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)
Annotated Bibliography on Aging, Disabilities, Advocacy and Environmental Design

Edited by
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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


   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.


   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.


   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.


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

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.


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


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.

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.


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.

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.


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.


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.


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.


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.

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 or disabled.


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.


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.

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.


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.

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.


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


   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.


   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.


   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.


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.


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.)


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.

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.


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.


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."

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.


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.

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.


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: 301-496-1752

   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.

    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.
   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