

Rethinking Aging and Daily “Difficulties” From Functional Bodies to Functional Communities

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Common sense allows that persons unable to handle a difficult problem can be labeled “disabled” . . . Cultural analysis shows that disability refers most precisely to inadequate performances only on tasks that are arbitrarily circumscribed from daily life. Disabilities are less the property of persons than they are moments in a cultural focus. Everyone in any culture is subject to being labeled and disabled. -- Introduction from “Culture as Disability” (McDermott and Varenne 1995: 5)

The measurement of ability has always played a central role in our understanding of aging. In some ways, the loss of ability is assumed to be a sign of aging itself. But, the relationship between the two is complicated. A greater degree of self-reflection is now changing the ways that we look at the tools and methods used to assess disability in aging studies. From the habits of clinical practice, to the assessment of function in community-dwelling elderly, and to the planning of “age-friendly” communities, I would argue that an anthropology of functional assessment is needed to examine the cultural constructs and practices at work in each domain.

For many older adults in the U.S. today, optimism for new ways of aging is still mixed with lingering fears of physical decline. Associated Press polling data (2012), show that the majority of “baby boomers” are “upbeat” and not really

feeling “old,” but when asked to rank their fears, loss of independence due to physical illness leads the way (45%) ahead of “running out of money” (41%) and “worrying about dying” (18%) (Cass and Anderson 2012: 2). In the study of population health and aging, the achievement of increased longevity is often overshadowed by the projected prevalence of “disability” with age. In 2006, for example, the Population Council observed that “a fundamental question surrounding the increase in survival is whether the extra years of life are being spent in good health or bad health” and “. . . subject to the most disagreement has been the trend in abilities to perform personal-care activities. . .” [my emphases added]. Similarly, demographic projections from the SCAN Foundation on the need for long-term care, suggest that while “70 percent of seniors will be unable to live in their own homes without some kind of help” only “37 percent. . . understand how likely they are to need assistance” (Weintraub 2011).

Yet, many have labeled this focus on physical decline and dependency as “ageist” (Butler 1975) and a tool for generating “alarmist” population demographics (Dant 1988; Longman 1999; Peterson 1998). In clinical practice, function and health are almost synonymous. The assessment of functional ability has been called the “lingua franca” of geriatric medicine (Mortimer 2003) where care is aimed at both assessing and preventing functional loss. As Gubrium (1993) observed, “the aging body” is both the subject and object of biomedical

encounters where "as subject, I describe; as object, I am described" (1993: 53). However, while the inevitability of decline and dependency seems so certain, it appears that after years of research on aging daily life through the assessment of ADLs (activities of daily living) and IADLs (instrumental activities of daily living), we are now in the midst of an intellectual and methodological crisis over the measurement and classification of disability in population studies.

In January 2009, the National Research Council (NRC) and the National Academy of Sciences (NAS) sponsored a summit meeting among experts in the field to improve the measurement of late-life disability in population surveys "beyond ADLs and IADLs" (NRC 2009: 1). With so many tools, scales, and variations in national survey items, it was concluded that there was "no standard for ascertaining the occurrence of disability" (2009: 20) and "substantial differences "in prevalence rates due to a diversity of "conceptual definitions" measures, wording, sampling, and modes of data collection (Wiener et al 1990). In other ways, the tools are not keeping up with the social transformations among older adults. The NRC participants, for example, cited data from the Health and Retirement Study (2006) showing that: 14 to 20% of those over age 65 were using "some kind" of assistive technology regardless of task difficulty, and that by the mid-1990s, almost 50% had already adapted their homes to reduce barriers (NRC 2009: 69-70).

At the root of this current debate, according to NRC, is also a growing ideological conflict over terminology and methods. On the one hand is the "medical view" where disability is seen as an "attribute" of the individual due to an underlying condition or impairment (2009: 6). On the other, is the "social view" where disability is seen as "the product of physical, organizational, and attitudinal barriers in society" (2009: 7). As the NRC participants noted, applying a more synthetic view would mean seeing that "disability is experienced when the person with functioning limitation interacts with the cultural expectations of the physical environment" and given that there are "far fewer measures of this type" to document this dynamic interaction, they recommended that this is "probably the direction that measurement should take to understand the full effects of functional limitations" (NRC 2009:16) [my emphases]. In further discussion about ways to improve measures of disability, a number of suggestions emerged including: 1) greater attention to the conceptual meanings of quality of life, coping, well-being, and social participation, 2) self-reflection not only on "what can be asked" but how, as well, and 3) the use of "vignettes"

and other qualitative measures to better understand the dynamic "pathways" to disability in different populations (NRC 2009: 85-86).

In the anthropological study of aging, the body, and disability, these suggestions should sound familiar and obvious. However, I would argue that this self-reflective turning point in the study of functional assessment is also an important opportunity for the role of anthropological inquiry in this growing debate between the "medical view" and the "social view" (NRC 2009: 6-7). The limitations of bio-medical approaches to "the body" (Burroughs and Ehrenreich 1993, Foucault 1978, Turner 1992), are familiar as cross-cultural studies in medical anthropology have challenged the naturalization of certain somatic states associated with aging including: senility (Cohen 1998; Traphagan 2000), menopause (Lock 1993), and urinary incontinence (Mitteness and Barker 1995). Again, as McDermott and Varenne (1995) have argued, "disabilities are less the property of persons than they are moments in a cultural focus" (1995: 5).

Where might this anthropological inquiry lead for improving the measures of "daily activity"? It means more than creating new surveys. It requires a deeper exploration of the concepts whose meanings are too often taken for granted. A number of recent works are doing just on terminology that shapes assessment including: independence (Portocolone 2011), autonomy (Leece and Peace 2010), neglect (Iris et al 2010), and lifestyle behaviors (Albert et al 2009). It requires, what one expert calls listening to the meanings "behind the words" of participants in the assessment process (Brody 2010). It also requires paying more attention to the ways in which "environments" (physical, social, and natural), can enable or disable individuals (DelaTorre et al 2012; Glass and Balfour 2003; Golant 1984). Over the years, my own work has taken me across different domains of function and activity from: 1) broadening the scope of "comprehensive medical assessments" in medical education to 2) the qualitative assessment of individual function in communities to 3) the assessment of "age-friendly" (WHO 2007) community capacity in the midst of urban planning and urban renewal. I would argue that these domains of analysis should not be seen as separate and that each is crucial terrain for a critical anthropology of functional assessment. For a more complete review of geriatric assessment tools and methods (see Gallo et al 2006: 193-240); for more on the classification of "disability" (see Nagi 1991 and WHO 2002), and for more on the status of "disability studies" (see Albrecht et al 2001 and Davis 2006).

Limitations in the Assessment of Daily Activity

Over time, institutional and administrative demands (for example, a lack of time in clinical practice) have changed the ways the tools have been used and have led to a loss of specificity when assigning the status of disabled. Even though the ADL index (Katz 1963) was originally designed to assess the rehabilitation process of hospitalized patients "with fractures of the hip" (1963: 915), to this day, the Katz Index remains the standard for assessing general "functional disability" for older adults in the community as well. Since it was first established and promulgated, several clinical investigators have remarked that the scoring system is one of its principal weaknesses (Gill and Kurland 2003, Philip et al. 1998). On paper, the scoring form itself encourages observers to make subtle distinctions in performance (unassisted and assisted) for a variety of tasks (eating, getting dressed, grooming, walking, getting in and out of bed, bathing, and using the toilet), but then the final scoring process reduces these distinctions to binary opposites (independent and dependent) (Bennett 1999). Kane and Kane (1981), for example, noted that "the individual who needs a corrective device to perform the function or who requires the help of another person is assigned an intermediate position between independence and dependence. [Yet] sometimes, these two forms of dependency are equated and receive the same score" (1981: 43). This simplification has tended to increase over the years, thus eliminating much of the variability of the data (Bennett 1999:23), as the original index has been modified for use in clinical practice (Hartford Institute for Geriatric Nursing 2007), where individuals receive scores of 1 for independent and 0 for dependent. For example, while Katz originally allowed for some types of mechanical or personal assistance in his definition of "independence" with bathing and toileting (Katz 1963:916), this has routinely been lost in translation over time.

Similarly, for the tasks in the IADL index (use of the telephone, shopping, preparing a meal, cleaning house, doing laundry, using transportation, managing medications, and managing finances (Lawton and Brody 1969, Lawton's 1971), the assessment options included a variety of intermediate scenarios between fully able and fully unable. For example, when using the telephone, options include: 1) being able to "answer" the phone and dial a "few well-known numbers" or 2) "answering" the phone, but no longer "dialing numbers." For shopping, an individual might: 1) be able to do "small purchases" on his or her own or 2) need to be accompanied (Lawton 1971: 473). Yet, in clinical practice, a simplification in scoring is often accepted. Citing "no systematic study of the relative

frequency of the use of different scoring methods," Graf (2008), suggests that one "common" option is to rate each item "dichotomously" (0 = less able, 1 = more able)" (2008: 54). Similar patterns are seen in population studies (for example, the National Long-Term Care Survey), where the criteria for "disabled" includes "any type of assistance, human or mechanical, for any ADL . . . or for any IADL, that had lasted or was expected to last, for a minimum of 90 days" (NLTC 2007/1999). However, when put to the test, items in the IADL index exhibit much more variability in performance than do the items in the ADL index owing to social, cultural, and economic factors (Diehl 1998, Horgas et al 1998, Jette 1994, Miller 2005). Cross-cultural uses of the index (Avlund et al 1996; Martin 1989) have shown that the universality of these items should not be taken for granted and that performance on each is highly variable. In Avlund et al's (1996) study of English, West Indian, Asian, and Danish individuals, they observed that "nearly all [ADL] activities were performed by everybody, while none of the [IADLs] were performed by everybody" (1996: 10) due to "cultural differences in washing habits and types of clothing" as well as "actual differences in health as well as differences in gender roles" (1996:12).

In my own research in New York City (Costly 2008) with 64 community-dwelling older adults between the ages of 69 and 91, an assessment of their ADLs and IADLs using open-ended interviews (in addition to a semi-structured survey), revealed a number of issues that should challenge the use of these standard indexes and give insight into the social worlds of aging bodies. Even when individuals agreed to be interviewed, it was clear that many had a critical view of the index questions and the scoring options. All the informants resisted being misrepresented as old or frail on scaled items that did not allow them to explain their answers in more depth. In some cases, certain questions about needing help with basic activities (like getting dressed or using the bathroom) were also seen as stigmatizing, or even a bad omen. For example, when I asked "Mr. Wilson," a 75-year-old African-American man, living alone, whether he ever needed any help to get dressed, he replied, "No, no. I don't need no help. You're trying to make me old, before I get old. I'm pretty fortunate. . . . I can hold my own. So far, so good." This reaction, I would argue, was not just avoidance and it should remind us not only to listen to others, but also to imagine how these questions sound to others. This reflexivity has always been a strength of anthropological inquiry. When Maria Vesperi (1998) explored the ways in which older adults became defined as a social problem in an economically challenged urban neighborhood in Florida, she also argued that we need to

move past examining what it is like to be old and examine what it feels like to be regarded as old, where old age is not a discrete physical state, but a cultural "concretization" of abstract and often unexamined assumptions and everyday social interactions (1985: 22) [my emphasis].

In my interviews, individuals routinely made important and meaningful distinctions between "needing help" and "having difficulty" that made scoring their functional status challenging. These distinctions did not always match with many examples of lived experience. One woman, "Mrs. Porter," (at age 77), exemplified what I called "collaboration as an extension of self." She was candid about needing help with walking (away from home) and bathing, but she said that managing her finances (normally considered a more complex task) was "easy." She said, "I have a checking account. . . . I can pay my bills by check each month. But, I ask my home attendant to mail my bills for me, and sometimes, I ask my brother to go to the bank to get me spending money. Sometimes, I need my home attendant to look at my insurance statements with me, too." When I asked her whether, in her opinion, she felt she had any difficulty managing her own finances, she said, "No."

In other ways, the scoring system itself often seemed irrelevant to many participants' lived experience. In one memorable encounter, for example, when I asked, "Mrs. Ivan" (at age 82) to describe (on a scale from 1-10) the level of difficulty that she was having while getting dressed in the morning she shot back at me, saying: "I manage. I have to do it. It's not easy, okay. Put whatever number you want. . . . I have to get dressed every day, so what's the use to cry over it. I have to do it; that's it. Listen, I had a very tough childhood, and there was no feeling about it. I never cried about things. You have to do it. I manage. I don't make a big deal out of it."

"I can manage" was a phrase that I heard repeatedly during the interviews. It came to be a defining and revealing response on many levels. On one hand, it reflected a fundamental, vital effort to be recognized and acknowledged as a competent being. On the other, I came to realize that it revealed a participant's resignation that social networks were weaker than expected. Many participants in their retirement were actively caring for other family members, both younger and older (e.g. grandchildren and parents), yet had very low expectations for receiving daily support from family members in the future. Proximity to kin was no guarantee of support

when extended families were struggling with their own burdens and limited resources. While 72% of participants indicated that they had grown children and close kin in New York, 56% said that no one would be able to help them with daily activities "on a regular basis" if needed. When I asked several people to imagine a future where they could not manage on their own, many sat silently, not answering. Some invoked the reluctance to become a burden to others. But, every participant's story, I learned, had its own logic and revealed a carefully crafted calculus of his or her unique situation.

Functional Bodies and Functional Communities

The assessment of disability must account for the social and material world in which people live and the numerous factors (psychological, social, environmental, and geographic) that affect function. The fact that older adults can be made vulnerable by their social and physical environments, especially in times of extreme heat, has been well documented (Klinenberg 2002). In many cases, we can also see that the greatest challenges to disability do not always begin with the individual. In my own study, an earlier community needs assessment, commissioned by a local non-profit agency (Rosenthal and Rubel 1989) had already estimated that over 4,000 of the neighborhood's elderly residents were "to some degree disabled" according to criteria from the Health Resources Administration. But, by suggesting that "problems of isolation were caused, in part, by a changing social environment, fear of crime, and a challenging physical geography," they argued that physical weaknesses were not the greatest limitations (1989: 6).

As more and more individuals, especially in large urban areas are now viewed as "aging-in-place" (AOA 2005), the qualities of our physical and social environments are getting more attention. Population aging is now an issue for urban planning and public health and a catalyst for a number of initiatives to develop: "age-friendly" cities (WHO 2007), "lifespan communities" (Stafford 2009), neighborhoods for "successful aging" (Abbott et al 2009) and more "walkable" communities to promote daily physical activity (Glicksman 2011). In 2010, Portland Oregon became the first U.S. city to join the World Health Organization's Global Network of Age-Friendly Cities (DeLaTorre et al 2012). New York City was second (NYAM 2008). In each case, substantial coordinated efforts are needed to ensure access to affordable healthcare and housing, safe and affordable public transportation, and opportunities for

employment and social relations. The common goal is to "create good place[s] to grow up and grow old" (Stafford 2009). But, with each of these initiatives, I would argue that we also need to stay focused on the ways in which disparities in geography, income, and homeownership patterns can lead to disparities in the distribution of these municipal investments and resources.

We also need a variety of ways to explore the relationships between individuals and their environments. In the NRC workshop, it was observed that while IADLs have typically been described as "concerned with a person's ability to cope with his or her environment" (NRC 2009:22) a focus on the body, per se, has led to a "neglect" of the home environment with few measures to assess how "features" of the environment and home affect individuals (NRC 2009:72). We know that the physical environment can affect behavior and activity, but it would be a mistake, I believe, to focus solely on the development of new objective measures of the physical environment.

Subjective views also matter in ways that require more study. For example, in Albert et al's (2006) study of variations in "clinician-rated and self-rated disability" with IADLs, among 33% of respondents there were "discordant cases" where clinicians rated individuals as having "inefficient" performance, but where individuals had no self-reported disability. In other cases where individuals had self-reported IADL disability, clinicians saw them as "competent" (2006: 829). The authors discovered that "respondents who considered themselves disabled in IADLs, but who were rated as competent by clinicians, lived in home environments that were rated as more cluttered and in need of repair . . . less adequate in space and comfort . . . and less secured for preventing crime...compared to the other [respondents]" (2006: 829). These results should challenge us to critically examine the impact of the environment not just on behavior, but also on the perception of culturally-constructed ideas of disability and competence. When individual perceptions, preferences, values, and expectations matter, the focus on measuring what "bodies can do" is inherently incomplete, especially when it seems to reinforce a western and a U.S. preoccupation (Portacolone 2011) with maintaining "independence" at all levels. As a cultural value, it has reached the level of a social fact (Durkheim 1966) as both socially reinforced and deeply internalized by individuals.

An anthropology of functional assessment is needed in multiple domains. It is needed to explore the degree to which older adults struggle with the imperative of dependence and the ways in which existing measures fail to match

lived experience. It is needed to explore the extent to which we reinforce the expectation of independence in existing tools and methods through a "medical" model that appears to be losing its primacy. It is needed to build "community" and explore the dimensions of the environment in multiple ways beyond the physical that can become enabling and disabling for older adults. This current period of methodological introspection is an opportunity not just for building better tools, but for developing more interdisciplinary and critical approaches to functional assessment.

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