Aging, Rights, and Quality of Life: Prospects for Older People with Developmental Disabilities

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In *Aging, Rights, and Quality of Life*, Professors Stanley Herr and Germain Weber bring together essays on legal rights and best professional practices with regard to older individuals who are mentally retarded or have other developmental disabilities. The book grew out of presentations made at the Sixth International Round Table on Aging and Intellectual Disabilities, which took place in Vienna in 1995. The editors organized the essays into sections of the book covering “Human Rights and Legal Considerations,” “Quality of Life and Quality Standards,” “Service Models and Innovations,” and “Future Directions.” The essays analyze the problems that older people with developmental disabilities face in securing shelter, income, and a rewarding daily life in the economically advanced countries of Europe and North America. The contributors explain the role of national and international legal standards and institutions in addressing—or failing to address—these problems. They describe the progress that has been achieved at some times and in some places and suggest strategies for duplicating those accomplishments.

The editors and contributors have ample qualifications to examine these topics. Herr is a professor of law at the University of Maryland and directs the school’s clinical program in disability rights. He serves as president of the American Association on Mental Retardation and is...
well known for the landmark litigation he has brought on behalf of people with disabilities. Weber is a professor of psychology at the University of Vienna and a leader in organizations that advocate for people with mental retardation in Austria. He has worked as a social services researcher and consultant throughout Europe. Other contributors to the collection include a clinical psychologist from Northern Ireland, social work and gerontology professors from the United States, a vocational expert from northern England, an individual with Down’s Syndrome who works as an advocate throughout America, a Swedish expert on mental retardation, and various additional authorities from Austria, Great Britain, Ireland, and the United States. Two of the contributors, Tamar Heller and Matthew Janicki, are associated with the University of Illinois at Chicago and its research programs on aging and developmental disabilities.

DEVELOPMENTAL DISABILITY AND DISABILITY RIGHTS

This book is particularly timely. There is a growing realization, both in the United States and abroad, that society frequently violates the basic human rights of people with disabilities. In the United States, this realization led Congress to pass the Americans with Disabilities Act (the “ADA”) in 1990. Both people with disabilities and their supporters brought to light the history of exclusion, condescension, vilification, and other unfair treatment of people with physical and mental impairments. Congress responded with an act that forbids discrimination in employment, public services, public accommodations, telecommunications, and other fields. Nevertheless, much more needs to be done to ensure the functional equality of people with disabilities in the United States. Throughout the country, such basic accommodations as curb cuts, wheelchair ramps, and accessible public transportation are frequently absent. Nearly a decade after the passage of the ADA, less than thirty percent of working-age people who identify themselves as disabled work even part-time, in contrast to almost eighty percent of others. About three-quarters of people with disabilities who do not work want to have meaningful employment. Due to their exclusion

4. See Harris Poll Results, REGION V NEWS (Great Lakes Disability and Business Technical Assistance Center), Spring/Summer 1998, at 1 (reporting on Louis Harris & Associates-National Organization on Disability poll).
from the working economy and the increased costs associated with having a disability, people with disabilities are disproportionately poor. The poverty rate for adults with disabilities that affect their ability to work is approximately three times that of those without work disabilities. Even those people with disabilities who have full-time jobs have a poverty rate triple that of other full-time workers.

The international dimension of this problem has also gained particular prominence in recent years. The United Nations declared 1983 to 1992 to be the International Decade of Disabled Persons. In 1993, it adopted Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Regional charters also condemn disability discrimination and affirm the rights of people with disabilities to full participation in society. In 1999, the Annual Meeting of the American Society of International Law featured a panel on international and comparative law relating to disability discrimination. An American writer and disability activist, James Charlton, has recently published a book based on a world-wide investigation of the conditions faced by people with disabilities, particularly those in the poorer areas of Africa, Asia, and South America.

The underenforcement of disability rights is particularly grave with respect to people who are elderly, because those individuals are often the object of age discrimination and maltreatment. Both Congress
and the United Nations have recognized the problem of age discrimination by adopting provisions to protect elderly people from unfairness and abuse. National and international demographics lend importance to the interaction of disability and aging. In the United States, people sixty-five or older accounted for just eight percent of the total population in 1950, but constitute over fourteen percent in 2000.

People with developmental disabilities once had much shorter life expectancies than the general population, but that is no longer the case. Accordingly, the population of Americans with mental retardation aged sixty and older is projected to increase from 526,000 to 1,065,000 by the year 2030. Similar trends are reported in other developed countries, though the number of elderly persons with developmental disabilities remains low in some parts of Europe because of Nazi programs, beginning in 1931, that killed children and adults with disabilities.

**ISSUES FOR OLDER PERSONS WITH DEVELOPMENTAL DISABILITIES**

Interestingly, many of the problems that the book identifies are comparable in the United States and Europe. These current challenges include: (1) a shortage of small-scale residential settings for older people with developmental disabilities, particularly for those who are not the subjects of large-scale deinstitutionalization efforts but instead live in the family home with care-givers of even more advanced age; (2) an absence of choices for daily activity, either in remunerative work or affordable leisure activity; (3) risks of abuse by care-givers and others; and (4) difficulties in obtaining appropriate acute medical care, given communication difficulties, insufficient sensitivity on the part of medical personnel to matters of consent and personal autonomy, and outright discrimination in provision of services on the basis of disability.

Sweden is one European country that has made tremendous progress towards solving these problems, and its social systems are described in a chapter by Lars Molander, a Swedish psychologist. These services

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14. See AGING, RIGHTS, AND QUALITY OF LIFE, supra note 1, at 36-38 (describing various instruments and their histories).
15. See id. at 3 (reporting United States Senate Special Committee on Aging data).
16. See id.
17. See id. at 4.
18. See id. at 150 (referring to the contribution of Tamar Heller).
19. See id. at xix, 25 (providing Herr’s description of this program).
20. See id. at 223-36.
include paid personal attendants (as well as volunteer companions, known as contact persons, whose expenses are reimbursed by the government), guaranteed placement in group homes, day center activities for individuals who are not employed, and disability pensions. In stark contrast, people in the Third World frequently lack any kind of income support or social accommodation and live out their lives in begging or peonage, except in notable cases in which they have organized to demand something better.

The stark contrast between an advanced country with a fully developed welfare state and poor countries with no governmental protections is matched by some differences between Europe and the United States. Most Western European countries have quota systems for the employment of people with disabilities in private firms. Though these programs do not provide a guarantee of full-wage-scale jobs for all people with developmental disabilities, they do create opportunities for many people to work. Similarly situated people in the United States, however, would be shut out of the wage economy altogether or allowed to work only in segregated, low-paying sheltered employment. In Europe, the income and satisfaction derived from the quota-system jobs maintain the well-being of the “young elderly” who have not yet reached retirement, while the jobs’ pensions support the “old elderly” who have retired. Americans with disabilities lack this type of financial support.

THE CONTRIBUTION OF THE AUTHORS

Beyond calling attention to the important topic of aging and developmental disabilities and providing useful national and international data on the subject, the book makes a number of contributions that make it noteworthy among disability literature. First, the international focus provides extremely revealing intersocial

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21. See id. at 228-29, 232. A recent news article points out that Sweden’s economy is booming despite the high rates of taxation that support social expenditures of the type Molander describes. See Edmund L. Andrews, Sweden, the Welfare State, Basks in a New Prosperity, N.Y. TIMES, Oct. 8, 1999, at A1. This reality demonstrates that social expenditures can function as investments in human capital that lead to long-term economic advantage.

22. See CHARLTON, supra note 11, at 37-44.


24. Other mechanisms to achieve social equality for people with disabilities whose ability to earn is necessarily diminished are discussed at length in Mark C. Weber, Disability and the Law of Welfare: A Post-Integrationist Examination, U. ILL. L. REV. (forthcoming 2000).
comparisons and contrasts. The book is notable as well for its focus on the rights and entitlements of people with disabilities. The contributors are adamant in viewing these individuals as human beings rather than the mere objects of social service delivery systems.

The method of exposition is also unique and noteworthy. Instead of having unbroken pages of descriptions of social services or medical delivery structures, the book contains numerous case studies in which the authors discuss how individuals with various conditions and histories fare under American and European social regimes. The results are revealing, for they demonstrate social systems in action and make more personal the successes and failures of the systems. The authors are particularly good at avoiding condescension in these accounts.  

CHAPTERS OF SPECIAL INTEREST TO AMERICAN LEGAL AUDIENCES

Because the book is written for both lay and attorney audiences, both within and outside the United States, not all parts have the same level of interest for those readers who are attorneys and who live and work in the United States. Nevertheless, several of the chapters are of particular appeal to that group.

Stanley Herr's chapter, "Legal Rights and Vulnerable People" is a detailed survey of federal and state sources of legal rights for persons with disabilities and older individuals. He covers such matters as placement in least restrictive residential settings, freedom from abuse and neglect, and nondiscrimination in general. He also covers access to legal services, something that is frequently necessary for the other rights to be secured. Attorneys in need of a general introduction to the topic could hardly be better served.

A chapter by John Goldmeier and Stanley Herr covers the important subject of the participation of people with developmental disabilities in designing and carrying out the mix of services that they need not just to survive, but to thrive and be a full part of community life. The chapter

25. There is a tendency to think of persons with disabilities, particularly those with mental impairments, as the philosophical "other," i.e., a subject to be acted upon rather than one whose autonomy should be respected. See Mark C. Weber, Foreword: A Symposium on Individual Rights and Reasonable Accommodations Under the Americans with Disabilities Act, 46 DEPAUL L. REV. 871, 871 (1997). This tendency must be resisted.

26. See AGING, RIGHTS, AND QUALITY OF LIFE, supra note 1, at 59-77.

27. See id. at 66-69.

28. See id. at 69-70.

29. See id. at 70-75.

30. See id. at 62-66.

31. This chapter is entitled "Empowerment and Inclusion in Planning." Id. at 311-26.
discusses the initiatives by Maryland and eighteen other states to enhance choice in public services for people with disabilities.\textsuperscript{32} It also mentions the danger of paternalism\textsuperscript{33} and the continuing risk that any services the government provides will be given in exchange for segregation, as has happened with residential services that are made available only in state institutions.\textsuperscript{34} Both representatives of providers and representatives of consumers need to be aware of the problems and opportunities that service planning presents.

In a chapter that should be highly useful to American lawyers who advise health care and rehabilitation services providers as well as to those who represent people with developmental disabilities, Stanley Herr and Sean Browhawn discuss managed care initiatives’ effects on services to elderly people with developmental disabilities.\textsuperscript{35} After describing the basic structure of Medicare, Medicaid, and current Medicaid managed care initiatives, they list the benefits and drawbacks of expanded managed care to cover individuals with disabilities—particularly elderly individuals with disabilities.

The potential benefits of these programs include: (1) greater service coordination; (2) managed care organizations’ preference for care in community, rather than institutional, settings; (3) the possible extension of Medicaid coverage to previously ineligible categories of persons (the near-poor, for example); and (4) the possible mandatory inclusion on managed care organization boards and payor committees.\textsuperscript{36} The main drawback is the lack of experience with capitated costs for service to persons with disabilities, which may cause inordinate incentives to managed care providers to avoid enrollments or to limit the services approved for any given patient.\textsuperscript{37} Moreover, even if the provider has enough information to know what rates to demand, the government’s appropriations are subject to political considerations, which may also result in a squeeze on services.\textsuperscript{38} Medicare rules currently require managed care organizations to have internal grievance procedures, but few consumers actually use them, and fewer still prevail.\textsuperscript{39}

\textsuperscript{32} See id. at 314-15.
\textsuperscript{33} See id. at 321-22.
\textsuperscript{34} See id. at 318-19.
\textsuperscript{35} See id. at 327-42 (including a chapter called “Managed Care”).
\textsuperscript{36} See id. at 334-35.
\textsuperscript{37} See id. at 335-37.
\textsuperscript{38} See id. at 332-33.
\textsuperscript{39} See id. at 337-39.
The move to managed care of some form may be inevitable, even for Medicaid beneficiaries with severe disabilities who require significantly more services than other Medicaid recipients. Advocates for older persons with disabilities must resist this development, however, unless adequate guarantees are provided that the quality and availability of services will not diminish.

ISSUES FOR FURTHER EXAMINATION

Two important topics are discussed briefly in the text, but remain mostly undeveloped at the book’s conclusion. These could profitably be made the subject of a follow-up volume or other additional research. The first is self-advocacy. The book makes a commendable foray into this topic with a brief chapter by Mitchell Levitz, a disability advocate who has Down’s Syndrome, and useful but short discussions by Tamar Heller and Herr and Weber. Nevertheless, the greater emphasis in the book is on the content of disability rights and the social support systems that exist to guarantee those rights. There is a lesser focus on the method by which the rights are asserted and the social supports obtained. By contrast, self-advocacy is the prime focus of some other recent work on disability rights, notably that of James Charlton. Over time, advocates have come to realize that the nature of different disabilities creates specific challenges and opportunities with regard to organized assertion of rights. In the history of civil rights advocacy by people with disabilities, the earliest effective political intervention was by blind people who organized to get fair consideration in matters of public safety, government contracting, the design of currency, and educational benefits.

41. See id. at 651-53 (discussing the “deliberate” pace of the move towards managed care for the disabled and special needs population in particular states).
42. See AGING, RIGHTS, AND QUALITY OF LIFE, supra note 1, at 279-87 (discussing how individual preferences and choices interrelate with the options society makes available to people with disabilities).
43. See id. at 159-60.
44. See id. at 359-60.
45. See CHARLTON, supra note 11. Other sources have also detailed the rise of self-advocacy and political organizing among people with disabilities. See, e.g., OLIVER SACKS, SEEING VOICES 125-59 (1989) (reporting on militancy among deaf students at Gallaudet University); JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1993) (discussing the civil rights activity of people with disabilities).
46. See Jacobus tenBroek, The Right to Live in the World: The Disabled in the Law of Torts, 54 CAL. L. REV. 841, 841 n.† (1966) (describing author’s role in political self-organization of
with mobility impairments followed. Each of those groups had the advantage of common experience, a core of articulate, aggressive, and educated leaders, and extraordinary timing in creating effective group and individual self-advocacy. What is needed is additional work on overcoming the obstacles to self-advocacy of people whose intellectual impairments may make access to some channels of power more difficult.

The second issue for further exploration is a major recent development in American disability law, the 1999 Supreme Court decision in Olmstead v. L.C. The reader of the book can be forgiven for wishing that the timing of publication had worked out so that Herr and Weber and their co-contributors could have given their insights on that Supreme Court case. The Supreme Court’s decision applied a regulation promulgated under Title II of the ADA, which requires administration of services in the most integrated setting appropriate to the needs of qualified individuals with disabilities. Specifically, the Court held that the law requires residential placement of persons with mental disabilities in community settings, rather than institutions, when: (1) the state’s treatment professionals determine that community placement is appropriate; (2) transfer from institutional care to the less restrictive setting is not opposed by the individual; and (3) the placement can be reasonably managed, given the resources available to the state and the needs of others with mental disabilities.

Herr does comment on the court of appeals’ decision in the case, which the Court affirmed in substantial part. The Supreme Court, however, modified the remand instructions of the court of appeals, by enhancing slightly the defense that the state might mount to charges of failure to place the individual in an integrated setting. The Court cautioned that a trial court, in enforcing the right under the ADA, had to consider not only the cost of providing community-based care to the individual, but also the range of services that the state provides others with mental disabilities, and the obligation to distribute those services equitably.

blind persons).

47. See supra note 45 and accompanying text.
50. See Olmstead, 119 S. Ct. at 2181.
51. See AGING, RIGHTS, AND QUALITY OF LIFE, supra note 1, at 73-74 (discussing L.C. v. Olmstead, 138 F.3d 893 (11th Cir. 1998)).
52. See Olmstead, 119 S. Ct. at 2185.
53. See id.
Though it is a somewhat more narrow declaration of rights than that of the court of appeals, the Supreme Court decision justifies Herr’s conclusion that *Olmstead* is an effective tool for community placement. Though the Court does permit states to work out reasonable means to provide desirable placements even-handedly, the states will be hard pressed to justify continued institutionalization of individuals when federal funding is available for community settings and institutionalization is extremely expensive.

Related to *Olmstead*, and in fact present as an issue in the *Olmstead* case but not a subject of the Supreme Court’s grant of certiorari, is the important legal question of whether Title II of the Americans with Disabilities Act exceeds Congress’ power with regard to state governments. In 1992, *New York v. United States* established that Congress, when acting under the constitutional power to regulate interstate commerce, cannot order states to do things when the same duties are not imposed on private entities. In enacting Title II, which imposes a variety of obligations on state and local government entities that are not imposed on private actors, Congress acted under its power to enforce the Fourteenth Amendment. The Supreme Court, however, has imposed limits on that power as well. *City of Boerne v. Flores* indicated that statutes enacted to enforce the amendment could proscribe conduct beyond the bare minimum that the amendment itself prohibits. Nevertheless, the prohibitions have to be proportional to the scope of the constitutional violations that they seek to protect against.

So far, most courts have found that Title II meets the test. The fact that some circuits have disagreed with the majority suggests that

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54. See AGING, RIGHTS AND QUALITY OF LIFE, supra note 1, at 74.
55. See id. at 73. As the Court hinted, there frequently are political reasons for states to maintain institutions, and these reasons are not grounds to keep people in those settings. See *Olmstead*, 119 S. Ct. at 2189 (discussing the state’s “endeavors to keep its institutions fully populated”).
56. See AGING, RIGHTS AND QUALITY OF LIFE, supra note 1, at 74 (mentioning the restricted grant of certiorari).
60. See Muller v. Costello, 187 F.3d 298, 307 (2d Cir. 1999); Amos v. Maryland Dep’t of Pub. Safety & Correctional Servs., 178 F.3d 212 (4th Cir. 1999); Kimel v. Florida Bd. of Regents, 139 F.3d 1426, 1433 (11th Cir. 1998), aff’d on other grounds, 120 S. Ct. 631 (2000), cert. dismissed sub nom. Florida Dep’t of Corrections v. Dickson, No. 98-829, 2000 WL 215674 (U.S. Feb. 23, 2000); Coolbaugh v. Louisiana, 136 F.3d 430, 438 (5th Cir. 1998), cert. denied, 119 S. Ct. 58 (1998); Clark v. California, 123 F.3d 1267, 1270-71 (9th Cir. 1997) (also finding waiver of
eventually the Supreme Court will need to decide whether Title II is a permissible exercise of power under the Fourteenth Amendment.\footnote{The Alsbrook case may provide this opportunity. See Alsbrook, 184 F.3d at 999.} Research on this topic could have an important influence on whether Title II rights remain enforceable and should be a major focus of the law-related efforts of the advocacy community in upcoming months.\footnote{In Kimel v. Florida Board of Regents, 120 S. Ct. 631 (2000), the Supreme Court ruled that the Age Discrimination in Employment Act ("ADEA") is not a proper exercise of congressional power under the Fourteenth Amendment, and so it does not abrogate states' Eleventh Amendment immunity from suits for damages. Efforts to distinguish Kimel will need to stress that the ADA is a far different statute from the ADEA in that the ADA is a proportionate response to widespread, intentional, and frequently hidden discrimination against people with disabilities by state governmental actors.}

CONCLUSION

*Aging, Rights, and Quality of Life* is essential reading for those concerned with the important issues of elderly people with developmental disabilities. With its international perspective and wealth of information about social service delivery systems, it commends itself to lawyers involved in health care and social services, to those who engage in individual representation of older clients with developmental disabilities, and to all students of the ways in which societies respond to their most vulnerable citizens.