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RESEARCH PAPER

What does participation mean? An insider perspective from people with disabilities

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Abstract

Purpose. Although participation is an important construct and valued goal, how it is conceptualized, defined and measured varies widely. This qualitative, multi-site study sought to gain an insider perspective from people with disabilities in grounding what participation means, how to characterize it, and the barriers and supports to participation.

Method. Sixty-three people self-identifying with diverse disabilities participated in qualitative focus groups across sites.

Results. Participants conceptualized participation as a cluster of values that included active and meaningful engagement/being a part of, choice and control, access and opportunity/enfranchisement, personal and societal responsibilities, having an impact and supporting others, and social connection, inclusion and membership.

Conclusions. No gold standard for ideal or optimal participation emerged; no one defined set or frequency of activities accounted for 'full' participation. Participants described needing to be free to define and pursue participation on their own terms rather than meeting predetermined societal norms. Participation was viewed as both a right and a responsibility, influenced by and ascribed to the person and to the society. Participation does not occur in a vacuum; the environment dynamically influences participation. Implications of this conceptual framing for assessment, research and systems level change to support participation of people with disabilities are discussed.

Keywords: *Participation, assessment, qualitative research*

Introduction

The concept of full participation in society is becoming increasingly important and represents a key goal and vision for many stakeholders, including constituents with disabilities, disability advocacy organizations, rehabilitation providers, community organizations, and policy makers. The move from 'handicap' to 'participation' within the International Classification of Functioning, Disability and Health (ICF) [1] has inspired a body of research on participation and measurement approaches. However, few studies have systematically focused on how participation is experienced and given meaning by people with disabilities. Qualitative methods and grounded theory that prioritizes the perspectives of people with disabilities can deepen the understanding of how participation is conceptualized, experi-

enced and valued by people with disabilities, an understanding that can inform more authentic assessment, research and social action change to promote participation.

Literature review

Since 2001, when the World Health Organization (WHO) substantially revised the conceptual framework of disablement by replacing the concept of 'absence of handicap' with 'participation', the concept of participation has gained prominence in rehabilitation and medical contexts as an outcome variable, therapeutic goal and research focus [1]. Although the ICF [1,2] represents advancements in nosology, critiques of its definition and resulting assessment of participation have been put forth by the disability community and researchers attempting

to apply the concepts in community, clinical and research contexts. These critiques range from political considerations about who and the extent to which people with disabilities were actively involved in revising constructs within the ICF [3], to specific concerns over how participation was defined, operationalized, and measured [4]. Disability studies scholars have critiqued the use of any classification system that universalizes the experiences of disability and participation without regard for the influence of social factors such as age, gender, culture, and economic status. When such a classification schema is created and institutionalized by public health, medical, rehabilitation and other professionals, it can perpetuate disability ideologies related to deficit and dysfunction, and further promote professional dominance [5–7]. One strategy to address this issue is to ground research on participation within the insider perspectives of people with disabilities, and to support active involvement of people with disabilities throughout the research process from construct conceptualization, to item generation, to member checks of the assessment tool, to interpretation of data and results generated, to translation of evidence to use within the community.

Integration of perspectives of people with disabilities

The ICF represents a significant improvement over previous classification efforts by including people with disabilities in the development process. However, the *ad hoc* nature of this involvement is a limitation [3,5]. Many grassroots disability organizations and people with first hand knowledge of the lived experience of disability lacked the financial, social, technological or political resources to participate in the process with international experts from academia, medical, rehabilitative and government agencies [3]. This muting of diverse constituent voices influenced how participation was conceptualized and measured, and represented a significant methodological and ethical issue considering that this research focuses on people with disabilities who face barriers to participation [8,9]. Additionally, there are few examples of the systematic and active involvement of people with disabilities in the conceptualization and construction of participation assessments. McColl et al. [10] analyzed 116 interviews from 18 people with brain injuries in the development of the Community Integration Measure. Gray et al. [8] conducted key informant interviews and focus groups with 98 participants (people with mobility impairments, significant others and health care professionals), using the previous ICIDH-2 (International Classification of Impairment, Disability and Handicap) as a contextual framework in the development of the Participation

Survey/Mobility (PARTS/M) (Gray et al., 2006). Given the revisions from the ICIDH-2 to the ICF, the inclusion of participation as a specific construct within the ICF, and the challenges to the ICF's definition of participation as a concept within the disability rights and disability studies communities, there continues to remain a critical need for participatory research that involves people with diverse disabilities and participation experiences in the grounded conceptualization of participation 'from within', and in the development and refinement of participation assessment tools that emerge from this grounded approach.

Application of the biopsychosocial model and the role of the environment

Due in part to the participation of the disability community, the theoretical foundation of the ICF underwent a major shift from a model that situated the problem of disability in the individual, to a model that asserts the interaction of individual biological and psychological traits with the social and physical environment [1]. This biopsychosocial model recognizes the influence that the social and physical environment has on peoples' experiences of health and participation [11]. However, in practice, these factors are separated; the person is assessed separately from the environment. This separation has been criticized for implying that the individual components, particularly those related to participation, can be separated and examined in isolation from the environment [9].

A transactive model has been proposed to capture the dynamic interdependence, and transformative interplay of environment and person within the realm of occupational performance [9,12]. The relatively recent adoption and implementation of the ICF means that there are few instruments developed specifically to reflect this interactive, or transactive, conceptualization of participation. Earlier instruments were predicated on the original ICIDH, the updated ICIDH-2 or a mixture of items representing body structure and function, activity, participation and, rarely, the environment. Researchers have criticized these instruments as being inadequate to capture the complexity and depth of participation as conceptualized within a person-environment interaction [8,13–16].

Conceptual ambiguity between activity and participation

In addition to issues of person-environment interaction within participation, critiques have been made about the conceptual ambiguity introduced in the ICF by the use of the term 'life situation', and the differentiation of activity and participation. The ICF

calls for a common taxonomy of activity and participation content areas that are then distinguished by qualifiers. Activity represents the 'capacity' to engage in a particular task; participation is the observable 'performance' within a life situation [1]. Conceptual overlap makes it difficult to adequately and distinctly operationalize the two concepts, and many instruments mix the two concepts together [9,17]. This conceptual overlap limits interpretation of findings [4,17,18].

Over-emphasis on individual performance

Both researchers and constituents within the Disability Rights Movement have also critiqued the ICF's emphasis on individual performance as a primary and defining characteristic of participation [13]. They contend that independence, and by extension participation, is not defined by the ability to perform tasks by oneself, but is more related to having access to resources and supports to participate freely [19–21]. The emphasis on individual performance is seen as penalizing people with disabilities who perform and participate in their communities in ways that differ from social norms [5,22], and it does not account for the role and supportive influence of social interdependence, community embeddedness, and support networks in the lives of people with and without disabilities [9,10,23]. Furthermore, instruments that focus on performance have also been criticized for overlooking the influence of free will [24,25], citing that what people are observed to do is not necessarily what they wish or choose to do [26]. Cardol, deJong and Ward [27] expanded upon this notion of free will by focusing on autonomy as a necessary precursor to participation. Autonomy is more than the ability to act as one wishes (executorial autonomy); it also includes decisional autonomy, that is, the opportunity to exert choice and control over how one lives and acts. The central role of autonomy is emphasized by researchers [28] and people with disabilities [6], yet many assessments of participation do not account for this important construct or treat it as important as performance.

The ICF's emphasis on performance as judged objectively by an outside observer has also been criticized for failing to adhere to the value of client-centeredness [9]. Client-centeredness is a core value in rehabilitation and recognizes individuals' rights to identify and establish their own therapeutic and clinical goals [12]. This value is predicated on ideas of informed choice, importance and satisfaction. Existing participation instruments vary significantly in the extent to which researchers systematically involved diverse people with disabilities in their construction, and the level to which the assessment

captured and focused on these perspectives of people with disabilities.

Failure to capture the subjective experience of participation

Ueda and Okawa [29] argued that by focusing participation measurement on performance of particular activities or roles, the meaning that a particular form of participation has for the individual is obscured and the concept's utility as an outcome measure is rendered meaningless. Objective measures of participation in activities do not adequately capture the full meaning of participation [25]. People with disabilities contend that the subjective experience of participation is more important than professional judgments and that by operationalizing participation as what can be observed and measured, the perspective of the professional over the person with the disability is perpetuated [5,7]. These critiques highlight the significance of developing participation assessments that capture the subjective and lived experiences of people with disabilities.

The previous findings and critiques of ICF-based assessments of participation point to several gaps in knowledge and implications for methods to examine these gaps. Fundamentally, participation needs to be conceptualized in a manner that reflects and prioritizes the perspectives and life experiences of people with disabilities. In response to these concerns, the purpose of this research was to: (i) identify and describe the meanings and indicators of participation from the perspective of people with disabilities; and (ii) develop a pool of participation indicators that could be used to guide assessments, services, programming, resource provision, and policy systems change to support full participation.

Research questions

The following questions were developed in collaboration with community partners to frame this research, and they were used as a guide for focus groups.

- (1) What does participation mean to you? (Probe: What does it mean to fully participate in life?)
- (2) What areas of everyday life are most important to you to participate in? Is there anything in your life that, if it were taken away, would feel like a major participation loss?
- (3) What issues or barriers most affect your participation?
- (4) What are your biggest supports to participation?

- (5) What strategies (individual, social, societal, policy) are most needed to promote and support full participation in our society?

Methods

Study design

A qualitative case study design [30] based upon a grounded theory approach [31] was utilized to explore the meanings of and factors influencing participation. A qualitative case study design involves intensive descriptions and analyses to gain a detailed understanding of a situation or phenomena, and the meaning given to those phenomena [30], in this case, to describe what participation means and how it is experienced by people with disabilities. Findings were inductively grounded in the data, that is, results and the development of theory emerged from the perspective of participants with disabilities, rather than specific theoretical approaches or hypotheses imposed on the data [31]. The research was reviewed and approved by human subjects review boards at the participating sites, and all participants provided informed consent.

Sample

As part of a larger qualitative study, several stakeholder groups were asked to explore and examine the concept of participation to document, compare and contrast their perspectives and priorities. These groups included people with disabilities, family members and other people who provided support, rehabilitation professionals, health care funders, and policy makers. This manuscript focuses on data from 63 people with disabilities who participated in six focus groups. Participants were recruited at sites in Illinois and Colorado that collaborated with rehabilitation centers, affiliated support groups, community-based Centers for Independent Living and other disability-related organizations. Participants included a diverse range of people by type of disability, age, gender, race and ethnicity (see Table I), all of whom were either living in community-based settings, or who were anticipating return to the community after rehabilitation or hospitalization.

Data collection procedures

Focus groups provide a means of learning how people from diverse social, geographic, and disability backgrounds perceive and describe a phenomenon of interest in their own words, based on shared life experiences [32]. Knowledge gained from focus groups can be used to draft items for use in

Table I. Participant demographic characteristics ($N=63$).

| | Frequency | Valid Percent |
|-------------------------------------|-----------|---------------|
| <i>Age (n = 57)</i> | | |
| 18–29 | 3 | 5 |
| 30–39 | 16 | 28 |
| 40–49 | 10 | 18 |
| 50–59 | 20 | 35 |
| 60–69 | 6 | 10 |
| 70 and up | 2 | 4 |
| <i>Gender (n = 56)</i> | | |
| Male | 31 | 55 |
| Female | 25 | 45 |
| <i>Race (n = 57)</i> | | |
| White | 22 | 38 |
| Black or African American | 28 | 49 |
| American Indian, Alaskan Native | 1 | 2 |
| Asian | 1 | 2 |
| Other | 5 | 9 |
| <i>Latino or Hispanic? (n = 56)</i> | | |
| Yes | 5 | 9 |
| <i>Education (n = 57)</i> | | |
| Less than high school degree | 4 | 7 |
| High school graduate/GED | 13 | 23 |
| Post high school educ. or degree | 40 | 70 |
| <i>Disability (n = 57)</i> | | |
| Stroke | 13 | 23 |
| Spinal Cord Injury | 9 | 16 |
| Traumatic Brain Injury | 19 | 33 |
| Other* | 16 | 28 |
| <i>Marital status (n = 55)</i> | | |
| Married | 14 | 25.5 |
| Committed relationship | 3 | 5.5 |
| Single, never married | 22 | 40 |
| Divorced | 8 | 15 |
| Widowed | 4 | 7.27 |
| Separated | 4 | 7 |
| <i>Employment (n = 56)</i> | | |
| Full time paid | 12 | 21 |
| Part time paid | 9 | 16 |
| Volunteering/unpaid employment | 9 | 16 |
| Unemployed, seeking employment | 12 | 21.5 |
| Unemployed, not seeking employment | 10 | 18.5 |
| Retired | 4 | 7 |
| <i>Living situation (n = 56)</i> | | |
| Single family home | 24 | 43 |
| Apartment | 26 | 46 |
| Supervised group living | 3 | 5 |
| Other setting | 3 | 5 |

*Note: Some participants did not disclose or answer specific questions therefore the table reflects n reported and valid percent of that number. Other disability includes: multiple sclerosis, polio, cerebral palsy, respiratory, arthritis, psychiatric disability, immune system disorder, fibromyalgia, visual, and hearing disabilities.

assessments, and provide a shared language for describing participation and phrasing items that is relevant, meaningful and culturally grounded [33,34]. The advantages of focus groups include (i) the active involvement and investment of participants

in the research process, particularly among members of socially marginalized groups who are rarely included in research except as subjects [34,35]; (ii) collection of descriptive data in respondents' own words; (iii) a process to examine individual and shared group perspectives, agreements and disagreements; (iv) a process to check interpretations within member audits; and (v) a means of data collection that can be adapted to meet the needs of diverse participants.

A structured protocol for facilitating focus groups was developed based upon Krueger and Casey's approach [32]. Focus groups were co-facilitated by a member of the research team and a person with a disability from the community. All facilitators were trained in advance on how to conduct focus groups and strategies to elicit and equalize participation. Focus group questions were created and revised based on feedback from community collaborators. A professional captioner provided real-time captioning of focus groups, serving both as an access accommodation and also producing a verbatim transcript which was used in subsequent analyses.

As an accommodation to people with cognitive and communication impairments, participants were given the questions in advance to give time to prepare and reflect. Other accommodations included extra time to communicate answers and assistive technologies such as augmentative communication. Facilitators used a round robin approach to equalize participation, repeated what participants said to verify understanding, and used a whiteboard to visually record a bulleted list of points. A member check was conducted with all participants at the end of each focus group to clarify, synthesize and prioritize findings, and to ensure trustworthiness in representing perspectives [36].

Data analysis

Verbatim, electronic transcripts from the captioner were transferred to ATLAS.ti software to store, organize and retrieve data [37]. Qualitative data were analyzed using a constant comparative approach in which transcripts were reviewed and open coded by multiple team members within three states to identify key themes and to triangulate findings [36,38]. The coding team included people with disabilities who co-facilitated and/or participated in the member checks during focus groups. We developed codes that represented content themes, narrative stories illuminating underlying processes and dynamics, and 'chunks' of data highlighting areas of agreement and differences in perspectives on specific issues [32,36]. Next, we reviewed the codes and transcripts to code categories using a process called axial coding. This

level of analysis involved a detailed coding of individual data within groups, followed by comparative analysis across individuals at the level of groups [38]. Maps of thematic codes and their relationships were developed to document and refine the emerging construct of participation.

Results

The following dialogue from a focus group epitomizes participant-directed conceptualizations of participation:

P1: Fully participating is having access to all those things. If you want to make a political contribution, then to fully participate you have access to the political arena. You're able to go to political meetings and rallies or organizational type things. If you want to make a contribution to your neighborhood, you have access to the homeowner's association. And it's not just physical access, but it's social access as well... I think that it's access and it's an opportunity to make a contribution in whatever arena that's in... Whether that's in employment, whether that's in some kind of social arena, whatever, it's having an access and opportunity to make a contribution and to give of oneself I think. That's what fully participating means to me. And to be able to do that without being patronized.

P2: And to not be penalized.

P3: I think it depends on what each one of us feel we need or we want to be fully participating. I may feel that I'm fully participating if I stay in bed all day. Or I might be feeling inadequate if I don't work 40 hours a week or 10 or 12 hours a day. So I think it's an individual thing. I don't think some foreign body can tell us what it is as to when – and if they do, quite frankly I don't give a damn. What I care about is what I want to do. I want to be satisfied that I'm fully participating in my life. I don't care if somebody over there says they think I need to be doing more or doing less.

This dialogue illustrates that participation is a complex, nuanced phenomena that can be experienced and play out quite differently for different people on individual, social, community and societal levels. Participation was defined as both a means and an end to the expression of personal and collective societal values. People viewed participation as an expression of their values rather than as a defined, preset or normative set of activities, arguing, 'Working, family, recreation, spiritual aspects, these types of things. Each of these categories – each of us based on our own value systems has more or less interest in pursuing them'.

Several themes related to core participation values emerged across the focus groups: (i) active and meaningful engagement/being a part of, (ii) choice and control, (iii) access and opportunity/enfranchisement, (iv) personal and societal responsibilities,

(v) having an impact and supporting others, and (vi) social connection, societal inclusion, and membership (see Figure 1). Respect and dignity were repeatedly identified as a critical feature of participation across all themes.

(1) *Active and meaningful engagement/Being a part of*: Repeatedly, people described and defined participation as ‘being a part of’, whether that entailed being a part of an activity, a context, a social scene and/or a social group. For example, participants defined participation in life as:

Just to be able to do whatever you want to do to your fullest extent to the best of your ability.
 Just to be able to have a voice and a place in society.

Many participants distinguished engagement from functionally independent performance. As one participant summarized, ‘I don’t want to be restricted by function’. Rather, it involved ‘freedom to pursue happiness, pursue whatever you want to do’. This pursuit involved going beyond an exclusive focus on day to day survival, to participation in opportunities that were highly meaningful, fun, enriching, and/or satisfying.

I think the key to participation is making life more wonderful. I think we participate to make our day more

wonderful and that’s a great thing to do and that’s why it’s so important to me that I do what I do.

In some cases, the pursuit of meaningful engagement involved a social interaction component, such as socializing in or out of the home, or going to cultural events. In other cases, this pursuit was more private but still highly valued, such as engaging in an intimate relationship, individual hobby or private spiritual activities. In this way, participation engagement was highly nuanced, personalized and customized to each individual’s needs, preferences, social world, and available resources, as illustrated in these quotations:

I think it depends on what each one of us feel we need or we want to be fully participating
 As a person with a disability or any other person, you don’t have to follow that same path to somebody else’s definition of fully participating, but you should have the opportunity or the option.

Active engagement was predicated upon feelings of safety and security. Safety referred more to a sense of personal security within a social environment, rather than cognitively and physically safe performance. Participants described this sense of security as providing a foundation to pursue challenges and take risks in their lives. It also involved having the power to make their own decisions about risk rather

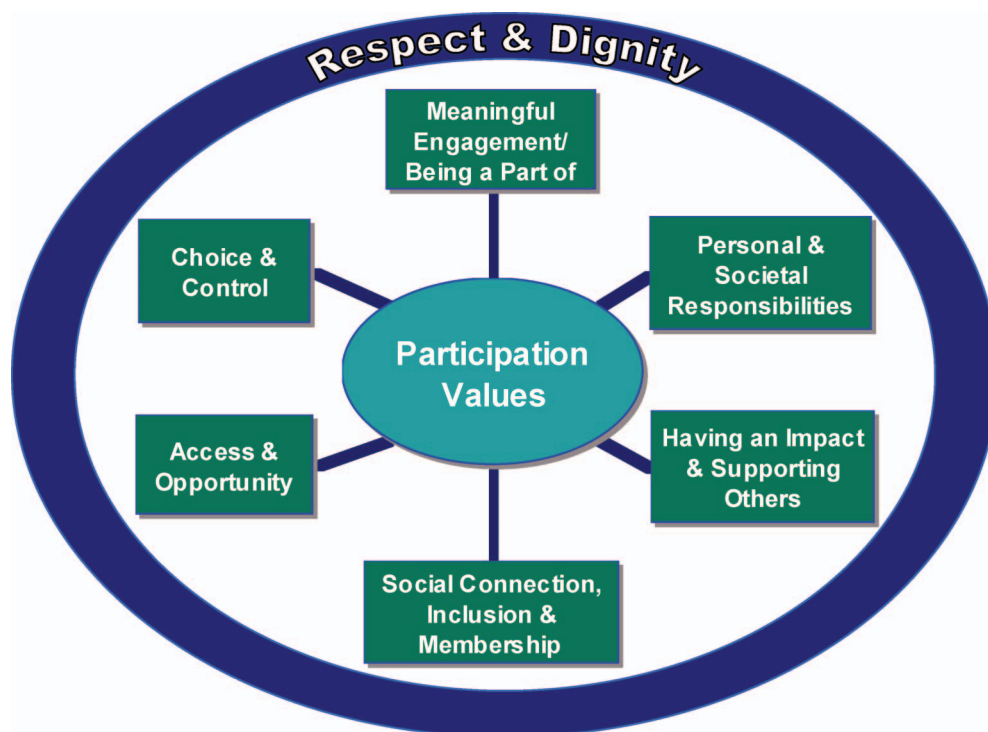


Figure 1. Qualitative theme areas epitomizing participation as described by participants.

than being subjected to constant surveillance by others:

There's a certain amount of opportunity that comes from being allowed to take risks... and spontaneity. What if you're a person that grew up with your disability and your family feels that you're better off being surrounded by them. You don't need to go out and be with your friends. You don't need to do this, because if you do, something is going to happen to you. [That's a] very big barrier for a lot of people. That is fine when you're a child. But when you're an adult, you have to function and adjust in society.

These data emphasize the dynamic interaction between an individual's willingness to take risks, and the opportunities that society and their immediate social world affords them to do so.

(2) *Control & Choice*: The issue of risk taking was closely tied to concepts of choice and control over the decision of how and when to participate. As described, participation was strongly associated with choice, control and a sense of personal power, 'Doing what you want when you want with who you want, it encompasses choice, control and freedom'.

Participants further distinguished managing and controlling participation from independent activity performance:

Simply because you don't walk does not mean that you don't talk... you still have that right, even though someone is helping you perform those duties. If you're competent enough to tell them what to perform, then they are supposed to accept what you have to say regarding your business.

Control and power were also described as part of a process of advocacy development:

To fully participate is to be able to self-advocate. Before we were injured if we had a problem with our dry cleaner or butcher or whoever, we knew how to deal with the issue and try to get it corrected. But now because of our disability we may not know how to deal with wheelchair barriers or employment barriers... I think that should be part of the rehab process, teaching what the channels are for complaining and how to follow up and how to get things taken care of.

Participants repeatedly emphasized that full participation was not just about meeting individual needs; it also encompassed collective power, control and voice in society for people with disabilities as a social group, as exemplified in the following discussion:

P1: I have a problem with people that don't have disability making rules and stuff for people with disabilities... I think there is a big gap with the able-body community and the disabled community because they – the people like the politicians... they can sit up there and make rules and cut this and cut that for us, when they don't know nothing about us.

P2: They have no idea.

P1: ...But what I'm saying is, I think there is a lack... where we are all working together to try to let people know what our needs are...

P3: Nothing about us without us.

(3) *Access & Opportunity/Enfranchisement*: Power, whether at the individual or collective group level, was intimately related to societal access and opportunity, another key value theme. One participant epitomized this access and opportunity as:

What does it mean to fully participate? I didn't think about disability. I just thought about what does this mean for anyone to fully participate... Well, I want to have access to romance. I want to have access to be able to realize my dreams, whatever those might be. I want to have access to be able to make a contribution, whatever that might mean. I want to have access to be able to work and to buy a home or to drive a car or to do those kinds of things.

Participants outlined how access and opportunities were closely related to their rights to social inclusion. These rights were framed by two distinct and at times contradictory perspectives related to equitable treatment as fellow human beings, while at the same time, the right to resources to support their participation. First they wanted to be treated as equal and 'normal' members of society not as 'special', charity cases or inspirations,

In some instance, even when you participate people are thinking what you are doing so out of extraordinary, that you're like this big exception and , oh, I can do that thing and that really makes you feel like almost a freak.

They discussed that all too often their contributions were minimized or overlooked. They expressed concern that their status and the negative social construction of disability limited their opportunities for engagement and recognition.

I feel like Disabled America is kind of swept under the rug like we're kind of useless. That we don't really have as much to contribute because you can't handle a full-time job and we're not raising 4 children and working and having an active social life like you don't have a valued opinion.

Participants spoke of how people in society treated them as if impairment in one area of function invalidated their abilities or access to opportunity in other areas.

My biggest problem is that I'm only functioning with one arm, and people that don't know me set limitations against me.

When they see me in a wheelchair, they talk to me like I'm deaf. I say I'm not deaf, my speech is impaired and I can't walk that fast but I'm not deaf. I'm in a wheelchair.

A second key feature framing the right to participation was the recognition that, as people with disabilities they had the right to resources to support full participation. The participants identified basic resources, like access to quality health care, assistive technology, and income assistance, as key rights, and prerequisites to participation.

If they take the Social Security away and disability, a lot of us would not be able to survive. We need those checks once a month to pay rent. You cannot live without money... If we didn't have that, where are we going? Into a nursing home?

Participation in a myriad of everyday activities was also influenced by access to reasonable accommodations. This included access to reliable, accessible and affordable transportation, which was repeatedly identified as a gateway and bridge to full participation.

If you don't have access to transportation, you don't have access to a whole lot of things. You don't have the opportunities to do very much. You become very limited.

Participants recognized that many people were limited by inaccessible housing and built environments.

Just having access to get out of your house, not only to get to transportation, but overall getting out of the house period. Some people may not have lifts or ramps to get out, so they're stuck in the house.

Accessible information was also identified as a key environmental resource for participation.

Education and information before participation... It always comes down to education and information – then you get to make a decision... in participation. If we have good education and good information we can make good decisions.

Participants saw their needs for accommodation as both universal in that many people in society could

benefit from more universally accessible environments, as well as individualized in needing access to customized supports. Regardless, participants did not want people to make assumptions about their needs; they wanted to be recognized as the experts regarding their needs, and wanted to be consulted in the design of participation accommodations.

I went back to college years ago and... they had a huge desk at the front of the room... This big handicapped table because I had a wheelchair and it wasn't necessary... They don't know how to treat you, so it's assuming instead of asking like they are scared to talk to me.

(4) *Personal & Societal Responsibilities*: Participants also spoke about participation as a responsibility – a responsibility to oneself and to one's family, community and society in general. The issue of personal responsibility for individual health and well-being was described as related to maintaining sobriety, managing health, and working hard in rehabilitation:

In my day, I snorted cocaine, I drank, I smoke cigarettes, I partied and now I don't do nothing and now I am able to fully participate in life. Because I got rid of all that stuff my mind is open now so I can be able to do it.

Participation also engendered a responsibility to set one's own destiny by making positive choices about over how and with whom time was spent.

First you got to have positive thinking. And second you've got to say, you know, believe that there is nothing that you can't do. And then the third thing is just to get up and start doing it.

The participants also expressed a strong sense of responsibility to make contributions to their communities and to society in general. In resistance to popular perceptions about people with disabilities as perpetually receiving help, the root of participation for many participants was defined not by what they can get from other people, but instead by what they can contribute back to others.

While personal responsibility was highlighted, participants across all groups repeatedly pointed to the reciprocal need for societal responsibility in supporting their participation choice through equitable opportunities and via resources to live and fully participate in the society, as highlighted under the access and opportunity theme.

(5) *Having an Impact and Supporting Others*: Having an impact and giving back to others were core values that reflected 'the need to contribute to society'. This

contribution could happen in many ways at different levels. One way to contribute was to be productive, whether that involved work, home management or community volunteering:

I think maybe for me it would be working . . . I got a real high need to be doing something useful. I have been forced into early retirement by the fact that if I do go back to work I could lose the benefits that I have right now. So for me it's looking for volunteer positions and things that I can do in the community . . . meet more people and get more involved in the community.

Beyond personal productivity, social impact and commitment were described as a need and a strong belief that permeated many participants' basic values, and heavily influenced their behavior.

The thing I found and I think it is a nice secret to learn, the way you do it is invest yourself in other people. To be of service, to be giving of your time and your abilities – to be able to give in a way that you can learn from the people that you're giving to. Pitching in to help the community. That is what makes me feel useful. At the risk of being silly, I like to make the world a better place and do some volunteering in open space, and I think that's helping out the community. People need that. So I figure I'm useful. I'm doing good work. I'm there.

(6) *Social Connection, Societal Inclusion & Membership*: Beyond giving back, a sense of social connection was described as central to participation, as this participant describes: 'To participate fully in life is to interact physically and mentally and socially with your peers and others in the community at large to the extent that you can'.

The social component of participation spanned from the highly personal and intimate to the very public and socially conscious. Participants discussed overcoming societal taboos by emphasizing their basic needs and desires for sexual and social intimacy. They expressed their frustration over a lack of information about alternate forms of sexual expression with disability and how perceptions of disabled people as asexual or undesirable limited their opportunities for satisfying intimate relationships and sexual engagement.

Cripple[sic] people say they don't need that [sex], they're saying that to protect themselves, when in actuality everybody needs someone . . . There may be times where you don't want to be with nobody else, but there comes a time when you need that for you to feel special about you. You already feel special about yourself, but for somebody else to feel special about you, it's a good feeling.

Intimacy was not, however, limited to sex. Participants also expressed a desire for companionship, friendships and trusting relationships with other people.

You can show your love without actual physical contact . . . It is more than that. There's a lot of truth in that it doesn't have to be physical.

Another important and deeply personal form of connection was expressed in people's religious or spiritual faith. Spirituality and faith were identified as an important source of strength, comfort and motivation.

Social support in the community was also identified as important component of participation. When asked to describe supports or barriers to participation, people spoke of social relationships as important factors that could serve as a support or barrier:

Relationships with other people in the community. If you have a supportive families or the flip side is negative relationships . . . [also] relationships in the disability community, and role models with disabilities . . . are really important.

Connection and community with other people provided opportunities to receive needed supports (instrumental, informational and emotional) and to provide support to others. As one participant described it, participation is not 'spectatoritis', rather it involves active membership in groups and communities of high meaning.

The public and social aspects of participation also extended beyond the individual to encompass the values of societal inclusion, integration and segregation, as reflected in the following dialogue:

P1: As a part of a being a human being – you know, being a person, that's what I am thinking about inclusion in all aspects of life. Not that word just, you know, 'included', but from that kind of separate way, that we're equal, but separate, you know what I mean? There is always – that the disability that stands out, and that's there, that's visible, that's part of who you are.

P2: It's just a matter of we're people, too.

P1: Exactly. That's my point! And we are part of the human race and that's what I mean by 'inclusion'.

Participants challenged the notion that full participation is predicated on inclusion with the 'rest of society', typically epitomized as integration with non-disabled people. Membership in disability communities and the ability to network with disabled people was described as important to creating a sense of

shared understanding, strength and community that then opens opportunities for participation.

If someone would have told me this before my accident that the day would come when I would like being around brain injured people I'd have told them they were crazy. And now there's nothing better that when I can sit here and I learn a lot just by listening.

Each one of us in our ways was close to death and we're here today and that's a benefit that we have to a positive contribution that we have that few people that haven't gone through what we have. We have a unique insight into life that a lot of people don't have.

Only a person that went through the same thing. But nobody, even if they tell you, 'Oh I understand you, and I know what you are going through.' No. no.

Although many of the participants valued the strengths of the disability community, they did not want their options limited to only interacting with other people with disabilities. One participant described her reservations about segregation.

I don't think that just segregation is a good idea. There is a point that we are content in our identity as a disabled person but it doesn't prepare you when you are grown, and there is no segregated city, there is no segregated stores and stuff. So, it doesn't prepare you if you're just in segregated anything.

Cross cutting meta theme: Across and within all themes, participants repeatedly pointed to a meta theme of participation, that of being treated with respect and dignity (see Figure 1), including being seen as a person of value in communities and the larger society.

Participants emphasized being treated with respect, 'just like everyone else', while at the same time having their differences also respected, not just accepted, as this participant describes:

I would like as far as the participation goes, that you're accepted as a person. It's like being people, too. Simply because you don't walk does not mean that you don't talk, and if you've ever been taking care of... you still have that right, even though someone is helping you perform those duties. If you're competent enough to tell them what to perform, then they are supposed to accept what you have to say regarding your business... In addition to that, I would normally have in mine, to be respected, a respected member of this community... It's not that they accept me or not, I want to be respected... I prefer to have respect versus acceptance.

Identity was connected with a sense of personhood and was related to how people internalized disability. In some cases, disability was seen as a negative part of identity; these participants discussed not being able to do what they did before and needing to seek

rehabilitation to 'be normal again' in order to participate. In this situation, remediation of impairment was viewed as a prerequisite to full participation.

I would like very much to, with my effort as hard as I can, work with the help of professionals to be restored as closely as possible to my physical, mental, all my capabilities prior to my stroke.

In most cases, however, participants discussed a sense of disability identity as an everyday part of who they were, but they 'just did things differently'. These participants actively strategized their participation and placed responsibility on the society to respect and accommodate their differences, thus moving from the individual remediation to environmental negotiation of participation.

Sometimes we kind of have to prove ourselves again that we are capable. Our brain may be jumbled up but we can definitely still use it. Maybe not the way we used it before but, you know, it's almost like here's proof that I can still be me. I can still do the things that I did, maybe in a different way, but I can still accomplish this or that. What society might think is normal is not necessarily normal for a person with a brain injury, and they're not going to fit the molds a lot of times... I think they really have to take that into consideration that they're not going to think the same way as society and that is okay in a lot of ways.

In some cases, participants went beyond this perspective to describe a sense of disability identity in the form of strength, pride and culture. This framing moved the focus of participation to the level of being a member of a social, collective group, and the benefits of that membership in terms of social capital and collective identity, control and power.

We have a unique insight into life that a lot of people don't have. I think that's really important when we're talking about participation that we can share with others that haven't experienced this... from our perspective. Instead of making us feel like we're lower class citizen, we should have our own new way to participate so that people CAN LEARN FROM US (emphasis added by speaker).

Being proud to be disabled and things like that helps to be able to participate... Yeah, disability pride.

Discussion

Participation as described by participants with disabilities in this study is a complex and multi-dimensional construct. There is no gold standard for ideal or optimal participation, no one defined set of activities or frequency of engagement that accounts

for 'full' participation. Participants described needing to be free to define and pursue participation on their own terms rather than measuring whether they met predetermined societal norms or standards. The participants stressed that participation through meaningful engagement required that they have access to a full range of opportunities, unrestricted by bodily impairments or disabling physical, social and political environments. Participation was not taken for granted; but instead, was viewed as a dynamic process that involved constant negotiation and balancing of competing needs and values across individual, social and societal levels, exerting a 'push-pull' influence on people's ability to participate in ways that they find meaningful and satisfying (see Figure 2). This dynamic may occur due to personal choice (e.g., person consciously desires to focus on specific areas and does not value others as much), and/or due to environmental influences (e.g., person does not have supports or resources available to make an informed choice or the environment dictates an emphasis on specific participation values).

This balancing act often hinged upon realizing values such as having an impact and developing a social connectedness based upon respect of difference and dignity of personhood. The right to exercise personal choice and control grew from this respect and dignity, and was epitomized as doing 'want we want, when we want, with whomever we want'. This emphasis is consistent with Cardol and associates' [27] assertion that the right to and recognition of decisional autonomy (the opportunity to actively be a part of one's decision making) may be more important than the ability to independently perform activities by oneself.

The participants also stressed that participation demanded both personal and societal responsibility. In keeping with Western cultural values of self-determination and personal responsibility [39] participants recognized that the onus was on them to seek, strategize and assert their rights to full participation in society on a par with their non-disabled peers. There was, however, a firmly held belief that governmental and social policies need to ensure enforcement and compliance of their rights to equal access and opportunities in housing, transportation, work and economics, and social and leisure pursuits to realize equal opportunities. These assertions are consistent with the philosophy of the disability rights movements which views oppressive social attitudes and policies, rather than bodily impairment or performance, as the primary barriers to full participation [40].

The focus group data challenge the prevailing definitions of participation and previous instruments used to measure this and related constructs. Parti-

cipation is conventionally defined as social engagement and for an activity to 'qualify' as participation it must have a social or interpersonal dimension, yet when participation is actually measured, the emphasis shifts to individual performance by the person. In contrast, participants in this study spoke about participation as a dynamic transactional process between the personal, the social and the societal. Participants emphasized both individual meaning as well as social connection and enfranchisement. Although participation is not done alone, data obtained using a grounded theory approach reveals that people with disabilities view participation as having a significant personal or individual component. While clearly participation does not occur in a vacuum devoid of social context, it can, as in the cases of spiritual participation, be realized at a very private and personal level. The recognition of the value of meaningful yet private engagement can have important implications for respecting the rights of people with disabilities who live in congregate or group settings in meeting the terms of participating in 'what you want, when you want, with whomever you want'.

The study results have clear implications for the definition and measurement of participation. Participation not only includes active engagement in life situations at the societal level, but it also includes the personal meaning and satisfaction resulting from that engagement. This points to the need for subjective and values-based participation assessment items. Specifically, this study suggests six participation themes that might serve in this capacity. As part of this continued research, these six themes have been translated into participation value statements for individuals to endorse or reject (see Table II). This approach extends the work of McColl and colleagues [10,41] and offers an alternative to satisfaction ratings of specific activities.

This qualitative study also provides insight into the development of measures of participation. The overwhelming message coming from the focus groups of people with disabilities was that no defined set of societal roles or social activities would be appropriate for all or indicative of 'full' participation. Any effort to measure objective participation would have to be flexible enough to deal with the fact that different people will need, desire and endorse different aspects of participation and that very different patterns of participation can still reflect full participation. This non-hierarchical conceptualization of participation is not consistent with the assumptions of classical measurement or item response theory approaches, further adding to the challenge of participation measurement.

If participation is seen as a social phenomena, future research needs to shift from its primary focus

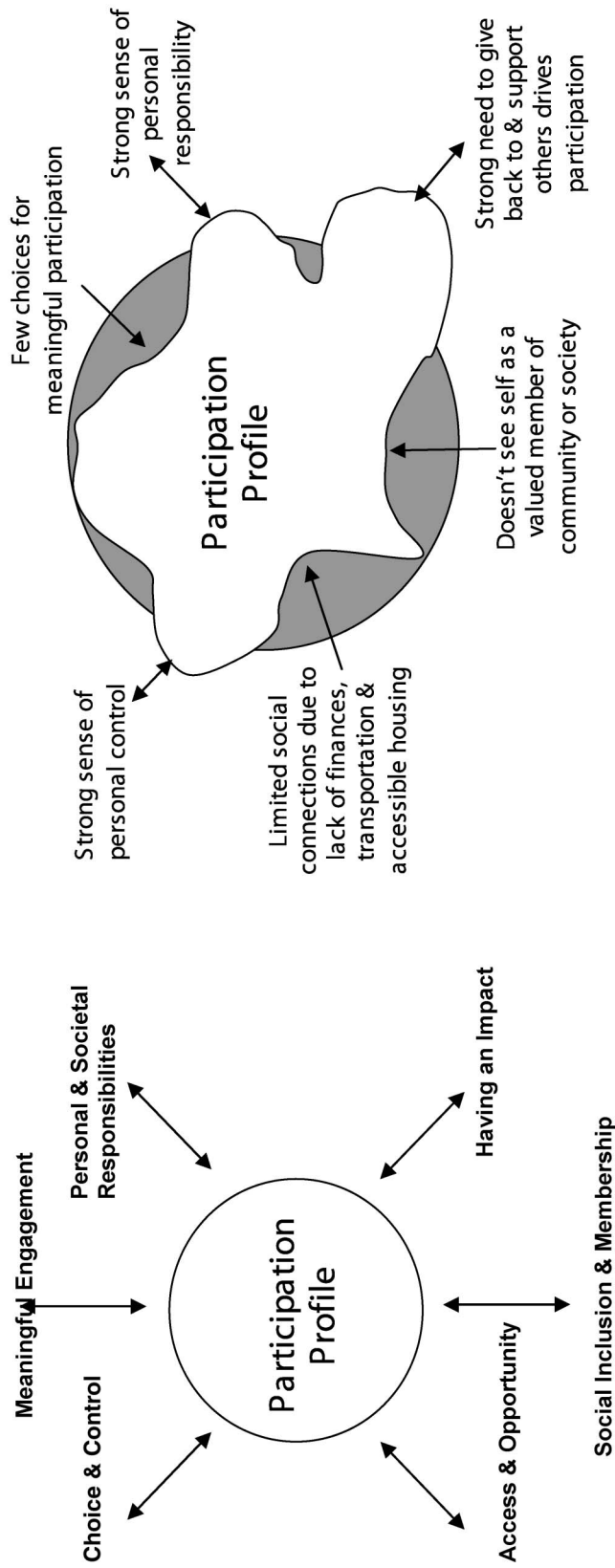


Figure 2. 'Wagon-wheel' depiction of participation. This figure illustrates the complex, multifaceted phenomena of participation. On the left, the graphic illustrates desired participation as fully supported across all value areas. The right graphic depicts a specific example of how specific participation values may influence a person's participation profile, and ergo, his/her overall evaluation of full participation. These profiles may change across contexts, depending on whether the environment is more or less supportive of participation. People may generate several participation profiles across contexts and across the lifespan. The graphic can also represent the experiences of a community or social group, such as disabled people as a minority group, that may share participation values or common sets of environmental factors limiting or supporting participation.

Table II. Potential participation value items.

| Items | Values | | | | | |
|---|-------------------|------------------|----------------------|------------------|-----------------------------------|---|
| | Active engagement | Choice & Control | Access & Opportunity | Responsibilities | Having impact & supporting others | Social connection, inclusion & membership |
| I live my life fully. | X | | | | | |
| I can go out and have fun. | X | | X | | | |
| I am able to pursue my dreams and desires. | X | | | | | |
| I look for new challenges. | X | | | | | |
| I participate in activities when I want or need to. | X | | X | | | |
| I have control over what I do and how I spend my time. | | X | | | | |
| I have the freedom to make my own decisions | | X | | | | |
| I am able to live my life the way I want to. | | X | | | | |
| I have choices about the activities I want to do. | | X | | | | |
| I have control over my own finances. | | X | | | | |
| I can engage in intimate and sexual relationships when I want or need to. | | X | X | | | X |
| I can get together with people when and where I want. | | X | X | | | X |
| I get out of my house to do the activities I choose. | | X | X | | | |
| I can get out and about whenever I choose. | | X | X | | | |
| I am free to participate in activities that I choose. | | X | X | | | |
| I have opportunities to meet new people. | | X | X | | | X |
| If I needed work, I have employment opportunities. | | | X | | | |
| I have access to the Internet/computers/phone when I want or need them. | | | X | | | |
| I have access to programs/services in my community. | | | X | | | |
| I have access to reliable transportation when I need it. | | | X | | | |
| I have the money to do the things that are important to me. | | | X | | | |
| I take responsibility for my own life. | | | | X | | |
| I am an advocate for myself | | | | X | | |
| I do important things with my life | | | | X | | |
| I have access to supports and resources to participate. | | | | X | | |
| I have a right to participate in my community and society. | | | | X | | |
| I spend time helping others. | | | | | X | |
| Other people count on me. | | | | | X | |
| I am an advocate for my community and/or other people. | | | | | X | |
| I can do things for other people when I want or need to. | | | | | X | |
| I do things that improve my community. | | | | | X | |
| I contribute to the general well-being of my community. | | | | | X | |
| I have influence in my community. | | | | | X | |
| I contribute to society. | | | | | X | |
| I have someone I can talk to when I want or need to. | | X | | | | X |
| I have people to do things with when I want or need to. | | X | | | | X |
| I feel that I am a part of my community. | | | | | | X |
| I am a valued member of my community. | | | | | | X |

(continued)

Table II. (Continued).

| Items | Values | | | | | |
|---|-------------------|------------------|----------------------|------------------|-----------------------------------|---|
| | Active engagement | Choice & Control | Access & Opportunity | Responsibilities | Having impact & supporting others | Social connection, inclusion & membership |
| I feel valued as a member of society | | | | | | X |
| Other people believe in me. | | | | | | X |
| Other people treat me like a human being. | | | | | | X |
| I count as a person in society | | | | | | X |
| My community respects me the way that I am. | | | | | | X |
| I am treated equally. | | | | | | X |

Note: Potential examples of items representative of a larger item pool or bank to dynamically assess participation values. Note that some items cut across or could be worded to represent different values.

on individuals with disabilities and their performance, to examine the complexity of participation at the level of diverse social relationships, groups, communities and cultures. Furthermore given the dynamic interplay between the person and the environment, assessment of participation must also consider the role that the environment plays in facilitating, obstructing and transforming participation. Finally, the emphasis on societal responsibility has important implications for the allocation of resources so people with disabilities can pursue ‘full’ participation as they define it. It is difficult to envision ‘full’ participation if one does not have basic supports to survive and/or to thrive in society.

While the strengths of this study lie in its interpretive approach to illustrating how participants with disabilities defined participation in their own words and experiences, there were also several limitations. First, this study was conducted with people with disabilities across sites in the United States and therefore did not reflect the diversity of participation values of people in different cultural, political and global contexts. The focus group questions represented broad strokes in conceptualizing participation, thus providing important insights, but less thick, rich description that could be pursued in future research. Because participants were recruited from state of the art rehabilitation hospitals and Centers for Independent Living, they may represent a particularly informed and socially integrated subsample of people with disabilities. People currently living in institutional settings were not included as part of the sample and would offer valuable insights into environmental influences on participation. To reflect the diversity of experience of people with disabilities, focus group methodologies also need to be expanded and replicated across different disability constituencies, geographic locations, living contexts, global and cultural contexts, class, race, ethnicity, gender, and sexual identity groups. Focus group data could also be supplemented with participant/environmental observation and participatory action research strategies to not only increase the trustworthiness of the findings and illuminate rich details of participation experiences, but to also begin to effect social action change at the same time to more fully realize full participation opportunities.

Conclusions

Participants with disabilities in this project defined participation as a multifaceted, transactive process involving interaction with and within physical, social, cultural and political environments and communities. They described several values that exemplified participation for them. They expressed a desire to shape and contribute to their broader social worlds,

while at the same time emphasizing their right to supports. They viewed participation as a right that is predicated upon access, opportunity, respect and inclusion. They also described participation as a personal and societal responsibility that required determination, advocacy and empowerment. Finally, participation was viewed as a means to experience social connectedness with other people and communities, pointing to issues of social capital. While the values associated with participation were shared by most of the participants, the routes to their realization were individualized. No one cluster of activities represented a “gold standard” for participation, nor would a count of activities or frequency with which each was performed epitomize what “full” participation meant to individuals. Instead, the values of social interdependence, “being a valued part of society” and having choice, control and freedom to pursue participation opportunities were emphasized over specific activity domains.

This study helps to illustrate the subjective experience of participation as an expression of personal and social values, and responds to criticisms levied at previous participation scholarship and classification efforts. Participants emphasized that participation and performance are not synonymous. The study results also provide evidence of the dynamic interplay between people and their environments, not just at the immediate person/environment level but also at the community, cultural social and societal levels. The findings challenge researchers to critically examine conventional means of measuring participation via performance of a standard set of roles and activities. To adequately reflect and capture the meaning that participation holds for people with disabilities, participation instruments need to address the values and meanings of participation for people, as well as the interactive and transformative influence of the environment on participation choice, control and opportunity.

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