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THE EVOLUTION OF A SOCIAL MOVEMENT

Sara D. Watson[†]

INTRODUCTION

The diverse stories presented in the following essays represent an evolution of the disability movement — an evolution that parallels similar developments in the civil rights and women's movements.¹ This introductory essay explores this evolution by drawing parallels between these movements, and demonstrates the need for third wave messages in two public policy debates: health care reform and personal assistance services.

Like other social movements, the disability rights movement developed a series of over-arching messages in order to achieve specific political and social goals. To combat centuries — if not millennia — of stereotypes, abuse, and neglect, these messages were purposefully drastic and sweeping. Society's first wave messages about disability were that disability was a tragedy, that people with disabilities were unemployable, and that they did not represent an identifiable constituency.

To negate these overwhelming images, the second wave messages developed by disability advocates had to be equally powerful. As a result, the second wave messages created the image that all people with disabilities were easily employable and would happily remain employed at the same jobs forever, that disability was desirable, and that people with disabilities were a tightly-knit minority group with similar views.²

Over time, these second wave messages are evolving into a third wave that reflects a more diverse array of knowledge and experiences. The third wave messages are no less revolutionary, but they are less homogeneous. The purpose of these four

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¹ FLORIA DAVIS, *MOVING THE MOUNTAIN: THE WOMEN'S MOVEMENT IN AMERICA SINCE 1960*, at 373 (1991).

² See generally Sara D. Watson, *A Study in Prejudice*, *DISABILITY RAG*, Mar.-Apr. 1993, at 17 (discussing the dichotomy between the stereotypical disabled person and the reality of persons with disabilities).

essays is to acknowledge the accomplishments of the second wave messages and explore how they began to evolve into the third wave. These essays will discuss both the risks and advantages of this evolution.

The essays in this collection chronicle the evolution of the disability movement from a diverse array of perspectives: law, economics, public policy, and social welfare. The authors have different personal, professional, and familial experiences with disability.

Professor Tucker explores how the deaf community, in order to combat the stereotype that deafness is a tragedy, has put forth the second wave message that deafness is desirable and discusses the issues thus raised. If deafness is so desirable that deaf people sometimes choose to remain deaf — by refusing cochlear implants, nerve implantation, or other potential "cures" — should society be obligated to pay for the accommodations made necessary by that choice? Professor Tucker asserts that people who choose to remain deaf when there is a real choice must bear the consequences of that decision, including the costs of adaptive equipment and other accommodations. Her essay demonstrates that a third wave message is needed to reflect the diversity of the deaf community. This image need not contradict the fundamental philosophy that disability is not a tragedy, but it must reconcile the contradictions that have arisen from the second wave message.

As an economist, Professor Baldwin encountered the second wave messages when she measured the productivity of people with disabilities and incorporated variables into her equations which captured the limitations on productivity caused by disabling conditions. She found that some persons with disabilities, in combatting the stereotype that all people with disabilities are unemployable, agreed with the second wave message that disability was virtually irrelevant to productivity. These people resisted even investigating whether disabling conditions affected productivity. Here too, however, a third wave message — that disability does affect productivity for some people with some disabilities in some jobs — is emerging. To deny this message is to render statistical investigations into employment discrimination invalid in the eyes of economists.

Bonnie O'Day argues that there is a broader problem created by the second wave message described above — that it sets up employees for failure and employers for disillusionment. To counteract the image that people with disabilities are expensive to employ, some proponents of the ADA stressed that

accommodations would be inexpensive and that people with disabilities would be model employees. O'Day argues that the danger in this second wave message is that potential employers may be given a false perception that it is cheap to accommodate people with disabilities, and may be quite unwilling or unable to hire someone with a more severe disability who requires a higher level of accommodation. It also unfairly pressures employees with disabilities to perform at higher levels than expected of non-disabled employees. O'Day argues that a third wave message — that some people with disabilities are not cheap to employ and that the cost-benefit analysis may not be positive for every employee — must therefore develop. By sole reliance upon the cost-benefit analyses of employees, society cannot ensure that all persons with disabilities — including those with severe disabilities or multiple disadvantages — have the fair opportunity to succeed. In this era of scarce resources, a third wave message must be developed which reaffirms that the dominant consideration is that people with disabilities must be protected from discrimination, while recognizing that the costs of accommodation cannot be ignored.

It is important to recognize that these third wave messages are not compromises: they do not constitute a weakening of the positions of advocates. Rather, they recognize that as social dynamics change, messages must change to keep pace with them. The existence of this third wave does not imply that the second wave messages were wrong: they were, and in many situations still are, necessary and effective.

The evolution from the second to the third wave message is not without risk. The third wave messages are longer, more subtle, more complex, and harder to communicate. Thus, many disability advocates do not wish to move to the third wave because making the messages more subtle risks watering down their impact. Similarly, broadening the constituency risks loosening the tight alliances within the disability community.

However, if the new messages can be communicated effectively, they offer at least three significant benefits for the disability community's political strategy. First, the resulting messages and public policy will better meet the needs of the diverse disability constituency. Second, the political stances taken will be less vulnerable to attack from those who support the disability community yet disagree with the second wave message. Third, the message invites additional people under the umbrella of the disability community, particularly persons with chronic illnesses and the elderly. The debates over health

care reform and personal assistance policy demonstrate that the third wave evolution is already underway and illustrate its advantages.

I. EXAMPLES FROM THE DEBATE OVER HEALTH CARE AND PERSONAL ASSISTANCE SERVICES

A. THE DEBATE OVER HEALTH CARE

The shift to the third wave has improved the disability community's ability to participate in public policy debates that affect it. For example, the disability community's efforts to separate the issues of disability from illness has affected its participation in the health care reform debate.³

A fundamental tenet of the disability movement has been to separate disability from illness by saying that disability is not a medical issue, that people with disabilities are not sick, and that disability is a social — rather than a medical — construct.⁴ Disability leaders have proudly and publicly proclaimed that they have not visited a doctor since the onset of their disabilities and that they were not "rate-busters" — meaning they did not use more health care resources than non-disabled persons.

The separation of disability from illness has had both positive and negative effects. While it has enhanced the ability of people with disabilities to control both their personal assistance services and their relationships with their medical providers,⁵ it has ignored the many people whose disabilities do have medical implications — such as those with heart disease, cancer, and arthritis.⁶ In fact, the people whose disabilities do

³ See generally Sara D. Watson, *An Alliance at Risk: The Disability Movement and Health Care Reform*, AM. PROSPECT, Winter 1993, at 60 (presenting several options which the disability community could utilize to overcome the difficulties health care reform presents to the community).

⁴ For example, the disability community would say that in a situation where a wheelchair user is confronted by a flight of stairs, the problem is not that the person uses a wheelchair, but that the stairs exist. A constant refrain has been that for most people with disabilities, the major problem is not the physical limitations imposed by disabilities, but in how they are treated by other people. The problem lies not in the medical condition, but in the way that society is constructed.

⁵ Gerben DeJong, *Defining and Implementing the Independent Living Concept*, in INDEPENDENT LIVING FOR PHYSICALLY DISABLED PEOPLE (Nancy Crewe & Irving Zola eds., 1983).

⁶ That is, while many disabilities — such as amputation — generally do

have medical elements far outnumber the people with "classic" disabilities — such as spinal cord injuries, hearing and visual impairments, and amputations.

One result of the separation of disability from illness has been that the disability movement has not adequately represented people with chronic illnesses or their organizations.⁷ Another result was that persons with disabilities did not enter the health care reform debate as early and visibly as other major constituencies — such as employers, insurers, and health care providers.⁸ Further, it was difficult to reconcile the disability community's public statements that disability was not a health care issue with the community's stated need to be a player in the health care debate.

In the past two years, the disability community's stance has recognized that many people with disabilities are ill and do have intense health care needs. This recognition has opened the way for disability groups to become more active and visible in the health care reform debate.⁹ It has also expanded the number of constituencies lobbying for health care reform under the disability umbrella. As a result, the membership of the Consortium for Citizens with Disabilities has mushroomed.

However, this shift in perception is not without risk. Part of the challenge facing future disability advocates will be how to present the more subtle message that while some people with

not result in continuing health problems once the person recuperates from the original disabling event, other disabilities — such as diabetes — are often accompanied by continuing health complications.

⁷ For example, in the debate over the ADA, the traditional disability organizations — such as Easter Seals, United Cerebral Palsy, Association for Retarded Citizens — and newer, activist organizations — such as Disability Rights Education and Defense Fund and the National Council on Independent Living — were involved from the beginning. However, other "illness" organizations, often with larger lobbying budgets and constituencies — such as the American Cancer Society — joined the debate much later and were not as active as the others.

⁸ For example, the major employer groups developed their own health care proposals and held many public events long before the disability lobby acted. The concentration on the ADA explains this late entry. *See generally* Watson, *supra* note 3 (discussing the role of advocates for disabilities in health care reform).

⁹ For instance, both the Consortium for Citizens with Disabilities and the National Council on Independent Living have developed their own health care reform proposals and have become extremely active in lobbying both on Capital Hill and at the grass-roots level.

disabilities are also ill, most are not, and disability is still largely a social construct.

B. THE DEBATE OVER PERSONAL ASSISTANCE SERVICES POLICY

The debate over personal assistance services (PAS) policy exemplifies how the third wave messages are both better tailored to the diverse needs of the disability community and more politically defensible. To combat years of disempowerment, second wave disability advocates focused on achieving complete autonomy and control for persons using PAS — services that assist people with disabilities in performing the tasks of everyday life.¹⁰ This strategy left out the PAS users who did not want to be responsible for all aspects of their PAS. The screening, hiring, and managing of attendants is a time-consuming process, and many PAS users would rather rely on others to perform those functions. Opponents of consumer empowerment needed only to present a person with a disability who was willing to forego total control over her PAS to cast doubts on the entire empowerment message. Now, however, advocates of PAS — such as the World Institute on Disability — stress a range of options that allow consumers to choose their areas of responsibility.¹¹

The third wave message represents the ultimate transition from no autonomy, to complete responsibility, to choice. In doing so, it more accurately reflects the diversity of the disability community, without compromising its call for a national PAS program.

II. PARALLELS IN OTHER SOCIAL MOVEMENTS

The disability community is not alone in the development of third wave messages. The evolution in the disability community parallels the three-stage evolution in general public policy that was the centerpiece of the Clinton presidential campaign and is being explored by numerous public policy analysts.¹² For ex-

¹⁰ See generally SIMI LITVAK ET AL., *ATTENDING TO AMERICA: PERSONAL ASSISTANCE FOR INDEPENDENT LIVING* (1987) (exploring issues regarding the use of PAS by people with disabilities).

¹¹ See, e.g., SIMI LITVAK, *A YARDSTICK FOR SYSTEMS REFORM: THE CHOICE MODEL* (1991).

¹² See, e.g., *MANDATE FOR CHANGE* (Will Marshall & Martin Schram eds.,

ample, Professor Beryl Radin of the University of Southern California has recently focused on the general evolution of public policy in the 1990s as a third generation that learns from the extremes of both the 1960s and the 1980s.¹³ Another political observer has labeled this general evolution "Neo-Liberalism."¹⁴ In particular, the movements to achieve racial and gender equality have presaged the path on which the disability community now travels.

A. THE BLACK CIVIL RIGHTS MOVEMENT

The black civil rights movement was born out of the denial of racial discrimination and proclaimed the universality of racial discrimination. Now, however, numerous African-American scholars and observers are striving to deliver a third wave message that is more subtle and diverse. Current writings about affirmative action exemplify this new message. In *Reflections of an Affirmative Action Baby*,¹⁵ Stephen Carter presents a complex message about affirmative action. He acknowledges the persistence of the discrimination that led to its creation, explores the disadvantages of this one-size-fits-all policy, and argues that it is time to look for more complex and custom-tailored remedies. Similarly, columnist William Raspberry has argued that affirmative action's message to black children — that racism is the root of their problems — de-emphasizes personal responsibility.¹⁶ Shelby Steele also explores the weakness of a single affirmative action policy applied universally to one group, stating that:

I think we need social policies that are committed to two goals: the educational and economic development of disadvantaged people, regardless of race, and the

1993) (publication of the Progressive Policy Institute).

¹³ Beryl Radin, Address at the University of Southern California Public Affairs Center in Washington, D.C. (Oct. 20, 1992) (on file with author).

¹⁴ Charles Peters, *The Second Coming of Neo-Liberalism*, N.Y. TIMES MAG., Jan. 17, 1993, at 30.

¹⁵ STEPHEN L. CARTER, REFLECTIONS OF AN AFFIRMATIVE ACTION BABY 11-28 (1992).

¹⁶ See, e.g., William Raspberry, *Race and Fairness at Georgetown Law: It's Time for a New Look at Affirmative Action*, WASH. POST, Apr. 19, 1991, at A23.

eradication from our society — through close monitoring and severe sanctions — of racial, ethnic, or gender discrimination Give my children [who are black] fairness: give disadvantaged children a better shot at development¹⁷

If one adds "disability" to Steele's categories of discrimination, his statement parallels remarks by those who argue that the ADA will not be a universal panacea for the problem of disparate employment conditions and must be accompanied by additional services for those disabled people who are more severely disadvantaged.¹⁸

Stephen Carter, William Raspberry, and Shelby Steele all explore the delicate and controversial subject of affirmative action out of an expressed love for African-American people. They argue that racial discrimination persists and that efforts are still needed to combat it.¹⁹ Like the civil rights community, the disability community needs to reconsider the messages it wishes to send. This re-examination need not be a compromise that hurts both parties. It does mean that messages and policies need to change along with the lessons of time and experience.

B. THE WOMEN'S MOVEMENT

In an earlier paper, this author explored several of the parallels between the women's and disability movements:²⁰ an appropriate example of this similarity is that of "interdependence." In both movements, the old stereotype was dependence and the second stereotype was independence. The third wave message is one of interdependence. In the women's movement this philosophy evolved as a reaction to the traditional male-created theory of justice based on self-interest and individual

¹⁷ SHELBY STEELE, *THE CONTENT OF OUR CHARACTER: A NEW VISION OF RACE IN AMERICA* 124 (1990).

¹⁸ Richard V. Burkhauser, *Beyond Stereotypes: Public Policy and the Doubly Disabled*, *AM. ENTERPRISE*, Sept. 1992, at 60.

¹⁹ See CARTER, *supra* note 15, at 217-20; STEELE, *supra* note 17, at 124; Raspberry, *supra* note 16, at 60.

²⁰ See Sara D. Watson, *Holistic Policy-Making: Neo-liberalism as Illustrated by the Women's and Disability Rights Movements*, *POLY STUD. J.*, Winter 1994.

rights.²¹ Women's views of society rely more on relationships than hierarchy.²² Instead of a Constitution based on rights, emphasizing individual responsibility and protection of boundaries, an alternative view would emphasize inter-connectedness. For example,

[f]eminists might not have been forced to argue that pregnancy must be treated like any other disability; they might have had a legal and philosophical basis for insisting that society must acknowledge its collective responsibility for childbearing and its medical costs. Menkel-Meadow suggested that perhaps Americans had a right to be connected to others and cared for, as well as a right to be let alone.²³

A parallel evolution is evident within the disability movement. Like women, people with disabilities were traditionally viewed as dependent, helpless, and passive. As a response to that stereotype, rehabilitation organizations pushed people with disabilities to strive for physical independence.²⁴ The emphasis on physical autonomy, however, has been as physically and psychologically damaging to people with disabilities as the overemphasis on independence has been to women. For example, as polio survivors age, they find that overuse of damaged muscles and nerves results in reduced capacity. Psychologically, "the biggest thing wrong with the traditional rehabilitation model was that it emphasized 'fixing' people beyond the point that their physical disabilities would allow. When they could not achieve physical recovery, this model denied them access to self-esteem and left them feeling hollow."²⁵

²¹ Kenneth L. Karst, *Woman's Constitution*, 1984 DUKE L.J. 447, 483-89 (1984).

²² See Milton Friedman, *Feminism and Modern Friendship: Dislocating the Community*, in FEMINISM & POLITICAL THEORY 143 (Cass Sunstein ed., 1990); CAROL GILLIGAN, IN A DIFFERENT VOICE: PSYCHOLOGICAL THEORY AND WOMEN'S DEVELOPMENT 24-63 (1982).

²³ DAVIS, *supra* note 1, at 481 (referring to Carrie Menkel-Meadow, *Portia in a Different Voice: Speculations on a Women's Lawyering Process*, 1 BERKELEY WOMEN'S L.J. 39, 62 (1985)).

²⁴ JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 73 (1993).

²⁵ Telephone Interview with Marcia Bristo, Director of Access Living and the nominee to chair the National Council on Disability (Jan. 28, 1993).

In reaction to the rehabilitation field's emphasis on complete independence, the disability rights movement now stresses that true independence does not require that all tasks be performed autonomously. Rather, inherent in true independence is the ability to live one's chosen lifestyle and to define what independence is for oneself, even if such "independence" includes reliance on others. An ideal society acknowledges one's needs without shame or condemnation, and provides appropriate supports.

Like the disability movement, the women's movement found itself faced with the dilemma of its new messages threatening the validity of the old.²⁶ The third wave is neither a compromise nor a weakened position: It is fully as revolutionary and demanding as the old ideals because, for it to work, society must be willing to provide the supports necessary to give the disabled person her chosen level of independence.

CONCLUSION

The examples described by Tucker, Baldwin, and O'Day in this compilation illustrate the evolution of a third wave of thought and strategy regarding the rights of those within the disability community. Public policies will become more effective as they reflect the diversity within the community and acknowledge the need to be flexible and responsive. Betty Friedan's assessment would work for people with disabilities (and others) by a simple vocabulary substitution of disability words for feminism words:

It seems to me that you can trust feminists — or any other "ists" for that matter — only when they speak from personal truth in all its complexity. Such truth is never black and white. . . . That feminine mystique had to be broken through so that we might be able to demand and be taken seriously in our demand for equal rights and opportunities in the world. The anger we felt, then, was real enough. But the rhetoric we used to assert our personhood denied — or somehow omitted, skipped over after so many years of overemphasis — other elements of our personal truth.²⁷

²⁶See generally Watson, *supra* note 20.

²⁷BETTY FRIEDAN, *THE SECOND STAGE* 45-46 (1981).

Friedan adds, "There is a reconciling of seeming opposites that has to take place now, a dialectical progression of thesis-antithesis (feminine mystique-feminism) to synthesis: a new turn in the cycle that brings us back to a familiar place, from a different vantage."²⁸

One of the greatest challenges for social science theory is to move from merely explaining the past toward predicting the future. The test of the evolutionary theory presented in this article will be whether further developments in disability policy follow a similar path. For example, one of the next great challenges for disability policy will be reforming the income security benefit programs: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). A major criticism of these policies is their "one-size-fits-all" design: one is either totally and eternally disabled or is not disabled at all. It will be significant to observe whether the recommendations from the current National Academy of Social Insurance panel on disability programs²⁹ and future legislative proposals reflect an evolution that is consistent with the themes explored in this paper: a transition to new policies that are flexible enough to go beyond narrowly defined categories and meet the diverse needs of people with disabilities.

²⁸ *Id.* at 81.

²⁹ This panel was created by the National Academy of Social Insurance at the request of the House Ways and Means Committee in 1993.