

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700 800/521-0600

PREVIEW

SELF-ADVOCACY SKILLS TRAINING FOR
ADOLESCENTS WITH PHYSICAL DISABILITIES

by

Shelly B. Levy

A Doctoral Project Submitted in Partial fulfillment of the
Requirements for the Degree of Doctor of Psychology in the
Department of Psychology at Pace University

NEW YORK

1996

UMI Number: 9626327

UMI Microform 9626327
Copyright 1996, by UMI Company. All rights reserved.

**This microform edition is protected against unauthorized
copying under Title 17, United States Code.**

UMI
300 North Zeeb Road
Ann Arbor, MI 48103

(Please type all information)

NAME: Shelly B. Levy

TITLE OF PROJECT: Self-advocacy Skills Training for
Adolescents with Physical Disabilities

DOCTORAL PROJECT COMMITTEE:

PROJECT ADVISOR: Dr. Arthur Ellen
(Name)
(Title) (Affiliation)

PROJECT CONSULTANT: Dr. Barbara Mowder
(Name)
Director-Graduate Psychology Program
(Title) (Affiliation)
Pace University

FINAL APPROVAL OF COMPLETED PROJECT:

I have read the final version of the doctoral project and certify that it meets the relevant requirements for the Psy.D. degree in School-Community Psychology.

Arthur Ellen
(Project Advisor's Signature)

5/23/96
(Date)

Barbara A. Mowder
(Project Consultant's Signature)

5-23-96
(Date)

TABLE OF CONTENTS

Chapter	Page
List of Tables.....	v
Abstract.....	vi
I. Introduction.....	1
II. Literature Review.....	7
Disability Models	
Contemporary History of Disability in the United States	
Adolescent Development	
Cognitive-Behavioral Psychology: Theory and Application	
Self-Efficacy	
Social Skills and Assertiveness Training	
Social Support and Self-help Groups	
III. Method.....	47
Subjects	
Setting	
Site Negotiation and Analysis	
Entry Issues	
Procedure	
Materials	

	Data Collection	
	Data Analysis	
IV.	Findings of the Project.....	78
	Log	
	Rating Scales	
	Interviews	
	Integration of Findings	
V.	Discussion.....	105
	References.....	124
	Appendices.....	134
	A. Proposed Self-Advocacy Group Training Outline	
	B. Participant Rating Scale	
	C. Project HAPPY Log Notes Summary	
	D. Interviews	
	E. Entry Log Summaries	
	F. Handout: Watch Your Language	

List of Tables

Page

Table 1.	Participant ratings: I was Satisfied with this Group Session.....	96
Table 2.	I Learned More about Self-Advocacy.....	97
Table 3.	I Feel Stronger as a Self-Advocate.....	98

PREVIEW

ABSTRACT

Theoretical and research models of disability traditionally focus on effects on personality development and interpersonal disturbances. An alternative model analyzes the social and political implications of disability and recommends modification of the environment as the intervention of choice. Strengthening competence to effect environmental changes may be accomplished through self-advocacy. Self-advocacy is comprised of a set of skills as well as a knowledge base about civil rights legislation such as the Americans with Disabilities Act. As a formative evaluation this project investigated the process involved in providing a self-advocacy skills group to adolescents with physical disabilities.

The goals of this group were to increase knowledge of disability rights and legislation, to increase skills needed to secure these rights, and provide a means of social support. The group was conducted as part of a weekend recreation and socialization program for adolescents who have disabilities.

Data was collected through a log recording the

investigator's observations during weekly self-advocacy group meetings, participant rating scales, and semi-structured interviews. Qualitative evaluation was conducted to identify themes and categories which emerged from the data and were related to the research questions.

Participants' levels of satisfaction, and strengths and needs of the group in meeting its objectives were assessed. Data can be utilized to develop and evaluate future groups.

Concerns with attitudinal barriers and social accessibility emerged as salient issues for participants in this group. Social support appeared beneficial to group members. Inconsistent attendance limited the implementation of structured skills training. Entry problems and site negotiation were reviewed as part of this project. Implications for future self-advocacy training groups are discussed.

Self-advocacy Skills Training for
Adolescents with Physical Disabilities

CHAPTER 1: INTRODUCTION

Psychology has a long history relative to children with disabilities. From Binet's work in assessment to the integral role of the school psychologist in the implementation of the Individuals with Disabilities Education Act (IDEA), psychologists have contributed to the understanding and improved functioning of people with disabilities. Traditionally psychologists focus on the interaction between the individual and the disabling condition. This approach takes as its premise the distressing nature of the disability itself as well as its impact on social relationships. An alternative approach is intervention at the community level.

The Americans with Disabilities Act (ADA), PL 101-336, was passed on July 26, 1990. This act is considered to have considerable significance for the disability community. The ADA provides civil rights legislation for individuals who have physical or cognitive disabilities or chronic medical conditions. Discrimination is prohibited and access mandated in education, employment, transportation, communications,

and public accommodations (Equal Employment Opportunity Commission & United States Department of Justice, 1991). The ADA is the most comprehensive legislation to date because the mandate extends to all programs and most facilities, not just those which are federally funded. In order to enhance the effectiveness of this legislation, the participation of people with disabilities is indicated. Self-advocacy is one such means of participation.

Self-advocacy is defined, for purposes of this project, as individuals identifying their needs, and using information about their legal rights as a person with a disability to secure equal opportunities or services. The legal rights relevant to project participants are disability related civil right laws, particularly the ADA. Development of a behavioral repertoire, including assertive statements, seeking clarification and verification, eye contact and voice modulation, is essential to effective self-advocacy (Sievert, Cuvo, & Davis, 1988).

Self-advocates must assertively express needs and legal rights, negotiate with others, and clearly communicate with school and other service providers, members of the community including those who work in stores and recreational facilities, and government offices. Self-advocates also need to be knowledgeable about their rights and appropriate

legislation (Sievert et al., 1988). Self-advocacy is comprised of both a set of skills and a knowledge base. Often organizations make advocacy a priority and establish consumer groups which try to function without the benefit of adequate training. Self-advocacy appears likely to be effective when a set of skills is identified and mastered. In addition to skills, advocacy training for those with disabilities includes information and awareness of anti-discrimination bills such as the ADA as well as the process to resolve grievances.

Parents are usually their children's advocates as they help them negotiate school and neighborhood. Just as adolescents developmentally begin to separate from parents and test identity by assuming greater responsibility (Petersen, Kennedy & Sullivan, 1991), so the adolescent with physical disabilities may begin to self advocate. As parents of disabled children learned over time, working together in groups provides both social support and a stronger impact for change (Wolfensberger, 1972). Parent advocacy has been significant on behalf of children with mental retardation and developmental disabilities.

Prominent organizations such as the Association for the Help of Retarded Children and the Association for Retarded Citizens grew out of parental advocacy (Shapiro, 1993).

These organizations, and others which serve individuals with developmental disabilities, are actively involved in implementing consumer self-advocacy groups.

Fewer groups are available for people with physical disabilities, particularly for adolescents with physical disabilities. Adolescents might begin working together in their own groups as they move toward autonomy. Adolescents may be considered an important target group because they are transitioning to the adult world. Job prospects, further education, use of community resources, and social issues need to be addressed. By providing adolescents with a set of enabling skills while they are still at the high school level, they may be better equipped to function independently in a variety of environments.

Physical disabilities can be either congenital or acquired. Congenital disabilities are evidenced at birth and include muscular dystrophy, spina bifida, and cerebral palsy. Acquired disabilities such as paraplegia or amputations result from accidents or trauma such as automobile accidents, gunshot wounds, and illness. These are also referred to as orthopedic disabilities. Sensory disabilities such as hearing or visual impairments may also be included as physical disabilities (Brown & Robertson, 1992). Approximately 43 million Americans have one or more

disabilities (Equal Employment Opportunity Commission and United States Department of Justice, 1991). According to a 1980 estimate up to 10% of school-aged children in the United States have a physical, cognitive, developmental, or emotional disability. Prior to the Education for all Handicapped Children Act, PL 94-142, only 25% of children with disabilities attended public schools although this figure represents an increase over the estimated 12% of children with disabilities attending school in 1948 and 21% in 1963 (Bowe, 1980).

Psychologists may assist adolescents with physical disabilities in managing their lives more efficaciously through self-advocacy skills training. Psychologists have a unique combination of professional training and experience in assertiveness and social skills programs, group process and dynamics, conflict management, and consultation required for the development of effective advocacy training (Goldstein, Sprafkin, Gershaw, & Klein, 1988). Community and school psychologists also have a knowledge of community resources. Finally, psychologists' understanding of developmental issues can be beneficial in working with an adolescent target group.

This project investigated the effectiveness of providing group self-advocacy training to adolescents with

physical disabilities. The goals of this self-advocacy group were to increase knowledge of disability civil rights and legislation, to increase skills needed to secure these rights, and provide a means of social support. This group utilized a cognitive-behavioral format by including a psychoeducational and a social skills training component. The psychoeducational, didactic aspect provides information about disability civil rights and instruction in self-advocacy. Social skills (see e.g., Goldstein et al., 1988) including communication, eye contact and voice modulation, requesting behaviors, initiation, use of feedback, and problem solving were targeted. Social support was provided by offering a group format wherein participants gave and received help.

This project assesses the development of one self-advocacy group for adolescents. Evaluation involved ongoing assessment of the group's strengths through participant satisfaction, aspects of the group participants would like to change, and the effects of social support provided through the group experience. A log, participant rating scales, and semi-structured interviews were utilized as assessment devices.

CHAPTER 2: LITERATURE REVIEW

Self-advocacy training for adolescents with physical disabilities may be thought of as social skills training. As such, this training is a cognitive-behavioral intervention which has as its goals modifying feelings and behaviors by changing thoughts (Hunt, 1993). The objective of this self-advocacy skills training is to increase opportunities for social, community, and program access. of responses.

Cognitive components of self-advocacy training include providing exposure to positive role models and information which promotes a change in attitudes about disability. Participants are assisted in modifying their self-perceptions to increase their sense of autonomy. Discussing legislation, for example, may encourage participants to think about themselves as active members of society who are entitled to inclusion instead of passive service recipients.

Changing participants' behavior may be achieved through psychoeducational instruction, modelling, and behavioral rehearsal (Alberti & Emmons, 1974). Participants' repertoire of responses may also be modified. Identifying

and practicing a goal behavior may be a part of a self-advocacy training program.

Prior to reviewing the relevant literature, key terms are defined. Adolescence, for the purpose of this project, is defined as ages 13 through 21 years old. A physical disability, whether congenital or acquired, is a physiological condition or anatomical disorder which significantly limits at least one major activity of life such as walking, talking, breathing, or caring for oneself (Equal Opportunity Employment Commission & U.S. Department of Justice, 1991). Self-advocacy is defined as using information about one's legal rights as a person with a disability to secure equal opportunities and services. Effective self-advocacy involves the process by which individuals identify their own needs, make those needs known to others, and pursue desired outcomes (Research and Training Center on Community Living Institute on Community Integration, 1990).

Self-advocacy may involve assertive communication with service providers, letter writing, lobbying, and working either in groups with others who share common goals and concerns or by oneself (Suarez de Balcazar, Seekins, Paine, Fawcett, & Matthews, 1989). Self-advocacy may be viewed as differing from assertiveness in that it takes place

specifically within a social-political context (Humes, Szmanski, & Hohenshil, 1989). Assertive behaviors involve expressing feelings or needs to obtain a goal (Alberti & Emmons, 1974). Assertive behaviors may be demonstrated in interpersonal situations or when obtaining goods or professional services. Self-advocacy goals involve obtaining legal or civil rights, and are thereby more political in nature than assertive behaviors. Self-advocacy, for instance, might specifically focus on gaining entrance to a public building which is not wheelchair accessible.

Social skills are those behaviors which are appropriate for obtaining outcomes such as peer acceptance and social reinforcement from significant others. These skills are necessary for interaction with others and include starting and maintaining conversations, providing compliments, and accepting critical feedback. Social skills training may either increase acquisition of skills by remediating their deficit, or increase performance of behaviors for those who already possess the requisite skills (Gresham & Nagle, 1980). Skills training in initiating conversation or requesting help for individuals who do not possess these abilities is an example of acquisition. Rehearsing the appropriate ways to provide and seek feedback, with individuals who have but

do not demonstrate these capacities, is a means of remediating a performance deficit.

The literature relevant to this study includes a variety of topics ranging from human development to the influence of social factors on the cultural meaning ascribed to disability. This chapter reviews literature pertinent models of disability, history of the treatment of people with disabilities in America, adolescent development, cognitive behavioral psychology, self-efficacy, social skills and assertiveness training, and social support/self-help groups. An overview of these areas provides the context within which this project was developed, and an explanation of the psychological constructs used to design the self-advocacy group intervention.

Disability Models

The medical and sociopolitical models present contrasting theoretical orientations to disabilities. The former focuses on biological impairment, while the latter emphasizes the analysis of disability as a minority or outgroup status. Traditionally, theories of disability have focused on the effects on personality development and interpersonal disturbances (Fine & Asch, 1988; Humes et al., 1989). Researchers examined personality factors associated with different disabling conditions, rates of

psychopathology, and difficulties in interpersonal relationships. This approach may be termed the medical model. In the medical model the disability itself is identified as the primary problem, and distress is in response to a physiological event. Psychological treatment within the medical model is directed toward rehabilitation and helping the individual adjust to the disability (Day, 1992). However, a disability is likely to be a chronic condition as opposed to an illness from which a person recovers, and what has been termed the sick role is thus complicated. A person who becomes ill may be unable to work and is then assigned the job of recovering from the illness. A person who cannot recover from a physical disability may be seen as not fulfilling the obligations of the sick role and is then assigned a position of social and political powerlessness (Gliedman, 1979).

In contrast, the sociopolitical model (Humes et al., 1989) maintains that individual and environmental factors should be considered as they interact, and suggests that it is society rather than the individual with the disability which should be the focus of analysis. The sociopolitical model asserts that by modifying the environment the effects of disabilities can be reduced or managed more efficaciously. Modifications may involve removing physical

barriers as well as changing perceptions of and attitudes towards people with disabilities. Such modifications may increase the educational and professional opportunities which previously have been denied to people with disabilities. Research and treatment models which focus on the disabling environment (Fine & Asch, 1988; Shapiro, 1993) recognize people who have disabilities as competent despite their physical status. Intervention in the context of the sociopolitical model emphasizes increasing efficacy and mastery of skills such as use of community resources, independent living, and making choices about education and work options.

Attitudes towards disability are developed within a social context in which disability is viewed as stigmatizing and individuals who have disabilities are devalued. Goffman (1963) examined this development of attitudes towards disability. He described the process by which the identities of individuals with disabilities are altered by the social aspects of the disability. These individuals become "reduced in our minds from a whole and usual person to a tainted, disoriented one. Such an attribute is a stigma. Sometimes it is also called a handicap" (Goffman, 1963, p.3). Further, an individual who is in any way different from the norm may be considered marked; the mark

does not have to be visible. Typically, others respond to the marked person by imposing attributes such as incompetence or moral and character flaws. These assumed attributes have the effect of discrediting the person (Jones et al, 1984). The marked or stigmatized person comes to be avoided by others and in extreme situations is excluded from participation in academic, vocational, and/or social settings. The reasons for exclusion may be attributed to the feelings of discomfort, anxiety, and guilt experienced by people who are not disabled. A person with a disability may represent human vulnerability and frailty which is distressing to confront, or challenge beliefs in the just, ordered nature of the world.

The Equal Employment Opportunity Commission (EEOC) and the United States Department of Justice reflected an awareness of the cultural aspects of having a disability in drafting the ADA. They recognized that people with disabilities have been intentionally excluded, both by architectural and attitudinal barriers, from full participation in American society. People with disabilities have had a history of unequal treatment, segregation, and lack of political power, and are therefore similar to other minority or disadvantaged groups (EEOC & U.S. Department of Justice, 1991). The ADA, because it is civil rights

legislation, examines disability as a social phenomenon recognizing a need for legislative intervention, and this is consistent with the sociopolitical model.

Barriers are presented as societal, architectural, and communication based. Societal barriers include stereotypes and attitudes rooted in lack of awareness and misunderstanding which can become translated into institutional or community policies limiting the inclusion or full participation of people who have disabilities. Architectural barriers prevent use of the physical environment, such as steps, narrow doorways, sinks or telephones which are mounted too high to be reached, and buses which cannot accommodate wheelchairs. Communication barriers occur when information is presented in only one medium, visual or auditory, which excludes those with sensory, and sometimes cognitive impairments (Bowe, 1980). These obstacles present real limitations beyond wheelchairs, walkers, spasticity, or blindness to people with disabilities.

As a profession, psychology also modified its attitudes. The American Psychological Association's (APA) Task Force on Psychology and the Handicapped, in its Final Report (1984), recommended research on improving accessibility, removal of educational barriers, development