

**THE GROWING PROMINENCE OF
INDEPENDENT LIVING AND
CONSUMER DIRECTION AS
PRINCIPLES IN LONG-TERM CARE:
A CONTENT ANALYSIS AND
IMPLICATIONS FOR ELDERLY
PEOPLE WITH DISABILITIES**

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Recently, the concepts of “independent living” and “consumer direction” have become highly popularized among individuals with disabilities who choose to control their long-term care and assistance. This trend has enabled people with disabilities to live independently in their communities. Research has documented that those disabled individuals receiving care under the independent living model are more

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satisfied with their treatment than those who receive care under the traditional medical model through nursing homes and home health agencies. In his article, Professor Andrew Batavia explores the advantages that consumer direction and independent living confer on those individuals with disabilities. Professor Batavia also examines why independent living and consumer direction have not been as widespread among elderly people with disabilities relative to younger disabled people. He dispels the notion that the independent living model is not applicable to older individuals with disabilities, even those with cognitive disabilities. Professor Batavia argues that elderly people with disabilities should not be limited to receiving care in institutions or under the control of health care providers. He concludes that independent living and consumer direction should be available options to all individuals, including elderly people, who require long-term care.

I. Introduction

The ethical concept of autonomy, often referred to as self-determination, has been a key principle in our health care system for several decades. It has been manifested most visibly in the context of informed-consent requirements for acute care procedures, and the now well-established right of patients to refuse care.¹ Justice Cardozo stated in the 1914 informed consent case of *Schloendorff v. Society of New York Hospital*² that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.”³ This right to refuse has been labeled by some ethicists as “negative autonomy,” in contrast to the “positive autonomy” right to determine affirmatively what services people would like to receive and how they would like to receive them.⁴ Recognition of positive autonomy rights has lagged behind the acknowledged negative autonomy right to refuse treatment.⁵

Perhaps the most powerful assertion of positive autonomy in health care today is the demand by many people with disabilities to control the circumstances in which they receive their long-term care

1. In 1990, the U.S. Supreme Court indicated in the *Cruzan* case “that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition.” *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 279 (1990).

2. *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92 (N.Y. 1914).

3. *Id.* at 93.

4. See Bart J. Collopy, *Ethical Dimensions of Autonomy in Long-Term Care*, GENERATIONS, 1990 Supp., at 9, 11–12.

5. See Marshall B. Kapp, *Enhancing Autonomy and Choice in Selecting and Directing Long-Term Care Services*, 4 ELDER L.J. 55, 56–57 (1996).

and personal assistance services.⁶ Recognition of such positive rights has been a key goal of the independent living movement, a social movement established in the early 1970s that attempts to eliminate the environmental barriers preventing people with disabilities from living independently in their communities.⁷ This demand for positive autonomy in long-term care by independent living advocates has been labeled “consumer direction.”⁸ Such positive control by individuals receiving the services may be achieved through health care programs requiring “consumer-directed care” and “consumer-directed personal assistance services.”⁹

This article examines the trend toward consumer direction and independent living in long-term care. It presents a content analysis of the legal and medical literatures to document the increase in consumer direction. It then considers the applicability of the concepts of consumer direction and independent living to the elderly population, particularly older people who currently have disabilities and require long-term care services. In doing so, the article critically examines the potential applicability of the independent living model of long-term care to the elderly population, focusing specifically on older people with cognitive impairments and limited capacity for self-direction. Although the emphasis is on elderly people, the article’s analysis also has substantial implications for younger people with cognitive disabilities.

6. See PAMELA J. DAUTEL & LEX FRIEDEN, INST. FOR REHABILITATION & RESEARCH, CONSUMER CHOICE AND CONTROL: PERSONAL ATTENDANT SERVICES AND SUPPORTS IN AMERICA (Aug. 1999), <http://www.ilru.org/pas/BRPPAS.html> (last visited Sept. 30, 2002).

7. See Gerben DeJong, *Independent Living: From Social Movement to Analytic Paradigm*, 60 ARCHIVES PHYSICAL MED. & REHAB. 435, 437 (1979).

8. A concept that is closely related to consumer direction is consumer choice. Consumer direction refers to control within a specified system or model of care and, therefore, contains an important element of choice. However, consumer choice also operates at a higher level to allow consumers to choose systems or models of care that permit greater or lesser amounts of consumer direction (much as consumers in the acute care context choose managed-care organizations that permit greater or lesser amounts of patient autonomy). Andrew I. Batavia, *A Right to Personal Assistance Services: “Most Integrated Setting Appropriate” Requirements and the Independent Living Model of Long-Term Care*, 27 AM. J.L. & MED. 17, 18–19 (2001).

9. See Gerben DeJong & T. Wenker, *Attendant Care as a Prototype Independent Living Service*, CARING, Spring 1983, at 26, 27.

A. Independent Living Model

The ultimate goal of the independent living movement is to allow people with disabilities to achieve “independent living”—the ability of such individuals to live “independently” in their homes and communities.¹⁰ The terms “independent living” and “independently” do not mean literally that the individual must do everything without the assistance of any other person or assistive device;¹¹ some individuals, by virtue of their specific disabilities (i.e., functional limitations), simply do not have the physical or mental capacity to conduct certain tasks alone.¹² For example, a person with quadriplegia may not be able to dress herself or to transfer herself from a wheelchair to a bed. However, this individual may be able to live independently in the sense that she can still maintain control of her life by hiring a personal assistant to conduct such tasks.

Thus, independent living is closely associated with consumer direction—the ability of consumers to control their lives, including their long-term care. Consumer direction can be achieved to some extent in virtually any long-term care setting.¹³ However, many people with disabilities contend that care provided by health care professionals, under the so-called medical model, is inconsistent with true consumer direction.¹⁴ These individuals insist upon being able to receive their care and assistance under the “independent living model,” in which consumers recruit, hire, train, manage, and, if necessary, fire their own personal assistants who are not health care professionals.¹⁵

The independent living model may be conceptualized as the approach that allows for the highest level of control on the continuum of consumer direction.¹⁶ For this reason, independent living is strongly supported by young and working-age people with disabilities who

10. NAT'L COUNCIL ON DISABILITY, TOWARD INDEPENDENCE: AN ASSESSMENT OF FEDERAL LAWS AND PROGRAMS AFFECTING PERSONS WITH DISABILITIES—WITH LEGISLATIVE RECOMMENDATIONS (1986).

11. Elias S. Cohen, *What Is Independence?*, GENERATIONS, Winter 1992, at 49.

12. *Id.*

13. See generally Robyn I. Stone, *Consumer Direction in Long-Term Care*, GENERATIONS, Fall 2000, at 5.

14. Bob Kafka, *Perspectives on Personal Assistance Services*, INDEPENDENT LIVING, Winter-Spring 1994.

15. See Andrew I. Batavia et al., *Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care for Persons with Disabilities*, 16 J. HEALTH POL., POL'Y, & L. 523, 529 (1991).

16. See Gerben DeJong et al., *The Independent Living Model of Personal Assistance in National Long-Term-Care Policy*, GENERATIONS, Winter 1992, at 89, 90.

generally demand the ability to exercise substantial control over their lives.¹⁷ The Medicaid waiver program, authorized by section 1915(c) of the Social Security Act,¹⁸ has made the independent living model increasingly available to working-age people with disabilities and people with developmental disabilities.

Studies demonstrate that consumers tend to be highly satisfied with the assistance they receive under the independent living model.¹⁹ In evaluating California's In-Home Support Services program,²⁰ which offers both agency-based services under the medical model and consumer-directed services under the independent living model, researchers concluded that consumers receiving care under the independent living model are more satisfied with the technical and interpersonal aspects of their care and assess their overall quality of life as better than consumers under the medical model.²¹ Similarly, early assessment of another consumer-directed program, the Arkansas Cash and Counseling Demonstration,²² indicates that all respondents expressed satisfaction with their relationships with their paid caregivers; ninety-six percent were satisfied with their overall care; eighty-two percent who received a cash allowance to obtain assistance indicated that it improved their quality of life; seventy-nine percent

17. Lori Simon-Rusinowitz et al., *Determining Consumer Preferences for a Cash Option: Arkansas Survey Results*, 19 HEALTH CARE FINANCING REV. 73, 76 (1997).

18. See JANE TILLY ET AL., URBAN INST., LONG-TERM CARE: CONSUMERS, PROVIDERS AND FINANCING: A CHART BOOK (2001).

19. Margaret A. Nosek et al., *Life Satisfaction of People with Physical Disabilities: Relationship to Personal Assistance, Disability Status and Handicap*, 40 REHAB. PSYCHOL. 191, 198 (1995); Phillip W. Beatty et al., *Personal Assistance for People with Physical Disabilities: Consumer-Direction and Satisfaction with Services*, 79 ARCHIVES PHYSICAL MED. & REHAB. 674, 677 (1998).

20. CAL. DEP'T OF AGING, MULTIPURPOSE SENIOR SERVICES PROGRAM, at <http://www.aging.state.ca.us/html/programs/mssp.htm> (last visited Sept. 30, 2002) (describing California's multipurpose senior services program, which provides social and health care management to help frail elderly people remain at home).

21. A.E. Benjamin & Ruth E. Matthias, *Comparing Consumer- and Agency-Directed Models: California's In-Home Supportive Services Program*, GENERATIONS, Fall 2000, at 85, 86.

22. UNIV. OF MD. CTR. ON AGING, CASH AND COUNSELING DEMONSTRATION AND EVALUATION OF A CONSUMER-DIRECTED MODEL FOR LONG-TERM SERVICES, at <http://www.inform.umt.edu/AGING/ccDemo/overview.html> (last visited Sept. 30, 2002) (describing cash and counseling program in Florida, New Jersey, and Arkansas) [hereinafter CASH AND COUNSELING DEMONSTRATION].

said the program improved their quality of life a great deal; and none reported that their quality of life had diminished.²³

One of the reasons for the independent living model's popularity is that it allows consumers to hire people they know and with whom they are comfortable. This hiring decision is important considering the intimate nature of the job. According to the Commonwealth Study,²⁴ consumer satisfaction has a direct correlation to the preexisting relationship with the assistant; consumers who knew their assistant previously are approximately three times more likely to be "highly satisfied."²⁵ Additional key factors that relate to a high level of overall satisfaction are whether the consumer helps to schedule and supervise the assistant; consumers who supervise their assistants are twice as likely to be "very satisfied."²⁶ Generally speaking, consumers are more satisfied if they have control and choices regarding their care; consumers who report having four or five indicators of control are significantly more likely to be very satisfied.²⁷

The independent living model also has assisted consumers in maintaining their health. Studies have found lower levels of hospitalization for consumers who receive care under the independent living model.²⁸ After discharge, people with major disabilities may have difficulties maintaining their health and performing daily activities without adequate personal assistance.²⁹ The study found a positive relationship between the adequacy of personal assistance and the ability of individuals with disabilities to maintain good physical and mental health.³⁰

23. LESLIE FOSTER ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS., CASH AND COUNSELING: CONSUMER'S EARLY EXPERIENCES IN ARKANSAS 8, 26 (2000), available at <http://aspe.hhs.gov/daltcp/reports/earlyAR.htm> (last visited Sept. 30, 2002).

24. See generally COMMONWEALTH COMM'N ON ELDERLY PEOPLE LIVING ALONE, THE IMPORTANCE OF CHOICE IN MEDICAID HOME CARE PROGRAMS: MARYLAND, MICHIGAN, AND TEXAS (1991).

25. *Id.*; Pamela Doty et al., *Consumer-Directed Models of Personal Care: Lessons from Medicaid*, 74 MILLBANK Q. 377, 393-96 (1996).

26. Doty et al., *supra* note 25, at 394, 396.

27. *Id.* at 396.

28. Jane Mattson-Prince, *A Rational Approach to Long-Term Care: Comparing the Independent Living Model with Agency-Based Care for Persons with High Spinal Cord Injuries*, 35 SPINAL CORD 326-27 (1997).

29. See generally Margaret A. Nosek, *Personal Assistance: Its Effect on the Long-Term Health of a Rehabilitation Hospital Population*, 74 ARCHIVES PHYSICAL MED. & REHAB. 127 (1993).

30. *Id.* at 128.

Finally, the independent living model enhances the productivity of people with disabilities while living in the community.³¹ Productivity must be considered in terms that are relevant to a consumer's age-specific expectations. For elderly people, the independent living model enhances their ability to take care of themselves and remain active members of the community; for working-age adults, it allows them to be productive in seeking and maintaining employment; and for children, this model assists them in their efforts to be independent in academic and recreational settings.³²

Overall, the independent living model has many advantages over the medical model in terms of autonomy, affordability, quality of care, and quality of life.³³ Its primary disadvantage relates to manageability, which includes the burden of having to manage complex personal assistance services and comply with regulatory, tax, and other legal requirements.³⁴ Mechanisms have been established to assist independent living model consumers in managing their care, but the model still poses significant management challenges.³⁵ Consumers who are willing and able to meet these challenges (or have surrogates who are willing and able to do so on their behalf) will succeed under this model.

The independent living model must be compared to all other care models; all models have strengths and weaknesses, and consumers should be able to decide which care model to use.³⁶ One of the primary impediments to widespread adoption of the independent living model is the notion that it is not applicable to older people with

31. MARGARET A. NOSEK, PERSONAL ASSISTANCE: KEY TO EMPLOYABILITY OF PERSONS WITH PHYSICAL DISABILITIES IN THE UNITED STATES REPORT (1990); Gordon W. Richmond et al., *The Effect of Consumer-Directed Personal Assistance Services on the Productivity Outcomes of People with Disabilities*, J. OF REHAB. OUTCOMES MEASUREMENT, Fall 1997, at 48.

32. NOSEK, *supra* note 31.

33. ANDREW I. BATAVIA, INDEPENDENT LIVING: A VIABLE OPTION FOR LONG-TERM CARE (forthcoming 2003).

34. SUSAN A. FLANAGAN, CONSUMER-DIRECTED ATTENDANT SERVICES: HOW STATES ADDRESS TAX, LEGAL, AND QUALITY ASSURANCE ISSUES 48-56 (1997) (discussing tax requirements of personal assistance services).

35. *Id.*; SUSAN A. FLANAGAN & PAMELA S. GREEN, CONSUMER-DIRECTED PERSONAL ASSISTANCE SERVICES: KEY OPERATIONAL ISSUES FOR STATE CD-PAS PROGRAMS USING INTERMEDIARY SERVICE ORGANIZATIONS 91 (1997). This report was prepared for the U.S. Department of Health and Human Services, offices of the Assistant Secretary for Planning and Evaluation, Division of Aging and Long-Term Care Policy.

36. Andrew I. Batavia, *Even Playing Field for Consumer-Directed Long-Term Care*, 21 HEALTH AFFAIRS 271 (Letter to the Editor) (2002).

disabilities, and particularly older people with cognitive difficulties.³⁷ This misconception is based in part on a cultural phenomenon referred to as the “elderly mystique,” the belief that elderly people are inherently dependent and need others to manage their lives.³⁸ This myth is being dispelled by the increasing numbers of older people demanding consumer direction and independent living.³⁹ It has been recognized that the independent living model is fully applicable to elderly people and even individuals with cognitive disabilities through the use of surrogate decision makers.⁴⁰

B. Recent Events in Independent Living and Consumer Direction

Various events illustrate that the concepts of independent living and consumer direction have been gaining prominence recently in the field of long-term care. These events include the following:

- the U.S. Supreme Court decision in *Olmstead v. L.C. ex rel. Zimring (Olmstead)*,⁴¹ ruling that unjustified institutionalization constitutes discrimination under the Americans with Disabilities Act of 1990 (ADA), and that Medicaid recipients must be provided care in the most integrated setting appropriate (i.e., typically the individual’s home and community);⁴²
- subsequent court decisions, disability rights advocacy efforts, state initiatives, and guidance from governmental agencies im-

37. See Hous. Research Found., *Public Housing and Seniors Housing/Service Models*, <http://www.housingresearch.org> (last visited Sept. 9, 2002).

38. Elias S. Cohen, *The Elderly Mystique: Impediment to Advocacy and Empowerment*, GENERATIONS, 1990 Supp., at 13, 14 [hereinafter Cohen, GENERATIONS]; Elias S. Cohen, *The Elderly Mystique: Constraints on the Autonomy of the Elderly with Disabilities*, GERONTOLOGIST, 1998 Supp. at 24, 24 [hereinafter Cohen, GERONTOLOGIST].

39. Sharon M. Desmond et al., *Consumer Preferences for a Cash Option Versus Traditional Services, Florida Elders and Adults with Physical Disabilities (Telephone Survey Technical Report—Background Research for the Cash and Counseling Demonstration and Evaluation)* (1998), available at http://www.hcbs.org/resources/one/one_research_c1.htm.

40. See Marshall B. Kapp, *From Medical Patients to Health Care Consumers: Decisional Capacity and Choices to Purchase Coverage and Services*, 3 AGING & MENTAL HEALTH 294, 295 (1999) [hereinafter Kapp, *Medical Patients*]; Marshall B. Kapp, *Consumer Choice in Long-Term Care: What the United States Can Teach and Learn from Others About Decisionally Incapacitated Consumers*, 24 INT’L J.L. & PSYCHIATRY 199, 200 (2001) [hereinafter Kapp, *Consumer Choice*].

41. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

42. See Batavia, *supra* note 8, at 32–37.

plementing the *Olmstead* decision in a manner that encourages consumer direction,⁴³

- leadership from the federal government and the foundation community in fostering consumer direction and developing new approaches to consumer-directed long-term care;⁴⁴
- the experience of the states⁴⁵ and other countries⁴⁶ offering long-term care with substantial consumer direction, including the early results of the Cash and Counseling Demonstration in which consumers are provided a cash allowance to pay for the services they choose;⁴⁷ and
- a national conference held on June 10–12, 2001, sponsored by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation (RWJF), entitled “Independent Choices: A National Symposium on Consumer-Direction and Self-Determination for the Elderly and People with Disabilities.”⁴⁸

43. *Id.*

44. See Pamela Doty, *The Federal Role in the Move Toward Consumer Direction*, GENERATIONS, Fall 2000, at 22, 22–23.

45. States have had substantial flexibility to incorporate consumer direction into their Medicaid long-term care programs since 1981 when Congress established the optional Home and Community-Based Care Waiver Program—section 1915(c) of the Social Security Act. A key goal of the waiver program is to reduce the strong institutional bias of the Medicaid program by offering consumers options to live in their communities. Different states use different models and coverage packages for their programs. Some are more consumer directed than others, but overall the program has been a significant step forward in providing greater consumer-directed care. The waiver program has grown significantly since the mid-1980s, but remains very small compared with long-term care services provided under the medical model of the traditional Medicaid program. See generally Nancy Miller, *Medicaid 2176 Home and Community-Based Care Waivers: The First Ten Years*, HEALTH AFF., Winter 1992, at 162, 162–63. Although several states offer services under the independent living model, many do not. Even those states that use the independent living model have adopted major features of the medical model in their home health policies. See A.E. Benjamin et al., *Comparing Consumer-Directed and Agency Models for Providing Supportive Services at Home*, 35 HEALTH SERVICES RES. 351, 352 (2000); Doty et al., *supra* note 25, at 377.

46. Jane Tilly et al., *Consumer-Directed Home- and Community-Based Services Programs in Five Countries: Policy Issues for Older People and Government*, GENERATIONS, Fall 2000, at 74, 83.

47. See generally Kevin J. Mahoney et al., *Early Lessons from the Cash and Counseling Demonstration and Evaluation*, GENERATIONS, Fall 2000, at 41.

48. *Independent Choices: A National Symposium on Consumer-Direction and Self-Determination for the Elderly and Persons with Disabilities*, at <http://aspe.hhs.gov/daltcp/reports/01cfpack.htm> (June 2001).

II. Methodology

Although a trend toward independent living and consumer direction in long-term care seems apparent, it is important to examine this trend through objective analysis. One approach to verify this trend is through a content analysis of the relevant academic and professional literatures. Adoption of these concepts in the literature reflects their growing prominence as important principles of long-term care; experts' use of the specific terms, "consumer direction" or "independent living," documents their credibility as concepts worthy of serious consideration and debate. Whether these experts support the concepts or not, simply referring to them in their work indicates a certain level of respect and professional acknowledgment. To the extent that the use of these terms can be documented over time, the results can serve as an objective indicator of societal trends concerning consumer direction in long-term care.

Two key areas of study related to consumer direction and independent care are health care and law. The health care literature is obviously relevant because we are attempting to discern the prominence of independent living concepts in the health care field generally and the long-term care field specifically. The legal literature is relevant because it provides a strong indicator of the extent to which these concepts have an impact on the legal environment of the health care field, which has strong implications for health care providers. The health care and legal literatures are arguably the two most influential academic/professional resources in the country and, thus, will have a profound impact on policy and practice in the health care field.⁴⁹

49. Several strategies were used for each literature search, using different combinations of the following terms: "independent living," "consumer-direction," "consumer-directed," "consumer choice," "care," "assistance," "personal assistance," and "long-term care." Each strategy was tested to determine whether it adequately identified relevant articles that address the concepts of independent living and consumer direction. Ultimately, the following search terms were used in the analysis:

"independent living and (care or assistance)"

"independent living and long-term care"

"consumer-directed and (care or assistance)"

"consumer-directed and long-term care"

The term "care or assistance" was used as a means by which to limit searches to articles relating the independent living or consumer direction concept directly to some aspect of health care. The term "long-term care" was used as a means by which to limit the search to articles directly relating the independent living or consumer direction concept to some aspect of long-term care. In adopting these search terms, it was recognized that they might result in searches that were

The following two computerized databases that index the health care and legal literatures were identified for purposes of conducting searches on consumer direction: Medline through PubMed (articles by experts in health care, including long-term care); and Lexis/Nexis Academic Universe (articles by legal scholars, including experts in health care law and disability law).

Six time periods consisting of five years each were specified: (1) 1971–75; (2) 1976–80; (3) 1981–85; (4) 1986–90; (5) 1991–95; and (6) 1996–2000. These time periods will be referred to in this article as the first through the sixth periods, respectively. For each period, the number of articles matching the applicable search term is enumerated, and the percentage of all articles published in that period is calculated by dividing the number of articles published in that period by the total number of articles published over all six time periods. Such percentages provide a means by which to compare usage of consumer direction terminology across time periods.

III. Results

Table 1 presents the results of the content analyses. The analyses of both literatures—health care and law—yielded consistent results. Relatively few articles using either of the terms “independent living” or “consumer-directed” were published in the 1970s. The first articles using the search term “independent living and (care or assistance)” began to appear in the first half of that decade; this represented only one percent of the articles. The frequency of the occurrence of this term increased in each successive five-year period, culminating in thirty-eight percent of such articles in the sixth period. A similar pattern of usage occurred in the legal literature, except that the first occurrence of this term did not occur until the third period. The growth in usage of the term in legal literature increased at a more rapid rate in the ensuing years—from three percent in the third time period to sixty-six percent in the final period.

The search term “independent living and long-term care” yielded a much smaller number of articles in both the health care and

both underinclusive (i.e., failing to identify some relevant articles) and overinclusive (i.e., identifying some articles that are not relevant) to some extent. However, they were accepted as the best available combinations by which to achieve their objectives, recognizing that there is no perfect combination of terms for such purposes.

legal literatures explored. In the health care literature, the number of articles citing this term increased from two to thirteen from the second to the sixth time period. Similarly, the number of articles including the search term increased from five to forty in the legal literature from the third to the sixth time period. However, while rates of increase remained substantial in both literatures, the absolute number of articles was small.

The search term “consumer-directed and (care or assistance)” also occurred less frequently than “independent living and (care or assistance)” in both sets of literature. The first occurrence of this term in health care literature was not until the fifth time period. Interestingly, the first occurrence of the term in the legal literature was two periods earlier, in the third time period. Again, absolute numbers were small, but rates of increase in usage were dramatic in legal articles—from one article in the third time period to fifty-six articles in the sixth time period.

Finally, the term “consumer-directed and long-term care” occurred the least in both sets of literature. The term was used in health care literature for the first time in the sixth time period, with only eight articles occurring during that period. In legal literature, the term appeared for the first time during the fifth time period and increased from two articles in that period to six articles in the sixth time period.

Table 1**Frequency of Independent Living Movement Language in the Literature**

Literature search	1971– 75	1976– 80	1981– 85	1986– 90	1991– 95	1996– 2000	Total
“Independent living” AND (care or assistance) Medline/PubMed ^a	4 (1%)	22 (7%)	30 (10%)	44 (15%)	85 (29%)	112 (38%)	297 (100%)
“Independent living” AND (care or assistance) Lexis/Nexis ^b	— ^c	0 (0%)	10 (2%)	19 (5%)	106 (27%)	260 (66%)	395 (100%)
“Independent living” AND “long-term care” Medline/PubMed	0 (0%)	2 (6%)	5 (16%)	3 (9%)	8 (25%)	13 (41%)	32 (100%)
“Independent living” AND “long-term care” Lexis/Nexis	—	0 (0%)	5 (7%)	2 (3%)	24 (34%)	40 (56%)	71 (100%)
“Consumer-directed” AND (care or assistance) Medline/PubMed	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (7%)	13 (93%)	14 (100%)
“Consumer-directed” AND (care or assistance) Lexis/Nexis	—	0 (0%)	1 (1%)	3 (4%)	16 (21%)	56 (74%)	76 (100%)
“Consumer-directed” AND “long-term care” Medline/PubMed	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	8 (100%)	8 (100%)
“Consumer-directed” AND “long-term care” Lexis/Nexis Law Reviews	—	0 (0%)	0 (0%)	0 (0%)	2 (25%)	6 (75%)	8 (100%)

^aThis database indicates all articles in which the search terms are located at least once in the title, abstract, or key works.

^bThis database indicates all law review articles in which the search terms are located at least three times anywhere in the article, including the title, abstract, or key words.

^cNo data available for these years.

IV. Discussion of Results

It is clear from the research that the general search term “independent living and (care or assistance)” has been accepted in both the health care and legal literatures, and it is increasing in usage at a rapid rate over time. The search term more specifically focused on long-term care, “independent living and long-term care,” was adopted in a later time period and is less widely used. This suggests that there has been some lag in applying independent living concepts directly to long-term care. In addition, both search terms were adopted more rapidly in the health care literature than in the legal literature. This is somewhat predictable in that the law is largely a derivative discipline that gains many of its substantive insights from the social sciences and other disciplines.⁵⁰ Therefore, we would predict that these terms would first occur in the health care literature before being adopted by legal scholars.

The term “consumer-directed” generally has not been adopted as widely as the term “independent living” in either discipline. Interestingly, the term “consumer-directed” was adopted earlier and more frequently in the legal literature than in the health care literature. This is inconsistent with the prediction above that the legal literature will generally lag behind the health care literature in using such new terminology. One possible explanation for this is that much of the early literature on consumer direction was published in reports and monographs rather than in health care journals.⁵¹ Law review articles, which traditionally require copious citations, often cite these difficult-to-access sources.

One pattern that clearly stands out in Table 1 is the dramatic rate of increase from each time period in usage of each of the search terms. Rates of increase exceeded fifty percent from one period to the next in the third to sixth time periods for almost every term search conducted, and exceeded 200% for some time periods. For example, the growth

50. See Graham C. Lilly, *Law Schools Without Lawyers? Winds of Change in Legal Education*, 81 VA. L. REV. 1421, 1425 (1995).

51. For examples of reports containing such information, see SIMI LITVAK ET AL., ATTENDING TO AMERICA: PERSONAL ASSISTANCE FOR INDEPENDENT LIVING (1987); SIMI LITVAK & JAE KENNEDY, POLICY ISSUES AFFECTING THE MEDICAID PERSONAL CARE SERVICES OPTIONAL BENEFIT (1991); SIMI LITVAK, NEW MODELS FOR THE PROVISION OF PERSONAL ASSISTANCE SERVICE: A RESEARCH AND DEMONSTRATION PROJECT (1990); TOWARD A UNIFIED AGENDA: PROCEEDINGS OF A NATIONAL CONFERENCE ON DISABILITY AND AGING (Constance Mahoney et al. eds., 1986).

in articles from the fifth to the sixth period for the Lexis/Nexis search of “consumer-directed and (care or assistance),” from sixteen to fifty-six articles, represents a 350% rate of increase. These results suggest that the terms “independent living” and “consumer-directed,” and the concepts and principles associated with them, are rapidly becoming accepted and utilized in both the health care and health law fields.

V. Implications for Older People with Disabilities Generally

As Americans, elderly people in this country cherish their freedom, autonomy, and privacy.⁵² Until recently, older people have resigned themselves to the notion that if they become sufficiently disabled to the point that they can no longer care for themselves, the only option available will be residing in a nursing home.⁵³ Recognizing that living in a nursing home necessarily entails sacrificing freedom, autonomy, and privacy, most older people attempt to postpone or avoid the necessity of moving into a nursing home to the fullest extent possible.⁵⁴ The relatively new option of residing in assisted living facilities has enabled a significant number of older persons to function with physical and mental limitations in environments that are still, in essence, their own homes.⁵⁵ However, these facilities may have rules that do not allow substantially disabled residents to live there permanently.⁵⁶ Many of these individuals believe they have no options other than nursing home care until the end of their lives.⁵⁷

Slowly, as the next generation ages and becomes disabled, the perception that the only available option for long-term care is in a nursing home is becoming less prevalent.⁵⁸ People have gradually become aware of options for home-based long-term care, including care provided by home health agencies under the medical model and con-

52. See LAWRENCE A. FROLIK & RICHARD L. KAPLAN, *ELDER LAW IN A NUTSHELL* 152 (2d ed. 1999).

53. See *id.*

54. See *id.*

55. ROSALIE A. KANE & KEREN BROWN WILSON, *ASSISTED LIVING IN THE UNITED STATES: A NEW PARADIGM FOR RESIDENTIAL CARE FOR FRAIL OLDER PERSONS* 10 (1993).

56. See Stephanie Edelstein, *Assisted Living: Recent Developments and Issues for Older Consumers*, 9 *STAN. L. & POL'Y REV.* 373, 378 (1998).

57. See KANE & WILSON, *supra* note 55, at 49.

58. See generally Korbin Liu et al., *Changes in Home Care Use by Older People with Disabilities: 1982-1994*, 55 *J. GERONTOLOGY* 5245-53 (2000).

sumer-directed personal assistance services by individuals who are not health professionals under the independent living model.⁵⁹ Through these models, and the general concept of consumer direction, individuals are realizing the prospects for maintaining control over their lives despite their increasing disabilities.⁶⁰

Studies have yielded different results concerning the extent to which elderly people desire consumer direction in their long-term care. One survey found that only eighteen percent of home health care recipients over age sixty indicated that they wanted more involvement "in determining the amount and type of services" they receive.⁶¹ Other studies suggest a substantial interest in consumer direction among elderly people.⁶² The varying results depend upon the specific circumstances of the elderly individual and the definition of consumer direction used.⁶³ While many elderly consumers may not be interested in managing a personal assistance employment relationship under the independent living model, it appears that most would like to be able to determine when they receive their care.

Consumer direction has been applied to the elderly population only relatively recently.⁶⁴ Currently, many providers of services under the medical model fail to acknowledge the right of elderly people to control their lives in terms of receiving care according to their preferences.⁶⁵ In dealing with a significant percentage of older people who have some cognitive and decisional capacity problems, these health care professionals have a tendency to treat all or most elderly people in a paternalistic manner.⁶⁶ This paternalism is associated with the elderly mystique, the cultural phenomenon of presumed dependency on the part of older people with disabilities.⁶⁷ Because long-term care policy has focused primarily on the older population, paternalism

59. *Id.*

60. *Id.*

61. Lillian Glickman et al., *Self Direction in Home Care for Older People: A Consumer's Perspective*, 16 HOME HEALTH CARE SERVICES Q. 41, 50 (1997).

62. Desmond et al., *supra* note 39.

63. See generally Glickman et al., *supra* note 61.

64. See, e.g., CASH AND COUNSELING DEMONSTRATION, *supra* note 22.

65. DeJong et al., *supra* note 16, at 90.

66. See Kapp, *Medical Patients*, *supra* note 40, at 295.

67. See generally Cohen, GENERATIONS, *supra* note 38; Cohen, GERONTOLOGIST, *supra* note 38.

is deeply ingrained in the service delivery system that treats all people with disabilities, not just elderly people.⁶⁸

Although the tendency toward paternalism also exists in the treatment of the younger disabled population, young people are more likely to react in a confrontational manner against such paternalism.⁶⁹ The older population has less of an ideological commitment to the concept of consumer direction and has been able to apply this concept more flexibly to a wide array of long-term care contexts.⁷⁰ Much focus has been placed on keeping older people with disabilities out of nursing homes; however, there has also been a strong emphasis on making nursing homes, home health agencies, and other traditional health care providers of long-term care incorporate consumer direction and consumer choice into their care procedures.⁷¹

In establishing the independent living model initially, young disability rights advocates, most of whom had disabilities, provided the impetus for advocating consumer direction.⁷² In contrast, progressive health care and social service professionals have spearheaded the consumer direction concept as it has been applied to the long-term care of elderly people.⁷³ These professionals depend financially on the medical model of long-term care and are unlikely to strongly support the independent living model; there is no financial benefit to health care professionals under the independent living model.⁷⁴

The independent living model is not for everyone. It is ideally suited for individuals who insist upon maintaining maximum control over their lives and who are willing to take full responsibility for such control. It also involves a substantial amount of work, including the necessity to recruit, hire, train, supervise, pay, and fulfill administrative responsibilities for their personal assistants. Obviously, applying the independent living model is easier for people who do not have substantial disabilities and co-morbidities, and it is much more diffi-

68. Pamela Nadash, *Independent Choices*, AMERICAN REHABILITATION, Summer–Autumn 1998, at 15.

69. See Tilly et al., *supra* note 46, at 77 (“[Y]ounger people with physical disabilities are the most vocal in expressing their preference for consumer direction . . .”).

70. See *id.* at 78.

71. See Marisa A. Scala & Tom Nerney, *People First: The Consumers in Consumer Direction*, GENERATIONS, Fall 2000, at 55, 56.

72. DeJong, *supra* note 7, at 436.

73. Scala & Nerney, *supra* note 71, at 56.

74. *Id.*

cult for people with significant cognitive impairments.⁷⁵ However, those who suggest that this model simply is not applicable to elderly people with major disabilities and co-morbidities are contradicted by the significant number of young and older people with major impairments, disabilities, and co-morbidities who are currently functioning under the independent living model.⁷⁶

The independent living model is much easier to manage for a person with a disability when the model is supplemented with the assistance of family members and other assistants who provide uncompensated care under the "informal support model."⁷⁷ Individuals with no available support have a substantial administrative task in managing the independent living model so as to ensure that all of their care needs are satisfied. Again, those who question the feasibility of the model must recognize that many individuals with disabilities operate completely under the independent living model.

Many independent living advocates stress that all people who require long-term care should not be obligated to use the independent living model; rather, the independent living model should be an available option to all individuals who require long-term care.⁷⁸ An analysis of the various models demonstrates that different consumers will value a specific model depending on their personal criteria and circumstances.⁷⁹ Some individuals, given this option and their personal circumstances, will choose home care or institutional care under the medical model.⁸⁰ Studies indicate that a larger percentage of elderly people tend to choose these medical model options than do younger people with disabilities.⁸¹ Choosing the medical model may be a completely rational choice for individuals who do not demand

75. Cohen, *GENERATIONS*, *supra* note 38, at 27.

76. Doty et al., *supra* note 25, at 379 (stating two-thirds of the Medicaid expenditures for home- and community-based long-term care services went to the mentally retarded and developmentally disabled).

77. FROLIK & KAPLAN, *supra* note 52, at 180.

78. DAUTEL & FRIEDEN, *supra* note 6.

79. *Id.*

80. *See generally id.*

81. Glickman et al., *supra* note 61, at 42; Kevin J. Mahoney et al., *Determining Consumer Preferences for a Cash Option: New York Telephone Survey Findings*, *AM. REHABILITATION*, Winter 1998, at 24, available at <http://www.inform.umd.edu/AGING/CCDemo/Publications/mahoney.html> (last visited Sept. 30, 2002); Tilly et al., *supra* note 46, at 78 (citing C. Woldringh & C. Ramakers, *Persoonsgebonden Budget Verpleging Verzorging Ervaringen van Budgethouders en Kwaliteit van Zorg* (Instituut voor Toegepaste Sociale Wetenschappen van de Stichting Katholieke Universiteit te Nijmegen ed. 1998)).

control, have limited energy and desire to manage a personal assistance relationship,⁸² and/or do not insist upon living independently.⁸³ However, studies indicate that a significant number of older people with disabilities choose the independent living model.⁸⁴

One study of California's Medicaid program found that although younger recipients embrace self-direction more enthusiastically than older ones, age differences are small in a majority of service outcomes.⁸⁵ On average, older users embrace this independent living model and manage within it much like younger users.⁸⁶ Some differences emerge between the young-old (sixty-five to seventy-four years old) and old-old (seventy-five years old and greater), but these are neither consistent nor determinative.⁸⁷ Old age is far from an inevitable barrier to self-direction.⁸⁸ As with other age groups, there are opportunities and obstacles to be addressed as this newer approach to home care is disseminated.⁸⁹ Those individuals who choose a version of the medical model, whether home-based through an agency or institution-based through a nursing facility, still have options for consumer direction.⁹⁰ The amount of consumer direction available under the medical model tends to be significantly less than the amount available under the independent living model; under the independent living model, the consumer can schedule all tasks and functions such as meals, baths, and transfers to and from bed, entirely according to their preferences and limited only by their ability to hire assistants willing to abide by their schedules.⁹¹

Depending upon their particular providers, however, care recipients under the medical model may maintain a certain amount of control. In recent years, there has been a significant shift in long-term care policy towards requiring providers to accept increased consumer direction.⁹² Although this shift has been largely rhetorical, some pro-

82. See generally DeJong, *supra* note 16, at 90.

83. *Id.* at 93.

84. See Tilly et al., *supra* note 46, at 78.

85. A. E. Benjamin & Ruth E. Matthias, *Age, Consumer Direction, and Outcomes of Supportive Services at Home*, 41 GERONTOLOGIST 632, 640 (2001).

86. *Id.*

87. *Id.*

88. *Id.* at 641.

89. *Id.*

90. Stone, *supra* note 13, at 6.

91. See DeJong et al., *supra* note 16, at 90.

92. Stone, *supra* note 13, at 5.

viders with a consumer direction philosophy offer a significant amount of consumer autonomy, at least by institutional standards.⁹³

VI. Implications for Older People with Cognitive Disabilities

Obviously, the greatest challenge to the independent living model is an individual with significant cognitive disabilities and, consequently, diminished decisional capacity.⁹⁴ The independent living model requires consumers to assess options, make complex decisions, and take responsibility for those decisions.⁹⁵ Analysts and advocates of the independent living model have argued that this model may apply to people with diminished decisional capacity through the use of surrogates, typically family members who conduct all the functions and tasks the individual would perform in managing the personal assistance relationship.⁹⁶

In our society, there is a legal presumption that people who have reached the age of majority have the capacity to make major decisions that affect their lives.⁹⁷ State laws vary on the standards by which this presumption may be rebutted for those individuals who do not have the decisional capacity to make sound decisions.⁹⁸ According to Professor Kapp, “[t]here is a broad modern legal and ethical consensus that the question of decisional capacity for any individual ordinarily ought to be examined and evaluated on a functional, decision-specific basis, rather than as a global, all-or-nothing phenomenon.”⁹⁹ Therefore, decisional capacity is determined by specific circumstances of the decision being confronted. An individual may have capacity to make certain types of decisions and not others; this capacity may vary over time.¹⁰⁰

Increasingly, state legislatures have recognized the transitory nature of decisional capacity and enacted statutes authorizing courts to grant guardianship on a limited or partial basis by considering an in-

93. *Id.* at 5–6.

94. *See generally* Richmond et al., *supra* note 31, at 48.

95. *See* Batavia, *supra* note 8, at 21.

96. *See generally* Kapp, *supra* note 5.

97. *Id.* at 85.

98. *See* Kapp, *Consumer Choice*, *supra* note 40, at 205.

99. Kapp, *Medical Patients*, *supra* note 40, at 295.

100. *Id.*

dividual's capacities and limitations in light of specific decisions.¹⁰¹ Yet, the approaches taken by the different states vary substantially, and include different combinations of guardianship/conservatorship proceedings, advance directives, family consent statutes, and informal approaches.¹⁰² Critics contend that these approaches are often complicated, ambiguous, decision-specific, subject to fluctuations over time, and highly ad hoc.¹⁰³

A study of people with cognitive impairments found that individuals with mild to moderate impairments were able to answer questions about their general preferences, provided valid responses to questions about their involvement in everyday care, participated in care decisions, and expressed values and wishes concerning care with a high degree of reliability and accuracy.¹⁰⁴ In addition, recipients of care were able to choose a person to make decisions on their behalf in the event that they were no longer able to make decisions for themselves.¹⁰⁵

Care recipients strongly preferred to pass decision-making authority to an individual of their choice.¹⁰⁶ As expected, ninety-three percent of the time the individual chosen was a family caregiver.¹⁰⁷ The caregiver was given decisional authority in six areas: health care, finances, personal care, social activities, living arrangements, and the possibility of living in a nursing home.¹⁰⁸ Care recipients reported that they discussed their daily care wishes with family caregivers and believed that their caregivers understood their wishes for both daily care and nursing home care.¹⁰⁹ Consistently, caregivers also indicated that they had discussed the recipient's wishes concerning daily care and nursing home care, and that they had a good understanding of the recipient's wishes for daily care.¹¹⁰

101. *Id.* Even without this statutory authority, courts are generally recognized as having equitable jurisdiction to tailor specific limited guardianship arrangements to meet the needs of a particular individual. *Id.*

102. *Id.*

103. Marshall B. Kapp, *Evaluating Decisionmaking Capacity in the Elderly: A Review of Recent Literature*, J. ELDER ABUSE & NEGLECT, Summer/Fall 1990, at 15–16.

104. LYNN F. FEINBERG ET AL., MAKING HARD CHOICES: RESPECTING BOTH VOICES—FINAL REPORT 3, 6 (2000), available at <http://www.caregiver.org/research/execsum200006C.html> (last visited Sept. 7, 2002).

105. *Id.*

106. *Id.*

107. *Id.*

108. *Id.*

109. *Id.* at 4.

110. *Id.*

The top five priorities of care recipients concerning their daily lives were as follows: to have a comfortable place to live; to receive assistance from a particular caregiver; to live in their own home; to feel safe at home, even if it restricts activities; and to allow caregivers not to put their lives on hold.¹¹¹ A substantial majority (seventy-eight percent) of these individuals with cognitive impairments indicated that it is very important to them to remain at home; seventy-three percent stated that they do not want to live in a nursing home.¹¹²

Surrogates, who are typically family members, have a variety of difficult decisions they must address, often involving conflicting factors.¹¹³ The most prominent conflict is between what the individual would have wanted under the circumstances and the ability of the surrogate or family to fulfill those desires.¹¹⁴ An individual may have indicated prior to the onset of the cognitive impairment that she did not wish to be taken care of by strangers under any circumstances, but this desire may conflict with the reality that no family members are physically able or psychologically willing to take care of the individual. Therefore, the individual's desires must sometimes be balanced against the needs, preferences, and capabilities of the family.¹¹⁵

Some states have public or volunteer guardianship programs to address the need for surrogates.¹¹⁶ Typically, the standard to which surrogates are held is that of "substituted judgment," which means they must do precisely what the consumer would have wanted to do under the circumstances.¹¹⁷ Obviously, this standard can only be strictly met in circumstances under which the consumers clearly articulated their wishes prior to becoming incapacitated. Otherwise, the surrogate must attempt to discern the consumer's wishes based generally on an understanding of the consumer's values and preferences.

111. *Id.*

112. *Id.*

113. *Id.*

114. *Id.*

115. The key threshold issue is to determine who would be the ideal surrogate decision maker on behalf of the consumer. In the context of informed-consent decisions, many states have enacted "family consent" statutes indicating which family members have responsibility for making decisions on behalf of the consumer in the event that the consumer does not have adequate capacity to make a decision. If no family members are available, the challenge is to identify other acceptable people who are willing and able to serve as surrogate decision makers, preferably individuals who are at least somewhat knowledgeable of the values and preferences of the consumer. Kapp, *Medical Patients*, *supra* note 40, at 296.

116. *Id.*

117. *Id.*

When the consumer's desire is not discernible, the surrogate must do what is in the best interests of the consumer.¹¹⁸

Individuals who oppose making the independent living model an available option for people with cognitive deficits are likely to argue that surrogacy is not a realistic option. However, experience demonstrates that surrogacy can work; it depends largely on the specific circumstances of the individual.¹¹⁹ Consumers with substantial cognitive disabilities and limited family support are not likely to be able to function under the independent living model unless a very dedicated individual is appointed as guardian and surrogate for decision-making purposes.¹²⁰

In addition, the extent of the individual's mental and emotional disabilities will determine the difficulty of the decision-making process and the time burden on the surrogate.¹²¹ Thus, surrogacy may not be a viable option for many individuals with substantial cognitive problems; however, one should not presume that the independent living model option is not viable for any particular consumer without first assessing that individual's circumstances. Independent living should be an available option, and a process should be developed to determine whether the individual would have wanted to receive care under this model and whether such care is feasible for the individual.

Many of the same issues that confront older people with cognitive disabilities apply to younger individuals with similar problems.¹²² Because of advances in medical care, the number of people with cognitive problems and limited decisional capacity is growing rapidly.¹²³ As a society, a need exists to develop viable options for the long-term care of these individuals. In developing such options, the independent living model should not be ignored or neglected simply because it requires complex decision making. Many of these individuals would

118. One key legal issue implicated in any surrogacy situation is the emergence of a conflict of interest. Conflicts of interest entail a breach of the surrogate's fiduciary duty of loyalty to the consumer, and may arise in any situation in which the surrogate's loyalties are divided such that the surrogate's interests prevail over those of the consumer. For example, if the surrogate is also an heir to the consumer, and will therefore inherit the consumer's estate, an effort to limit the consumer's needed services solely to preserve the estate would violate the duty of loyalty. *Id.* at 297.

119. FROLIK & KAPLAN, *supra* note 52, at 26.

120. *Id.*

121. *See generally* Feinberg, *supra* note 104, at 3.

122. *See generally* Scala & Nerney, *supra* note 71.

123. *See generally* AGING AND HUMAN PERFORMANCE (Neil Chambers ed., 1985).

prefer to live and receive care under the independent living model if they were currently legally competent to make such choices.¹²⁴

VII. Conclusion

The concepts of independent living and consumer direction have been discussed in health care since the early 1970s. In the past decade, they have received much attention from health care policy makers at the federal and state levels, as evidenced by various consumer direction programs, demonstrations, and conferences. However, the extent to which these concepts have percolated deeply into the health care and long-term care fields is unknown. The current analysis of the health care and legal literatures suggests that the concept of independent living is being used in both fields of study. In contrast, the concept of consumer direction has been adopted less widely, but appears to be increasing in usage at a rapid rate.

Based upon the clear pattern of increased usage of independent living concepts, there is reason to believe that these concepts will continue to enter into the various literatures and thereby into the thought processes of decision makers in the field. Until now, with the exception of a few seminal articles, the academic and professional literatures have largely trailed behind the actual practice of implementing consumer direction in long-term care. However, a critical mass of studies and reports concerning consumer direction that are currently being conducted, particularly under the independent living model of long-term care, will likely further fuel the expansion of consumer-directed care. It will be important to track the evolution of long-term care and its literature to determine whether the principles of independent living and consumer direction are fully assimilated.

The concepts of independent living and consumer direction were popularized by disability rights advocates attempting to expand long-term care options for young and working-age people with disabilities so they could live independently and productively in their communities.¹²⁵ Consumer direction already has been applied to elderly people with disabilities receiving care from home health agencies and nursing homes, although implementation has been uneven throughout the

124. Batavia, *supra* note 8, at 21 (noting “the independent living model of long-term care has become the model of choice by many working-age people with disabilities”).

125. See Kapp, *supra* note 5, at 56.

industry.¹²⁶ At this stage, the key question is not whether independent living and consumer direction will be a permanent part of the long-term care landscape, but rather how deeply they will penetrate into long-term care policy for elderly people.

Consumer direction and independent living have already been incorporated into long-term care policies for the younger disabled population through application of the independent living model.¹²⁷ Current evidence suggests a sufficient interest in the independent living model among elderly people to warrant offering it to them as a long-term care option.¹²⁸ Older people with disabilities should have the same range of choices as younger people, and both should be allowed to receive care in their homes and communities in a manner based on their preferences and according to their direction. People with disabilities, including elderly people, should not be limited to receiving their care in institutions or under the control of health care providers.

126. *See id.* at 59.

127. *See* Batavia et al., *supra* note 15, at 531 (noting that the independent living model has emerged as the long-term care model of choice among working-age disabled persons).

128. *See* Nadash, *supra* note 68, at 15.