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Communities with participation-enabling skills: A study of children with traumatic brain injury and their shared occupations

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ABSTRACT

Many ideas about participation in rehabilitation literature focus inwards towards individuals, or individuals and their family, acting in but apart from their environment. Authors position individuals as "participating in" occupations or social settings, or point towards the outcomes for those who do or do not participate. This perspective arguably contributes to occupational injustices, hampering positive change. Literature has not furnished a broader gaze that appreciates individuals and their participation context as one. Actions that occur amongst people collectively with context, in an ongoing cycle of change, receive little attention. Guided by a Deweyan transactional perspective, six case studies exploring the participation of 9–12 year old children with traumatic brain injury generated more contextualised understandings. Interviews with children and community members, photographs, observations, and document-review provided information about actions and changes occurring amongst children and their environment, where these were seen as continuous with one another. This paper describes the Participation-enabling skills that were revealed amongst children and adults who shared in occupations. Community members demonstrated varying ability in using actions that facilitated both themselves and others to take part in occupations. The Participation-enabling skills were fostered during shared occupation. The congruence of the skills with themes in occupational science and therapy literature is explored, and their relevance to social change is proposed.

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Participation; transaction; community; enabling; occupation

A body of research highlights the agency of the social environment in shaping people's participation experiences. The actions of family, friends, peers and other community members can influence the participation of people with disabilities. For children with disabilities, this influence extends beyond any single participation situation, with the social environment impacting on their development, and on feelings of competence and involvement in their communities as they move through to adulthood. Despite this, evidence about ways in which the social environment may be changed to better facilitate participation of people with disabilities remains emergent. Contributing some new understandings about the issue, this Aotearoa New Zealand study of children's participation after traumatic brain injury identified and described a specific set of skills used by community members for supporting others to participate in shared occupation.

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Participation and the Social Environment

The United Nations Convention on the Rights of the Child (The Office of the United Nations High Commissioner for Human Rights, 1989) is an international treaty which holds that children with disability should be facilitated to actively participate in their communities. Signatories to the convention have a responsibility to maximise the social integration and development of children with disabilities. The convention directs attention beyond children's disabilities and any constraints that this might place on participation, and outwards towards the social environment, with a specific focus on the obligations of the state.

Participation has been defined by the World Health Organization (WHO) as "involvement in a life situation" (2001, p. 213). The WHO has been a key driver of societal concerns for participation of children with disabilities. The WHO's International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) recognises not only the way the state can affect participation, but also the role of people in children's immediate social environments and the subsequent effect on children's development (WHO, 2007). The WHO has specified the influence of those who either facilitate or pose barriers to children's involvement in activities and wider society through varying levels and types of support, relationships, and attitudes. In drawing on both medical and social models of disability, the WHO pointed to the responsibility of people to enable participation of all community members.

Rehabilitation literature reflects the ICF-CY's depiction of participation as an important aspect of health (WHO, 2001) and, in information about the important aspects of participation for children with disabilities, the social environment is prominent. Research involving children with disability and their families consistently highlights the social context as both central to the participation experience, but also as one of the main barriers to participation, the latter a theme that appears to have changed little over a number of years (Anaby et al., 2013; Bedell et al., 2013; Coster et al., 2013; Heah, Case, McGuire, & Law, 2007; Imms, 2008). For children with traumatic brain injury in particular, the social environment plays a prominent role. Qualitative literature suggests some in children's communities may find it difficult to adjust to the changes in the children, especially changes in their behaviour, with increased isolation occurring for those children over time (Chleboun & Hux, 2011; Gauvin-Lepage & Lefebvre, 2010; Roscigno, Swanson, Vavilala, & Solchany, 2011).

On a more positive note, theoretical models of participation show the social environment as acting to either support or inhibit participation, with increasing recognition of this dual capability, and also of its potential for change (Hammel et al., 2015; Kang, Palisano, King, & Chiarello, 2014). Further, it has been argued that whilst barriers may exist in the physical environment, it is the social environment that holds the power for addressing such concerns (Law et al., 1999).

Despite this, evidence about ways in which the social environment can be modified to better facilitate participation of people with disabilities gives little surety. Recent occupational therapy research suggests change to the environment is an effective means of facilitating children's participation but, beyond working with family, includes little description of how change might be made to social aspects of the environment, and provides limited information about the changes that take place in that wider social environment (Darrah et al., 2011; Law, Anaby, Imms, Teplicky, & Turner, 2015; Law et al., 2011). Studies have explored intervention approaches targeting some aspects of children's social environments, such as attitude change (Godeau et al., 2010), disability awareness (Lindsay & Edwards, 2013), peer support systems (Carter, Cushing, & Kennedy, 2009), friendship circles (Frederickson & Turner, 2003; Schlieder, Maldonado, & Baltes, 2014) and social networks (Glang, Todis, Cooley, Wells, & Voss, 1997). However, evidence for the effectiveness of such approaches in terms of participation outcomes for those with and without disabilities, and outcomes in a range of environments remains to be fully established. It is possible some of the difficulty rests in the ontological and epistemological basis from which such interventions have been developed and evaluated. Notably, the WHO's model of functioning, disability and health adopts two-way arrows to depict the interaction

of the environment and a person's activities and participation (WHO, 2001). This depiction suggests that not only does the environment influence a person's participation, but that the person's participation will influence the environment. The latter aspect of the interaction, however, is seldom recognised in rehabilitation literature.

Critique of Individualistic Perspectives of Participation

The argument presented here is that many of the perspectives of participation in earlier rehabilitation literature directed the focus inwards towards individuals, or towards individuals and their immediate family members, acting in but viewed, nonetheless, as separate or *apart* from their environment. Authors most often positioned individuals as wanting to participate or participating "in" particular occupations or "in" social settings (Law, 2002). Conceptually this can be likened to a person wanting to move "into" or being "in" water. The body is near or "in" the water, but is differentiated from and discontinuous with that water. Literature has also focused on what happens to those individuals who do or do not participate. When such perspectives are interpreted from a therapeutic perspective, responsibility for change resides within the individual. It is reasoned that facilitating change to the individual should bring about change to their participation. At other times, researchers have classified and measured the ways in which the social environment presents a block to individuals who are differentiated on the basis of disability (for example, other people's negative attitudes get in the way of a person who has an acquired brain injury). Again, these individuals are seen as existing apart from the environment, but attempting to participate. Cutchin and Dickie (2013) have described such world views as "dualistic, individualized (decontextualized), linear, and mechanistic" (p. 3). Moreover, the views are, arguably, disempowering because they fail to recognise those individuals as active agents, capable of bringing about change. Occupational injustices may be perpetuated, and understandings about ways of making positive societal change hampered (Bailliard, 2016; Whalley Hammell, 2015).

It is proposed here that a transactional perspective (Cutchin & Dickie, 2013) can furnish a broader, encompassing view of participation which appreciates individuals and their participation context as one. That perspective is able to provide a more effective platform for understanding the continuous, complex, collective changes associated with participation. The study described in this paper was underpinned by such a viewpoint, with understandings drawn from Dewey's pragmatist philosophy.

Assumptions from Dewey's Pragmatist Philosophy Informing the Study

Dewey consistently depicted people, their activities, their thinking, and their experiences as *continuous* with all aspects of the environment through time and space. Although he recognised that people are capable of focusing on a static snapshot of an experience or time when thinking or acting, Dewey urged that we always look to all relevant material, and to the past, the present, and the future. Because humans were viewed by Dewey as continuous with and part of the world, he also saw that humans with their world continuously evolve. He proposed that while people may act habitually, the changing world presents obstacles to activities and well-being (Dewey, 1925/1981). He believed that responding to this, humans have a natural capacity to lead change and resolve such issues through mindful inquiry and action (Dewey, 1929/1988).

In a publication undertaken with Arthur Bentley (1949), Dewey proposed the idea of transaction to describe the inquiry-based need for full observation and exploration of the two-way changes that unfold when people act in connection with their context. Here, he wrote:

> human life itself … consists of transactions in which human beings partake together with non-human beings … From birth to death every human being is a Party, so that neither he nor anything done or suffered can possibly be understood when it is separated from the fact of participation in an extensive body of transactions- to which a given human being may contribute and which he

> modifies, but only in virtue of being a partaker in them (Dewey, 1949, p. 271).

Dewey saw transactions as essential to learning. "Only by direct active participation in the transactions of living does anyone become familiarly acquainted with other human beings and with things that make up the world" (Dewey, 1925/1981, p. 272). Consistent with recognition of continuity over time, Dewey took the position that learning is processual: that is, learning is the catalyst for further activity and inquiry, leading to further learning. Limiting opportunities for children of any ability to transact with the diverse aspects of their environment is, therefore, a barrier to ongoing learning and development (Dewey, 1949, p. 272).

Dewey consistently argued that such ideas should be considered in the context of democracy. Democracy from Dewey's standpoint could maximize learning and growth as it enabled participation, free exchange of information, and changes in understanding, recognising the potential of all its members. Dewey therefore anchored democracy firmly with notions of shared activity, experience, open communication, and transaction. A community which welcomes diversity, and which facilitates free exchange of experiences and ideas, including those of the more vulnerable, was conceived as necessary to the well-being of all its members. "Expression of difference is not only a right of the other persons, but is a means of enriching one's own life-experience, is inherent in the democratic personal way of life" (Dewey, 1939/1998, p. 342).

Dewey's understandings of continuity, transaction and democracy framed the research aim in the study described in this paper, and gave direction to the choice of methodology and methods. Information was not only gathered about the children with TBI, but also about their transactions as a part of the context, and the changes and learning that occurred amongst children and context. These understandings were pivotal to supporting glimpses of participation that moved beyond perspectives of people and environment being separate. Further, the ideal of democracy promoted a concern with diversity of perspectives, and directed attention to participation situations where democracy was hampered.

Study Aims

The study aimed to describe important aspects of community participation for children with traumatic brain injury, and people's perceptions of facilitators and barriers to successful participation.

Methodology and Methods

Case study methodology

Drawing from Dewey's philosophical perspective, case study was selected as a methodology with potential to explore the complexity and continuity of children's participation in situations after traumatic brain injury. Case studies investigate "a contemporary phenomenon … in depth and within its real-world context" particularly in circumstances where "the boundaries between phenomenon and context may not be clearly evident" (Yin, 2014, p. 16). The methodology has previously been adopted to guide occupational science research framed by a transactional perspective (Hart & Heatwole Shank, 2016; Wicks, 2013). For the project described here, Stake's (1995) interpretive case study approach was used due to its emphasis on the meaning of events and experiences situated as part of real-life settings and time, and its valuing of both singular and shared meanings. Although each case was viewed as unique, there was a concern with applying the information to other, similar contexts, therefore the study was instrumental in nature. Six case studies were undertaken, with a case defined as a child with traumatic brain injury, and family and community stakeholders who were involved with that child. The study was granted ethical approval from the Northern Y Regional Ethics Committee, New Zealand (reference NTY/06/12/134).

Recruitment and informed consent

Recruitment to the study reflected a concern with maximising diverse perspectives, but, recognizing some developmental variability in participation (King, Law, Hurley, Petrenchik, & Schwellnus, 2010), adopted a focus on children aged 9–12 years. This age group was chosen as it reflected a stage when participation outside

of the home becomes increasingly important (Case-Smith, 2015; Vroman, 2015), suggesting good potential to yield information about childhood participation experiences both at home and the wider community.

An invitation to take part was extended by rehabilitation providers to a whānau/family if their child met the following inclusion criteria: aged 9–12 years; had sustained a moderate-severe TBI; discharged at least 6 months prior from hospital/inpatient rehabilitation; living in the community with whānau/family; whānau/family able to converse using English language; and not currently receiving rehabilitation from the first author or her place of work. There were no exclusion criteria.

Families who expressed interest were sent a detailed information sheet about the study, and a simplified version for them to use for explaining the study to their children. The researcher visited the family to answer questions, and to gain signed informed consent. Proxy consent was sought for the children but, where they were able, their signed informed consent was also sought. Whanau/family then provided details of other community members they felt would furnish important understandings about the child's participation, and those people were similarly provided with information before gaining their informed consent.

Participants

As only small numbers of children met the inclusion criteria, all families who gave informed consent were accepted onto the study. Nevertheless, the case studies provided diversity in children's ages, gender, severity of injury, time since injury, family situation and geographic setting. A total of 35 participants were directly involved across the six cases (refer to Table 1 for an outline of the cases).

The cases were culturally situated in Aotearoa New Zealand and reflected understandings from both Māori, the indigenous people, and non-Māori participants. To facilitate understandings for participants who identified as New Zealand Māori, cultural support was given with recruitment, data collection, and data analysis. For example, a kanohi ki te kanohi (face-to-face) approach was arranged involving a whāea (mother) from the researcher's place of work. The whāea led the tikanga (protocols) during the visit, and provided advice regarding further visits for data collection and data interpretation.

Unexpectedly, the focus on children with a diagnosis of traumatic brain injury proved a valuable source of information about children's participation when there was a sudden interruption. As noted by Reed, Hocking and Smythe (2010) a recent change in occupation, including that stimulated by an injury, threw people's occupations into high relief and helped them to articulate what was important. For other children who experienced earlier injuries, insights were gained about how their participation underwent further change over time, providing opportunity for people to reflect on more gradual change processes that stood out to them.

Data collection

Data sources included semi-structured interviews with parents and extended family, the children, teachers, teaching support staff and community members; written narratives from observations of activities nominated during interview as being important at home, and in class, the playground and a range of community settings; photographs taken by the children of things representing occupations that were important to them; and a review of rehabilitation documents to gain insights into the perspectives of rehabilitation providers (refer to Table 1). Rehabilitation legislation and policies were reviewed.

Data analysis

Each case was treated as a unique situation. However, data collection and analysis were iterative, responding to emerging information and, because the case studies were carried out sequentially, learnings from previous cases. Aldrich and Laliberte Rudman (2016) have recently described the utility of Clarke's situational analysis, a mapping process for supporting research into complex situations, proposing its consistency with a transactional perspective of occupation. Responding to similar considerations, the analytic strategy for cases in this study also drew from a cognitive mapping process (Northcott, 1996). The strategy

Table 1. Overview of Children with Traumatic Brain Injury in Case Studies

Name	Age	Gender	Cultural identity	Family and community details	Injury severity	Years since injury	Data sources
Anna	10	F	NZ European	• Lives with mother & younger brother, fortnightly weekends with father • Growing semi-rural township • Attending local primary school full-time	Severe	8	Interviews: Mother; child; teacher; teacher aide; special education needs coordinator. Child photographs of objects representing important occupations. Observations; Classroom (x3- art, circle time & reading, maths & power walk); weekend afternoon at home. Rehabilitation documents; Support needs assessment report; training for independence plan; training for independence outcome report.
Tish	11	M	NZ Māori	• Lives with father, stepmother, older brother & 2 stepsisters. Visits mother in holidays. • Small rural township • Attending local primary school full-time.	Severe	2	Interviews: Father & stepmother; child; teacher; teacher aide. Child photographs of objects representing important occupations. Observations; Classroom; manual training classroom; Kapa Haka performance; junior rugby game. Rehabilitation documents; Education needs assessment report; training for independence outcome report; speech language pathologist report.
Anton	11	M	NZ European	• Lives with mother, father, younger brother • Semi-rural outskirts of city • Attending special-needs class across city full-time and special-needs holiday programme	Severe	5	Interviews: Mother; father; teacher; teacher aide. Observations; Classroom; school swimming; home (after school); scouts; soccer; holiday programme. Rehabilitation documents; Support needs assessment report; training for independence plan; training for independence outcome report; assistive technology report; individual education plan.
Dana	10	F	NZ Māori	• Lives with mother, mother's cousin, & younger sister • Attending nearby religious primary school 5 AMs & 3 PMs/week	Severe	1	Interviews: Mother; child; adult cousin; family friend; teacher; teacher aide. Child photographs of objects representing important occupations. Observations; Classroom- morning; classroom & playground; school religious ceremony & playground; home (after school). Rehabilitation documents; Support needs assessment report; training for independence outcome report.

(*Continued*)

Table 1. Continued

Name	Age	Gender	Cultural identity	Family and community details	Injury severity	Years since injury	Data sources
Bob	12	M	NZ European	• Lives with mother, father, younger brother • Semi-urban seaside community • Attending local primary school full-time	Severe	1	Interviews: Family (mother, father, child); child; teacher 1; teacher 2. Child photographs of objects representing important occupations. Observations; Classroom visit and walk to beach for swimming; Classroom (language) & playground. Rehabilitation documents; Inpatient rehabilitation discharge report; support needs assessment report; education needs assessment report; paediatrician review report; neuropsychological assessment report.
Ash	9	M	NZ Māori	• Lives alternate weeks with mother and father • City suburb • Attending local primary school 4 days/week	GCS not available, Moderate	6	Interviews: Mother; father; child (x3); paternal grandmother, paternal grandfather and step-grandmother; teacher; teacher aide, special education needs coordinator. Child photographs of objects representing important occupations. Observations; School Kapa Haka practice; classroom (Monday AM, Friday AM, circle time, reading). Rehabilitation documents; Support needs assessment report; individual education plan (x2); education needs assessment report.

Note: NZ = New Zealand, F = Female, M = Male. GCS = Glasgow Coma Scale (Teasdale & Jennett, 1974). Injury severity classified on basis of GCS or, where not available, as reported by rehabilitation documentation.

facilitated analysis in which contiguity of information about the situation was maintained (Maxwell & Miller, 2008) rather than separating elements of data and the contexts in which they were gathered.

After case study reports were written for each case, a cross-case analysis was conducted guided by Stake's methods (2006). The cross-case analysis merged findings from the cases, with reference to the research questions, the ability of cases to generate information about those questions, key findings from each case, and the prominence of particular findings within cases. The cross-case analysis culminated in assertions about important aspects of participation from all six cases. A detailed explanation of the process used in the cross-case analysis is provided in the thesis for the study (Jones, 2014).

Validity

Researchers who used case study methodology adopt particular strategies to support the validity of their research findings (Simons, 2009). Although such strategies cannot guarantee the truth of knowledge gained from the study, their use assists others to consider what they may usefully learn from the case (Stake, 1995). For the present study, key strategies included a presuppositions interview to aid the researcher's awareness of her pre-understandings that may have influenced the data and their interpretation; the use of a reflective journal throughout the study to support responsiveness to unexpected themes in the data; triangulation of participant perspectives and data-collection sources; peer de-briefing with supervisors to check interpretations and to prompt consideration of alternative explanations from the data; and progressive focusing, where earlier interpretations were queried in relation to new data, with refinements made to the data collection processes and interpretations where necessary.

Findings: Cross-case Assertions

The findings confirmed the centrality of Shared Occupation to participation, and named four Participation-enabling skills that individuals exhibited to a greater or lesser degree. Those skills were Driving, Leading, Including and Performing. Participation-enabling skills were Learned in the context of Shared Occupation. Figure 1 shows the four Participation-enabling skills in the context of Shared Occupation and the Learning that took place.

Shared occupation

Shared Occupation was found to be a central and important aspect of participation, referring to involvement in activities that were meaningful and that included others. Sharing occupations involved engaging collectively to carry out an occupation which a group wanted or needed to do, situated with a particular context and at a particular time, with people contributing to the occupation as they were able. As observed by Parten (1932), occupations were sometimes shared in parallel, with people taking part in an occupation side-by-side. At other times, they were shared cooperatively, where there was collaboration or where someone carried out a task that contributed to the function and well-being of the group. Occupations were also shared vicariously, or indirectly, where children or adults shared experiences verbally, in writing, or symbolically, as with pictures, mementoes or certificates.

For the children with traumatic brain injuries, analysis revealed that occupations were frequently shared with family, and also with non-human participants, such as pets, toys, insects, and movie or play-station characters. This suggested some imbalances in the patterns of children's participation, but also a human need to engage in occupations with an "other" and the essentially social nature of participation. For example, Dana's teacher described how class movie-making at school provided an important opportunity for her to share occupations directly with her peers, but how it also promoted opportunities to share occupations indirectly with extended family and others in the community.

> *We made class movies. … She was in a group with that, she had a starring role. … She needed a lot of prompting … Her classmates were really good at helping her. … We had an award ceremony … We invited all the parents & grandparents along & we provided free popcorn & drinks*

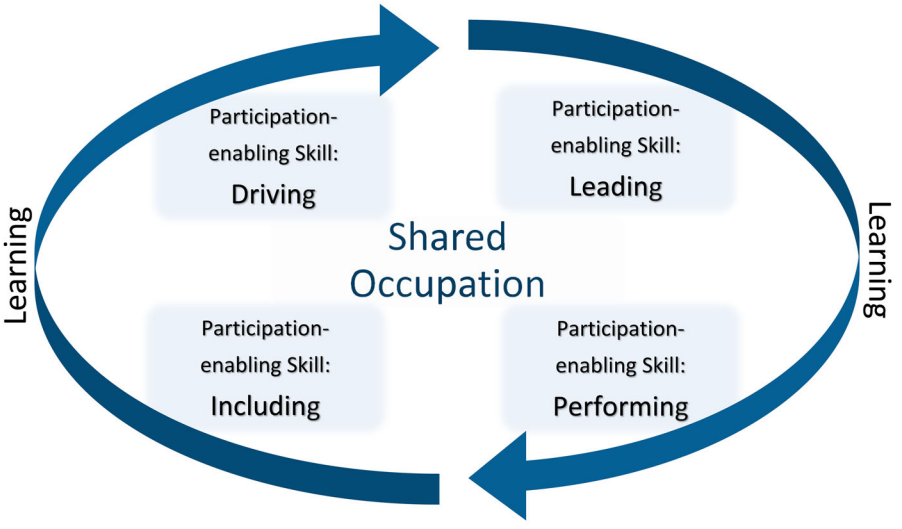

Figure 1. Shared Occupation, Participation-enabling Skills and Learning

& we sold DVDs … We hired a red carpet & some photographers & they had an autograph table (Mitchell, Teacher Interview, pp. 12–13).

People with Participation-enabling skills

Analysis revealed that community members used particular sets of actions, named Participation-enabling skills, which were directed towards facilitating one another to take part in shared occupation. Participation-enabling skills were observable and were also described by participants. The skills were found amongst family members, teaching personnel, children (including those children who had traumatic brain injury), and adult community members, but were not used by all people, and were used with varying levels of competence. People with a range of Participation-enabling skills were useful to support participation; where a skill was deficient amongst group members, participation experiences were less positive. Four different areas of Participation-enabling skills were identified: Driving, Leading, Including and Performing.

The Participation-enabling skill of Driving

Driving was identified as a Participation-enabling skill that refers to visioning, learning about, weighing up, planning for, preparing for, resourcing, and pressing someone towards a Shared Occupation. It emphasised networking, communicating information with others, and facilitating children to express their preferences. People who Drove participation were skilled at seeing openings for participation, and for weighing these against children's wishes and abilities and the realities of what would be needed. They often Drove opportunities to share occupations in which they themselves had some expertise or experience.

Participants often referred to Driving as "Having a Go". Several of the children with traumatic brain injury Drove participation themselves, but many lacked confidence or were discouraged from their ideas on safety grounds. In these instances the role for Driving was often taken on by adults, most typically parents. Driving skills were also used by peers in the classroom or in the playground, where they would take advantage of a time-frame and physical situation to conceptualise an opportunity for an occupation, and would promote this idea to other children.

Dana's cousin, Dean, was keen to help her spend more time in outdoor activities with other children, although this was frequently constrained by concerns over the need to avoid a repeat head injury. He said "*I'd love to get her into those things [water sports]. Just, you know just get her to try it. If she likes it. If she doesn't*

then I wouldn't push her" (Cousin Interview, p. 3). Dean described the way he Drove an opportunity at school camp for Dana to experience yachting. Dana lacked confidence, but with practice and encouragement she was able to share the occupation.

> *I know how to sail. So I gave her, you know just gave her a chance. She didn't like it at first, because we weren't going fast enough. So we went again a second time, and she was, you know she was shocked how fast we were going the second time, and she liked it and she didn't get out of the boat for about an hour and a half. So I was in it [the small sailing boat]. Had my feet out of the boat, but, I was still in there! It was still good fun. She enjoyed that and once she was with her friends and they were doing it, yeah she didn't have any problem trying it* (Cousin Interview, p. 5).

The Participation-enabling skill of Leading

Leading refers to the actions of those "in charge" in a Shared Occupation, who direct, guide, teach, model and coach others to promote the involvement of all group members. People who were able to Lead well were adept at regulating and adjusting a situation to support involvement. They recognised and monitored group members' contributions, and were accepting of different ways of being involved. Leading skills were observed with teachers, but also with community members and with children. Sometimes, although not often, the children with traumatic brain injury had an opportunity to Lead an occupation, and showed good ability to support other's involvement.

Bob's parents reported how Miss W., Bob's teacher, quickly adapted the class activity to include him soon after he had been discharged home from rehabilitation.

> *He was happy we got into his class and all the other kids were trying to get into his room. The teacher had to tell them to go away. And ah, they sat down, they ended up doing a game with him and, throw oh passing a ball around the room … Silent ball that's what it was and it was quite good for about 10 minutes, and then we, we zipped him home … At that stage it was still not too, get the brain too active for too long like. It was good for the kids, good for him* (Parent Interview, p. 22).

The first author also observed Miss W. using her Leading skills to facilitate group involvement during a discussion. Children seemed to pick up on the skills, mirroring them in interactions with one-another, including Bob, in other activities outside class. The following was recorded;

> *Miss W. asks the class to share what they did yesterday. Bob does not speak during this discussion, but is listening. A lot of hands go up, and Miss W. indicates to children, requesting them one at a time to share with the class. Like their teacher, the children are engaged and interested, listening respectfully to one another's experiences, and commenting or laughing appropriately. One child interrupts someone's story, and Miss W. asks her to wait for her turn to speak. I guess this is helping the children to learn to feel part of a community* (Class Observations, pp. 2–3).

The Participation-enabling skill of Including

Including refers to a range of actions used by adults and children to immediately involve one another into a Shared Occupation. Across all cases, it was important that actions used by group members treated people in the same way, so that individuals were not singled out. Multiple Including actions were identified such as noticing another person needed help, greeting, introducing someone, inviting, listening, asking, explaining, reciprocating, sharing resources, turn-taking, giving and receiving help, and encouraging. For Anna, a school-based art class observed by the first author was structured informally, and the Including actions children used towards one another supported a sense of participation for the whole group.

> *Anna looks at some other children's pictures. She interacts with another girl -*

> *she's asking to use the buttons from a bag. Now she asks the teacher where the glue is, puts on the glue herself, and puts on a button. Anna is watching the other children at the front of the room. Another boy talks to her - he gets the glue. Children in the class are asking each other where items are around the room* (Observations, School Visit 1, p. 8).

Possibly reflecting the ages of children in the study, or their culture, touch was a commonly used Including action. Both boys and girls demonstrated touch as a means of Including one another, with actions such as a hand on an arm, an arm around another's shoulders, good-natured wrestling or pushing, and hand-holding. In Dana's playground, the first author observed the following interaction. "*Dana gets up and draws another girl in with her and her friend. Two others greet each other - two hands up, recognising the gesture. They put their arms around each other, touch, laughing, agreeing on a game, five of them moving off*" (Playground Observations 2, pp. 4–5).

Including actions were particularly evident in some communities, where they appeared to be a cultural norm. In Case Study One, Anna spent frequent periods of time in rehabilitation activities, which interrupted her schooling, and at school, she was typically accompanied by Joanne, her teacher aide. Including actions were less evident in Anna's community, but children who had shared occupations with her used actions that supported her feelings of involvement in playground activities. Her teacher aide reported "*Even the younger children in the school playground, they get to know her name, and it's 'Hi Anna, hi Anna' and she goes 'Oh everyone knows me!' Yeah she quite likes that*" (Teacher Aide Interview, p. 10).

The Participation-enabling skill of Performing

Performing was the Participation-enabling skill area typically addressed by rehabilitation providers. Performing refers to people's capacities to carry out and achieve a Shared Occupation. Performing an occupation when it was shared by a group supported success in achieving the occupation, but also fulfilled an important role by coaching or modelling the occupational performance for others. Those with less ability to perform the occupation, such as some of the children with traumatic brain injury, were enabled to take part in the occupation through instruction from others, and from observing and copying others' actions. Where there were diverse performance abilities amongst those participating in a Shared Occupation, participation was enhanced; those with less performance skill did not stand apart from others but were part of a natural scattering of abilities. In Ash's class during a writing activity, the first author recorded:

> *Children are prompted to seek help from someone who has finished if they are unsure of what to do. Milly stands beside Ash while he works at the computer. She helps him with starting the programme, and prompts him as to where to click the mouse … Typing remains effortful … He seems to find it hard to look at the story his teacher wrote down for him from his oral dictation and to then shift his gaze between the computer screen and the keyboard. Milly works patiently with him, standing at his side, responding gently to errors, reading the words out for him, and spelling the letters for most words … Ash perseveres, and finishes the writing in time for the bell for lunch* (Classroom Observation, pp. 10–11).

Learning Participation-enabling skills

Varying levels of Participation-enabling skills were reported and demonstrated. The skills were not unique to adults, nor to non-disabled community members. Indeed, some good skills were demonstrated by the children with brain injury. Participation-enabling skills were learned by adults and children through engaging in Shared Occupation. As people learned, they were better able to support one another to share in occupation. Conversely, where people were not involved in a Shared Occupation, they were hampered in their ability to learn how to perform, and how to facilitate one another to participate. Thus, Learning

Participation-enabling skills was cyclical. Where people with skills were participating, their Participation-enabling skills increased further. Where people were not participating, neither they, nor others were able to learn.

After Ash's brain injury, with direction from adults and with frequent opportunities to share in play, his cousins began to acquire skills at enabling him to participate with them. Ash's koro or grandfather explained:

> *He's not left out by his cousins at any stage. Through the years I've explained to them that you've got to include Ash in these things. He might be a bit slower, and they realise that. I sit down and say 'Ash has been through a bit of trauma in his life. You've got to look after him, take care, and include him in your games, have a bit of patience with him.' They started to realise, and they're starting to cotton on [understand] now* (Grandfather Interview, p. 7).

Discussion

Situating shared occupation and participation-enabling skills with rehabilitation and occupational science literature

The study was guided by the pragmatist philosophical understandings of John Dewey, and adopted a transactional view of participation. The findings revealed a group of skills specifically used to support others' involvement in a shared occupation, which were named Driving, Leading, Including and Performing. The actions encompassed by those skills have been described, and it has been proposed that they are learned in the context of Shared Occupation.

It is important to recognise the limitations of the study when considering the findings. Firstly, because the children in the study experienced receptive and expressive communication difficulties secondary to their injuries, the degree to which they were able to express their perspectives was limited. Further, although others' accounts and observations were used, the case studies didn't gather data directly from children's peers, which might have provided another useful perspective on actions that facilitated participation. Lastly, but importantly, because the results derive from only six cases, caution is needed when generalizing those understandings to other settings, or to children of different ages or with different diagnoses.

Despite these constraints, some elements of Participation-enabling skills have been identified previously, lending some confirmation to the findings. Bedell, Cohn and Dumas (2005) investigated the things parents did to facilitate their children's participation after traumatic brain injury. Focusing on parents' actions, one strategy was directed at the environment rather than the children themselves, and involved Creating Opportunities (p. 279). The actions Bedell and his colleagues described in Creating Opportunities align with those observed in the Participation-enabling skills of Driving. The study described in this paper lends support from another context to Bedell et al.'s findings, while also pointing to the opportunities created by teachers, community support people, and peers. The present study also suggests that creating opportunities, on its own, is not enough to support participation. People also need to Lead in a way that facilitates involvement and Include the children in Shared Occupation. People are needed within a Shared Occupation who have good ability to Perform that occupation. In these ways, further Learning of those involved is promoted.

A more recent study of an environmentally-focused intervention approach similarly reports the use of strategies that support participation, these also showing some congruency with the Participation-enabling skills reported in the current paper. The focus of the intervention involved youth with disabilities and their parents, but targeted the wider environment, with some involvement of the social environment (Anaby, Law, Majnemer, & Feldman, 2016). Many of the therapist actions encompassed strategies that aligned with the Participation-enabling skill of Driving, and were focused on establishing opportunities for participation in the community, including networking and preparing for participation. Other actions targeted leaders of shared occupations, providing them with information about how to modify activities and items so that youth could be involved, these fitting with the notion of Leading. However the intervention contrasts with

the findings of the case studies in this paper in that it followed a collaborative, solution-based approach with a coaching component rather than directly engaging in Shared Occupation to bring about change.

Suggestions of the presence of Participation-enabling skills are also evident in earlier literature. In 1973, Anne Cronin Mosey described the theoretical basis and implementation of activity therapy, proposing that people develop and use group interaction skills alongside task skills when sharing in occupations. She suggested five levels of ability for group interaction, reflecting increasing degrees of cooperation in performing tasks and amounts of interaction. In contrast with the present study, however, Mosey did not specify *actions* that are involved with the various levels of group interaction skills. Therefore it is unclear whether group interaction skills align with Participation-enabling skills for facilitating each other's involvement, or whether they instead reflect individuals' skills for enabling themselves to take part. However, consistent with the present study findings, Mosey (1973) did posit that group interaction skills are learned collectively in a context where people engage together in occupation.

The significance of the skills observed in this and Bedell et al.'s (2005) study becomes evident in Humphry's (2005) Processes Transforming Occupation (PTO) model. It relates such skills to the way children learn to perform occupations and how the meaning of those occupations develops in childhood, underlining the importance of constructing opportunities to take part in occupations. Humphry drew attention to the role played by both directly and indirectly Shared Occupation in learning, a central finding in the present study. However the present study suggests some further directions for the understandings contained in the PTO model, by indicating the relevance of Shared Occupation to understandings of children's participation. Children not only learn how to perform occupations but learn how to support one another to participate. The present study further suggests the need to recognise the things children do to support one another's involvement in Shared Occupation and hence, learning.

The notion of Shared Occupation also aligns with Pierce's (2009) explanation of co-occupation. Here, Pierce referred to her earlier (2003) work in defining co-occupations as highly interactive occupations, in which the experiences of one person require the interactive responses of the other person or persons involved. Pierce posited that the essence of co-occupation is simply the degree to which the occupations of two or more individuals are interactively shaping each other. The present study adds to this concept by suggesting that when sharing occupation, people may deliberately use skills or actions that support the other's involvement, and by naming and describing those skills.

Several of the Including skills observed in the study overlap with some of the Social Interaction Skills reported by Fisher and Griswold (2014). These include actions such as Touching, Questioning, Replying, and Thanking. Fisher and Griswold's (2008) notion of Social Interaction Skills aligns with the concept of Participation-enabling skills, in that they are observable aspects of social behavior occurring during occupational engagement. However Participation-enabling skills contrast, in that they were used to facilitate not necessarily oneself, but others to take part. They are also broader in nature, in that they were not solely focused on the social as it occurs *during* an occupation, but were also concerned with enabling future group *performance* of an *occupation*. Establishing the relationship of the Participation-enabling skills identified in this study to Fisher's Social Interaction Skills remains for future clarification.

More recently, Townsend and her colleagues (2013) stated that occupational therapists use a particular set of skills directed at supporting individual and social change so that people may engage in occupation. Such skills, termed "Occupational Therapy Enablement Skills" are explained as being "beyond the ordinary enablement that occurs in everyday life by parents, friends, and others" (p. 112). Whilst this literature recognises that everyday people do use skills that enable others to engage in occupation, those skills used are not further explored, and the emphasis is, instead, on the specialised skills used by occupational therapists. These skills include Adapting, Advocating, Coaching, Collaborating, Consulting, Coordinating, Design/Build, Educate, Engage, and Specialize. It could be argued that some of the Participation-

enabling skills observed in the present study overlap with the Occupational Therapy Enablement Skills. For example, those with Leading Skills in the present study adapted occupations. Likewise, those with Driving Skills used those skills to connect with resources and to facilitate interactions with those who could provide opportunities for participation. It is possible that some of the skills observed in this study were learned from occupational therapists, although the data from documentation indicated a rehabilitation focus on supporting the children to Perform occupations. Acknowledging that skills develop amongst non-professionals when they share in occupation subtly shifts the balance of power from therapists to communities. It raises the question, however, whether professionals can directly facilitate the development of Participation-enabling skills, or whether they are only acquired through active engagement in occupation.

Shared occupation, participation-enabling skills and social change

There is increasing awareness of the importance of people connecting with one another amongst the varied tapestries of communities, to support health and well-being, to support effective functioning within the workforce and to create social change. Yet less attention has been paid to what people need to do in order to achieve such connections, or how they might learn the necessary skills. Data from Statistics New Zealand (2014) indicate life satisfaction is associated with the size of people's social networks. Despite this, 1% of New Zealanders have been identified as having no supportive family or friends, and international indicators are that loneliness is a public health issue (Gerst-Emerson & Jayawardhana, 2015). One start-point to addressing loneliness is an awareness that not everybody is similarly equipped to form social networks, and that strategies for supporting the participation of others is essential to incorporating those people into the social fabric of communities. Furthermore, by sharing occupations with those who are at risk of isolation, those participation-enabling skills can be further developed amongst community members.

The necessity for communities equipped with Participation-enabling skills becomes even more apparent given that fact-to-face contact is an essential, and inbuilt need, reflected in humans' neurological structure and function, health, development, and ability to build and maintain relationships (Pinker, 2015). More specifically, research suggests that the adequacy of individuals' connection with other people has an effect on cognitive function (Crooks, Lubben, Petitti, Little, & Chiu, 2008; Fratiglioni, Wang, Ericsson, Maytan, & Winblad, 2000), predisposal to and recovery from illness (Cohen, Brissette, Skoner, & Doyle, 2000; Lutgendorf et al., 2009; Vogt, Mullooly, Ernst, Pope, & Hollis, 1992), survival after cancer (Reynolds & Kaplan, 1990) and longevity (Holt-Lunstad, Smith, & Layton, 2010). The ability to show empathy and work cooperatively with a range of people is a valued employment skill and is essential to effective team function (Colvin, 2015). Similarly, the participation of, and collaboration with, diverse group members is suggested as being a key factor in creating social change for environmental sustainability (Harre, 2011) and in civil resistance movements (Chenoweth & Stephan, 2013).

Internationally, it is recognised that attitudinal change is particularly needed to support a society that is inclusive of people with diverse abilities and experiences, and from diverse socio-cultural and religious backgrounds. For instance, the Oslo Coalition on Freedom of Religion or Belief, in cooperation with UNESCO (2004) has developed recommendations for teaching for tolerance, respect and recognition. However such concerns and recommendations fall short of translating these ideas into action. What is it people need to do in order to support one another's participation? To create societal change at an international level, people need capacities for working with others from a multitude of situations towards common goals. Perhaps the key to translating ideals of tolerance, respect and recognition is through recognising and valuing the skills that people use to enable one another to share in occupations.

The concept of Participation-enabling skills, as found in this study, remains to be further explored and tested. Nevertheless, if these do prove to be skills that a range of people can deliberately use to support others to participate

together, what type of society might be created? What would it mean to be in a society where people have Participation-enabling skills? By naming and describing the skills observed to enable children with brain injuries to share occupation, but with application in any context, people may learn to create a society that values and actively enables participation of diverse peoples within communities and wider society.

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