaded on 8/23/07 from <http://www.thearc.org/NetCommunity/Document.Doc?&id=143>.

III. DISABILITY COMMUNITY PERSPECTIVES

Are issues of advance care planning the same for all individuals, regardless of the presence of a physical or intellectual disability? Or does having a physical or intellectual disability -- and responding to the reaction of health care professionals and the wider society to disability -- influence one's experiences, attitudes, and values on matters related to advance care planning? Because of a lack of research, the answers to these questions are largely unknown.

As a starting point, the framework for advance care planning applies equally to all. All individuals have legal rights and personal interests in preparing advance directives and engaging in planning conversations with family members, significant others, and health care professionals. Although these rights may be constrained by diminished decisionmaking capacity, even those with limited capacity should be encouraged to participate in advance care planning to the extent their abilities allow. So why consider advance care planning for people with disabilities as a separate, significant issue?

There is an extensive history of discrimination and stigma against people with disabilities that has often impeded their full participation in society. In enacting the ADA -- designed to remediate years of discrimination, stereotyping, and neglect -- Congress found that:

Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.⁹

Unfortunately, such discrimination has also included mistreatment by the health care system and lack of access to care.¹⁰ Such bias may come in the form of paternalistic attitudes,¹¹ institutional abuse,¹² environmental barriers,¹³ and questionable care.¹⁴

⁹ ADA, 43 U.S.C. § 12101(a)(7).

¹⁰ ADA, 42 U.S.C. § 12101(a)(3).

¹¹ Gill, C, "Health professionals, disability, and assisted suicide: An examination of relevant empirical evidence and reply to Batavia," *Psychology, Public Policy, and Law*, 2000, 6:526-545.

¹² See practices at Willowbrook Developmental Center, described in Beauchamp, TE & Childress, JF, *Principles of Biomedical Ethics*, 5th Ed. (Oxford University Press: Oxford, 2001): 428-430; Gordon, H, "After Willowbrook," *The New York Times*, September 27, 1979. Downloaded 8/29/07 from <http://select.nytimes.com/mem/archive/pdf?res=FA0D1EFB3D5C12728DDDAE0A94D1405B898BF1D3>.

¹³ Centers for Disease Control, "Environmental barriers to health care among persons with disabilities -- Los Angeles County, California, 2002-2003," *MMWR Weekly*, 2006, 55:1300-1303. Downloaded 8/29/07 from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5548a4.htm>.

Articles and websites of disability organizations evince a profound struggle in the community for respect, humanity, and access to care. This worldview has been well-articulated by attorney Harriet McBryde Johnson in *The New York Times Magazine* in an article describing her dialogues with bioethicist Peter Singer:

The peculiar drama of my life has placed me in a world that by and large thinks it would be better if people like me did not exist. My fight has been for accommodation, the world to me and me to the world. As a disability pariah, I must struggle for a place, for kinship, for community, for connection...I am still seeking acceptance of my humanity.¹⁵

Arguably, the “similar experiences of stigma, isolation, rejection, and discrimination” faced by all persons with disabilities foster the creation of a minority, perhaps cultural, community, whose unique needs should be considered, addressed, and included in policy analyses of advance care planning.¹⁶

Finally, advance care planning for people with disabilities may reflect some different considerations about specific life-supporting interventions. People with no significant history of disability may clearly indicate in their advance directives preferences to forgo life-sustaining measures, such as ventilators or artificial nutrition and hydration. However, for some people with disabilities, these interventions may represent routine care that supports everyday life. For example, some people with Duchenne’s muscular dystrophy use ventilatory supports successfully for many years;¹⁷ individuals with certain developmental disabilities may obtain daily nutrition from feeding tubes.¹⁸ While such ongoing care may be desirable for these individuals, some non-disabled people may find these interventions unacceptable. Although it is not known whether such views regarding life-sustaining care, which often focus on specific medical interventions rather than the clinical circumstances, differ between persons with disabilities and non-disabled persons. Knowing whether different preferences exist is central to understanding how to better promote advance care planning among diverse groups.

¹⁴ Bach, JR, “Threats to ‘informed’ advance directives for the severely physically challenged,” *Archives of Physical Medicine and Rehabilitation*, 2003, 84:S23-S27.

¹⁵ Johnson, HM, “Unspeakable conversations,” *The New York Times Magazine*, February 16, 2003. Downloaded 4/3/07 from <http://query.nytimes.com/gst/fullpage.html?sec=health&res=9401EFDC113BF935A25751C0A9659C8B63>.

¹⁶ Asch, A & Mudrick, NR, “Disability,” *Encyclopedia of Social Work*, 19th Edition (NASW: Washington, DC, 1995): 752-761; also see, Treloar, LL, “People with disabilities -- The same, but different: Implications for health care practice,” *Journal of Transcultural Nursing*, 1999, 10:358-364.

¹⁷ See for example, Bach, JR, “Threats to ‘informed’ advance directives for the severely physically challenged,” *Archives of Physical Medicine and Rehabilitation*, 2003, 84:S23-S27.

¹⁸ See for example, Strauss, D, Kastner, T, Ashwal, S, & White, J, “Tubefeeding and mortality in children with severe disabilities and mental retardation,” *Pediatrics*, 1997, 99:358-362.

A. Advance Care Planning for People with Physical Disability

There are limited research studies, position papers, or materials on advance care planning about or for people with physical disabilities. In view of the extensive professional literature and discourse during the past two decades on end-of-life and palliative care, as well as on advance care planning and health care decisionmaking, it may appear that the attitudes and concerns of people with physical disabilities have largely been absent from the radar screen of many in the health professions, even in the literature concerning end-of-life care and diverse cultural communities.

While the literature on advance care planning for people with physical disabilities is limited, disability theorists, advocates, and organizations have addressed related issues of autonomy in end-of-life decisionmaking, mainly in the context of assisted suicide and surrogate decisionmaking. First, because of a history of unequal access to health services, advocates forcefully responded to societal discussions during the 1990s and beyond on whether or not assisted suicide should be legalized and on the impact of assisted suicide on the disability community. At the same time, the legal battle over the care for Terri Schiavo encouraged discussion regarding the parameters of surrogate decisionmaking on behalf of people with disabilities who lack decisional capacity. Debate regarding these matters provides some insight on the disability community concerns that may influence advance care planning, such as the degree to which health care professionals (and society) value and respect the lives and perspectives of people with disabilities, as well as overall access to health care.

Policy and professional discussion on the legalization of assisted suicide resulted in numerous articles, primarily (although not entirely) opposed to physician aid-in-dying.¹⁹ Gill examines the literature on the attitudes of health care professionals on disability, and relates these attitudes to perspectives on assisted suicide and a lack of regard for people with disabilities. In contrast to studies finding that most people with disabilities are “glad to be alive” and rate “the quality of their lives as good to excellent,” regardless of “degree of physical impairment,” she describes research on the attitudes of health care professionals towards people with disabilities that:

Are as negative as public attitudes, and sometimes more so. More specifically, health professionals significantly underestimate the quality of life of persons with disabilities compared with the actual assessments made by persons with disabilities themselves...Such pessimistic professional views of life with disability are implicitly conveyed to patients and their families while they are in the midst of decisionmaking about new disabilities...[and] are related to professionals' views about whether or not to offer life-sustaining treatment options to persons with disabilities.²⁰

¹⁹ See for example, a range of articles on assisted suicide through a disability perspective in the *Journal of Disability Policy Studies*, 2005, 16.

²⁰ Gill, C, “Health professionals, disability, and assisted suicide: An examination of relevant empirical evidence and reply to Batavia,” *Psychology, Public Policy, and Law*, 2000, 6:526-545.

These attitudes are found to carry over into medical care, through recurrent “distressing encounters” with physicians and other health professionals described as lacking “aware[ness] of disability issues, patronizing, and disrespectful. A common concern...is, ‘Doctors need to realize that I have a real life and it’s a valuable life.’”²¹

Furthermore, research suggests that physician attitudes regarding disability may predict whether or not life-sustaining care is provided. In a study of ventilator use with patients with severe neuromuscular diseases, such as Duchenne’s muscular dystrophy and amyotrophic lateral sclerosis (Lou Gehrig’s Disease), Bach reported that clinic directors who “most underestimated the ventilator users’ life satisfaction...were least likely to encourage ventilator use...Physicians’ assessment of patients’ quality of life and about the relative desirability of certain types of existence determine the likelihood of individuals receiving therapeutic interventions like mechanical ventilation.”²² Bach concludes that the “patient’s attitude towards the use of ventilatory aids seems to reflect his/her physician’s attitude and the nature of the treatment options being presented rather than his/her own informed rational decision.”²³

Gill’s findings are reflected in the numerous websites of disability advocacy organizations, such as Not Dead Yet and the Disability Rights Education and Defense Fund (DREDF), that post documents opposing assisted suicide.²⁴ DREDF lists 12 nationally prominent disability organizations that have stated their opposition to the legalization of assisted suicide.²⁵ The National Council on Disability issued a position paper summarizing the perspective of disability groups:

Current evidence indicates clearly that the interests of the few people who would benefit from legalizing physician-assisted suicide are heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities and entail an intolerable degree of intervention by legal and medical officials in such decisions.²⁶

Hwang attempts to deflect attention from national disability advocacy organizations to emphasize the views of individuals with physical disabilities regarding assisted suicide. Using websites frequented by members of the physical disability community, she conducted polls on attitudes towards assisted suicide, self-perceptions of “vulnerability,” and acceptability of assisted suicide for oneself. While the sample was self-selected and relatively small, Hwang uses her “exploratory” findings to show that

²¹ *Ibid.*

²² Bach, JR, “Threats to ‘informed’ advance directives for the severely physically challenged,” *Archives of Physical Medicine and Rehabilitation*, 2003, 84:S23-S27.

²³ Bach, *ibid.*

²⁴ See for example, <http://notdeadyetnewscommentary.blogspot.com/> and <http://www.dredf.org/>.

²⁵ See, http://www.dredf.org/assisted_suicide/assistedsuicide.html.

²⁶ National Council on Disability, *Assisted Suicide: A Disability Perspective*, 1997. Downloaded on 4/3/07 from <http://www.ncd.gov/newsroom/publications/1997/suicide.htm>.

“people with disabilities hold a wide variety of views with regard to [physician-assisted suicide] that cannot be easily summed up by any one position...Ultimately, the question, ‘What kind of life is worth living?’ is a highly individual one” that transcends the positions of disability advocacy groups.²⁷

The concerns of disability advocates regarding the withholding or withdrawal of life-sustaining interventions are a logical extension of the assisted suicide debate. For example, Werth argues that many more people with disabilities will die through decisions to forgo treatments than through assisted suicide.²⁸ Therefore, the fears behind the assisted suicide debate -- societal (and more specifically, physician) devaluation of the lives of people with disabilities, the costs of care, and resource allocation -- are equally applicable to decisions to withhold or withdraw treatments and to futility decisions.²⁹

In response to the legal debates and public attention surrounding the care of Terri Schaivo, leading disability advocacy organizations issued policy statements on life-sustaining care. *A Statement of Common Principles on Life-Sustaining Care and Treatment of People with Disabilities*, coordinated by The Center on Human Policy at Syracuse University, declared that the “rights to life-sustaining care and treatment and to self-determination and autonomy” are “fundamental rights.” The *Statement* notes that “[d]isability has been used as a justification for depriving people of their fundamental rights.” Therefore,

Absent clear and convincing evidence of the desires of people with disabilities to decline life-sustaining care or treatment, such care and treatment should not be withheld or withdrawn unless death is genuinely imminent and the care or treatment is objectively futile and would only prolong the dying process.³⁰

Although not explicitly stated, it can be presumed that advance directives are “clear and convincing evidence of desires -- informed decisions [that] must be respected”³¹ and could be encouraged.

Likewise, United Cerebral Palsy (UCP), The Arc, and the American Association of People with Disabilities declared that “the provision of medical treatment must always be non-discriminatory and never denied, delayed or withheld due to the existence of a disability.” The organizations argued: “[t]he courts, the political system and the general public must not allow policy to develop that will de-value any individual, no matter what

²⁷ Hwang, K, “Attitudes of persons with physical disabilities toward physician-assisted death,” *Journal of Disability Policy Studies*, 2005, 16:16-21.

²⁸ Werth, JL, “Concerns about decisions to withholding/withdrawing life-sustaining treatment and futility for persons with disabilities,” *Journal of Disability Policy Studies*, 2005, 16:31-37.

²⁹ *Ibid.*

³⁰ *A Statement of Common Principles on Life-Sustaining Care and Treatment of People with Disabilities*. Downloaded 4/3/07 from <http://thechp.syr.edu/endorse/>.

³¹ *Ibid.*

the extent of that individual's disability or incapacity."³² This statement also notes that individuals may document their preferences through advance directives.

It is encouraging that these organizational statements explicitly support the use of advance directives by individuals with disabilities. A handful of other disability organizations have taken a more direct approach in support of advance care planning. For example, the Multiple Sclerosis Association of America (MSAA) published a detailed article for consumers explaining the importance advance directives as part of life-planning, with instructions and resources for their completion.³³ Clinical practice guidelines developed for the Paralyzed Veterans of America supported discussion of advance directives with patients following spinal cord injury to determine the validity of documents completed prior to traumatic injury.³⁴ These guidelines might also encourage discussion of advance directives among patients with capacity following spinal cord injury when there are no earlier documents. Finally, Allen and her colleagues described a unique effort to use American Sign Language to survey Deaf seniors on end-of-life concerns and present educational information on health care directives and end-of-life care.³⁵

B. Advance Care Planning for People with Intellectual Disability

There is a legal presumption that all persons have the capacity to make their own health care decisions unless they are declared incompetent through a legal process. However, adults with intellectual disability "have historically been excluded from various spheres of decisionmaking about their lives, on the presumption that they are incapable of making informed decisions."³⁶ Health care providers, administrators, and families commonly assumed a protective stance toward people with intellectual disabilities, even when decision-specific capacity may have existed.³⁷ Recent trends have encouraged providers, researchers, and advocates to question this paternalistic approach for three reasons.

First, medical advances are increasing the longevity of people with intellectual disabilities. For example, life expectancy for people with Down's Syndrome has

³² UCP, *Disability Rights Organizations Voice Support for Terri Schindler-Schiavo: Florida Women's Case Concerns Millions with Disabilities*. Downloaded 6/14/07 from http://www.ucp.org/ucp_generaldoc.cfm/1/9/10020/10020-11840/5165?PrintFriendly=Yes.

³³ Norris, C, Stein, GL, & Courtney, SW, "Planning for the future: The importance of advance directives," *The MSAA Motivator*, Fall 2005: 7-19.

³⁴ Consortium for Spinal Cord Medicine, *Respiratory Management Following Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals*, 2005: 25. Downloaded 4/3/07 from <http://www.pva.org/site/DocServer/resmgmt.pdf?docID=703>.

³⁵ Allen, B, Meyers, N, Sullivan, J, & Sullivan, M, "American sign language and end-of-life care: Research in the deaf community," *HEC Forum*, 2002, 14:197-208.

³⁶ Friedman, RI, "Use of advance directives: Facilitating health care decisions by adults with mental retardation and their families," *Mental Retardation*, 1998, 36:444-456.

³⁷ See Botsford, AL, & King, A, "End-of-life care policies for people with an intellectual disability: Issues and strategies," *Journal of Disability Policy Studies*, 2005, 16:22-30.

doubled during the 1980s and 1990s.³⁸ As individuals with intellectual disabilities age, they and their caregivers face issues of aging and chronic illness as never before. Second, this time period has witnessed significant cultural changes regarding medical decisionmaking, end-of-life care, and advance care planning, as bioethical principles evolved from a paternalistic to an autonomy-based approach.³⁹ Third, although the needs of people with intellectual disabilities were largely absent from early discussions to promote advance care planning and palliative approaches to care, providers and advocates have sought to bolster the autonomy of community members and brought their concerns to the table.⁴⁰

Decisional Capacity. Advance care planning by and for people with intellectual disabilities is complicated by the wide range of cognitive abilities and limitations and by differing needs for assistance among members of this community.⁴¹ For example, those with mild impairments may reside independently in the community, with a support system that includes social services staff, personal care attendants, family and community advocates, and vocational and residential services. These individuals “usually need information on their service options when confronting life-threatening illness, especially on hospice and palliative care services, assistance in documenting their preferences through advance directives, and support in navigating their way through complex health care systems.”⁴² Others with more serious cognitive impairments have intermittent decisionmaking abilities or have never had the capacity to make health care decisions. Their “health-related decisions are made by surrogates, primarily parents and other (public or private) guardians, who act in their child’s or ward’s best interest and need information and support in selecting the most appropriate health care.”⁴³

People with intellectual disabilities should not be presumed to lack capacity for making health care decisions. A panel convened by the Midwest Bioethics Center (now known as the Center for Practical Bioethics) in 1996 issued guidelines to facilitate individual decisionmaking and more accurate professional assessments of decisional capacity. The guidelines provide recommendations to assess “whether patients meet a

³⁸ Tuffrey-Wijne, I, “The palliative care needs of people with intellectual disabilities: A literature review,” *Palliative Medicine*, 2003, 17:55-62.

³⁹ For example, see Beauchamp, TL, & Childress, JF, *Principles of Biomedical Ethics*, 5th Ed. (Oxford University Press: Oxford, 2001): 57-112.

⁴⁰ For example, see Gaventa, WC, & Coulter, DL, “Preface: End of life, religion, disability, and health: Where all the paths converge,” *Journal of Religion, Disability & Health*, 2005, 9:19-23.

⁴¹ Stein, GL, & Esralew, L, “Palliative care for people with disabilities,” In *Living With Dying: A Handbook for End-of-Life Healthcare Practitioners*, ed. Berzoff, J, & Silverman, PR (Columbia University Press: New York, NY, 2004): 499-507.

⁴² *Ibid.*

⁴³ *Ibid.*

minimum level of understanding.” Limitations in intellect and communication abilities are bolstered by supporting areas of individual strength and by offering assistance.⁴⁴

Clinical practice and legal standards have moved away from global determinations of capacity to more finely-tuned task-specific determinations of capacity. The capacity to make health care decisions has been defined as the ability to understand the information about a proposed care plan, appreciate the consequences of a decision, and reach and communicate an informed decision.⁴⁵ Unlike competency, which is an “all or nothing” judicial determination, capacity is specific to the decision at hand.⁴⁶ This more flexible methodology to assessing abilities creates a multi-tiered approach to decisionmaking. For example, individuals who lack abilities to express preferences or goals of care in a living will may be able to appoint a health care proxy. Similarly, those unable to make decisions about life-sustaining interventions may have the capacity to make less complex decisions, such as on low-risk medications, diet, or recreation. Beltran summarizes the challenge in accurately assessing decisionmaking capacity: “There is a need to balance protection from harm with the patient’s right to self-determination. This balancing requires skilled listening, the proper level of advocacy from caregivers, and pragmatic models of shared decisionmaking.”⁴⁷

A 2003 study assessed health care capacity among adults with mild, moderate, and no mental retardation to make “low-risk” medical treatment decisions. The study used standardized treatment vignettes to measure the capacity of adults to reason about treatment-related information. Cea and Fisher found that “most adults with mild [86%] and no [95%] mental retardation and almost half of adults with moderate mental retardation [45%] were able to make and justify treatment choices and fully or partially understand treatment information.”⁴⁸ These findings are used to support claims that many adults with mild mental retardation, and some adults with moderate retardation, “do indeed have the ability to provide adequate consent to standard low-risk health-related treatments.” Moreover, capacity to consent “could be enhanced with supportive decisionmaking or educational techniques in preparation for treatments or procedures requiring their consent.”⁴⁹

Policy Statements. Key intellectual disability organizations support efforts to promote rights to autonomy and self-determination. The American Association on Intellectual and Developmental Disabilities (AAIDD, formerly called the American

⁴⁴ Midwest Bioethics Center and the University of Missouri-Kansas City Institute for Human Development Task Force on Health Care for Adults with Developmental Disabilities, “Health care treatment decision-making guidelines for adults with developmental disabilities,” *Bioethics Forum*, 1996, 12:S1-7.

⁴⁵ For example, see Beauchamp, TL, Childress, JF, *Principles of Biomedical Ethics*, 5th Ed. (Oxford University Press: Oxford, 2001): 57-112.

⁴⁶ Miller, TE, “Advance directives: Moving from theory to practice.” In *Quality Care in Geriatric Settings*, ed. Katz, PR, Kane, RL, & Mezey, MD (Springer: New York, NY, 1995): 68-86.

⁴⁷ Beltran, JE, “Shared decision making: The ethics of caring and best respect,” *Bioethics Forum*, 1996, 12:17-25.

⁴⁸ Cea, CD, & Fisher CB, “Health care decision-making by adults with mental retardation,” *Mental Retardation*, 2003, 41:78-87.

⁴⁹ *Ibid.*

Association on Mental Retardation -- AAMR) issued a *Position Statement on Caring at the End of Life* in 2005. The statement advocates:

- Discovering and honoring the treatment wishes of persons with intellectual disabilities through: observing and interacting with individuals over time to understand what is important to them; encouraging expressions of preferences regarding end-of-life care “before situations requiring decisionmaking occur”; and for capable individuals, documenting preferences through “living wills, personal vision statements, health care proxy instructions, and other indicators of one’s wishes.”
- “Withdrawing or withholding care may be appropriate in some situations,” but not “because the person has a disability.”
- “The presumption should always be in favor of treatment...[but] may be overcome in...clearly specified situations.”
- These situations, where “continued life may not be in the person’s best interest include: (1) where “life-sustaining treatment is clearly ineffective and would only prolong the process of dying with no prospect of reversing it; (2) the person is in an irreversible coma or permanent vegetative state; or (3) the treatment itself would impose excessive pain and suffering.”
- Hospice care and adequate pain relief should be available.
- “Permissible treatment options at the end-of-life are the same for persons with intellectual or developmental disabilities as for everyone else.”⁵⁰

Similarly, a 2002 joint policy statement of The Arc of the United States (formerly called the Association for Retarded Citizens) and AAIDD, supported the availability, use, and “honoring” of advance directives for individuals with mental retardation “whenever informed consent is assured.” In addition, the “decisions involving the refusal of medical treatments, or nutrition and hydration when such refusal will result in the death of the individual,...should be confined to those situations in which the person’s condition is terminal, death is imminent, and any continuation or provision of treatment, nutrition and/or hydration would only serve to prolong dying.”⁵¹ Unlike the 2005 policy statement of AAIDD, the earlier position does not list irreversible coma or permanent vegetative state as permissible reasons to forgo life-sustaining care.

Resources and Innovations. Materials and innovative approaches to advance care planning have been developed to promote better end-of-life decisions. Last Passages, a three-year public-private partnership funded by the U.S. Administration on

⁵⁰ AAMR, “Position Statement on Caring at the End of Life,” June 2005. Downloaded 4/3/07 from http://www.aamr.org/Policies/pos_end_of_life.shtml.

⁵¹ The Arc and AAIDD, “Policy Statement: Health Care,” November 2002. Downloaded 6/14/07 from <http://www.thearc.org/NetCommunity/Page.aspx?&pid=1372&srcid=217>.

Developmental Disabilities and the Project on Death in America, provides an array of electronic materials to assist service providers, policymakers, and consumers.⁵² Resources include descriptive information, a manual about end-of-life care for people with developmental disabilities, sample documents for advance care planning, links to national organizations and projects, and an extensive bibliography.

NYSARC, Inc., in collaboration with Last Passages, developed a monograph and resource manual (primarily focused on New York State) to inform consumers, family members, and providers about hospice and end-of-life care, advance care planning, and bereavement.⁵³ The Center for Practical Bioethics's *Healthcare Treatment Decision-Making Guidelines for Adults with Developmental Disabilities* provides model standards for policymakers considering revisions to public or institutional policies on health care decisionmaking or advance directives.⁵⁴

Kingsbury advocates "person-centered planning" to help consumers, family members, and providers identify and document preferences for end-of-life care. "Person-centered planning is not an event; it is a process" for advance care planning discussions with people with intellectual limitations. "Person-centered planning can help people identify their wishes, such as who they would like to have present, how they would like to be made comfortable, what kinds of treatment they wish to have or not have, [and] what religious or spiritual support they want."⁵⁵ Planning tools involve deliberate, ongoing communication that emphasizes listening, learning, understanding, and acting on what is important to support people who are aging and dying, and their caregivers.

Is it possible to augment the decisionmaking capacity of individuals with cognitive limitations? Friedman supports the concept of "assisted capacity," through which "individuals who may be unable to make advance directives decisions completely independently, but who could participate in decisionmaking with the proper degree of assistance and support from others."⁵⁶ Such support could come from families, friends, clergy, advocates, and formal health care and service providers. While this strategy may facilitate advance care planning, there is the potential for helper influence to act as a coercive force in decisions that are made.

⁵² Last Passages materials. Downloaded on 8/30/07 from <http://www.albany.edu/aging/lastpassages/index.html>.

⁵³ NYSARC, Inc., *End-of-Life Care: A Guide for Supporting Older People with Intellectual Disabilities and Their Families* (NYSARC, Inc.: Delmar, NY, 2000). This manual may be downloaded from <http://www.albany.edu/aging/lastpassages/manual-entire.htm>. Also see, NYSARC, Inc., *End-of-Life Care: A Guide for Supporting Older People with Intellectual Disabilities and Their Families, Resource Supplement* (NYSARC, Inc.: Delmar, NY, 2000).

⁵⁴ Midwest Bioethics Center and the University of Missouri-Kansas City Institute for Human Development Task Force on Health Care for Adults with Developmental Disabilities, "Health care treatment decision-making guidelines for adults with developmental disabilities," *Bioethics Forum*, 1996, 12:S1-7.

⁵⁵ Kingsbury, LA, "Person Centered Planning in the Communication of End-of-Life Wishes," *Exceptional Parent*, 2004, 34:44-46.

⁵⁶ Friedman, RI, "Use of advance directives: Facilitating health care decisions by adults with mental retardation and their families," *Mental Retardation*, 1998, 36:444-456.

To help elicit the preferences of people with disabilities with varying degrees of decisional capacity, the Center for Practical Bioethics and Missouri's largest public guardianship office (the Jackson County Public Administrator), established Project BRIDGE. Through an intensive process of "inviting" public wards to express their health care preferences, "listening" carefully when the invitation is accepted, and "reporting" relayed stories and preferences to public guardians, project staff offered individuals who were often overlooked the opportunity to express and document their preferences to inform the guardians who made decisions for them.⁵⁷ Although this approach requires significant staff time, it offers a creative way of understanding the wishes and values of people with limited capacity, as well as those with limited communication abilities.

For individuals with limited and no decisionmaking capacity, Beltran and Martyn propose a standard of "best respect" (similar to a best interests decisionmaking standard), with health care choices made by a team rather than an individual surrogate. The proponents of "best respect" suggest convening those individuals most familiar with the patient's life and values for an informed dialogue that results in a consensus on treatment decisions. This "shared decisionmaking" (distinguished from the shared decisionmaking between patient and provider) should occur within the context of the patient's "community of care," which may be a developmental center, community group home, or independent living arrangement. An ethics committee could convene key parties, such as family members, friends, or other supportive caregivers, as well as the interdisciplinary team caring for the individual.⁵⁸ In the best respect model, physicians offer "objective" information about the patient, including diagnosis, prognosis, available treatment choices, and quality of life issues. Subsequently, the:

search for subjective information...[examines] what the person has communicated in the past about her own life and its pleasures, pains, dignities, indignities, and dependencies. Second, the group should consider what this information tells them about the subjective value of life to this patient. Finally, given what has been shared, [a determination would be made on] which decision best respects the individual expression of this unique individual.⁵⁹

With more effective public outreach promoting the benefits of advance care planning, some parents and guardians of individuals with limited or no capacity desire to complete advance directives on their children's or ward's behalf. These parents and guardians, motivated by the desire to plan for their own death or incapacity, are surprised to learn that they cannot do so -- that directives may be completed only by individuals with capacity to do so. In response, Beltran encourages parents/guardians to "write a letter expressing their values and concerns" for placement into their child's/ward's permanent planning records. While noting that such "values" letters have

⁵⁷ Reynolds, DF, "Project BRIDGE -- People with disabilities participate in their health care decisions," *Bioethics Forum*, 1999, 15:36-45.

⁵⁸ Beltran, JE, "Shared decision making: The ethics of caring and best respect," *Bioethics Forum*, 1996, 12:17-25.

⁵⁹ Martyn, SR, "Substituted judgment, best interests, and the need for best respect," *Cambridge Quarterly of Healthcare Ethics*, 1994, 3:195-208.

no legal force, they can “provide guidance to health care providers seeking to provide treatments that are in keeping with the patient’s values.”⁶⁰ Beltran recommends the development of a “legal mechanism for parents to document values to assure their wishes are carried out after they die.”⁶¹ Physician orders -- such as Physician Orders for Life-Sustaining Treatment (POLST), where patient and surrogate preferences are incorporated into doctors’ orders,⁶² or out-of-hospital Do-Not-Resuscitate Orders -- may provide models for such long-range planning if the hurdles regarding decisionmaking can be surmounted.

Professional education has been recognized as a critical component to improving end-of-life care and promoting better informed advance care plans and medical decisions. Frequently, health care professionals (physicians, nurses, social workers, clergy, and others), including hospice and palliative care staff, lack training on the special needs of people with intellectual disabilities and on methods to assess their decisional capacity.⁶³ Furthermore, staff of public agencies and private organizations serving people with disabilities should be trained in the special needs of people with intellectual disabilities for advance care planning, options for hospice and palliative care to manage life-threatening illnesses, and special concerns in providing and consenting to care.⁶⁴ For example, in a rare study of end-of-life decisions in a developmental center (where residents commonly have more severe intellectual disabilities than those living in community placements), Lohiya and her colleagues found that among 38 residents who had died during a 2½ year period, only ten residents (26%) had an end-of-life decision made on their behalf. Of 850 residents, only two had ever completed an advance directive. The researchers suggest that more frequent discussions of patients’ best interests before death might lead to better end-of-life care.⁶⁵

⁶⁰ Beltran, JE, “Shared decision making: The ethics of caring and best respect,” *Bioethics Forum*, 1996, 12:17-25.

⁶¹ *Ibid.*

⁶² For an overview and example of POLST, see <http://www.ohsu.edu/polst/index.shtml>.

⁶³ Friedman, RI, “Use of advance directives: Facilitating health care decisions by adults with mental retardation and their families,” *Mental Retardation*, 1998, 36:444-456. Also see, Botsford, AL, & King, A, “End-of-life care policies for people with an intellectual disability: Issues and strategies,” *Journal of Disability Policy Studies*, 2005, 16:22-30.

⁶⁴ Stein, GL, & Esralew, L, “Palliative care for people with disabilities,” In *Living With Dying: A Handbook for End-of-Life Healthcare Practitioners*, ed. Berzoff, J, & Silverman, PR (Columbia University Press: New York, NY, 2004): 499-507. Also see, Botsford, AL, “Integrating end of life care into services for people with an intellectual disability,” *Social Work in Health Care*, 2000, 31:35-48; and Botsford & King, *ibid.*

⁶⁵ Lohiya, GS, Tan-Figueroa, L, & Kohler, H, “End-of-life decisions in a developmental center: A retrospective study,” *Western Journal of Medicine*, 2002, 176:20-22.

IV. GAPS AND BARRIERS

While the process for advance care planning for people with physical and intellectual disabilities is the same as for non-disabled people, there are unique community perspectives and issues to be addressed in policies seeking to promote such plans. For people with all disabilities, and especially for people with physical disability, the literature demonstrates over-riding concerns about under-treatment for serious medical conditions due to:

- devaluation of and lack of respect for the lives of people with disabilities;
- negative attitudes of health care professionals and the public, including overly pessimistic perceptions of quality of life and misconceptions about life satisfaction; and
- lack of access to care and services based on discrimination, cost concerns, and environmental barriers.

Advance directives guiding care toward the end-of-life are irrelevant when one's concern is the denial of care: unwanted interventions at the end-of-life are not the central issue (although individuals could specify in their directives a preference for continuing with aggressive, curative care). There is a need for more information on access to and quality of end-of-life care for people with all disabilities, and how this may be different or the same from non-disabled individuals generally.

In addition, for people with intellectual disability, there is a need to replace paternalistic attitudes and stereotypes about cognitive limitations with skilled, careful assessments of decisional capacity and abilities, strategies for assisted and shared decisionmaking and life-planning, and more thoughtful communication about medical options. Research and discussion of these issues is relatively recent, and much more needs to be done.

The following gaps and barriers should be addressed:

- **Limited Research, Programs, and Attention.** There are few studies, service programs, and educational outreach efforts on advance care planning, and improved end-of-life and palliative care for people with physical and intellectual disabilities. To develop effective care and services, more information is needed on:
 - *Attitudes, concerns, and values about end-of-life care:* What do diverse disability populations regard as desirable care in times of life-limiting illness and severe adverse health states?
 - *Experiences regarding and strategies for advance care planning:* How do health care professionals approach advance care planning among patients with diverse disabilities? Are these strategies different from non-disabled patients? Which approaches are most effective among diverse disability communities?

- *The quality of end-of-life care:* Are perceptions of quality end-of-life care among disability communities the same or different from non-disabled populations? Do people have access to quality hospice and palliative care services based on current professional guidelines? Is this the type of care that individuals with diverse disabilities prefer?
 - *The impact of health care professional and public attitudes:* What are the perceptions and attitudes regarding the care of life-threatening illness among diverse disability populations? Have attitudes changed over time? How have attitudes influenced patient care?
- **Research and Guidelines for Assessing Decisional Capacity.** Balancing respect for autonomy and self-determination among people with intellectual disability with protection of vulnerable individuals from harm is a most difficult challenge. There are needs for research and practice guidelines to assist professionals in assessing decisional capacity, especially the ability to make difficult and complex choices near the end-of-life. Moreover, evaluation research is needed on various approaches to assisted or shared decisionmaking and life-planning.
 - **Community Distrust.** A history of discrimination, neglect, and abuse toward people with disabilities has occasionally led to distrust among some community members toward health care professionals. Negative experiences with health care providers, which research has shown to be all too common, results in fears about discriminatory practices and denial of care.
 - **Advance Directives May Be Inappropriate For Some.** The model for advance care planning -- legal documents completed by people with decisional capacity -- is insufficient for many people with intellectual disability. Many individuals with limited decisionmaking capacity cannot complete advance directives; parents, family members, and guardians would benefit from additional legal options for end-of-life planning.
 - **Conflict Management.** End-of-life choices present complicated dilemmas for patients, surrogates, families, health care providers, administrators, policymakers, and the legal system. Parents and guardians may disagree with their adult children and wards, especially those legally adjudicated as “incompetent.” People with disabilities may disagree with their health care providers. Providers and administrators are always mindful of the potential for legal liability when parties disagree.

V. TRENDS

- **Inclusionary Dialogue.** To promote respect for people with disabilities among health care providers and policymakers and to help overcome years of community distrust, end-of-life researchers, policymakers, programmers, and educators should include meaningful participation by members of disability communities, as well as advocacy and service organizations serving the community, as part of the planning, implementation, and oversight of their activities. Health care professionals and consumers with disabilities should be recruited to participate on ethics committees and programs. As stated by Asch, recent events “demonstrate how desperately the disability perspective needs to become part of the conversation rather than being excluded from it.”⁶⁶
- **Research Needs.** Innovative research design, as well as public and private funding, is needed to inform new service initiatives to improve end-of-life and palliative care, and advance care planning for people with physical and intellectual disabilities. Specific topics for research are suggested for each of the gaps noted in the section above, including:
 - attitudes, concerns, and values about end-of-life care;
 - experiences regarding and strategies for advance care planning;
 - the quality of end-of-life care for diverse disability populations; and
 - the impact of health care professional and public attitudes.
- **Understanding and Assessing Decisional Capacity.** Research is needed on approaches and tools for assessing the parameters of decisional capacity among people with intellectual disability, especially regarding the range of complex choices near the end-of-life. Prior research using vignettes of low-risk health-related treatments may provide a model.⁶⁷ In addition, studies should examine the effectiveness of strategies and tools for advance care planning among those with limited capacity, such as shared decisionmaking and assisted capacity. More information is needed on which strategies support decisionmaking abilities, and whether these approaches unintentionally influence decisions that are made.
- **Integrating Policy Statements.** Several disability organizations and advocacy groups -- such as AAIDD, The Arc of the United States, the National Council on Disability, and the Center on Human Policy Study at Syracuse University -- have developed major policy statements regarding health care decisionmaking and the quality of end-of-life care. These statements bring powerful voices to advocate for respecting the rights of individuals with disabilities to make autonomous

⁶⁶ Asch, A, “Recognizing death while affirming life: Can end of life reform uphold a disabled person’s interest in continued life?” *Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Report Special Report*, 2005, 35:S31-36.

⁶⁷ Cea, CD, & Fisher CB, “Health care decisionmaking by adults with mental retardation,” *Mental Retardation*, 2003, 41:78-87.

decisions, and for access to the full-range of care and services. The dialogue on these issues should continue to evolve. Furthermore, policy announcements should be acknowledged and respected by providers and policymakers. Future practices, policies, and research should integrate these statements, while reconciling, justifying, and bridging differences, wherever possible.

- **New Models for Advance Care Planning.** Legal and planning mechanisms are needed to better enable parents, families, and guardians of people with limited decisional capacity to plan for serious illnesses affecting their loved ones and wards. Family and guardian “values” letters present one such approach, but lack a legal basis. Policymakers, in conjunction with the disability community, should consider new planning mechanisms for end-of-life planning. In addition, guidelines to better integrate end-of-life planning into current “person-centered” habilitation and life-plans would be helpful for family members and other guardians, as well as for service and residential programs. These guidelines should be evaluated for usability and effectiveness.
- **Outreach on Advance Care Planning.** Many organizations advocating on behalf of people with disabilities recognize the importance of advance directives to provide evidence of an individual’s preferences for end-of-life decisions. Furthermore, several innovative approaches -- such as Last Passages, life-centered planning, assisted capacity, shared decisionmaking, the best respect standard for decisionmaking, Project BRIDGE, and staff training -- have been developed to assist people with intellectual disability. Similarly, organizations representing people with mental health disabilities generally support the legalization and use of “psychiatric advance directives” for use during times of incapacity due to psychiatric conditions.⁶⁸ These programs and policies provide unique opportunities for community outreach to encourage more effective advance care planning among people with diverse disabilities.
- **Models for Consensus-Building.** Models for ethics committees and conflict resolution provide opportunities for mediating disputes involving persons with disabilities;⁶⁹ providing patient, family, provider, and community education; formulating institutional policy; and appropriately resorting to the courts when all else fails. Research and resources should be developed to promote various models for consensus-building, policymaking, professional training, and community outreach to improve advance care planning and patient care on behalf of all people with disabilities.

⁶⁸ For example, see the National Disability Rights Network’s website, providing resources on psychiatric advance directives. Downloaded 4/3/07 from <http://www.ndrn.org/issues/advdir/>.

⁶⁹ For example, see New Jersey Health Decisions, *Disability Ethics Network* (undated organizational brochure); and Midwest Bioethics Center and the University of Missouri-Kansas City Institute for Human Development Task Force on Health Care for Adults with Developmental Disabilities, “Health care treatment decision-making guidelines for adults with developmental disabilities,” *Bioethics Forum*, 1996, 12:S1-7.

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