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Conceptual issues in the measurement of participation among wheeled mobility device users

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Abstract

Purpose. To review current measurement approaches to activity and participation among wheeled mobility users and suggest key factors researchers should consider as they continue to develop and refine both the concept of participation and its measurement.

Methods. Literature review and expert opinion.

Results. Four issues are reviewed:

1. Participation as a concept and as a key domain of the revised International Classification of Functioning, Disability and Health (ICF).

2. The ‘perspective’ of current participation self-reports as they reflect the underlying cultural values of autonomy and independence.

3. The lack of sensitivity in current participation measures to assistive technology.

4. The significance of the ICF qualifiers ‘capacity’ and ‘performance’ to the accurate assessment of activity and participation among wheeled mobility users.

Conclusions. The following suggestions are offered as researchers continue to develop increasingly sophisticated instruments and methods: (1) participation measures need to be device-specific; (2) measures ought to capture both ‘capacity’ and ‘performance’; (3) methods need to be sensitive to those factors that impact mobility device use over time; (4) methods need to be sensitive to the complexities of both the social and physical environment as they impact device use; and (5) measures need to reflect the impact of multiple mobility device use.

Keywords: Participation, ICF, outcomes, wheelchair

Introduction

This paper will locate the concepts of activity and participation within the current International Classification of Functioning, Disability, and Health (ICF), review current measurement approaches to participation in rehabilitation, and offer suggestions for future development of participation data-gathering methods. It is argued that current measures of participation are inadequate to the task of measuring activity and participation among wheeled mobility users. Indeed, the focus here will be on those tools that raise important conceptual issues for participation measurement among wheeled mobility users, rather than the full range of current instruments available across all disability and assistive technology (AT) studies. Issues to be discussed include the effect of the perspective of the instrument as it relates to the cultural values of autonomy and independence, measures’ sensitivity to the impact of AT, and the significance of the ICF qualifiers of capacity and performance and their importance to measuring activity and participation among wheeled mobility users. In addition, a new methodology that synthesizes passive, technology-based quantitative data collection and self-reports will also be described. It will be argued that activity and participation measures need to be developed with reference to
device(s) used within the context of their homes, communities, and within the network of physical and social environmental features that frame an individual’s experience of disability.

Increased participation in society by people with disabilities is a major goal of the Americans with Disabilities Act (ADA) and, more recently, the New Freedom Initiative (NFI). These mandates reflect a shift away from the influence of a medical model (e.g., functional performance) towards a social model of disability. This social model emphasizes the lived experience of people with disabilities as reflected in the notions of participation and access to community life. This transition presents an opportunity for re-examination and redesign of current measures of participation.

Notwithstanding the ADA and NFI directives, participation in society remains a challenge for people who use wheeled mobility devices. Despite having more accessible buildings, housing, schools, and recreational facilities, mobility device users still make fewer trips outside the home, and engage in fewer activities than people without disabilities [1]. Moreover, people with severe disabilities, which includes wheelchair users, have attained the lowest levels of education and remain the nation’s largest class of chronically unemployed individuals [2].

Although wheelchair users comprise less than one-quarter of mobility device users, the need for more participation-focused studies, better measurement tools and study designs transcends the size of the population. Reasons for this need include: first, wheelchairs are highly visible signs of disability and have, in fact, become symbols of disability, both literally (the international symbol for handicap) and culturally. Second, wheelchair users are more likely to be limited in everyday activities than other mobility device users. More than 90% of wheelchair users report activity limitations and only 14.7% are able to complete all of the activities of daily living (ADL) mobility tasks. Third, prevalence of wheelchair use has doubled in the last decade and is growing rapidly [3].

Lack of participation in home and community activities is the result of many factors, both intrinsic and extrinsic to the person. The recently revised ICF offers a classificatory system that attempts to capture the range of factors potentially impacting a person’s experience of disability [4]. Participation and activity are one of four interrelated domains that together comprise peoples’ experience of disability as described within the ICF. Two additional domains include medical descriptors of body structures and functions. The fourth domain identifies contextual factors.

Contextual factors include first, the environment which contains those features outside the individual that form the context of everyday interaction and includes everything that a person encounters during participation as a human being in society [5–8]. The link among environmental barriers, activity, and participation has long been recognized as a key aspect of participation [9–11]. Yet, until recently, studies of wheelchair mobility focused primarily on technical requirements for accessibility, such as ramp slope and surface materials, rather than the larger context of use and living [12]. As a response, a growing body of research has begun to focus on identifying barriers to outdoor mobility, such as distance traveled, changes in the level of terrains, and width of walkways [10,13–15]. Contextual factors also encompass personal variables within the individual that impact the disability experience, e.g., personal attitudes. The combined interrelationship of these four domains is meant to capture, ‘all aspects of human health and some health-relevant components of well being’. That is, the lived experience of being disabled must be comprehended as the interaction of health, social, personal, economic, and political factors.

Overview of ICF definitions of activity and participation

The ICF defines activity as the ‘execution of a task or action by an individual’ and participation as ‘involvement in a life situation’. Participation replaced the older term handicap, in part because of its associated pejorative connotations, and in part because the authors wanted to represent participation in a more open-ended and semantically neutral continuum. They state:

‘Handicap’ is now described as a participation restriction. As Dijkers notes, the current use of participation encompasses previous related research aspects of its current meaning including social support, social adjustment, community (re)integration, and independent living [17].

In addition to defining activity and participation, the ICF notes two essential measurement qualifiers.

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In addition to defining activity and participation, the ICF notes two essential measurement qualifiers.

The first is performance (‘what an individual does in his or her current environment’), and the second is capacity (‘the ability to execute a task or an action’).
Capacity is most often determined through clinical measurements of basic functional activities such as reach. Performance is typically evaluated through self-report of activities in the context of a person’s natural environment.

This distinction is important to outcomes researchers. For example, a person may demonstrate the capacity for reach within a clinical environment using a mobility device, but be unable to reach an item located on their kitchen countertop (performance), either because of the placement of the item or the height of the countertop. For rehabilitation purposes, it becomes important to discern between the functional capacity inherent within an individual (including his or her mobility device skills), and those features in an individual’s everyday environment which may hinder or facilitate the performance of activities. Capacity therefore tends to reference the ICF domains of body structures and function, while performance reflects the impact of contextual factors. Thus, the measurement of activity and participation may be viewed as a synthesis or intersection of these domains.

The concept of participation and the social model of disability

Most reviews of the concept of participation as it relates to rehabilitation trace its origin to Nagi’s conceptual framework of disability e.g. [16,18]. Nagi articulated the relationship among the biological, functional, and social consequences of disability and was one of the first theorists to reference the social context and limitations that frame a person’s experience of disability [19]. In particular, Nagi’s ideas drew on Parsons’ concept of social roles [20] in order to describe that context. Others also trace development of participation to the social deviance and stigmatization theories of social researchers such as Goffman [21,22] and Friedson [23]. These theories describe how cultural and societal notions of what is ‘normal’ help to create and sustain what we perceive as disabling through medical discourses, healthcare professions and institutions, social policies, and politics. Most recently, growing numbers of studies are emerging within the social sciences that examine the relationship between assistive technologies and the meaning of disability as it is enacted in people’s everyday lives [24,25].

It is notable that the current use of participation as an analytic concept emerged in the development discourses of the 1980s and 1990s. It was intended to reflect social, political, and economic inequities between different groups of people, whether these were expressed along ethnic, cultural, racial, gender, or class lines – including doctor–patient and researcher–subject. Large organizations such as the World Bank, as well as international, national, and local non-governmental organizations (NGOs), and individuals began to frame economic development projects within a concern for the rights of the indigenous peoples they intended to aid [26,27]. Emphasis on participation emerged along with calls for ‘partners in development’, ‘stakeholders’, ‘grassroots participation’ and ‘community based initiatives’. Within this context, participation has been described as both a means and an end, and also as an empowering process necessary to correct power imbalances between groups. It embraces the idea that all stakeholders should take part in research/development decision-making processes that directly affect them.

During the past two decades the discourse of participatory development has spread beyond government and international development agencies to include other vulnerable populations, including people with disabilities [28]. The National Institute on Disability and Rehabilitation Research (NIDRR) reflected the impact of this increasing activism within the disability rights movement in its call for ‘participatory action research’ [29,30]. Within outcomes research the impact of participation was reflected in the development of conceptual models and outcome instruments that included the interests and perspectives of disabled individuals in addition to those of researchers and social policy makers.

This current social model of disability maintains that the experience of being disabled – generally described and defined medically in terms of impairments, handicaps, functional limitations, and/or diseases processes – is the product of societal norms and expectations which define ‘normal’. The effects of these expectations and norms produce the experience of being disabled within societies and cultures (which may define or experience disability very differently). One outcome of this lived experience is expressed in terms of a person’s activities and participation. Indeed, Jette and Haley describe ‘functional outcomes’ as including both activity and participation domains [31]. Thus, the measurement of activity and participation is not just a domain of disability; it embodies one definition of disability itself. Its measurement, therefore, is underscored both as a domain and as one measure of disability.

Application of the ICF in assistive technology outcomes research

In considering activity and participation within the context of the ICF classificatory scheme, one of the ICF’s strengths is that it identifies a range of possible variables through which to define the impact of AT across multiple domains. However, several authors also identify a significant lack of detail and
specificity that impact its usefulness to AT outcomes [14,32,33].

One illustration of this is that the breadth and purpose of existing ‘assistive products and technology’ codes are not adequately captured within the ICF. As Lenker [33] and Smith [32] note, the codes do not connect the purpose or use of a particular device with a specific domain such as body dysfunction or activity and participation, making it difficult to articulate the relationship between device and outcome. In particular, Smith notes that this lack of specificity prevents linking a specific functional deficit with a particular device, making it difficult for researchers and clinicians to probe the effects of an AT intervention. Further, he notes that under the capacity qualifier, questions regarding assistance used to perform an activity do not differentiate between human and technological aide. This lack of specificity contributes to imprecision and reliability issues when using such assessment tools as the ICF Checklist.

In addition, there is little consensus on what to measure in assessing participation. Although the ICF taxonomy provides a useful framework, it is not clear that all four defined domains need to be referenced in a single instrument for all devices and/or disability populations. That is, the ICF taxonomy offers a guide, not a script for measurement. It is up to stakeholders to generate appropriate constructs. For example, it may not be necessary to assess all aspects of communication when examining participation outcomes among wheelchair users. Researchers may address particular domains while ignoring others. They may elaborate certain categories and/or specify relationships between different domains. Despite these challenges, however, the ICF offers all stakeholders an opportunity to clarify and define the conceptual relationship between assistive technologies (AT) (including wheeled mobility devices) and its taxonomy. As Fuhrer et al. note, the ICF classificatory taxonomy should be given preference as stakeholders develop device-specific conceptual frameworks within which AT outcomes can be measured [34].

Measuring activity and participation

Self-report instruments

The most common method of measuring activity and participation is through self-report instruments. The past two decades have seen the development of numerous self-report measures that examine participation and activity in various disability populations [35–42]. There are a number of articles containing excellent reviews of existing participation measures [31,37,41–48]. Perenbroom et al., assess the applicability of ICF definitions of participation within a variety of instruments commonly used in rehabilitation practice [46]. They conclude that, although many reference one or more categories listed under the ICF domain of activity and participation, none capture its full range. Salter et al., contribute to the analyses as they include a comprehensive review of the psychometric properties of many instruments [43].

A number of self-report tools were developed using the old ICF concept of ‘handicap’ or participation restriction. In this sense, current measures reference the lower limits of participation, rather than investigate the range of behaviors that could be identified as participatory. Although many of these instruments are technically compatible with current ICF descriptors of participation [46], none exploit its current, more positive, semantically neutral connotations. For the purpose of measurement, participation restriction does not define participation, rather, it assumes it. This lack of conceptual clarity prevents a systematic and rigorous understanding of both activity and participation as defined by the ICF and underscores the need for further development.

The ICF acknowledges that distinguishing between activity and participation can be difficult. Jette et al., argue that a conceptual distinction between the two is important in order to accurately operationalize and measure them. They distinguish between mobility activities (e.g., basic and advanced mobility skills such as sit to stand); daily activities (e.g., bathing and dressing); and participation which refers to ‘much more complex categories of life behaviors such as preparing meals’ [20]. Activities and participation are viewed as hierarchically related or ‘nested’, with activities forming the building blocks of increasingly complex participatory social behaviors. Thus, the measurement of activities is more amenable to testing the capacity of an individual’s functional abilities while participation is measured in terms of both social and occupational roles as performance.

Articulating the difference between activity and participation, Jette et al., clarify essential aspects of the concept of participation and its measurement vis-à-vis activity. However, an instrument that intends to measure participation among wheeled mobility users and to examine the effects of mobility devices on these behaviors needs to be device-specific. Measurement, whether it is in terms of effectiveness of performing activities or in the performance of social roles, needs to reference the device as it impacts the behavior to be assessed.

Sensitivity to AT impact. Of the examined participation measures only two consider the role of assistive technology and, of these, one penalizes the respondent for his/her use in the scoring procedure (LIFE-H). The other considers the role of assistive
technology as it facilitates or hinders participation (CPPRS) [49]. This trend is consistent with the results of a recent review of 100 instruments commonly used in rehabilitation research [50]. Rust and Smith report that few instruments mention AT and, if included, AT use tends to lower the overall score. This suggests that using technological aids reflects a negative rehabilitation outcome. In addition, scoring procedures are inconsistent across measures revealing ambivalence and lack of clarity regarding the role of AT in rehabilitation goals. In order to measure the impact of wheeled mobility device use on activity and participation among its users, researchers need to design instruments that first, assume the potential positive effects of AT use in the performance of their everyday activities and participation. Second, instruments need to be device-specific. That is, activities and participatory behavior need to be examined with reference to device use in everyday life. Most participation measures continue to be inadequate for AT use generally, exemplified among wheeled mobility users.

Current measures – whether they are aimed at all disability populations or target a specific type – include questions intended to assess the effectiveness and/or ease with which activities of daily living and social roles are performed. They focus on such variables as economic self-sufficiency, occupational roles, physical independence, mobility, social integration and relationships, and coping skills.

However, one recent instrument – the Community Participation and Perceived Receptivity Survey (CPPRS) [39] which was developed exclusively for people with mobility disabilities – takes a different approach. Instead of querying social roles and basic activities, it examines mobility-related participation in terms of common destinations people such as grocery stores, homes of family and friends, pharmacies, restaurants, and the like. For each location it asks for frequency of visits, assistance used, mobility device used, pain and fatigue levels, overall accessibility, transportation, effects of social attitudes, importance, choice, and satisfaction. In addition, it evaluates the impact of environmental barriers and facilitators that make each location accessible or inaccessible. From a mobility-specific point of view, the CPPRS offers an innovative basis for measuring participation. The CPPRS is grounded in the assumption that mobility is essential in order to accomplish tasks and participate within the community. For those with mobility disabilities, mobility devices are enablers for activities and participation in the home and community. These devices are examined as they provide transition from one destination to another. The CPPRS captures mobility-specific characteristics that can be linked directly to activities and, by extension, to social roles.

Operationalizing a mobility-relevant approach to activity and participation measurement for AT outcomes requires that participation be conceptualized and measured with reference to those ICF categories that these devices potentially impact. In addition to the progress reflected in the CPPRS, there are two additional considerations that will help to elaborate more effective participation measures for AT users generally and wheeled mobility users specifically. These are the perspective of the instrument and the development of the capacity and performance qualifiers of activity and participation.

**Perspective of the instrument**

‘Perspective’ here means the assumptions, societal values, and biases that underlie the choice of questions and scoring scale within a particular instrument. Understanding the perspective of a particular instrument allows two actions: first, it can help gauge the measure’s appropriateness to generate data that answers a particular research question; and second, it forces us to critically assess the strengths and weaknesses of our underlying concepts of activity and participation as we continue to develop new tools and refine constructs.

The Craig Handicap Assessment and Reporting Technique (CHART) represents one of two general approaches to participation measurement [36]. It is one of the oldest and most widely used participation measures in rehabilitation research. Designed to be administered across all disability types, it examines assistance, mobility, transportation, physical independence, social relationships, and financial resources. It was originally developed to provide an objective measurement of participation—restriction within the older ICF concept of handicap, and strove to reflect normative values consistent with a medical model of rehabilitation goals. Subjects’ responses are compared to an established standard of ‘normal’ and deviations are expressed quantitatively as handicap or participation—restriction.

In contrast, more recently developed measures such as the Impact on Participation and Autonomy Questionnaire (IPA) and the Assessment of Life Habits (LIFE-H) employ a subjective, person-perceived approach [37,48] reflecting the current social emphasis within disability studies. Like the CHART, they are intended for use across all disability populations and they query similar categories. However, where the CHART asks how many hours per day you work and then compares the response to a normative value, the IPA asks, ‘can you work, when you want and how you want?’

The IPA and CHART represent opposite ends of a continuum for participation measurement and the impact of a normative versus person-perceived...
perspective. However, both speak to deeply held values regarding autonomy and independence as the basis for participation measurement. The use of a particular measure reflects researchers’ questions and underlying orientation to the concept of participation.

Autonomy and independence. The cultural values of autonomy and independence lie at the heart of many self-report perspectives of participation. A measure of independence or dependence is accomplished when examining the effectiveness of activity and participation as assessed by, for example, how much or little aid is used for assistance purposes; how self-sufficient economically and socially an individual is in the performance of activities (e.g., CHART, LIFE-H). By comparison, the IPA is explicit in its use of autonomy as a basis of measurement that lends itself to a subjective, person-perceived appraisal of satisfaction with participatory activities.

Autonomy, roughly defined as self-governance, is widely regarded as an axiom of European and Euro-American cultural values [51,52,53]. It is closely associated with western values of freedom and independence [53]. Indeed, Cardol notes that the notion of autonomy tends to be equated with physical independence; that is, independence is a necessary precondition for autonomous behavior [48]. Consequently, physical independence, expressed here as the potential for mobility, provides users the means for independence and may form one basis for participation measurement.

Independence itself is regarded as a self-evident goal for assistive technology users [54,55]. It is linked to both successful functional outcomes and viewed as a prerequisite to successful participation. For social policy makers independence signifies the restoration of an individual as a non-dependent member of society; one who contributes to society economically, socially, and politically. For rehabilitation experts independence is an indicator of an individual’s regained functional abilities. This is, in part, because US rehabilitation goals emphasize individualistic values; that is, the measurement of rehabilitation is aimed at the individual rather than the community or societal level. Indeed, rehabilitation policies and practices – including assessments, programs, community supports and success criteria – are based on meeting expectations of independence within the individual, and assume no implicit communal support imperatives. For many AT users themselves, independence denotes a regained freedom to go where one wants, when one wants. Independence is inextricably linked to an overall sense of well-being, e.g. [56]. Dependence – whether on human or technological aids – is viewed as a drain on societal resources and a compromise to quality of life.

However, an individualistic view of independence is not reflected across all cultures, societies, or ethnic groups. The independence-dependence dichotomy blurs the broader connected relationship between society and the individual [51], thus obscuring the interconnectedness among all society members. As an example, interdependence among family and community members may signify a positive cultural value in different societies and ethnic groups [57]. Moser and colleagues point out in separate examples, that dependence on others – even in its most extreme form – can still reflect autonomous decision making [45,58,59]. The choice of dependency may be non-intuitive and even alarming to rehabilitation experts, social policy makers, and insurers who may feel the burden of increased resource use; however, it must be acknowledged as a viable option in our assessment tools.

In addition to independence, the notion of autonomy has been recently challenged as a basis for participation measurement. The authors of a new instrument – The Participation Scale [42] – argue that autonomy is not a universal cultural norm. People in different societies may have substantially differing choices in social roles and responsibilities. Social roles may be culturally circumscribed according to gender, age, geographic region, class, caste, and/or ethnicity, making them difficult to assess. To address this issue, the authors offer a ‘peer comparison concept’. A peer is defined as ‘someone similar to the respondent in all respects (socio-cultural, economic, demographic) except for the disease or disability’. For instance, people are asked ‘do you get invited to social functions as often as your peers?’

This measure is an attempt to gauge activity and participation in non-industrialized populations easily overlooked in service provision. One issue with the peer concept is that it encourages the respondent to self-identify as being disabled or ‘other’ relative to his/her peers. This may be problematic for some. For example, not all elderly wheelchair users will self-identify as disabled. Therefore they do not self-perceive as being different from their peers in spite of their use of mobility device(s). Dijkers also notes, that the term ‘peer’ may require careful framing if respondents are to use the correct comparator. As a case, a person with leprosy who, because of societal stigma, may have reduced expectations for marriage, work, and income and might mistakenly reference ‘peer’ as others who are uneducated, unemployed, and/or unmarried individuals [60].

Questioning the cross-cultural validity of autonomy and independence enhances the depth and transparency of our conceptual work and tools in
two critical ways. First, and most obviously, it draws our attention to the fact that not all groups, ethnicities, cultures, countries place a cultural value on independence in the same way. As we develop measures intended to target a variety of populations and consistent with the intent of the ICF taxonomy, we need to be sensitive to differences in value, meaning, and emphasis. Second, it allows us to critically assess the assumptions embedded in these values that may be incorrectly expressed in our measures. The emphasis on the worth of independence as an individualistic value may mute or obscure the interconnectedness between family and caregivers which we, as various stakeholders, need to address in our outcome assessments. This is important to defining participation with greater conceptual clarity as we continue to develop measures for AT users.

It may be concluded that no single measure can target all populations. Furthermore, independence and autonomy need to be carefully broached among people with disabilities. AT may allow an individual physical independence in the performance of basic activities, but remain interdependent in other meaningful activities. From a subjective standpoint, researchers must address the complex nature of families and communities in order to assess participation outcomes among AT users. In developing measures for wheeled mobility, stakeholders need to take into account, not only the impact of AT use and personal assistance on individuals, but the complex network of social and cultural interdependencies in which the individual lives and participates.

Capacity and performance

Understanding the perspective of research instruments helps us to define more clearly how we should approach participation and what we should measure for wheeled mobility users. The values of independence and interdependence need to be separated conceptually and operationally. One way to do this is to distinguish between functional or physical independence (inherent to the ICF qualifier of capacity and which references body structures and functions) and independence/interdependence as it is performed socially among family and community members. In the latter case, the person-perceived assessment of participation in terms of satisfaction, choice, and quality of life will prove the most effective measure of participation. For rehabilitation stakeholders, it is essential to understand the relationship between capacity – discussed here as functional or physical independence necessary to perform basic tasks necessary to activity as per Jette [20] – and the performance of participation as the outcome of wheelchair use in the everyday environment.

Current participation measures vary in their ability to capture this distinction. Most measures focus on capturing the range of domains categorized under activity and participation and are less concerned with the perspective of the measure or distinguishing between capacity and performance. The CHART, which was developed prior to the revised ICF definition of participation, strives for an objective assessment of handicap in the performance of activities and does not operationalize the ICF distinction between capacity and performance. Neither does the LIFE-H which distinguishes between assessing effectiveness by querying the level of difficulty a person has in performing various activities and social roles on the one hand, and the level of satisfaction with the way it was accomplished on the other. The IPA’s measurement of participation restriction in terms of autonomy is confined to examining the performance of participation in terms of satisfaction and perceived limitations in performing an activity.

Only one measure thus far – the Late-Life Function and Disability Instrument (LLFDI) – has articulated the distinction between capacity and performance within a single measure [38]. The LLFDI has two parts. The first examines functional limitations (defined as those limitations in a person’s ability to do discrete actions or activities which is roughly equivalent to capacity). Among others, it queries a person’s ability to unscrew a jar lid, or hold a glass of water in one hand. The second part measures disability as the performance of socially defined tasks roughly equivalent to ‘participation’, such as visiting homes of family or friends or keeping in touch with people. It asks respondents to estimate both the frequency of activity performed and the level of difficulty associated with performing it. Although each part can be administered on its own, together they seek to present a complete participation measure. The LLFDI was developed for geriatric populations who are at least partially ambulatory, making it less appropriate for use among younger and/or full-time wheeled mobility users. However, it is an example of a recent effort to systematically incorporate capacity and performance within a single measure.

Activity monitoring instruments

Self-reports will continue to be developed in AT outcome measures of activity and participation. With advances in item response theory (IRT) and computer adaptive testing (CAT), they will provide the most time-efficient quantitative assessment tools across large populations. But there are trade-offs when relying exclusively on self-reports for outcomes assessments. As cognitive psychologists in the field of survey development note, numerous issues may
affect the quality of data [61]. Although the relationship between these insights into survey development and psychometric testing has not been fully developed, it is clear that question format, wording, closed-responses, and context can result in inconsistencies in data [62]. In particular, frequency and rating scales, characteristic of many participation measures, invite inconsistent and systematic differences across subjects [61,63,64].

One methodology developed to supplement self reports obviates these accuracy issues. It consists of the recent adaptation of activity monitoring equipment such as wheel revolution counters, seat sensors, and global positioning systems (GPS) to monitor wheeled mobility use surrounding peoples’ daily activities. Accelerator-based physical activity monitors have been demonstrated to accurately record levels of physical activity over a long period of time in ambulatory populations [65–67]. In addition, GPS has been used in recent transportation and travel studies [68–71] and their accuracy in reporting the number and length of trips has been established [68,72,73]. These technologies provide independent quantitative data which can be used by researchers to probe more extensively into activities and participatory behaviors. Activity monitoring equipment provides an essentially descriptive methodology that documents the ‘performance’ of participation among wheeled mobility users as they use device(s) in their everyday lives.

Wheelchair use is an essential aspect of device-specific measurement and forms the basis for understanding how people engage their wheeled mobility devices in the context of activity and participation performance. Various studies document the importance of wheelchair use, not only to better understand activity and participation, but to offer insight into such issues as wheelchair abandonment and AT intervention effectiveness [74–77]. Using activity monitoring technologies, mobility patterns can be measured in terms of frequency and duration. These data, in turn, can provide the basis for more in-depth analysis of the context of use through self-reports or prompted recall interviews.

Examples from recent research being conducted at the Center for Assistive Technology and Environmental Access (CATEA) at the Georgia Institute of Technology illustrate some of this methodology’s feature. Here quantitative data and prompted recall information are combined to describe wheelchair use at various destinations. Activity purposes are determined through prompted recall interviews. Two subjects are highlighted in Table I.

Although Subject B visits fewer places on the average day than Subject A, the majority of Subject B’s wheelchair use (percent time spent wheeling, number of bouts of mobility, and distance wheeled) takes place out of the home performing daily living tasks (e.g., grocery shopping) and social activities. Figure 1 geographically represents Subject C’s activity patterns in terms of the time spent at each destination and activity type.

Such graphic representations of subjects’ participatory behavior can link different combinations of quantitative and prompted recall variables and serve to validate recalled reporting. For example, activity type and destination can be linked to number of hours spent there per day to determine relative temporal or spatial intensity of various activities per day. In turn, such maps can be linked across a range of variables (e.g., type of disability, number of mobility aides, income, age, or gender) in order to examine broad patterns of activity and participation.

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<th>Table I. GPS, Wheel revolution counter and prompted recall interview data in two subjects.</th>
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<td><strong>Activity type</strong></td>
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In addition to providing objective data from which to examine participation performance, this methodology offers unique advantages to measurement among wheeled mobility users. First, it allows researchers to probe data without the use of preconceived categories such as work and recreation or expectations of independence. This is more consistent with grounded theory approaches that advocate for the generation of theory from data [78]. Second, it provides an opportunity for researchers to probe more extensively into the relationship between social and physical environmental facilitators and mobility patterns. The social context of mobility device use can be explored more extensively to better understand how users employ their devices in their everyday lives. Lastly, instrumentation can be used by clinicians to track the effectiveness of interventions by comparing clinical assessments of capacity in terms of function and wheelchair skills with a person’s performance within their natural environment.

**Conclusion**

The measurement of activity and participation among wheeled mobility users is complex. It is clear that no single self-report instrument or methodology can capture all aspects of this domain as outlined in the ICF. Wheeled mobility users encompass a wide range of medical and functional descriptors, demographic characteristics, and societal and cultural contexts. Trade-offs and choices are inevitable and need to consider not only particular research interests, but pragmatic issues such as subject and researcher burden of administering instruments and/or analyzing data. There has been, however, an increase in both appreciation of the challenges and the tools to address them. The following general suggestions are offered towards developing self-reports and methods to measure participation among wheeled mobility users with yet greater sensitivity, accuracy, and sophistication:

1. Participation measures for wheeled mobility users need to be device specific. They should reflect the complex interdependent, interaction among wheelchair use, basic activities, and participation in the home and community. Most participation measures (with the exception of the CPPRS) do not address participation among AT users. Because mobility itself is the result of a dynamic interaction within the person-device-environment [79], participation measures need to reference the device(s) as it (they) impact how activities and participation are enacted.

2. Participation measures should capture both capacity and performance as defined by the ICF. Rehabilitation professionals will benefit from understanding the capacity for activity and participation, measured as functional and health outcomes, and the performance of participation in everyday life. Further, the performance of participation needs to take into account individual goals which may vary in terms of independence and interdependence preferences and be linked to such subjective constructs as comfort, satisfaction, and an overall sense of well-being.

3. Measures need to be sensitive to change over time and recognize the dynamic nature of disability and its impact on AT requirements. Health and life changes as well as ongoing accommodations to the environment may alter assistive technology needs, goals, and expectations. Outcome studies need to control – either methodologically or statistically – for the range of variables that impact participation outcomes over time.

**Figure 1.** Subject C’s activity patterns are represented geographically (a) by the time spent at each destination (red, home; black, short time —; white, long time) and (b) by activity type (black, home; red, daily living tasks; blue, entertainment; radius of large circle is the farthest distance traveled for that purpose).
4. Activity and participation need to be examined in the context of a person’s social network. Because rehabilitation goals tend to be individualistic in nature, it is easy to overlook the complex, often interdependent, interaction between family, community, caregivers, and individuals which will affect AT use. The roles of family and community members need to be articulated and measured in order to effectively gauge the effectiveness of AT use on participation and activity.

5. People who use mobility devices often use a combination of mobility technologies such as walkers, canes, and wheelchairs to move about their homes and communities. Researchers need to develop methods to better assess the range and specific purposes of these technologies. The function of assistive devices may vary according to the different social roles and responsibilities of an individual. Moser does this as she describes the multiple roles a wheelchair may embody depending on the context of its use [59]. It may be a means of transportation from one destination to another, a ‘rig’ allowing its user to play basketball, a chair to sit at a table and eat dinner or play computer games, and an uncomfortable symbol of disability in certain social situations, or of illness in a doctor’s office. A wheelchair can be both a limiting and liberating tool – depending on the context of its use in everyday life.

6. We need to better understand those environmental and personal variables that either facilitate or deter wheelchair use in the home and community. There are increasing numbers of measures in development that examine environmental effects on disability, e.g. [80,81]. Key factors impacting wheelchair use include fundamental physical environmental features such as curb cuts, parking, accessible bathrooms, and ramps. In addition, social support systems, social policies, and financial well being can encourage or discourage AT use.

Activity and participation are maturing concepts in AT research. This maturation process needs to include rigorously conceptualized understandings and definitions. Likewise, the nature of independence/interdependence and autonomy need to be articulated more clearly. We are now honing the relevant ICF categories of activity and participation to increase their value and effectiveness for AT outcomes assessment. In so doing we build better conceptual models that more accurately reflect the relationship between environmental factors, wheelchair use, and health conditions as they impact the lives of people who use wheeled mobility devices.

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References


