The Disability Rights Movement: From client to consumer

In this edition of reSearch, we explore the topic of the disability rights movement. It will be part one of a two-part series on attitudinal changes in disability and rehabilitation over time. The research began with an interest in how practitioners approached rehabilitation over the years from a traditional model to a more community/consumer-based model of services; and what social constructs led to those changes. This led us to research various disability laws; the transition in rehabilitation paradigms; the de-institutionalization, de-medicalization and disability rights movements; and the shift community-based services. The result was an astounding number of abstracts. A search for “civil rights” and “disability” in the ERIC database resulted in over 400 abstracts! We narrowed the scope considerably, dividing the project into three issues and devoting the first part to the disability rights movement. The research citations presented here are by no means comprehensive. They are meant to provide a “snapshot” of the disability rights movement over time.

The main search terms were disability rights movement, disability activism, self-advocacy, social justice, civil rights and disability, consumer advocacy, self-determination, and disability rights. The combined total of the NARIC, ERIC, and PubMed descriptors was over 70 terms. A sample of these terms can be found on the back page of this document.

The REHABDATA search resulted in 57 documents ranging from 2006-1981. PubMed’s database search resulted in nine documents ranging from 2005-1993. By focusing our search terms for ERIC, we identified six documents ranging from 2001-1988. The complete citations are included at the end of this research brief.

In addition to document searches, NARIC searched its Program Database of the National Institute on Disability and Rehabilitation Research (NIDRR) projects to locate grantees/projects related to the topic of the disability rights movement and disability rights. NIDRR-funded projects and their publications are offered as additional resources for our patrons.

NIDRR has a history of funding projects that focus on advocacy, independent living, self-determination, participation, and civil rights. In the last ten years, NIDRR has funded projects to increase voter participation, facilitate self-advocacy and self-determination, and promote home ownership and full community participation. Several fellowships have sought to gather the historical accounts of the disability rights movement and bring its participants into the well-deserved spotlight. Following is a sample of previously funded projects whose work can be found in the NARIC collection:

- **NIDRR Research in the Disability Rights Movement**
  - **Disability Activism in Post-Communist Europe: Implications for American Disability NGOs.** Daniel Holland, PhD, MPH, University of Arkansas, Little Rock.
    - Project Number: H133F050023
    - Project completed in 2006.
  - **Disability Rights and the Independent Living Movement: The Formative Years Nationwide.** Charles B. Faulhaber, PhD, University of California/Berkeley.
    - Project Number: H133G000083
    - Project completed in 2004.
  - **The Empowerment Project: Promoting Equality for People with Disabilities Through Electoral Participation.** Kay Schriner, PhD, University of Arkansas/Fayetteville.
    - Project Number: H133G990188
    - Project completed in 2002.
  - **A Life Course Approach to Peerage and Leadership in the Disability Rights Movement.** Devva Kasnitz, PhD, World Institute on Disability.
    - Project Number: H133F000044
    - Project completed in 2001.
  - **The Disabled Persons’ Independence Movement: The Formative Years in Berkeley California.** Charles B. Faulhaber, PhD, University of California/Berkeley.
    - Project Number: H133G60193
    - Project completed in 2000.
  - **Disability Rights Leadership Archive.** Paula Johnson, University of San Francisco.
    - Project Number: H133G60192
    - Project completed in 2000.
  - **“The Godfather of the Modern Disability Rights Movement”: The Life and Times of Ed Roberts.** Steven E. Brown, PhD, Institute on Disability Culture.
    - Project Number: H133F6001
    - Project completed in 1997.
The NIDRR Program Database includes more than 1,600 projects funded from 1988 to the present. The research covers a wide spectrum of disability and rehabilitation issues, from medical rehabilitation to ethnographic study. We encourage you to explore NIDRR’s rich history through this database, available at www.naric.com/research.

Documents from NARIC’s REHABDATA search listed are listed below:

2006

NARIC Accession Number: J50746
ABSTRACT: Histories of the disability movement contain many references to different aspects of physical and social access. Communication access, however, is often overlooked. The author demonstrates how histories currently written are biased against communication access and considers why this is so. She concludes by describing what a new disability history would look like if communication access were given a more prominent role.

2005

NARIC Accession Number: J49891
ABSTRACT: Article examines the legal authority granted to guardians in making life and death healthcare decisions for people with disabilities. Several examples illustrate how the court has ruled regarding a guardian’s right to withhold life-sustaining treatment from a person deemed to be incompetent.

NARIC Accession Number: J49388
ABSTRACT: Author examines the questions of equality and social justice for people with disabilities in sports and other civil societal practices that involve the pursuit of excellence. He argues that such practices come within the purview of justice depending on the interplay between political activism, institutionalized anti-discrimination statutes such as the Americans with Disabilities Act (ADA), and the internal norms of a practice. His argument for a right to a pursuit of excellence requires that the ADA be understood as an anti-caste principle, which demonstrates how even voluntary, ostensibly apolitical social practices can stigmatize people with disabilities.

2004

NARIC Accession Number: J47691
ABSTRACT: Article analyzes the 1999 strike of people with disabilities in Israel in the context of the emergence of the disability rights movement in the United States and in Israel. Descriptive data collected from Israeli daily newspapers are presented to summarize the press coverage on participants, demands, and political response.

ABSTRACT: Book examines the self-advocacy movement from the perspective of self-advocates and people with intellectual and other types of developmental disabilities. The self-advocacy movement is a recognized movement that has grown out of and learned from the civil rights movement in the U.S. and the women’s equal rights movement internationally. Self-advocacy means people with intellectual disabilities speak or act on behalf of themselves or others concerning issues that affect them directly.

2003

NARIC Accession Number: J47467
ABSTRACT: Article focuses on views of disability from the perspectives of people with disabilities and people who are non-disabled. The literature suggests that people with disabilities do not always want to be associated with other disability groups for a variety of reasons, including: (1) competing for scarce allocations of funding/resources, (2) sexual attraction, and (3) stigma. The author finds that future research is required to explore people with disabilities’ attitudes toward other people with disabilities, and that this research could help to expand the knowledge base on the degree to which people with disabilities view themselves. These findings could help the disability movement to achieve a greater sense of overall inclusion.
NARIC Accession Number: J46621  
**ABSTRACT:** Article presents a personal analysis based on the author’s experience as a disability rights activist and as a member of the World Council of Disabled People’s International. He discusses the attitudes of groups of people with disabilities before the formulation of the International Classification of Impairment, Disability and Handicap (ICIDH) in 1980, the growth of the international disability rights movement since 1980, its subsequent involvement in the revision process, and it hopes to the effectiveness of the revised ICIDH, the International Classification of Functioning, Disability and Health (ICF) in the future.

NARIC Accession Number: J45624  
**ABSTRACT:** Article reports the findings of interviews conducted with eight highly accomplished individuals with disabilities regarding historical developments and future issues affecting the disability rights movement. Excerpts from the interviews with these disability rights advocates reveal their: (1) greatest source of pride, (2) personal connections to the disability rights movement, (3) perceptions of the most cherished achievement of the disability community, and (4) predictions of what will be the most pressing disability issue in the year 2020.

NARIC Accession Number: R08372  
**ABSTRACT:** Presents an overview of the disability rights movement by focusing on changes to the social meanings of disability and the social interactions of people with and without disabilities. The first chapter looks at the concept of disability has moved from medical definitions of impairments in the body and brain to attitudinal and behavioral practices of society that limit functional activities of humans. The second chapter focuses on issues related to the historical development of the disability rights movement. The author next compares the disability minority group to the historical racial and ethnic minorities and discusses how they are viewed and treated in society. The book also documents the 3 major waves of deinstitutionalization involving persons with mental illness, mental retardation, and physical disabilities. The final chapter discusses the still growing wave of self-determination.

NARIC Accession Number: J46672  
**ABSTRACT:** Paper presents a sociological overview of the development of the disability rights movement in the United States. The disability rights movement arose to empower with disabilities to take control of their own lives and to influence social policies and practices to promote full integration of people with disabilities into mainstream society. The movement developed in three phases: (1) definition of the problem, (2) proposed solutions, and (3) response to the aftermath of new policies and practices.

NARIC Accession Number: J45427  
**ABSTRACT:** Article discusses the lack of a disability rights approach in the development of bioethics theories. Bioethics theories are supposed to develop ethical principles to govern science, technology, and biomedical research. The disability rights approach does not view disability simply as a medical problem in need of a medical solution, but primarily as a social justice issue looking for societal solutions. Author describes the debate on bioethics issues as it relates to disabilities, using the debate over sex selection and disability de-selection as an example.

2002

NARIC Accession Number: J45424  
**ABSTRACT:** Author applies the methods used in the women’s rights movement to develop a model for the future growth of the self-determination and disability rights movements. The direct involvement of people with disabilities is emphasized with specific methods and recommendations in four areas: academic/theoretical, leadership, political, and economic.

2001

Herr, Stanley, S. (2001). **Rights, values and social change: Towards equality for people with disabilities in Israel and the world.**  
NARIC Accession Number: O14298  
**ABSTRACT:** Monograph compiles articles reflecting the need for greater equality and social justice for people with disabilities in Israel and around the world.
2000

NARIC Accession Number: J40293
ABSTRACT: Article discussing issues related to multiple minority status, starting from the author’s personal status and her story as an Italo-Anglophone in Quebec, a woman in a male-dominated world, and a woman with multiple impairments. The author concludes that examining exclusionary practices within the disability movement may help create the multiple collective consciousness we need in order to take on the challenges of oppression that will be imposed by globalization.

NARIC Accession Number: O13782
ABSTRACT: Paper presenting an “event history” model of the process by which individuals have become leaders in the independent living (IL) and disability rights movement. The model focused on the various ways in which knowledge of, contact with, and identification with others with disabilities have an impact on the development of leadership. Findings are summarized based on informant interviews, pilot case studies, and intensive life history interviews.

NARIC Accession Number: J40941
ABSTRACT: Article on issues related to sexuality and reproduction of people with disabilities, including the marriage penalty for Social Security benefits, retention of child custody, inadequate sex education, and lack of privacy and sexual freedom for individuals living in institutions.

NARIC Accession Number: O13784
ABSTRACT: Paper presenting a life course event history approach used by the author and colleagues in a study of how knowledge of, contact with, and identification with other people with disabilities affects the advocacy careers of leaders in the independent living movement. Findings from the study are also summarized.

NARIC Accession Number: J40090
ABSTRACT: Historical case study of the League of the Physically Handicapped, a disability rights activist group in New York City in the 1930’s, which sought the inclusion of people with disabilities in work relief programs such as the Works Progress Administration and New York City’s Emergency Relief Bureau. The tactics of the League, its views on disability policy and disability identity, and its relationships to other political groups and disability groups are discussed, along with implications of this history for current debates. The article is accompanied by comments from 11 authors.

NARIC Accession Number: J41266
ABSTRACT: Article arguing for the abolition of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The author argues that the ICIDH medicalizes disability, rejects the social model of disability, blames the victim, assumes normal is good, and uses pejorative handicapper language, and it is therefore a threat to the worldwide community of persons with disabilities. The author also examines the persistence of the ICIDH despite the objections of persons with disabilities, and concludes that barring a philosophical revolution (which will take time) people with disabilities must take to the streets.

NARIC Accession Number: J40940
ABSTRACT: Article on issues of sexuality and its place in disability studies. The author supports a social constructivist model of sexuality, but with reservations. He questions whether people with disabilities should want to be normal and whether more sex is the right goal. He concludes with some suggestions about connecting sexuality to the agenda of the disability movement.
NARIC Accession Number: O13157

NARIC Accession Number: J38577
ABSTRACT: Article arguing for a number of points regarding disability politics and its relations to disability studies and the politics of other oppressed groups. The author argues (1) that the identities of persons with disabilities are fluid and complex; (2) that academic disability theory is a threat to disability politics because it can rob it of its experiential, subjective, and emotive knowledge; (3) that an individual who is oppressed through one identity may be an oppressor through another; and (4) that non-disabled people cannot be included in the disability movement without denying disabled people their own politics.

NARIC Accession Number: O13026
ABSTRACT: Paper presents an executive summary of the results of discussions among 25 focus groups on the concerns of people of color with disabilities given their over-representation in the educational and criminal justice systems and their under-representation within health care and social service delivery systems. Focus groups were held in Nebraska, Kansas, Missouri, Illinois, and Minnesota over a two-year period. Members included community leaders, health and services industry representatives, individuals with disabilities and their culturally and ethnically diverse families. Each focus group addressed four questions: (1) What are the economic/socio-political environments for people of color in your community? (2) What must happen to improve the economic and socio-political environments within the community? (3) How are people of color with disabilities affected by economic and socio-political situations within your community? (4) How can people of color with disabilities be better served or included in the programs you are conducting? Members of each focus group are listed and individual statements and contributions are presented and attributed by group and location.

NARIC Accession Number: R07945
ABSTRACT: Booklet on the history, present, and future of disability rights law. Topics include: historical overview from the 1960’s to the 1990’s; current issues related to the Americans with Disabilities Act (ADA) and criminal justice; and challenges facing the disability rights movement in the 21st century related to employment, health, housing and community support, treatment and rehabilitation, education, and criminal justice. This publication is based on the proceedings of a June 1998 conference on disability law and policy.

NARIC Accession Number: O13118

1997

NARIC Accession Number: O12939
ABSTRACT: Collection of training materials for state-wide independent living council (SILC) staff participat-
ing in a training program run by the IL NETWORK National Training and Technical Assistance project, which promotes a national independent living (IL) network through training and technical assistance activities. Materials cover the following topics: the history and philosophy of the independent living movement and the disability rights movement; the Rehabilitation Act; and SILC appointments, composition, roles, and funding.

Brown, Steven E. (1997). *A report on the fellowship year of the godfather of the modern disability rights movement: The life and times of Ed Roberts: And why this report is more about me than Ed.*

NARIC Accession Number: O12502

ABSTRACT: Set of essays about disability culture, language and identity, and the history and future of the independent living movement. The author explains the absence of Ed Roberts’ name in the essays by saying that “his spirit is present. Ed believed in power, creativity, and pushing the envelope. ... The ideas in each will contribute to the kind of book about Ed that I wish to write.”.

Hershey, Laura. (1997). *Judith Heumann: Making the system work.* New Mobility, 8(42), 38-55.

NARIC Accession Number: J33190

ABSTRACT: Article profiling Judith Heumann, director of the Office of Special Education and Rehabilitation Services (OSERS) in the U.S. Department of Education. Discusses the director’s career as a disability advocate, and current issues faced by her as OSERS director. Topics include: the reauthorization of the Individuals with Disabilities Education Act (IDEA), and disagreements over school discipline policy that accompanied the debate over IDEA reauthorization; the need for reform in the vocational rehabilitation system, and why it is not a high priority of the disability rights movement; and the director’s international activities, including her experiences as a delegate to the United Nations Fourth World Conference on Women in Beijing in 1996, and her observations from a personal trip to Mexico. Also presents her view of Washington, DC, as a city in which to live.


NARIC Accession Number: J33237

ABSTRACT: Article summarizing the findings of a qualitative study of the views and experiences of adults in the United Kingdom with acquired physical impairments, and in particular, their views and experiences with regard to the National Health Service and other social services. The results of the study are related to the health and social policy context of recent years in the UK, which has been characterized by consumerism and by intensified activities of the disability movement.


NARIC Accession Number: R07756

ABSTRACT: Handbook on the disability rights movement. Contains alphabetically-arranged entries on individuals, organizations, concepts, laws, court cases, historical events, books, periodicals, movies, and other topics related to the disability rights movement. Also includes a chronology and a bibliography.

**1996**


NARIC Accession Number: R07019

ABSTRACT: Book about the barriers people with disabilities have faced and continue to face in their quest to obtain the freedoms enjoyed by the mainstream of American society. Eight chapters address the following topics: (1) the historical basis of bias toward persons with disabilities and the ways in which they have been disenfranchised; (2) the organization, goals, and strategies of the disability rights movement; (3) major legislative actions that have had an impact on the lives of persons with disabilities; (4) factors that have shaped society’s attitudes toward persons with disabilities and the attitudes persons with disabilities have of themselves; (5) self-concept and self-esteem and the influence of body image on their development; (6) families’ reactions to a relative with a disability and the impact of those reactions on the person with a disability; (7) strategies for developing an effective relationship with professionals and for dealing with negative attitudes held by society; and, (8) the steps that need to be taken before people with disabilities can be truly free.


NARIC Accession Number: R07248

ABSTRACT: Book on the history of the disability rights movement. Written for young readers, the book traces the development of this movement to fight discrimination and secure civil rights for people with disabilities. Individuals who played key roles in this effort are highlighted.


NARIC Accession Number: O11875

ABSTRACT: Quarterly publication on a variety of disability related topics. This issue includes a memorial ad-
dress for the founding editor of the publication, eight articles on general disability issues, book reviews, news about upcoming and recent events, resource descriptions, and other announcements and bulletins. The eight articles address the following topics: 1) services and supports in a human rights framework; 2) proposed cutbacks in early intervention programs; 3) revision of the World Health Organization’s International Classification of Impairments, Disabilities, and Handicaps; 4) the World Bank methodology for allocation of health care and development funds; 5) one man’s personal experience with prostate cancer; 6) the role of the public program evaluator; 7) leadership in the disability rights movement; and 8) critical review of ADA implementation studies which use empirical data.

1995


ABSTRACT: Reviews and discusses the implications of the history of the disability rights movement and disability legislation as expressed in the Individuals with Disabilities Education Act (IDEA).

1994


ABSTRACT: Paper examines the process of leadership and peer support as linked to the effectiveness of the independent living movement. The movement’s origins are described through the activities of persons with disabilities in their fight for self determination. This process is explored through the leaders beginning of personal empowerment gained from self advocacy that led to leadership roles. Individuals were analyzed by a data model that identified predisposition to leadership, onset of disability, self-identity changes, and discrimination experiences. This interview analysis suggests policy development strategies particularly in disability rights. Leaders are identified as those that have a disability identification and visibility. Leaders will develop a broad and deep peer contact. Education was an uncertain element as the first disability leaders were already established in mid life. Peer contact, education, and training opportunities are encouraged for new leadership development.


ABSTRACT: Personal account of the author’s acceptance of her psychiatric impairment and decision to assume the label “disabled.” She describes her initial discomfort with the new identification, how she learned that the Americans with Disabilities Act (ADA) applied to persons with psychiatric disabilities, and how she felt about using the label disabled when her disability was largely invisible. She relates how, despite five years of advocacy work in the mental health arena, she felt excluded from the broader disability knowledge base and the power of a unified cross-disability movement. She explains some of the protections afforded people with disabilities under the ADA, and suggests that there is much to gain from using the label disabled to take advantage of these protections and become an active member in the cross-disability community.


ABSTRACT: Discussion of issues associated with the disability movement. Acknowledging that differences in disabling conditions require varying individual accommodations, the one united goal of the disability is full access, self-empowerment, and self-sufficiency. Through examination of the Civil Rights Restoration Act, the Fair Housing Amendments Act of 1988, and the Americans with Disabilities Act, the complexity of the disability movement is recognized and illustrates the tenuousity and adaptability of the disability community. Implications of this legislation for policy planning and program development are discussed.


ABSTRACT: Discusses the impact associated with the small amount of media attention associated with the passage of the ADA. Disability movement lobbyists feared that media’s clichéd characterizations of persons with disabilities would prevent acceptance of disability rights. However, after ADA passage, lack of media attention has created the opposite—a group of Americans who don’t comprehend the importance of the ADA or the necessity of accessibility civil rights for persons with disabilities.

NARIC Accession Number: J28794

ABSTRACT: First in a series of four essays arguing for a new wave in the disability rights movement. To combat society’s first wave messages were that disability is a tragedy, that people with disabilities are unemployable, and that they do not represent an identifiable constituency, disability advocates developed a powerful set of second wave messages. These messages created the image that disability is desirable, that all people with disabilities are easily employable, and will remain happily employed at the same jobs forever, and that people with disabilities are a tightly knit minority group with similar views. Over time, these second wave messages are evolving into a third wave that reflects a more diverse array of knowledge and experiences. In this essay, the author examines both the risks and advantages of this evolution. Examples from the debates over health care reform and personal assistance policy are used to demonstrate that the third wave evolution is underway and to illustrate its advantages. Parallel evolutions within the black civil rights movement and the women’s movement also are discussed.

1993


NARIC Accession Number: R06468

ABSTRACT: Book on the history and legal framework of the Americans with Disabilities Act (ADA) and review of the major provision of the act as well as discussions of the related issues. The disability rights movement and political strategies are placed in perspective to the enactment of the ADA in part I of the book. The four Titles of the ADA are discussed in detail in Part II. Part III discusses the impact of the ADA on the mental health system, disabled persons, and the developmental disabilities movement and their future directions.


NARIC Accession Number: O11398

ABSTRACT: Monograph on traditional and changing views of disability in developing societies. The monograph contains three papers. The first paper explores the historical factors and socio-cultural variables influencing beliefs about disability in developing countries. The data sources included disability specialists and advocates in India, Indonesia, Kenya, Malaysia, Nepal, Nigeria, Pakistan, Thailand, and Zaire as well as official policy related documents issued by government agencies. The second paper examines attitudes toward disability in traditional African societies. The author compares the beliefs and behaviors of disparate ethnic groups including the Igede, Igbo, and Yoruba of Nigeria and the Ndembu of Namibia. The third paper discusses the disability rights movement in Zimbabwe and examines the economic, cultural, and political factors influencing this movement.


NARIC Accession Number: R06554

Abstract: Handbook offering how-to information about getting news coverage for disability rights issues. The book is organized into four sections. Section 1 discusses basic information about working with reporters, including making disability rights issues newsworthy, being available as a source, developing a media strategy, building relationships with news media, getting coverage for an event, and changing Hollywood images. Section 2 describes actual media campaigns on various disability rights issues and gives suggestions for developing successful media campaigns. Section 3 provides sample opinion page articles written by members of the disability rights movement which have been published in newspapers. Section 4 contains a list of resources. Additional information about media outlets, key personnel in news media organizations, and language guidelines, and a glossary are included in appendices.


NARIC Accession Number: J25679

ABSTRACT: Examines the ways in which people with disabilities have emerged as a coherent political force in the last 20 years and explores the implications of this development with respect to “new social movement” theory. The author focuses on the disability movement and direct action orientation in Great Britain and the United States, and develops comparisons both between the approaches and priorities in the two nations and between the disability movement and the movements of Blacks, women, and gays and lesbians for autonomy, recognition, and resources. He argues that new social movement theory, while useful in the analysis of environmentalism and post-
materialism, does not fully grasp the essence of liberation politics.

1992


NARIC Accession Number: J22243

ABSTRACT: Explores what independent living could mean for people with psychiatric disabilities. The first part of the article uses the story of a young man’s efforts to move from a chronic care apartment to his own apartment to explore what independent living means to a person with a disability. The second part considers three aspects of independent living in relation to their relevance for people with psychiatric disabilities: (1) independent living as a grassroots movement for social justice and civil rights that is made up of people with disabilities; (2) independent living as a “lived philosophy” that grew out of the experience of people learning to regain control over their lives; and (3) independent living as service delivery and advocacy centers that are consumer controlled.


NARIC Accession Number: O12994

ABSTRACT: Quarterly publication on disability-related topics, with articles, book and film/video reviews, and a variety of news items. The theme of this issue is the politics of disability. Articles include: “ADA, Disability Rights, and U.S. Foreign Policy” (R.A. Vachon); “Whose Life Is It?: The Issue of Control of Personal Assistance Services” (J.A. Racino and J. Heumann); “Psychiatric Survivors and Other Disabilities” (J. Chamberlain); and “Wake Up” (on parallels between the disability rights movement and Malcolm X, by C. Wieck and E. Roberts).


NARIC Accession Number: O11191

ABSTRACT: The paper presents a final report from a project that focused on (1) development of a conceptual framework to analyze the disability rights movement (DRM) as an American social movement, (2) document the origins of disability-specific and cross-disability organizations and make projections about their future, and (3) describe the innovative role of bi-partisan politics in shaping disability policy. There are five appendices: (1) introduction to the conceptual framework, (2) disability pride, (3) social movement theories, (4) roots in the English system of public welfare, and (5) the rise of national disability private voluntary organizations (PVOs) 1850-1935, focusing on first and second generation PVOs.

1989


NARIC Accession Number: J11882

ABSTRACT: Looks at progress achieved by disability movement of 1970s, noting role of disability advocates. Expresses concern that some people claiming to be advocates for the disabled do not actually represent these peoples’ interests, and true interests of disabled people may not be adequately communicated. Worries about proper roles of people participating in disability policy making process, noting problems posed by intermingling of roles of policy advocates, policy makers, and policy researchers. Discusses background and importance of disability movement and describes disability advocate. Looks at issue of representation. Questions whether or not researchers should act as advocates and should call themselves disability advocates. Concludes that terms like advocate, representative, and disability advocate mean different things to different people, and use of such terms in misconstrued fashion can result in failure to achieve important goals. People have different expectations of appropriate role of participants in policy making, and policy makers and advocates must have accurate information to make informed decisions (relying on researchers). If researchers actively lobby for disability policy, they may compromise the objectivity of their research.


NARIC Accession Number: J14572

ABSTRACT: Proposes a new approach to the politics of disability, arguing that the present approach with its narrow focus on pressure group and political party activity is inadequate for understanding either the historical significance or current relevance of the disability movement. In addition, it is unlikely to produce real gains in assuring the full integration of disabled people into society or in improving the quality of their lives. Suggests, instead, that the politics of disability can be properly understood only when the disability movement is centrally placed as part of the newly emergent social movements of all kinds. The discussion is organized into the following topics: the political participation of disabled people; the politics of pressure group activity; the campaign for a national disability income; the emergence of new social movements; the disability movement as a new social movement; new directions for the future; and, counter-hegemonic politics.
1988


ABSTRACT: The speaker addresses the issues of general social attitudes and our beliefs about people with mental retardation (MR), the concept of equal rights as a basis for care of people with MR, the relation of people with MR to the rest of the population, and the methods and reasons a good community looks after people with MR. The speaker makes a case for help and support to people with MR as a matter goodness, not as a legal right or justice. See related citation AN R05463.


ABSTRACT: Discusses the historical significance of the disability rights movement and civil rights legislation, and their challenges to the medical model that has dominated public disability policy. The “right to treatment” philosophy of the medical model has been rejected for the “right to belong,” and the status of patient has been rejected for the status of equal citizen. Self-determination has become the anthem of the movement, and traditional notions of disability and charity have been attacked. Two pieces of legislation have been particularly significant: Section 504 of the 1973 Rehabilitation Act, by adding disability to the general body of anti-discrimination law, and the Education for All Handicapped Children Act, by establishing the right of disabled children to a free education in the least restrictive environment. This paper examines the significance of these laws to the disability rights movement. It discusses issues related to their implementation, and reviews relevant case law illustrating the tension between the medical and civil rights models.

1984


ABSTRACT: Reports the results of a conference in East Lansing, Michigan, August 1982, assessing the state of the art of independent living for disabled persons. The conference also identified problematic areas and focused on issues, problems and solutions. Discusses the philosophy and design for independent living, including disabled people designing and running their own community based and community responsive programs which provide services and advocate change in the broader community. Discusses the development of the independent living and disability rights movement, operational issues in maintaining independence such as funding and leadership, and future options and strategies in achieving independence. Includes recommendations on support and technical assistance for operations and management, networking, leadership development and training of disabled people, research, policy development, and long-term planning with linkage with the disability rights movement.


ABSTRACT: Description of the development of the style of social policy litigation featuring greater client involvement. Presents the development of conditions in the larger political environment that have made social policy litigation feasible. Discusses the political context of the accessibility transit cases with a review of the development of the disability rights movement. Presents five transit case studies. Describes how this type of litigation protects disabled people, determinants to client participation and other factors related to the success of transit cases. Includes bibliography and index.
tion (UCIR), Michigan State University. The study was undertaken to examine the process of evolution within disability groups, and to identify practical knowledge useful in stimulating similar development in the United States. Reports on voluntary associations, governmental organizations, special purpose organizations, organizations of the disabled, and handicapped councils. Appendix lists organizations of and for disabled people in Sweden. Tapes of report available from the National Library Service.


NARIC Accession Number: O06989

ABSTRACT: Study of the independent living (IL) programs in the United States based on site visits and personal experience. Intended to focus on the problems and goals of the IL and disability rights movement and to suggest concept and activities directions for the 1980s and 1990s. Discusses the philosophical foundation of the movement, with definitions of IL; progress, reality and future prospects; focus and nature of responsibility including the responsibility for oneself; quality of life and the values of life; the IL program; and movement toward a more responsible and self-reliant movement. Contains 64 pages of text and 62 pages of related quotations.

1981


NARIC Accession Number: R03355

ABSTRACT: Describes support for persons with disabilities in Sweden. Provides background on the history of the country and of the disability movement. Outlines political goals for the independence of persons with disabilities. Addresses legislation; housing; and aspects of the physical environment including legislation, social services, institutional living, care, habilitation, rehabilitation and technical aids, communication, child care, education, culture, working life and social insurance. Provides additional sources for information.

Full-text copies of many of these documents may be available through NARIC’s document delivery service. To order any of the documents listed above, note the accession number and call an information specialist at 800/346-2742. There is a charge of cents for copying and shipping with a $5 minimum on all orders.

**Documents from the National Library of Medicine PubMed search at** [www.pubmed.com](http://www.pubmed.com) **are listed below:**

2005


PMID: 16354435

(No abstract available).

2003


PMID: 14629581

ABSTRACT: It has sometimes been assumed that religiously based explanations for and attitudes to having a disabled child have led to the low uptake of health and social services by ethnic minority families in the UK. A series of semi-structured interviews were held between 1999 and 2001 with 19 Pakistani and Bangladeshi families with a disabled child as part of an evaluation of an advocacy service. The families’ understandings of the causes of their child’s impairment, whether they felt shame and experienced stigma, and whether these factors influenced service uptake and their expectations of their child’s future are reported. While religious beliefs did inform the ways in which some families conceptualized their experience, the families’ attitudes were complex and varied. There was little evidence that religious beliefs and associated attitudes rather than institutional racism had resulted in the low levels of service provision which the families experienced prior to the advocacy service. There was also no evidence that the families’ attitudes had been informed by the disability movement. The implications for service providers and the movement are considered.


PMID: 12587137

ABSTRACT: Using prenatal tests to prevent the birth of babies with disabilities seems to be self-evidently good
to many people. Even if the testing will not help bring a healthy baby to term this time, it gives prospective parents a chance to try again to conceive. To others, however, prenatal testing looks rather different. If one thinks about the history of our society’s treatment of people with disabilities, it is not hard to see why people identified with the disability rights movement might regard such testing as dangerous. For the members of this movement, living with disabling traits need not be detrimental to an individual’s prospects of leading a worthwhile life, or to the families in which they grow up, or to society at large. Although the movement has no one position on prenatal diagnosis, many of its adherents believe that public support for prenatal diagnosis and abortion based on disability contravenes the movement’s basic philosophy and goals. Copyright 2003 Wiley-Liss, Inc.


2002


2001

ABSTRACT: Social workers, especially those in health care and rehabilitation systems, must consider practice changes necessitated by recent legislation and the growing activism of disability rights groups. The authors review essential elements of the emerging sense of both oppression and empowerment that is occurring for many people with disabilities and groups; consider key aspects of ADA and other pertinent legislation that place new emphases on the self-determination of people with disabilities; and discuss what implications changing practice roles might have for social workers’ relationships and patterns of interaction with other professionals in medical, health care and rehabilitation settings. The authors outline a beginning effort at designing a conceptual framework that promotes practice that: (1) maximizes clients’ involvement in exploring an expanded range of options and choices; (2) prepares clients to be more effective in dealings with professionals, bureaucrats and agencies that often do not understand nor appreciate their need for self-determination; and (3) at the organizing level, mobilizes and helps to empower groups of people with disabilities to consider policy and program alternatives that can improve their situation. This framework may also be useful in work with people who have other long term care needs, chronic conditions.

1996

ABSTRACT: From the earliest recorded history, people with disabilities have been ostracized, rejected, and discriminated against in society. Although social work has a history rich in advocacy for oppressed people, the profession has been hesitant to become involved with people with disabilities. This article addresses historical and contemporary issues concerning disability. Recent developments in the disability movement, including independent living, are discussed and compared to social work’s approaches to disability. Finally, a plea is made to the social work profession and the disability movement to combine efforts to enhance the lives of people with disabilities.

1995

ABSTRACT: PIP: Oxfam’s experience with groups of disabled people has revealed that gender affects how disabled people are treated in various cultures. This experience runs counter to the often voiced (even by a consultant hired by Oxfam) assumption that gender analysis serves only to confuse any analysis undertaken of disability-based circumstances. This assumption is echoed in the disability movement itself where activists fear fragmentation through the introduction of gender analysis. Thus, gender is not yet understood as a factor which af-
fects every aspect of life including race, class, ethnicity, caste, and disability. Because 75% of the 250 million disabled women in the world live in developing countries, development programs must consider the specific needs and rights of disabled women who suffer from double discrimination and are more likely than disabled men to live impoverished and isolated lives which lead to depression and despair. In many societies, disabled women, but not disabled men, lose their rights to marriage, family life, education, and health care. Mothers of disabled children are stigmatized, and fathers tend to “blame” defective genes on the mothers and to ignore their disabled offspring. These factors combine to make it difficult to improve the status and livelihoods of disabled women through development work. Disabled women activists have also voiced complaints about their lack of access to the preparatory meetings for the Fourth UN Women’s Conference, but disabled women intend to use the Conference to lobby for their rights and to call for scrutiny of health policies which discriminate against the disabled.

1993

PMID: 8109615
ABSTRACT: People continually redefine the meaning of disability for themselves through interaction and interpretation. Negative assumptions about disability result in low expectations for persons with disabilities and contribute to policies that keep them in isolation and out of the mainstream of life. Disability rights activists have begun to strip away some of the old stigmas and assumptions by redefining the meaning of disability to themselves and to others, and by organizing themselves into groups for purposes of discussion, education, and protest. Their efforts have resulted in improvements in attitudes about and opportunities for persons with disabilities. They need to remain vigilant to maintain the rights they have won, as well as to address new issues. Those who are interested in equal opportunities for persons with disabilities need to become advocates. Persons with disabilities learn to advocate for themselves through interaction with others who are committed to activist goals. They also learn through trial and error, gaining strength as they experience success, and they learn through formal advocacy training. Occupational therapists can actively contribute to the redefinition of disability through self-reflection and through advocacy training.

Documents from the Education Resource Information Center (ERIC) search at www.eric.ed.gov are listed below:

2001

ERIC #:EJ639208
ABSTRACT: This article discusses a court case of an adolescent labeled retarded who was sexually assaulted. It examines implications of being spoken about and of others speaking for the labeled person. It then considers how a disability rights/People First framework could shift public and professional understandings and responses to human abuse.

2000

ERIC #:EJ609724
ABSTRACT: This article identifies three “waves” of the disability movement (the professional, parent, and self-advocacy waves) and applies them to issues of control and choice in the lives of people with developmental disabilities. It identifies issues related to the self-advocacy movement such as group identity and the long-term role for people who are not disabled. A definition of “self-determination” is offered.

1999

ERIC #:EJ590896
ABSTRACT: Provides a historical link between the civil rights movement in the 1960s and the disability rights movement. The origins of the Civil Rights Act of 1964, the Americans with Disabilities Act, and the Rehabilitation Act of 1973 are discussed from the sociopolitical context at the time of their passage. Links are drawn between these laws, affirmative action, cultural diversity, and multiculturalism.
1995

ABSTRACT: This article recounts the words and deeds of Burton Blatt, a writer, educator, and expositor of abuses of human rights in institutions housing people with mental retardation. His life is seen as an inspiration for those now providing moral leadership in the continuing fight against indifference to human rights abuses and social darwinism.

1994

Robertson, Barbara, A. (1994). Disability culture, community, and pride. ERIC #:ED399733
ABSTRACT: This report discusses the societal oppression of people with disabilities and the growing awareness of a new group consciousness and an emerging disability culture. It examines social attitudes toward individuals with disabilities; the effects of using a medical model of disability, with its implications for the objectification and control of people with disabilities; the movement of people with disabilities toward a sociopolitical model as members of a distinct minority group; and the values of this emerging culture such as accepting a disability as a source of pride and viewing life with a disability as worth living and celebrating. The functions of a disability culture are presented, including: (1) providing symbols, rituals, and values that serve to strengthen personal and group identity; (2) uniting people with disabilities and experiences, facilitating group action; (3) empowering people with disabilities by providing a variety of ways to inform others about themselves; and (4) inspiring other people with disabilities to self-identify. The paper also discusses the need for greater societal access and for stronger implementation of the Americans with Disabilities Act.

1988

Abstract: Critiques the assumptions about the nature and meaning of disability advanced in social-psychological writing, suggests the origins of these assumptions, and proposes a return to a Lewinian/minority-group analysis of the situation of people with disabilities. Introduces the other articles in this issue.

ABSTRACT: Discusses both the barriers to the formation of a social movement of disabled people and the ways in which these barriers have been overcome. The role of public policy in the evolution of this movement is discussed, as are the current status and prospects of the disability rights movement.
### Search Terms for The Disability Rights Movement: From client to consumer

- Accessibility
- Activism
- ADA
- Adjustment
- Advocacy
- Agency Role
- Area Studies
- Attitudes toward persons with disabilities
- Capacity Building
- Case Studies
- Change Strategies
- Civil Rights/Liberies
- Classification Systems
- Client Satisfaction
- Community/Centers/Involvement/Living/Programs/Resources
- Community-Based Services
- Compliance (Legal)
- Consumers
- Court Cases
- Court Litigation
- Cultural Context
- Cultural Pluralism
- Daily Living
- Deinstitutionalization
- Delivery Systems
- Disabilities
- Disability Determination/Discrimination/Studies
- Empowerment
- Evaluation
- Focus Groups
- Health Promotion
- History
- Home Care
- Housing
- Inclusion
- Independent Living
- Individual Needs
- Institutionalization
- Interdisciplinary Approach
- International Rehabilitation
- Legislation
- Long-Term Care
- Mainstreaming
- Needs Assessment
- Normalization
- Outcomes
- Participatory Action Research
- Perceptions
- Physical Medicine
- Policy
- Political Attitudes
- Program Design/Development/Effectiveness/Evaluation/Models
- Quality of Life
- Reform
- Rehabilitation Centers/Facilities/Research/Methodology/Utilization
- Residential Living
- Resource Allocation
- Rural Services
- Section 504
- Self Concept/Determination/Evaluation
- Service Coordination/Delivery/Integration
- Social Action/Adjustment/Attitudes/Change/Discrimination/Influence/Integration/Services/Support
- Statistics
- Stereotypes
- Surveys
- Transitional Programs
- Vocational Rehabilitation

### Quick Looks

Google Search on the Disability Rights Movement resulted in over 1,000,000 results:
[http://tinyurl.com/34uuuj](http://tinyurl.com/34uuuj)

Google Search on Disability Rights resulted in over 30,000,000 results: [http://tinyurl.com/ytecp3](http://tinyurl.com/ytecp3)

Smithsonian National Museum of American History Disability Rights Movement Exhibit Online: [http://americanhistory.si.edu/disabilityrights/welcome.html](http://americanhistory.si.edu/disabilityrights/welcome.html)


About reSearch:

reSearch is a new information product from the National Rehabilitation Information Center (NARIC). Each issue is based on real-world queries received by our information specialists from researchers, educators, and rehabilitation professionals around the world.

We search several sources both in-house and online, to fill these requests including:

- REHABDATA and the NIDRR Program database
- Education Resources Information Center
- National Clearinghouse of Rehabilitation Training Materials
- Campbell and Cochrane Collaborations
- PubMed and other National Library of Medicine databases
- Agency for Health Care Policy and Research databases
- Center for International Rehabilitation Research Information and Exchange

and other reputable, scholarly information resources.

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- NARIC Information and Media Team
The study of disability has become increasingly important as the disability rights movement has advanced in many countries. The ideology of the movement has been built around a sociological conception of disability which maintains that impairments may or may not result in disability, depending on social organization and the physical environment. In essence, whether an impairment becomes a disability depends on physical access to community facilities, social attitudes, and discrimination with respect to employment and other types of social participation, and the types of accommodations the comm