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ABSTRACT

This annotated bibliography covers articles, books, and other publications related to aging, advocacy, disabilities, and environmental design. The bibliography brings together these topic areas to demonstrate how environments limit the independent functioning and choice-making opportunities for older adults with developmental disabilities. The bibliography is organized into the following sections: (1) age-related changes (6 listings); (2) aging and self-advocacy for people with developmental disabilities (15 listings); (3) environmental design and aging (12 listings); and (4) further resources (5 catalogs, 3 resource centers, and 17 organizations). (JDD)

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Annotated Bibliography on Aging, Disabilities, Advocacy and Environmental Design

**Edited by
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1993

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Introduction

As part of the graying of America, the developmentally disabled population is aging. Life expectancy for people with developmental disabilities is paralleling that of the general population. At the same time, the number of people with disabilities related to hearing, ambulation and vision are increasing due to the aging of the population. Those numbers will continue to increase as the population ages.

The following annotated bibliography covers articles, books, and publications related to aging, advocacy, disabilities, and environmental design. This is an attempt at bringing together these topic areas to demonstrate the close relationship between aging, advocacy, and the physical environment. Environments limit the independent functioning and choice making opportunities for older adults with developmental disabilities. Environmental design that enables older people with disabilities to use the environments will benefit all of us as we age.

This bibliography has been organized in the following sections:

- I. Age-Related Changes
- II. Aging and Self-Advocacy for People with Developmental Disabilities
- III. Environmental Design and Aging
- IV. Further Resources

I. Age-Related Changes

1. American Foundation for the Blind. (1987) Aging and vision: Making the most of impaired vision. New York: American Foundation for the Blind, 15 West 16th Street, New York, NY 10011.

An overview of visual changes that commonly occur as people age is provided. Specific visual diseases that occur more often in the older person are discussed along with modifications or adjustments that can be made to the environment to minimize the effect of these age-related changes or diseases. Specific information is provided on communication and traveling options.

2. National Institute of Health. (1980). To understand the aging process, The Baltimore Longitudinal Study of the National Institute on Aging (NIH Publication No. 80-134). Available free of charge through the U.S. Department of Health and Human Services, National Institute on Aging and National Institute of Health.

The National Institute on Aging (NIA) has provided in this publication a review of NIA's longitudinal study on older people and health. The study, begun in 1958 and still ongoing, looks at aging as a biological and social process and examines ways to better understand the aging process. Volunteers were recruited with baseline measures taken. The volunteers return every two years for 2 1/2 days of testing which includes measurements on memory, learning, behavioral patterns, and physical examinations. The major weakness of the study is that only men participated in this study until 1978, in spite of the fact women live longer and there are larger percentages of women over 65 than men. As a result of this weakness, little is currently known about women and aging in relation to this study. The study continues

with a series of overlapping longitudinal studies and update reports will continue to be provided. One of the most pertinent conclusions for this bibliography currently drawn from this study is that as people age it becomes more difficult to deal with various environmental stresses.

3. Jech, A. O. (1990, January). Preventing falls in the elderly. Geriatric Nursing, 34, 43-44.

An overview of changes that can occur as one ages, including loss of balance, decreases in vision, and thinning of the bones are discussed along with the implication for increased danger of falls. Medications with possible side effects can also affect the balance of an older person. Some studies demonstrate that a person 65-74 is at three times the risk of falling while a person over the age of 75 has a risk factor that is 20 times the general population. Falls account for a significant number of injuries and death in older people. Ways to prevent falls, including removing throw rugs, non-skid wax and well-fitting shoes, are discussed.

4. National Osteoporosis Foundation. (1991). Living with osteoporosis. Washington, DC: National Osteoporosis Foundation, Suite 602, Department J, 2100 M Street, N.W., Washington, DC 20037-1207.

Prevention of falls through awareness and environmental modifications is discussed in this pamphlet.

5. National Osteoporosis Foundation. (1992). Stand up to osteoporosis: Your guide to staying healthy and independent through prevention and treatment. Washington, DC: National Osteoporosis Foundation, Suite 602, Department J, 2100 M Street, N.W., Washington, DC 20037-1207.

This publication provides a definition of osteoporosis along with information on understanding the risk factors and prevention of osteoporosis. Exercises and environmental modifications to prevent falls are also presented.

6. Machermer, R., & Overeynder, J. (Eds.) (1993). Aging and developmental disabilities--An in-service curriculum. Rochester, NY: University of Rochester.

This manual was developed as a curriculum guide for people who would like to understand current information about the aging process and developmental disabilities and to use as a guide for training. The topics covered in this manual include biology of aging, developmental disabilities, service systems, family caregiving, aging and specific disabilities such as cerebral palsy and Down Syndrome, and the environment and aging.

II. Aging and Self-Advocacy for People with Developmental Disabilities

1. Bowe, F. G. (1992, Fall). Empowerment: Dependence versus independence. OSERS News in Print [Feature issue on Empowerment], V(2), 4-7.

The importance of empowerment for adults with disabilities is discussed in this article. While most service providers discuss the need for independence, this author feels that the very systems put in place such as Social Security Disability benefits often legislate and encourage dependence. The importance of using resources such as Independent Living Centers and the Americans with Disabilities Act is emphasized.

2. Bradbury, S., & Janicki, M. (Eds). (1992). Creating choices: New York's third age programs. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities, Bureau of Aging and Special Populations.

Background information, including demographic information on the aging of the developmentally disabled population is provided. Development of integrated social adult day care programs is discussed along with specific lessons learned from program development in New York through demonstration projects. The need to train and foster relationships with the aging network is emphasized along with the need to develop options for activities other than day treatment placement or workshop placement.

3. Cohen, E. S. (1990). The elderly mystique: Impediment to advocacy and empowerment. Generations Supplement, 13-16.

The author of this article feels strongly that "the elderly mystique" still exists for people who are aging and disabled and that this mystique has created a new ageism by looking only at deficits in relation to the disability. Cohen feels that this ageism is promoted by the terminology about elderly people with a disability and that in this context advocates' pronouncements become just as harmful as overt ageists. As it is outlined in this article, elderly people themselves accept the "incompetence model" and thereby do not seek rights that they do not feel they are entitled to in the first place. Any disability, then is seen as unsuccessful aging. The need for self-advocacy and consumer control over services is evident in this article.

4. Cotten, P., & Sison, G. (1989, June). The elderly mentally retarded person: Current perspectives and future directions. Journal of Applied Gerontology, 8(2), 151-157.

As the elderly mentally retarded population grows it becomes more important to understand the aging process with this population so that service delivery needs can be met and future research recommendations made. One consideration is the effect of institutionalization on the rate of aging and what variables related to the institutionalization of the person have affected that rate of aging, if any. (For example, are there aspects of the physical environment that increase or decrease the rate of aging.) This article discusses the stressors that are unique to this population such as the fact that only 15% of this population live at home with families as compared to 60% of people without developmental disabilities who are elderly and medically frail.) It is also suggested in this article that one needs to ensure that service delivery is based on needs of the individual rather than diagnosis which may limit options, result in infantilization of individuals, and cause frustration for individuals and family members.

5. Dalron, A., Janicki, M., Overeynder, J., & Turk, M. (1992). "I'm worried about the future...": The aging of adults with cerebral palsy. Albany, NY: New York State Developmental Disabilities Planning Council.

The findings of a subcommittee, under the auspices of the New York State Developmental Disabilities Planning Council, which was developed to address the issues related to the medical and physical aspects of aging in persons with cerebral palsy are presented in this publication. Published literature was reviewed and public hearings held to gather the current information available. Recommendations were

made as a result of the hearings and literature review. The need to focus on assessment and intervention in the area of design of "enabling physical environments" was emphasized.

6. Deegan, P. E. (n.d.). Spirit-breaking: When the helping professions hurt. The Humanistic Psychologist, 18(3), 301-313.

This very thought provoking article written by a clinician who is also a consumer of the mental health system speaks about the importance of not losing the person and basic humanity of a person as clinicians provide services. Too often the human services system dehumanizes people and often destroys the dignity of the consumer. The clinician\consumer relationship is a very powerful relationship and is one that should be reciprocal in nature rather than the clinician holding all of the power. Placing clinicians with all the power serves to "spirit-break" the consumer and also results in a loss of humanity to the clinician as well. Examples of "spirit-breaking" are provided in this article. Spirit-breaking for older adults with disabilities is even more likely because of the increased vulnerability as a person with a disability ages.

7. Eustis, N. N., & Fischer, L. R. (1992). Common needs, different solutions? Younger and older homecare clients. In E. Ansello & N. Eustis (Eds.), Aging and disabilities: Seeking common ground (pp. 25-35). Amityville, NY: Baywood Publishing Company.

The authors compare the needs of individuals who are aging and medically frail thereby requiring Homecare Services to the needs of individuals who are developmentally disabled and utilizing the Homecare Services. A comparison of

service needs was done with a conclusion drawn from this non-random sample that service needs in many areas such as activities of daily living (ADLs) were similar. The relevancy of the Independent Living Movement for elders is discussed in this chapter with a conclusion that desire for choice and preference is common to both populations and the central theme to the Independent Living Movement.

8. Evenhuis, H. M. (1990). Clinical studies of Alzheimer's dementia and hearing loss in Down's syndrome. Unpublished Thesis funded by Vereniging Johannes Stichting. Available from: Helena Evenhuis, M.D., Hooge Burch, Postbus 2027, 2470 AA ZWAMMERDAM, Netherlands.

This study of people with Down Syndrome at the Hooge Burch, an institute for people who are mentally retarded in the Netherlands, looks at the issue of dementia and premature aging. Diagnostic measures were evaluated as well as the aspects of differential diagnosis. While research and related literature currently indicates a 100% prevalence of the neuropathological lesions symptomatic of Alzheimer's Disease found during postmortem autopsy, this study attempts to clarify the incidence of clinical dementia in this population. The incidence of hearing impairments was also explored. The significant outcome of this study in relationship to this bibliography is the need to consider hearing impairment as a contributing factor in social and mental deterioration with people who are middle aged and are diagnosed with Down Syndrome.

9. Hotte, E. B., May, E., & Waggoner, N. R. (1974). Independent living for the handicapped and the elderly. Boston: Houghton Mifflin Company.

While outdated in technology suggestions and modifications, this book strongly suggests that it is not the nature of the disability that determines where an elderly or handicapped person will live but the degree of dependence or independence with managing food, shelter, and clothing. If this is true, then we should develop environments that facilitate independence rather than disabling people. It is also discouraging to see how old this book is and to realize we have not come as far as we would like to think we have in terms of enabling people who are elderly and/or disabled.

10. Lewin, T. (1990, October 28). As the retarded live longer, anxiety grips aging parents. New York Times.

The anxiety of parents who are providing care and supports to their aging adult children with developmental disabilities is stressed in this article. For many parents, this is an issue they had not expected to encounter as they had been advised at a very early age that the life expectancy for their children was short and it was not expected that the children would outlive their parents. It is now estimated that there are at least 200,000 people who are retarded and over the age of 60 in the United States. As a result of this aging of the population of people with retardation, questions now arise such as when should a person retire, what supports are available for retirement and how can people be integrated into existing senior programs. Long range planning including permanency planning for the adult child is an extremely

stressful and often avoided task. Sibling responsibilities for caregiving, often something assumed by the parents, is also an emotional issue. Supports need to be developed to address the issue of long range planning and increasing options for older adults with retardation and their families.

11. Lutfiyya, Z. M. (Ed.). (1991, Summer). Social relationships. Policy Bulletin No. 1. Syracuse, NY: Center on Human Policy, Syracuse University.

Discussion of the development of social relationships between people with disabilities and community members is provided in this publication. The articles are a review of findings during a qualitative study entitled "The Community Study" that focused on the meaning of living in the community for people with developmental disabilities. How and with whom people were socially integrated was reviewed. The situations of people with disabilities who developed relationships and what the relationships are like is discussed in the articles. Of particular interest for this bibliography is the article "Problems in Paradise" which covers a staff\client relationship with an older physically frail individual and a paid staff person. The staff person was effectively able to facilitate relationships with community members that were not likely to have occurred without that facilitation. As older people are moved into independent living situations, consideration needs to be given to some ways to facilitate socialization so that people do not remain isolated in the community.

12. Rinck, C. (1992, February). Fast facts on aging: Physical changes as persons with developmental disabilities age (No. 64105). Kansas City, MO: University of Missouri-Kansas City.

This pamphlet provides an overview of physical changes due to aging which includes hearing, vision, musculoskeletal changes, cardiovascular, and central nervous system changes. Sources for further information in each of these areas as well as suggestions for prevention or management of age-related changes are provided.

13. Seltzer, M. M. (1992, Winter). Training families to be case managers for elders with developmental disabilities. Generations, 65-70.

This article covers the fragmentation of health and social services for older people with developmental disabilities and the importance of involving families, when appropriate, as case managers. For many individuals who are disabled, the families are the major caregiver and often assume the informal role of case management. Case management is defined as a "method of coping with life's bureaucracies." With the complexities of the aging and developmental disabilities service provider systems it appears even more important that families be trained in the accessing of community resources. A study of a program which provided training and a resource manual to families in the Boston area was conducted. The researchers concluded from this study that families who are trained in resource attainment actually do more resource attainment, have less dependency on the system, and have greater autonomy with decision making.

14. Wisconsin Life Long Planning Initiative. (1992, September). I want to visit the Grand Ole Opry. Learning from listening to elders with developmental disabilities. Washington, DC: The Administration on Aging.

As a result of a study in Wisconsin which involved looking at the prevailing attitudes about people with developmental disabilities, this publication was developed. It was found that the current beliefs and attitudes were negative and lead to a variety of inappropriate tendencies in the system's response to people. It was also found that if you have been diagnosed with a developmental disability it is likely that you would have already experienced societal devaluation, often worsening with age. Diminished capacity in an older person with a developmental disability is often viewed as a problem within the person rather than a result of accumulated failures in the settings she or he had been placed throughout the person's life. When interviewing older people with developmental disabilities, it was found that people wanted to continue to learn and try new experiences, contrary to the prevailing thoughts about what older people want. This study emphasizes the need to listen to what people want and to be willing to explore creative retirement options for older people with a developmental disability.

15. Wisconsin Life Long Planning Initiative. (1992, September). Respecting the past, enjoying life now, and embracing the future: Lessons learned from listening to parents. Washington, DC: The Administration on Aging.

Two families' stories from parents of adult children with a developmental disability are shared in this publication showing the hopes and concerns these families have for their adult children with a developmental disability. This publication can be

used as a working document for parents who would like to form focus or support groups for futures planning for their adult children with developmental disabilities.

IV. Environmental Design and Aging

1. Baker, G., Carmone, F., Griffith, B., & Krauser, C. (n.d.). Report on products and services to enhance the independence of the elderly. Maryland: Center on Aging, University of Maryland.

Losses that may occur as part of the aging process such as loss of muscle strength, lack of accommodation of the eye and decline in physiological function are discussed with recommendations to adapt to better meet these losses.

2. Bishop, K. (1993). Environment and aging. In R. Macheimer & J. Overeynder (Eds.), Understanding aging and developmental disabilities (pp. 131-143). Rochester, NY: University of Rochester.

This curriculum guide provides an overview of accessibility and usability of environments. Changes that typically occur as part of the aging process are discussed with specific recommendations on environmental modifications and changes that can minimize the effect of the aging process.

3. Christenson, M. (1990). Aging in the designed environment. Binghamton, NY: The Haworth Press, Inc.

Physiological changes that often occur as part of the aging process are discussed in detail with practical suggestions provided on designing the environment to meet the changing needs. Sensory changes and sensory stimulation issues are provided with extensive and specific suggestions provided on designing the long-term

care facility that have been traditionally poorly designed to meet the needs of the users. This is one book that anyone interested in this topic should read for practical advice and the theoretical background.

3. Duncan, J., Gish, C., Mulholland, M., & Townsend, A. (1977, December). Environmental modifications for the visually impaired: A handbook. Fullerton, CA: Committee on Architectural and Environmental Concerns of the Visually Impaired, 2454 Salem Place, Fullerton, CA 92635.

This article outlines standards for accessibility for people with visual impairments along with specific environmental modification requirements. Orientation aids and a listing of additional resources is also provided.

4. Eastern Paralyzed Veterans Association. (1992). Removing barriers in places of public accommodation: The Americans with Disabilities Act. Jackson Heights, NY: Author.

With the background of the American with Disabilities Act, clear guidelines are provided in this publication for barrier removal for people with physical disabilities (though some attention is paid to other disabilities such as visual impairments.)

5. Eastern Paralyzed Veterans Association. (n.d.). Access: State and local government, your rights and responsibilities under Title II of the Americans with Disabilities Act. Jackson Heights, NY: Author.

This publication provides clearly understandable guidelines on meeting the Americans with Disabilities Act as well as suggestions for reducing barriers in state and local government agencies.

6. Eastern Paralyzed Veterans Association. (n.d.). Wheelchair house designs. Jackson Heights, NY: Author.

Specific house designs for people who use wheelchairs are provided in this publication which was developed by members of the Eastern Paralyzed Veterans Association. Each design includes a listing of the adaptive features included in the design.

7. ITT Hartford Insurance Group. (n.d.). How to modify a home to accommodate the needs of an older adult: The Hartford House. Hartford, CT: Community Affairs Department, The Hartford House, ITT Hartford Insurance Group., Hartford Plaza, Hartford, CT 06115.

Included in this brochure is a list of 120 modifications designed to make a residential setting more usable for older adults. Such areas as lighting, safety, colors and acoustics are discussed. A product listing is also included with specific ordering information. A film, free of charge, is also available on loan with design recommendations.

8. National Library Service for the Blind and Physically Handicapped. (1993, July). Accessibility: Designing buildings for the needs of handicapped persons. Washington, DC: The Library of Congress.

An annotated bibliography consisting of books, articles, reports and films on barrier-free design for persons with disabilities: "It is intended as an introduction to the subject for architects, administrators, and other persons planning accessible facilities."

9. Raschko, B. (1991). Housing interiors for the disabled and elderly. Van Nostrand Reinhold.

Detailed design recommendations for each room of the residential setting are provided. The philosophical basis is outlined in chapter one which includes the importance of the residential setting as very often the only place where a person with a disability can function independently. The importance of the appropriate environmental fit is emphasized, especially as one ages and disabilities tend to increase. The challenge that this book begins to meet is to design environments so that disabilities do not become handicaps and people can use the environment with continuing dignity.

10. Rickman, L. (1991). A comprehensive approach to retrofitting homes for a lifetime. Upper Marlboro, MD: NAHB Research Center, 400 Prince George's Boulevard, Upper Marlboro, MD 20772-8731.

Demographics concerning the aging of the United States' population are provided along with statistics concerning the physically limiting chronic conditions that can occur as people age. These conditions can limit a person's ability to perform activities of daily living which are so important for a person to be able to remain independent. It is emphasized that often people who are elderly do not need supportive services when housing can be designed to meet the needs of the person. Specific design modifications are offered in this publication along with an environmental checklist.

11. Salmen, J. S. (1985). The do-able renewable home: Making your home fit your needs. Washington, DC: Consumer Affairs, Program Department, American Association of Retired Persons.

The intent of this publication, distributed by the American Association of Retired Persons, is to provide practical design information to help keep an older person as independent as possible. Staying in one's own home is the number one preference of most older people. The emphasis throughout is that of practical ways to design adaptability and accessibility into the home. Each area of the house is discussed with specific design specifications provided.

12. Senate Select Committee on the Disabled. (1992, March). Reasonable accommodations: Accessible employment for people with disabilities. Washington, DC.

A definition of reasonable accommodations under the American's with Disabilities Act is provided in this publication along with suggestions for developing reasonable accommodations at the workplace. A listing of resources is also provided. Job opportunities for people who are older with disabilities need to be one of the range of choices available; reasonable accommodation at the workplace becomes extremely important then for an aging population.

V. Further Resources

Catalogues (The listing of the catalogues is not an endorsement of the products sold.)

1. The Directory of Accessible Building Products
The NAHB Research Center
400 Prince George's Boulevard
Upper Marlboro, MD 20772-8731
Telephone: 301-249-4000

A directory listing available accessible building products.

2. adaptAbility, Products For Independent Living
P.O. Box 515
Colchester, CT 06415-0515
Telephone: 1-800-243-9232

A commercial catalogue sent periodically with a listing of available products.

3. Accessolutions for the Hearing Disabled
Harc Mercantile, Ltd.
P.O. Box 3055
Kalamazoo, MI 49003-3055

A commercial catalogue listing available materials geared for people with hearing impairments.

4. Products for People with Vision Problems
American Foundation for the Blind
15 Sixteenth Street
New York, NY 10011
Telephone: (212) 620-2172

A catalogue of products for people with visual impairments.

5. Mealtime Manual for People with Disabilities and Aging
Mealtime Manual
Box 65
Ronks, PA 17572

Hints for everyday food preparation, products and useful adaptations.

Resource Centers

1. Center for Therapeutic Applications of Technology
515 Kimball Tower
University at Buffalo
Buffalo, NY 14214
Telephone: 1-800-628-2281

A resource center for products, consultation in design and software computer programs that provide up to the date information on accessible products.

2. Research and Training Center on Accessible Housing
North Carolina State University
Box 8613
Raleigh, NC 27695-8613,
Telephone: 919-515-3082
TDD 919-515-3082
FAX 919-515-3023

A resource center for training and materials related to accessible housing.

3. Research and Training Center on Blindness and Low Vision
Mississippi State University
P.O. Drawer 6189
Mississippi State, MS 39762
Telephone: 601-325-2001
TDD 601-325-2001
FAX 601-325-8989

A resource center for training and materials related to blindness and visual impairments.

Organizations

1. American Association of Retired Persons
1909 K Street, N.W.
Washington, DC 20049

A wide array of materials, pamphlets and resources available; many free of charge or at minimal cost.

2. National Institute of Senior Housing
600 Maryland Avenue, S.W.
Washington, DC 20024

3. National Osteoporosis Foundation
Suite 602, Dept. J
2100 M Street, N.W.
Washington, DC 20037-1207
Telephone: 202-223-2226

Pamphlets and brochures with information regarding osteoporosis.

4. National Institute on Aging and National Institute of Health
Information Office
Building 31, Room 5C-35
9000 Rockville Pike
Bethesda, MD 20205
Telephone: 303-496-1752

A wide array of resources and pamphlets related to the aging process is available; many free of charge.

5. Gerontological Society of America
1275 K Street, NW
Suite 350
Washington, DC 20005
6. National Stroke Association
300 East Hampden Avenue, Suite 240
Englewood, CO 80110-2654

A monthly newsletter and resource materials are available; many free or at a minimal charge.

7. American Academy for Cerebral Palsy
1255 New Hampshire Avenue, N.W.
Washington, DC 20045
8. American Association of Homes for the Aging
1050 17th Street, N.W.
Suite 770
Washington, DC 20045
9. American Institute of Architects
1735 New York Avenue, N.W.
Washington, DC 20006

10. American National Standards Institute
1430 Broadway
New York, NY 10018

Americans with Disabilities Standards and minimal standards for accessibility are set by this agency.

11. Architectural and Transportation Barriers Compliance Board
330 C Street, S.W.
Washington, DC 20201

This agency provides oversight to implementation of the American's with Disabilities Act in the area of transportation.

12. Committee on Barrier-Free Design
U.S. President's Committee on Employment of the Handicapped
1111 20th Street, N.W.
Washington, DC 20542

13. Equal Employment Opportunity Commission
1801 L Street, N.W.
Washington, DC 20507

The commission serves in an advocacy role for equal employment opportunities for persons with a disability.

14. New York Office of Advocate for the Disabled
One Empire State Plaza, Tenth Floor
Albany, NY 12223

Acts in an advocacy role for people with disabilities in the state of New York. The advocates office is available in every state. Also available are resources and information to assist persons with a disability.

15. Eastern Paralyzed Veterans Association
75-20 Astoria Boulevard
Jackson Heights, NY 11370-1117
Telephone: 718-803-EPVA

Pamphlets and brochures available in many areas related to accessibility; many of which are free of charge.

16. National Council on Independent Living
Troy Atrium
4th Street and Broadway
Troy, NY 12180

17. Institute for Rehabilitation and Disability Management
Washington Business Group on Health
777 North Capital Street, N.E.
Suite 800
Washington, DC 20002