Expanding the Definition of Disability: Implications for Planning, Policy, and Research

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particularly those stemming from chronic conditions, is burgeoning. International, federal, state, and research definitions of disability vary widely, however, despite efforts to reach a consensus on the meaning of disability and how to measure it (Reisine and Fifield 1988). Gender presents a particularly troublesome question when defining disability because of the striking differences between men and women in lifetime employment patterns, family work participation, and disease prevalence. The implications of these ambiguities for policy and the well-being of affected individuals are important because politicians and planners may rely on data of limited relevance to persons with disabling health conditions (Greenwood 1984; Alonso and Starr 1987; Kirshner 1990; Scotch 1990; Zola 1990).

In this article we discuss major approaches to the indicators of disability and how well they measure its scope in people with rheumatoid arthritis (RA). We briefly review the best-known definitions and present the available data on arthritis-related disabilities in the United States. Data from an ongoing national study of patients with RA are the basis for constructing rates of disability using common definitions of disability. Finally, we discuss the implications for health care policy of includ-

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ing family work in the definition of disability (Reisine, Goodenow, and Grady 1987).

Disability and Rheumatoid Arthritis

The issue of disability definitions and the needs of the disabled are particularly relevant to persons with rheumatoid arthritis (RA). RA affects three times more women than men and usually develops during the child-rearing years (Zvaifler 1988, 1990). Because RA is characterized by a pattern of flares and remissions, people with RA may not fit the usual definitions of disability. For example, people with RA often do not qualify for Social Security work disability benefits because their work limitations are episodic rather than long term, as required by the Social Security Administration definition.

The development of indicators of functional ability in arthritis parallels the increasing sophistication in the measurement of functional ability and the growing awareness of the multiple ways in which arthritis affects people (Liang 1987; Fries et al. 1980; Guccione and Jette 1990). For instance, we now have unidimensional indicators that assess primarily any impairment of physical functioning and offer better psychometric properties than earlier scales (Steinbrocker, Traeger, and Batterman 1949; Guccione and Jette 1988).

Psychometrically sound multidimensional measures have been created for assessing the social, psychological, and physical impact of arthritis (Jette 1980; Guccione and Jette 1990). Among the more commonly used instruments are the Arthritis Impact Measurement Scales (AIMS) (Meenan, Gertman, and Mason 1980; Meenan et al. 1982), the Functional Status Questionnaire (FSQ) (Jette et al. 1986), and the Stanford Health Assessment Questionnaire (SHAQ) (Fries, Spitz, and Young 1982).

The literature on RA documents extensive limitations in functional ability. For instance, work disability rates among RA patients average around 50 percent. SHAQ scores, which can range from 0 to 3, tend to average between .8 and 1.1 among people with RA (Fries, Spitz, and Young 1982). When scores on the various subscales of the AIMS are standardized to a score of 0 to 10, they tend to range from a low of 1.0 on the activities of daily living (ADL) scale to 4.8 on the household ac-

tivity scale to 6.4 on the physical activity scale (Meenan, Gertman, and Mason 1980).

Work and Family Work Disability

Several investigators examine functional losses in defined social roles among people with RA, including paid work and family roles (Yelin et al. 1987; Allaire, Meenan, and Anderson 1991; Reisine, Goodenow, and Grady 1987; Reisine and Fifield 1988; Verbrugge 1990). Most disability research in RA focuses on paid work disability, which is defined as loss of paid employment after the onset of RA. Rates of work disability vary, but cross-sectional studies typically find that about half of the individuals employed before developing RA are no longer working at the time of the study. One longitudinal study found that more than 50 percent of participants suffered losses in paid employment over a tenyear period (Yelin et al. 1987).

Most arthritis investigators recognize the importance of family functioning, but few examine functional losses in family roles. Studies that do address the issue demonstrate that arthritis does cause disability in family role functioning. Meenan, Gertman, and Mason (1980) reported significant impact on the family economy when the homemaker is affected with RA. Yelin et al. (1987) also found that estimated economic losses in household functioning surpassed those of paid work. Finally, several researchers (Reisine, Goodenow, and Grady 1987; Reisine and Fifield 1988; and Allaire, Meenan, and Anderson 1991) found that women with RA experienced significant levels of disability in both the instrumental and the nurturant dimensions of their work in the home.

Program Definitions of Disability in the United States

Political influences and societal beliefs shape the way in which disability is defined and measured in the United States (Mudrick 1983; Berkowitz 1990; Oliver 1990). Guiding much of U.S. health policy today is a concept of health that defines it as an optimum level of performance in a variety of daily roles and tasks (Sullivan 1971; Parsons 1972; Adams and Hardy 1988). In any society, roles include expectations about proper

work for men and women both in the home and in the paid labor market (Deaux and Kite 1987) and the perceived relative value of these roles. In American society, family work is given relatively little monetary value. Sokoloff (1980) suggests that this is because the American market economy relies on cheap labor in the home to maintain these necessary functions for society. American beliefs about health, gender, and the economic value of work in the home all contribute to definitions of disability that assess women's work in the home in only a secondary or limited way. Men's family work is not assessed at all (Pleck 1985).

Social Security programs perhaps wield the greatest political influence in shaping current notions about definitions of disability. Even before the Social Security statutes were expanded to include income replacement programs for the disabled, Social Security legislation of the 1930s was shaped by, and in turn greatly affected, American political thought about women and work and subsequent definitions of disability. Social Security legislation originally was conceived when the country was trying to recover from severe economic problems. Patriarchal political philosophy, reflected in many New Deal entitlement programs, aimed to preserve the nuclear family and the male family wage (Boris and Bardaglio 1983). For example, Mothers' Pensions and Works Progress Administration (WPA) nurseries were restricted to women outside the nuclear family-single mothers or women on relief. Furthermore, the National Industrial Recovery Act of 1933 set women's wages from 14 to 30 percent lower than men's wages. The Social Security Act of 1935 excluded a number of occupations that were typically women's work, such as hospital and domestic service. This early legislation, which greatly benefitted American society, also created a situation that fostered both the financial dependence of women upon men and women's greater responsibility for home and family work and contributed as well to the notion of women's work as being outside the market economy (Boris and Bardaglio 1983). Even today, women earn, on average, 59 percent of men's average wages. Many still think that women's natural role is in the work of the home, whereas men need to make a wage to support a family.

Developed as an extension of the Social Security Act of 1935, the Social Security Disability Insurance (SSDI) program became effective in 1956 and provides income replacement for individuals who are unable to do paid work because of disabilities. It covers insured workers who meet both medical and work history criteria. In order to qualify for ben-

efits, a person must be unable to engage in gainful employment, must meet specific medical standards for a given condition, and must have been employed for at least 5 of the 10 years preceding the disability. Unpaid family work is not considered gainful employment. Thus, women are disadvantaged under this program in two ways. Women's work in the home is not considered gainful employment, and the heavy involvement of women in family work means that many do not have a paid work history, making them ineligible for Social Security coverage. Also, women, more than men, tend to be employed in occupations that may not participate in Social Security, such as teaching and domestic services. Despite the restrictions imposed on the SSDI program, 2,786,000 people were receiving income in 1987, with an average monthly benefit of \$508 (U.S. Department of Health and Human Services 1991).

Mudrick's (1983) analysis of income support programs for disabled women showed that only one-third of married women and one-half of unmarried women are receiving income from this Social Security program. Married women whose work histories are limited by their commitments to working in the home are at an even greater disadvantage than unmarried women. Furthermore, even women who qualify for benefits have a lower percentage of their income replaced than men. In 1971 the median income replacement rate for women was 44 percent of gross earnings (Mudrick 1983). In addition, 12 percent of disabled women were receiving the minimum benefit under SSDI, reflecting long years of low wages. This gap between men and women continues to exist and is growing. Even in 1989, men's monthly average benefit of \$646 under SSDI was considerably greater than the monthly benefit of \$438 for women. Widows of disabled men fare somewhat better than disabled women. In 1989, the average monthly payment to widows of disabled men was \$525.

Although progressive for its time, Social Security definitions of work disability are not consistent with more contemporary notions about women, paid work, and the function of men in the family. Most women are employed outside the home at some point in their lives. Currently, women make up over 50 percent of the paid work force (U.S. Bureau of the Census 1990). Yet, even though 57 percent of women with children under six years of age work outside the home, women still bear major responsibilities for work in the home and experience more erratic work histories. Today, women are more likely to qualify for Social Security

payments, but benefits are unlikely to increase because their base salaries upon which benefits are calculated are lower.

Although family work appears to have little direct exchange value when measured by estimated replacement costs (Meenan et al. 1978), functional losses in family work are costly to society, to the family, and to the women who experience losses. The family performs a major social function through its transmission of cultural values, status production, and the stability of the social order (Ferree 1983; Sokoloff 1980). Women who experience losses in family role functioning, particularly the nurturant aspects of family work, report dissatisfaction and a diminished life quality. Yet, despite the importance of family work, it is rarely the central focus of disability reports.

National Health Surveys

National health surveys reflect the current view of family work in measuring rates of disability. Functional losses in family work are included as an adjunct to paid work. The best-known health survey in the United States is the National Health Interview Survey (NHIS), which is conducted annually by the National Center for Health Statistics. Compared with other surveys, the NHIS uses a fairly broad definition of disability that includes both paid and family work (Reisine and Fifield 1988; Adams and Hardy 1989). This reflects the policy goals of congressional mandates to estimate disability rates for national needs assessment, program development, and health status evaluation.

Although chronic activity limitations more accurately reflect disability among women in family work, measures of these limitations do not include the nurturant responsibilities of family work (Adams and Hardy 1989). They also underestimate disability among women because household limitations are measured only for unemployed women. That is, if women have some paid employment outside the home, limitations in household responsibilities are not measured.

In 1988, arthritis was the second most common chronic condition in the United States (129.9 per 1,000) (Adams and Hardy 1989). The most recently published reports on limitations of activity associated with selected chronic conditions (Murt, Parsons, and Harlan 1986) show that arthritis is the major cause of activity limitations, accounting for 18.9 percent of all causes of chronic activity limitations. Nearly twice as many women (24.6 percent) as men (12.4 percent) are limited by arthritis.

In this study, we collected data on several indicators of disability, in-

cluding information on the number of people actually receiving Social Security disability program payments, paid work disability since onset of disease, and family work disability.

Methods

Nine hundred ninety-eight patients with a diagnosis of classical or definite RA were recruited from 56 randomly selected private rheumatology practices in the United States (see Fifield, Reisine, and Grady [1991] for details on recruitment). Patients were interviewed by telephone and their doctors submitted medical information from their charts to the study. The interview was a structured questionnaire, consisting of over 100 questions about perceived health status, mood, employment status, work characteristics, family role responsibilities, role functioning, and social support.

Definitions of Disability

Several definitions of disability are used here:

- 1. The Social Security work disability definition includes all people unemployed at the time of the interview and who report actually receiving Social Security disability benefits.
- 2. The NHIS definition includes persons unable to work because of RA or who report some limitation in housekeeping measured as being affected on at least half of the family role responsibility items discussed below. For women, limitation in housekeeping is counted as a disability only if keeping house is reported as the primary occupation of the respondent (Adams and Hardy 1988).
- 3. In the American College of Rheumatology (ACR) definition, patients were evaluated by their physicians using the college's criteria and were assigned to a functional stage category, which is a measure of a physician's assessment of the patient's functional ability. The definitions for each category are as follows:
 - I. Complete functional capacity with ability to carry on all usual duties without handicaps
 - II. Functional capacity adequate to conduct normal activities despite handicap or discomfort or limited mobility of one or more joints

- III. Functional capacity adequate to perform only a few or none of the duties of usual occupation or of self-care
- IV. Largely or wholly incapacitated with patient bedridden or confined to wheelchair, permitting little or no self-care (Steinbrocker, Traeger, and Batterman 1949)

4. Arthritis Research Definitions:

- A. Stanford Health Assessment Questionnaire Items (Fries, Spitz, and Young 1982): Each patient completed a modified version of the SHAQ, consisting of 13 items. Questions related to housework activities were not used in order to shorten the questionnaire as much as possible and because of potential correlation in subsequent analyses with other dimensions of disability used in the study. Scores on each item were added and divided by the total number answered, ranging from 0 to 3. Although not directly comparable to the original Stanford Health Assessment Questionnaire, it is a measure of physical disability associated with arthritis.
- B. The *Paid Work Disability* definition includes participants who were employed at the onset of the RA and who are no longer employed because of RA.
- C. In the definition of Family Work Disability, family work was conceptualized as having two dimensions, capturing both the nurturant and instrumental aspects of family work (see Reisine, Goodenow, and Grady 1984). An index of disability was created consisting of four and six items, respectively, for each dimension. The measure of disability was whether arthritis affected their ability a lot, some, or not at all. Nurturant items included the ability to listen, take care of sick people, make arrangements for others, and maintain family ties. The instrumental items included ability to cook, clean, shop, care for the car, do yard work, and tend to financial matters.

Results

Description of the Sample

The average participant is 50 years old. The majority of respondents are female, white, and married (table 1). The educational and income

		F15 (2.)55)	
Variables	Percent	Mean	s.d.
Age (years)	_	50	10
Female	77	-	_
White	87	-	_
Married	72	-	_
Education (years)	-	13	2.5
Number in the family	-	2.7	1.2
Family income (dollars)			
<10,000	12	-	_
10-19,000	19	_	_
20,000-29,000	19	_	_
30,000-49,000	28	_	_
50,000 or above	22	-	-
Working	50		

TABLE 1

Demographic, Family, and Work Characteristics of the Sample (N = 988)

properties of the sample are similar to those of overall U.S. statistics (U.S. Bureau of the Census 1990). In 1987, the median number of school years in the United States was 12.7 and the median money income of families was \$30,853 (U.S. Bureau of the Census 1989).

Prevalence of Disability. Table 2 presents the prevalence of disability, using different definitions and the percent of those defined as disabled receiving SSDI payments. In our sample, 21 percent of the participants report receiving Social Security disability payments at the time of the interview. Using the NHIS assessment of chronic activity limitation, 34 percent of those in the study have a disability related to arthritis. Notably, only 46 percent of persons defined as disabled by the NHIS are receiving income replacement benefits under Social Security programs, primarily because the NHIS includes family work disability only for unemployed women and Social Security excludes such work.

The ACR functional classification system shows that physicians rated 17 percent of the participants in functional class III. These patients demonstrate serious limitations in functional abilities. Although the functional classification system may not be particularly sensitive, especially given other proven indicators of disability, it overlaps considerably

29

42

71

60

118

30

.08-.99 (some difficulty)

1.0-1.9 (much difficulty)

2.0-3.0 (cannot do)

Mean score (s.d.)

	Percent	Persons receiving Social Security payments	
Definition `		Percent	Number
Social Security ²	21.0	-	_
National Health Interview Survey ^b	34.1	46	155
ACR functional class			
I	20.0	10	10
II	63.0	15	83
III	17.0	50	72
IV	1.0	87	7
Modified SHAQ			
0 (no difficulty)	9.1	1	1

TABLE 2 Prevalence of Disability Using U.S. Definitions (N = 988)

58.5

28.1

4.3

.739 (.6)

Abbreviations: NHIS, National Health Interview Survey; ACR, American College of Rheumatology; SHAQ, Stanford Health Assessment Questionnaire.

with the Social Security definition of disability in this sample. In separate analyses (not shown), 61 percent of persons not employed and in functional class III are receiving Social Security disability income replacement benefits. This overlap probably reflects a reliance on the physician's judgment of physical disability needed to qualify for Social Security income replacement programs.

Using the SHAQ items, the majority of participants have some disability associated with arthritis, as only 9 percent report "no difficulty" with any item. Relatively few people are severely limited, with the vast majority reporting some intermediate level of difficulty, but 27 percent

^a This definition includes people who are currently receiving Social Security disability benefits.

^b The NHIS definition of percent with activity limitation includes those who are not working because of RA and, for women, those who are not working and who report some limitation on at least half of the family role items.

report that they are "unable to do" one or more items on the scale; 3 percent said they are "unable to do" more than half the items (not shown). Although the modified SHAQ scale is a more quantitative indicator of disability, the dilemma of establishing the cut-off score to define disability still remains. There is a positive relation between functional abilities reflected in the modified SHAQ scores and receiving Social Security income replacement benefits. As the modified SHAQ score increases, so does the percentage of people receiving disability benefits; there are also large differences in the modified SHAQ scores between those receiving benefits (mean modified SHAQ = 1.6; s.d. = .6) and those not receiving benefits (mean modified SHAQ = .59; s.d. = .5). This probably reflects the reliance of Social Security program definitions on medical criteria and on measures of limited physical functioning.

The rate of disability varies widely, depending upon how disability is defined. Furthermore, relatively few among the persons who might be defined as disabled are receiving income replacement through Social Security programs.

Functioning in Work and Family Roles. Table 3 presents data on ability to function in paid work and family work roles. Thirty-six percent of previously employed persons left work because of arthritis. Only about half of these people (49 percent) are receiving paid benefits under Social Security, illustrating how the Social Security definition of disability underreports those who are unable to work because of arthritis. There are several possible explanations for why persons unable to work are not receiving replacement income. Some people who apply do not qualify for medical reasons or for work history reasons. However, only about 25 percent of actual applicants are denied benefits. Many people never apply, even though they may qualify. Thus, many people who cannot work because of RA are not enumerated in the Social Security data, thereby underestimating paid work disability in this population.

RA also affects family role functioning among these patients. Ninety-one percent of the participants stated that they are affected "a lot or some" on at least one item assessing instrumental activities, and 67 percent are affected on at least one item of the nurturant dimensions of family work. Further, 46 percent are affected on more than half of the instrumental items and 33 percent are affected on more than half of the nurturant items (not shown). Twelve percent are affected "a lot" on

TABLE 3
Prevalence of Disability Using Family and Work Role
Functioning Definitions (N = 988)

	Percent	Persons receiving Social Security payments ^c	
Definition		Percent	Number
Paid work role ²	36	49	174
Family work role ^b Instrumental activities			
Cooking	65	27	172
Cleaning	76	24	180
Shopping	71	35	172
Car care	28	27	73
Yard work	50	21	99
Bills/financial matters	30	36	107
Affected on one or more item	91	22	196
Nurturant activities			
Maintain ties	56	25	138
Care of sick	41	26	106
Make arrangements	35	26	89
Listen	34	32	108
Affected on one or more item	67	25	169

^a This includes only people who were working at the onset of the disease (n = 723). Persons who left their jobs because of RA comprise the "percent not working." Participants were asked specifically whether RA was the main reason for leaving their jobs. ^b This includes respondents who reported that they were affected either "a lot" or

more than half of all the items. The instrumental tasks are affected more often than the nurturant dimension, probably because of their physically demanding nature.

Separate analyses of family work disability for persons who are working (not shown) reveal that those who are employed outside the home have fewer functional limitations in family work than those who are disabled at work. Sixty-eight percent of the employed are affected "a lot or

This includes respondents who reported that they were affected either "a lot" or "some" by their arthritis in their ability to perform each item. "Percent affected on one or more item" includes respondents who said they were affected "a lot" or "some" by their arthritis on at least one item of the scale.

^c These columns comprise the percent (and number) of people who are affected and who also receive Social Security disability payments.

some" on cleaning, 63 percent on shopping, 45 percent on maintaining ties, and 28 percent on making arrangements. However, the people who manage to remain employed and who experience functional limitations in family work (particularly in the nurturant dimensions) are never counted in any of American definitions of disability.

Table 3 also presents data showing the relation between family role functioning and Social Security payments. Relatively few of those limited in instrumental and family role functioning are receiving Social Security payments. Again, this may have more to do with having an eligible work history than with medical criteria. Notably, a relatively high percentage of people receiving benefits report difficulties with bills and financial matters.

Differences Between Men and Women on Functional Disabilities. Table 4 illustrates differences between men and women in rates of disability. The same percentage of men and women receive benefits from Social Security. However, relatively more women than men who have lost paid work do not receive Social Security payments. Unemployed women may not be receiving benefits because of work history ineligibilities rather than because of medically defined criteria. These results contrast with a higher overall number of women, compared with men (38 percent of women versus 30 percent of men), who report that they cannot work because of RA (numbers have been rounded).

Using the NHIS definitions, women also have higher rates of disability than men. The NHIS rates of disability in this sample may be somewhat higher than in national samples because this sample was recruited from rheumatology practices, where patients may have more advanced disease. However, the data replicate the data from national surveys by showing a higher rate for women when family role disabilities are included for individuals whose primary occupation is housekeeping.

Women report more physical limitations on the modified SHAQ compared with men. However, significantly more men than women are rated as functional category III-IV by their physicians. Physical limitations cannot explain physicians' judgments about appropriate functional levels for men compared with women, but perhaps these stem from physicians' expectations that men will maintain gainful employment and will assume limited family role responsibilities.

Men and women are affected differently in the home, as they assume very different responsibilities there. Women also are affected to a much greater extent on the nurturant dimension of family work. These differ-

TABLE 4

Prevalence of Disability Using Social Security, NHIS, ACR, and Modified SHAQ Role Functioning Definitions by Sex (N = 988)

Definition	Percent of females (n = 761)	Percent of males (n = 227)
Social Security income	21.0	21.0
NHIS ²	36.1	27.3
Paid work role-not working because of RA	37.6	30.1
Family work role-Percent affected some/a lot		
Instrumental activities		
Cooking	73.0	35.6
Cleaning	84.7	4 7.8
Shopping	77.2	49.6
Yard work	42.9	71.4
Car care	19.9	55.9
Bills/finances	31.7	25.5
Percent affected on one or more items	93.3	83.7
Nurturant activities		
Maintain ties	60.8	37.9
Listen	35.6	29.1
Make arrangements	38.4	24.7
Care of sick	45.2	28.9
Percent affected on one or more items	73.2	50.0
ACR functional stage		
I	18.3	24.5
II	65.1	54.2
III	15.8	20.3
IV	0.8	1.0
Modified SHAQ items		
Mean (s.d.)	.786 (.57)	.584 (.57)

^a NHIS defines as disabled those who are not working because of RA and, for women, those whose family role functioning is affected "a lot" or "some" on more than half of the items.

Abbreviations: NHIS, National Health Interview Survey; ACR, American College of Rheumatology; SHAQ, Stanford Health Assessment Questionnaire.

ences in responsibilities are a reflection of cultural values as well as the division of labor within the home. The analysis of functional disabilities by sex illustrates the potential for underestimating the extent of this disability when traditional definitions are used.

Discussion

Our data show that rates of disability vary widely depending upon how disability is defined. A comparison of disability rates, using both Social Security income replacement program and expanded definitions of disability, demonstrates the selectivity of Social Security programs and how the current measures underestimate disability in women. Social Security disability programs exclude a significant number of people who cannot work because of RA, but do not meet work history, medical, or income guidelines. They also exclude persons who experience limitations in life functions other than paid employment. For example, more than half of those who experience chronic activity limitations by NHIS definitions do not receive Social Security income replacement benefits. The NHIS definition used in this study is a fairly liberal estimate of disability. That is, people were defined as having a chronic activity limitation if they were not employed outside the home because of arthritis. Women who stated that housekeeping was their primary occupation had to be affected on at least half of the ten family role items. Using NHIS data, many more people are disabled than receive income replacement benefits. Among persons who state that they are no longer working because of arthritis, the number is even higher. Almost half of the persons employed at the onset of RA stated that subsequently they left their jobs after the onset of the disease because of their health. This statistic is higher than the NHIS measure because it includes women who have left paid work, but who do not have severe functional limitations at home.

We do not think that there should be income replacement programs for full-time homemakers unable to obtain paid work. Rather, attention should be focused on developing programs that meet the needs of persons who experience functional losses in a variety of life domains. We must reassess the scope and focus of the Social Security programs, recognizing and valuing the work of both men and women in the home for the important contribution it makes to the family and the stability of

the society. Programs addressing replacement of services in the home, rather than income, should be considered. Further, because women's workforce participation is increasing, we need to examine work patterns over the life cycle in order to assess the possibility of changes in eligibility criteria for SSDI programs in light of family commitments. Finally, surveys of the disabled should include data collected on the perceived needs of persons who experience limitations in functional capacities in order to develop better policies and priorities for meeting these needs.

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