

THE DISABLEMENT PROCESS*

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Abstract—Building on prior conceptual schemes, this article presents a sociomedical model of disability, called The Disablement Process, that is especially useful for epidemiological and clinical research. The Disablement Process: (1) describes how chronic and acute conditions affect *functioning* in specific body systems, generic physical and mental actions, and activities of daily life, and (2) describes the *personal and environmental factors* that speed or slow disablement, namely, risk factors, interventions, and exacerbators. A main pathway that links Pathology, Impairments, Functional Limitations, and Disability is explicated. Disability is defined as difficulty doing activities in any domain of life (from hygiene to hobbies, errands to sleep) due to a health or physical problem. Feedback effects are included in the model to cover dysfunction spirals (pernicious loops of dysfunction) and secondary conditions (new pathology launched by a given disablement process). We distinguish intrinsic disability (without personal or equipment assistance) and actual disability (with such assistance), noting the scientific and political importance of measuring both. Disability is not a personal characteristic, but is instead a gap between personal capability and environmental demand. Survey researchers and clinicians tend to focus on personal capability, overlooking the efforts people commonly make to reduce demand by activity accommodations, environmental modifications, psychological coping, and external supports. We compare the disablement experiences of people who acquire chronic conditions early in life (lifelong disability) and those who acquire them in mid or late life (late-life disability). The Disablement Process can help inform research (the epidemiology of disability) and public health (prevention of disability) activities.

Key words—disablement, disability, function, age

INTRODUCTION

In the mid and late life, chronic conditions tend to cross diagnostic thresholds, and individuals often accumulate several of them (comorbidity). The most common chronic conditions are nonfatal: For middle-aged and older women, the highest prevalence conditions include arthritis, high blood pressure, chronic sinusitis, tinnitus, hearing impairments, hay fever without asthma, chronic back conditions, varicose veins, hemorrhoids, migraine headache, cataracts, and visual impairments [1, 2]. The only fatal conditions in women's top-15 titles (rankings of age-specific prevalence rates) are ischemic heart disease, diabetes, and (at ages 75 +) atherosclerosis. For middle-aged and older men, fatal conditions have higher prevalence rates and ranks than for women, but nonfatal conditions (the same titles as noted for women) still predominate.

Thus, people mostly *live with* chronic conditions rather than *die from* them [3]. In both the short and long run, symptoms and disability are the principal outcomes, and they become the focus of protracted personal and medical care.

This article presents a conceptual scheme for disability that has broad utility in social science,

medicine, and public health. A conceptual scheme is a rudimentary scientific model that guides terminology, measurement and hypotheses. It is the basic architecture on which research, policy, and clinical care are built.

We begin by reviewing two contemporary conceptual schemes, then state the extensions and innovations offered in our model, named "The Disablement Process". The Disablement Process: (1) describes how chronic and acute conditions affect functioning in specific body systems, fundamental physical and mental actions, and activities of daily life, and (2) describes the personal and environmental factors that speed or slow disablement; namely, predisposing risk factors that propel dysfunction, interventions inserted to avoid, retard or reverse it, and exacerbators that hasten it. The importance of viewing disability as a gap between personal capability and environmental demand, and the problems in embedding that perspective in empirical research, are discussed.

BACKGROUND

In the past decade, two conceptual schemes have informed discussions and research on disability.

1. The *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) is a taxonomy of disease impacts developed by the World Health Organization [4]. It was designed to parallel the

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International Classification of Diseases, the standard taxonomy of diseases used in medicine and health statistics. The ICIDH has three central concepts: Impairment, Disability, Handicap (Fig. 1). For each, ICIDH provides an inventory of numerous specific titles and their code numbers. The ICIDH has facilitated international discussions of disablement and it has promoted similarity in statistics reported by nation states. Despite such political acceptance, scientific researchers have had trouble using ICIDH as a basis for hypothesis development and study design, citing problems of conceptual clarity, internal consistency, and measurement feasibility in surveys [5–7]. Prompted by these and other critiques, the World Health Organization is currently sponsoring preparation of an updated version; an extensive revision will probably be launched soon thereafter.

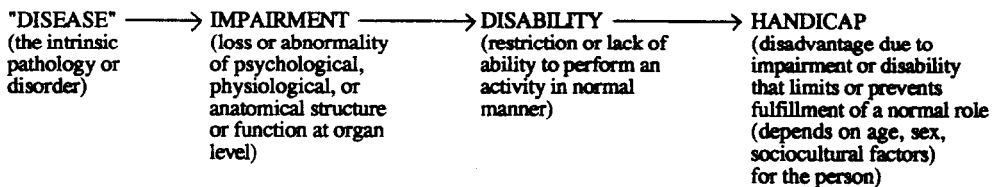
2. Another scheme was conceived and developed by the sociologist *Saad Nagi* [7–9]. It has four central concepts: Active Pathology, Impairment, Functional Limitation and Disability (Fig. 1). The concepts of Functional Limitation and Disability cover essentially the same scope as ICIDH's Disability. There is no parallel concept for Handicap. Sociological theory underpins Nagi's work, not taxonomic interest. The scheme has general intellectual scope that can be adapted and operationalized in specific research endeavors. Before the late 1980s, Nagi's work was not

widely known, but it had stood up well to critiques and gradually gained a strong following among disability researchers. An Institute of Medicine panel, convened to consider disability prevention and policy, adopted Nagi's basic framework. The panel's published report [10] has brought it rapid and great visibility; it is now often called the Institute of Medicine scheme. Other prominent scientific and public health groups are adopting it [11, 12]; an exception is [13].

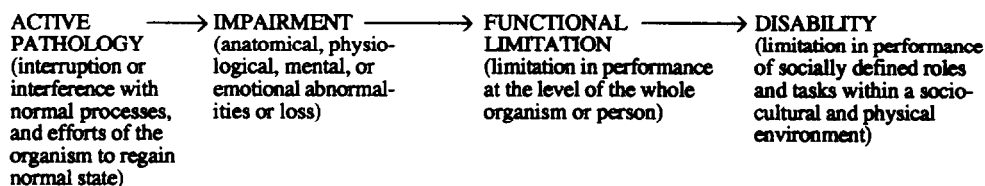
Our model has its main foundation in the Nagi scheme, but it also draws on the scope and detail of ICIDH and on public discussions comparing the two schemes. The Disablement Process model is an extension and elaboration of the Nagi scheme that is especially useful for research design.

In development of the Nagi and ICIDH schemes, the central focus was to delineate the pathway from pathology to various kinds of functional outcomes. The Disablement Process restates that pathway in language that suits medical and survey research, then puts most attention on predisposing and introduced factors that speed up and slow down the pathway. This is because in real life, the main pathway does not occur in a pure untampered way. There are always social, psychological, environmental (etc.) factors operating to alter it. Increasingly, proponents of the Nagi and ICIDH schemes are turning attention toward social and psychological factors that modify

International Classification of Impairments, Disabilities, and Handicaps (ICIDH)



Nagi Scheme



For the ICIDH, see [4]. Definitions above are simplified from the ICIDH text. For the Nagi scheme, see [7-9]. The IOM scheme [10] has the same concepts but different defining language (Pathology: "interruption or interference of normal bodily processes or structures"; Impairment: "loss and/or abnormality of mental, emotional, physiological, or anatomical structure or function: includes all losses or abnormalities, not just those attributable to active pathology; also includes pain"; Functional Limitation: "restriction or lack of ability to perform an action or activity in the manner or within the range considered normal that results from impairment"; Disability: "inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment").

Fig. 1. Two conceptual schemes for disablement.

the pathway. Our work joins and contributes to that current momentum.

THE DISABLEMENT PROCESS

“Disablement” refers to impacts that chronic and acute conditions have on the functioning of specific body systems and on people’s abilities to act in necessary, usual, expected and personally desired ways in their society. The term “disablement” is general, covering all consequences of pathology for functioning. The term is routinely used by United Kingdom and European researchers; it may be new to some North American readers. The term “process” reflects interest in the dynamics of disablement; that is, the trajectory of functional consequences over time and the factors that affect their direction, pace, and patterns of change.

In this article, we shall emphasize chronic conditions and their long-term, but not necessarily static, consequences. That is the most common health situation in mid and late life, and the aspect of most interest to gerontology. But the model is not limited to chronic conditions and their sequelae. It is also applicable to acute conditions and the brief disability associated with them (such as a head cold that causes several days of work absence). And it is applicable to lifelong disability due to childhood and youth-onset conditions (such as mental retardation or spinal cord injury); we discuss this issue later.

THE MAIN PATHWAY

A. Pathology and its functional consequences

The main pathway from pathology to disability is shown in Fig. 2. We now define the four concepts, discuss how they are measured, and give examples.

1. Pathology refers to biochemical and physiological abnormalities that are detected and medically labeled as disease, injury or congenital/developmental conditions. Chronic pathology encompasses progressive diseases, injuries with longterm sequelae, and enduring structural/sensory abnormalities. Acute pathology is short-term diseases and injuries, usually <3 months in duration.

Abnormal biochemical and physiological changes are deeply “interior”, and they are not always directly measurable in contemporary medical practice. Detection of pathology often relies on evaluation of more-manifest signs and symptoms (Impairments; see next paragraph). Abnormalities that cross defined thresholds of clinical significance constitute a “diagnosed condition”. Patients, survey respondents and medical records report diagnoses; this is the public language of pathology. Examples of pathology (stated as diagnoses) are osteoarthritis, lung cancer, cataracts, tinnitus, Alzheimer’s disease, vertebro-

genic pain syndrome, cerebral palsy and mental retardation.

2. Impairments are dysfunctions and significant structural abnormalities in specific body systems. “Significant” means that the abnormality can have consequences for physical, mental or social functioning. Impairments occur in the pathology’s primary locale, but they may also occur in secondary locales, either immediately or delayed. (For example, diabetes has primary impact on the metabolic system, but it can also affect cardiovascular, renal and other systems.) Minimal (subclinical) pathology may not produce any impairment in its body system; pathology in remission may also show no current impairments. Typically, pathology that has crossed defined clinical thresholds and been given a diagnosis does have manifest impairments.

Medical procedures to evaluate impairments include clinical examination, laboratory tests, imaging procedures and patients’ medical history and symptom reports. The results are used directly to score severity of pathology. (As noted above, when necessary, they are also used to ascertain presence of pathology.) Many of the clinical evaluation procedures for impairments can be successfully transferred to home surveys (examples in Refs [13, 14]), and this is a current goal of epidemiological research.

3. Functional limitations are restrictions in performing fundamental physical and mental actions used in daily life by one’s age-sex group. These are generic actions, recruited in many specific circumstances. They indicate overall abilities of body and mind to do purposeful ‘work’. Fundamental physical (body) actions include overall mobility, discrete motions and strengths, trouble seeing, trouble hearing and trouble communicating; examples are walking, lifting objects, climbing stairs, reading standard-size print and hearing other people speak in a room. Basic mental (mind) actions include central cognitive and emotional functions; examples are short-term memory, intelligible speech, alertness in daytime activities, orientation in time and space and positive affect. In short, such physical and mental actions constitute the basic interface between a person and the physical and social milieu in which s/he does daily activities.

Tests of physical and mental actions have various formats: (i) self-reports or proxy reports (spouse, parent, personal physician, etc.) of difficulty doing an action (no difficulty, some, a lot, unable); (ii) an interviewer’s observation of the subject doing an action, with a rating of her/his performance (fully able, partially able, unable) or sometimes counts (of steps, of repetitions before fatigue, etc.); and (iii) equipment-based evaluation of performance, including timed tasks. All measure a person’s ability to do tasks “on your own”. This always means “without someone’s assistance”; sometimes it also excludes regularly-used devices (cane, glasses,

EXTRA-INDIVIDUAL FACTORS

MEDICAL CARE & REHABILITATION
(surgery, physical therapy, speech therapy, counseling, health education, job retraining, etc.)

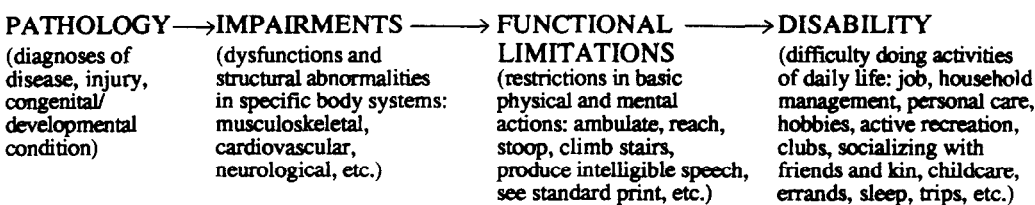
MEDICATIONS & OTHER THERAPEUTIC REGIMENS
(drugs, recreational therapy/aquatic exercise, biofeedback/meditation, rest/energy conservation, etc.)

EXTERNAL SUPPORTS
(personal assistance, special equipment and devices, standby assistance/supervision, day care, respite care, meals-on-wheels, etc.)

BUILT, PHYSICAL, & SOCIAL ENVIRONMENT
(structural modifications at job/home, access to buildings and to public transportation, improvement of air quality, reduction of noise and glare, health insurance & access to medical care, laws & regulations, employment discrimination, etc.)



THE MAIN PATHWAY



RISK FACTORS
(predisposing characteristics: demographic, social, lifestyle, behavioral, psychological, environmental, biological)



INTRA-INDIVIDUAL FACTORS

LIFESTYLE & BEHAVIOR CHANGES
(overt changes to alter disease activity and impact)

PSYCHOSOCIAL ATTRIBUTES & COPING
(positive affect, emotional vigor, prayer, locus of control, cognitive adaptation to one's situation, confidant, peer support groups, etc.)

ACTIVITY ACCOMMODATIONS
(changes in kinds of activities, procedures for doing them, frequency or length of time doing them)



Fig. 2. A model of The Disablement Process.

wheelchair, etc.; "without equipment assistance"). Over the past decade, there has been marked shift in scientific preference and data collection from self-reports to performance-based measures [16]. Sometimes respondents are asked to perform tasks in a standardized manner (using instructions and props), sometimes in their own usual way (no special instructions or props). Current performance-based protocols use a mixture of interviewer ratings, counts and timed tasks. Such protocols are in the National Health and Nutrition Examination III, the MacArthur Project on Successful Aging, and the Established Populations for Epidemiologic Studies of the Elderly. Whether there will be further shift toward sophisticated, lightweight equipment for

such evaluations, especially in household surveys, is uncertain now; many researchers are engaged in work on such technology.

4. Disability is experienced difficulty doing activities in any domain of life (the domains typical for one's age-sex group) due to a health or physical problem. Our definition contains two important and novel features:

First, chronic conditions can affect any activity domain, from hygiene to hobbies, from errands to sleep. Current studies often focus on just 3 domains: personal care (basic activities of daily living; BADL or ADL), household management (instrumental activities of daily living; IADL), and job (paid employment). ADLs are abilities to eat, toilet, transfer

(get in and out of bed/chair), dress and bathe. IADLs are abilities to prepare own meals, do light housework, manage own money, use the telephone, and shop for personal items. ADLs are necessary for survival; IADLs are necessary for maintaining a dwelling in a given sociocultural setting.* But there are other common and valued domains of activity: house and yard chores (besides those noted as IADLs); shopping and errands; job (paid employment); sleep; care for children and others; hobbies and other leisure at home; active sports and physical recreation; entertainment away from home; religious services or activities; public service/clubs/adult education; socializing with friends and relatives; local transportation; and distant trips. Why the limited scope exists and persists, and why an expanded scope is desirable, are discussed in Ref. [17].

We adopt a comprehensive and more democratic view of human activities. Disability questions for all domains should be crafted or at least fairly considered [18]. Presumptions that some domains matter more than others should be abandoned, or at least openly stated when they are held. (As a telling illustration, an older professor acquaintance with rheumatoid arthritis had to abandon his favorite hobby, making pots. This was the most distressing impact of the condition on his life.) Data covering obligatory, committed and discretionary aspects of daily life reflect the pervasive nature of disability in real-life; more restricted choices of domains simply cannot do so.

Second, the fundamental feature of disability is difficulty doing activities in one's regular milieu. Disability is measured in simple, direct manner by self-reports or proxy reports about degree of difficulty (none, some, a lot, unable). By contrast, many studies use dependency (having someone's help to do an activity) as the fundamental indicator of disability.† There are two reasons: Dependency presumably indicates "severe difficulty", and it is considered a more credible, reliable indicator of severity than a question about difficulty. Although this sentiment is common in current research, we think it causes theoretical and empirical confusion. What dependency really measures is presence of an intervention to reduce disability. It measures a buffer to

disability, not disability itself. And we see no added virtue in an objective item, since subjective ones reveal the experience of disability in apt and direct manner. In short, a dependency indicator should be used for exactly what it is (an intervention), not as a proxy for something that can be asked directly anyway.

How is disability measured? The standard, and only economical, procedure is to interview individuals about difficulties (self-reports or proxy reports), with simple ordinal or interval scoring of degree-of-difficulty. An alternative is to observe performance of an activity in the person's usual milieu, but this approach is very time-consuming. This is especially true for activities done outside the home, such as shopping, since the interviewer and subject must venture forth together for the performance assessment. Moreover, how to score restrictions can be troublesome; interviewers must rate degree of difficulty according to some known standards, and operational rules for timing an activity and its components can be cumbersome.

B. The difference between functional limitations and disability

The words "action" and "activity" are simple devices to distinguish the concepts of functional limitations and disability. They help convey the generic (situation-free) features of one and the social (situational) features of the other. The words "task" vs "role" also help distinguish the concepts. Both pairs in terms were coined by M. LaPlante [19].

This distinction has been recognized and described by others: "Functional limitations refer to individual capability without reference to situational requirements" [6]. "Disability [is] a social process—the pattern of behavior arising from the loss or reduction of ability to perform expected or specified social role activities of extended duration because of a chronic disease or impairment" [6]. "Disability refers to the expression of a functional limitation in a social context" [10]. These echo Nagi's initial statement: "Disability [is] a pattern of behavior that evolves in situations of long-term or continued impairments that are associated with functional limitations" [8].

Functional limitations and disability refer to different behaviors, not to different aspects or ways of measuring the same behavior. Explicating this point: (1) Some researchers characterize functional limitations as "can do" and disability as "do do". The words separate a person's capabilities from her/his ultimate patterns of behavior. The researcher is really interested in measuring *two aspects of the same behavior*, not two different behaviors. (2) In a similar vein, current interest in comparing verbal reports and performance-based evaluations is a matter of *different measurement strategies for a given concept*. For example, a person's rating of own walking ability can be compared to interviewer

*In gerontology discussions, it is often stated that IADLs are necessary for "independent living" in a society. We have chosen to use other descriptors since "independent living" has a different, and very distinctive, meaning among persons with lifelong disability [42–44].

†The standard question about dependency is: if a person has someone's help to do an activity. (Sometimes the wording is "needs help" rather than "has help".) The scope of dependency can be broadened to include standby assistance (if someone must be present in case the person needs help) and supervision (if someone must provide supervision for the person to accomplish an activity). Occasionally, it is stretched still further to include use of special equipment (cane, wheelchair, etc.).

ratings or timed performance of walking. The content throughout is "walking"; the differences are in modes of measurement.

What is the conceptual niche for personal care (ADL) and household management (IADL) behaviors? They are aspects of disability, not of functional limitations. ADLs and IADLs are activities a person does as a member of society—even if they occur in private, rather than public, settings! Each depends on some basic physical and mental capabilities (functional limitations). ADLs and IADLs are *not* "physical functions", a label that appears quite often in the literature. To reinforce this point, readers might consider if bathing/showering (ADL) is more akin to visiting friends than to lifting a 10-pound object, or if doing light housework (IADL) is more similar to attending a movie than to hearing speech in a small room. These comparisons are chosen to challenge thinking, not steer it. We believe that assignment of ADLs and IADLs to disability has conceptual integrity, but recognize that some researchers disagree.

C. *Bedlam vocabulary and mixed protocols*

In the absence of a well-accepted conceptual scheme, the scientific literature on disability contains a bedlam vocabulary. Terms have been invented and operationalized in myriad ways. Common terms such as disability, impairment and functional limitations have various and overlapping meanings.* The same occurs for dysfunction, incapacity, disablement and handicap. Combining words usually obscures rather than illuminates the matter (e.g. "functional disabilities" [20]; "impaired physical functioning in daily living activities" [21]). Energy and alertness on readers' part are necessary to understand terms being used.

The problem is compounded by research protocols that combine items from different concepts. For example, impairment and functional limitation items often occur together [22, 23] or mobility and ADL items [24]. The mixing happens for many reasons (field efficiency, available equipment, the relative importance of functional outcomes to other topics); conceptual confusion is *not* necessarily the cause. Fine examples that have conceptual integrity are Tinetti's tests of gait and balance [25]; their content is entirely functional limitations (gait test) or impairments (balance test).

The problems of bedlam vocabulary and mixed protocols will fade as the research community develops more conceptual consensus.

D. *Measurement issues*

We have discussed how the Disablement Process concepts are usually measured. Here, we note three general issues about measurement that researchers debate: (1) What constitutes appropriate detail in scores? (2) Should dysfunction (negative valence) or function (positive valence) be measured? (3) Why are functional limitations so hard to measure?

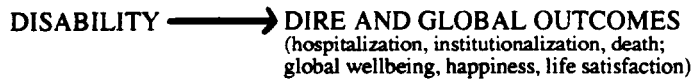
1. *Precision.* Continuous scores that tap full ranges of ability found in a population are desirable. Their utility for both scientific analysis and public health statistics is enhanced, compared to ordinal scores. Researchers can choose whether to develop prediction models of high or low function; by contrast, ordinal scores with few categories can prove too gross-grained for use as predictors or as dependent variables in scientific analyses. Public health officials can choose various cutpoints for determining disability prevalence in the population. Tests with continuous scores may cost more in training, equipment and administration time, but their value also rises.

2. *Negative and positive valences.* The concepts of impairment, functional limitation and disability are all worded in negative manner; they refer to dysfunction or low function. This negative valence is the classic perspective of medical and public health research; we want to know who has problems and why? Alternatively, one can study successful aging [26], focusing instead on rates and prediction of high function; who is doing very well and why? This is positive valence. Continuously-scored items with full range can be used for either a negative or positive orientation. Ordinal ones often emphasize one orientation (e.g. no difficulty, some, a lot, unable) and are thus unattractive to researchers of the other.

3. *Measuring functional limitations.* Researchers have encountered problems in designing protocols for functional limitations. In real life, basic physical and mental abilities do not occur solo, but are combined into doing specific activities. As a result, researchers are sometimes compelled to choose items for these generic abilities that, on the surface, look like they measure disability, not functional limitations. For example, a test on "bringing a comb to one's head" may be intended to measure "reaching" ability (functional limitation), not "comb hair" (disability). Similarly, a test to button a jacket may be intended to measure "pinch" actions, not "dressing oneself". When this approach is unavoidable, researchers must be careful to clarify their conceptual intent in reports, rather than leave the matter unclear.

*One of the most troublesome examples is Impairment. (1) In the United States, the National Center for Health Statistics uses the term for longterm structural/sensory abnormalities. These are viewed as chronic conditions and given ICD-like codes, in the same way chronic diseases are given ICD codes. Thus, impairments sit within the overall concept of Pathology. This usage is longstanding and unlikely to change. (2) By contrast, the Disablement Process and other disability schemes (ICIDH, Nagi) use the term impairment for the initial functional consequences of Pathology.

1. Quality of Life



2. Secondary Conditions and Dysfunctions

Within a Disablement Process:



A New Disablement Process:

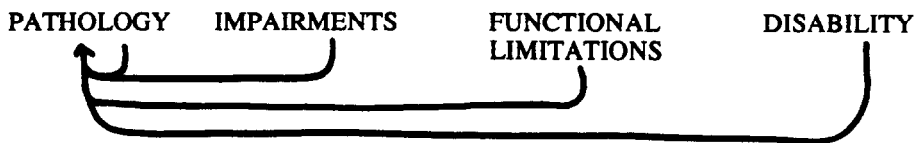


Fig. 3. Other outcomes.

OTHER OUTCOMES

Over time, the disablement process can prompt some global outcomes and two kinds of feedback effects.

1. *Quality of life.* Disability is a precursor for important outcomes such as hospitalization, institutionalization, and death. It also has a powerful effect on happiness, life satisfaction, and other global wellbeing indicators. These ensuing outcomes stand to the right of Disability (Fig. 3).*

2. *Secondary conditions and dysfunctions.* A given disablement process can lead to downward-spiraling functions, and sometimes even prompt new pathologies and their associated dysfunctions.† All of these are feedback effects, visualized as arrows pointing right to left—from Functional Limitations or Disability toward any concept to its left (Fig. 3). We distinguish feedback effects that occur within

a particular disablement process, from those that launch new pathology and its consequences. (1) Within a disablement process. Feedback loops are common for frail or longtime-disabled persons. For example, a woman with painful arthritis may restrict her recreational walking (disability); this eventually reduces her cardiopulmonary function and induces muscle weakness (feedback effects to impairment), further reducing mobility and social activities (functional impairment and disability). Loops like this can become vicious spirals; a flareup or a fall can cause swift interrelated declines in many systems, eventuating in institutionalization or death. (2) A new disablement process. Clinicians who help longtime-disabled persons focus intently on preventing new pathologies causally induced by a prior condition, its dysfunctions, or medical therapy. Examples are diabetes retinopathy (directly related to diabetes) and bed sores (due to bed disability for an initial condition). Medical professionals may visualize the situation chronologically (a primary disablement process with a secondary one strung to its right), while researchers see it as feedback loops from an initial process back to a new one (Fig. 3). In disability discussions, it is becoming clear that researchers must find ways to detect secondary conditions/dysfunctions and distinguish between the

*The Institute of Medicine report includes "quality of life", but places it in a more ambiguous position [10].

†The Institute of Medicine report uses the term "secondary conditions" very inclusively to cover all feedback effects, whether they involve pathology, impairment, functional limitation, or disability [10].

two types (within a disablement process vs a new one). Longitudinal analysis techniques now exist to handle feedback effects.

RISK FACTORS, INTERVENTIONS AND EXACERBATORS

A. Key social concepts

The main pathway from pathology to disability posits a "natural" sequence of events. One can think of the main pathway as a set of probabilities, or effects, that occur if a chronic condition operates in a social vacuum, with only medical factors operating. This is scarcely true. We now extend the model so it attains full sociomedical scope.

Certain longstanding behaviors or attributes elevate the chances of functional limitation and disability, when chronic conditions occur and progress; these are *risk factors*. Certain overt actions taken in response to disease/dysfunction reduce those chances, while others actually increase them; these are *interventions* and *exacerbators*, respectively.

1. Risk factors are defined in standard epidemiological manner. They are demographic, social, lifestyle, behavioral, psychological, environmental and biological characteristics of an individual that can affect the presence and severity of impairment, functional limitation and disability. They are predisposing; that is, they exist at or before the outset of the disablement process. They are usually long-term or permanent features of individuals, because those are the sorts of causes that prompt chronic conditions and enduring impacts.

In Fig. 2, risk factors are placed on the left side, signaling their predisposing status.

2. Interventions to reduce restrictions/difficulties are made by individuals on their own and by others (medical professionals, legislators, etc.). They serve as "buffers". Interventions include medical care and rehabilitation, medications and other therapeutic regimens, external supports (personal assistance, special equipment and devices), modifications of the built/physical/social environment, lifestyle and behavior changes, psychosocial attributes and coping, and activity accommodations. They are not predisposing, but instead are inserted during the disablement process in an effort to avoid, retard or reverse outcomes. They are numerous, changeable and often multiple (co-existing). The timing of their effects may be immediate, delayed, or cumulative. These diverse features make estimating the effects of specific interventions problematic in observational (that is, nonexperimental) research.

The locus of action for interventions can be intra-individual (they spring from or operate within a person) or extra-individual (they are performed or inserted from outside her/him). This distinction is so basic and important, we use it to portray buffers in Fig. 2. Interventions can operate on all four features

of the main pathway. Generally, medical interventions work on the left side (pathology and impairments); personal and allied health profession interventions work on the right side (functional limitations and disability); and societal interventions work on the far right side (disability).

3. Exacerbators are less common than interventions, but they can have great power in prompting or maintaining dysfunctions. Exacerbators happen in three ways: (1) Interventions can go awry; for example, drugs have side effects and surgery can make matters worse. (2) In response to their health and function problems, people sometimes adopt behaviors or attitudes that have pernicious consequences, actually increasing their limitations and disability. Examples are fear of falling, increased alcohol intake, anger at disease. (3) Society often places impediments in the path of limited/disabled people so they cannot do the things they want and are able to do. Examples are inflexible work hours, architectural barriers, social prejudice and disincentives from employment that exist in disability insurance programs. This third form is the essence of "handicap", or "social disadvantage".

Some exacerbators are introduced during the disablement process, in direct response to it (the first and second forms), while others are predisposing (the third form). All have negative consequences for functioning, certainly unintended (the first and second forms) or of debated intent (the third form). In designing research, we should always consider the nemesis presence of exacerbators and include likely suspects.

B. Intrinsic and actual disability

Personal assistance and special equipment are common, efficacious interventions used to reduce the impact of functional limitations on disability. ("Personal assistance" includes both humans and trained animals.)

The difference between a person's intrinsic ability (difficulty doing Activity X without personal or equipment assistance) vs actual ability (difficulty with personal or equipment assistance) can be very great. For example, morning help to button clothing or special fasteners can keep a person dress in 'suitable' manner for a high-profile executive job. Using a cane can improve outdoor mobility, making it possible for someone to continue attending movies, concerts and church services.

Contemporary surveys tend to ask only about intrinsic disability. A typical question is: "By yourself and without using special equipment, do you have difficulty [doing Activity X]?" Surveys ignore how well a person is actually doing with assistance (personal or equipment); that is, her/his actual disability. This has prompted great complaint by disability rights advocates. They note that many profoundly impaired individuals acquire external supports

that allow them to function very adequately. They demand that statistics report not only their intrinsic disability but also their (lesser) actual disability, for which they are justly proud. An appropriate question to capture actual disability is: "All in all, *with* [types of external support], do you have difficulty [doing Activity X]?"

Although the complaints arise from those with lifelong disability, they are equally apt for late-life disability. Older persons with chronic conditions also strive to overcome intrinsic disability by use of personal and equipment assistance, and they are often very successful.

The distinction between intrinsic and actual disability is not esoteric. It has strong implications for public health statistics, for design and development of disability technology, and for long-term care policy.

EXAMPLES OF THE DISABLEMENT PROCESS

We illustrate the disablement process by three examples.

1. A woman age 74 with osteoarthritis in both hands (pathology) has weak grip and restricted finger flexion (impairments). This causes difficulty in grasping and rotating fixed objects (functional limitations), and she has trouble opening jars or doors (disability). She purchases kitchen devices and special door handles (interventions) to overcome the difficulty.

2. A man age 52 with advanced emphysema (pathology) has very restricted lung capacity and feels perpetually tired (impairments). He cannot climb stairs or walk for more than several minutes (functional limitations). He is finally forced to quit his job as a foreman (disability).

3. A woman age 90 has no specific diagnoses (pathology), but her sight, hearing, and senses of taste and smell have diminished significantly in recent years and she is forgetful and feels confused (impairments). Gradually she stops socializing (disability) and becomes deeply depressed (quality-of-life outcome). She spends most of the time tearful and seated (functional limitations; feedback effects from disability). Her physical frailty steadily increases (impairment; feedback effect from functional limitation). One night she dies while sleeping.

The conceptual scheme's atpness and flexibility become apparent with its use in discussion and research. Initially, it may be difficult to decide which conceptual niches fit one's variables of interest. That does not reflect a flawed scheme, but instead diverse professional orientations and conventions, the specific pathology or research questions being studied, and the complex interwoven nature of late-life health. (For instance, depression can be especially difficult to place; it can represent pathology or function or quality-of-life, depending on the specific research topic.)

DISABILITY AS A GAP BETWEEN PERSON AND ENVIRONMENT

So far, the discussion implies that disability is a personal feature, in the same way as age or occupation. In truth, disability is not inherent in a person. Instead, it denotes a relationship between a person and her/his environment (also Refs [6 and 7]). Disability occurs for a given activity when there is a gap between personal capability and the activity's demand. Disability can be alleviated at either side, by increasing capability or by reducing demand.

In medical and public health settings, discussions tend to focus on interventions that will improve or maintain people's capability. This ignores the importance and malleability of demand. In real life, efforts to reduce demand are a common feature of the disablement process. Disability can be diminished swiftly and markedly if the physical or mental demands of a given task are reduced.

To reduce demand, the options are activity accommodations, environmental modifications, psychosocial coping, and external supports. (1) Activity accommodations. In the presence of disease or dysfunction, people modify their activities to reduce the physical and mental demands posed. Accommodations can involve "what, how, how long, how often". More formally, these words mean: the specific activity, procedures to do it, amount of time spent, and frequency of doing it. Examples are: A man with rheumatoid arthritis quits a high-stress management job and becomes a free-lance editor ["what"]; a woman with osteoarthritis shifts from knitting with small needles to big ones ["how"]; a man with scleroderma decides to spend more time brushing his teeth and less time grooming his hair ["how long"]; and a woman with diabetes decides to travel just once a year to visit her children rather than twice a year ["how often"]. (2) Built, physical and social environment. Modifications of the built environment, changes in ventilation, heat and light, social attitudes and social laws can reduce demand sharply. Examples are: A woman has handles installed in the bathtub; a man moves to a house without stairs; an employer buys special furniture for employees with chronic back pain; a city offers special bus services for mobility-limited persons or makes its entire fleet accessible; laws prohibit employment discrimination for disability. (3) Psychosocial coping. Persons with chronic conditions and dysfunctions gradually accept some of the symptoms and limitations. This can occur through private paths (prayer, rethinking life's purpose and value) or more social ones (peer support, confiding in someone). These coping behaviors serve to alter a person's standards about how s/he should "be" and "behave"; they help create a new definition of self that is "less demanding". (4) External supports. Personal assistance and special equipment operate at the immediate periphery of a person, and whether their effect is to reduce demand or to

augment capability is somewhat ambiguous. This ambiguity is keenly felt by disabled persons. Adopting external supports (especially personal assistance) is psychologically difficult, because they affect self-definition, public labeling, and public behavior towards a person. In this article, we shall view external supports as demand-reducing.

The Disablement Process diagram in Fig. 2 includes these demanding-reducing interventions, but it does not highlight their distinctive nature. The diagram has a person-centered emphasis. Environmental aspects are not emphasized. Figure 4 redraws the model from a person-environment perspective. It gives better visual balance to the dual importance of these realms for disablement.

Why does the person-centered perspective exist and persist so strongly in science? There are three reasons. (1) Medical perspectives have enduring, and often unconscious, influence in health research. Medicine aims to influence pathology and impairment by drugs, surgery and other therapeutic modalities that act on individuals' soma and psyche. Social scientists extend this purview to include demographic, social and psychological characteristics that affect pathology, impairment and other functional outcomes. Although this improves scope, the person still remains at center stage and the medical model is still in force [27-30]. (2) Surveys are the standard technique for obtaining information about health and disability. Survey methodology is well developed

for samples and interviews of individuals, and this inevitably steers scientific questions to be framed from that perspective. (3) The notion of demand has been captured in qualitative research on coping with chronic disease [31, 32]. But how to measure it in quantitative manner has perplexed researchers. Are there compact ways to describe built, physical and social environments? Can personal interviews yield reliable and valid responses about the environment? Do people know of and remember the activity accommodations they have made over time [18]? Finding efficient strategies to assess current demand and changes in demand over time is on survey researchers' agenda.

"Person-environment fit" models have been proposed in the social sciences [33-36] for topics other than disability. This literature should be sought out as disability researchers consider the importance and measurement of demand.

The person-centered focus has been successfully removed in one discipline, human factors research. It gives equal attention to person, physical environment and machine environment to understand performance problems [37-40]. Remedies are considered and applied to the capability side (person), the demand side (environment) or both. Adopting a human factors approach in disability research is feasible for very specific questions [41], particularly those with an applied engineering flavor: e.g. "What kitchen equipment can help older persons with arthritis prepare

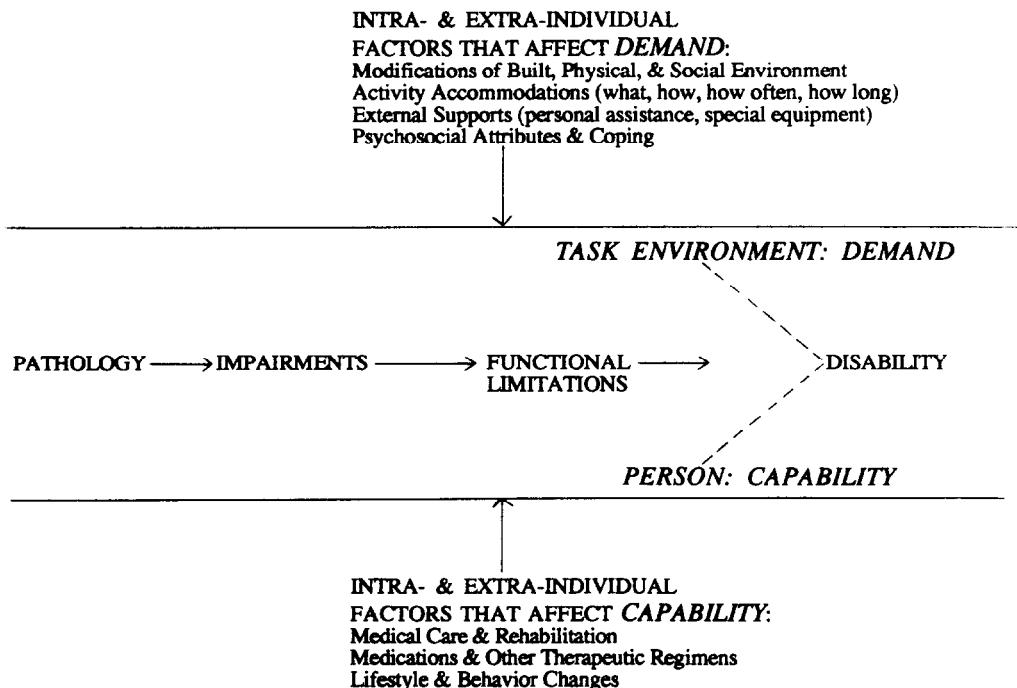


Fig. 4. Disability as a gap between capability and demand.

meals easily?". It is simply not feasible for the sorts of general questions posed in this article.

Nevertheless, the importance and fundamental veracity of seeing disability as a relationship, not a personal characteristic, must be kept firmly in mind as we go about doing person-centered research.

LIFELONG AND LATE-LIFE DISABILITY

Disability is an experience that spares no age group. We use the terms "lifelong" and "late-life" to designate when a serious chronic condition begins: in childhood or youth vs mid or late life. That timing makes a great difference in the nature and duration of the disablement experience.

The usual causes of lifelong disability are congenital/developmental conditions and severe injury in childhood or youth. Disability is often profound, pervasive and (for injuries) rapid in onset. By contrast, the usual causes of late-life disability are chronic diseases, whose usual onset is at middle or older ages. Disability tends to be mild or moderate, initially restricted to a few activity domains but expanding over time, and slow to accumulate.

There are many differences in the disablement process for the two groups. Lifelong disabled persons do not enjoy the expansion of skills and activities in adult years, or the total diversity of lifetime experiences, as their nondisabled peers. For many, the issue of activity accommodation is effectively moot. Capabilities are very restricted and usually stable (not easily or at all remediable). Demand looms large for virtually any activity. In this situation, attention focuses on external supports and on environmental and social access. High quality and reasonable expense for equipment are paramount concerns. Achieving personal control after years of dependency is a courageous goal; it is the central theme of the independent living movement [42-44]. Access to buildings, vehicles and jobs is demanded as a basic social right. For very good reasons, a constant plaint of lifelong disabled persons is "Change the milieu, not me!"

By contrast, late-life disablement is a gradual process, and people devote attention to restoring the capabilities they once enjoyed and recall very well. Their diverse experiences and adaptations to other troubles over a lifetime serve as resources when activity accommodations need to be made. External supports come into daily life gradually, and problems of access are more limited. The disablement process involves gradual adjustment and a good deal of personal choice. At the extreme—when capabilities are greatly reduced by disease, external supports are present and critical, and mobility is greatly diminished—late-life disability comes closest to looking like lifelong disability. . . . But the sentiment is never the same; the difference between a young disabled adult who yearns to experience life's delights

and an elderly disabled person who has done so is indubitably vast.

A good model of the disablement process should encompass both lifelong and late-life disability. The conceptual scheme in *The Disablement Process* is suitable for both experiences, but the relative importance and dynamics of the conceptual pieces vary greatly for the two situations.

EPIDEMIOLOGY AND PREVENTION OF DISABILITY

The disablement model extends traditional epidemiological, medical and public health perspectives so that they focus on functional outcomes. It offers an architecture for research design and for applications of research results in health policy and medical care.

A. Research: the epidemiology of disability

The epidemiology of disability is the study of disease consequences rather than disease etiology, using the perspectives and techniques of social epidemiology. (The term "epidemiology of disability" was coined, we believe, by Nagi [45].) Succinctly stated, the focus is $P\{\text{Disability}|\text{Disease}\}$, not $P\{\text{Disease}\}$; P is probability. Observational studies can uncover presumptive causes of dysfunction for specific diseases or populations. They suggest interventions whose efficacy can be studied by experimental research in clinical or community-dwelling populations. Ultimately, observational and experimental research guide public health policies and programs.

B. Policy and care: the prevention of disability

The term "prevention of disability" is becoming popular, an indication of increasing concern among public health professionals and clinicians about people's functioning in the presence of disease, not just the onset and course of disease and fatal outcomes.

There is a well-established typology of prevention strategies used in medicine and public health that describes where professional efforts are aimed [46, 47]. Primary prevention aims to avert onset of pathology. Secondary prevention is early detection and management of pathology. Tertiary prevention is interventions to reduce disease impacts; it includes efforts to avoid onset of secondary conditions, to sustain life (heroic care), and to maintain and restore function ("prevention of disability"). The broad sweep of tertiary prevention—it encompasses functional limitations, disability, dire and global outcomes, feedback effects—reflects the relative disinterest in disease *consequences* that characterized medicine earlier in this century when the words were coined. Some researchers propose that "tertiary prevention" now be limited just to disease-related efforts (avert secondary conditions and avert death) and that the term "quaternary prevention" be used

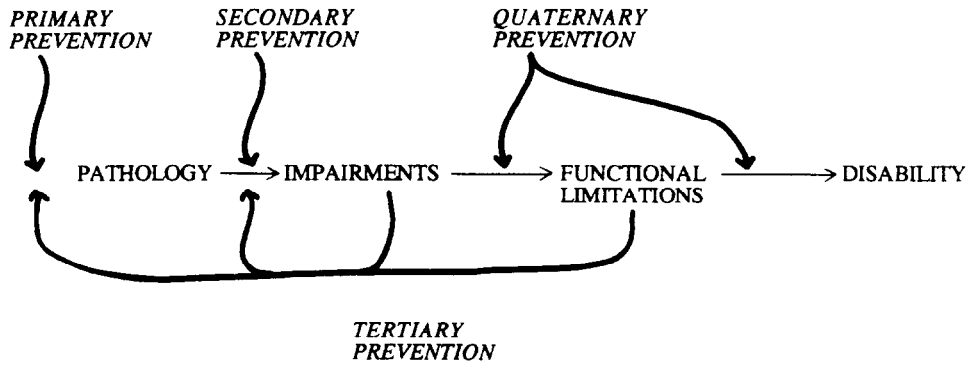


Fig. 5. Prevention strategies.

for function-related efforts (maintain and restore function).*

Figure 5 shows the position, or timing, of the four types of prevention in the disablement process. Primary prevention acts ahead of pathology, secondary before impairment, tertiary on feedback effects for new pathology and new impairment, and quaternary before functional limitations and disability.

The goal of disability prevention is to sustain and restore functional capacity and to maximize older person's social involvement and independence. Primary and secondary prevention are the desirable strategies; they protect against potentially disabling pathology and impairments. Efficacious interventions for those stages will evolve as knowledge of disease etiology expands. For the foreseeable future, tertiary and quaternary prevention will be the active strategies, helping people to overcome and diminish disability. Research on effective and affordable interventions, ranging from technological to psychological, should be high on the agenda of gerontology.

CONCLUSION

Prevention of disability is a rising theme in public health policy, well-timed with societal changes that will boost both disability prevalence rates and the numbers of disabled persons for coming decades.

Disability prevalence rates are likely to rise in all age groups for two reasons: First, contemporary medicine excels in detection and management of life-threatening chronic diseases. This prolongs life for many persons (called marginal survivors), but their added years are often disabled ones [48–50]. Second, rising proportions of females in the oldest age groups are an ongoing feature of our aging population [51–54]. Disability rates are typically

higher for women than men in a given age group. There are many likely reasons; key ones are women's higher average number of chronic conditions and their higher prevalence rates of nonfatal conditions [1, 2, 55]. Even without fully knowing those reasons, we can expect rising disability prevalence as the older population becomes more female. The numbers of disabled persons will rise due to the combination of increased age-specific disability prevalence rates (just discussed) and overall population aging (which swells the number of persons with chronic conditions and their associated dysfunctions).

The need for research and health policy on disability is discussed in recent reports [10–12]. Adopting a similar conceptual architecture, they are helping to establish common ways of thinking and talking about disability. This article complements and advances those reports.

The Disablement Process is a thoroughly socio-medical model, paying attention to both medical and social aspects of disability. We explicate the pathway from pathology to disability in ways suitable to medical sociologists, epidemiologists and clinical researchers. We elaborate that basic scheme by incorporating risk factors, interventions and exacerbators. The concept of disability is given new sociological heft: We stretch its scope to all activity domains, defend the metric of difficulty over dependency, introduce the notions of intrinsic and actual disability, and discuss the virtue and verity of a person-environment perspective. The Disablement Process compasses both lifelong and late-life disability, but there is great need for more theoretical work about how onset and duration affect the disablement experience.

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*One author (LMV) likes the new usage of "quaternary prevention"; the other (AMJ) prefers standard usage.

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