Disability Identity and Attitudes Toward Cure in a Sample of Disabled Activists*

HARLAN D. HAHN

University of Southern California

TODD L. BELT

University of Hawai'i at Hilo

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This study investigates the assumption that disabled people want improvements in their functional abilities, or complete cures. Contrary to this assumption, many disabled activists are found to have attitudes in which they refuse treatment that promises a cure. In order to explain this attitude, different sources of disability identity are isolated as potential predictor variables. A multivariate model reveals that self-identity related to a personal affirmation of disability is a significant predictor of refusal of treatment, as is the age of onset of disability. Implications for interactions with medical professionals and utility-based modeling of medical treatment seeking are discussed.

In recent years, the growing influence of the disability rights movement has prompted several new and significant questions about health-related conditions and attitudes toward medical care. What proportion of disabled participants in the movement want to be cured? Why do some individuals seek to ameliorate or eliminate their impairments while others do not?

Prior surveys of small groups of disabled people by Weinberg (1978, 1988) found that a majority did not want to be cured. This, as Stefan (2001) has noted, may be due to the fact that "some [disabled] people made it clear that they do not want to be 'cured' and fade into the mainstream. Instead, they want to be accepted and appreciated, to have society make room for them as they are" (p. 48). In fact, many disabled citizens now regard living with their disability as a valuable experience that can yield a positive source of personal and political identity instead of viewing their disability as a negative defect or deficiency that results in a loss or decline of bodily functions.

Rejection of the possibility of a cure can be illustrated by the refusal of cochlear implants by deaf persons who fear that striving to rid themselves of their disabilities might result in the loss of valuable assets including sign language and deaf culture (Jankowski 1997; Lane 1992; Niparko 2000). Similarly, many disabled individuals may consider the desire for a cure less important than cultural and political motivations. The purpose of this study is to examine potential correlates of disabled activists' attitudes toward cure.

Data for this analysis were obtained from disabled activists in an organization called ADAPT, which once stood for Americans Disabled for Accessible Public Transportation and now represents Americans Disabled for Assistance Programs Today. The change in the words used to signify ADAPT reflected a shift in goals from changing laws to gaining the right to ride on public vehicles, which was finally addressed by the Americans with Disabilities Act, to a program that would per-

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mit disabled people to remain in their own homes rather than requiring them to live in nursing homes. This shift in objectives did not appear to disrupt a strong degree of consensus that had emerged within ADAPT, which may reflect the increasing maturation of the group in terms of cohesion. As Gill (2001) stated, "Concepts such as disability pride and culture, once controversial, are becoming mundane elements of the disability lexicon" (p. 368).

The views of ADAPT members may not be regarded as representative of the general population of disabled people, or even of activists in the disability movement (Shapiro 1993). Nonetheless, activists affiliated with an organization such as ADAPT can provide valuable information about two significant questions. First, do disabled citizens who routinely confront the police in political demonstrations really want to be cured? Second, what is the relationship, if any, between their attitudes about disability and sentiments concerning medical intervention to restore their physical abilities?

CONCEPTUAL ORIENTATION

Why do some individuals seek treatment for health problems while others do not? Researchers have approached this question with respect to obesity (Fitzgibbon, Stolley, and Kirschenbaum 1993; Higgs et al. 1997), alcoholism (Kaskutas, Weisner, and Caetano 1996), cocaine and marijuana dependence (Budney et al. 1998), psychiatric problems (Godard et al. 1986), help with bereavement (Rynearson 1995), and psychological trauma among battered women (West, Kantor, and Jasinski 1998). This question has not, however, been addressed with respect to persons with disabilities. If Stefan's (2001) proposition that some disabled people reject a cure because they do not want to "fade into the mainstream" (p. 48) is accurate, individual identity with disability might provide an explanation.

Most of the objectives sought by disability activists are political goals that can only be accomplished by major changes in government policy. Moreover, ADAPT is part of a political struggle that is similar to social movements based on race or ethnicity, gender, or sexual orientation (see Gliedman and Roth 1980). Since prior studies have shown that group identity is associated with participation in other social and political movements (see Brewer 1979; Brown 1995; Burke and Reitzes 1981, 1991; Citrin, Reingold, and Green 1990; Conover 1984; Gergen 1971; Hogg, Terry, and White 1995; Huddy 2001; Stryker 1980; Tajfel 1981), several variables regarding political identity were also addressed in this study. As a result, the study also provides an opportunity to explore the proposition that, at least among disabled activists, political strivings may be more closely related to the willingness to seek medical treatment, including the desire for a cure, than health concerns.

Drawing from the aforementioned social and political identity research, two concepts of group identity seem relevant to the study of disability. The first concept we have labeled "communal attachments"; this concept is based on a disabled person's relation to the "disabled minority" (Hahn 1994). In this sense, the group is the focus of reference for the individual's affectations. The second concept we have labeled "personal identity"; this concept is based on an individual's cognitive and emotive views of himself or herself as a disabled person.

In thinking about explaining disabled persons' rejection of a cure, an additional consideration which is specific to disabled persons' health attitudes is warranted. Disabled persons are subject to much medical attention over the course of their lives. Maintaining adequate health oftentimes becomes a full-time undertaking. The source of health maintenance is, therefore, an important consideration. Does proper health maintenance come from following the orders of medical professionals, or is it to be found elsewhere? Research has shown that when an individual believes that health professionals play a major role in determining his or her health, the individual tends to be more receptive to the idea of a "cure" for his or her malady (Abbott, Dodd, and Webb 1996; Wrightson and Wardle 1997). Therefore, this attitude, known as "health locus of control," deserves consideration in any model predicting acceptance or rejection of cure.

Propositions

The disability rights movement was begun by students who refused to live in nursing homes. Many participants in this movement have made the difficult transition from a self-image filled with shame and denial to an understanding of disability as a source of dignity and pride. At one time, the visible indications of a disability were so heavily stigmatized that persons bearing these traits simply remained indoors or in "back bedrooms" to avoid the humiliation of appearing in public. Hence, many became isolated or reclusive. Others who manage to venture into the public gaze still hide their own disabilities. These factors might provide additional incentives for disabled people to seek a cure for their disabilities.

On the other hand, the emergence of the disability movement also provided disabled people with an opportunity to develop a sense of attachment to the disability community and to achieve a positive sense of personal identity as disabled individuals. Both of these possibilities could be associated with unfavorable opinions about cures for disabilities. In sum, we expect that individuals who have stronger affirmative communal attachments and personal identity with "the disabled minority" will be more likely to reject treatment. Additionally, we expect that individuals whose locus of health control is centered on health professionals will be less likely to reject a cure.

METHODS

Sample

Perhaps the principal feature that distinguishes the sample for this survey—the members of ADAPT—from other disabled activists and disabled individuals in general is the group's commitment to the principle of civil disobedience (see Barnartt and Scotch 2001). This being the case, members of the group frequently face the prospect of arrest and punishment as probable outcomes of their activity. Frequent attempts by police officers to infiltrate ADAPT to learn about planned demonstrations prevented the use of strangers as survey interviewers. As a result, the survey was implemented by the senior author who, as a disabled person involved in the disability rights movement, was at least somewhat known to the group. Nonetheless, intensive efforts were needed in building rapport with respondents, only three of whom refused to respond to the survey.

A total of 161 demonstrators with disabilities were surveyed during two ADAPT social action events in 1995 and 1998. Most of the survey questionnaires were completed by the disabled demonstrators themselves, rather than by nondisabled attendants, friends, or family members. In addition to the difficulty of building rapport with the members of ADAPT, there was a high proportion of respondents who needed to be surveyed in face-to-face interviews directly by the lead author, due to disabilities which prevented them from communicating through ordinary verbal or written methods.[1] In addition to the three respondents who refused to complete the questionnaires, five questionnaires were deemed not complete enough to keep in the study. This resulted in a final tally of 156 completed questionnaires for the analysis (n = 77 in 1995 and n = 79 in 1998). Differences between the two samples on important demographic, dependent, and independent variables used in this analysis were negligible.

Survey respondents were almost evenly split between men and women (50.6% male, 49.4% female). The overwhelming majority of the respondents were white (80.1%), with a few Latinos (5.8%), African Americans (9.6%), and "others" (2.6%). The age of respondents ranged from 17 to 73 years old, with a median age of 42. There was also considerable variation in education levels among respondents, with some having attained advanced degrees, while others had no formal education at all. The median amount of schooling for the sample was 15 years. The respondents were nearly evenly divided in terms of employment, with 55.8 percent indicating that they were currently employed. Only 19.9 percent of the respondents indicated that they were married (see Table 1).

Measures

In the ADAPT surveys, a seven-point Likert-type item indicating the degree to which disabled respondents would want to be cured is the sole dependent variable. The question asked, on a scale of one to seven, how strongly the respondent agreed or disagreed with the statement, "even if I could take a magic pill, I would not want my disability to be cured."[2] Responses ranged from a value of one (strongly disagree) to a value of seven (strongly disagree), with points in-between. This variable is only an attitudinal measure and not a behavioral assessment. The question of whether attitudes about a cure for disabilities would actually affect the conduct of disabled individuals, either in accepting a cure or in utilizing other health services, is a separate, albeit intriguing, matter.

Independent measures from the ADAPT surveys were based upon an adaptation of concepts of ethnic identity developed by Phinney (1990) and upon indexes of collective and individual self-esteem created by Major, Sciaccitano, and Crocker (1993). Some of the items in the questionnaire were derived from prior scales, and some were developed by the senior author specifically for this study. Since data about identity with disability had not been examined previously, evidence from earlier studies could not be utilized in assessing the validity or reliability of these disability variables. Measures for the health locus of control variable were also seven-point Likert-type items adapted from common social-psychological locus of control measures (Robinson and Shaver 1974).

Analysis

Exploratory factor analysis was employed to examine all of the items in the ADAPT surveys concerning communal attachments and personal identification with disabled persons. This technique was selected in part to reduce the number of items in the independent variables to a manageable number. In addition, the process was designed to investigate the dimensionality of the data. Questionnaire items that were thought to theoretically represent different notions of communal and personal identity were isolated for analysis and selected to be used in the factor analysis if they demonstrated high levels of inter–item correlation. The isolated factors and other controls were then used in a multivariate regression model to predict rejection of cure.

TABLE 1. ADAPT Sample Characteristics

Characteristic	Percent
Sex	
Male	50.6
Female	46.4
Ethnicity	
White	80.1
Latino	5.8
African-American	9.6
“Other”	2.6
Employment	
Employed	55.8
Unemployed	43.6
Marital Status	
Married	19.9
Never Married	51.3
Divorced	14.1
Widowed	5.8
Separated	7.1

Note: Some demographic categories do not sum to 100 due to missing data.

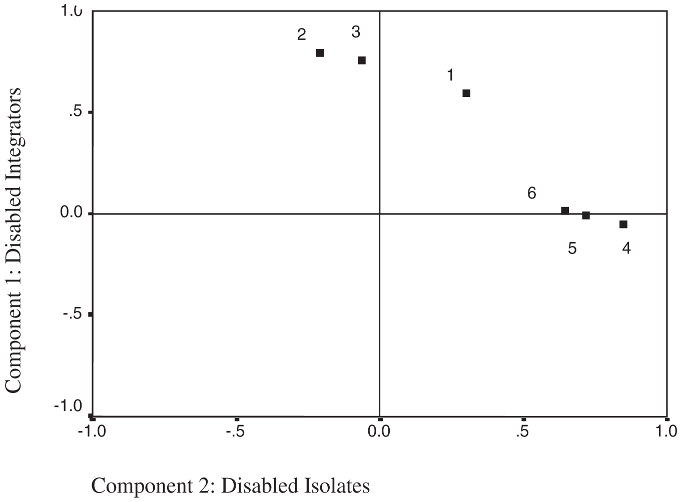
FINDINGS

Factor Analysis

The results appear to provide renewed evidence that identity often consists of individual feelings and a sense of affiliation with a broader community. Each of these analyses yielded two major factors. Figure 1 presents the plots for the dimensions isolated by the factor analysis designed to detect patterns of communal attachment. Evidence of a sizeable degree of independence between the variables labeled as “disabled integrators” and “disabled isolates” is indicated by the tendency of the first three items to cluster along the first component (integration) axis. In contrast, the other three items clustered around the second (isolation) axis. Hence, these items seem to reflect different dimensions in the data.

The questionnaire items isolated by the communal attachments factor analysis are presented in Table 2, along with their factor loadings. The items in these factors seemed to reflect contrasting reactions to the development of a sense of belonging vis-à-vis the disability community. The component “disabled integrators” appeared to represent the feelings of disabled activists who wish to immerse themselves in studying the common experiences and history of disabled people and to present a favorable image of this community to the rest of society. Unlike the traditional distinction between “integrationists” and “separatists” that has divided prior social movements, this dimension did not seem to revolve around desires to avoid or to merge with the dominant nondisabled majority; instead, this factor refers to “integrators” who have favorable opinions about unifying with the disability community. Both temporal variations in the emergence of social movements and the initial

FIGURE 1. Communal Attachments Rotated Factor Loading Plot



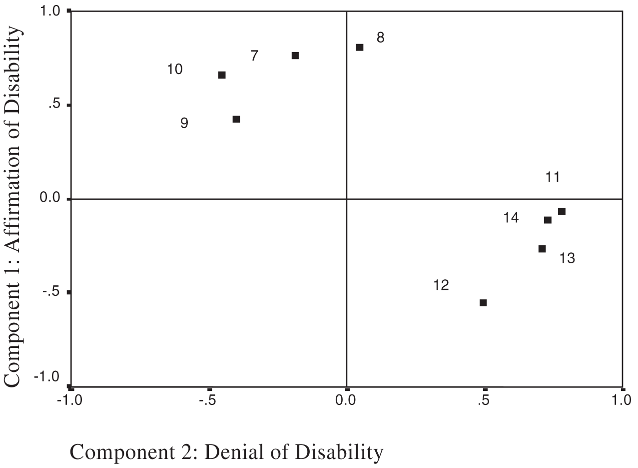
Note: **Varimax Rotation with Kaiser Normalization**

difficulties of forming a clear sense of disability identity with a newly discovered community seem to be implicitly evident in this factor.

The second component of communal attachments we label "disabled isolates." Respondents who weighed in heavily on this factor allegedly felt worthless or useless to other disabled people, but they did not try to become friends with nondisabled individuals either. Their reluctance to affiliate with either segment of the population seemed to place them in a vulnerable position. Perhaps some of them were attending the ADAPT demonstrations as part of a quest to find a group with which they felt they could align themselves. Such speculation can, of course, only be confirmed or refuted by additional research.

The dimensions identified by the personal identity factor analysis reveal a strong orthogonal separation. Most of the items reflecting a positive sense of identity with disability can be found in the first quadrant of the factor loading plot. All of the items labeled as a negative sense of identity are located in the third quadrant. These plots are displayed in Figure 2, and as the figure indicates positive and negative

FIGURE 2. Personal Identity Rotated Factor Loading Plot



Note: **Varimax Rotation with Kaiser Normalization**

TABLE 2. Communal Attachments Factor Analysis (Principal Components Analysis)

	Component	
Item	1 Disabled Integrators	2 Disabled Isolates
1. People with disabilities have a great deal in common	.597	.300
2. I want to learn more about history of people with disabilities	.792	–.206
3. How others feel about people with disabilities is important to me	.757	–.062
4. I don't have much to offer people with disabilities	–.054	.851
5. I don't try to become friends with people who are not disabled	–.011	.721
6. I feel useless to people with disabilities	.016	.647

personal identity form distinct dimensions. They are not opposite sides of the same coin—if they were, they would load on opposite sides of one axis, instead of along two distinct axes. The factor loadings from this analysis are presented in Table 3.

We label the two personal identity factors "affirmation of disability" and "denial of disability." These variables seemed to reflect feelings generated within the disabled individual rather than reactions formed in relation to the disability community. The two factors do not seem to be opposites; instead, they appear to indicate different perspectives that may be the outcome of varied experiences in the process by which disabled people develop feelings about their own disabilities. They represent separate and independent facets of disability identity. The sense of positive identity with disability is a position that does not receive extensive cultural support in society. In fact, disabled people must defy the heavy weight of social customs and conventions in order to espouse this position. Although general views of disability are changing continually, statements expressing a favorable view of disability and disability pride still seem relatively radical. As a result, respondents who advocate these opinions could be expected to endorse unconventional opinions about other subjects such as the wish for a cure.

Additionally, a fifth index measuring respondents' locus of health control was derived the same way. This factor analysis consisted of four questionnaire items which are listed in Table 4. The factor loadings calculated in all of the factor analyses were used to weight indexes for each distinct dimension, and the weights can be found in the shaded areas of Tables 2 and 3, as well as the single column of Table 4. Following item-weighting, all of the indexes were homogenized to a range of zero to one to insure compatibility in interpretation (see Table 5).

Regression Model

All five of the indexes plus two control variables related to disability identity were combined to form a multivariate model predicting rejection or acceptance of curative treatment. The first control was the age of onset of disability. The age of onset of an individual's disability can have a powerful effect on their life-course and self-perceptions (see Campbell 1996; Mona, Gardos,

TABLE 3. Personal Identity Factor Analysis (Principal Components Analysis)

	Component	
Item	1 Affirmation of Disability	2 Denial of Disability
7. In general, I'm glad to be a person with a disability	.768	–.185
8. Being a person with a disability is an important reflection of me	.806	.049
9. I have a clear sense of what my disability means to me	.427	–.401
10. I feel proud to be a person with a disability	.663	–.453
11. My disability sometimes makes me feel ashamed	–.069	.790
12. I do not feel good about being a person with a disability	–.549	.495
13. I regret that I am a person with a disability	–.263	.706
14. I do not have a sense of belong to the disability community	–.109	.732

TABLE 4. Health Locus of Control Factor Analysis (Confirmatory Factor Analysis)

Item	Weight
If I see a doctor regularly, I am less likely to have problems	.381
Health professionals keep me healthy	.880
Following the doctor's orders is the best way for me to stay healthy	.703
I can only maintain my health by consulting health professionals	.656

and Brown 1994). Individuals with an early age of onset of disability might be expected to be less likely to seek a cure than individuals who had an onset of disability at a later age due to a longer-standing self-identity as being disabled. In addition, as mentioned above, it is expected that curative treatment would be seen as a threat to this long-standing identity, and thus would be less desirable to the individual. Accordingly, a variable was created to differentiate among those whose age of onset occurred before and after adulthood (18 years of age).

The second control variable has to do with the number of ADAPT actions in which the individual had participated. Because the development of disability identity may be closely related to both affiliation with ADAPT and participation in its activities, it is important that any predictive model control for this level of affiliation. Accordingly, the number of protest actions in which members indicated they had participated was used as this control, with the assumption that individuals more active in the movement would be more likely to reject a cure.

As in Weinberg's studies (1978, 1988), the disabled respondents in the ADAPT surveys were evenly divided by the question of a cure. Forty-seven percent agreed with the statement, "even if I could take a magic pill, I would not want my disability to be cured" (response value = 5 through 7). Only 8 percent were ambivalent (response value = 4); 45 percent disagreed with the statement (response value = 1 through 3). This item is used as the acceptance-rejection of cure variable (dependent). The factor weighted indexes as well as the two controls became the independent variables in a multivariate regression model to predict attitudes regarding curative treatment.

The results estimated by the regression model are presented in Table 6. As the coefficients reveal, only two variables significantly predicted opinions about cure of an individual's disabilities (all predictors range from 0 to 1). These variables were an affirmative sense of personal identity with disability and an early age of onset of disability. These findings support the notion that the promise of curative treatment is often rejected due to the fact that it poses a threat to one's positive construction of self around the identity of being disabled. By contrast, those individuals who stated that they wanted to be cured lacked a positive self-affirmation as being disabled.

TABLE 5. Factor-weighted Indexes

Independent Variables	Mean (St. Dev.)
Communal Attachments	
Disabled Integrators	.685
	(.223)
Disabled Isolates	.190
	(.206)
Personal Identity	
Affirmation of Disability	.744
	(.228)
Denial of Disability	.266
	(.235)
Health Locus of Control	.328
	(.250)

Note: All indexes range from 0 to 1

TABLE 6. Regression: Predicting Rejection of Cure for Disability

Independent Variables	Coefficient (SE)
Communal Attachments	
Disabled Integrators	.672
	(.774)
Disabled Isolates	.783
	(.922)
Personal Identity	
Affirmation of Disability	3.488***
	(.911)
Denial of Disability	–1.330
	(.925)
Health Locus of Control	–.591
	(.743)
Age of Onset	–.722*
	(.364)
Number of ADAPT Actions	.402
	(.229)

* $p < .05$; *** $p < .001$ (two-tailed tests)
Note: $R^2 = .263$, n = 155.

DISCUSSION

Disability Identity

The relatively high average value for communal attachments (.685) and affirmation of disability identity (.744) among the ADAPT members may reflect a growing interest among portions of the disability movement to develop a coherent understanding of disability identity as a means of coping with discrimination in everyday life. Many disabled activists support a "minority group model" that emphasizes social discrimination and environmental barriers instead of physical impairments or functional limitations as the principal problems encountered by disabled people. However, they lack a sense of "generational continuity" which might otherwise permit them to transmit information about cultural legacies, including means of combating prejudice from one cohort of disabled people to the next (see Hahn 1985, 1993a, 1993b, 1994, 2000). In some respects, disabled people are a "uni-generational minority" anxious to overthrow the burden of what they perceive to be social oppression (see Gliedman and Roth 1980), including the oppressive weight of medical authority, through identification with a political movement and the construction of a positive, affirmative sense of personal disability identity.

Acceptance/Rejection of Cure

The finding that personal identity is associated with acceptance or rejection of cure is not surprising given the importance that individuals place on their self conceptions. Individuals with stronger positive affirmation of personal identity as being disabled are more likely to reject a cure because curing their disability takes away their source of self affirmation. Conversely, individuals who lack this positive affirmation are more likely to seek a cure for their disabilities due to the fact that they do not derive the same affirmation from their disabilities.

While the explanation regarding disability identity is straightforward, the finding that an early age of onset of disability leads to rejection of curative treatment may be explained two ways. As speculated above, it is likely that individuals who have an onset of disability prior to adulthood are more likely to have a stronger personal sense of identity as being disabled, which, in turn, leads to rejection of cure. The data support this notion, as they indicate that individuals who had an age of onset of disability prior to adulthood also had higher average scores on the personal affirmation of disability index than those whose age of onset occurred during adulthood (.790 versus .666, respectively, $F\,(1, 154) = 11.679$, $p < .001$). Additionally, onset of disability prior to adulthood was related to higher average scores on the disabled integrators index of communal attachments than a later age of onset (.713 versus .639, respectively, $F\,(1, 154) = 4.053$, $p < .05$).[3] These results indicate that an early age of onset is associated with positive notions of communal integration and affirmation of personal disability identity, and not with denial of personal disability identity or communal isolation.[4]

An alternative explanation as to why an early onset of disability may lead to rejection of treatment may have to do with the doctor-patient relationship. Perhaps it is because those with an earlier age of onset have had more experience with failures in medical treatment, and they have become more skeptical of promises of cures. If this is the case, then we would expect that individuals with an early onset of disability would place less trust in medical authorities than those individuals with a later onset of disability, resulting in a lower value for the health locus of control index (indicating less trust in doctors for health maintenance). However, the data do not support this explanation. It appears, then, that the importance of an early age of onset of disability, in terms of treatment rejection, is due to the influence it has in personal identity construction.

The data also provide a brief glimpse of opinions within the disability movement with which nondisabled observers might not be familiar. The tau-beta correlation for rejection of cure was inversely related to the belief that "disabled people should be considered courageous for having overcome their disabilities" ($-.24$, $p < .001$).[5] Many people in the disability movement want to be regarded simply as ordinary human beings, so they also wish to refute the myth that they are inspirational or endowed with extraordinary courage.

CONCLUSION

While some disabled adults seek health care and others do not, those who do may have different motives for doing so. Many, and especially those who have had lengthy experience with a permanent disability, no longer search for a cure for the disability. In fact, disability, and even functional impairment, is neither a "disease" nor a bodily attribute that can be removed by medical intervention. In fact, some disabled people complain that doctors tend to ignore immediate health problems in order to concentrate on what may be perceived as another futile attempt to find a "cure" for their impairments (DeJong, Batavia, and Griss 1989). However, like most people, they contract colds, get sick with the flu, and attempt to cope with a wide range of acute illnesses. Some of them are vulnerable to secondary conditions such as ulcers on the skin that stem from circumstances related to their disabilities, but medical visits stimulated by such problems hardly reflect a desire for a cure for disability. Even though increased numbers of disabled people may survive for extended lengths of time, the full restoration of "normal" functioning usually is not a viable prospect. Disabled individuals might often seek health care, but they seldom "need"—or perhaps want—medical treatment due to their permanent impairments. Any attempt to study correlations between responses to support for the elimination of disability and utilization rates for health services runs the risk of ignoring the importance of disability identity.

Since a plurality of ADAPT members said that they would not want to be cured, the data also were not compatible with a utility approach to variables that the respondents would be willing to exchange for a desired health status (Kirscht 1988; Torrance 1987). This is especially true when considering that there is no "opt-out" choice for disabled individuals in game-theoretical models which explain political movements (Chong 1991). While the results gleaned from this study may seem counterintuitive to medical professionals and researchers in rational choice paradigms, they must be understood within the context of experience with disability.

The importance of experience with disability is underscored by the importance of disability identity and age of onset in predicting treatment rejection. It should be noted, though, that not all sources of identity were important in predicting cure rejection—only personal affirmation of disability identity was important. This finding underscores the explanation that a "cure" poses a threat to positive self identity. In contrast, the prospect that an individual might be "cured" of disability does not seem to pose a great enough threat to an individual's communal attachments to the disabled minority to warrant treatment rejection. Thus, acceptance or rejection of a cure is best understood as a deeply personal issue that is related to personal life experience, and thus, identity.

It is important to note that personal identity carries important social and political ramifications. To date, the importance of political identity has been neglected by health care utilization studies. Major medical challenges in the future may revolve increasingly around disabilities and chronic health conditions rather than acute illnesses. If visits to the doctor acquire socio-political connotations, even for a relatively minor share of the population, this behavior could be reduced, especially among people with permanent impairments who are unlikely to obtain a prompt amelioration of symptoms or physical conditions through the prescription of medication or therapy. Thus, there could also be need to modify traditional concepts such as Parsons' (1950) definition of the "sick role," which is usually interpreted as requiring the pursuit of "full recovery" as a condition for exemption from ordinary social obligations (see Richman 1987; Twaddle 1979; Waitzkin and Waterman 1974). For many people with permanent disabilities, of course, this may not be perceived as an attainable or even a desirable goal.

The uncovering of factors that indicate that there is no universality in demands for the removal or cure of significant physical impairments poses a distinct challenge to research on health care. Standard medical practices are designed to be applicable to all segments of the population, regardless of their personal views. The possibility that either disabled or nondisabled individuals would reject legitimate treatment to increase functional capacities might be considered almost unthinkable. In fact, the aims of medicine are predicated on suppositions both that no harm will be inflicted on "patients" by physicians and that everybody, virtually without exception, will be receptive to medical procedures that have been proven safe and effective. In addition to the area of disability, there has appeared to be a growing resistance to medical authority in certain medical issue domains such as women's health and terminal illness. The existence of these sources of resistance to standard medical practices poses a challenge to prevailing models of treatment seeking. That all disabled people are presumed to want to eliminate their impairments and that nearly everyone would accept whatever doctors prescribe for them comprise two suppositions which form the core of utility-based models of treatment-seeking (see Becker 1974; Kirscht 1988). The research presented here indicates that these models may not be applicable to all populations.

In addition to personal identity, at least three other variables not discussed in this study should be investigated in future research regarding the treatment seeking behavior of disabled individuals. First, the particular type and severity of an individual's disability may act as an important antecedent condition to the model presented in this study. It is possible that certain types of disability and levels of severity of disability create a stronger sense of personal identity as being disabled, and therefore have an influence on treatment seeking or rejection. Second, the degree of risk that an individual perceives in living with a disability without treatment can be thought to influence treatment seeking behavior. Conversely, the perceived risks and consequences entailed by certain treatments may be influential as well. Finally, it might be hypothesized that some individuals might reject curative treatment in order to maintain a "sick role" to qualify for disability benefits. However, this consideration may not apply to the activists involved in ADAPT, whose goal has been to secure new benefits that enhanced disabled individuals' capabilities, rather than increasing current entitlements for disability. These three variables, unfortunately, were not measured in the ADAPT survey and could not be tested. However, it is hoped that this study contributes a foundation for subsequent investigation into the behavioral consequences of such attitudes.

NOTES

1. The standard method of survey implementation for this study was a self-response pen-and-paper method where possible, except where not physically possible due to a respondent's disability. This method of interviewing permitted the inclusion of a segment of the population (individuals with communications difficulties) which has otherwise been underrepresented in surveys with other sampling and implementation procedures (for a discussion of these considerations, see Freeman et al. 1982). A research note on methods of data collection and preliminary findings for the ADAPT surveys has been published elsewhere (Hahn and Beauliaurier 2001).
2. While it is true that many persons with disabilities sometimes seek medical treatment for amelioration of symptoms rather than complete cures for their conditions, the survey item used here was deemed by the authors to balance the broadest possible generalizeability of results with simplicity of question wording.
3. The correlation between age of onset and the two indexes was not strong enough to pose an autocorrelation problem for the regression model.
4. Mean differences among the early and late age of onset groups was small and insignificant for disabled isolates and denial of disability.
5. This item did not load on any of the relevant identity factors and therefore was not included in the regression model.

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Harlan D. Hahn is Professor of Political Science and Professor of Psychiatry and Behavioral Sciences at the University of Southern California. He specializes in disability policy, American politics and urban politics. Among his books are: *Disabled Persons and Earthquake Hazards* (co-authored), *Referendum Voting: Social Status and Policy Preferences* (co-authored), *Readings in Urban Politics: Past, Present, and Future* (co-authored), and *Corruption in the American Political System* (co-authored). He has written numerous articles on the subject of disability politics and has testified before many agencies on this field.

Todd L. Belt is Assistant Professor of Political Science at the University of Hawai'i at Hilo. His fields of specialization are American politics, research methodology, and international relations. He has written several conference papers on issues in political psychology, such as political identity, alienation, emotions, and candidate evaluations among voters.