Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability

CHRISTINE IMMS[1,2,3] | MATS GRANLUND[4] | PETER H WILSON[1] | BERT STEENBERGEN[1,5] | PETER L ROSENBAUM[1,2] | ANDREW M GORDON[6]

1 Centre for Disability and Development Research (CeDDR), Australian Catholic University, Melbourne, Vic, Australia. **2** CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, ON, Canada. **3** Murdoch Childrens Research Institute, Melbourne, Vic, Australia. **4** CHILD Research Group, Swedish Institute of Disability Research, Jonkoping University, Jonkoping, Sweden. **5** Behavioural Science Research Institute, Radboud University, Nijmegen, the Netherlands. **6** Cerebral Palsy Research Centre, Teachers College, Columbia University, New York, NY, USA.

Correspondence to Christine Imms at Centre for Disability and Development Research (CeDDR), School of Allied Health Australian Catholic University, Locked Bag 4115, Fitzroy, Melbourne, Vic 3065, Australia. E-mail: Christine.Imms@acu.edu.au

PUBLICATION DATA

Accepted for publication 14th July 2016.
Published online 19th September 2016.

ABBREVIATIONS

fPRC	Family of Participation-Related Constructs
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth

This review outlines a conceptual approach to inform research and practice aimed at supporting children whose lives are complicated by impairment and/or chronic medical conditions, and their families. 'Participation' in meaningful life activities should be an essential intervention goal, to meet the challenges of healthy growth and development, and to provide opportunities to help ensure that young people with impairments reach their full potential across their lifespan. Intervention activities and research can focus on participation as either an independent or dependent variable. The proposed framework and associated hypotheses are applicable to children and young people with a wide variety of conditions, and to their families. In taking a fresh 'non-categorical' perspective to health for children and young people, asking new questions, and exploring issues in innovative ways, we expect to learn lessons and to develop creative solutions that will ultimately benefit children with a wide variety of impairments and challenges, and their families, everywhere.

The World Health Organization's International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)[1] defines participation as 'involvement in a life situation' (p. 9). The ICF-CY provides a classification system to rate functioning and disability. It also promotes a framework for health that illustrates relationships among the six core domains: presence of a health condition; body structures and functions; activity performance; participation; environmental factors; and personal factors. The ICF-CY provides a very strong foundation for understanding body structure and functions of individuals, and the relationship between having a health condition and body structure and function outcomes. Within the activity and participation domains of the ICF-CY, less is understood about the processes that define the constructs.[2–5] More importantly, very little is known about the transactions among ICF-CY[6] domains, and this knowledge gap greatly limits our capacity to design more effective interventions.

The focus of this paper is on the participation construct and, in particular, its interrelationships to constructs within the activity and body function components of the ICF-CY. Our reason for this specific focus is that a recent systematic review of participation interventions[7] in childhood disability found that approaches continue to be directed at intervention at the level of the person, or body function, with the expectation of downstream effects on participation – despite strong bodies of literature on the importance of the interaction between the environment and the person on participation outcomes.[8] There is a significant body of literature about participation,[9–11] which, although it has its roots in much earlier work, has grown exponentially since publication of the ICF in 2001.[12] Participation is understood to be a complex multidimensional construct that is discussed and applied as both a process and an outcome;[13,14] thus, in the context of research, it can be studied as an independent or a dependent variable. This 'bi-directionality' presents a challenge to researchers, who need to carefully articulate their thinking and their research question(s), and then construct paradigms that test causality and inform intervention.

PURPOSE STATEMENT

The purpose of this paper is to use current knowledge and concepts about participation to suggest ways forward for research and practice, particularly when these ideas concern participation for individuals with a need for special support. We propose that participation can be both an entry point (a 'process') and an outcome (endpoint) of health and education services, even when these services are concerned with ameliorating impairments and promoting activity performance. The Family of Participation-Related Constructs (fPRC) framework will be presented and used to promote and advance conceptual clarity and consistency

 DOI: 10.1111/dmcn.13237

in language. We will recommend directions for research that can further our understanding about what enables positive participation outcomes for people with childhood-onset impairments. In particular, we propose that if interventions are provided that enhance both attendance in activities and involvement while attending those activities, we will improve our understanding of outcomes across activity competence, sense of self, and preferences for patterns of participation. This will enhance long-term health and well-being in children with childhood onset impairment.

BACKGROUND

A biopsychosocial approach to participation

The ICF-CY is a biopsychosocial framework that describes functioning and/or disability as the outcome of interactions among the domains.[1,12] The framework was designed to provide an international, whole-of-community perspective on functional outcomes. However, research in childhood disability has focused mainly on the interventions for, and performance of, individuals, even if data are aggregated at a group level. In contrast, social models of disability[15] focus on participation of groups at a societal level, with interventions intended to support individual participation through environmental and social change, rather than by addressing individual determinants. Importantly, interventions within social models are focused on environments, for example drafting of legislation related to discrimination, or building requirements to support accessibility.[16] Significant outcomes of social approaches and disability rights movements include the promulgation of laws and international conventions for human rights,[17] including for those with disability,[18] and for children.[19]

Research concerning people with impairments who need special support has been founded in two traditions. The first, based on 'biomedical' thinking, involves interventions that address issues within the individual's 'body structure and function' through 'treatments' to promote the development of functional skills, for example, motor performance or working memory.[20] The implicit assumption is that these interventions will lead to functioning (i.e. reduced impairment of illness, or increased activity capacity) that will in turn lead to more functional everyday skills and increased participation. Research designs associated with this kind of framework often use univariate, unidirectional approaches to explore the relationship of 'this' intervention to 'that' outcome, controlling for other 'sources of variation' that might influence the effectiveness of the intervention. Currently, there is little evidence that single interventions aimed at changing specific physiological or psychological functions at the level of body structure and function will necessarily transfer to global changes in participation.[7,21,22]

The second tradition is a multidimensional approach that concerns social models of disability, principles of inclusion, and resistance of those with disabilities to deterministic and exclusionary medical models.[17] This tradition argues that categorization (e.g. of disability) leads to exclusion and ableism. Accordingly, young people in need of special support should be included in mainstream schools with required environmental support provided by ordinary teachers, rather than attend special classes or special schools.[23] Support should be provided to ameliorate difficulties experienced with functioning in school. Research designs in this tradition often involve a host of independent variables and analytic approaches that take these many 'sources of variation' into account at the same time. A recent systematic review,[24] however, provided no evidence that children who need special support in mainstream classes had a better social situation or well-being than children in special classes.

Thus, the evidence for both these traditions impacting an individual's participation is weak. While acknowledging that the medical and social approaches are not binary, but rather complementary, current evidence suggests that the two approaches need to be merged more effectively into a model of individual functioning that unites aspects of functioning at the level of body structure/function and activity with functioning in everyday life. A primary focus on participation can achieve this aim. At the level of societal interventions (such as laws/policy), there is essential regulation of the opportunity for people to take part in the same activities as others, but that does not mean that an individual person will be able to do so. Put simply, it is not possible to regulate the adaptations and accommodations that might be required to enable an individual to participate. Social, rights-based interventions are very important;[1] the focus of this paper, however, is on participation at the individual level, rather than the societal level per se.

What this paper adds

- An innovative conceptual framework to support participation-based research and practice.
- Recommendations for future participation-based research.

Participation and development

The contemporary focus of outcomes of health and education services for people with impairments, or in need of special support, is increasingly on their participation in life situations over their lifespan.[1,18] At an individual level, participation can be seen as a universal outcome – one that is important for both learning and development as well as health and well-being.[25,26] Traditionally, health and education interventions have focused on supporting development over the lifespan. Disentangling participation from development is an important yet unfinished task. Indeed, the difficulty of the task may be one reason why health and education research has focused primarily on the capacity, or competence, of individuals, despite the challenges of distinguishing natural developmental change from the effects of interventions. Traditional notions of development are related to increasing complexity of behaviour.[27] Implicit in this notion is the idea that people will participate more in everyday life if they are able to complete

more complex activities (i.e. they become more competent). This focus on development has also led to a set of values and principles that suggest there is a typical or right way of performing activities, rather than principles related to the effectiveness of the outcome of the activity (i.e. that the person is engaged with, or is undertakng, the desired task and completing it in their own way).

The ICF-CY framework separates the constructs of activity and participation but the classification system does not.[1,12] Although there is a description of how participation can be measured using the qualifiers within the classification system, the choices are to measure either capacity, defined as performance ability within a standardized or ideal environment (i.e. activity), or performance, defined as ability within the individual's current environment. While the performance qualifier is identified as a participation measure,[11] both capacity and performance are essentially measures of competence – the ability to do something in relation to a reference standard. Hence, functioning is described using a developmental approach – that is, development as competence in performing increasingly more complex behaviours. In short, current ICF-CY qualifiers may provide a mechanism for assessing degrees of activity competence, and not aspects of participation. Further qualifiers focusing explicitly on attending and degree of involvement while attending are needed.[28] A framework that postulates the relationships among variables related to participation would assist in clarifying outcomes and processes that lead to outcomes.

A FAMILY OF PARTICIPATION-RELATED CONSTRUCTS

A recent systematic review of participation outcomes following health, education, or psychological interventions for children with impairments[7] found considerable conceptual inconsistencies related to participation as an outcome. From a content analysis of research notions about participation, a family of participation-related constructs was developed – what the current authors call the fPRC.[29] These constructs, and the framework, can be used to describe the relationships among important within-person factors that are influenced by past participation, and that influence future participation. Further development of the proposed framework[29] is shown in Figure 1, and definitions for key concepts used within this paper are presented in Table I.

The participation construct

Within the fPRC, participation has two essential components: attendance, defined as 'being there' and measured as frequency of attending, and/or the range or diversity of activities; and involvement, the experience of participation while attending. Involvement might include elements of engagement, motivation, persistence, social connection, and level of affect.[29] Attendance is a necessary but not sufficient requirement for involvement, hence involvement is embedded within the attendance dimension.

Although they are embedded constructs, the relationship between attendance and involvement is not fully understood.

> Box 1: Participating in soccer
>
> George and Henry are both 8 years old, and both express a keen desire to play soccer with their friends. During games, Henry is observed to be focused on (looking at, yelling about) the ball or his team mates, clearly 'involved' in the game. George is often observed to be deeply interested in whether he can pull his socks up beyond his knees, and comparing and talking about the height of his socks (and the colour of the uniform bands that are visible when pulled up) with those of players who are near him. He appears deeply involved in this activity. Both boys attend the soccer game. Both boys are involved in soccer, but not the same aspects of soccer.

Previous studies have reported that the probability of being involved in an activity increases if it is an activity that one attends relatively frequently.[30] However, children with impairments were also found to spend more time at low levels of engagement in the activities they were attending compared with age-matched peers.[30] Maxwell et al.[31] found that children self-report higher engagement when also describing that they are 'mentally there' (i.e. thinking about the activity attended). People can, however, attend to different aspects of the same activity, perhaps related to being motivated by different goals; thus, they can actually be involved in different aspects of the same activity. In effect, this individual variation in task engagement within the same activity creates different participation contexts (see Box 1). In some circumstances, measuring involvement or engagement may need to be undertaken in relation to the specific contextual element of the activity with which the person is engaged (i.e. has the focus of their attention) to understand what the individual is participating in; for other purposes, understanding the overall level of involvement (regardless of context) may be important. Although it is not uncommon for studies to measure participation as 'on-task' behaviour, the 'task' in these studies is typically defined by the researcher or observer, not the participant.[29] The extent to which, and how, the perspective matters in terms of long-term outcomes is not well understood, although a number of authors discuss the need for varying perspectives in measurement of participation outcomes.[14,32]

Intrinsic factors that influence, and are influenced by, participation

Intrinsic person-related concepts that are related to participation in the fPRC, but are not the same as participation, include activity competence, sense of self, and preferences.[29] These intrinsic factors influence future participation and are influenced by past and present participation.

Activity competence is defined, in a manner consistent with the ICF-CY,[1] as the ability to execute the activity being undertaken according to an expected standard, and includes cognitive, physical, and affective skills and abilities. Activity

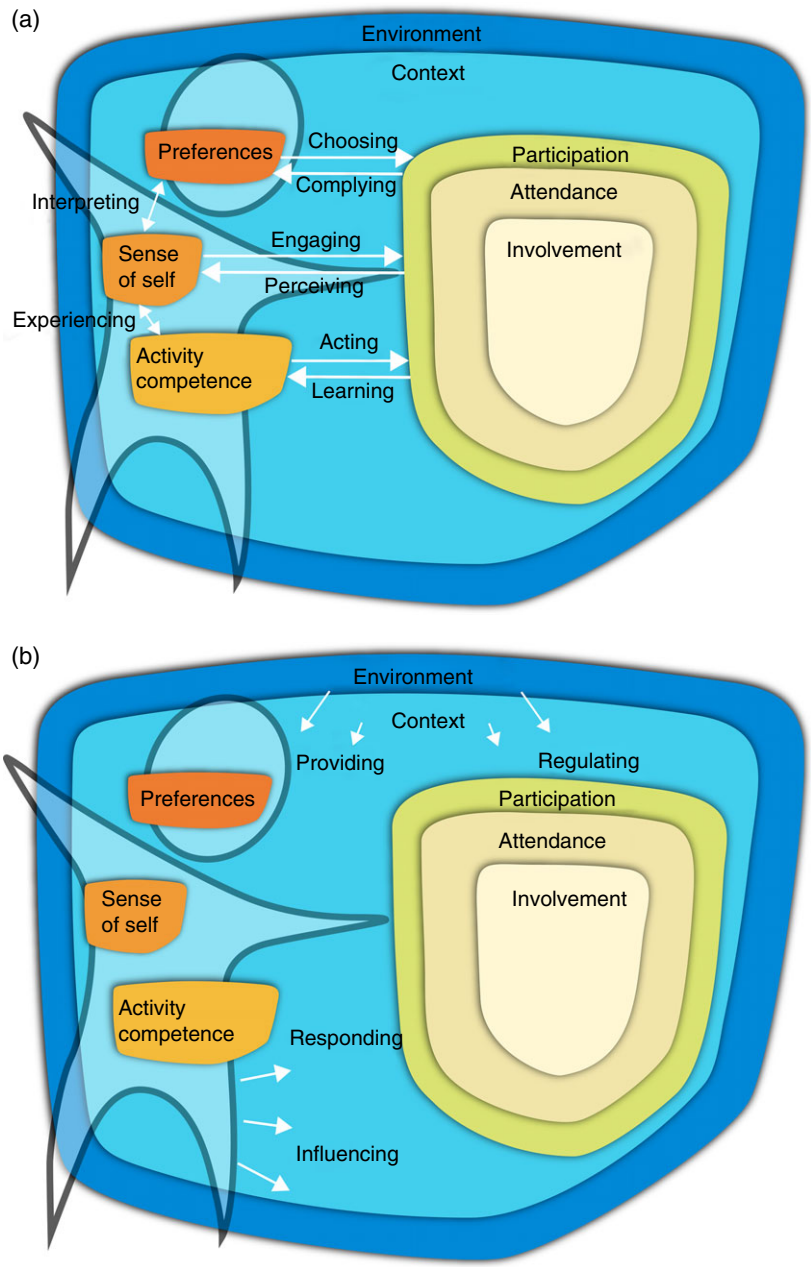

Figure 1: Family of participation-related constructs: (a) person-focused processes, (b) environment-focused processes. [Colour figure can be viewed at wileyonlinelibrary.com].

competence is often measured in intervention research as developmental competence – for example, the ability to use objects for the purpose they were designed, or performing a task for the same amount of time as expected, or completing a task independently.[11,29] Activity competence can be measured as (1) capacity – a measure of the highest level of ability of the child within a structured environment such as that created for test taking; (2) capability – defined as the skills and abilities an individual can use in a daily environment; or (3) performance – the skills and abilities the child actually uses in an everyday setting.[1,32–34]

Sense of self refers to a personal perception related to one's confidence, satisfaction, self-esteem, and self-determination.[29] These intrapersonal factors facilitate participation by helping the person engage, but are also shaped by participation and associated perceptions of control, effectiveness, or flow.[35] These intrapersonal factors can be seen as a family of constructs focused on perceptions of self, such as autonomy, optimism, self-determination, and self-esteem.[28]

Using a timeframe perspective, some self-related concepts are focused on the past (e.g. self-esteem and

Table I: Definitions of key concepts included in the paper

Concept	Definition
Participation	Attending and being involved in life situations[a]
Attendance	'Being there' and measured as frequency of attending, and/or the range or diversity of activities in which an individual takes part
Involvement	The experience of participation while attending that may include elements of engagement, motivation, persistence, social connection, and affect
Engagement	Engagement is seen as a unifying construct across ecological levels. Thus, it can be defined depending on the ecological level in which it is examined: (1) the person level – the internal state of individuals involving focus or effort; (2) between systems level – an active involvement in interactions between systems; (3) at the macro level – active involvement in a democratic society
Preferences	The interests or activities that hold meaning or are valued
Activity competence	The ability to execute the activity being undertaken according to an expected standard; includes cognitive, physical, and affective skills and abilities. Activity competence can be measured as capacity, capability, or performed skill
Capability	Skills and abilities that the child can use in a daily environment
Capacity	Best ability of the child within a structured environment like that created for test-taking
Performance	Skills and abilities the child uses in everyday settings
Sense of self	Intrapersonal factors related to confidence, satisfaction, self-esteem, and self-determination
Self-regulation	Executive processes that enable the individual to direct and monitor their thinking, emotions, actions, and interactions
Context	Setting for activity participation that includes people, place, activity, objects, and time[b]
Environment	Broad, objective social and physical structures in which we live

[a]Based on the ICF definition.[12] [b]From Batorowicz et al.[6]

contentment), some on the present (e.g. engagement, happiness, or flow), and others on the future (e.g. hope and self-determination).[35–37] There is a strong overlap between sense of self in the present and the notion of involvement/engagement. Sense of self perceptions focused on the past, such as self-esteem based on past performance, seem to be related to consequences of previous experiences of involvement (and perhaps perceptions of success and failure). On the other hand, future-directed perceptions such as self-efficacy and autonomy may be seen as precursors to participation in activities: high self-efficacy for a particular activity, for example, is likely to predict future engagement in that activity. Future-directed perceptions of sense of self have been related to participation outcomes for persons with impairments,[38,39] and are likely to be stronger predictors for future participation than perceptions focused on the past.[40]

Preferences are defined as the interests or activities that hold meaning or are valued.[29] To prefer something is to set or hold it above another option in one's estimation. Preferences can be used to explain and predict human action and social practice,[41] both at an individual and a cultural level. Preferences are established through interactions with people in social groups who share particular beliefs and values, through past experiences of enjoyment and success, and through place attachment or build-up of positive associations with particular environments and experiences.[41–44] Preferences are therefore both antecedent to, and a consequence of, participation.

Extrinsic factors that influence, and are influenced by, participation

As seen in Figure 1, and strongly supported by a body of research about the relationship between the environment and participation,[8,45–49] all participation occurs within a contextualized setting. The conceptual separation of the environment from context proposed by Batorowicz et al.[6] provides a very useful model for considering how the setting affects a person's participation. Context is personal, considered from the perspective of the person participating, and relates to the people, place, activity, objects, and time in which participation is set. This way of thinking is also explicit in other theoretical models such as SCOPE-IT: Synthesis of Child Occupational Performance and Environment in Time model.[50] Environment is external, and refers to the broader, objective social and physical structures in which we live. The environment affects the person both directly (e.g. the impact of geographical features, or medication that targets body function), and indirectly (by affecting our perceptions of the activity context – e.g. whether an individual perceives a hill as steep when trekking is dependent on the physical shape of the geography as well as the person's motor skills or fitness).

However, the person also affects the environment through engagement in activities within places.[6] These transactional relationships between the person and context result in changes to both the individual and the environment over time.[49,51,52] This also means that the context – the nodal point between the person and the environment(s) in which people are involved – may vary between people, even when they are present in the same activity. Box 1 provides one example of this. For another example, two people taking a walk can be involved in the context of 'conversation', or in the context of 'walking', depending on what they perceive they are engaged in. If one person has difficulties walking, and the other does not, one person might actually be 'involved' in walking and the other in talking. This example highlights the complexities in untangling the constructs of involvement and engagement from other psychological processes such as attention. To focus on attentional resources is to focus on aspects of competence – this may be important, but it is not the same as participation.

The processes operating among the constructs

The fPRC (Figs 1a and b) displays hypothetical processes that operate among the factors and the participation construct. The bi-directional arrows and their associated verbs represent the active processes or transactions that occur

between the constructs or factors. The verbs reflect the direction of influence. The environment and context are thought to be providing and regulating participation (Fig. 1b). The participating child also influences the environment by reacting, collaborating, or other actions.[51,52] Passive children, those that are not involved physically, cognitively, or emotionally, may have less influence on their contexts/environments.

Figure 1a displays the relationships among participation and intrinsic factors. Between participation and activity competence are the processes of acting and learning. For example, if competence is both an outcome of actions (i.e. learning skills over time through activity participation) and a precursor or predictor of future participation, research and intervention can focus on participation as either an independent or dependent variable, depending on the research question. Children are more likely to participate in activities in which task competencies have been learned. Where more rudimentary skills are involved, participation might be encouraged by the assistance of skilled peers or adults (such as parents, teachers, or therapists) in an 'apprenticeship in learning', akin to Vygotsky's notion of zone of proximal development.[53]

The interaction between participation and sense of self involves the processes of engaging and perceiving. The sense of self evolves as a result of participation, and perceptions of self can predict future participation.[38,39] Engaging can be seen as an internal state, and perceiving involves imagining one's ability or opportunity to participate. The relationship between participation and preference is expressed through choosing and complying. The importance of having the opportunity (or not) for choice and control over participation has been highlighted by many authors.[11,29,54] Children choose what they will participate in (e.g. a preferred sport), or they comply (or cope) with choices made by others (e.g. reading at school), based on prior participation experiences and expectations of/for future participation.

There are also processes that occur between the intrinsic constructs described in the fPRC. The individual experiences a sense of competence (or not), which colours his/her sense of self – a self as someone who acts in the world to achieve (or not) certain ends or goals. Indeed, the self is intimately bound up with goal-directed activity and goal attainment in embodied views of the person and mind.[55] Between sense of self and preferences is the act of interpreting: the interpretation of past or current experiences in relation to the sense of self and competence influences development of preferences. It is through both the experience and the interpretation of the experience that preferences are formed.

Self-regulation

The fPRC framework identifies that a general, self-regulatory process binds together the intrinsic factors. Diagrammatically, this is portrayed as the person in the framework. Self-regulation includes the processes that enable the individual to direct and monitor their thinking, emotions, actions, and interactions[56] in the perceived context, that is partly defined by the task (e.g. listening to a story read by the teacher) and the broader environment (e.g. a hot afternoon in an open-air classroom). Regulation cuts across all aspects of human functioning[57] and, for the individual, is the cornerstone of our efforts to help people develop competencies through participation in everyday life.[58] Thus, in the participation framework, self-regulation can be seen as the glue that binds intrapersonal factors, activity competence (e.g. movement skill), sense of self (e.g. self-efficacy), and preferences (e.g. interests): self-regulatory processes mediate the interactions among the two dimensions of participation and intrapersonal characteristics.

Engagement as a linking construct

The term 'involvement' is often used interchangeably with 'engagement' to describe the participation experience. In the proposed fPRC framework, engagement is a construct that can be expressed at multiple levels of human functioning according to ecological models of lifespan development.[27,53] Although terms vary between authors, these ecological levels describe the environments (e.g. family, school, community, and society) that directly or indirectly affect humans during the whole lifespan.

The varied definitions and operationalizations of engagement provide support for the notion that engagement is present at different ecological system levels. At the level of the person, 'engaging in'[59] is the internal state, often described as having several components: cognitive (e.g. motivation, attention, focus), behavioural (e.g. effort, persistence), and emotional (e.g. reactions, sense of belonging).[35,60–64] In addition, there are also neurophysiological components signifying attention. Opportunities for engagement at the person level probably lead to outcomes related to competence, sense of self, and preferences. At the level of the environment, such as school, or the relationship among environments such as family–professional collaborations, the focus is on connection to contexts, where 'engaging with'[59] processes are important, for example, in the engagement between a child and therapist within therapy activities, or between parents and professionals in therapy decision-making for children.[65,66] Active engagement at this level might support higher levels of meaningful engagement over time in these contexts, and opportunities for engagement probably lead to outcomes such as more stable perceptions of subjective well-being and

> Box 2: The soccer game
>
> Henry is intensely focused on the ball during the soccer game and on what he and his team mates can do to kick a goal. He directs his engagement to the game. George is interested in being a part of the team and in interacting with team mates. He is less focused on getting goals. He directs his engagement to other aspects of the sport, like the uniform and team mates.

meaningfulness. The different definitions of engagement also suggest that researchers using the construct see both a frequency/duration dimension in engagement, (i.e. the time spent in situations that enhance engagement), as well as an intensity-of-focus aspect of engagement. In short, engagement has a sense of 'directedness' with respect to external things, people, and events. The type and level of engagement will vary with the context and its complexity (see Box 2).

Synthesizing the ideas

If participation is considered to be the entry point for learning and personal development, it should be possible to identify the impact of participation experiences on activity performance and body structural and functional changes. For example, attendance and involvement in a weekly soccer game is expected to be associated with improved cardiovascular fitness. Conversely, maturational changes in body structures and functions enable different forms or modes of participation (e.g. increased size, strength, and fitness enable a more skilled engagement with sports like soccer). A participation-focused approach to working with children and young people with impairments is consistent with general systems theory that describes the multiple pathways to the same outcomes (equifinality) and the multiple outcomes that can result despite similar starting points (multifinality).[67] The view that participation can be considered to be both the entry point and the outcome of intervention also enables us to focus on what matters across the life course: for example, 'Can the child engage with friends and establish peer relationships?', rather than 'Can the child construct a five-word sentence or initiate a conversation?' – skills that risk being decontextualized, and are hard to generalize, and thus are not useful out of context. Taken together, participation-focused research must therefore be designed to provide a way to consider diversity of both outcomes and 'causes' of outcomes.

The fPRC does not specify the life situations in which participation occurs, whether they be defined by context (home, community, school)[68] or type (discretionary, non-discretionary).[11] In this framework, participation is separated from the life situation conceptually so that the constructs can be applied in a range of culturally relevant contexts. The processes highlighted as being of interest for further investigation could indeed be understood in terms of discretionary (i.e. the process of choosing, in relation to preferences and participation) versus non-discretionary activities (i.e. the process of complying or coping). We argue that this further delineation of the concepts and processes might enhance the development of measures and interventions that has been highlighted by many others as important.[32]

DISCUSSION

This paper provides a conceptual framework – the fPRC – that positions participation as both an entry point and primary outcome of intervention (depending on the clinical or research goal), as well as identifying the transactional mechanisms by which participation is expressed in life. Participation-focused research provides room for the fact that multiple causes drive diverse outcomes in participation. Thus different interventions might support the same outcome and vice versa. The framework is designed to provide conceptual and terminological consistency, and to inform education and health research, as well as practice, for children and adults living with long-term impairments or health conditions. The essential challenge for practitioners, researchers, and consumers of this literature is to ask, 'What is the question we are trying to explore?', and then to carefully situate variables like 'participation' in the correct (causal) alignment with respect to other factors of interest.

Research arising from the framework will be aimed at understanding the forces that shape human functioning in everyday life and health of children and young people with childhood-onset conditions and their families by addressing their developmental, mental, physical, psychosocial, and environmental challenges. These challenges often threaten to compromise the capacities and potential of young people. Considered from a life-course perspective, the framework supports attention to both the immediate and long-term outcomes of lives that are impacted by childhood chronic illness, disadvantage, and/or impairment, by examining the interacting forces on the individual child and his/her family within the contexts in which they live.

Participation research needs to identify how changes over time in involvement, or 'engaging in', can be conceptualized in individuals. Changes in participation over the life course, as well as differences in levels of participation between people or settings, are likely to occur as a result of complex transactions among the following: aspects of the individual that develop over time; the context or setting in which participation occurs, including the nature of the participation activities; and the overarching environment in which people live. Changes in the involvement component of participation over time may be more complex to conceptualize than changes in attendance. While notions of high and low engagement can be understood as an internal state that may or may not be observable in behaviour,[59] engagement is complex to measure.

Along with measures of change in involvement, the socially and culturally constructed contexts in which children participate – such as their school, home, or community – can be used to describe changes in the patterns of participation attendance over the life course. Changes might also be described in terms of changing roles in relation to those contexts. There is evidence that individuals increasingly choose contexts that 'fit' their competencies, whereas contexts that do not match competencies are avoided.[67] For example, as young people recognize that their skills and abilities in physical sports do not match those of their peers, they may choose to stop taking part in team sports. In childhood, there are fewer choices because children are required by parents, teachers, and/or

legislation to participate in well-defined contexts like school, for example. With age, individuals generally experience (or attend) a greater range of contexts and are able to exert more preference about them. If those with impairments have fewer situations in which they can participate and fewer opportunities to choose whether they wish to participate, their behaviour may become over-specialized, less flexible, and less adaptable in new environments. Reduced attendance in turn negatively influences development of a variety of skills and abilities of the individual, thus potentially further reducing the contexts in which they can participate. Understanding who is choosing in relation to the participation of those with impairments is as important as knowing whether the participation opportunity exists in the first place.[32]

The ICF uses bi-directional arrows to indicate that influences might occur in various directions; however, there is as yet no language to describe the dynamic relationships that are implied or indeed the more likely causal pathways. The framework proposed in this paper extends the ICF-CY framework by discussing how phenomena such as activity competence, sense of self, and context are linked, and provides guidance for future research and practice. Language terms that might be of use can be found in systems theory, such as circular causality (i.e. A causes B, but B can also cause A). For example, involvement in physical activities might increase motor skills but increased motor skills might also increase enjoyment and engagement in that activity, thus in turn increasing the probability that a child will participate in physical activities in future.[33] Process words in the proposed framework signal the content of the links between the constructs, for example the process between participation and activity competence is expressed using the verbs 'acting' and 'learning'. That is, the child acts within the participation context using current skills, and through that action learns and develops further skills. The aim of these reflections is to provide conceptual clarity for future research questions and methods.

The fPRC framework proposes the nature of transactional processes between the elements within it, which provides fruitful avenues for research. Understanding the transaction between the domains and supporting processes is important: it is where important knowledge resides about how/what changes occur over time, as well as the entry points for intervention. Focusing on transaction means that the centre of attention is on the bi-directional impact of the elements over time. This implies that research must be hypothesis-driven (to test specific questions), longitudinal (to be able to include time as a dimension of the thinking), and aimed at connecting ecological levels.[52] Where correlational research is concerned with finding out about whether one behaviour is associated with change on another (causation aside), transactions are about mapping how the actions of one person or element alter those of another, and vice versa. This requires a shift in research design. To study a transactional process, longitudinal studies with a sufficient number of time points are necessary. Studies of this type will enable the researchers to better isolate periods of time or development at which the child or the environment have the most crucial effect.[52] The timing of these observations must be based on hypothesized relationships among elements.

In terms of interventions, a transactional focus requires measurement of outcomes for the children as well as for the parents, interventionists, teachers, and/or others involved. To link ecological levels (e.g. the person to family, to services, to community), the elements studied have to be measured longitudinally at theoretically based intervals and at different, selected ecological levels. For example, to study enhanced child engagement in preschool, a link needs to be made between child engagement at time point 1, and support provided to preschool staff to enhance child engagement from rehabilitation services at time point 2, and child engagement in preschool activities at time point 3. A transactional focus also requires the use of analytical methods that connect ecological levels, for example multilevel analysis using structural equation modelling. For example, how a child's engagement is perceived by professionals in the preschool setting might be influenced by the proportion of children with impairments in the unit as one element of the context. Research questions might include the nature, size, and direction of various forces on one another, potentially leading toward understanding causal connections. This approach is the logical and imperative step beyond cross-sectional studies that can, at best, identify associations.

It is possible that engagement can serve as a unifying construct, one that can be used as a focus for participation research within ecological levels as well as between ecological levels. This is because engagement can be observed, and therefore potentially measured, at neural (brain), behavioural, interpersonal, and societal levels. Research that not only identifies and further develops valid, reliable measures of engagement at each level for children with impairments but also links levels with the help of these measures will provide the knowledge we require to advance exponentially our understanding of longitudinal participation outcomes.

CONCLUSION

This paper challenges the view that participation should be seen primarily as a downstream effect of rehabilitation at the body function and structure or activity level, and instead promotes a view of participation as the entry point for changes at the activity and body function/structure level. Although not addressed in this paper, this notion also involves challenging the view that participation restriction can be solved only by addressing environmental barriers. Interventions at the level of the 'body' or the level of society may be necessary to promote participation in individuals, but neither alone is likely to be sufficient. The fPRC framework, addressing issues at the level of the individual in context, expands the activity and participation domain of the ICF-CY by further detailing related constructs within an overarching environmental framework.

The fPRC can be used to guide critical thinking in the development of future research and practice.

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the earlier work of the wider participation systematic review authorship team, including Dr Brooke Adair, Prof. Deb Keen, and Dr Anna Ullenhag, which provided a foundation for this conceptual paper. The authors gratefully acknowledge Lachlan Stewart's support with the preparation of the diagram portrayed in Figure 1. The authors have stated that they had no interests which might be perceived as posing a conflict or bias.

REFERENCES

1. WHO. International Classification of Functioning, Disability and Health: Children and Youth version: ICF-CY. Geneva: World Health Organization, 2007.
2. Jette AM, Haley SM. Blending activity and participation subdomains of the ICF. *Disabil Rehabil* 2007; **29**: 1742–50.
3. Jette AM, Haley SM, Kooyoomjian JT. Are the ICF activity and participation dimensions distinct? *J Rehabil Med* 2003; **35**: 145–49.
4. Maxwell G, Alves I, Granlund M. Participation and environmental aspects in education and the ICF and the ICF-CY: findings from a systematic literature review. *Dev Neurorehabil* 2012; **15**: 63–78.
5. Perenboom RJM, Chorus AMJ. Measuring participation according to the international classification of functioning, disability and health (ICF). *Disabil Rehabil* 2003; **25**: 577–87.
6. Batorowicz B, King G, Mishra L, Missiuna C. An integrated model of social environment and social context for pediatric rehabilitation. *Disabil Rehabil* 2016; **38**: 1204–15.
7. Adair B, Ullenhag A, Keen D, Granlund M, Imms C. The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Dev Med Child Neurol* 2015; **57**: 1093–104.
8. Hammel J, Jones R, Smith J, Sanford J, Bodine C, Johnson M. Environmental barriers and supports to the health, function, and participation of people with developmental and intellectual disabilities: report from the State of the Science in Aging with Developmental Disabilities Conference. *Disabil Health J* 2008; **1**: 143–49.
9. Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? An insider perspective from people with disabilities. *Disabil Rehabil* 2008; **30**: 1445–60.
10. King G, Rigby P, Batorowicz B. Conceptualizing participation in context for children and youth with disabilities: an activity setting perspective. *Disabil Rehabil* 2013; **35**: 1578–85.
11. McConachie H, Colver A, Forsyth RJ, Jarvis S, Parkinson KN. Participation of disabled children: how should it be characterised and measured? *Disabil Rehabil* 2006; **28**: 1157–64.
12. WHO. International Classification of Functioning, Disability and Health: Short version. Geneva: World Health Organization, 2001.
13. Granlund M. Participation–challenges in conceptualization, measurement and intervention. *Child Care Health Dev* 2013; **39**: 470–73.
14. King G. Perspectives on measuring participation: going forward. *Child Care Health Dev* 2013; **39**: 466–69.
15. Swain J, French S. Towards an affirmation model of disability. *Disabil Soc* 2000; **15**: 569–82.
16. Goldstein DN, Cohn E, Coster W. Enhancing participation for children with disabilities: application of the ICF enablement framework to pediatric physical therapist practice. *Pediatr Phys Ther* 2004; **16**: 114–20.
17. Gabel S, Peters S. Presage of a paradigm shift? Beyond the social model of disability toward resistance theories of disability. *Disabil Soc* 2004; **19**: 585–600.
18. United Nations. Convention on the Rights of Persons with Disabilities. New York: United Nations, 2006. Available at http://www.un.org/disabilities/convention/conventionfull.shtml (accessed 20 June 2016).
19. United Nations. Convention on the Rights of the Child. New York: United Nations, 1989. Available at http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf (accessed 20 June 2016).
20. Klingberg T. Training and plasticity of working memory. *Trends Cogn Sci* 2010; **14**: 317–24.
21. Wright F, Rosenbaum PL, Goldsmith CH, Law M, Fehlings DL. How do changes in body functions and structures, activity and participation relate in children with cerebral palsy? *Dev Med Child Neurol* 2008; **50**: 283–89.
22. Janeslatt G, Kottorp A, Granlund M. Evaluating intervention using time aids in children with disabilities. *Scand J Occup Ther* 2014; **21**: 181–90.
23. Nilholm C. Special education, inclusion and democracy. *Eur J Special Needs Educ* 2006; **21**: 431–45.
24. Göransson K, Nilholm C. Den sociala situationen för barn och elever i skolsvårigheter som undervisas i reguljära klasser och förskolegrupper. (The Social Situation for Children and Students in Need of Special Support in Main Stream Classes – A Systematic Review). Stockholm, Sweden: Swedish Research Council, 2015.
25. Arvidsson P, Granlund M, Thyberg I, Thyberg M. Important aspects of participation and participation restrictions in people with a mild intellectual disability. *Disabil Rehabil* 2014; **36**: 1264–72.
26. Fuhs MW, Farran DC, Nesbitt KT. Preschool classroom processes as predictors of children's cognitive self-regulation skills development. *Sch Psychol Q* 2013; **28**: 347–59.
27. Bronfenbrenner U, Evans GW. Developmental science in the 21st century: emerging questions, theoretical models, research designs and empirical findings. *Soc Dev* 2000; **9**: 115–25.
28. Granlund M, Arvidsson P, Niia A, et al. Differentiating activity and participation of children and youth with disability in Sweden: a third qualifier in the International Classification of Functioning, Disability and Health for children and youth? *Am J Phys Med Rehabil* 2012; **91**: S84–96.
29. Imms C, Adair B, Keen D, Ullenhag A, Rosenbaum P, Granlund M. 'Participation': a systematic review of language, definitions and constructs used in intervention research with children with disabilities. *Dev Med Child Neurol* 2016; **58**: 29–38.
30. Eriksson L, Welander J, Granlund M. Participation in everyday school activities: for children with and without disabilities. *J Phys Dev Disabil* 2007; **19**: 485–502.
31. Maxwell G, Augustine L, Granlund M. Does thinking and doing the same thing amount to involved participation? Empirical explorations for finding a measure of intensity for a third ICF-CY qualifier. *Dev Neurorehabil* 2012; **15**: 274–83.
32. Morris C. Measuring participation in childhood disability: how does the capability approach improve our understanding? *Dev Med Child Neurol* 2009; **51**: 92–94.
33. Smits DW, Gorter JW, van Schie PE, Dallmeijer AJ, Ketelaar M; PERRIN+ study group. How do changes in motor capacity, motor capability, and motor performance relate in children and adolescents with cerebral palsy? *Arch Phys Med Rehabil* 2014; **95**: 1577–84.
34. Hwang AW, Yen CF, Liou TH, et al. Participation of children with disabilities in Taiwan: the gap between independence and frequency. *PLoS ONE* 2015; **10**: e0126693.
35. Seligman ME, Csikszentmihalyi M. Positive psychology. An introduction. *Am Psychol* 2000; **55**: 5–14.
36. Ryan RM, Deci EL. Intrinsic and extrinsic motivations: classic definitions and new directions. *Contemp Educ Psychol* 2000; **25**: 54–67.
37. Ryan RM, Deci EL. On happiness and human potentials: a review of research on hedonic and eudaimonic well-being. *Annu Rev Psychol* 2001; **52**: 141–66.
38. Almqvist L, Granlund M. Participation in school environment of children and youth with disabilities: a person-oriented approach. *Scand J Psychol* 2005; **46**: 305–14.
39. Clarke MT, Newton C, Griffiths T, Price K, Lysley A, Petrides KV. Factors associated with the participation of children with complex communication needs. *Res Dev Disabil* 2011; **32**: 774–80.
40. Gustafsson JE, Allodi M, Alin-Akerman B, et al. School, Learning and Mental Health – A Systematic Review. Stockholm, Sweden: Royal Swedish Academy of Sciences, 2010.
41. Skille E, Osteras J. What does sport mean to you? Fun and other preferences for adolescents' sport participation. *Critical Public Health* 2011; **21**: 359–72.
42. Anderson DH, Fulton DC. Experience preferences as mediators of the wildlife related recreation participation: place attachment relationship. *Human Dimensions Wildlife* 2009; **13**: 73–88.
43. Bult MK, Verschuren O, Lindeman E, Jongmans MJ, Ketelaar M. Do children participate in the activities they prefer? A comparison of children and youth with and

without physical disabilities. *Clin Rehabil* 2014; **28**: 388–96.

44. Dahan-Oliel N, Mazer B, Majnemer A. Preterm birth and leisure participation: a synthesis of the literature. *Res Dev Disabil* 2012; **33**: 1211–20.

45. Anaby D, Law M, Coster W, et al. The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. *Arch Phys Med Rehabil* 2014; **95**: 908–17.

46. Colver A, Thyen U, Arnaud C, et al. Association between participation in life situations of children with cerebral palsy and their physical, social, and attitudinal environment: a cross-sectional multicenter European study. *Arch Phys Med Rehabil* 2012; **93**: 2154–64.

47. Eriksson L. The relationship between school environment and participation for students with disabilities. *Pediatr Rehabil* 2005; **8**: 130–39.

48. Garton AF, Harvey R, Price C. Influence of perceived family environment on adolescent leisure participation. *Aust J Psychol* 2004; **56**: 18–24.

49. Mallinson T, Hammel J. Measurement of participation: intersecting person, task, and environment. *Arch Phys Med Rehabil* 2010; **91**(Suppl. 9): S29–33.

50. Poulsen AA, Ziviani JM. Health enhancing physical activity: factors influencing engagement patterns in children. *Aust Occup Ther J* 2004; **51**: 69–79.

51. Sameroff AJ, Chandler MJ. Reproductive risk and the continuum of caretaking casualty. In: Horowitz FD, Hetherington EM, Scarr-Salapatek S, Siegel GM, editors. Review of Child Development Research. Chicago: University of Chicago Press, 1975: 187–244.

52. Sameroff AJ, Mackenzie MJ. Research strategies for capturing transactional models of development: the limits of the possible. *Dev Psychopathol* 2003; **15**: 613–40.

53. Lerner RM. Concepts and Theories of Human Development, 3rd ed. Mahwah, New Jersey: Lawrence Erlbaum Associates Publishers, 2013.

54. Heinemann AW, Magasi S, Bode RK, et al. Measuring enfranchisement: importance of and control over participation by people with disabilities. *Arch Phys Med Rehabil* 2013; **94**: 2157–65.

55. Pezzulo G. Coordinating with the future: the anticipatory nature of representation. *Mind Machin* 2008; **18**: 179–225.

56. Zelazo PD. Executive function: reflection, iterative reprocessing, complexity, and the developing brain. *Dev Rev* 2015; **38**: 55–68.

57. Shonkoff JP, Phillips DA, editors. From neurons to Neighborhoods: The Science of Early Childhood Development. Washington, DC: National Academy Press, 2000.

58. Karoly P. Goal systems and self-regulation. In: Hoyle RH, editor. Handbook of Personality and Self-Regulation. Oxford, UK: Blackwell, 2010.

59. Bright FA, Kayes NM, Worrall L, McPherson KM. A conceptual review of engagement in healthcare and rehabilitation. *Disabil Rehabil* 2015; **37**: 643–54.

60. Fredricks JA, Blumenfeld PC, Paris AH. School engagement: potential of the concept, state of the evidence. *Rev Educ Res* 2004; **74**: 59–109.

61. Bedell GM, Khetani MA, Cousins MA, Coster WJ, Law MC. Parent perspectives to inform development of measures of children's participation and environment. *Arch Phys Med Rehabil* 2011; **92**: 765–73.

62. Abuhamdeh S, Csikszentmihalyi M. Intrinsic and extrinsic motivational orientations in the competitive context: an examination of person-situation interactions. *J Pers* 2009; **77**: 1615–35.

63. McWilliam RA, Bailey DB. Effects of classroom social structure and disability on engagement. *Topics Early Childhood Special Educat* 1995; **15**: 123–47.

64. Kishida Y, Kemp C, Carter M. Revision and validation of the Individual Child Engagement Record: a practitioner-friendly measure of learning opportunities for children with disabilities in early childhood settings. *J Intellect Dev Disabil* 2008; **33**: 158–70.

65. Dempsey I, Dunst CJ. Helpgiving styles and parent empowerment in families with a young child with a disability. *J Intellect Dev Disabil* 2004; **29**: 40–51.

66. Trivette CM, Dunst CJ, Boyd K, Hamby DW. Family-oriented program models, helpgiving practices, and parental control appraisals. *Except Child* 1996; **62**: 237–48.

67. Wachs TD. Necessary but not Sufficient: The Respective Roles of Single and Multiple Influences on Individual Development. Washington, DC: American Psychological Association, 2000.

68. Coster W, Law M, Bedell G, Khetani M, Cousins M, Teplicky R. Development of the participation and environment measure for children and youth: conceptual basis. *Disabil Rehabil* 2012; **34**: 238–46.