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This report summarizes a three-year project conducted from 1974-1977 by the Building Research Advisory Board (now the Advisory Board on the Built Environment) of the National Research Council. The project was to develop a strategy for the Department of Health, Education and Welfare (now the Department of Health and Human Services) that could be used to educate and orient the building industry to be responsive to the needs and concerns of the disabled. The report describes the developmentally disabled in terms of their capabilities and the traditionally negative impact that existing facilities have on them. The institutional structure of the building industry is also described and the development of performance criteria to foster the normal development of the disabled is explored. Barriers to normalization are identified and methods for overcoming these barriers are suggested.

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BARRIER-FREE DESIGN
FOR THE DEVELOPMENTALLY DISABLED

Report to the
Department of Health and Human Services

by

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Natalie Langue, Staff

Committee on Accessible Environments for the Disabled
ADVISORY BOARD ON THE BUILT ENVIRONMENT
Commission on Engineering and Technical Systems
National Research Council

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NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the Councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

This report was authored by a consultant and an ABBE staff member who reviewed the results of earlier work performed by the Advisory Committee on Accessible Environments for the Disabled as well as current literature and prepared a draft report. Revisions suggested by reviewers selected by the National Research Council have been incorporated.

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PREFACE

This report completes a project conducted by the Building Research Advisory Board (BRAB) of the National Academy of Sciences for the Administration on Developmental Disabilities of the U.S. Department of Health, Education, and Welfare (HEW).* The purpose of the project was to develop for HEW a strategy that could be used to educate and orient the building industry to be responsive to the needs and concerns of the disabled. The HEW project officer for this project was Ashot Mnatzakanian.

In 1974 a BRAB Committee on Accessible Environments for the Disabled was appointed to conduct the study. BRAB's contract with HEW called for a report to be submitted at the end of each year of the three-year project. Although the committee met regularly and held various workshops and seminars, no reports were produced in the three-year period. In September 1977, just after the contract's original termination date, the sponsor agreed to accept an authored report as fulfillment of the contract. In 1982, through the efforts of a consultant and the staff of the Advisory Board on the Built Environment, this report was produced to fulfill this obligation. It must be noted, however, that the report is based primarily on information developed through 1977. Although most of the problems discussed in the report still exist, many other factors have changed and the reader is urged to consider the material presented in light of those changes.

The major objectives of the study were:

1. Characterization of the disabled population based on the collection and analysis of data on the demography, capabilities, and limitations of the disabled.
2. Identification of functional requirements (common to the total population and those unique to the disabled) that the man-made physical environment should possess if it is to be accessible to the disabled.

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*BRAB is now the Advisory Board on the Built Environment (ABBE) and HEW is now the Department of Health and Human Services (HHS).

3. Description of the decision-making process involved in the development and redevelopment of the built environment and any inherent constraints in this process that prevent increased accessibility.

4. Identification of information required by the building community to respond to the needs of the disabled.

5. Development of principles to guide the design of physical facilities accessible to the disabled and of a tentative strategy for educating the building and development community in the adaptation and implementation of these principles.

6. Identification of research and other requirements for full and effective implementation of the strategy.

In developing this report, it was assumed that the general population is composed of individuals ranging from those with little functional capability to those with extraordinary capability. A companion assumption was that the population norm, with respect to physical and/or mental functioning, is defined in terms of the ability of an individual to perform independently and easily in the built environment. The developmentally disabled are those who cannot perform in this manner, even with readily available personal devices or service assistance.

This report discusses the developmentally disabled and explores their capabilities and the negative impact of traditional facilities on their development. The building community also is described briefly and the development of performance criteria to foster the normal development of the disabled is explored. Barriers to normalization are identified and methods for overcoming these barriers are suggested.

JOHN P. EBERHARD
Executive Director

1
THE DEVELOPMENTALLY DISABLED

DEFINITIONS

The term "disability" is a general one used to describe any reduction in an individual's ability to perform normal activities as a result of an acute or chronic health condition. "Developmental disability" is a term used for federal legislative purposes.

Prior to 1978, the definition included in Public Law 94-103 was used. It defined the term "developmental disability" to mean a disability that:

> . . . is attributable to mental retardation, cerebral palsy, epilepsy, or autism; . . . to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior . . . or requires [similar] treatment and services; or . . . to dyslexia resulting from [the disabilities described above] . . .
>
> . . . originates before such person attains age 28
>
> . . . has continued or can be expected to continue indefinitely and
>
> . . . constitutes a substantial handicap to such person's ability to function normally in society.

In 1978, Public Law 95-602 provided a new definition:

> The term "developmental disability" means a severe, chronic disability of a person which . . . is attributable to a mental or physical impairment or a combination of mental and physical impairments; . . . is manifested before the person attains age 22; . . . is likely to continue indefinitely; . . . results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic sufficiency; . . . reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

These two definitions are based on different concepts and terms. The pre-1978 form is considered to be a diagnostic definition--i.e., it speaks of impairments in terms of medical and physical problems and specifically includes those persons diagnosed as being mentally retarded, autistic, or having cerebral palsy or epilepsy. The 1978 definition focuses on functional impairment--i.e., the effect or restriction that the handicap places on the ability of a person to lead a "normal," self-sufficient life. The differences in the definitions can be illustrated by considering an individual with a mild form of epilepsy who would be covered by the pre-1978 definition but would not come under the 1978 definition since functional impairment was slight

The selection of the particular definition to be used is dependent on the purpose of the user. Federal and state legislators require demographic data based on both definitions. For example, in developing a new facility for the mentally retarded the diagnostic definition would be used whereas in developing a program of vocational training and rehabilitation, a statistical breakdown in terms of functional capabilities would be required.

The functional definition has been favored in recent years for several reasons. First, the diagnostic definition uses classifications such as "mentally retarded" and "autistic" that do not describe the severity of the problems of the handicapped individual. Second, these classifications imply that the people included in a category are similar to one another with respect to the characteristic being examined, and this is misleading for any but medical or legislative purposes. The mentally retarded, for example, do not constitute a homogeneous group with regard to their ability to function in society--i.e., some individuals in this group can cope effectively with their daily needs whereas others are so severely impaired that they require a great deal of personal attention.

The functional definition also has disadvantages. One is that many of the services provided to the handicapped by means of legislation are based on diagnostic categories. If a person does not come under an appropriate category, then he or she is ineligible to receive financial or other aid. Another problem caused by the 1978 functional definition is its use of seven "major life activities." To be considered developmentally disabled, a person must have substantial functional limitation in three or more of the seven areas; however, not all seven areas are relevant and/or useful at all times in a person's life. For example, neither economic sufficiency nor a capacity for independent living is expected of a child, and, although the ability to learn is important throughout one's life, attending school is not a major activity for an adult.

The focus of this report is on the 1978 functional definition of the developmentally disabled; therefore, it is useful to clarify and explain several of the key terms used. The term "severe, chronic disability" appears in the first sentence of the definition and can be defined as a disability that is "likely to continue indefinitely and results in the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are

individually planned and coordinated" (Boggs and Henney, undated). A limitation in any one of the seven major life activities is one that "limits the individual in the performance of that activity in comparison to his or her peers," and a "substantial limitation is one which effectively prevents him/her from performing or requires that he/she receive frequent assistance from other persons or requires the use of devices which are expensive to maintain or replace" (Boggs and Henney, undated). For example, a student with a slight hearing problem that requires him to sit at the front of a classroom in order to understand the teacher's presentation does not have a substantial limitation in learning ability because the problem is easily solved. However, a student who is totally deaf and needs the services of another person to "translate" the lecture into sign language does have a substantial limitation in his/her ability to learn.

Another key to understanding the 1978 definition of developmental disability is to define the seven major life activities (Boggs and Henney, undated):

1. Self-care. . . A person who has a long-term condition which requires that person to need significant assistance [at least one half of the time] to look after personal needs such as food, hygiene, and appearance. . . .
2. Receptive and Expressive Language . . . A person who has a long-term condition which prevents that person from effectively communicating with another person without the aid of a third person, a person with special skill or with a mechanical device, or a long-term condition which prevents him/her from articulating thoughts.
3. Learning . . . A person who has a long-term condition which seriously interferes with cognition, visual or aural communication, or use of hands to the extent that special intervention or special programs are required to aid that person in learning.
4. Mobility . . . A person who has a long-term condition which impairs the ability to use fine and/or gross motor skills to the extent that assistance of another person and/or a mechanical device is needed in order for the individual to move from place to place.
5. Self-direction . . . A person who has a long-term condition which requires that person to need assistance in being able to make independent decisions concerning social and individual activities and/or in handling personal finances and/or protecting his/her own self-interest.
6. Capacity for Independent Living . . . A person who has a long-term condition that limits the person from performing normal societal roles or which makes it unsafe for that person to live alone to such an extent that assistance, supervision, or the presence of a second person is required more than half the time.

7. Economic Sufficiency . . . A person who has a long-term condition which prevents that person from working in regular employment or which limits his or her productive capacity to such an extent that it is insufficient for self-support.

DEMOGRAPHIC DATA

Demographic data on the developmentally disabled are elusive and must be gathered from a variety of sources. Even when census reports and surveys include specific questions concerning the disabled, the accuracy of the results must be questioned. One reason is that people often are reluctant to reveal the existence of a disability in their household. The use of the term "employed" also affects survey findings because the questions asked often are dependent on whether diagnostic or functional issues are being explored.

The data available for both the pre-1978 and the 1978 definitions of developmental disability are quite sketchy and not very useful. With regard to the pre-1978 definition, some studies generated data on the four diagnostic categories (mental retardation, autism, cerebral palsy, and epilepsy), but the data are difficult to use and compare because different definitions, age ranges, geographical locations, and methodologies were used in the collection efforts.

Demographic data for the 1978 functional definition also are of little value. This definition has been in use for only a few years, and sufficient time has not been available to collect the required data. In order to do this correctly, a better understanding is needed of the interrelationships between the various functionally limiting conditions a disabled person might have. These relationships must be understood to avoid the problems associated with categorization that, in the past, have resulted in overestimates of the actual number of disabled people because individuals were counted in several categories.

Despite the difficulties noted above, several attempts have been made to collect demographic data. Table 1 presents estimates of the number of developmentally disabled persons in the four diagnostic categories of the pre-1978 definition and the number of disabled persons considered to have substantial handicaps.

Although these data indicate that a substantial number of people fall within the concerns of this report, a comparison of Tables 1-3 reveals that the numbers vary widely. Table 1 shows a total 1978 developmentally disabled population of 9,560,000, and of that number, 5,425,000 are considered to be substantially handicapped. The total number in Table 3, however, is 3,350,000 for 1976.

Tables 2 and 3 are based on data collected in 1976 for a U.S. Bureau of the Census Survey of Income and Education (SIE). The survey was not designed specifically to answer questions about developmental disabilities, and the numbers in the tables were developed by the EMC Institute (Boggs and Henney, undated) by imposing the characteristics of the 1978 definition (primarily the seven major life activities) on

TABLE 1 Estimated Numbers and Rates of Developmentally Disabled Persons by Category for the United States: Data from 1978 Fiscal Year State Development Disabilities Plans

Categories	Estimated Number	Number per 10,000 Population
Overall rates		
Combined	9,560,000	414
Mentally retarded	5,660,000	247
Cerebral palsied	912,000	42
Epileptic	2,386,000	97
Autistic	71,000	3
Substantial Handicaps		
Combined	5,425,000	236
Mentally retarded	3,414,000	160
Cerebral palsied	524,000	30
Epileptic	1,034,000	53
Autistic	67,000	3

SOURCE: Congressional Research Service (1979).

the SIE data. Table 2 shows the estimated numbers and percentages of non-institutionalized individuals having a substantial limitation in one or more of these seven major life activities. Table 3 represents an attempt to combine the data to eliminate overlap and arrive at a total figure for the developmentally disabled population.

The difference between the two estimates can be explained in several ways. A major consideration is that Tables 2 and 3 consider only non-institutionalized individuals whereas Table 1 does not make the distinction between those who are or are not institutionalized and, therefore, one may assume that both groups are counted. Another consideration is that Table 1 is based on the pre-1978 definition of developmental disability whereas Tables 2 and 3 are based on the 1978 definition. A lower figure is to be expected with the functional definition since those people with minor functional impairments would not be included.

Nevertheless, despite the fact that plausible reasons can be given for discrepancies in the findings of completed demographic studies, all of these findings are suspect to some degree. No definitive data on the developmentally disabled have been collected to date, and such data are essential.

TABLE 2 Estimated Percent and Number of Non-institutionalized Individuals 3 Ye of Age and Over with Functional Limitation Which Had Onset Before Age 22 in the Seven Major Life Activities Listed in Public Law 95-602

Major Life Activity	Percent of Population 3 Years of Age and Over with a Substantial Functional Limitation	Millions of Individual 3 Years of Age and Ove with a Substantial Functional Limitation[a]
Capacity for independent living	1.90[b]	3.8
Learning	1.60	3.2
Economic sufficiency	1.49[b]	3.0
Receptive and expressive language	1.22	2.5
Self-direction	0.56	1.1
Mobility	0.38	0.8
Self-care	0.37[b]	0.8

[a]Based on a 1976 non-institutionalized population 3 years of age and over of 202,462,000.
[b]Based on actual data on the population aged 18-64 in the SIE survey and inferred to the age group 3 years of age and over.
SOURCE: Boggs and Henney (undated).

TABLE 3 Estimated DD Population in Four Age Groups Derived from SIE Data (in thousands)

Age Group	Total Population	Major Activity	DD as % of Population	DD Population
Infants, 0-2	11,027,000	--	3.0	331,000
School age, 3-17	56,113,000	Learning	1.87	1,053,000
Adult, 18-64	124,628,000	Working	1.49	1,858,000
Senior citizen, 65+	21,721,000	--	0.5	108,000
Estimated total	213,488,000[a]		1.57	3,350,000

[a]Based on a 1976 non-institutionalized population of all ages of 213,488,000.
SOURCE: Boggs and Henney (undated).

TRADITIONAL FACILITIES AND THEIR EFFECTS

Wolfensberger (1977) has explored the relationship between the design of facilities and the assumptions about the handicapped population being housed. He notes that the environment can express the expectation that a user will act violently and is not supposed to take any responsibility for his or her actions. Wolfensberger describes features of institutional facilities as being consistent with treating the handicapped as "social deviants." The following examples (Wolfensberger, 1977) illustrate this viewpoint:

1. The Deviant as a Sub-human--When the retarded, severely retarded, physically handicapped, or emotionally disturbed person's learning skills are belittled and little potential for improvement is assumed, the conclusion is that extraordinary control, restriction, and supervision are needed. The handicapped person is expected to behave in a primitive and uncontrolled manner; therefore, the environment is designed in an abuse-resistant fashion (i.e., indestructible wall and floor materials, unbreakable windows, and sturdy furniture and equipment are used and locked areas are provided). Residents often have few possessions and little opportunity to communicate freely or express individuality.
2. The Deviant as a Diseased Person--When the handicapped are viewed as being diseased, service facilities follow the medical model. Administration is highly institutionalized and medical personnel make personal decisions for their "patients" about work, training, and other services despite the fact that the medical professionals often have no particular expertise in those areas.
3. The Deviant as an Object of Charity--When little change in the condition of the handicapped person is expected and little learning or adaptation is anticipated, the handicapped person is viewed as an "eternal child," requiring paternalistic and permanent care. Facilities therefore are designed that provide the individual with minimum opportunities to control the environment or to acquire new skills of any kind.

Roos (1974) has examined facilities for the handicapped from the standpoint of the "environmental messages" transmitted to the general community and to those housed in large facilities. He observes that the environmental messages received by the handicapped residents of large institutions can include the following: Since one lives behind bars and locked doors, one must be dangerous. Since one lives in an environment with no privacy and no personal property, one must have little personal worth. Since one lives in a regimented group situation, one must have little consequence as an individual. Since the environment is replete with barriers, one must not really belong and is not wanted there. Since one is in an environment where controls (e.g., television, light switches) are not accessible, one must be thought to be childlike.

Similarly, a set of environmental messages are being transmitted to the community in which the large institution is located. The physical separation of the building conveys the thought that the people inside are different. The characteristics of the structure (e.g., barred windows) imply that the people inside are dangerous. All in all, the message is "stay away."

In a discussion of large facilities for the mentally handicapped, Gunzburg (1971) describes the present general approach as being directed, not toward improvement of the functioning of the individual, but rather toward creation of an existence sheltered from normal life experiences. She indicates that the inhabitants of such institutions are under-functioning, and she terms this a "benevolent storage" concept that impedes the ability of the individual to live and experience a normal rhythm of life at varying levels, depending on the degree of handicap that exists.

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2
THE BUILDING COMMUNITY--THE MAJOR DECISION POINTS

The set of institutions and organizations involved in the design, production, and management of buildings and communities in the United States is large and diverse. Although this collection of institutions is sometimes called an "industry," it has few of the generally accepted characteristics of an industry and, consequently, is more easily referred to as a "community." The building community includes primarily small firms in the design, fabrication, and field construction sectors. The manufacturers of building materials and equipment are sometimes large corporations, and some of the financial institutions who provide investment captial or mortgage money are quite large. It is best for the purposes of this report to think of the building community as geographically decentralized, small businesses pursuing individual objectives within a highly competitive and rather traditional framework. There is only a thin veneer of research and development activity surrounding this community. Changes are introduced slowly and take a long time to diffuse into the community in sufficient volume to be visible on a national level.

It is not feasible to attempt to communicate with all participants in the building community to initiate changes that would make facilities more adaptable to the developmentally disabled. The key is to identify the major decision points in the design or production of the built environment and to initiate activities that will influence those who make these key decisions. The decision points in the design and production of housing are quite different from those in the design and production of public facilities. Architects, for example, are used extensively for the design of public facilities (and, consequently, can be very important with respect to providing adaptable environments in such facilities) but rarely for the design of residential units. Home builders and developers of housing communities are naturally most concerned with the response of the "marketplace" as are the financial institutions that provide the funds for investment or mortgages.

All buildings are subject to the norms and regulations of local and national codes and standards. It is through these codes and standards that public concerns with health, safety, and welfare are expressed.

Whether an architect is designing a public school or hospital or a developer is seeking a building permit for a new high-rise complex, the local building code review process comes into play. Therefore, a strategy for accomplishing change that would be supportive of the developmentally disabled could effectively focus on acceptance in standards and codes.

STANDARDS

Many states have simply adopted, in its entirety or in part, the American National Standard Institute's (ANSI) Standard A117.1-1961, Making Buildings and Facilities Accessible to, and Usable by, the Physically Handicapped.* As the title implies, the standard addresses only the physically handicapped, and it is universally regarded as being inadequate even in this respect. In addition, however, the scope of the standard embraces only nonresidential, publicly owned buildings and, thus, obviously excludes public buildings that serve as "public housing."

A broad range of standards control the design of specific products, systems, and applications. They therefore can have a significant impact on the use of buildings and facilities and their components by the disabled.

FEDERAL LEGISLATION

At the national level, several laws--notably the Housing Act of 1964, the Architectural Barriers Act of 1968, the Rehabilitation Act of 1973 (the provisions of which do not extend to the U.S. Department of Housing and Urban Development)--have been passed in an effort to ensure that accessibility is realized. However, excluding activities currently under way that may result in change and some isolated policy directives (e.g., as reflected in the Minimum Property Standards issued by the Department of Housing and Urban Development), the federal construction agencies currently depend almost exclusively on ANSI Standard 117.1-1961. Thus, even buildings constructed by federal agencies suffer, to a significant extent, the same accessibilty limitations as those built at the state or local level.

Federal construction agencies that provide public facilities are not subject to the code provisions of state and local jurisdictions (although many of these agencies attempt to comply with local requirements whenever possible). The federal agencies are governed by federal procurement regulations in which construction standards are mentioned only generally. The procurement regulations do allow the agencies to

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*A new ANSI standard, American National Standard Specifications for Making Buildings and Facilities Accessible to and Usable by Physically Handicapped People, ANSI A117.1-1980, was published in 1980.

reference national standards when appropriate. Since there is no single agency coordinating federal construction, each agency is responsible for developing its own procedures for assuring sound construction and each has developed a variety of design manuals, guide specifications, standard drawings, and general design and construction criteria documents. Many of these documents reference national standards.

Other nonconstruction federal agencies develop standard requirements that regulate compliance with their specific programs. The Department of Housing and Urban Development (HUD) mandatory Minimum Property Standards (in three volumes--single-family housing, multifamily housing, and nursing and intermediate care facilities) supplemented by a nonmandatory Manual of Acceptable Practices establish standard criteria for determining the acceptablity of HUD-assisted housing. The Minimum Property Standards also are used by the Farmers Home Administration and the Veterans Administration and for some military housing programs as well as by nonfederal organizations such as conventional lending institutions. The Minimum Property Standards reference national standards but many of the provisions have been developed independently by HUD.

MODEL CODES

Model codes, in effect, are standard codes relating to buildings in general. They serve as a basis for state and local codes in that they can be adopted on a jurisdiction-by-jurisdiction basis. There are three model codes that are developed through the consensus process by organizations whose memberships consist of state and local building officials. These three codes each serve a different region of the country and are: (1) the Basic Building Code developed by the Building Officials and Code Administrators International (BOCAI) and generally used in midwestern and eastern states, (2) the Uniform Building Code developed by the International Conference of Building Officials (ICBO) and generally used in western states, and (3) the Southern Building Code developed by the Southern Building Code Congress (SBCC) and generally used in the southern states.

Other standard national codes dealing with specific aspects of building have been developed by industry associations and the model code groups, and many of these have been promulgated as ANSI standards. Examples of these national codes are: (1) the National Building Code dealing with fire safety developed by the American Insurance Association, (2) the National Fire Code developed by the National Fire Protection Association, (3) the Standard Plumbing Code developed by SBCC, (4) the Basic Mechanical Code developed by BOCAI; (5) the Uniform Plumbing Code developed by International Association of Plumbing and Mechanical Officials of ICBO; and 7) Life Safety Code developed by the National Fire Protection Association (in which is included provision for elevators).

In addition to the general and specific national standards and codes discussed above, numerous national building product and application standards have been developed independently by recognized manufacturing, professional, and trade constituencies within the building industry. These also are often developed through consensus action and are adopted and promulgated as ANSI and other national standards. Examples of the areas covered include plumbing, electrical, elevator, window and door, and appliance products and applications. These standards frequently are referenced in or promulgated by the national standards and codes discussed above and may be referenced in regulatory documents such as state and local codes.

STATE AND LOCAL CODES AND ORDINANCES

States, under those constitutional powers relating to the general welfare, control or regulate the planning, construction, and use of buildings and land through the enactment of codes and ordinances. These codes and ordinances are intended to provide for the health, safety, and general welfare of the public and it is through these codes and ordinances that the community reflects its concerns about the character and quality of the built environment. Thus, it is important to understand the organization and purpose these regulatory tools and their potential application to the special needs of the developmentally disabled. A state may develop its own codes and ordinances for use throughout the state or it may relegate this authority to local governments (counties and municipalities). The manner in which the state and local jurisdictions adopt or reference national standards and model and national codes is extremely important. For example, if a 1961 ANSI standard is cited, only the provisions in that standard would apply (i.e., no subsequent revisions to that standard would be applicable). In addition, a standard may be cited with the intention of relating to a particular provision therein, but unless the provision itself is called out, the entire standard is binding even though some of its provisions may be inappropriate or undesirable in some instances.

BUILDING CODES

A building code establishes requirements for the construction and occupancy of buildings and contains: standards of performance and specifications for materials; methods and planning criteria that affect structural strength, adequate light and ventilation, sanitation, and electrical supply; and other considerations related to the design, construction, alteration, and demolition of buildings. States, counties, and municipalities may write their own codes or may adopt one of the national model codes with or without modification. A code becomes law when it is adopted by a jurisdiction as a public ordinance and is administered at the local level.

Some 15 to 20 states have enacted or are in the process of enacting state-wide codes that generally are based on one of the national model codes; however, most have significantly amended the model codes, which contributes to a lack of uniformity. The multiplicity of codes and the diversity of code administration is further demonstrated by the fact that there are some 38,000 local jurisdictions (cities, counties, towns, villages, and boroughs); those not governed by a state code either write their own codes or adopt model and national codes, in most instances also with modification.

OTHER CODES AND ORDINANCES

In addition to building codes there is a wide range of local housing, zoning, environmental protection, fire prevention, rehabilitation, sanitation, and other codes, requirements and ordinances that may be enforced by other than building code officials (e.g., fire officials, planning officials, and public health officials). There may be overlap and conflict among both state and local regulations and enforcement agencies. Since all of these codes and ordinances are intended to be legally binding, difficulties arise in determining which takes precedence and what the risks and liabilities of noncompliance are in the event conflict does occur.

3
PERFORMANCE CRITERIA--FACILITIES FOR THE HANDICAPPED

In the past decade the professionals and researchers working on the problems of the developmentally disabled have increasingly come to believe that this group should be integrated into the community to the greatest extent possible. The concept of integration is embodied in the principle of "normalization," first articulated in 1969 by the International League of Societies for the Mentally Handicapped: "If care in an institution becomes necessary, it should be provided in surroundings and under circumstances as close to normal as possible." Since that time, the subject of "normalization" has received considerable attention by all of those working on the problems of the developmentally disabled.

NORMALIZATION

The premise for normalization is that the architectural design and layout of a building and its surroundings can either restrict further development or serve as the outer framework for the growth and development of the individual (Dybwad, 1974). Normalization implies that disabled people should have the full rights of citizenship and the same opportunity to live normal lives that other people enjoy. It means accepting the individual with a disability and providing him or her with the means to function effectively, including special treatment, education and training as required. It means that disabled people should have the opportunity to live in a home-like environment, to work and earn money commensurate with their skills, and to engage in leisure activities enjoyed by other members of society.

Wolfensberger (1977) maintains that acceptance of the normalization concept has several implications:

1. The attitudes and values of society and professionals should be shaped so as to become more accepting and tolerant of harmless types of differences such as appearance, demeanor, intelligence, and speech.

2. The mentally handicapped must be presented and interpreted to society in a way that emphasizes their similarities to others rather than their differences.

3. The mentally handicapped should be assisted to function within the acceptable norms of their society by exposure to a culturally normative social environment, pattern of life, and physical environment.

He also notes that "ideology" must be recognized as the single most important determinant of human service system environments. Values, ideologies, and role perceptions, not money or technical architectural considerations, are said to be the ultimate source of most environmental features as well as clinical and administrative processes. The ideologies needed must be developmental, normalizing, and status-enhancing rather than growth-inhibiting, segregative, and stigmatizing.

The basic philosophy of the normalization process has been presented by the National Association for Retarded Citizens (1973). The organization points out that all Americans have freedom of choice but that a retarded citizen is faced with a narrower range of choices. He or she is not free to live in a desired location or in a style of choice or to have any say in the system of care that is provided--which is often restricted to living at home or in a large institution. The Association maintains that (National Association for Retarded Citizens, 1973):

> The right to live in one's community and in facilities which offer access to good programs as well as adequate care is essential to growth and dignity. Basic to the concept of keeping the handicapped person in the community and as close to home as possible is the concept of the community as the focal point for the delivery of care, treatment, education and recreation services.

Sokoloff (1977) indicates that normalization implies that a disabled person will function more normally as a result of increased stimulation from more culturally normative and less restrictive surroundings because all people, regardless of their degree of disability, can develop and make progress. However, he states that, the real meaning of normalization does not depend on the increased level of functioning. Rather, normalization is concerned with the basic right of a person to have maximum opportunity and experience; it is a matter of human dignity. Conversely, according to Sokoloff (1977), the disabled person "has the right not to be isolated in a large facillty far away from the mainstream of activities of the society and has a right not to experience the consequences of such isolation."

Community Homes as "Learning Machines"

Sokoloff (1977) describes a building as a component of a service system, and he considers the residential facility to be a training apparatus in which the disabled can learn the skills needed to function as contributing members of society. The facility must be designed to challenge disabled residents to learn new skills (but must not make things so difficult to master that it reinforces feelings of inadequacy. In describing a community home environment, Sokoloff (1979) indicates that learning to live means acquiring the means to manipulate the environment (e.g., switching lights on, opening doors) and developing physical skills to take care of grooming and the social habits needed to conduct interpersonal relationships. The facility is also a teaching machine for the staff of a group home and the families of the disabled individual. It affords them the opportunity to learn the support techniques that may be required to facilitate the progress of the developmentally disabled person.

According to Bayes and Francklin (1971), the richest learning opportunity for all of those engaged in the development of a service system for the handicapped is the design process. It permits each individual involved to share information and exchange views concerning the adequate functioning of a community home. The success of the ultimate design depends largely on the quality of the decisions made collectively by these people as they work toward the common goal of achieving an environment that facilitates the normalization process.

The Design Process as a "Change Agent"

Bayes and Francklin (1971) note that a new approach to designing for the disabled will place more demands on the architect who will need a greater understanding of the needs of the people concerned. They summarize their philosophy as follows:

> "We are concerned with the fulfillment of the developmental needs of the handicapped. Different forces, according to the makeup of the individual, must be brought into play to ensure that progress is achieved intellectually, socially, and emotionally in a balanced way. The task is to manipulate the environment, whether human, physical or natural, and in all its dimensions, to bring each person the maximum possibility of achievement and balance. The architect, who creates the physical environment, which in turn encompasses and penetrates the natural and social environment, to a great extent determines the scope and ability of staff and handicapped to achieve. Only when the problem is viewed in these terms can we fully see the role of the environment, which is to enable the task to take place, to be an educational tool, to be a physical support or challenge, to encourage appropriate social interaction. Any attempt to give environmental support to a program in these terms presupposes a thorough understanding

> on the part of the architect of the total needs for development of the handicapped to be housed in the building and the way that the building will fulfill them.

These researchers further conclude that the integration of the disabled into the community should have profound implications for design. They maintain that for the imaginative architect, awareness of the disabled could open up exciting new challenges and lead to an enhancement of the environment for all.

Bayes and Francklin (1971) further suggest that a reassessment of the architect's aims, role, and entire approach to planning and design is imperative because the rigid process now used is not meeting the needs of the handicapped. They state that the design subculture traditionally has designed for itself without adequately considering the different values, images, and ideals of other groups and the conflicts generated by these differences.

Sokoloff (1976) points out that the success of any building depends in large part on the acceptance of those who use it; therefore, the staff and residents of a facility for the developmentally disabled are essential contributors to the design team as are family members, maintenance personnel, and a variety of other people who contribute to the service system. They are important participants in the process not only because of the information that they contribute but also because their involvement is likely to motivate them to "help make the building work" once it is completed.

Bayes and Francklin (1971) support this view. They maintain that facility design is an enterprize for a team of concerned individuals, not just an architect, and that by experiencing the design process, the whole team will be able to understand fully the aims and functions of the resulting design and will be able to use the environment to its fullest potential. They believe that the interest of the staff in the planning process actually may be more important than the final design result, and they emphasize that follow-up is needed with the staff to enable them to adjust to the environment and facilitate its use.

Gunzburg (1971) cautions that those involved in team design must be prepared to subordinate their professional knowledge, skill, and experience in order to achieve the goal of normalization for the residents of group homes: the architect must make suggestions in a way to facilitate general understanding, the nursing staff must consider changing long-used routines, the administrator must appreciate the need to allocate funds for amenities, etc. Problems must be defined jointly by all those participating in the design process and participants must try not to force the problems into a form consistent with their own particular professional concept.

Additional Criteria for Normalization

Dybwad (1974) emphasizes that in the design of group homes the architect must build from "the inside out," taking as his point of

departure the individual and his or her living space, rather than from "outside in," the approach very much in evidence that results in an organizational pattern of wards and houses to care for predetermined categories of illnesses. He suggests that planning should focus first on the place where the resident will sleep, then on where eating, working and recreation will take place, and finally on the interrelationships between them.

Wolfensberger (1977) identifies several key issues that require consideration in planning community homes. Among them is individualization which he describes as differentiation of a person from others and self-expressivity in one's uniqueness. It can be enhanced, he explains, by providing a person with life spaces (territory) and privacy, by encouraging redecoration of rooms in a personal way, and by promoting the use of furnishings that suit individual tastes and needs.

Wolfensberger (1977) also maintains that the developmentally disabled must be permitted to control and interact with their environment to the greatest extent possible. The environment should promote the development of functioning, and, within the limits of prudence, the disabled should be exposed to some risk of injury since it is only by sometimes taking risks that mastery of some activities can be achieved.

Wolfensberger (1977) also cites the need to bring down the barriers between the staff and the residents of facilities. He believes that the disabled and those who serve them should live as equals rather than with the disabled being in a permanent position of subordination. Thus, he maintains that the facilities for the disabled should have the same amenities as those enjoyed by the staff.

PHYSICAL REQUIREMENTS

According to Wolfensberger (1977), the location of a service facility can greatly affect the type of world and people with whom the developmentally disabled have contact. The historical pattern of locating services for the mentally handicapped in rural and remote sites is, in his view, part of a real system of segregation. Physical distance from population concentrations decreases the ability of the handicapped to reach the service setting for day and residential programs, and it also can contribute to a sense of isolation from friends and relatives.

With respect to community homes, Gangnes (1977) notes that the home is a place to eat; to sleep; and to find respite, companionship, and acceptance. It should not be used for formal education and training or be a place to work. He believes that these activities should occur in other locations as they do for the general population.

Weeks (1971) emphasizes the importance of flexibility in the design of buildings for the developmentally disabled. He notes that continual change is one of the primary features of the pattern of care for the disabled. The architect's role should be to help implement the decisions of the client in a way that expresses concern for building users, but in doing so, he should avoid enclosing routines forever in

permanent envelopes (i.e., systems should be planned to offer options to those using the building).

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4
BARRIERS TO NORMALIZING THE ENVIRONMENT

To provide direction for the present study and to establish its scope, accessibility problems for the disabled were identified through an extensive literature search (see the Bibliography). The concerns of the building and financial communities with regard to constructing homes for the developmentally disabled also were addressed at a 1977 workshop conducted by the BRAB Committee on Accessible Environments for the Disabled. These efforts revealed that there are no categorical headings that can readily and unambiguously be used in discussing accessibility problems. This chapter has been organized under a somewhat arbitrary list of such categories to facilitate discussion, and the reader is urged to keep in mind that most of the issues discussed are multifaceted.

LEGAL AND ADMINISTRATIVE BARRIERS

A pervasive problem is that existing federal and state laws are inadequate with respect to coverage of requirements and/or enforcement provisions to ensure an accessible environment for the developmentally disabled. For example, although statutory requirements addressing accessibility exist in 49 states, most of these remain mere resolutions or statements passed by the various legislatures. In only a limited number of states were regulatory agencies directed to promulgate rules and regulations for subsequent incorporation into building or other codes. Most states do little more than indicate their concern about the problem and then only with respect to new, publicly owned buildings. Even in those states where regulations have been developed, compliances and enforcement are difficult because of the lack of definitive requirements (most use vague terms such as "shall be accessible," "insofar as possible," "reasonable," and "economically practical") and the inclusion of waiver clauses. Another major shortcoming in most existing laws is the failure to address enforcement. With respect to coverage, most state laws or codes address only non- and semi-ambulatory persons and give no specific consideration to those with other disabilities (e.g., seeing, hearing, or mental disorders).

At the 1977 workshop, a lawyer specializing in mental disability and the law explained that the zoning authority of local communities has been used as a potent weapon to delay and/or prevent the establishment of group homes for the developmentally disabled. He noted that zoning is a legislative and administrative device by which communities plan for the orderly use of land and that zoning codes reflect a process of public decision-making about the ways to organize the activities of a community. He indicated further that an important feature of the zoning process is the substantial amount of discretion exercised by administrative officials--especially when new kinds of uses for property are being examined and many interpretive decisions must be made--and that zoning authority has been misused concerning new proposals to establish quasi-family homes in residential areas for individuals needing a supportive environment since such facilities are not a new land use (only the relationship of the people in the residence is different).

Zoning laws have provided a focal point by individuals and organizations opposed to establishing small residential facilities for the developmentally disabled. The zoning fights that have occurred have been disastrous in terms of public education because they give credence to the most extreme fears and stereotypes concerning the mentally retarded (e.g., it is argued that the retarded are a threat to safety, that they will not maintain their property, that they will be bad neighbors, and that the nature of the community will be changed). Zoning fights also place even the most enlightened public officials in an untenable position in that they are forced to choose between two "goods"--protecting the rights of disabled people and protecting the sanctity of neighborhoods and the safety of children.

Although white, middle-class communities have been very successful in using zoning to exclude community homes, the opposition in many urban areas has been less well organized and has lost zoning disputes. Thus, community homes often have been located in unstable areas, which are considered to be transitional ones in terms of racial and economic characteristics. This situation leads to a higher degree of danger for the residents of community homes, who are easy targets for criminals.

Another barrier presented by zoning laws is that a lawyer must be hired to establish a group home. This procedure is expensive and results in considerable delay even when the litigation is ultimately successful.

REGULATORY BARRIERS--CODES AND STANDARDS

According to Sokoloff (1976), the building of new facilities or the remodeling of existing ones is inhibited by the very life safety code regulations intended to protect residents. These regulations involve special plan arrangements, exit requirements, building materials, and construction techniques that are viewed by the building community as major obstacles to the construction of cost-effective buildings.

At the 1977 workshop, the member of a large architectural firm noted that many people consider the formulation of strict codes to be the most effective means of obtaining barrier-free environments (including those related to the developmentally disabled) but that there are many problems with this viewpoint. He explained that new codes will have virtually no influence on the existing building stock and that current codes exhibit little consistency or uniformity--i.e., there are conflicts among provisions of codes, different codes are used in different jurisdictions, and even when the same code is used in several jurisdictions, dissimilar editions often are employed. Many jurisdictions and authorities also are involved in the interpretation and enforcement of codes, and indicated that in some states as many as 30 people exercise some code authority over a building. He also noted that the code-writing process itself contributes to the formation of barriers since participants are not concerned solely with safety but also with potential legal liability in case of accident and that this latter consideration often leads to over designing for occupant safety, especially since cost-effectiveness generally receives inadequate attention.

Gangnes (1977) observes that building codes are often a serious impediment to the construction of group homes. For example, the Uniform Building Code defines a family as "a group of blood-related people or no more than five non-blood-related persons," which has the effect of unduly limiting the size of group homes. Some codes and ordinances also use terms such as "child care homes" and "institutions for retarded persons" that can exclude certain living areas within communities from use by the developmentally disabled and that can increase the cost of construction and/or renovation by requiring design and mechanical features for such facilities that are "foreign" to other homes.

ECONOMIC AND FINANCIAL BARRIERS

At the 1977 workshop a building community marketing and economics specialist identified some of the fears associated with barrier free or adaptive design as economic loss, market risk, and managerial problems. A major community developer discussed a series of other concerns as well.

Economic Costs

Both the real estate developers and marketing specialist indicated that providing housing for the developmentally disabled is more costly than constructing equivalent accommodations for the general population. (This assumption was questioned by other workshop participants, but definitive data are lacking.) They noted that every dollar increase in initial construction has a direct influence on the permanent debt service and that, because of a "multiplier effect," even small cost increases at the outset result in a substantial increase in the amount

of capital required for construction. They explained that these costs do not increase the appraised value of the building, which is determined by the appraiser and/or mortgage lender, and therefore cannot be added to the total building costs. Thus, these costs must be "traded off" against other design amenities (e.g., landscaping), and priorities are established on the basis of such factors as the greatest return for the risks incurred. Another major obstacle to the construction of adaptive buildings identified by these workshop participants is the lack of appropriate tax incentives or financial subsidies that would reduce the risk for those builders who would like to respond to the needs of the developmentally disabled.

Market Risk

Uncertainties about the market for homes for the handicapped are based on the lack of information and marketplace experience. At the 1977 workshop, the marketing specialist explained that estimates of the size of the disabled population vary so widely that they are useless for planning purposes, especially with respect to a local market. He noted that even if a substantial demand exists, there is a question about whether people will move into such homes since they presumably are already living somewhere and have accommodated to an existing life style.

The desire to move into an adaptive environment is not sufficient; the resources are needed to pay for such a facility, and there is considerable evidence that the disabled as a group are economically disadvantaged (Congressional Research Service, 1979). Even when the desire and financial resources exist, the timing of such moves is critical and the builder faces the prospect of considerable loss if the housing is not occupied soon after construction.

The community developer participating in the 1977 workshop summarized the orientation of many builders. He maintained that if a demand existed for adaptive buildings, the free building community would have responded to it as a potential source of profit. He also stated that most builders have tended to ignore the handicapped as a potential market but that if some builders design for the handicapped, their competitors are likely to do the same because competition is so important in the marketplace.

Management Problems

The marketing specialist at the 1977 workshop indicated that operating a building designed to be barrier-free or adaptive presents unique management problems ranging from uncertainty about being able to rent the space because the exterior and interior of the building and its various special systems and materials will be considered to be unsightly and strange by potential renters to questions concerning special maintenance schedules (e.g., the need for more frequent cleaning of floor surfaces).

He also noted that finding a building manager for an adaptive building might pose problems. Good building managers are in short supply for facilities accommodating the general population: therefore, the availability of qualified people who would be capable and/or willing to provide any additional service that might be required by people who are handicaped or developmentally disabled is a concern.

The problem of risk and reliability is another issue that makes owners and managers of buildings reluctant to accommodate handicapped or disabled individuals. There is considerable uncertainty as to what measures can be taken to ensure the safety of either a casual disabled visitor or a resident with a handicap during a fire or other emergency. In the absence of a definitive law concerning the liability of building owners and managers with respect to the disabled in the event of such an emergency, many owners may be reluctant or unwilling to rent to the disabled.

COMMERCIAL BARRIERS--SERVICES AND PRODUCTS

Currently, goods and services offered to the public need not be made accessible to disabled users. Barrier-free stores, restaurants, theaters, churches, places of amusement, and parks are the exceptions rather than the rule. There is no known legal precedent for requiring that these public offerings be made equally available to all.

With respect to making products for the handicapped or the disabled, the community developer at the 1977 workshop indicated that marketing products for such a specialized and small segment of the population is not thought to be economically feasible, and, as a result, there is a shortage of such products and the cost of those that are available is high. He pointed out that building product manufacturers are vitally interested in standardization of their wares and that the problem would be solved to everyone's satisfaction if the same products could serve the general population and the handicapped or disabled.

DESIGN-RELATED BARRIERS

Of central importance to the design of facilities for the developmentally disabled are the state bureaus of construction. Existing state bureaus generally follow old practices and program concepts developed to produce large facilities. Their charge traditionally has been to construct large government buildings and to emphasize initial cost considerations, heavy-duty construction, and low maintenance. In the typical state design process, funding controls are exercised before any meaningful design has been accomplished and are related to money rather than programmatic effectiveness (Sokoloff 1977).

Sokoloff (1977) notes that the vast majority of the dollars currently available to support the developmentally disabled is spent to support large institutions and that a number of factors tend to

contribute to this situation. A large institution represents a degree of permanence to the family of the disabled person. This type of structure is more attractive to the architect since it results in a larger fee and presents him with an opportunity to create a "major" building, which increases the likelihood of professional recognition. In addition, since facilities for the developmentally disabled represent a major building type, considerable design information is available for ready access. A large project is also likely to attract large donors of money, who are interested in perpetuating their name for a worthy charity. Such a project also rewards an administrator seeking responsibility and the opportunity to exercise his or her organizational skills. It provides the staff of the institution with a measure of stability and job security and also provides a concentrated market for suppliers of goods and services.

Informational Shortcomings

The information available to designers of facilities for the developmentally disabled is inadequate in several respects. Informational shortcomings exist with regard to building design considerations, the functional capabilities and limitations of the people to be served, the costs associated with barrier-free or adaptive design, and the education and training available to architects. At the 1977 workshop, the community developer concluded that the continued existence of physical barriers results in large measure from the inability to identify all of the architectural elements that constitute barriers for the handicapped. He suggested that people not intimately knowledgeable about the daily activities of the handicapped find it difficult to fully understand the nature and extent of the physical barriers that they encounter in buildings. The requirements of adaptive spaces to the needs of those who are developmentally disabled, but are not handicapped, are all the more difficult to identify.

The Education and Training of Architects

All individuals are strongly influenced by their training and experience. According to the community developer at the 1977 workshop, the environmental needs of the handicapped have been neglected for years by the design profession and traditional barriers have been taken for granted. He explained that most architects tend to feel that architectural practices would have been developed to deal with it the problem if it existed and, consequently, the needs of the developmentally disabled have not received much special attention.

The formal training of the architect also contributes to this problem. Bayes and Francklin (1971) suggest that the discipline required to analyze and review inputs to design programs is lacking as is the necessary analysis of design decisions. As a result of the insufficient emphasis on the need to develop and analyze information (especially that related to the needs of users), the architect frequently relies on his or her own experience and values instead of

developing and using other sources of information (e.g., the various contributors to the service system of the handicapped). Another shortcoming in the typical university curriculum for architects is that two topics central to the subject of this study--barrier-free design and building codes--are neglected.

Goldsmith (1976) cites another problem traceable to traditional training and practices. Building designs are intended to respond to the needs of 90 percent of the population, and the 5 percent extremes in both directions are largely ignored (e.g., very short and very tall people). The disabled individual, like those in these other extreme catagories, is all too often among the 10 percent excluded from consideration.

INSTITUTIONAL AND ORGANIZATIONAL BARRIERS

A broad range of institutional barriers stand in the way of a "new" approach to housing the developmentally disabled. Considerable fragmentation exists among organizations serving the handicapped and disabled. There is also a history of confrontation among several groups who view the needs of the handicapped and disabled from different perspectives. The service system now in place has strong vested interests in maintaining the status quo.

Single-Issue Organizations

Many organizations currently provide services for the handicapped and disabled, but unfortunately their efforts often are not effectively coordinated. Each tends to view its constituency as having a unique set of problems that requires unique solutions. Consequently, although many such organizations share similar broad objectives, they often find themselves competing with one another for support in the public and private sector (Frank Porter Graham Child Development Center, 1975). This approach results in considerable duplication of effort and inefficiency in meeting their own goals, and promotes a feeling of confusion among the general public because of the multiplicity of deserving charities. Few institutional mechanisms exist to coordinate the efforts of separate organizations that could mutually benefit from such a cooperative effort, e.g., those serving the developmentally disabled.

Contrasting Professional Roles

Several professions with the potential for making joint contributions to the developmentally disabled often find themselves to be working at cross purposes to one another (e.g., the building community often is at odds with code officials, architects and service professionals frequently have different viewpoints about building designs, advocates of community homes are in conflict with local officials). Despite this

history of conflict, prominent members of the various professions are in general agreement about the need to respond to the building requirements of the developmentally disabled; therefore, mechanisms must be developed that permit professional groups to work together in an amicable way to meet common objectives.

Lack of Federal Focal Point

At the present time there is no effective point source of authority in the federal government to coordinate all activities and programs related to the developmentally disabled or any one place to go for information or guidance. No one federal agency possesses all of the knowledge and expertise needed to administer effectively all such activities and programs. In the absence of a body to coordinate the capabilities that exist throughout the federal government, confusion and frustration exist in both the private- and public-sector local organizations seeking assistance in aiding the developmentally disabled.

ATTITUDINAL BARRIERS

The most elusive of all barriers, negative attitudes, present a great problem because they cannot be legislated out of existence. In general, society at large tends to view the disabled with apathy, fear, anxiety, pity, discomfort, and/or paternalism. These prevailing attitudes are believed to reflect educational and cultural experiences or lack of knowledge about the disabled. The effects of attitudinal barriers are manifested in the man-built environment in innumerable ways. Possibly, the "out-of-sight, out-of-mind" concept is the root cause for the fact that so many disabled people are housed together in an isolated setting.

A number of explanations have been formulated to explain the attitudinal barriers that exist. A medical researcher at the 1977 workshop indicated that everyone makes numerous assumptions about how other people feel and behave. He explained that the strongest assumptions have their basis in the belief that most people are alike (e.g., the typical person assumes that all people can use stairs and telephones, know how to read and write, and can take care of their personal needs) and that it is the typical individual's difficulty in imagining that some people are different that creates many problems for the developmentally disabled.

The Disabled As Different

The researcher at the 1977 workshop suggested that visual cues play an important role in the formation of attitudes about people and that an individual's initial evaluation of a person is based largely on appearance. He noted that when a physical handicap exists, the handicap dominates the attention of the "normal" individual to the exclusion

of other attributes that ordinarily would be included in the initial evaluation and that this type of response occurs because one develops a "set" concerning how people look, behave, speak, and move based on personal experiences. If something "violates these expectations," one often develops feelings of fear and anxiety, and these emotional responses create sizable barriers to normal interpersonal relationships.

The Disabled As "Socially Deviant"

Wolfensberger (1977), as noted earlier, views the history of the treatment of handicapped and disabled people from the standpoint of "social deviancy." Social deviants are judged to be different by others "who consider the different attribute (or combination of attributes) to be important, and who value the difference negatively." Deviancy is therefore a socially determined characteristic. When a person is perceived to be deviant, strong expectations are aroused in the mind of the perceiver and the person being perceived. Social roles are anticipated and played out by both parties, and, in the case of the disabled person, the role becomes a self-fulfilling prophecy (i.e., the person acts in a way that is expected of him or her).

Language and Categorization

The medical researcher at the 1977 workshop pointed out that language has an important influence in shaping attitudes and that the effects of language have been particularly unfortunate with respect to the disabled. The most fundamental problem is that instead of dealing with issues of <u>people</u> with handicaps, the emphasis has been on the <u>handicaps</u>. This orientation has resulted in disabled persons being depicted in a fragmented and stereotypical fashion rather than as individuals as complex and different from one another in terms of desires, emotions, interests, and abilities as the population at large.

The tendency to categorize people also strongly supports the existing stereotypes of the developmentally disabled and other handicapped individuals. Furthermore, there is a tendency to oversimplify to an even greater extent by using dichotomies such as handicapped versus normal, mentally retarded versus normal, and mobile versus immobile. This process supports the belief that handicaps are permanent states rather than conditions that can be altered, and, therefore, is in direct contradiction with the concept of normalization. Categorization also can be misleading because categories frequently are considered to be mutually exclusive (e.g., if a person is a member of a category called "mentally retarded," it is easy for the layman to ignore the possibility that the same person might be physically handicapped as well).

A major factor contributing to the public's view of the handicapped and the disabled is the medical diagnostic terminology now in general use. This language and viewpoint serves to focus attention on disabilities and diseases (e.g., what the person cannot do) and tends to

ignore other aspects of the individual. Even in rehabilitation therapy, the approach emphasizes skills that often can never be perfected rather than the development of alternative ways of performing the same function. This approach has the additional shortcoming of contributing to the belief of the handicapped individual that he or she will never be able to cope with certain activities in the way that a "normal" person does (i.e., it tends to support the notion of dependency).

PHYSICAL BARRIERS

Perhaps the simplest of the problems to identify are physical barriers but they nevertheless dictate to a great extent the degree to which the developmentally disabled are capable of moving about and functioning within the built environment. Not only do these barriers prevent accessibility in a physical sense but also they frequently have a profound psychological impact on a disabled individual (i.e., repeatedly being unable to cope with seemingly simple tasks such as using steps or opening doors has a demoralizing and defeating effect).

Although many physical barriers can be avoided or corrected by designing to a performance specification, there are many other issues facing designers about which too little is known. The developmentally disabled may have perceptual and orientation difficulties in particular spaces. The use of forms and materials to define space so that it is easily perceived and understood and of orientation cues to differentiate environments "by size, shape, form, materials, texture, color, and detail" is fundamental (Hammerman and Duncan, 1974). Steinfeld (1979) provides a rather extensive listing of physical barriers in his concept of the "Enabler" (Figure 1).

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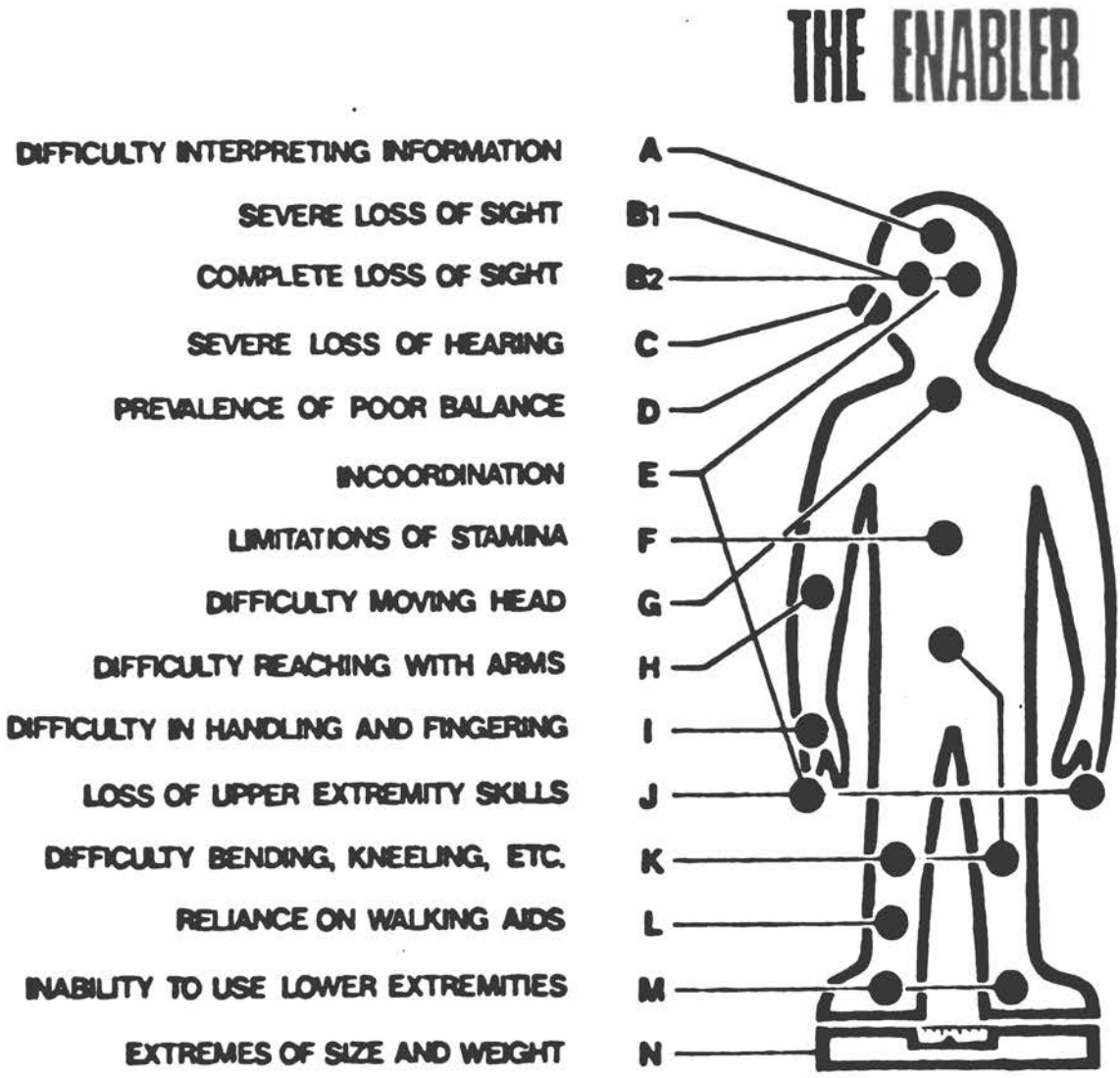

FIGURE 1 The Enabler developed by Steinfeld (1979). It represents a person's abilities as a basis for design. It illustrates the 15 different disability concerns that should be considered in design. They are presented in logical order, from top to bottom, as concerns of: (1) mental functioning, (2) the senses, (3) internal body regulation, and (4) motor impairment.

5
OVERCOMING BARRIERS TO NORMALIZING THE ENVIRONMENT

Although this report is the work of a consultant and the ABBE staff rather than a committee, a number of recommendations have been identified in the literature reviewed. These recommendations for normalizing the environment for the developmentally disabled are presented here in the following catagories:

1. Information, publication, and education programs;
2. Classification, definitions, and data;
3. Planning and design criteria;
4. Codes, regulations, and zoning;
5. Financial incentives and coordination by government;
6. Improved education and training for design professionals; and
7. Education for the general public and the building community.

INFORMATION, PUBLICATION, AND EDUCATION PROGRAMS

Programs concerned with the developmentally disabled cover a broad spectrum of activities. Within the building community those engaged in research and development activities cover an equally broad spectrum. In the United States alone, trade and professional organizations and societies number in the hundreds and cover all aspects of building, planning, design, and construction. Added to these are colleges and universities; agencies of the federal, state, and local governments; and private organizations.

Efforts to disseminate information on the activities of the disabled are fragmented, however, and even the most successful ones are directed toward and reach only a specialized audience and, perhaps more important, generate only minimal opportunity for communication among researchers and users. It often is valuable to know who is conducting research and their capabilities when a specific solution to a given problem is being sought.

Research and Programs Directory

A project should be established through which a research programs directory can be developed and updated on a continuing basis. This directory should serve as a guide to sources of information on current research dealing with barrier-free design and should include:

1. A listing of relevant organizations and agencies including national associations and societies, private research, development and testing facilities, colleges and universities, federal and state agencies, and international organizations and universities.
2. A subject index organized according to standard subject classifications.
3. Data sheets on relevant organizations and agencies that describe the organization; the executive and research personnel, the research programs; the educational programs and publications; and any specialized functions, services, and capabilities.

Information Dissemination Service

A mechanism should be established to provide a single comprehensive source of information. It should provide for a clearinghouse type of operation that would:

1. Identify and classify relevant information such as market data, design criteria, research and development programs, and existing and pending legislation.
2. Identify data sources.
3. Disseminate information in the form of indices, bibliographies, and other publications.
4. Answer inquiries and refer inquiries to public and private organzations as appropriate.

CLASSIFICATION, DEFINITIONS, AND DATA

Standard Classifications and Definitions

Standard classifications and definitions should be developed to permit analysis of the disabled population in terms of cause of disability, type of dysfunction, and basic functional tasks that must be performed in the conduct of daily activities in the built environment. The classifications and definitions should reflect to the maximum extent possible the physical and mental manifestations resulting from such causes as

1. Difficulty in interpreting information,
2. Impairment of sight and/or hearing,
3. Emotional impairment,

4. Susceptibility to seizures,
5. Impairment of speech, and
6. Inability to use legs or feet.

teinfeld (1979) suggests that classifications and definitions established to characterize the basic functional tasks performed within the built environment should reflect, to the maximum extent possible, tasks common to multiple dysfunctions. These would include:

1. Passing through openings;
2. Entering and exiting moving conveyances;
3. Operating hardware, controls, and mechanical devices;
4. Movements along routes of travel;
5. Negotiating a series of movements in a confined space;
6. Negotiating changes in level;
7. Transferring from one body posture to another;
8. Obtaining and interpreting information; and
9. Using fixtures, appliances, accessories, and work surfaces.

Demographic Data

Mechanisms and procedures should be established to ensure that adequate statistical data are obtained to portray by classification and type of dysfunction and special aid:

1. Number involved,
2. Age,
3. Sex,
4. Geographic distribution,
5. Level of income,
6. Whether institutionalized, and
7. Degree of special care required.

The procedure also should ensure that sufficient anthropometric data are collected to determine the dimensional and operational characteristics associated with the completion of relevant functional tasks.

Additional Data Requirements

During the 1977 BRAB workshop on barriers to building homes for the disabled. the following specific informational requirements were identified:

1. A comprehensive listing of physical barriers.
2. Cost information (first and long term) on community homes versus institutional care.
3. Detailed cost information on barrier-free design, new construction, and rehabilitation.

4. Evaluations of existing facilities, domestic and foreign.
5. Case studies of barrier-free designs and an analysis of why they did or did not work.
6. Maintenance procedures required for serving the developmentally disabled (if special ones are required).
7. Management procedures to accommodate the developmentally disabled.

Landesman-Dwyer (1981), who has been an active researcher of the needs of the developmentally disabled, identifies the following data as being of special importance:

> The development of a useful typology of residential facilities and services. (Discard terms such as "institution," "community based residence," and "deinstitutionalization," none of which convey or imply information about program content or quality).
> Review federal guidelines for residential programs in order to minimize unnecessary and arbitrary restrictions, particularly regarding program creativity and flexibility to meet the needs of a client.
> As much as possible, assess the quality of life from the viewpoint of individual clients--their personal preferences, needs, and capabilities--rather than doing this from our own perspective (e.g., Would I like to live here?).
> Encourage and support research and objective evaluation about alternative programs in actual service delivery settings to help define who benefits from what types of programs at which times in their lives.

Data Collection Procedures

Sackett, Landesman-Dwyer, and Morin (1981) have developed and refined procedures for making naturalistic observations in the school and the home. Since observation and description of basic phenomena are prerequisites for scientific explanation, their approach is an important step in achieving a more fundamental understanding of how the developmentally disabled actually function in their environments. The researchers have used "ethograms" to measure basic categories of behavior and describe the environmental settings where the behavior occurs. They have achieved considerable success in categorizing the behaviors of both handicapped individuals and the staff that serves them. However, further refinements of the technique are required to achieve their goal of determining how the environment may be used to encourage desirable and discourage undesirable behaviors. Their fundamental objective is to develop the procedures necessary to promote the normalization process. Table 4 illustrates their approach.

TABLE 4 Names, Definition, and Overall Percentage of Occurrence for the Classification of Nine Mutually Exclusive, Exhaustive, Major Activity Categories

Major Activity Category	Definitions	Overall % Occurrence
Inactive	Subject is not engaged in any focused interaction with the social or inanimate environment, is not receiving direct input from others, is not moving, and is perceived as "doing nothing."	45.5
Physical activity	Subject is locomoting or participating in a non-social gross-motor activity.	14.8
Self-care activity	Subject is eating, dressing, grooming, toileting, or attending to other aspects of personal care.	4.2
TV, radio, or stereo	Subject is actively watching and/or listening to TV, radio, record player, or other media communication.	6.6
Object-focused activities	Subject is behaving in a focused and appropriate manner and is involved in fine motor and craft activities, academic-oriented work, household chores, and tasks set up specifically to train such behaviors.	6.2
Undesirable, idiosyncratic, asocial activities	Subject is behaving in an inappropriate, abnormal, or unacceptable manner that does not directly involve others. Behaviors include destroying property, self abuse, loss of temper, and other idiosyncratic patterns.	4.5
Positive social behavior	Subject is interacting with others; initiates, receives, or mutually engages with other person(s) planning, supervising, teaching, care giving offering affection, assisting.	13.0
Negative social behavior	Subject imitates, receives, or mutually engages in any of the following with one or more others: physical or verbal aggression, scolding or punishing, annoying, obstructing, teasing, or actively disobeying.	0.7
Other	Subject leaves premises, is unobservable because of being in a private area, or cannot be found.	4.5

SOURCE: Sackett et al. (1981).

PLANNING AND DESIGN CRITERIA

Design criteria based on the physical and functional requirements of the developmentally disabled should be developed and should reflect the desired performance requirements of buildings and facilities, as well as their surroundings. Such criteria could be used in developing new standards, codes, and other regulations and in evaluating existing ones with respect to whether they provide for the appropriate performance levels. The criteria should reflect the following:

1. Urban Planning Needs--Criteria should be applicable to neighborhoods, communities, urban complexes, and relationships among facilities such as siting and transportation linkages to buildings. Attention should be given to the necessity for the continuum of all kinds of shelter and auxiliary care facilities within the community.
2. Facility Planning Needs--Criteria should reflect physical and functional needs of the developmentally disabled by building or facility type and relationships among building components (spaces, materials, products, and systems).
3. Building or Facility Component Needs--Criteria should reflect the physical and functional needs of the developmentally disabled with respect to individual building or facility elements (spaces, materials, products, and systems) by building type.

CODES, REGULATIONS, AND ZONING

It generally is accepted that codes, standards, and regulations which include the technical, health, safety and public welfare provisions used in the creation of the built environment inadequately address adoption of the built environment to meet the needs of the disabled. Several recommendations have been made to improve this situation. A cooperative activity should be initiated among the model and national code groups relative to accessibility. A review should be made of the definitions and classifications reflected in codes that restrict the occupancy in certain classes of facilities.

An architect participating in the 1977 workshop cited many opportunities for the building community to become involved in the formulation and revision of building codes. He noted that anyone can have some influence on the provisions covered by codes. For example, modifications to the National Fire Protection Association (NFPA) Life Safety Code are reviewed by the general public and comments can be made by mail or by testimony at public hearings. NFPA meetings are also open to the public so that any interested individual can become familiar with the organization's ongoing activities. A substantial contribution could be made by the building community if it became involved in the numerous subcommittees of the NFPA and participated actively in the activities of other code-writing organizations. At present, NFPA subcommittees typically have few representatives from the building community, and such involvement would be welcomed.

A lawyer participating in the 1977 workshop suggested that zoning has the potential for facilitating the establishment of group homes in the local community, but for this to happen, local officials need to be convinced that they can find a way to prevent the types of disputes that arose in the past. He explained that this could be done by first recognizing that many community members have legitimate concerns that should be addressed and then formulating a land use planning process to deal with these concerns (e.g., overcrowding and the proper maintenance of homes). The process should include the use of regulations that have the "force of law: (e.g., licensing) to ensure that proper safeguards to community values and standards are in place. He noted that such a systematic and orderly process would limit the widespread discretion now exercised by administrators, often in the direction of excluding group homes from residential communities, and would help the community to recognize that community group homes represent an important "land use" that should be permitted so long as certain conditions are met (i.e., those responding to the major concerns of the community).

Another means of fostering community homes entails the active involvement of the states in instituting policies that integrate the developmentally disabled into local neighorhoods by means of antidiscrimination legislation. Some states already have passed such legislation (e.g., California and Minnesota). State governments have a strong interest in de-institutionalization since it will reduce expenses (i.e., the high cost of operating and maintaining large institutional facilities). The federal government also can play a significant role in fostering the group homes concept by adopting appropriate antidiscrimination legislation.

FINANCIAL INCENTIVES AND COORDINATION BY GOVERNMENT

Financial Incentives

A large community developer participating in the 1977 workshop maintained that financial incentives are needed if builders and real estate developers are to appropriately respond to the needs of the developmentally disabled. He noted that tax benefits or credits, low-interest loans, debt retirement, and direct grants for rehabilitation will encourage owners and developers of residential and nonresidential buildings to accommodate the disabled.

Coordination of Accessibility Programs

Institutions now working on single-issue accessibility problems should be encouraged to coordinate their efforts to meet the common goals. When feasible, institutional mechanisms should be created to facilitate such coordination and cooperation among the many groups who influence the service system of the developmentally disabled. Among the groups and professions who would benefit from such efforts are

private charities, architects, the legal and human services professions, builders, code officials, and local zoning authorities. Such organizations represent both the public and private sectors of the economy, and members of the general public also should be encouraged to participate.

Federal Programs

A single authority within the federal government should have the responsibility for coordinating all federal accessibility programs affecting developmentally disabled. This authority also should coordinate federal agency programs with those of state, local, and private organizations and should analyze ongoing programs to identify research and legislative requirements.

IMPROVED EDUCATION AND TRAINING FOR DESIGN PROFESSIONALS

Both researchers and professionals serving the handicapped have called for improved education and training as a necessary step for creating appropriate environments for the developmentally disabled. Efforts are needed in the following areas:

1. Architectural Practice--Familiarize architects with the community home as an alternative to institutional care. Incorporate considerations of barrier-free design in Architectural Board examinations.
2. Education--Develop curricula for treating barrier-free design, codes, and zoning as major subject areas in universities.
3. The Design Process--Promote the importance of an analytic approach in making design decisions. Foster the team approach for developing the information necessary to respond to the special needs of the developmentally disabled. Emphasize the importance of evaluating buildings as a means of achieving technical and programmatic advances.
4. The Developmentally Disabled Client--Sensitize the profession to individual differences among all building users and among the developmentally disabled. Emphasize the "service system" concept of facility design. Explain the normalization process.

An essential part of a program designed to support barrier-free environments is the development of new design information based on research. A broad range of research is required to clarify the needs of the developmentally disabled with respect to buildings. Only a limited number of research issues that have received particular attention in the literature will be mentioned here.

Bayes and Francklin (1971) emphasize the need to acquire the tools for further analysis and manipulation of the design process as a means of better understanding the interaction of programmatic goals with physical and functional specifications. They call for a systematic and

scientific data base that will clarify the relationship between design and human needs. This would be partially accomplished by developing a detailed functional program that lists needs, aims, policies, and objectives. They also emphasize the importance of having built-in mechanisms to react to changing needs and improved procedures. Development and timely application of improved data also is identified as major requirements by Pederson (1970), He notes that the planning and programming of facilities for the handicapped is a long-term activity in that between 5 and 10 years elapse beween initial planning and occupancy of new facilities. During this interval it is essential that relevant information continuously be made available to ensure that the final building is not obsolete before it is completed.

An integral part of the design process is evaluation of its results. Bayes and Francklin (1971) emphasize the importance of post-occupancy evaluation as a means of determining whether or not problems exist in facilities and, if they do, whether the problems are related to design features. Just as important is a determination of which designs work and why. Such follow-up investigations are essential to improvement in future designs.

Demonstration programs involving all types of residential shelter alternatives should be undertaken to illustrate accessibility design solutions that can be incorporated into dwelling units and that, at the same time, enhance the marketablity of the unit. In developing these programs, special attention should be given to:

1. Site selection criteria that ensure that various topographic and climatological conditions are considered.
2. Cost assessment of specific design solutions or elements thereof that would result in no additional cost, relatively little additional cost, and significant additional cost.
3. Priority items such as entrances, changes in levels, openings through which individuals must pass, kitchens and bathrooms, and hardware and controls.
4. Design solutions that permit post-construction modifications to meet the needs of different occupants.

In carrying out demonstration programs, assistance and cooperation should be sought from such organizations as the National Association of Home Builders, the Urban Land Institute, the American Institute of Architects, the American Planning Association, and the Department of Housing and Urban Development.

EDUCATION OF THE GENERAL PUBLIC AND THE BUILDING COMMUNITY

To a great extent, the plight of the developmentally disabled with regard to building accessibility is caused by ignorance on the part of the general public and the building community. Educational efforts directed at broadening the understanding of the public regarding the developmentally disabled, their needs, and their potential to function

in society can result, in the long term, in a shift in public attitudes and a consequent lessening of barriers. Since there is a high correlation between the building community's understanding of the disabled and that of society in general, it is reasonable to assume that a program of public awareness will cause a shift in the attitudes of members of the building community.

National Public Awareness Effort

The Frank Porter Graham Child Development Center (1975) at the University of North Carolina investigated how best to implement a media campaign designed to sensitize the general public to the developmentally disabled. Emphasized is the need to survey the media (the amount of time and space devoted to the problems of the developmentally disabled), to determine what is now being produced by organizations dealing with the problem, and to determine what information and media coverage is required to perform the necessary tasks. Specific recommendations made in the Center's report include the following:

> Use the pictorial approach wherever possible as a way in which the public can be helped to get closer to the actuality of persons with developmental disabilities. We must aim for familiarity if we are to achieve acceptance. The mystery must be taken out of handicaps.
>
> Getting the mass media to talk about developmental disabilities in its many manifestations and to drive at developing more accepting public attitudes toward people with such disabilities requires:
>
> Interesting and efficient tools in the form of printed materials, films, and other audio-visual materials.
>
> A program for creating interfaces between such materials and editors, broadcasters, and other communicators.
>
> Facilities for writing or visualizing special messages when they are required.

Among the specific types of materials suggested for use are: motion pictures, radio and television spot announcements, media information kits, audio-visual presentations, a traveling exhibit of photographs, educational materials, books, and magazine articles.

The Building Community

With respect to residential buildings, any strategy developed to educate and orient the building community to be responsive to the needs of the disabled should focus on activities that will influence builders, subcontractors, mortgage lenders, building product

manufacturers, labor, and realtors associated with both single-family and multifamily residential units. Table 5 on the following page summarizes this strategy.

CONCLUDING STATEMENT

The recommendations presented above cannot be considered to represent either a comprehensive or a detailed program, but they do provide an indication of the kind of program that would be needed to provide an information base and design guides for the building community and the type of research needed to support the program. The key first step is the need for the Administration of Developmental Disabilities of the Department of Health and Human Services to make a commitment to organize and support a program for this purpose.

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TABLE 5 Meeting the Informational Needs of the Building Community (*Relevant)

Activity	Segment Affected: Financial Institutions	Design Professionals	Owners and Managers	Subcontractors and Labor	Building Product Manufacturers	Mortgage Lenders	Residential and Other Builders
Conduct workshops at state, regional, and national level to:							
Review problems of the developmentally disabled, supply demographic information, describe market potential	*	*	*			*	*
Review scope of deficiencies related to buildings	*	*	*			*	*
Present available design information	*	*	*			*	*
Describe methods of achieving berrier-free design	*	*	*			*	*
Arrange for participation in national, state, regional conferences dealing with the problems of the disabled in buildings	*	*	*			*	*
Provide information for publication in journals, newsletters, trade publications	*	*	*	*	*	*	*
Explore mechaniems for lenders to influence builders to construct for the developmentally disabled	*					*	
Review deficiencies of present building products regarding use by the developmentally disabled; promote development of products for all		*			*		
Explore and identify mechaniems for information exchenge programs		*	*	*		*	*
Review problems of developmentally disabled with installation and materials		*		*	*		
Explore problems with fire and other risks		*	*				*

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