ORIGINAL REPORT

PARTICIPATION: A COMPARATIVE ANALYSIS OF MULTIPLE REHABILITATION STAKEHOLDERS' PERSPECTIVES

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Objective: To examine how participation is conceptualized by different rehabilitation stakeholder groups.
Design: Qualitative case study design.
Subjects: A total of 148 participants from different stakeholder groups in 2 US states and the District of Columbia. Stakeholders included people with disabilities ($n=63$), caregivers ($n=28$), rehabilitation professionals ($n=32$), funders ($n=10$), and policy makers ($n=15$).
Methods: Eighteen focus groups were conducted to examine what participation means, how it is conceptualized, and the barriers to realizing full participation. Focus groups were transcribed verbatim; transcripts were analyzed using a constructivist grounded theory approach.
Results: Stakeholders agreed on 3 primary domains of participation: (*i*) productivity and economic participation; (*ii*) social participation and relationships; and (*iii*) leisure/recreational participation. Participation within each domain was characterized by its diversity, individuality and environmental influences. Differences emerged in the emphasis stakeholders placed on the relevance of the participation domains in the lives of people with disabilities. Stakeholders' emphasis was influenced by their roles within the rehabilitation process and created distinct needs for participation outcome measures.
Conclusion: While there was agreement about what constitutes participation, stakeholders emphasized different aspects of participation based on their positions in the rehabilitation process. Recommendations are offered for integrating study findings into the development of new participation measures.

Key words: community participation, qualitative research, rehabilitation, outcome assessment, disabled persons, caregivers, policy makers, healthcare providers.

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INTRODUCTION

Participation, defined within the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) as "involvement in life situations" (1; p.10), is central to all major models of disability (1–3). Participation refers to active engagement in real-world activities and environments. Because participation is directly relevant to how people live their lives and integrate into community life, people with disabilities and their significant others identify participation as one of the most highly valued rehabilitation outcomes (4). The ICF is emerging as the dominant classification schema of disability. A review of contemporary measures of participation indicates that most measures are conceptually grounded in the ICF (5). Yet neither the ICF's definition of participation as "involvement in life situations", nor its classification system provide a fully articulated framework of what participation is or how it is conceptualized by rehabilitation stakeholders. This conceptual ambiguity has made it difficult to operationalize, and therefore measure, participation. Participation measurement is further stymied by the decision to combine the ICF concepts of activities and participation into a single, albeit exhaustive, group of codes (4, 6). Many contemporary participation measures rely on arbitrary distinctions between activities and participation. For example both the participation measure for post-acute care (7) and the PRO-PAR (8) limited or excluded self-care items because the developers were closely aligned with existing self-care measures (9, 10). Theoretical efforts aimed at disentangling activities and participation emphasize the need for empirical research to operationalize participation as a distinct construct (6).

The past decade has seen a proliferation of efforts to develop new measures of participation that correspond to contemporary definitions; yet, there is no "gold standard" for measuring participation (11). The majority of participation measures are based on the expert opinion of rehabilitation researchers and adherence to established frameworks, such as the ICF (7, 8). Many of these instruments incorporate legacy items from earlier instruments designed to measure community integration (12, 13) and handicap (1, 14), with additional items written to capture aspects of participation not previously addressed. When the perspectives of other stakeholders, such as people with disabilities, are elicited, it is usually *post hoc* to assist in the refinement rather than the generation of items. This method privileges the perspectives of experts over other rehabilitation stakeholders and can lead to the retention of outdated concepts and items (15).

Efforts to develop participation measures that capture the insider perspective of people with disabilities tend to focus on specific disability groups, such as people with traumatic brain injuries (12, 16) and mobility impairments (17), and may not be applicable to all rehabilitation consumers. A limited number of participation measures, such as the Participation Survey/Mobility (17), have been developed using qualitative methods to gain an in-depth understanding of the lived experience of participation from the perspective of people with disabilities, their significant others, and their rehabilitation therapists. These efforts are more inclusive of multiple stakeholders, but do not elicit the perspectives of people who make decisions about rehabilitation funding and policy.

Multiple stakeholders have vested interests in participation outcomes including rehabilitation consumers such as people with disabilities and their caregivers; rehabilitation professionals who provide direct services; funding organizations that pay for services; and policy makers who shape rehabilitation and disability legislation and resource allocations. It is unclear how stakeholders' relative roles in the rehabilitation process shape their understandings of what participation means and, by extension, how it can best be measured.

There is growing recognition that qualitative methods can help identify and fill gaps in outcome measures (15). Our qualitative research with people with disabilities is an example of how patient input can both identify and begin to fill gaps in how participation is conceptualized and measured. Analysis of data from focus groups with people with disabilities revealed a set of core participation values that included; (*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 (18). Participation values were related both to what makes participation meaningful and what makes participation possible. These participation values occurred across domains of participation – such as in the ICF categories of domestic life, major life domains, social relationships, and community, social and civic participation.

Patient involvement in outcome measurement is not only good science; it is being codified in the instrument development process. For example, the US Food and Drug Administration now requires patient involvement in all stages of development of patient-reported outcomes used in clinical trials, from the development of conceptual models to item generation (19). The National Institutes of Health's Patient Reported Outcome Measurement Information System (PROMIS) includes patient focus groups as part of their standard instrument development protocol as a means of defining core concepts and generating items (20, 21).

Constructivist grounded theory posits that "people create and maintain meaningful worlds through the dialectical process of conferring meanings on their realities" (22–24). Focus groups provide a unique opportunity for people to create meanings through discussion and dialogue. In this way, abstract concepts such as participation can be made concrete. The goal of constructivist grounded theory is not to catalogue participant responses but to build middle-level theoretical frameworks through a rigorous process of comparative analysis.

A fresh approach to define and measure participation is needed that is informed by all stakeholders' perspectives in order to minimize the conceptual limitations of existing instruments. Improved measures of participation should be based on a clear conceptualization of participation from diverse stakeholder perspectives. Thus, the objective of this study was to describe participation from the perspectives of rehabilitation consumers, caregivers, providers, funders and policy makers.

METHODS

Study design

We used a qualitative case study design (25) based on constructivist grounded theory (22, 26) 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 (25), in this case, to describe what participation means to different stakeholder groups in the rehabilitation process. Findings were grounded inductively in the data; that is, results and the development of theory emerge from the perspective of participants, rather than specific theoretical approaches or hypotheses imposed on the data (26). The research was reviewed and approved by human subjects review boards at the participating sites, and all participants provided informed consent.

Sample

Stakeholder groups, including people with disabilities, caregivers (both family and paid), rehabilitation professionals, healthcare funders, and policy makers, were asked to explore and examine the concept of participation in their own lives and the lives of people with disabilities. A total of 148 people across 18 focus groups participated in this study. The focus groups were composed of people with disabilities (5 groups), caregivers (6 groups), rehabilitation professionals (4 groups), funders (1 group), and policy makers (2 groups). Participants were recruited from rehabilitation centers, affiliated support groups, community-based Centers for Independent Living and other disability-related organizations in Illinois, Colorado and Washington, DC. Participants with physical disabilities (primarily stroke, traumatic brain injury and spinal cord injuries) ($n=63$) were oversampled to reflect their voice in more detail (17). Caregivers ($n=28$) included both paid and unpaid family caregivers and personal attendants. Rehabilitation professionals included nurses, therapists (occupational, physical, speech, recreation), social workers, physicians and case managers across different practice settings ($n=32$). The healthcare funder focus group ($n=10$) included representatives from federal and state Medicare and Medicaid, private insurance, healthcare certifying and accrediting organizations, and healthcare provider networks. The policy maker ($n=15$) focus groups were conducted in Washington, DC, and Springfield, IL, USA, and included representation from the legislative and administrative branches of Federal and State governments.

Data collection procedures

We developed a structured protocol for facilitating focus groups in collaboration with community partners based on Krueger & Casey's approach (27). All facilitators were trained on how to conduct focus groups including strategies to elicit responses and promote equal participation. A professional captioner provided real-time captioning[1] of focus groups; producing a verbatim transcript that was used

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[1]In the process of real-time captioning, the captioner is in the room and types the transcript during the proceedings. Captions may be projected on to a screen and thereby serve as a disability accommodation.

in subsequent analyses. Two groups, one with policy makers and one with funders, declined to have their discussions captioned and transcribed, results from these groups were summarized in field notes that included direct quotations, when possible. All participants were given the questions in advance in order to give them time to prepare and reflect. See Appendix I for focus group guide. At the end of each session, the facilitator summarized the group's discussion, affording participants the opportunity to make corrections and amendments to the facilitors' preliminary synthesis of the data, and to further triangulate findings within groups.

Data analysis

Verbatim, electronic transcripts from the captioner were transferred to ATLAS.ti software (28) to store, organize and retrieve data. Consistent with the principles of constructivist grounded theory (22), qualitative data were analyzed using a constant comparative approach in which transcripts were reviewed and open coded by 2 team members to identify key themes and to triangulate findings (29, 30). We developed codes that represented content themes, highlighting areas of agreement and differences in perspectives on specific participation issues (27, 29). 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 data within each stakeholder group, followed by comparative analysis across the different stakeholder groups (30). This paper emphasizes similarities and differences across stakeholder groups that emerged from comparative analysis of the stakeholder data from the entire sample.

RESULTS

There was general agreement about the value of full participation for people with disabilities and about the key domains that constitute participation. However, stakeholder group differences emerged in which participation domains were emphasized and, by extension, how they should be measured. We first highlight the participants' agreement on key participation domains, as well as the nuances of diversity, individuality, and environmental influences that characterize participation for people with disabilities. We then examine group differences that reflect stakeholders' roles and responsibilities in the rehabilitation process.

Agreement across stakeholder groups

Major participation domains. When asked specifically to identify what constitutes participation, all of the stakeholder groups, including people with disabilities, indicated domains best described as: (*i*) productivity and economic participation; (*ii*) social participation and relationships; and (*iii*) leisure/recreational participation.
  "Participation is to work, play and love and otherwise engage in all aspects of society." *Rehabilitation professional*
  "I would break the topics down into 4 or 5, and I'm sure there are dozens more. Working, family, recreation, spiritual aspects. Those types of things. Each of those categories – each of us based on our own value systems." *Person with a disability*

Productivity and economic participation. Productivity and the opportunity to make meaningful contributions to society were cited by all stakeholder groups as a key component of participation. Funders emphasized paid employment and self-care. When asked "What does participation mean to you as a funder?" funder responses centered around, "Productivity… It could be active on a job, it could be home life".

Other participants extended the definition of productivity beyond paid work to include a broad range of productive pursuits including volunteering and giving back to the community in some way. Participants emphasized that productivity needed to be meaningful to both the individual and to the society.
  "With my son, it's people just giving him a chance to do what he wants to do. If he doesn't have a good job … give him a chance to give back in his own way. Maybe not as much as someone else might do but in his way… he can make a difference." *Family caregiver*

Economic participation was seen as extending beyond traditional worker roles.
  "These folks can become a very vital part of our economy… This could profit everyone in the long run, not only functional profit, financial profit, but emotional profit." *Paid caregiver*

Social participation and relationships. All stakeholder groups cited the centrality of social relationships to participation, as seen in the following focus group exchange:
  "Relationships are very important, casual or intimate. It's very important to be accepted." *Paid caregiver*
  "It's a basic human need, I think." *Family caregiver*

The importance of intimate relationships and sexual expression within these relationships was also emphasized.
  "Crippled [sic] people say they don't need that [sex], they're saying that to protect themselves when in actuality everybody needs someone… You always have your family. You may even have your friends, but having a significant other, I wouldn't say that I'd give that up, because I wouldn't." *Person with disability*

Leisure and recreational participation. Leisure and recreational engagement was deemed to be an important participation domain – especially when stakeholders spoke about what participation meant in their own lives.
  "Don't let life live you. Live life. When I say "live life," don't just live your life working all the time. Do something. Go out and have fun and make yourself use some of that money that you worked for…Do something for yourself." *Person with a disability*
  "I think recreation is a really big area for our clients. We can't be all work and no fun. It's important to your mental status just to have fun and be accepted. Recreation is very important." *Paid caregiver*

Policy makers also recognized the importance of being out and about in the community and being able to participate in the social life of the community. As one policy maker said: "Participation is just the stuff we do and take for granted".

Diversity. Rather than creating an exhaustive list of all the ways of participating, the stakeholders recognize that within

each domain there was a variety of ways of engaging and need to capture that diversity. One therapist described participation as:

"The choice of wanting to participate in things and the choice across a broad range. If I want to participate in politics… I can choose to read about it in the paper or I can choose to go and vote or I can choose to write a letter. I can do all different levels of things that are a part of being… valuable to society".

Individuality. Participation's diversity was attributed to the highly individualized ways that people choose to participate. These choices were shaped in part by individual interests.

"It's really the opportunity for choice and you don't have to, 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." *Rehabilitation professional*

"The level of full participation is different week to week and it doesn't have anything to do with my disability *per se* but my inclination." *Person with a disability*

Personal and collective responsibilities were also described as shaping participation.

"Participation choice is really good but sometimes, just when you're a human being in life, there are just things that you're expected to do." *Rehabilitation professional*

"Participation can be different depending on what other competing roles we have going on at the same time and something about how these roles interact is important to consider… depending on someone's limited resources or limited energy or… intersecting roles you make decisions to participate in different things." *Rehabilitation professional*

People with disabilities stressed, however, that they did not want to be compared to a pre-defined non-disabled norm.

"It depends on what each one of us feel we need or we want to be fully participating… 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." *Person with a disability*

Environmental influences and barriers. All of the stakeholder groups identified participation barriers and saw access to resources as the gateway to participation.

"I think somebody with a disability, they're not able to do as much as they'd like to do and there are barriers to prevent them from doing some things they could do and want to do but they can't because of said barriers." *Rehabilitation professional*

Some participation barriers were seen as inherent in the individual due to impairment effects, such as fatigue or lack of cognitive awareness.

"I have to start balancing; and I'm in the process now of figuring out when I have to say no to things… I really want to do everything, and I try to do half of it and I burn out... I have to take a 4 hour nap everyday." *Person with a disability*

"[My son] doesn't really have that self awareness. I mean, he knows he's in the chair and he's messed up, but it's almost like the head injury doesn't allow him to realize that he's, he does have behavior [that limits participation]." *Caregiver*

More commonly, however, people emphasized how impairments interacted with barriers in the environment to limit participation.

"Someone who may not have been depressed upon discharge finds out that the system is choking them to death, become depressed then become suicidal, why should I do this?" *Caregiver*

The lack of transportation, inaccessible environments, lack of access to information, and negative attitudes about disability were the most frequently cited environmental barriers. For example, participation was described as inextricably linked to transportation availability.

"If you don't have access to transportation, you don't have access to a whole lot of things. I mean, you don't have opportunity to do very much. I mean you become very limited." *Person with disability*

"Some of the programs we work with, you're allowed 5 trips of non-medical variety within certain distance and... you have to plan out 72 hour beforehand exactly where you want to go and when you want to be there and they can cancel at the last second." *Paid caregiver*

Similarly, access to public spaces was seen as vital to participation.

"I think people just get so frustrated sometimes to go to places and it turns out that they're not accessible and a lot of times they'll just stop. So I think that's a big hindrance to independency [sic] and participation." *Paid caregiver*

Not only do inaccessible environments limit participation, one caregiver elaborated how constantly having to confront environmental barriers can erode a person's sense of self-worth.

"I've had clients that I've had to take them to the cargo elevator in the back to get into the building. It is extremely demeaning. It's very embarrassing for these people… I've seen people break down and cry." *Paid caregiver*

Information access was also described as a vital resource to enable participation.

"It always comes to education and information. Then you get to make a decision on your participation. If you have good education and good information, we can make good decisions." *Person with a disability*

As one funder pointed out, "Lack of information can be as isolating as any physical barrier". Unreliable information was described as limiting participation.

"The insurance companies say one thing; the doctors tell you something else. Your therapist tells you something else, and in the end you're so confused about what to do because if I do this I have to do that and so on. I might as well sit here and do nothing." *Paid caregiver*

Negative societal attitudes about disability were also cited as barriers to participation.

"I would say attitudes is, I think, probably the biggest barrier that often times I face. Attitudes which deny me access or opportunity or become a barrier to access and opportunity… at times it's like a constant wearing down to the point where it takes a lot of energy to deal with. More than – sometimes more than participating." *Person with a disability*

All of the stakeholders recognized that economics influenced participation, as a caregiver stated: "To be blunt, money. There's just not enough of it out there".

Differences across stakeholder groups

Across stakeholder groups there was agreement about the domains of participation; group differences emerged about the priority placed on different domains.

People with disabilities. People with disabilities emphasized their right to full participation and highlighted the critical role that advocacy played in their ability to participate in all domains.

"To fully participate is to be able to self-advocate. 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… so that we can all begin to have a stronger, more unified voice in trying to change those barriers that still exist despite the ADA (Americans with Disabilities Act) being around for 15 years."

People with disabilities emphasized the need for both self and collective advocacy in order to realize full participation.

"You have to self-motivate yourself and not wait for the people around you and you have to be your own advocate… You can advocate and you have someone who could show you how to advocate."

Caregivers. Caregivers echoed the emphasis on the right to full participation and often assumed the roles of advocates and champions to ensure participation opportunities, as seen in the following caregiver's description of her battle to secure funding for disability services.

"If he did not have the family resources to pay for service, he may or may not be functioning well, reintegrating back into his employment and still maintaining his home, his vehicle, and all the other resources that we've been able to provide through family private pay… I have had to fight the whole time to retain services… because they are so funding focused, not… very task focused. So re-educating the insurance companies, redefining some of the resources that are available and making them payable."

Caregivers stressed that within their role as caregiver they had an obligation to set limits when they perceived the person's participation choices to be risky or inappropriate. Caregivers also made judgments about the appropriateness or relative importance of certain forms of participation because as one family member said, "What they want and what they need might not be the same thing". While well-meaning, there was recognition that over-protectiveness may interfere with people's opportunities for participation.

"A lot of times, family members can become saboteurs as well… Family members are so overwhelmed from their injuries that they tell the person "don't worry about doing that, I'll do it for you. Oh, no, no, no, you can't do anything. I'll do that for you"… They would just rather have the person sit and do everything for them… They sabotage their loved one's own abilities."

Rehabilitation professionals. Rehabilitation professionals emphasized a conflict between their appreciation for the value of participation and the practical constraints imposed by rehabilitation settings and funding systems. These constraints often prevented rehabilitation professionals from addressing participation in their practice. For example, one professional described how the emphasis in inpatient rehabilitation often precluded participation-based interventions.

"In rehab, you know your focus has to be on getting them home and being more independent and we really don't focus on any of the social fun stuff… It seems to be very, very limited."

Practice guidelines within rehabilitation settings further limited opportunities for participation-based interventions.

"Even just having to be outside the hospital to work on those [participation] things makes it difficult for us… We had to get permission from the physician and an order… It should be therapy, regular therapy… I shouldn't have to jump through all these hoops."

Rehabilitation professionals also described a sense that immediately after the onset of disability, patients were not ready to address participation and instead the focus was placed on remediating impairments or regaining lost function.

"People feel like if they could just be stronger and walk and a number of more impairment things got better they could just automatically be able to be out in society."

"Walking is like the most obvious thing that they've lost, they've lost a lot of other things they don't know they've lost yet. They don't know they've lost their ability to engage in social, leisure activities. They don't know that their family relationships are going to change."

Rehabilitation professionals expressed interest in client-centered assessments that could be used to guide participation-based intervention.

"Have this pool of questions and obviously you base them on what's important to the patient. Let's say, they say going out with friends and being social [is important] and then something about why aren't they able to do that so that you could narrow it down."

"You could go over a series of different things that you ask them about. Relationships, employment, whatever you want to do… and see if there's anything that falls out… and those are the things that we say "Can we change that?" And in some cases the answer is 'yes', maybe we can and in other cases, we can't."

Rehabilitation professionals expressed concern about being held accountable for participation barriers that were beyond their ability to control during rehabilitation.

"What you are looking for is outcomes and what you're finding is that the barriers are things that cannot be overcome by our intervention."

"Part of the issue is even if we know what the problem is, participation is something that is so big and it is out of the hospital, I feel like there are some things we won't be able to impact or control."

Funders. Funders talked about the diversity of participation in their own lives. Yet, when it came to priorities for people with disabilities, they tended to focus narrowly on economic factors related to paid employment and decreasing the societal burden of funded disability services.

"In order to get funding, the things that don't typically seem to be related to return to work, you really need to show relevance to how this is going to get the person ahead to productivity or towards decreasing the amount of care that they need at home or geared towards something that then creates less dollars spent."

Funders described a need to guard against what they described as an entitlement mentality and the secondary gains of disability.

"There is an entitlement ethic that may be distorted... The further they get away from the time of their injury the more of a burden they become to their family, their society."

In an effort to minimize entitlements and societal burden, funders deemed some types of participation beyond their responsibilities – especially leisure and social participation. Like rehabilitation professionals, funders expressed a need for measures that could provide evidence of the efficiency and cost effectiveness of specific interventions. Funders wanted measures that could objectively document performance and outcomes, so that their funding decisions could be based on "more on evidence, less on anecdotal" sources. Another funder suggested that:

"Being able to look at the treatments or the programs being offered and being able to relate them back to the individuals that are becoming more productive, which in the world means going back to work or it means productive in society"

Policy makers. While they were interested in the careful stewardship of public resources, policy makers were focused on how laws and policies could ensure that people with disabilities have access to the same rights and opportunities to participate as any other citizen. Policy makers viewed people with disability as constituents, and as such, they emphasized the need to know how these individuals would like their representatives to vote and act on various issues. Their interest in participation focused on the extent to which people with disabilities have a voice in their community in regard to policy and resource allocation decisions. Important aspects of participation identified by policy makers included: the opportunity to vote and express views in public forums; access to religious gatherings and entrepreneurial opportunities; and parenting rights, including adoption. They expressed interest in identifying and documenting participation barriers, disparities and outcomes to assist in guiding policy at state and national levels.

"We need access to both research and individual stories and testimonials, but we also need community level data that is representative of constituents – could be an assessment tool used in rehab but also some format of it then used in community to prioritize issues and show where constituent priorities are on a collective or state by state level."

Policy makers also emphasized the invisibility of the disability community as a collective group and expressed skepticism about information disseminated by special interest groups representing specific impairment or diagnostic groups. Policy makers spoke of how the "absence of an effective and unifying movement" prevented them from attending to the needs of people with disabilities. They discussed that the voice of a single impairment group is less likely to be heard than the shout of the disability community as a whole. Further, policy makers suggested that groups be organized around issues and desired outcomes (e.g. improving supports to live in the community or to work) rather than their type of disability or impairment. Policy makers stressed that: "Congress is reactive and driven by the voice of constituents", and that they were unlikely to implement programs and policies to address participation barriers without increased political participation by people with disabilities.

Policy makers also conceded that there was a knowledge gap between themselves and people with disabilities, yet they placed the responsibility on people with disabilities to find ways to bridge that gap, "We can't tell you what disabled people want or need. They need to tell us".

Policy makers prioritized outcome data that could be used to document participation disparities experienced by people with disabilities at the national, state and community levels.

"There is no good information across the population other than the Harris Poll. The data is not consistent and tell us little, like the census data. There really is no comprehensive data about people with disabilities in the community... it typically comes from the perspective of who is asking for the money."

Establishing evidence and data on the economic impact of decreased participation was particularly valuable to policy makers. Both funders and policy makers highlighted their role in guarding the public trust; however their emphasis was different. Funders emphasized the "careful use of resources across the life span of that individual" whereas policy makers sought research that could document participation disparities at national and state levels.

DISCUSSION

This study confirms and deepens our conceptual understanding of participation. There was conceptual agreement across stakeholder groups about 3 key domains of participation: productivity and economic participation, social participation and relationships, and recreations and leisure participation. These 3 domains are consistent with many contemporary frameworks of participation, including the 3 ICF chapters most frequently addressed in participation measures: major

life domains, interpersonal relationships, and community, civic, and social participation (5). Furthermore, since the ICF combined the concepts of activities and participation in 2001, there has been ongoing debate on how and if the 2 concepts can be distinguished (6, 14). This study provides empirical support for a narrower set of participation domains than is currently contained in the ICF. The use of a smaller set of participation domains may help increase the ICF's ease of use and clinical relevance. The qualitative data also helped create a deeper more nuanced understanding of participation by emphasizing participation's diversity and individuality. Participants described how environmental influences played a role in setting the stage for participation by limiting some opportunities and creating others. For example, disability discrimination limited participation in paid work but opened up the roles of advocate, mentor and political activist. Access to resources to overcome barriers to participation was recognized as the gateway to participation.

The focus on participation domains tended to narrow, the further stakeholder groups were from first hand experience with disability. For example, whereas people with disabilities were broadly focused on all aspects of productive, social and leisure participation, funders were more narrowly focused on paid work. Funders' narrow focus on productivity and decreasing the cost of care was influenced by their responsibilities to be careful stewards of financial resources. Caregivers and people with disabilities lamented that funders seemed to be more attuned to finances than the experiences and support needs of people with disabilities.

The different focus on participation domains may be explained by roles and responsibilities in the rehabilitation process. For example, policy makers acknowledged that they were not aware of the needs of people with disabilities. They observed that the disability community's invisibility and lack of a unified voice made it relatively easy for policy makers and legislators to ignore the concerns of people with disabilities. Because of the reactive nature of the legislative process, the needs and participation restrictions of people with disabilities must be made more visible to policy makers. Due to the pejorative connotations of "catering to special interest groups", policy makers also expressed the necessity of unbiased and cross disability data on participation disparities that occur at the state and national levels.

Caregivers' focus on participation domains was more contested. Many caregivers expressed a deep commitment to participation and were actively involved in advocacy efforts to promote opportunities for their loved ones. They also spoke of the need to serve as protectors and restrict participation deemed risky or inappropriate. People with disabilities described how caregivers' efforts to ensure safety created a "slippery slope" towards over-protectionism, effectively constricting participation opportunities.

Rehabilitation professionals' focus on participation was also contested. They professed a deep commitment to full participation for people with disabilities, yet they reported that they were limited in their abilities to address participation clinically due to constraints in their practice environments,

such as reimbursement issues, short lengths of stay, and patient readiness.

In summary, stakeholder differences in emphasizing different participation domains are shaped by their responsibilities within the rehabilitation process. These differences in emphasis also create different needs for participation outcome measurement.

Implications for measurement and practice

Addressing the needs of different stakeholders in the rehabilitation process requires instrument developers to balance competing perspectives. The use of broad conceptual categories, such as those identified in this study, may prove more useful than efforts to create an exhaustive, albeit ultimately incomplete, list of all the ways that a person may choose to participate in "life situations". Discussions about individuality and diversity point to the need for instruments with the flexibility to measure a construct that may be expressed very differently within and across stakeholder groups.

Rehabilitation professionals also wanted measures that can guide client-centered intervention. Therefore, an evaluative item that asks the person to rate satisfaction with level of participation in different life domains could, in combination with items rating performance, help identify participation restriction in areas of relevance to the client, help establish treatment priorities, and evaluate whether interventions were effective in meeting the client's goals. People with disabilities, caregivers, and rehabilitation professionals were more likely than members of other stakeholder groups to emphasize the individual's subjective experience: participation measures that reflect client priorities may be of greatest utility to these stakeholders.

The participants, especially rehabilitation professionals, funders and policy makers, expressed the need for participation measures that could be used to build an evidence base to support the utility participation-focused interventions and services. Policy makers and funders valued data on the economic impact of participation restrictions and cost effectiveness of participation-focused programming and services. They expressed a need for objective measures of participation across key domains.

Policy makers expressed a need to know the priorities of their constituents, but at a population rather than an individual level. Both funders and policy makers called for objective evidence of needs and program effectiveness. Policy makers were most concerned that people with disabilities be afforded the same participation opportunities as their non-disabled peers.

Policy makers cited the disability community's lack of a unified voice as a barrier to system change at the legislative level. Generic measures of participation would allow the aggregation of data across impairment groups to provide a more complete picture of participation disparities among people with disabilities in general, while still allowing comparisons across impairment groups. Such measures could supply people with disabilities and their allies with data to support their advocacy efforts. The aggregation of participation data at the population level would help to shed light on participation restrictions and

create the "unified voice" that policy makers identified as critical to advancing disability issues on the legislative agenda.

Environmental influences and access to resources were identified by all stakeholder groups as vital to participation for people with disabilities. Researchers are faced with the challenge of how to measure participation barriers and supports and how to document their impact across domains. The purposeful inclusion and documentation of environmental barriers and supports as linked to specific domains of participation (e.g. productive, social, leisure) could serve as a tool for treatment planning amd help document the need for resources to support participation at an individual and population levels.

Given the high value that people place on participation, it is also imperative that the fields of disability and rehabilitation research find ways to operationalize and measure the components of participation in ways that reflect the perspectives of rehabilitation stakeholders. It may not be possible for one instrument to be all things to all stakeholders. Yet, based on our grounded theory research with rehabilitation stakeholders, we have begun the process of developing an instrument that measures participation outcomes across the domains of productivity, social participation and recreation. The Community Participation Indicators (CPI) seeks to build on the tradition of participation measures that integrate both subjective and objective nature of participation (16).

The CPI uses an integrative approach by asking people to rate their participation in key domains according to frequency of performance, importance, and desire to change (31). This approach has the potential to document objective performance as well as individual values and priorities for change. Data can be aggregated to provide information on disparities and priorities at group or populations levels. The gap between what people are doing and what they want to be doing ought to be the target of rehabilitation services and disability policies.

Limitations

While we elicited the perspectives of a broad range of stakeholders in this project, they were recruited primarily from 3 geographic regions, which are home to major rehabilitation centers with international reputations for excellence. Future research should evaluate the needs and perspectives of people in rural and less resource rich environments. Focus group composition was restricted to a single stakeholder group. Future action-oriented research should examine the impact that heterogeneous stakeholder groups have on defining participation across rehabilitation stakeholder groups. The focus group guide, developed in collaboration with community partners, specifically probed the relationship between participation barriers and the environment. This line of questioning led to rich discussions, stakeholders' awareness of the impact of environmental barriers may not be representative.

In conclusion, stakeholders agreed upon 3 key domains of participation: productive and economic participation; social participation and relationships; and leisure and recreational participation. The emphasis they place on each domain shifted based on their roles and responsibilities in the rehabilitation

process. The more direct experience they had with disability, the more they tended to emphasize full participation across all domains. There was, however, no single optimal form or level of participation, rather participation within and across domains was characterized by its diversity and individuality. Participation was described as strongly influenced by the physical, social and policy environment. Based on the findings of this study, participation measures should include objective measures of engagement in productive, social and leisure domains as well as subjective appraisals of importance and satisfaction. Measures that capture environmental influences on participation are likely to be valued by all stakeholder groups. Conceptually grounded and stakeholder validated participation measures can facilitate participation research and inform evidence-based practice, client-centered care, funding allocation, and disability policy.

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APPENDIX I. Focus group guide

What does the word "participation" mean to you?
Probe: What does it mean "to participate"
Why is participation important to you?
What areas of everyday life are most important to you?
Describe the activities most important to participate in
Group activities into categories with the group
What settings do these take place in or go across?
For each major area defined by the group
What defines full participation?
What barriers affect participation?
What problems have you experienced?
What are your biggest supports?
What roles do you participate in?
What roles define you and who you are as a person?