# SOCIAL CONTEXT OF CHILDREN WHO USE AIDED COMMUNICATION

# SOCIAL CONTEXT, PARTICIPATION, AND GOAL-ORIENTED COMMUNICATIVE INTERACTION OF SCHOOL AGED CHILDREN WITH MOTOR IMPAIRMENTS WHO USE AUGMENTATIVE AND ALTERNATIVE COMMUNICATION: VOICE AND CHOICE

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## Abstract

This dissertation explores the social context of children with severe motor and communication impairments who use augmentative and alternative communication (AAC), examining how they participate socially, and how they interact in a goal-oriented play activity.

Chapter One provides the context by reviewing literature concerning the children who use AAC: describing their presentation, outlining the role of environmental influences, and reviewing what is known about their social context, participation and communicative interactions. This chapter reviews the issues faced by children who use AAC and outlines the thesis purpose and objectives.

Chapter Two presents a qualitative study that explores the children's social context, participation and social relationships from both children's and parents' perspectives. This study provides insight into children's communicative abilities but highlights their limited social context and opportunities and supports for communicative interaction and social participation.

Chapter Three presents a study that explores the communicative interaction within goal-oriented play activity. This study found that, if you give children who use AAC a 'voice', they experience communicative success. Group differences were evident, however. Compared to their peers, children using AAC were less specific, made more and different errors and received more help from partners. This study provides evidence of how contextual elements within activity settings could be altered so children could actively participate.

Chapter Four presents a conceptual framework for understanding social context. This chapter integrates person-focused and environment-focused perspectives and leads to development of a framework that depicts the transactional influences of children and social environments. Recommendations for future studies are presented.

Finally, Chapter Five discusses the implications of this dissertation, placing the insights gained from the empirical studies in the context of the proposed framework. Suggestions for further research and interventions are made that may improve health and developmental outcomes in children with severe motor and communication impairments.

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Thanks to my colleagues from the *Becoming Aided Communicators* project for their support, laughter and friendship – you have been with me on this journey. I thank

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## Preface

This preface summarizes all author contributions to each of the manuscripts found in this dissertation.

Data for two empirical studies (Chapter Two and Three) were collected as part of an international project involving 16 countries and addressing the developmental achievements and challenges of young people who used aided communication. This project was led internationally by Dr. Stephen von Tetzchner, with each country making an independent contribution. Beata Batorowicz was leading the project in Canada and was part of a core international group who collaborated on development of the project methods. Beata Batorowicz managed the project in Canada with Dr. Cheryl Missiuna overseeing; obtained funding with support of Dr. Gillian King; completed the ethics approval process for Canadian children at multiple sites; recruited participants; secured the equipment; hired/managed the research coordinator and assistants; and completed the data collection for the two manuscripts.

For the manuscript entitled *"Social Participation of School-aged Children Who Use Communication Aids: The Views of Children and Parents"* Beata Batorowicz formulated the research question, designed the study, analyzed and interpreted the data, and prepared the manuscript. Dr. Cheryl Missiuna advised as to the design of the study and together with Fiona Campbell assisted in data analysis as required by the chosen qualitative approach. Dr. Stephen von Tetzchner assisted with interpretation of the study findings.

Dr. Gillian King provided feedback and all authors provided editorial assistance with the preparation of the manuscript.

For the manuscript entitled *"Children Who Use Communication Aids Instructing Peer and Adult Partners During Play-Based Activity"* Beata Batorowicz formulated the research question, designed the study, developed the protocol for analysis, analyzed and interpreted the data, and prepared the manuscript. Dr. Stephen von Tetzchner collected Norwegian data, provided feedback on development of the analysis protocol and assisted with interpretation of the study findings and the preparation of the manuscript. Kristine Stadskleiv assisted with the protocol development and details of the data coding and analysis. Dr. Cheryl Missiuna provided feedback and editorial assistance with the preparation of the manuscript.

For the manuscript entitled "*An Integrated Model of Social Environment and Social Context for Pediatric Rehabilitation"* Beata Batorowicz together with Dr. Gillian King formulated a need for a conceptual review. Lipi Mishra, assisted with the initial literature review and analysis. Beata completed a review of the interdisciplinary literature, synthesized the information, integrated conceptual approaches, and prepared the manuscript. Dr. Gillian King provided guidance and assisted with refining aspects of the conceptual approach. Drs. Cheryl Missiuna and Gillian King provided feedback on the model itself and editorial assistance with the preparation of the manuscript.

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## List of Abbreviations and Symbols

AAC = Augmentative and Alternative Communication

AC = Aided Communication

C = Child

CFCS = Communication Function Classification System

GMFCS = Gross Motor Function Classification System

KBIT-2 = Kaufman Brief Intelligence Test, second version

M = Mean

MACS = Manual Ability Classification System

MVPT-3 = Motor-Free Visual Perception Test, third edition

O = Older than 10 years

P = Parent

PCS = Picture Communication Symbols ™

OT = Occupational Therapist

SD = Standard Deviation

SLP = Speech Language Pathologist

SPSS = Statistical Package for the Social Sciences

SN = Naturally Speaking

TROG-2 = Test for the Reception of Grammar, second edition

Y = 10 years old or younger

## Declaration of Academic Achievement

This dissertation presents original work undertaken by the doctoral candidate. The candidate supervised and conducted the studies, participated in all data collection, analysed the data, and interpreted findings of the work. Collaboration with the thesis supervisor and thesis advisory committee led to refinements of various aspects of the work presented here. The doctoral candidate is the sole author of this work, and has benefitted from review and feedback from thesis advisors.

# Chapter One: Introduction

As a little girl
I lived in a silent world
Oh, I had a **voice**
Though it was unclear
If people listened, they
Would discover I could make
Intelligent **choices**
Instead, I sat in a chair all day
And wasn't **allowed to play**

*Whitney Lyons in S. W. Blackstone, 51*

The social environments in which children live, learn, and play, shape their development (Bronfenbrenner, 2005; Karpov, 2005; Vygotsky, 1976; Wells, 2009). The literature indicates that social connections, interactions, and participation with others in typical childhood activities, as well as appropriate structure and supports, are crucial to children's growth, health and well-being (Eccles, Barber, Stone, & Hunt, 2003; Imms, 2008; Law, 2002; Law, Petrenchik, Ziviani, & King, 2006; Petrenchik & King, 2011). Current developmental theories and models emphasize the importance of understanding the social context of children and the reciprocal nature of child-environment interactions (Bronfenbrenner, 2005; Sameroff, 2010). They emphasize both the influence of environments on children and the *active* role of children in their contexts, suggesting that children contribute to shaping their own development as well as to shaping the social environment (Sameroff, 2010).

The terms 'social environment' and 'social context' have often been used implicitly in the rehabilitation literature referring to some factors that affect the person in his/her

surroundings. Typically, social environment is a construct denoting broad external circumstances that may be considered as either enabling or constraining to functioning, participation or development (Petrenchik & King, 2011); the term social context is used to refer to the particular system of social relationships and circumstances in which the child is situated (Bronfenbrenner, 2005).

Despite our knowledge of the importance of the social environment to child development, little is known about the social context of children who have little or no functional speech and who use augmentative and alternative communication (AAC). Particularly, being active poses a tremendous challenge for children who have severe motor impairments and rely on AAC. These children have difficulty both physically acting on their world, as well as participating in the social context through communication. The emerging evidence suggests that: children who use AAC tend to participate less frequently in typical childhood activities with others (Clarke, McConachie, Price, & Wood, 2001; Clarke et al., 2011; Thirumanickam, Raghavendra & Olson, 2011); they have limited interactions with their peers (Clarke & Kirton, 2003); and they have small social networks which consist mainly of family and professionals (Beukelman & Mirenda, 2005; Blackstone, Williams, & Wilkins, 2007). Young adults who use AAC have reported profound loneliness and a desire to be socially involved (Cooper, Balandin, & Trembath, 2009). Evidence supporting these findings is limited, however, so it would be beneficial to explore children's and parents' perspectives about the social participation experiences of children who use communication aids.

Research indicates that interactions of children using AAC are dominated by their communication partners (Kent-Walsh & McNaughton, 2005; von Tetzchner & Martinsen, 2000) and that the children are considered to be 'passive' (Finke & Quinn, 2012; Tavares & Peixoto, 2003). Given their physical and communication challenges, how can children be active within typical childhood activities? Communication of directions may be a way for children to exert control over their lives and their social contexts. Instructional activities are of interest because giving instructions is a functional activity that is crucial to everyday independent living and relates to self-care, decision-making, and autonomy (e.g., Collier & Self., 2010). Only a couple of studies have described interactions of adults who use AAC that required providing precise, autonomous instructions (Collins, 1996; Collins & Markova, 1999); however, we do not know how children who use communication aids manage these kinds of tasks. We need to understand how children provide instructions using their methods of communication, the strategies that they use, and the strategies that their communication partners use. This knowledge may inform clinical practice and provide guidance regarding interventions that will support children and families.

It is probable that children change as a result of their interaction with their social environment (e.g., Karpov, 2005; Nelson, 2007; Sameroff, 2009; 2010). The question, then, is how can we shape this change for children who have motor and communication impairments in positive ways, to support optimal developmental outcomes, and to prevent disability? We need to better understand the reciprocal interactions between the specific characteristics of activities and the actual experiences of children who use AAC. This is

in contrast with the more typical approach often used in therapy of teaching children skills outside of the social context. A conceptual model that provides a more sophisticated understanding of social influences on the daily lives of children may provide a new framework for thinking about environmental interventions that will support children's long-term development.

This introductory chapter provides a review of the literature forming the foundation of the dissertation research questions. It includes the following sections: (a) description of children with motor and communication impairments who use AAC; (b) social environment and social context; (c) social and communicative participation; and (d) communicative interactions, including goal-oriented interactions. Within each section, the theoretical foundations guiding this dissertation are discussed first, followed by what is known about children who use AAC, linking all four sections together. Lastly, the chapter provides a statement of the research questions that will be addressed in this thesis, a summary of study objectives and a brief description of subsequent chapters.

## Description of Children with Motor and Communication Impairments Who Use AAC

Many children who are unable to use speech as their primary mode of communication rely on some type of aided language system. These systems can include letters, words and word-based messages, or some type of graphic symbols (e.g., Picture Communication Symbols ™ or Blissymbolics) representing words and messages. The AAC systems can be electronic, such as a computer with specific

language/communication software, or they may involve non-technology solutions such as printed communication books or lap tray communication displays (e.g., Beukelman & Mirenda, 2005; von Tetzchner & Martinsen, 2000). These AAC systems can have individual symbols representing either letters or words or full sentences; most communication aids include a combination of these options, depending on the language level of the child as well as the need to serve different communication functions (e.g., full sentences may be preprogrammed for social greetings which need to be delivered quickly). Aided systems have been shown to be important in supporting the development of language, literacy and communication in children with little or no functional speech (e.g., Beukelman & Mirenda, 2005; Light, Beukelman, & Reichle, 2003; Smith, 2005; von Tetzchner & Martinsen, 2000).

Research demonstrates that the use of aided language has unique characteristics and is not simply a non-vocal expression of spoken language (Smith, 2003; Smith & Grove 1999; Sutton, Soto & Blockberger, 2002; Waller, 2006; Yoder & Kraat, 1983). However, there are no detailed descriptions of the language development of children who use aided systems. Knowledge in this area is based mainly on descriptions of individual people (Liboiron & Soto, 2006; Light, Collier & Parnes, 1985; Smith, 2003, Sutton, Morford, & Gallagher, 2004; von Tetzchner, Brekke, Sjothun, & Grindheim, 2005; Waller, 2006).

Children who require communication aids are heterogeneous in their motor and cognitive abilities (Binger & Light, 2008; Light, Beukelman, & Reichle, 2003; Schlosser, 2003; Smith, 2005). Children with severe motor impairments often require alternative ways to operate their AAC systems (Beukelman & Mirenda, 2005). Direct ways to access

the AAC system may involve pointing to the desired message or symbol using a body part or with the support of assistive technology (e.g., index finger; light pointer attached to a headband; joystick to operate a computer; eye-gaze). Indirect ways to access AAC systems involve scanning. Different types of scanning can be set-up with one or multiple switches, depending on the individual's motor and cognitive abilities (Beukelman & Mirenda, 2005; von Tetzchner & Grove, 2003). Using switches to operate an electronic device provides independent access to vocabulary stored on a communication aid; however, it also poses additional demands on the child. In general, it has been recognized that AAC systems pose multiple cognitive, motor, sensory and perceptual challenges, which need to be carefully considered (Raghavendra, Bornman, Granlund, Bjork-Akesson, 2007).

The slow rate of communication using aids, lack of access to an aid, or lack of access to vocabulary on a communication aid (i.e., pre-programmed messages on an electronic device or graphic symbols in a communication book) have been mentioned as common issues faced by children (Kent-Walsh & McNaughton, 2005; Murphy, Markova, Collins, & Moodie, 1996; Shepherd, Campbell, Renzoni, & Sloan, 2009; Smith, Murray, von Tetzchner, & Langan, 2010). Studies have reported that aided communicators have difficulty with initiating conversation and rely on others to continue the interaction (Basil, 1992; Finke & Quinn, 2012; Harris, 1982; Kraat, 1985). However, we know little about the potential achievements of children using AAC – some develop literacy skills and become competent language users and communicators, while others do not (Smith, 2005).

This thesis specifically concerns school-aged children who are in the expressive group who have severe physical impairments, who have no cognitive delays and who use communication aids. The expressive group has been described as those children who have demonstrated a large gap between comprehension and production of spoken language (von Tetzchner & Martinsen, 2000) and who are able to make use of communication aids. Given their cognitive abilities and the fact that these children understand spoken language (i.e., without AAC support), they could potentially learn similarly to their peers, however, their experience might be limited due to physical and expressive challenges.

**Social Environment and Social Context**

The role of the environment in children's development has been emphasized by scholars across a range of disciplines. This discussion is characterized by complexity and critical distinctions, given different worldviews. Social psychological theories (e.g., Bandura, 1986) and social ecological models (e.g., Bronfenbrenner, 1979) have characterized the nature of the relationship between person and environment. The literature highlights the importance of environments that offer opportunities for skill-building and reinforce positive social connections (Eccles et al., 2003; Imms, 2008; Larson & Verna, 1999; Law, Petrenchik, King & Hurely, 2007; Law et al., 2006; Robeiro, 2001; Scaffa, Pizzi, & Chromiak, 2010). However, despite the widely recognized importance of environment to a child's life, social environment is a diffuse construct that includes different scope and varied broad social, physical, institutional, and cultural aspects (King, Rigby, & Batorowicz, 2013).

Both the bioecological model of Bronfenbrenner (2005) and the transactional model of Sameroff (2009; 2010) emphasize the social context and the inter-connectedness of individuals and their social contexts. Bronfenbrenner's model explains how the child is influenced within a complex system of social relationships while Sameroff's model highlights how the interactions of the child with the social context explain development and the positive or negative outcomes for children. Outcomes are not a function of the individual alone, or of the context; rather, they result from this interaction (Sameroff, 2009; 2010).

The unified theory of development combines four models important to understanding children's development: (a) the personal change model (how children change over time – trait, growth, and development); (b) the contextual model (child's ecology); (c) the transactional regulation model (dynamic systems perspective between a child and context – self-other bi-directional regulation); and (d) the representational (meaning) model (Sameroff, 2010). The development is understood as a product of continuous dynamic interactions of the child and the experience provided by social settings; however, the specific processes of interdependent child-social environment effects are not described.

Within rehabilitation science, the International Classification of Functioning Disability and Health, and the child and youth version (WHO, 2001, 2007 respectively), present contextual factors as including both the environmental and personal factors and suggests that disability results from the interaction between impairments and environment; however, they do not explain the mechanisms through which people affect their environments or how environments affect people. A clear definition of social

context and social environment and identification of specific units of analysis could help to study the social context of children in a more systematic way within pediatric rehabilitation. To capture the changing relations between the child and the context, integrative and transactional models are needed (Phillips & Cameron, 2012). A framework that integrates disciplinary perspectives would be beneficial to conceptualize and study various aspects of social environment and social context in relation to child health and disability; however, it does not exist.

### *Social Context and Aided Language*

*The development of language [...] involves two people negotiating" (Bruner, 1983, p. 39)*

Different approaches have emerged from schools of linguistic thought as to the relationship between language and context. In currently prevailing non-nativist theories, language acquisition is understood as the result of a social construction within a biological context. The desire to solve communicative challenges is one of the forces underlying the development of language (Nelson, 1996; Tomasello, 2003). This view is congruent with other general developmental theories, which underscore the interplay of nurture and nature and the complexity of the multiple factors that contribute to development (Sameroff, 2010). Consequently, differences in the quality of social contexts lead to important variations in experiences, which influence children's language and communication development.

In order to develop skills, the child needs to receive help from more competent members of society, such as teachers, parents, or peers (Vygotsky, 1962; Karpov, 2005). The opportunity to practice specific skills in a supported way leads to mastery. The child's social interaction, with guidance from more competent language users who can engage in linguistic interactions is therefore important (Renner, 2003; Tomasello, 2003; Vygotsky, 1962). The language uptake by the child is the most relevant to language development (Harris, 1992) and represents his/her experience. A child has to hear enough of a certain kind of language and practice to be able to make conclusions and generalize, as well as to learn language rules (Nelson, 2007) and social rules of communication (Light, 2003). Children who have significant problems in the acquisition of speech and language may develop language through interaction using communication aids and through the support that is provided in rehabilitation.

Early on in development, infants who will need AAC are exposed to parents' spoken language and they are typically introduced to aided language systems at age 3 or later (Light, 1997a). Expression in aided language is generally not present in their social context. Therefore, most often the source of language input is the spoken language of the home. Consequently, children need to develop receptive skills in spoken language; thus language input and output are in different modalities, with output being multimodal (e.g., gestures, facial expressions, vocalizations, communication aids). Children are expected to extract rules from spoken language and to apply them to alternative, very different systems (Smith & Grove, 2003). This asymmetry between input and output modalities may have crucial implications for language development (Blockberger & Sutton, 2003;

Sutton, Trudeau, Morford, Rios, & Poirier, 2010) and the success of children's communicative interactions.

The literature on typical language development indicates that adults provide scaffolding to support their children's language learning and then gradually transfer control to their children (Nelson, 1996). Scaffolding support provided to children with little or no functional speech seems different because adults continue to provide support, even when such support seems no longer needed (Light, 1997b). Moreover, it is often the case that only a few or none of the child's daily communication partners master his or her alternative communication device better than the child (Renner, 2003).

In addition to adult support, regardless of perspective (e.g., Bruner, 1983; Piaget, 1962; Vygotsky, 1962) child development theories indicate that children's interactions with their peers provide means and context for developing cognitive and communicative abilities. Peer interactions offer a forum to test developing competencies without all of the scaffolding support of adults. Unlike speaking children, children who use aided communication interact more frequently with adults than with their peers but rarely interact with peers in any of the contexts (Romski & Sevcik, 1996) and have few opportunities to "practice" language.

**Social and Communicative Participation**

Participation is closely connected with social context (i.e., participation with whom and in what?) (King, 2013). Communication provides the power to participate with others, to have an influence on social environment (Beukelman & Mirenda, 2005; Light,

1989) and it provides a means to attain personal and social goals (Lund & Light, 2007). Children typically communicate within child-directed activities (Wagner, 1985).

Rehabilitation science has been positively influenced by the ICF framework and WHO's definition of participation as involvement in life situations (WHO 2001; 2007). This approach considers barriers and enablers of participation, entry into life situations, and places emphasis on independent functioning (King et al., 2013). However, people with disabilities have indicated that participation is also about choice and control, access and opportunity, meaningful engagement, social connection, inclusion and membership, having an impact, and supporting others (e.g., Hammel et al., 2008). Thus, the subjective and experiential aspects of participation are important (Almqvist & Granlund, 2005; Almqvist, Uys, & Sandberg, 2007; King, 2013; Shernoff, & Vandell, 2007) and should elucidate the meaning derived from interacting with others (Nelson, 2007), and there is a need for self-reports of experience (King et al., 2013).

Research on positive child development highlights the importance of participation in typical childhood activities and according to children's interests (Eccles & Wigfield, 2002). All children have a need for participation in activities and places that provide an appropriate level of challenge, social engagement, belonging, and a balance between adult supervision and autonomy (Connell, Gambone & Smith, 2000; Petrenchik & King, 2011). On-going participation in developmentally supportive situations, where children (a) have supportive relationships with adults and peers, (b) have meaningful opportunities for involvement, and (c) participate actively in challenging and engaging activities, is crucial to children's long-term health and development (Petrenchik & King, 2011).

Recent literature on child participation describes characteristics of supportive positive environments. These include opportunities for making choices, having fun, feeling successful, doing things independently, and being with others (Heah, Case, McGuire, & Law, 2007; Lawlor, 2003). Research evidence also indicates that participation, especially with peers, has secondary impacts related to engaging in life in a meaningful way and forming and strengthening social networks and friendships (Blackstone & Hunt-Berg, 2003; Law 2002; Imms, 2008; Law, et al., 2006) as well as promoting mental health (Petrenchik, King & Batorowicz, 2011).

Despite the widespread assumption that certain environmental characteristics have specific effects on participation experiences, the supportive evidence is very limited, due to challenges in conceptualizing and measuring environment and participation (Noreau & Boschen, 2010; Whiteneck & Dijkers, 2009; Mallinson & Hammel, 2010).

### *Social and Communicative Participation of Children Who Use AAC*

The emerging evidence concerning children who have little or no functional speech suggests that they (a) have suboptimal participation experiences and opportunities; (b) need support to participate; and (c) have communication participation experiences and opportunities that differ in important ways from the experiences of naturally-speaking peers (Bailey et al., 2006; Clarke et al., 2011; Raghavendra et al., 2011).

Communication underlies all aspects of life, however, children who use AAC may have limited access to their aided systems in their different everyday settings and consequently may need to rely on unaided means (e.g., gestures, vocalizations, pointing

to objects with eyes) for major portions of their time. Reasons may include limited vocabulary, a fast pace of interaction, working on too many "goals" during the day, or adults' perceptions of when children need to communicate during activities (von Tetzchner & Martinsen, 1996). In some settings, others may anticipate children's needs and wants and may place lower expectations socially and academically (Smith, 2005) or place expectations that the child will just relax (Calculator, 1997) rather than engage in activity with peers. Furthermore, parents or other caregivers, including siblings, often assume a role of primary intervention agent or teacher (Smith, 2003). This may change the expectation of the communication partner from emphasizing the effective use of language for communication purposes to the "correct" use of language and may subsequently lead to ignoring legitimate social communication attempts (von Tetzchner & Martinsen, 2000).

Research consistently reports that children who use AAC spend more time on daily routines than their peers and consequently have less time than their peers for play and social activities (Light & Kelford-Smith, 1993; von Tetzchner & Martinsen, 1996). On the other hand, parents who have a child with disability face extra caring demands and consequently have less time left for play or other typical parent-child activities. During play activities, parents of children using AAC have been found to have few expectations for their children to communicate and focused instead on just enjoying being together with their children (Light, Binger & Kelford-Smith, 1994). However, higher parental expectations have been linked to better language outcomes (Williams, Krezman & McNaughton, 2008).

In general, the AAC research has focused mainly on school settings with little attention to community settings and very few studies have reported on the participation of children using AAC outside of school (e.g., Batorowicz, McDougall, & Shepherd, 2006; Bloomberg, 2004; Shepherd & McDougall, 2008). Knowledge comes from a few studies that measured broad indicators of participation, such as frequency and diversity (i.e., number of activities done) (Raghavendra et al., 2011; Thirumanickam et al., 2011). We need to hear voices of children and their parents as participation happens in the family context and is strongly influenced by the family members (Clarke et al., 2011).

**Communicative Interaction of Children Who Use AAC**

A significant body of literature describes interaction patterns between children using AAC and partners who use natural speech. Research has demonstrated that speaking parents and teachers dominate interactions in play situations, story reading, and classroom activities, take a leading role in conversation, provide more contributions, and use a greater number of communicative functions than the children using communication aids (e.g., Pennington & McConachie, 1999; von Tetzchner & Martinsen, 1996). Parents and/or professionals are reported to control the face-to-face interaction by directing conversational topic, (Hjelmquist & Sandberg, 1996; von Tetzchner & Martinsen, 1996), taking more turns, initiating interaction, and asking more questions (e.g., Light et al., 1985; Pennington & McConachie, 1999; von Tetzchner & Martinsen, 1996). Adults also tend to interrupt, fail to acknowledge communication attempts, and focus on the technology rather than on the child (Kent-Walsh & McNaughton, 2005).

Children's peer interactions reflect asymmetries observed in adult-child interaction with naturally speaking peers initiating interaction and children using AAC responding by confirmation or denial, using communication aids infrequently (Clarke & Kirton, 2003). Peer interaction with partners without disabilities is the more challenging the younger the children are. At an early age (e.g., three and four years), children do not seem to have developed the skills required to deal with graphic symbols even though they master the corresponding spoken language structures (Sutton et al., 2010). Thus even if children with little or no functional speech became aided communicators early, their interaction with their peers will depend on adults as interpreters for a long time.

Communication messages are often co-constructed during a sequence of turns, where speaking partners ask yes no questions and work with aided speakers, and their roles are intertwined (e.g., Smith, 2003; von Tetzchner & Martinsen, 1996). Because communication partners rely on asking yes/no questions during interactions with children and provide support in co-construction of messages (e.g., Light et al., 1985; 1994), children have limited experiences to independently produce messages and communicate more autonomous ideas. Partners define the children's semantic-syntactic expressions by the questions they ask. Sutton & Dench (1998) found that significant syntactic learning occurred by receptive experiences alone. Some children tend to ask questions, however such a communication strategy, although it seems to give control over situation, becomes a constrained pattern, leaves the responsibility to others and children have typically little contribution to content (Smith & Grove, 2003). In summary, these patterns of interaction

and experiences are crucial to future communication attempts and may also affect how children are perceived by others.

### *Goal-oriented Communicative Interactions*

Despite physical challenges, many children who rely on augmentative and alternative communication can develop literacy and language skills, having control and autonomy over their lives (e.g., by directing others; see Collier & Self., 2010) and being contributing members of society. Precision in communication is needed to operate in the world. Children must develop lexical knowledge, semantic-syntactic proficiency, and pragmatic competence with AAC systems (Light, 2003); and need to learn how to represent and convey deeper meaning and become autonomous communicators. Engaging in genuine communicative interactions when they are required to use language within typical childhood activities with others, rather than only responding to questions or asking questions, may be a beneficial approach to intervention. However, very little is known about providing control to children with motor and communication impairments within the context of childhood typical activities. One such activity is construction play, where children build or construct something together (Pellegrini, 2009). Specifically, goal-oriented play interactions are of interest, because (a) there are widely recognized developmental benefits of play activities; (b) we lack knowledge on how children who use AAC can autonomously take part in play activities; and (c) goal-oriented interactions in two studies where adults used AAC have been shown to break the partner dominance and ensure more equal contribution of communication partners.

**The Research Problem**

Little is known about the social context, participation and goal-oriented communicative interactions of school-aged children who have severe motor and communication impairments and use communication aids. This knowledge is crucial to guide rehabilitation intervention, given: (a) the importance of children's social context in child development; (b) the importance of active participation in typical childhood activities as pathways to development, and (c) the 'passivity issues' of children who have severe motor and communication impairments and use aided language. A better understanding of the social context and ways in which children who use AAC may actively engage with others could help us to design interventions that will support children's development.

The overarching question of this dissertation is: How can we give 'voice' to these children so they can actively participate in typical childhood activity settings? Specifically, what is the social context of these children, and can children actively engage with others? As such, this research corresponds to the three research principles identified in the AAC field, specifically, active participation of individuals in activities, communication partners and their role, and societal opportunities (Blackstone et al., 2007). Because our knowledge and research are limited in the area of social participation of children with motor and communication impairments, descriptive studies are needed to help us identify and further study specific issues.

**Objectives**

- To describe children's and parents' views on the social context, participation experiences and meaning of the communicative interactions and social relationships of children using aided communication.
- To describe the success, challenges and strategies used by children who use aided communication as they communicate with different partners, when they are given the opportunity to lead a goal-oriented interaction within typical play activity.
- To develop an interdisciplinary understanding of social environments and social contexts and to propose a conceptual model that identifies the structure and processes of child-environment transaction to help researchers and clinicians evaluate specific aspects of children's social context and design optimal environmental interventions.

**Overview of Thesis Manuscripts**

Chapter Two presents the results of a qualitative study exploring children's and parents' views on the social context, social participation, communicative interaction and relationships of children who use communication aids. Chapter Three focuses specifically on goal-oriented communicative interactions and presents the results of a study exploring how children who use communication aids provide instructions and solve tasks with different communication partners, within a structured play situation, when they are given an opportunity to be actively involved. Chapter Four proposes a conceptual framework for understanding the social environment, social context and child-environment transaction in relation to interdisciplinary practice in rehabilitation science. Finally,

Chapter Five discusses the findings of this dissertation in the context of other current rehabilitation literature, highlights implications for theory, research and practice.

The first manuscript has already been published in a peer-reviewed journal; the other two are under review and they are presented in this thesis in the submitted format, according to the requirements of a respective journal.

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## Chapter Two

### Title of Paper (Published Article): Social Participation of School-aged Children Who Use Communication Aids: The Views of Children and Parents

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**RESEARCH ARTICLE**

# Social Participation of School-aged Children Who Use Communication Aids: The Views of Children and Parents

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**Abstract**

Social participation is crucial for children's development and well-being; however, little is known about the social participation of children who use communication aids. This article presents findings from interviews with eight 5- to 14-year-old children who used communication aids and their parents about social participation, communicative interactions, and peer relationships. Video- and audio-recordings were transcribed and analyzed using thematic content analysis, and five themes were identified. Two themes reflect parents' views: Communication partners and strategies and Access to aided communication. Three themes reflect perceptions expressed both by children and parents: Participation in society, Interaction opportunities, and Social relationships. The findings provide insights into both the achievements and the challenges experienced by young people who use aided communication.

**Keywords:** *Aided communication; Participation; Children; Interview; Augmentative and alternative communication; Complex communication needs*

## Introduction

The social environments in which children live, learn, and play, contribute to shaping their development (e.g., Bronfenbrenner, 2005; Sameroff, 2010). While there is much literature on the importance of the social environment in the development of children without disabilities, less is known about the social context and social participation of children who use aided communication. Studies of children who use communication aids and other forms of augmentative and alternative communication (AAC) have indicated that the children have small social networks, consisting mainly of their family and professionals (Blackstone, Williams, & Wilkins, 2007); have limited interactions with peers (Clarke & Kirton, 2003; Bailey, Parette, Stoner, Angell, & Carrol, 2006); and limited locations for activity engagement (Raghavendra, Virgo, Olsson, Connell, & Lane, 2011; Thirumanickam, Raghavendra, & Olsson, 2011). Many studies have suggested a passive communicative role of young people who use aided communication (Basil, 1992; Fey, 1986; Finke & Quinn, 2012; Harris, 1982; Kraat, 1985; Salminen, 2001; von Tetzchner & Martinsen, 1996), with communication partners dominating the interactions (Kent-Walsh & McNaughton, 2005; Light, Collier, & Parnes, 1985; von Tetzchner & Martinsen, 1996, 2000) and a slow pace of aided communication (Smith, 1996; Smith & Grove, 2003; von Tetzchner & Martinsen, 2000).

Social participation and interactions with others are crucial for children's and adolescents' development and well-being (Imms, 2008; Law, Petrenchik, Ziviani, & King, 2006; Nelson, 2007; Petrenchik, King, & Batorowicz, 2011), and have been identified as important areas of functioning in the International Classification of Functioning, Disability and Health (World Health Organization, 2007). Children spend a lot of their time talking in the context of play and other child-directed activities (Wagner, 1985) and in late childhood and early adolescence conversations replace play as the main activity outside of school and

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home (von Tetzchner, 2012). As children mature, their social interactions change, as well as communicative demands and expectations (Smith, 2005).

Social participation is a prerequisite for developing relationships with peers, and interactions with peers are important to forming long-term social bonds and connections. As children grow older, they usually spend more time with peers, outside the parents' surveillance (Ellis, Rogoff, & Cromer, 1981; Sroufe, Egeland, & Carlson, 1999). Children's peer and friendship experiences have been found to influence their academic achievements and to have long-term developmental psychosocial benefits (Dunn, 2004; Petrenchik & King, 2011).

Unfortunately, research on the social participation of children who use aided communication indicates that they have difficulties establishing meaningful relationships with peers at school (Raghavendra, Olsson, Sampson, McInerney, & Connell, 2012). The social participation of young people who use aided communication outside of school settings has received only limited research attention (e.g., Batorowicz, McDougall, & Shepherd, 2006; Shepherd & McDougall, 2008). Emerging evidence on activity participation of children who use communication aids suggests that they participate in activities close to home and mostly with family, while their peers without disabilities engage in activities with peers/friends and in and beyond their communities (Clarke et al., 2011; 2012; Raghavendra et al., 2011; Thirumanickam et al., 2011). Furthermore, there seems to be no association between degree of communication impairment and restriction in social participation (Hammal, Jarvis, & Colver, 2004; Clarke et al., 2011). However, in these studies researchers evaluated some aspects of social participation of children who use communication aids by measuring broad indicators of the level of participation, mostly diversity (number of activities done), intensity (frequency) and context (with whom, where, and enjoyment) (i.e., using the Children's Assessment of Participation and Enjoyment; King et al., 2004). More specific information is needed about children's social participation experiences and the nature and meaning of their communicative interactions and social relationships. While a few studies have addressed some aspects of children's participation at school and their friendships from the perspective of professionals, classmates (Anderson, Balandin, & Clendon, 2011) and parents (Bailey et al., 2006), the young people who use communication aids are rarely asked for their opinions. It is important to hear directly from these children and their parents because the social participation of children is strongly influenced by family members (Clarke et al., 2011). Knowledge about child and parent views could be useful for planning adaptations of social environments to ensure that the best opportunities and supports are offered, so that children who use aided communication will be able to take part in the variety of activities and events that constitute children's and adolescents' lives and contribute to identity development.

The purpose of this study was to examine the views of children who use aided communication and their parents, on social participation, communicative interactions, and relationships. This article reports findings from interviews with eight children and their parents in Canada.

## Method

The present study is part of an international project involving 16 countries and addressing the developmental achievements and challenges of young people who use aided communication (von Tetzchner et al., 2010, 2012, 2013). In this smaller study, a qualitative descriptive approach was used to gain insight into the social experiences of children. Ethical approval was obtained from university and hospital Research Ethics Boards in Canada, which are not named to protect the confidentiality of participants: The pool of candidates fitting the research criteria is relatively small, increasing the likelihood of identification. Approval was also granted by the respective research committees of the three rehabilitation centres from which the children were recruited.

### *Participants*

With assistance from three rehabilitation centres, 10 children were identified initially who met the following search criteria: (a) were between ages 5 and 15 and attended school, (b) had used communication aids for a minimum of 1 year, (c) had normal hearing and vision (with corrective technology), (d) did not show evidence of cognitive delay according to the child's AAC therapist (speech and language therapist/SLP and occupational therapist), (e) did not have a diagnosis of autism spectrum disorder, (f) had speech comprehension presumed to be adequate for their age, with speech production either missing or very difficult to understand (according to the child's SLP), (g) communicated better with a communication aid than with speech and/or manual signs alone (according to the AAC therapist), and (h) used aided communication as the main form of communication. The children were confirmed by their AAC therapists as meeting these criteria and, therefore, could be described as a group of people who demonstrated a large gap between comprehension and production of spoken language (von Tetzchner & Martinsen, 2000), and who made expressive use of communication aids. Because all of the children were under age 16, a parent of each child gave consent for participation, and all of the children were asked to assent. Information about the study and the process of assenting to participate in the study was supported by the use of aided language (as described by Teachman & McMain-Klein, 2012), which has been shown to be useful in obtaining assent from children who do not use speech for communication (Rabiee, Sloper, & Beresford, 2005). Ten children were recruited; however, one withdrew from the study due to illness, and information from one other child

 

was incomplete (use of the child's partial data was not appropriate). Therefore, the final sample consisted of eight children.

Table I summarizes the characteristics of the sample, which included six girls and two boys who ranged in age from 5;7 (years/months) to 14;1 ($M = 10;9$; $SD = 3;5$). All of the children were Canadian-born. Their physical mobility was assessed with the Gross Motor Functional Classification System (Palisano et al., 1997). Most were in Level IV and V, which indicates that they used devices such as a wheelchair for mobility. All of the children used a graphic communication system on a speech-generating device (SGD). To operate the SGD, four of the children used scanning, and four pointed to a touch screen. Five of the children were attending special classes and three were attending mainstream classes.

Two fathers and six mothers participated in the interviews. Five of the parents were born in Canada, one was born in Europe, and two were born in Asia. Their educational levels ranged from completion of high school to a post-graduate level.

Individualized information is not provided in order to protect the confidentiality of the participants. Quotes have been identified as being from a child (C) or a parent (P) with participants numbered from 1 through 8. The age of the child is identified as either 10 years of age or younger (Y) or older than 10 years of age (O). For example, C3Y indicates that the comment came from child number 3, who is younger than 10 years old, and P7O indicates the comment came from the parent of child number 7 (who is older than 10 years of age). In addition, *he* has been replaced by *she* in citations to protect confidentiality of the two boys.

Table I. Participant Characteristics ($n = 8$).

| Characteristic | *n* (%) |
|---|---|
| Age | |
| 5;7–10;0 | 4 (50%) |
| 10;1–14;1 years | 4 (50%) |
| Sex | |
| Female | 6 (75%) |
| Male | 2 (25%) |
| Diagnosis | |
| Cerebral palsy | 7 (87.5%) |
| Not specified | 1 (12.5%) |
| GMFCS level | |
| I | 1 (12.5%) |
| IV | 4 (50%) |
| V | 3 (37.5%) |
| Graphic system | |
| Picture communication symbols | 6 (75%) |
| Minspeak | 2 (25%) |
| Traditional orthography | 4 (50%) |
| Communication aid | |
| Electronic with speech output | 8 (100%) |
| Communication access method | |
| Direct | 4 (50%) |
| Scanning | 4 (50%) |
| School | |
| Segregated class | 5 (62.5%) |
| Inclusive school | 3 (37.5%) |

*Procedure*

Face-to-face individual interviews were conducted in quiet locations, with the children being interviewed separately from parents using semi-structured interview guides (Appendices A and B). The interview guides had been developed as a part of the larger project by an international group of researchers. The two authors who conducted the interviews had previous experience with interviewing and extensive experience working clinically with children who use various forms of augmentative and alternative communication (AAC) and their families. Each child interview lasted 1–2 hours across two sessions, and gathered information on children's views of their communication, communication partners, and friendship. All interviews with the children were videotaped with two cameras, one camera recording the entire scene and the other aimed at a child's communication system, to ensure that all communication modes (verbal and non-verbal) were captured.

Parent interviews ranged from 2–4 hours, over one or two separate appointments. The interviews included a combination of open-ended questions and probes about the children's social participation, communicative interactions, and social context. Follow-up questions were used when needed for clarification and for encouraging more in-depth descriptions or explanations. Interviews with the parents were audio-recorded digitally.

All 16 interviews were transcribed verbatim by a trained research assistant, who removed identifying information to ensure anonymity. The videotaped interviews with the children were transcribed for research purposes using the notational conventions for alternative means of communication (von Tetzchner & Basil, 2011).

*Data Analysis*

Thematic content analysis was selected because of its appropriateness for qualitative studies of an exploratory nature (Hsieh & Shannon, 2005). Specifically, an inductive process was utilized, an approach that has been identified as suitable when research in a given area is relatively limited (Braun & Clarke, 2006). The six stages of thematic analysis described by Braun and Clarke were followed by three of the authors (BB, FC, and CM), all of whom have a professional background in occupational therapy and speech-language pathology and previous experience with qualitative research. First, the researchers read and re-read the transcripts to become familiar with the interviews and obtain a sense of the data as a whole. The researchers then read the transcripts and independently generated initial codes to capture the key thoughts by highlighting exact words and making notes about initial impressions and analysis. After this independent review, the group met to share their thoughts, impressions, and reflections about the key messages. Individual biases and assumptions were documented and initial codes were reported and discussed. At that meeting, researchers began to link codes

into meaningful clusters that formed categories. During this process, key messages and illustrative passages were identified. Categories were developed collaboratively, based on the original codes and their clusters.

This discussion was summarized by the first author and circulated to the others for feedback and reflection. Following a review of the summary and another independent and iterative review of all transcripts, a second meeting took place, during which commonalities across interviews (supported by illustrative quotes) were further discussed. Key terms and categories and selected participant quotes were conceptually mapped into subthemes and overarching themes. A diagram was developed to organize findings and provide definitions for each category with exemplars. Finally, a summary of the themes, sub-themes, and illustrative passages was documented and circulated to obtain agreement as to the groupings and clusters and the naming of the themes. This iterative process was undertaken to ensure that the group members reached consensus.

Parents were given a written copy of the analyses and asked to discuss them with their children and to provide feedback about the themes. In particular, they were asked to identify what did and did not resonate with them, and whether anything important was missing. Six of the eight families responded to this participant-checking correspondence and all indicated overall agreement with the proposed themes. The use of three raters enhanced the trustworthiness of the analysis, and participant checking helped to establish credibility of the findings (Creswell, 2007). The researchers used ongoing reflexivity throughout the analytic process regarding (a) the importance of the themes to the research questions, and (b) coding data without trying to fit them into authors' preconceptions (Braun & Clarke, 2006). Two of the researchers involved in the analysis have extensive experience working clinically with children who use communication aids, although in different settings and in different professional roles. The third researcher's lack of clinical experience with these children provided an outsider's view, thereby reducing bias in the coding.

## Findings

Five major themes were identified to summarize the perspectives of children and/or parents on children's communicative participation and social context: (a) Communication partners and strategies, (b) Access to aided communication, (c) Participation in society, (d) Interaction opportunities, and (e) Social relationships. Table II lists the themes and corresponding subthemes. In general, children's responses were brief and parents provided more in-depth responses, frequently elaborating on issues stated by children. Issues related to the themes Communication partners and strategies and Access to aided communication were discussed only by parents, while both parents and children discussed the themes Participation in society, Interaction opportunities, and Social relationships. This may have been a reflection of differences in the interview questions (see Appendices A and B) and/or the children's and parents' perspectives. Each theme and subtheme is described in the sections that follow, and representative quotes are provided.

### *Theme A: Communication Partners and Strategies*

This theme captures parents' descriptions of their children's interactions with different communication partners, including their children's competencies, their efforts, and the strategies they used when interacting with others. Parents emphasized time usage as a key factor in their child's social experiences. Constructing an utterance with a communication aid often took time, especially through scanning. The extended length of the conversational turns made it necessary for the communication partner to have enough patience to wait and listen while a message was being communicated by the child. Parents emphasized the tremendous effort their

Table II. Themes and Subthemes.

| Theme | Subtheme |
|---|---|
| Communication partners and strategies (parents) | Familiar partners |
| | Impatient partners |
| | Effort and strategies |
| Access to aided communication (parents) | Different environments |
| | Device breakdowns |
| Participation in society (children and parents) | Family routines |
| | Conversational routines |
| | Conversational control |
| Interaction opportunities (children and parents) | Social opportunities |
| | Leisure opportunities |
| | Peer interactions |
| | Conversations with strangers |
| | Opportunities to meet persons who use aided communication |
| Social relationships (children and parents) | Friendships with peers |
| | Relationships with siblings |
| | Barriers to building relationships |
| | Interactions with others |

child showed in communication with others, and how challenging the conversations could be, especially with impatient communication partners. They described the aided language competence of adults and children in the school as generally limited, except for the classroom educators and the AAC therapist.

*Familiar Partners.* Parents reported that their children seemed to adapt their communication to the partner. They often used shortcuts while communicating with familiar partners and expected them to understand what these meant. Sometimes the message was short, leaving a lot of interpretation work to the communication partner. "A lot of the times, she'll put in a couple of words and she'll look at me like, 'OK, read my mind now'" (P8Y). However, even these experienced communication partners sometimes had difficulties decoding the message or guessing what the child wanted to say. "She mentioned something, but she used an abbreviation, took us an hour to figure it out" (P1O).

Children, especially those who were older, did not use as much abbreviated language with communication partners outside the family, who could not be expected to have the knowledge they needed to decipher these utterances. "If it's around family, she'll cut it as short as she can 'cause she knows that we'll ask. Whereas if it's somebody else, she knows that she'll have to explain herself a little bit more" (P3O). Parents also indicated that, despite experiences with communication failures, the children did not have good repair strategies and that it was the communication partners who had to figure out where the communication had broken down. When misunderstandings occurred, conversations could take a long time.

*Impatient Partners.* Parents of younger and older children described some partners as "The ones, you know, they're in too much of a hurry" (P4Y); that is, they did not give the child a chance to express thoughts or ideas beyond small talk:

> Again, they would understand her if they would give her a chance. But they're in a hurry or if they're leaving, or whatever. No, they'll be just people that just don't have the time to, you know, because it will take a good five minutes for her to say something back and forth, right. . . People are in a hurry all the time. (P1O)

In these situations the child would try to communicate as fast as possible. "Like I said, she'll try and get it out the quickest way possible because she realizes people lose interest quite quickly" (P7Y). When people were not patient enough to wait for the child to produce the message, he or she would not participate fully in the communicative exchange and might become upset. As one parent noted:

> Sometimes I can see she does want to communicate, but the computer itself is slow ... people might not have the patience to sit there, and it takes her a while, she might not be finished communicating with them and the person's already left, so ... sometimes she'll get upset because she's saying, 'I'm not finished and I wasn't done.' (P2O)

*Effort and Strategies.* When asked about aided language competence, parents of both younger and older children described their child as a skilled communicator and identified communication as their child's strength. "She's – yes, she's a whiz at this. She amazes me" (P3O). "I would say with her skills [referring to child's strengths], it is her communication, regardless of... she is very communicative, she expresses herself and she's very social" (P8Y). They also noted how use of a communication aid influenced the child's communication and social experiences. "They just. . . they think that she's not intelligent, but obviously she is, and the technology is helping her to find a way to express that" (P2O).

Parents reported how their younger and older children tried to adjust communication to decrease the effort needed and invented strategies to communicate in the most efficient way. "She will come up with something and she helps me to understand her" (P6Y). Parents described their child's multiple modes of communicating: symbols, written words, and gestures; shortcuts and abbreviations; and pointing at objects or moving to a physical location. "So she'll use her foot to point at something, like at the calendar because she wants to know what's on the thirteenth" (P3O). "If there's something in the fridge that she wants, she'll drive her chair up to the fridge. Or if she wants to go somewhere she'll stop her chair there, so you know that" (P4Y).

Parents also described a trade-off between the children producing fast messages and getting things said. Older children especially would sometimes abandon interactions and change topics, but they persevered if something was truly important to them:

It'll be an hour before we figure out the one word – and she's patient enough that she'll do it. But if you get off topic a bit, she pulls you back in. Like, because she needs to get that point across (P1O).

When discussing communication partners, even parents of younger children recognized their child's ability to distinguish between people who were willing to have an interaction with them and those who were just passing by.

> There's two kinds of people out there outside of the core family and school. There's the people who make an effort and get it, and there's the people who think it's all a little bit strange and don't know how to deal. So the former group make a real effort. You know, they'll bend over, get down to her eye level 'cause she's sitting in her wheelchair and ask her how she's doing and ... And she will actually interact with them. But the other people, you know, kinda walk up 'Hi (Child), how are you?'. . . and she just sits there 'Cause I know you're not really interested in me.'(P7Y)

When asked about the future, parents perceived that both the level of impairment and the amount of time required to use the communication device were central to the children's communication: "It depends on her speed probably, using her system. I hope that she'll be able to use both hands and that would make her much faster" (P8Y).

> I wish I could talk to Bill Gates and say 'Hey, come on, come up with a program' maybe something directly linked to the brain too, like the thought processing, when you think how advanced the technology is now, if they can have something linked to the brain to move limbs already, well why can't they do that with the speech. (P5O)

*Theme B: Access to Aided Communication*

This theme reflects parents' views and concerns about children's access to communication aids in different environments, as well as issues related to breakdown of communication devices. The social participation of young people who use aided communication seemed to be influenced by the frequent lack of communicative access. Parents described many situations throughout a day when the electronic communication aid was not available, and the device could not easily be substituted with a communication board or book.

*Different Environments.* Parents of younger and older children mentioned various settings in which the electronic communication device was difficult or impossible to use. They talked about issues encountered by their children when they spent time in outdoor settings, for example, when camping:

> We went camping and she brought her computer because she needed it obviously, but it was difficult to figure out how to keep it charged when there were no outlets. So, it was difficult because the battery had died and we could only use sign language ... it just took forever. (P2O)

Parents also described difficulties in using speech output in public places and noisy situations:

> We do take it to church with us, and ... sometimes when we're outside for a walk, but what I find is that when you're out in a ... like in a mall, or in a place like that ... other people around aren't used to that kind of a voice and they're turning around and looking at me... it takes everybody else by surprise. But it's also hard to hear because the ambient noise of wherever it is you are, you don't realize how quiet it is, and you really can't hear it. (P4Y)

When the children were sitting with others on a couch or on the floor, or were lying in bed, they were often unable to access their communication device and to participate in the conversation, and were limited to yes/no answers using gestures or vocalizations. As one parent commented, "She has no seating and mount in the basement so her sister guesses what she wants in the basement playroom" (P7Y). Parents also described the challenge of needing to place their child in a specialized seating system (so as to provide access to the AAC device) even when this was difficult to do:

> But there are times where she's not feeling well...and I have to put her in her chair at three o'clock in the morning and put her device on so she can tell me that she has a sore throat, or her stomach is not feeling well. (P1O)

Parents noted that a number of rules and regulations precluded the use of the devices in a range of environments. For example, one family would leave their child's communication aid behind on vacations, because insurance for the aid was often not valid outside of the country. Similarly, school-specific safety regulations sometimes forbade the child from using the communication aid in certain situations, such as outdoor recess. The result was that the child was present but without access to a communication aid. Travel to and from school in a car or school bus were other situations in which the child's communication device was removed from the wheelchair for safety reasons, which made chatting problematic or impossible.

> I may not talk to her as much. You know what I mean? Cause with her brother I can talk to him in the car. But with (Child) because she can't answer me in the car ... I don't ask her questions. (P3O)

*Device Breakdowns.* Parents of both younger and older children said that device breakdowns made reliance on a single piece of equipment frustrating for themselves and their children. They noted, for example, how communication aids often had to be sent away for repair, sometimes leaving the children without a voice for several weeks: "She feels lost without it, so ... if [it] needs to be fixed or sent away, it would be a major disappointment. It's really essential, it's part of her life" (P8Y).

> Imagine, telling a person 'Don't use your voice for two weeks'. It's really not fair, it's not right, so ... I think that something should be in place, whether that's, pushing the government to have sort of a backup system there. (P5O)

Some children had backup systems such as a communication board or book that they used with direct access or partner-assisted scanning; however, these non-electronic forms of communication took more time and placed more demands on the communication partners:

> So we went a week and a half without it [Gasp] it was not great, and it was not fun for (Child). And we had books but it just takes forever, and like, obviously books open to pages with different vocabulary but it takes so much longer to go through a book as opposed to the system ... it was very slow communication. (P2O)

*Theme C: Participation in Society*

This theme captures both children's and parents' descriptions of the child's daily activities outside of school, as well as typical conversation topics. Both child and parent interviews reflected that, regardless of age, children's lives were planned and structured by adults, were highly predictable, and were filled with family routines. The children were nearly always in locations and participating in activities supervised by adults; and activities in which younger and older children participated were scheduled and arranged by parents and professionals who also tended to talk with the children about their daily schedules and future plans.

*Family Routines.* When asked about their child's participation in activities, parents of both younger and older children described how daily life revolved around the family, and noted that the children seemed to spend most of their time with the family. "Most of the time, yeah, she's involved with us, the family. Where we go, she goes, kind of thing. And we're a busy, busy family. We're always gone out somewhere. Her brother is very involved, so she follows" (P1O). Children who used communication aids often attended their siblings' organized activities, but were spectators in these organized activities or entertained themselves in an informal activity set-up by their parents:

> (Child) goes to her sister's soccer games, but she sits in her wheelchair and watches. So everything, all of our activities are organized from the perspective of yeah, Mom and Dad organize it, like, we get a water table out in the back yard and let her dump water all over the place and play, but it's not like an organized team type [group activity]. (P7Y)

Both parents and children indicated that young people who used communication aids typically did not participate in activities with their peers.

*Conversational Routines.* Both younger and older children and their parents described conversational routines that featured predictable content that may have reflected the structured nature of their lives. When the interviewer (I) asked the children what they typically talked about, they often mentioned daily schedules and planning:

> *I:* Can you give me an example of what you typically talk about?
> C: *"The next day."*
> *I:* The next day. So you like to talk about the next day. What's going to happen the next day. So that's what you like to talk about?
> C: 'Yes' (nods). (C2O)

Adults contributed to communicative predictability by engaging the child in routine patterns of communication, often related to what the child had been doing or planned to do:

> It's always a series of questions that she can answer yes or no to, so that we can narrow down activities, or how much of your lunch did you eat, you know, did you eat your soup, did you eat your crackers, did you eat your celery, did you eat your carrots, did you eat your fruit? (P8Y)

*Conversational Control.* When children were asked if they could always communicate what they wanted to say, they emphasized the importance of their communication aid. *"I use this communication device to help me talk. I can't do it myself"* (C8Y), *"Well, if I don't have my communication device on, it is hard to understand me"* (C5O), *"It has been a miracle!"* (C5O), *"Awesome!"* (C2O), *"Awesome, but keeps freezing"* (C7Y).

Parents, especially of older children, noted that children sometimes asked questions to change the topic and course of the conversation:

> She's more of an interviewer than the person who tells. She's more of an 'ask the questions' instead of a story teller. I'll say, 'What did you do at school today?' and she's more, 'no, what are we doing tonight' or, 'What did you do?' She's more of a question person. (P1O)

This excerpt illustrates both planning and discussing activities as a core communication topic, and how the children sometimes used questions to break the predictability and dominance of the communication partner and to take more control over the conversation and turns in the dialogue.

*Theme D: Interaction Opportunities*

This theme reflects parents' and children's description of the child's social context, including social and leisure opportunities, peer interactions, conversations with strangers, and opportunities to meet persons who use aided communication. When asked to describe the social contexts of the children, the children and parents mentioned mostly people from home, school, and local shops. Both children's and parents' answers indicated that the children, regardless of age, had limited exposure to the social world outside of home and school, and limited contact with other people in general.

*Social Opportunities.* Younger and older children indicated that they liked to do, as many said, everything with everyone, and parents talked about their child being social and wanting to be with other children. The children were described as happy being a part of anything social that was available to them. "I'd say, you know, she likes to be part of the action, whatever the action is. So she likes to be involved, she likes taking part" (P8Y). Parents described a wide range of activities that were preferred by their children, and emphasized the importance of a strong social component. "[She] likes football games, hockey games, concert, movies, loves going to restaurants, things like that, like that social life, she loves that" (P3O). However, communication was specified as

a preferred activity by parents of both younger and older children. "There were times – before the [name of communication device], she would want to be on the floor playing or whatever, but she will bypass playtime so she can communicate because that's more important" (P2O).

When the opportunity to be social presented itself, there was no doubt about the child's preference for social participation. Parents reported that their child would nearly always choose being with others over solitary play:

> Like I ... yesterday after school, again, my husband was happy to, you know, take her straight downstairs and have her watch TV, but she clearly wanted to talk to me. I was washing dishes and getting dinner ready and stuff when she got home, she didn't want to be downstairs. (P4Y)

*Leisure Opportunities.* Outside of school, children who use communication aids participated either in solitary activities at home, or group activities such as yoga and swimming; it is interesting to note such activities may have limited opportunities for creative interactions with peers. When children were asked what they did after school, they indicated: *"Mall"* (C1O), *"I sometimes visit family"* (C2O), *"Games on my computer"* (C3O); *"Watch too much, watch too much TV"* (C4Y), *"Read books"* (C5O), *"Watch the movies"* (C6Y), *"Play with mom"* (C7Y), *"Shopping"* (C8Y). In fact, hanging out at home in the kitchen seemed to be the most common leisure-time activity, especially for younger children, and this usually involved only the family members or adults. "If we go to a friend's house … (Child) will stay with us in the kitchen, (be)cause if she goes with the other kids she gets left out" (P7Y). The children who use aided communication usually attended specific seasonal leisure activities that were available within the local communities and neighborhoods. This sometimes led to limited opportunities for interaction when a sports season ended. As one parent commented (describing the lack of activities) "Other than baseball? Right now, no. That would be the baseball, the summer camp – then, just our family" (P1O).

Parents pointed out the importance of varied social experiences for children in general, and the need for a broader range of social opportunities for their children, especially after school and during leisure time was a recurrent theme. "I think just being a part of society, like not sheltering her and keeping her at home (...). I think that the more that they experience, even if she can't talk, the more that they understand" (P3O).

The rehabilitation center and other support services were noted as important elements in the lives of children, and the parents expressed their own dependence on these services. "We've moved. Now we're dealing with (Child's rehabilitation centre). I don't know, we're just trying to wait and see what programming is going to come in place from them. We're still waiting on leisure" (P2O). However, they also mentioned the important role that they play as parents in providing social opportunities for children: "So ... that is our responsibility to let them enjoy and mix them together with the other people" (P8Y).

*Peer Interaction.* Parents of younger and older children mentioned that their children spent most of their time with adults and were rarely left alone to interact with peers. "The other kids move on so we keep her with us so she is not alone" (P3O).

> When we have a birthday party or something she is quite happy to be on her own with some adults 'cause all our friends love her, somebody's paying attention to (Child). But she has never been left alone to work with and socialize with her peers. (P7Y)

When children were asked about people they talk to, younger children mentioned adults: *"Aid at school"* (C6Y), *"Mom"* (C4Y, C8Y), *"Mom, dad, sister, nurse"* (C7Y), and older children noted their peers: *"Classmates"* (C1O), *"Friends from school"* (C2O), *"My friends"* (C3O), *"Mostly my friends"* (C5O). However, when older children were asked specifically about peers they talk to outside of school, they only mentioned siblings or adults: *"My brother"* (C1O), *"Social worker"* (C5O), *"Helper"* (C2O).

*Conversations with Strangers.* Children who use aided communication reported that they did not have many opportunities for interactions with unfamiliar people and said that they did not talk with strangers; when an interaction did occur, older children thought it felt "*weird*" (C2O; C5O) while younger children said they felt timid.

> *I:* Do you ever talk to strangers? The people you don't know?
> C: 'Yes' (nods).
> *I:* You do? How is it?
> C: *"Shy."*
> *I:* Shy; so you are a bit shy?
> C: 'Yes' (nods).
> *I:* Or they are shy?
> C: 'No' (shakes head) 'I' (points to self). (C8Y)

The parents also noted that their children rarely, if ever, were in situations where they needed to talk to unfamiliar people.

*Opportunities to Meet Persons who use Aided Communication.* Although some younger children saw peers at school who used communication aids, all of the children indicated that they did not often meet and interact with others who use communication aids. Parents said that the children showed interest and curiosity when they did notice others who used communication aids. "Like if she sees someone in the mall, or something. And of course she's interested and gets a big smile because there's someone just like

her (...)" (P1O). However, the adults did not always act on the child's interest by facilitating communication between him or her and the other person who used aided communication.

> And someone was leaving – a young girl was leaving with the same type of (device) … she was like, 'oh, look, someone like me.' And of course she's interested because there's someone just like her; and they don't necessarily communicate. No. It's just a passing kind of thing. (P1O)

*Theme E: Social Relationships*

This theme captures children's and parents' descriptions about children's friends and friendships and relationships with others, as well as parents' reflections on building relationships. When asked about their friends, the children listed their parents, classmates, educational assistants, teachers, and younger children – even researchers that they had recently met. All parents seemed to have limited knowledge about specific relationships that their children might have at school with peers, and they described their children as having little contact with peers outside of the school setting. The familiarity of other children and adults with children who use aided communication was noted as supporting successful interactions and building relationship; assistive technology, especially when it was viewed by others as intimidating, was identified as a barrier to social relationships.

*Friendships with Peers.* When children were asked what a friend is, the answers of older children reflected general qualities: *"Nice. Person nice to person"* (C1O), *"A friend is someone who likes you"* (C3O), or they mentioned communication as a quality of friendship: *"Someone you talk with easy"* (C2O). Younger children typically provided specific girls' or boys' names and they indicated that friends made them feel *"happy"* (C7Y; C8Y). When asked who they liked to communicate with, they all said *"friends"* and many provided names of classmates. When asked to describe their best friend, the younger and older children mentioned something that they had in common with the friend. *"She had the same homework"* (C8Y). *"Her name is (Name), in grade 7 we were locker neighbours"* (C2O). Friendship thus seemed to be tied to school activities. Only one older child who always walked to school with a peer, defined friendship more intimately. "*A friend is someone you can trust and hang out with and tell secrets to*" (C5O). When asked about her best friend she said: *"She is hilarious. She sticks up for me"* (C5O).

When the parents talked about their children's friends, they typically mentioned other children at school, rather than naming a best friend. "No. There's nobody, no ... there's nobody ... she doesn't know anybody outside [of school]" (P6Y). Parents had limited insights into specific relationships the child might have at school:

> I'm not sure, because I'm not there at school. And she – to tell you – she doesn't have a lot of friends that do come over to the home. (P2O)

> (...) at school, I'm not sure who she ... she doesn't really talk about them, like she'll say hi to them if he sees them and she tells me who they are, but I'm not sure who she interacts directly with there. (P1O)

The parents' knowledge did not seem to reflect conversations with their children about friends; they mostly knew about the peers and friends from conversations with the school staff. According to parents, the children did not see peers after school or in shared activities, and few peers visited children at home:

> No-one comes. We've invited them but nobody comes. For her birthday this year it did work, two kids actually came. But we asked last year at the end of the school year if any of her classmates would mind just popping over in the summer time, spending an hour with her, or going to the movies with her, and no-one volunteered, so ... [long pause] ... now she ... she likes to be by herself and work on her computer and look up information. She doesn't regard herself as disabled, so she'll ... she wants to try everything. (P3O)

The younger and older children's answers also reflected limited contact with their peers.

> *I:* Who do you mostly like to communicate with?
> C: *"Friends from school."*
> *I:* How many friends do you have there?
> C: *"Six."*
> *I:* Do they come to visit you at home?
> C: 'No' (shakes head)
> *I:* Do you visit them?
> C: 'No' (shakes head). (C2O)

*Relationships with Siblings.* Siblings often appeared to be the children's closest relationship and were mentioned as friends. Parents described brothers and sisters communicating well with each other, regardless of their age or age difference: "They seem very close, they can communicate about anything. Sometimes they have private little things that they're chatting about, and they do not want me to know 'Mom go away, we're playing, we're having fun'" (P8Y). "They can fight, they're just like regular siblings. They pick on each other constantly – they're just ... they're brother and sister. You wouldn't know that (Child) has a communication problem" (P3O). Parents reported that there seemed to be a special understanding between the siblings, like a communicative bond. "Her brother – the two of them, they complete each other's sentences, like they're that close" (P1O).

*Barriers to Building Relationships.* All parents described their children as social but were concerned about barriers that they perceived in social interaction and building

relationships. They talked about the wariness of other people, especially those who did not know the child and were unfamiliar with aided communication. The electronic device mounted in front of the wheelchair seemed to contribute to the perceived unease of unfamiliar partners:

> But she's a young woman in this wheelchair with this device in front of her. It's ... intimidating for people to approach her. Like they – because they don't know. And then once they start – she starts talking to them – like she'll ask people questions and things like that. And then they, 'Oh, there is a little brain in there and it is functioning ...' but a lot of times, people just – they don't understand, that she is able to communicate with you. (P1O)

*Interactions with Others.* Interviews with children and parents indicated that regardless of age, children's interactions with people who spent sufficient time with and had prior knowledge of how to communicate with them, were positive and successful. *"I swear my Mom can read my mind!"* (C5O). Outside of the family, it was mainly professionals who worked with the children who had such knowledge. The parents noted limited or nonexistent aided language competence in other people. "Yeah, probably people that don't understand (Child) are people that don't spend a lot of time with her" (P7Y).

Parents emphasized the significance of long-term shared activities for establishing conversational success. People who did not know the children often did not seem to understand their cognitive skills and receptive and expressive language abilities, and the children did not want to communicate with them.

> *I:* Do you ever communicate with strangers?
> C: *"A little."*
> *I:* Why is that?
> C: *"They treat me like I'm a baby. I absolutely hate it."*
> C: *"Well, I do not like people judging me, people who treat me differently because of my disability."*
> *I:* Are there many people like that?
> C: *"People who do not know me."* (C5O)

## Discussion

This study sought to gain insights into the social participation of young people who use communication aids. The findings illuminate key aspects of social and communicative participation of children such as (a) communication partners and strategies, (b) access to aided communication, (c) participation in society, (d) interaction opportunities, and (e) social relationships. A complex picture emerged from the interviews, implying both possibilities for and challenges of communication and interaction.

In many respects, parents and children described issues similar to those reported by other researchers, including: (a) limited locations for activity engagement outside of school and home (Raghavendra et al., 2011; Thirumanickam et al., 2011), (b) limited contact and interactions with peers (Bailey et al., 2006; Clarke & Kirton, 2003), (c) slow pace of communication (Smith, 2005; von Tetzchner & Martinsen, 2000), (d) communication partners dominating interactions (Kent-Walsh & McNaughton, 2005; von Tetzchner & Martinsen, 1996, 2000), (e) frequent technology breakdowns (Shepherd, Campbell, Renzoni, & Sloan, 2009), and (f) lack of close relationships with peers (Anderson et al., 2011; Raghavendra et al., 2012). However, this study provides a unique account of children's and parents' perceptions of these issues as they relate to children's social participation. Furthermore, the findings of this study illuminate important new details in relation to these broad areas, details that may assist in the planning and development of improved services for children and families. These details, many of which may be specific to the expressive group of children who use aided communication (i.e., children showing a large gap between comprehension and production of spoken language), include (a) the potential active role of children in interactions and specific strategies they use with different communication partners, (b) complexity of issues related to time involved in social interactions, (c) importance of the electronic communication aid to child and family, (d) time spent mostly under adults surveillance, regardless of age, (e) importance of specific social context and affordances perceived by families and children, and (f) lack of experiences leading to building meaningful relationships with peers, despite parents efforts and children's desires to be with peers.

### *Communication Partners and Strategies*

Parents reported that the children made some choices about how they engaged with potential communication partners, often apparently on the basis of the communication partner's efforts, body language, and apparent ability to be patient. The children used abbreviated messages with family members, but expanded their language with communication partners who did not have the communicative experience and competence of the family members, suggesting some strategic flexibility among especially the older children. Some past studies have classified children as active or passive communicators, suggesting that active communicators are initiators and regulators, and passive communicators are responders (Fey, 1986; Finke & Quinn, 2012). Findings in the present study suggest that being a passive or an active communicator may be partner specific or environment-specific rather than child-specific. Thus, whether a child is a passive or active communicator may not be a general characteristic of his or her communication or personality but rather a characteristic of the child's communicative relationship with each individual partner.

Parents expressed a desire for children to communicate more quickly. The issue of communication efficiency in aided communication is a recurrent topic. For example, von Tetzchner and colleagues (2012) found that the

average production time for naming drawings of simple objects was more than 40 times longer for children who used aided communication than communicators with natural speech. Improving the rate of communication has been a major goal for individuals using communication aids as well as for manufacturers designing such aids (Todman, Norman, Higginbotham, & File, 2008). Previously, researchers discussed many issues and strategies related to communication efficiency, including trade-offs children need to make between speed and precision, co-construction of messages with communication partners, using contextual knowledge about a child to expand messages and infer meaning, and parents asking questions that require only one word answers, particularly yes/no questions (Light, Binger, & Kelford-Smith, 1994; Light et al., 1985; Smith, 1996; Smith & Grove, 2003; Soto, 1999). However, parents in the present study said that the issue of time also had another meaning: the time that others are willing to take to engage in communicative interaction. Adults who use aided communication have also described the willingness of communication partners to invest time in a conversation as one of the most important issues related to communication and support from service providers (Smith & Murray, 2011). The present study provides further support for focusing on training potential communication partners and ensuring that partners allocate enough time when they interact with young people who use communication aids. Giving sufficient time to children to compose their own messages may be especially important to the development of children's communicative autonomy (Batorowicz, Stadskleiv, & von Tetzchner, 2013).

### *Access to Aided Communication*

Parents reported that children mainly accessed their communication devices while in their wheelchairs, and noted many situations when children were seated on the floor, in bed, or the couch and were unable to take part in communicative interactions. They also mentioned long periods without a communication aid due to technical breakdowns, repairs, and a lack of replacement devices, implying that the children were hindered from taking part in usual everyday conversations. Similar findings have been reported since the beginning of the 1980s, when the first computer-based communication aids appeared (Hjelmquist & Sandberg, 1996; McDonald et al., 2008; McNaughton et al., 2008). In a recent study, Shepherd and colleagues (2009) found that 40% of new communication devices with speech output required repairs within the first year.

In spite of limitations in use and equipment breakdown, it was the electronic aid that was considered the primary communication tool of the children. Parents were used to communicating with the electronic device and found the communication board slow and difficult to use. Some parents indicated that they asked questions that could be answered with a yes/no response when the aid was not available. Parents' reliance on asking yes/no questions during interactions with their children has been reported by many researchers (e.g., Light et al., 1985; Light et al., 1994), and using the communication board only as a last resort has also been previously noted (see von Tetzchner & Martinsen, 1996). In our study, children's and parents' strong reliance on the electronic communication aid may have reflected their wish for children to be more autonomous communicators (Angelo, 2000; Clarke et al., 2011) or a lack of competency in using other communication tools that involve co-construction of messages (Murphy, Markova, Collins, & Moodie, 1996).

### *Social Participation*

Both younger and older children spent most of their time in school and with family. Older children with typical development usually take part in out-of-school social activities with their peers (King, Law, Hurly, Petrenchik, & Schwellnus, 2010; Smith, 2005; von Tetzchner, 2012). The data in this study suggests that the home-bound experiences of children who use communication aids may be related to the particular social environments and supports within the home rather than the child's age. This is congruent with recent research findings (Clarke et al., 2012) and thinking about child development as nested within levels of social relationships (Bronfenbrenner, 2005).

This study suggests that children who use communication aids may take part in only a small number of activities that characterize the everyday life of most children in Canada. This corresponds with findings from other countries showing that young people who use communication aids tend to engage in fewer activities and have a lower activity level than their peers (Clarke et al., 2011; 2012; Raghavendra et al., 2011; 2012; Thirumanickam et al., 2011). Research has shown that older children who use communication aids more frequently selected passive recreational activities with adults (i.e., reading a book, watching TV), and were more likely to take part in activities involving adults, compared to children with other disabilities (King et al., 2014). Neither does it seem to be the case that older children who use communication aids decrease involvement in recreational activities and shift to different types of activities with age, which was typical for children without disabilities (Clarke et al., 2012). Similar to the current study, this suggests that young people who use communication aids and their families do not make use of the community programs that are used by the families of children without disabilities. Perhaps more supports are needed in relation to entry to the programs and support within activity settings (Batorowicz et al., 2006) so that children who use aided communication feel welcome and perceive programs as opportunities for meaningful engagement with peers.

The content of daily conversations outside of school seemed to be concrete and predictable, consisting mostly of small talk with conversations revolving around food and daily routines. For children with motor impairments,

routines are time-consuming and take up a lot of their day, and there may be few new personal experiences to talk about. The predictability in activities and communication illustrate the close relationship between participation in activities and topics addressed in conversations. An intervention focus on small talk and establishing social closeness (cf. Light, 1997) without true content may contribute to such interactions. Predictability implies a known context of interaction, which may have supported such conversations but may also have negative long-term consequences for language development because children may not have the opportunity to explore the unknown (Nelson, 2007). Moreover, if the conversation is predictable there are fewer breakdowns because most of the information is given and less is new (Prince, 1981). Although fewer communication breakdowns may appear positive, this may reduce learning and, in the long term, might also reduce the children's ability to engage in collaborative repair of the conversation.

*Interaction Opportunities*

Parents reported the importance of children having social experiences; however, their responses indicate lack of ongoing opportunities to engage with peers in typical childhood activities such as birthday parties. When King and colleagues (King et al., 2014) evaluated the opportunities offered and self-reported experiences of youth who used AAC, they found that youth took part in settings that afforded great opportunities for interaction with adults but that they experienced low levels of meaningful interactions. In addition, as previously reported (e.g., in Blackstone et al., 2007), children in the current study had limited opportunities to engage in interactions with unfamiliar people, and it was unusual for them to see others who communicate using AAC. This suggests that children may lack experiences with individuals who are competent AAC users, and do not have experience in seeing persons who might serve as models for participation in social contexts, which is important to development (Nelson, 2007; Renner, 2003).

*Social Relationships*

In the present study, across all ages, children's descriptions of friends included persons who interacted with them, even those from the past. This suggests that they may lack experiences with peers that provide a sense of loyalty and commitment and lead to closeness or intimacy, which typically characterize friendships of children and youth without disabilities (Doll, 1996). This is similar to the findings from other studies indicating that children who use AAC tend to rely on adults rather than peers for emotional support (Raghavendra et al., 2012) and that the friendships of children and adolescents who use communication aids lack depth (Anderson et al., 2011). Anderson and colleagues suggested that friendships between children using communication aids and children with natural speech may be more asymmetric than those between children with natural speech, because the former are more likely to include helping relationships. In the present study, the one child who participated in daily, typical peer-like interactions with a child with natural speech described friendship as more intimate. Thus, it may be that the particular experiences of young people who use communication aids may contribute to their understanding of friendships, and that providing more opportunities for positive interactions and experiences with peers may support building friendships.

Past research provides evidence that adult assistance may reduce the opportunity to explore and establish relationships with peers (Carter, Sisco, Brown, Brickha, & Al-Khabbaz, 2008; Madge & Fassam, 1982). Children without disabilities experience social closeness with peers without adult control (Dunn, 2004), which, over time, may lead to closer and more intimate peer relationships. When adults organize activities, children may develop relationships based on learned dependency and passivity (Tavares & Peixoto, 2003). Although it may be challenging for some children who use aided communication to communicate without adult support, it may be important to identify times when they can be with their peers without constant adult supervision, as this may help in the development of personal autonomy.

*Study Limitations*

Limitations in sample selection, size, and design suggest that general conclusions cannot be drawn about the social environments and participation of the children in this study. They and their parents were recruited from three communities and their experiences may reflect only their particular living situation. Furthermore, many children were in segregated classrooms that provided adult support; participation and communication may be different in inclusive schools. The voices of parents and children are reflected in the many subthemes reported in this article; however, it is possible that other researchers might have organized these subthemes differently, resulting in different overarching themes. Although we asked children who use aided communication about their experiences, they provided mostly brief answers. Future studies could employ different methods than face-to-face interviews in order to give children more time to respond and reflect. For example, communication via email, in addition to face-to-face interviews, was used successfully in a recent study by Gibson and colleagues (Gibson et al., 2013).

Future studies are needed to gain understanding of the social environments and nuances in the social participation of children who use aided communication, an understanding that is needed to support children in building friendships. Knowledge is required about how to provide opportunities and supports so that children can have a range of social experiences, especially outside of school.

## Conclusion

The children and parents who were interviewed for this study described both positive and negative experiences

related to communication and social participation. The findings provide evidence that children who use aided communication may have communicative abilities that are not always recognized by others outside the home, even when they show some strategic flexibility with different communication partners. The findings also highlight partner-specific issues related to time and familiarity and emphasize the importance of teachers and professionals allocating enough time when interacting with children who use aided communication. The study suggests a reliance of children and their parents on the electronic communication aid and describes some of the challenges that families and children encounter concerning communication access – issues which may be addressed through training and policy changes. In addition, the findings indicate that children who use aided communication may have structured social lives and limited opportunities to engage socially, especially with their peers, and that this lack of interaction may be reflected in the content of their communication. Furthermore, the children also lacked interaction and experiences with individuals who are competent AAC users; these more experienced individuals might provide models of social interaction that could be important to the children's development. This suggests a need for more services that support children's entry to a variety of after-school inclusive programs and promote meaningful engagement with peers in these programs. Finally, this study suggested that children who use communication aids may lack close relationships with peers that might have contributed to their understanding of friendships. These results contribute to an emerging body of research investigating social and communicative participation of children who use aided communication.



## Author Note

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## Appendix A

*Interview Guide for Children: Topics and Questions*

1. Communication partners and communicative interactions
- Who are your favourite communication partners?
- What do you mostly talk about?
- Do you ever communicate with strangers?
- How is it?
- Can you always communicate what you want to say?
- What do you communicate about?
- What is most difficult to communicate about?
- Do you like to communicate with many in a group or one-to-one?

2. Relationships with peers: Friendship
- Could you tell me what a friend is?
- Tell me about your best friend.
- What makes him/her your friend?
- What do you think about the society you live in? (asked only to older children)

## Appendix B

*Interview Guide for Parents*

1. Social participation
- What are your child's interests?
- What kind of activities does your child participate in mostly?
- With whom?
- Where?
- Is there any organized leisure time for your child outside school?

2. Communicative interaction: Using aided communication
- Can your child communicate what s/he wants to say to others?
- Does your child use the communication aid in different situations or activities?
- What do you communicate most about?
- What are your favourite conversation topics?
- How do you think your child will communicate when he/she is 25 years old?

3. The child's social and communicative context
- Who are your child's usual communication partners?
- Is there anybody your child only communicates with occasionally?
- Does your child meet adults who use communication aids?
- How would you characterize your child's communication with others?
- How is your child's ability to express himself/herself compared to his/her peers?
- Are there people that do not understand your child when s/he wants to communicate with them?
- How well does s/he solve communicative problems compared to others?
- How is the aided language competence of others?

## Chapter Three

## Title of Paper: Children who use Communication Aids Instructing Peer and Adult Partners During Play-Based Activity

Authors: Beata Batorowicz, Kristine Stadskleiv, Stephen von Tetzchner, Cheryl Missiuna
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## Abstract

Little is known about how children with severe motor impairments who use communication aids provide instructions when given control over interaction. In this study, 5–15 year-old children -- 18 who used communication aids and 17 who were natural speakers -- were videotaped in play-based activities. Both groups successfully instructed partners to build replications of models the partners could not see. The results demonstrate that children using communication aids can have an active role in play-based activities, using language, but also that their experience with activities is limited and their instructions take longer to give. The naturally speaking children provided more detailed instructions and were given less assistance. Creating opportunities for active participation in similar activities may be important for the development of communicative autonomy.

*Keywords:* Aided language; Children; Participation; Construction play; Referential communication

## Introduction

Children's daily experiences and social interactions, and the events they actively take part in, contribute to their social and cognitive development and constitute an important basis for understanding the world (Karpov, 2005; Nelson, 2007; Sameroff, 2013; Wells, 2009). Play is a meaningful and motivating childhood activity which may contribute to children's learning and development (Pellegrini, 2009; Piaget, 1962, Vygotsky, 1976). In play, children encounter and solve a variety of problems; they communicate, express themselves to others, clarify their thinking, learn to consider other people's perspectives, negotiate roles and plans, develop self-regulation, and may expand language and literacy skills (Frost, Wortham, & Reifel, 2005; Pellegrini, 2009). Although many theories of development emphasize the value of play and its significance for children's social, emotional and cognitive development (e.g., Nicolopoulou, 1993; Piaget, 1962; Vygotsky, 1976), it is not known how limited access to play may influence children who have severe motor impairments as they develop aided language, that is, language constructed with communication aids (von Tetzchner & Martinsen, 2000).

Construction play consists of activities where something is constructed, such as building with blocks, making clay figures or making a vehicle with Mechano (Johnson, Christie, & Wardle, 2005). During typical development, it appears in middle to late toddlerhood, increases with age and accounts for more than 50% of children's play activity in preschool settings (Frost et al., 2005). Construction play is assumed to contribute to understanding the rules that govern physical reality and spatial relations, and influence cognitive development (Piaget, 1962). Constructing three-dimensional patterns

may help children learn about spatial relationships, talk about the physical world, learn new vocabulary, solve physical problems, and may foster creativity, decision making, and task persistence (Cohen, 2006; Drew, Christie, Johnson, Meckley & Nell, 2008; Miyakawa, Kami & Nagahiro, 2005). Because construction play involves the manipulation of physical objects, children with limited hand movements encounter challenges. Moreover, it may not be possible for children with severe motor impairments to gain physical independence in object manipulation and play, even with the use of assistive technology.

Children with motor impairments who have little or no functional speech may use communication aids when they express themselves. Aided language development is the emergence of language produced with graphic symbols and letters and the help of communication boards or electronic devices, including devices with speech output. Compared to speech, aided vocabulary is more restricted and utterances usually take longer to construct (von Tetzchner et al., 2014). In spite of this, language is often the best skill of children with severe motor impairments and little or no speech and it is through language they are able to participate actively in play and other activities (Batorowicz, Campbell, von Tetzchner, & Missiuna, 2014; Batorowicz, Shepherd, & McDougall, 2006; Kent-Walsh & McNaughton, 2005; Smith, Murray, von Tetzchner, & Langan, 2010; von Tetzchner & Martinsen, 1996).

Using communication aids, children can, for example, instruct others to act for them in aided play (von Tetzchner, 1987). However, it is not known to what extent children and adolescents who use communication aids direct the actions of others. In general,

interactions involving individuals who use communication aids are described as being dominated by the naturally speaking partners (Kent-Walsh & McNaughton, 2005; von Tetzchner & Martinsen, 1996) and studies have found that the speaking partners tend to take the lead in the play (e.g., Light, Collier, & Parnes, 1985a, b; von Tetzchner & Martinsen, 1996). Children who use communication aids may be asked to choose between play actions decided by the partner or only to confirm what the partner proposes to do (Light et al., 1985a, b; von Tetzchner & Martinsen, 1996).

To take the lead and direct another person to perform actions that are not already known to the other implies the use of what often is termed referential communication, that is, making an act of reference by naming or describing objects, people, places or actions so that another person can identify them (Asher, 1979; Bruner, 1983; Krauss & Glucksberg, 1969). When delivering a message, an individual must determine what features are necessary to distinguish a referent from a non-referent, decide which of these should be made salient for the listener, and structure the message accordingly (Glucksberg, Krauss, & Higgins, 1975). Efficient communication includes the minimal number of features that are necessary to distinguish the referent from the non-referents (Lloyd & Beveridge, 1981). When describing something unknown to another person, the explanations of preschool children are often private, lacking details and even adults may have difficulty deciding what they are referring to. The descriptions of school-age children gradually become more specific and easier to understand (Krauss & Glucksberg, 1969).

Barrier games have been suggested to improve referential communication skills of children (Bunce, 1989). They typically involve two players sitting across from each other with a barrier between them and each player has duplicate objects. The directing player chooses how to set up the scene and tells the other player to follow (Clark, 1992). Barrier games and activities similar to referential communication experiments, where an individual has to describe an object or a drawing to a person who does not see the object or drawing, have been suggested as an intervention strategy for people who use communication aids (Kagan & Gailey, 1993), and a few studies have used this approach (Collins, 1996; Collins & Marková, 1999; Hagemoen et al., 2004; Smith, 2003). However, the studies describe only a few individual interactions, some of them involving adults who use communication aids (Collins, 1996; Collins & Markova, 1999) and there is limited knowledge of how children who use communication aids manage this kind of tasks. On the one hand, the children may be less competent than speaking children because they have less varied experience with using language and engaging in construction play activities. On the other hand, giving instructions is a way for them to participate in many activities and they may, therefore, be more experienced and skilled in instructing others to perform specific actions.

Despite the benefits that play is assumed to have on children's cognitive and social development, descriptions are lacking of how young children who use communication aids participate autonomously in play. Specifically, information is lacking about children's authentic instructions to others (i.e., self-made and unknown to a communication partner) and how efficient they are in using such instructions. The present

study investigates how children aged 5 to 15 years who have motor impairments and use communication aids manage to give instructions during structured constructive play activities to peers and adults when the content is not known to the partners. This study-specific questions are as follows:

(a) To what extent do children who use communication aids succeed in leading the goal-oriented interaction? How do the children perform? How do partners perform?

(b) Are there associations between children's success and their characteristics, partners' contributions or the time spent interacting?

(c) Do the children who use communication aids give instructions similarly or differently than typically developing children?

## Method

The data in the present study were collected as part of an international, multi-site, cross-cultural investigation: Becoming Aided Communicators (BAC) (von Tetzchner et al., 2014). The project involves children from 16 countries who use communication aids due to severe speech and movement disorders and addresses their language and communication competencies, achievements and challenges. This study reports on the performance of children in two of the countries -- Norway and Canada -- where the child instructed a partner to construct something not known to the partner.

### Design

The study is cross-sectional and its's purpose is: comparative description, exploring associations between variables of interests, and group comparison. The specific objectives of the study correspond to three research questions and are: (a) to describe the

performance of children with physical impairments who used communication aids and their typically developing peers on a series of construction tasks with different communication partners; (b) to examine the relationships between the success of children, their age, children's characteristics and partners' contributions, and time of interaction; and (c) to compare the success of children who use communication aids with peers without disabilities because we do not know how they would complete these tasks. Ethical approval was obtained from ethics boards and committees of the participating institutions.

**Participants**

The participants were recruited through convenience sampling through healthcare professionals in the specialized healthcare system and special education system who provide services to children with little or no functional speech in each country.

**Inclusion criteria.** The study inclusion criteria were that the children should: (a) be between ages 5 and 15 and attended school; (b) have used communication aids for a minimum of one year; (c) have normal hearing and vision (with corrective technology); (d) not be considered cognitively delayed by their therapist (speech and language therapist/SLP and/or occupational therapist/OT) or teacher; (e) not have a diagnosis in the autism spectrum; (f) have speech comprehension adequate for their age while speech production was absent or very difficult to understand; (g) have communication skills considered significantly better with a communication aid than with speech and/or manual signs alone; and (h) have aided communication as the main form of communication. Children were confirmed by their therapists or teachers as belonging to the expressive

language group (von Tetzchner & Martinsen, 2000) and meeting the study inclusion criteria. This information was also confirmed by the researchers with parents during the first visit.

**Assessment.** Motor functioning, visual perception, communication, language comprehension and non-verbal reasoning were assessed in the children who used communication aids. Assessments were conducted either by OTs and SLPs or by psychologists, reflecting differences in service delivery models in the two countries. Also, the use of different tests of non-verbal cognition (described below) reflects different practices. Parents provided information about children's educational setting, communication aids, and access mode (also confirmed during the first session with each child).

***Motor functioning.*** Gross motor functioning was measured by the Gross Motor Function Classification System (GMFCS), a five-level system for children with cerebral palsy with evidence of good content, construct, discriminant validity, and inter-rater reliability (Palisano et al., 1997). The children's performance in handling objects during daily activities was measured by the Manual Ability Classification System (MACS), a five-level classification for children with cerebral palsy, with acceptable reliability and validity (Eliasson et al., 2006).

***Communication functioning.*** A five-level Communication Function Classification System (CFCS) for children with cerebral palsy was used to classify the children's everyday communication on the bases of their performance as senders and receivers, and pace of communication with familiar and unfamiliar partners. The CFCS has adequate

content validity, test-retest reliability, and interrater reliability, but moderate parent-professional concordance (Heidecker et al., 2011).

***Speech intelligibility.*** The quality of the child's speech production was assessed with the Viking Speech Scale (VSS; Pennington et al., 2010), a four-level classification where level IV indicates that the child has no understandable speech.

***Language comprehension.*** Language comprehension was assessed using the Test for the Reception of Grammar, second edition (TROG-2; Bishop, 2009). In TROG-2, which is normed in both Canada and Norway, a phrase is spoken by the examiner and the child indicates one of four pictures that corresponds to the spoken phrase.

***Non-verbal reasoning.*** Non-verbal reasoning was assessed with the matrices subtest from the Kaufman Brief Intelligence Test (KBIT-2; Kaufman & Kaufman, 2004), in the Canadian children and with the Raven Matrices (Raven, 2008; Raven, Raven & Court, 2000) in the Norwegian children. Both KBIT-2 and the Raven Matrices assess non-verbal reasoning by asking the child to select the one item from a limited number that completes a visual pattern.

***Visual perception.*** Visual perception was assessed using the Motor-Free Visual Perception Test, third edition (MVPT-3; Colarusso & Hammill, 2003). The tasks in the MVPT-3 measure perception of visual closure, visual discrimination and figure-ground, but they are also assumed to reflect visual matching and short-term memory (Canivez, 2005).

The TROG-2, the KBIT-2, Raven's Matrices and MVPT-3 require minimal motor involvement for the child to complete the test. These tests were administered through

direct selection with hand or eye gaze, or partner-assisted scanning (i.e., the researcher pointed in a systematic manner to the reply options and asked the child to indicate choices with a yes or no (Schiørbeck & Stadskleiv, 2008).

The standardized scores from TROG-2, KBIT-2, Raven Color Matrices and MVPT-3 and percentiles from Raven Standard Matrices were transformed into z-scores. The z-scores were classified as being either within the normal range (within one standard deviation from the age mean), borderline (between one to two standard deviations below the age mean) or low (more than two standard deviations below the mean) (Table 1).

Insert Table 1 Approximately Here

**Children using communication aids.** The study involved 18 children who used communication aids (AC group). As shown in Table 2, 11 children (61%) had GMFCS Level V, 10 (56%) had MACS Level V, and all 18 children had VSS Level IV, indicating that the majority of children used a wheelchair for mobility, had severely limited ability to handle objects, and had no functional speech. Eleven children (61%) had CFSC Level II, which means that they alternated sender and receiver roles with familiar and unfamiliar people; however, with a slow pace of communication. Eight of 10 children from Norway attended fully integrated schools, one partially integrated and one special school, while in Canada, two children were in fully integrated schools, one in partially integrated and five in special classrooms/schools. There were no other notable difference between the countries as to children's characteristics.

**Children with typical development.** The study involved 17 children with typical development, matched on age and gender (the speaking naturally (SN) group). The

children ranged in age from 5;6 (years; months) to 15;10 (*M* = 10.11, *SD* = 2.10). There were 12 girls and 5 boys. Two girls in the AC group were 2 months apart in age and from the same school; therefore data from only one comparison child was collected. The children in the SN group were classmates of the children who used communication aids or attended the same school or a school in a neighborhood. They did not have any known developmental challenges or learning difficulties, as confirmed by their teachers and/or parents, hence, were presumed to be functioning within a normal range. To provide some control for this assumption, the comparison children completed the TROG-2 in Norway and the KBIT-2 in Canada.

**AC and SN Groups.** The children varied in their verbal comprehension, non-verbal reasoning, and visual perception skills. Table 1 shows the scores for both groups of children. The mean z- scores for verbal comprehension were not significantly different in the two groups. On the test of non-verbal reasoning the AC group (*M* = -1.68, *SD* = 1.03) obtained significantly lower scores than the SN group (*M* = 0.38, *SD* = 0.79, *t*(21) = -4.71, *p* = .000).

Insert Table 2 Approximately Here

**Communication partners.** Children interacted with three familiar communication partners; one of their parents, a professional and a peer who was a friend or sibling of their choice. The professionals who were communication partners of children using communication aids were teachers in Norway and SLPs in Canada.

In the AC group, communication partners included 13 mothers and 4 fathers, 10 special educators, 5 SLPs, and 1 OT, 12 friends and 4 siblings. The siblings participated

because children who attended special schools could not identify friends with whom they wanted to complete the tasks. In the SN group, all children identified friends from school or the neighborhood as peers for interaction; and the adult partners included 6 mothers and 1 father, and 12 teachers.

**Construction Tasks**

The tasks were developed by the BAC research group of 25 investigators to represent objects and construction play activities in which children around the world typically engage. Two training tasks on which the child received as much support as needed to understand what was expected were not included in the analysis. The remaining eight tasks fell into four categories: dressing a doll, making a bead necklace, building a tower with Blocks, and making a pattern of domino tiles. In total, these tasks included 29 objects and 67 attributes necessary to describe them, their size, shape, color, location, orientation, and sequence. Table 3 lists the tasks and their elements. Because each type of task consisted of two items, a learning effect was expected; the first item of the task was considered to be more demanding than the second. To ensure that type of task was not confounded with type of partner, there was a predetermined variation in the order in which the tasks were completed.

Insert Tables 3 & 4 Approximately Here

A coding system (Table 4) was developed based on a detailed analysis of the videos of four children, each interacting with three different partners (32 tasks out of 131, or 24%). The initial agreement between the two independent raters who watched the videos and scored tasks was 82% for one participant (i.e., 8 tasks, total of 29 items scored).

Following the initial scoring, a detailed guide was developed, where utterances, key variables and scores were entered. Subsequently, two independent raters scored the remaining interactions with close to 100% agreement and consulted in 3 cases with respect to the remaining children, when clarification was required; this was in relation to orientation and sequence errors, which were subsequently combined. The coding consists of five broad categories: (a) success (b) time usage, (c) misunderstandings, (d) child contributions, and (e) partner contributions (Table 4).

Success was measured in two ways: (a) percentage of precisely built models, and (b) number of errors in built models. Time was calculated in seconds, beginning right after the instructions had been read to the child and the partner and lasting until the child indicated that the task was finished. Misunderstandings were counted when the child or the partner did not act or respond as clearly indicated by the utterance. Child contributions were evaluated for each element within the task in relation to the quality of the utterance that the child used to instruct the partner. This involved naming of elements, objects and attributes, and the specificity of the child's message. Specificity was defined as the preciseness of the child's description and was judged on both the initial explanation that the child provided and all the information that was given by the child during the task. Partner contributions included style of interaction, amount and type of help provided to the child, and the elements chosen by the partner. The partner style was scored on the basis of level of attentiveness and whether it allowed the child to take the lead. Instances of help provided by a partner were counted for each element and an average was calculated for each task. Purely confirmatory statements such as, *OK, so I take a green*

*sweater,* were not counted as help. They were easily distinguished from questions in the video-recordings on the basis of intonation, eye contact, or waiting.

**Procedure**

First, the protocol, which provided instructions and outlined the roles of each partner, was read aloud to the child (separately) and then to his or her communication partner who was called to join the child. The child was asked to begin the interaction. The task of the child was to instruct the partner to construct a figure or pattern that the child could see throughout the whole task, but which was hidden from the partner's view. Partners had an array of objects in front of them, which included the objects that were needed for each task. Both partners communicated until the child indicated that he or she was satisfied with the model built by the partner. Thus, it was the child who decided when the task was finished. At the end, the partners compared the model. The researchers (first and third author) videotaped each dyad consisting of the child interacting with a peer, a parent or a professional at home or at school. In order to capture the verbal and non-verbal communication modes, interactions with the children who use communication aids were videotaped with two cameras, one focused on the entire scene and the other one on the child's communication aid. It took the children 2-4 sessions to complete the interactions, because often each partner needed to be scheduled at a different time. Individual sessions for the children who used communication aids were 1.5 to 2.5 hours long and the child could take breaks as needed.

The children used their own communication systems, with their vocabulary, typical access method and setup and in their everyday familiar settings (home or school). The

vocabulary was not changed for the duration of the study. This was specifically requested at the study inception and checked with children and parents in between appointments.

**Overview of Data Analysis**

The video recordings were transcribed in the original language using notational conventions for augmentative and alternative communication (von Tetzchner & Basil, 2011). The Norwegian transcripts were translated into English by the second and third author and the first two authors coded the interactions. In the AC group, the amount of missing data was 8.3% with 6% caused by missing video recordings. The selected analyses corresponded to the three purposes of the study. Descriptive statistical analysis was performed to examine data distribution, central tendency and dispersion for both groups of participants. To examine degree of association between the children's success and: children's age, their functioning levels and partner contributions, or time of interaction, Spearman Rho rank order correlations were calculated because some variables were ordinal (with p value referring to null hypothesis that rho =0). Cohen's standards were used to determine the strength of the relationships (Cohen, 1988). The Mann -Whitney *U* test was calculated to examine whether there was a statistically significant difference between success variables in two groups, because normal distributions could not be assumed. The statistical analyses were performed with SPSS, version 22.

# Results

## Interactions of Children with Partners

Examples of children's interactions are provided in Figures 1 and 2. In general, children in SN group provided more details when describing the elements, for example the child from this group said: *Striped shirt, it's got sheep on it from the looks of it or maybe a mountain goat* vs. the child from AC group said "*Striped shirt".* Overall, there was little interaction in SN group as partners were focused on doing – constructing the model, while listening to instructions. The interactions of children in AC group were filled with waiting time for partners, while the child composed the message and more interaction related to the partner's need to understand exactly what to do.

Insert Figures 1, 2, & 3 Approximately Here

## Success

Figure 3 illustrates the data distribution for success variables in AC and SN groups. The children who used communication aids precisely solved 89 of 131 tasks (68%). On 41 tasks, they made one or more errors, a total of 110 errors, 43 of which (39%) were related to naming of the objects (Table 5). The errors were not distributed evenly as 5 of the 18 children made no errors, 7 made 1-4 errors, 4 made 10-14 errors, and 2 made 20-27 errors. Three of 18 children had errors on all the task items. Table 6 describes the group of children who had four or more errors in comparison to the remaining children and shows that these groups vary. Children from the group with four or more errors used almost twice the amount of time than the children from the other group and majority of them had CFCS level III, while the other children level II.

The naturally speaking children precisely solved 100 of 107 tasks (94%). They made a total of 7 errors on 6 tasks, with 5 errors (71%) related to sequence and orientation. The AC group and the SN group differed significantly in the average number of precisely solved tasks and errors, with the SN group performing better than the AC group (Table 7).

Insert Tables 5, 6 & 7 Approximately Here

In the AC group, children who used an orthographic system alone or in combination with graphic symbols ($M$ = 87.8, $SD$ = 13.1) solved more tasks than children using a graphic system alone or a graphic system in combination with gestures ($M$ = 33.5, $SD$ = 35.9, $t(16) = 4.45$ $p < .001$). There was no significant difference between children who used direct access ($M$ = 49.3, $SD$ = 41.7) and children who used scanning ($M$ = 81.5, $SD$ = .422.0, $t(16) = 1.97$, $p = .066$).

**Time Usage**

Table 8 shows that, on average, it took children using communication aids and their partners 509.2s to complete a task compared to 92.9s for SN children and their partners. However, time varied among tasks and participants. The 10 children who used communication aids with direct access needed significantly less time to solve a task ($M$ = 366.3, $SD$ = 199.0) than the 8 children who used scanning ($M$ = 689.6, $SD$ = 221.1); $t(16) = 3.25$, $p = .005$).

Insert Table 8 Approximately Here

**Misunderstandings**

In the AC group, there were 27 misunderstandings with partners of which 15 (56%) were with parents (Table 5). The comparison children had no misunderstandings with their partners. The misunderstandings in the AC group were not distributed evenly. They occurred with 11 children (61%) of which 6 children (55%) had 1 misunderstanding, 1 child (9%) had 3, 3 children (27%) had 4 and 1 child (9%) had 6 misunderstandings. The 25 misunderstandings (93%) were due to partners not understanding the child -- only 2 (7%) were due to children misunderstanding the partner - and 16 (59%) of the misunderstandings were resolved: 6 (38%) by the children, 6 (38%) by both a child and a partner, and 4 (25%) by a partner alone.

**Child Contributions**

**Elements and objects.** The children in the AC group indicated correctly 295 out of 475 elements (62%). When the child was dressing a doll or making a necklace, it was necessary to name and describe the object (e.g., a red, small star). Of a total of 227 elements, the children using communication aids on average named 64% correctly, 10% incorrectly, and did not name 26% of the objects (Table 8).

**Attributes.** On average, the children using communication aids mentioned as many attributes as needed ($M$ = 1.02, $SD$ = 0.59; where 1 indicates the number of required attributes). The number of attributes varied in both groups (Table 8).

**Specificity.** Table 8 shows that the children in both groups had lower initial specificity than final specificity scores, indicating that they added more precise descriptions as result of their interactions with partners. While children in AC group had

scores below 3, which represent lower than expected precision, the scores of children in SN group were above 3, indicating that children provided more details than required.

Insert Figure 4 Approximately Here

**Partner Contributions**

**Style of interaction.** Figure 4 illustrates data distribution for the AC and SN groups in terms of partners' style of interaction and shows that in both groups the most frequent partner style was attentive, allowing the child to lead. However, the interaction styles of the partners in the AC group varied more than in the SN group.

**Help provided.** The partners in the AC group provided more help than the partners in the SN group (Table 8). Table 5 shows details on type of help provided by the partners in both groups of children. The most frequent help in the AC group was a question together with organization of the material (44%). The partners in the SN group pointed to items (44%) or asked a question (35%), but did not do both together. The partners of children using communication aids tended to ask for specific information (e.g., the child stated: *"The other oval"* and the partner asked: *Do you mean this barrel?),* to give choice questions (e.g., holding two objects: *Do you mean this one or that one?*), and to sometimes offer a sequence of such questions. The partners in the SN group also asked specific questions (e.g., *The yellow over the blue?* referring to the position of a yellow block), as well as open-ended questions (e.g., *Which way?* referring to a domino tile).

**Elements chosen by the partner.** The partners in the AC group selected an average of 82% (394) of the correct elements and the partners in the SN group 100% of correct elements (475) (Table 8). This means that the few errors made by the comparison

children were related to the sequence/orientation of the elements rather than to selection of the elements themselves.

**Relationships in AC Group**

Table 9 presents the details of Spearman's rho associations between success of children in AC group and their age, functioning levels, time of interaction, and children's and partner's contributions. The strength of all of the significant relationships, which are listed below, was large (above .50) (Cohen, 1988).

Insert Tables 9 and Figure 5 Approximately Here

Older children had more success in solving the task. In addition, the children that had more success had also higher communication functioning levels and better non-verbal reasoning. There were no significant correlations between success, verbal comprehension, or visual perception.

There was also no significant association between the success and time used to complete the tasks. The children who were more specific had better success in solving tasks. The partner's style of interaction was not related to success; except for the professionals. When the professionals took the lead from child, the child tended to solve fewer tasks ($r_s$ = -.641, $p$ = .004). There was no significant relationship between amount of help and success. The children who provided more specific descriptions were given less help ($r_s$ = -.515, $p$ = .029).

Figure 5 shows the relationship between the partner's style and the average amount of help provided by each partner. The parents who were more attentive provided more

help ($r_s$ = 630, $p$ <.05). The similar relationship was observed for peers ($r_s$ = .601, $p$ <.05), but not for teachers ($r_s$ = .252, $p$ <.05).

The correlations were not calculated for the SN group as there was a minimal variance within that group.

**Learning Effect**

Table 5 shows number of tasks with errors within each task category, in the first and the second task of each type (e.g., Doll 1 vs. Doll 2). The AC group made errors in 41 of the 131 tasks (31%), the majority of them in both first and second task item (e.g., the child made errors in both Blocks 1 and Blocks 2). The SN group made errors on 6 tasks, 4 of them on the first task item only (e.g., the child made an error in Domino 1, but not in Domino 2).

## Discussion

Children with motor impairments have difficulties engaging in play that involves manipulating objects. This study explored how children with severe motor impairments used communication aids to express self-made instructions to partners who then physically constructed the models. The results show that the children successfully used autonomous communication to instruct others. Because the partners did not have content knowledge, the tasks allowed the children to be in communicative control and also represented a situation in which autonomous / authentic communication was required. The children who used communication aids had to find words or graphic symbols on their displays for describing physical constructions that the partners should build (communicative problem solving). The results support other studies that have found that

games that assign the role of knowledge provider to the child can be a way of altering the asymmetry in roles typically reported in the everyday interactions of children who use communication aids (e.g., Collins & Markova, 1999).

Although the children in the AC group made more errors than the SN group, they solved the majority of the tasks precisely. This demonstrates significant language and communication achievements, especially when one considers that they have other sensory, cognitive, language, and motor challenges in constructing utterances than children who speak naturally. Other studies using a referential communication task design have reported similar achievements and challenges in a few individuals using communication aids and their communication partners (Collins, 1996; Collins & Marková, 1999; Hagemoen et al., 2004; Smith, 2003). Studies of typically developing children indicate that referential communication skills are related to age (Glucksberg & Krauss, 1967). A similar relationship was found in this study.

It took the children who use communication aids five times longer to solve the tasks than their naturally speaking peers, and children from the AC group who made four errors or more took almost twice as much time as the other children in the AC group. The children who used scanning needed twice as much time as children who used direct access. A slow pace of communication in children who are using scanning has been reported in other studies (e.g., von Tetzchner & Martinsen, 1996). However, access method were not related to overall success, which suggests that variation in success scores was caused by other factors and that the physical and time demands placed on the children using scanning did not interfere with solving the task.

It is important to note the generally larger variation within the AC group than in the comparison group. These findings may reflect differences in children's experience with play and with communicating something that others do not know. The particular experience related to using a communication aid and available vocabulary may also have contributed to the results. The limited access to a communication aid in daily situations and a restricted vocabulary were noted as common among children using communication aids and are likely to have an impact on their participation and communication (Batorowicz et al., 2014; Blockberger & Sutton, 2003; Salminen, Petrie & Ryan, 2004; Salminen, Ryan & Petrie, 2004; Sutton, Soto, & Blockberger, 2002). Worth to note is a large variation in partner's style in the AC group, with majority of parents having the optimal style and more diversity among teachers and peers. This may suggest that the most familiar partners know how to be attentive and let the child take a lead.

In the present study, the children using communication aids did not always name simple objects correctly. It is a common observation that nouns are overrepresented in communication aids (e.g., Beukelman & Mirenda, 2005) but, with a limited vocabulary, each symbol must have a broad semantic extension, and more subtle differences among objects (e.g., cube vs. square) are not likely to be represented or given prominence in interactions as activities are often routinized and the intended meaning is rather predictable (Batorowicz et al., 2014).

Children using communication aids who provided more specific instructions and named more elements correctly were more successful in solving the tasks. When the utterances were imprecise, the partners were less likely to select the correct elements. The

children may have been used to communicating in situations where they are understood by their partners, even when the communication is not precise. The partners tended to guess and expand the aided message, often using shared contextual knowledge (e.g., Alm & Newell, 1996; Batorowicz et al., 2014; Binger & Light, 2008; von Tetzchner & Martinsen, 1996). This interpretation is supported by the finding that the majority of the misunderstandings occurred with parents who are, presumably, the most familiar partners. When children who use communication aids need to tell others in words what they intend (i.e., rather than others interpreting and assigning such intent), brief and precise messages may be most efficient, especially when the pace of the aided communication is slow. Precise instructions with aided language allow people with motor impairment and little speech to act on the world through others, and precision in communication may be particularly important for developing social control and autonomy later in life.

In the present study, children using communication aids were given help mainly in the form of questions and pointing. In the comparison group, partners pointed to materials or asked a question, but not both. The differences in partner help may reflect that interventions have tended to focus on modeling aided language and supporting verbal comprehension (e.g., Binger & Light, 2007; Solomon-Rice & Soto, 2009). The amount of help given was not significantly related to success, possible reflecting that the help was not always useful. The partners in the comparison group gave less help and more open questions that encouraged elaboration and autonomous communication. This is likely to reflect the higher language proficiency in the SN group and the slow communication pace

and limited vocabulary in the AC group, but also the partner's expectations and their established communication habits.

Misunderstandings occurred only in the AC group and were mostly due to the partner not understanding the child's utterance. These may have been caused by difficulties in interpreting the aided utterance but also by a lack of attention in the partner due to the long time the partner had to wait for the message to be constructed. The misunderstandings could be also attributed to the imprecise vocabulary used by a child, either because the target word was not on the communication aid or was there but for some reason the child did not select it. The majority (60%) of the misunderstandings were resolved, which is in line with the repair strategies reported in other studies of children using communication aids (Hjelmquist & Sandberg, 1996; Light, 2003). However, in the present study the children using communication aids resolved more than one third of the misunderstandings on their own. This may reflect the language competence in this selected group of communicators and suggests that children using communication aids can learn to use repair strategies if given sufficient opportunity. Because the children in this study had control over the tasks, the unresolved misunderstandings may indicate a lack of persistence or possibly the presence of perceptual or other problems, which are common in children with cerebral palsy (Jenks et al., 2007).

Although the children using communication aids were identified by professionals as not having a cognitive delay, their verbal and non-verbal cognitive functioning varied, and some of the children scored below average. Two thirds of children, however, obtained scores within the normal or borderline range. For the others, test results may

indicate learning difficulties that had not been identified. Other studies indicate that individuals who use communication aids may have learning problems which are not recognized (Binger & Light, 2008).

**Implications for Research and Practice**

Only a few studies have described scripted activities designed to encourage communication and participation in play with peers (e.g., Batorowicz et al., 2006; Taylor & Iacono, 2003). There is little systematic knowledge about intervention strategies promoting autonomous communication and most are related to narrative skills (e.g., Soto, Yu, & Kelso, 2008; Waller, 2006). Communicative autonomy means that communicators are able to say what they want and when they want it (von Tetzchner & Grove, 2003) and communicative competency includes the ability to understand others, express one's own thoughts, problem-solve, repair communicative breakdowns, and accommodate to various partners (Light, 1989). Children with motor impairments need language to operate on the world; however, many children using communication aids are reported to be binary responders, as most of their communication consists of answering yes/no and other binary questions (e.g., Salminen et al., 2004 a, b). Interventions that tend to focus on operational or functional use of the aided system, rather than on children's activities, may not support the development of aided language in a variety of situations (Renner, 2003; von Tetzchner & Grove, 2003).

Maximizing opportunities for children to engage in typical childhood activities with others can affect their development in positive ways (Sameroff, 2013). An appropriate level of support in play that facilitates communicative intent and the child's expression of

thoughts and establishes conversational referents may represent a scaffold for aided language development. Activities that are similar to the tasks described here may provide opportunities for engaging children who use communication aids in communicative problem solving and give them reasons to create their own messages, and for the partner to genuinely try to understand the child.

Communication barrier games have been previously suggested as a way to practice receptive and expressive skills (e.g., Bunce, 1989; Kagan & Gailey, 1993). For the expressive group of children who have severe physical impairments, such games can be modified as described in this article, so a child who uses AAC gives instructions and another child is responsible for 'doing'. As reported in the literature, such games and activities can provide the opportunity for both children to practice conversational responsibilities of giving clear and concise directions, listening for details, questioning and clarifying when needed, using and understanding vocabulary, and reflecting on the activity (Bunce, 1989; Clark, 1992). The current study suggests that coaching partners to: give sufficient time, wait, attend and allow the child to lead and problem solve might be important to children's success. Possibly, the interventions focused on engaging children who use communication aids in activities using authentic communication may help them develop communicative autonomy, enabling them to be responsible for their own expression, and expressing themselves in accordance with their own intentions (von Tetzchner & Grove, 2003).

This study is limited by use of a convenience sample due to the limited pool of potential participants meeting the criteria, and the heterogeneity in their cognitive

abilities. However, a random selection of participants would not have been feasible given the relatively small population of children using communication aids (Binger & Light, 2008). A study would be beneficial when children could be matched with peers on the basis of cognitive abilities. Future research could employ a micro level of analysis to look at the individual interactions of children and utterances. In addition, this study did not look at children's specific vocabulary, rather we observed what children did using their own systems. Future studies could address how available vocabulary, especially for children who use graphic symbols, is associated with children's performance. Lastly, a limitation could be variability in partner behaviors based on familiarity with the child; future studies could include unfamiliar partners who used a standard set of responses, if instructions were not exact.

**Conclusion**

Children with motor impairments are hindered in participating in ordinary constructive play, in manipulating objects, and in acting directly on the physical world. The results of the present study demonstrate the children's significant communicative achievements as well as their challenges when using language for action. Children who used communication aids showed that they could autonomously direct the actions of others in constructive play. They were somewhat less successful than their naturally speaking peers, which may reflect both the high complexity of constructing aided utterances when using language to direct others in construction play and the children's limited experience with using aided language in such activities. Interventions focusing on providing opportunities for autonomous communication in structured activities with

others may promote the development of aided language and autonomy in children with severe physical impairments and little or no speech.

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Table 1

*Verbal Comprehension, Non-verbal Reasoning and Visual Perception in the AC Group and the SN Group*

| | Verbal comprehension | | Non-verbal reasoning | | Visual perception |
|---|---|---|---|---|---|
| | AC group (*N*) | SN group (*N*) | AC group (*N*) | SN group (*N*) | AC group (*N*) |
| Normal range | 6 | 6 | 2 | 7 | 2 |
| Borderline range | 4 | 2 | 9 | 0 | 2 |
| Low range | 7 | 1 | 5 | 0 | 12 |
| Total *N* | 17 | 9 | 16 | 7 | 16 |
| *M* (*SD*) | -1.56 (1.13) | -.75 (.85) | -1.68 (1.03) | 0.38 (0.79) | -2.23 (1.58) |
| Min-Max | -3.00-.60 | -2.47-.73 | -3.65-.35 | -0.08-2.16 | -4.00- 2.80 |

*Note.* In the SN group, verbal comprehension was tested in one of the countries, and non-verbal reasoning was tested in the other. On the test of verbal comprehension, children in both groups had a mean below the age mean. This test was only completed with Norwegian comparison children and the sample used for standardizing the test was quite small. It seems plausible that the standard deviation in this standardization sample is smaller than in a larger and more representative sample. Therefore, the verbal comprehension of children using communication aids in the current study on average might lie closer to the normal range that the norms seem to indicate.

Table 2
*Characteristics of the Children in the AC Group*

| | AC group (*N*=18) |
|---|---|
| Age * *M* (*SD*); range | 10.9 (1.2); 5;7-15;10 |
| Sex | |
| Boys / Girls | 5 (28%) / 13 (72%) |
| Educational Setting | |
| Mainstream | 12 (67%) |
| Special class/school | 6 (33%) |
| Diagnoses | |
| Cerebral palsy | 17 (94%) |
| Other | 1 (6%) |
| GMFCS | |
| Level I | 1 (6%) |
| Level IV | 6 (33%) |
| Level V | 11 (61%) |
| MACS | |
| Level I | 1 (6%) |
| Level III | 1 (6%) |
| Level IV | 6 (33%) |
| Level V | 10 (56%) |
| CFCS | |
| Level I | 0 |
| Level II | 11 (61%) |
| Level III | 6 (33%) |
| Level IV | 1 (6%) |
| VSS | |
| Level I | 0 |
| Level IV | 18 (100%) |
| Communication aid used | |
| Manual board / book | 2 (11%) |
| Electronic, speech output | 12 (67%) |
| Both | 4 (22%) |
| Communication aid used | |
| Graphic (PCS) | 4 (22%) |
| Graphic (Blissymbols) | 4 (22%) |
| Orthographic | 5 (28%) |
| Orthographic + graphic | 5 (28%): PCS (17%) & Minspeak (11%) |
| Access mode | |
| Direct, hand | 6 (33%) |
| Direct, eye gaze | 4 (22%) |
| Scanning, two switches | 7 (39%) |
| Scanning, one switch | 1 (6%) |

*Note.* PCS = Picture Communication Symbols™; Minspeak™ = semantic encoding
* Norwegian children were older (*M* = 11.2, *SD* = 0.8) than Canadian (*M* = 10.8, *SD* = 1.2) but the difference was not statistically significant.

Table 3

*Tasks and Their Elements (total of 29)*

| Task | Element 1 | Element 2 | Element 3 | Element 4 |
|---|---|---|---|---|
| Doll 1 | Green jacket | Long blue pants/jeans | Blue hat | Blue shoes |
| Doll 2 | Striped shirt | Green/khaki pants | Blue socks | Brown bag |
| Necklace 1 | Red cylinder | Green cube | Red star | - |
| Necklace 2 | Green barrel | Blue triangle | Yellow cube | - |
| Blocks 1* | Large red | Small green, small blue | Large green | Small blue, small yellow |
| Blocks 2* | Small blue, small red | Large green | Large green | Small red, small blue |
| Domino 1 | 1/4 | 6/6 | 3/blank | - |
| Domino 2 | 4/3 | 2/6 | 2/5 | 4/5 |

*Note:* *Four layers, from bottom to top and left to right; domino patterns are listed in order from left to right

Table 4

*Coding of Construction Tasks*

| Category | Subcategory | Description |
|---|---|---|
| Success | Exact model [a] | Number of exact model built |
| | Errors [a] | Number and type (size, color, shape, sequence/orientation, number) |
| Time [b] | | Time it took to complete each task, in seconds |
| Misunderstandings | Type [a] | Child/partner (who misunderstood who) |
| | Solved [a] | Yes/no |
| | Who solved [a] | Child/partner |
| Child contributions | Elements [b] | Number of correct elements named by child |
| | Objects [a] | Number of objects named: correctly, incorrectly, and not named |
| | Attributes [a] | Number of attributes named |
| | Specificity [a] | Precision of objects and attributes; scale 1 to 5, with 3 indicating the best precision: 1 = too general, only superordinate category; 2 = correct object, but too few or incorrect attributes; 3 = correct objects and attributes; 4 = correct objects, one too many attributes; 5 correct object, two or more too many attributes |
| Partner contributions | Style [a] | Degree of attentiveness and lead; scale from 1 to 5, with 3 indicating the best style; 1 = not attentive; 2 = attentive but slow to follow child's lead; 3 = attentive and letting the child to lead; 4 = attentive, but tends to take over a lead; 5 = tries to solve the task on his/her own, dominates |
| | Help [a] | Number of times help was provided<br>Type of help: verbal, organization of material, giving instructions, and all combinations of these three |
| | Elements [a] | Number of correct elements chosen by partner |

*Note.* [a] were evaluated at the item level; [b] were evaluated at the task level

Table 5

*Total Number (and Percentage) of Tasks Completed with Different Partners, Misunderstandings, Errors and Help Provided*

| | AC group (*N* = 18) Tasks = 131 | SN group (*N* = 17) Tasks = 107 |
|---|---|---|
| Tasks completed with different partners | | |
| Parent | 44 (34%) | 20 (19%) |
| Professional | 49 (37%) | 71 (66%) |
| Peer | 38 (29%) | 16 (15%) |
| Misunderstandings | | |
| Total | 27 (100%) | 0 |
| With parent | 15 (56%) | 0 |
| With professional | 6 (22%) | 0 |
| With peer | 6 (22%) | 0 |
| Errors | | |
| Total | 110 (100%) | 7 (100%) |
| Type: Size | 16 (15%) | 0 |
| Orientation/sequence | 25 (23%) | 5 (72%) |
| Colour | 16 (15%) | 0 |
| Object | 43 (39%) | 1 (14%) |
| Shape | 1 (1%) | 0 |
| Number | 9 (8%) | 1 (14%) |
| Tasks with errors: | 41 (100%) | 6 (100%) |
| First | 11 (27%); AT | 4 (66%); N, B, & D |
| Second | 2 (5%); N & B | 1 (2%); B |
| Both | 28 (68%); AT | 1 (2%); N |
| Help provided | | |
| Total | 256 (100%) | 55 (100%) |
| Verbal question | 89 (35%) | 19 (35%) |
| Organizing or pointing materials | 13 (5%) | 24 (44%) |
| Giving instructions | 5 (2%) | 4 (7%) |
| Verbal questions and organizing | 113 (44%) | 5 (9%) |
| Verbal questions and instruction | 11 (4%) | 1 (2%) |
| Organizing and instruction | 4 (2%) | 2 (3%) |
| Verbal question, organizing and instructions | 21 (8%) | 0 |

*Note.* AT = all tasks; N = necklace; B = blocks; D = domino.

Table 6

*Results for AC group: Children with Higher and Lower Levels of Success*

| | AC (<4 errors tasks) *N*=12 | | | AC (≥4 errors on tasks) *N*=6 | | |
|---|---|---|---|---|---|---|
| | M(SD) | 95% CI | *Mdn* | M(SD) | 95% CI | *Mdn* |
| Age | 132.3 (37,1) | [108.7, 155.8] | 137.0 | 121.7 (35.0) | [84.9, 158.4] | 128.5 |
| Test results (in z-scores) | | | | | | |
| TROG | -1.2 (1.1) | [-1.9, -0.4] | -1.1 | -2.3 (0.9) | [-3.2, -1.3] | -2.4 |
| Raven/KiBIT | -1.2 (0.8) | [-1.8, -0.7] | -1.3 | -2.7 (0.7) | [-3.5, -1.8] | -2.7 |
| MVPT | -2.1 (1.8) | [-3.3, -0.9] | -2.7 | -2.6 (0.9) | [-3.7, -1.4] | -3.0 |
| Tasks results | | | | | | |
| Time (sec) | 411.5 (194.5) | [287.9, 535.0] | 422.8 | 704.8 (284.4) | [406.3, 1003.3] | 778.4 |
| Solved (%) | 78.7 (30.9) | [59.0, 98.3] | 83.0 | 33.5 (31.4) | [0.6, 66.5] | 31.5 |
| Errors (ave.) | 0.23 (0.30) | [0.04, 0.42] | 0.13 | 2.29 (0.89) | [1.35, 3.23] | 2.30 |
| Help | 4.90 (3.64) | [2.59, 7.21] | 3.90 | 5.51 (4.15) | [1.15, 9.87] | 3.90 |
| Partnerstyle | 3.18 (0.62) | [2.79, 3.58] | 3.00 | 3.09 (0.81) | [2.25, 3.94] | 2.88 |
| Characteristics of AC groups N (%) | | | | | | |
| Gender | | | | | | |
| Girls | | | 7 (58.3) | | | 6 (10.0) |
| Boys | | | 5 (41.7) | | | 0 |
| School setting | | | | | | |
| Fully integrated | | | 8 (66.7) | | | 2 (33.3) |
| Partly integrated | | | 1 (8.3) | | | 1 (16.7) |
| Special | | | 3 (25.0) | | | 3 (50.0) |
| CFCS level | | | | | | |
| II | | | 10 (83.3) | | | 1 (16.7) |
| III | | | 2 (16.7) | | | 4 (66.7) |
| IV | | | 0 | | | 1 (16.7) |

*Note. Mdn* = median

Table 7

*Mean (Standard Deviation), Confidence Intervals, Median, and Mann-Whitney for Success: AC and SN Groups*

| | AC group *N* = 18, *M* (*SD*) | 95% CI | *Med* | SN group *N* = 17, *M* (*SD*) | 95% CI | *Med* | *U* | *z* | *p* | *r* |
|---|---|---|---|---|---|---|---|---|---|---|
| Success | | | | | | | | | | |
| Solved (%) | 63.6 (37.3) | [45.0, 82.2] | 75.0 | 94.9 (8.7) | [90.7, 99.0] | 100 | 75 | -2.771 | .007* | .46 |
| Errors per task | 0.91 (1.14) | [0.35, 1.48] | 0.35 | 0.06 (.09) | [0.01, 0.09] | 0.0 | 69 | -2.971 | 004* | .50 |

*Note.* CI = confidence interval; *Med* = median; *$p < .05$

Table 8
*Mean (Standard Deviation), Confidence Intervals, and Median for Time, Child and Partner Specific Variables*

| | AC group *N* = 18 | | | SN group *N* = 17 | | |
|---|---|---|---|---|---|---|
| | *M* (*SD*) | *95% CI* | *Mdn* | *M* (*SD*) | *95% CI* | *Mdn* |
| Time in seconds | 509.2 (261.7) | [379.1-639.4] | 486.1 | 92.9 (57.6) | [61.0,124.8] | 81.3 |
| Child contributions | | | | | | |
| Elements named (%) | 61.9 (31.1) | [46.4-77.3] | 69.3 | 89.9 (11.3) | [84.1, 95.7] | 90.5 |
| Objects [a] | | | | | | |
| Correct (%) | 63.6 (27.5) | [50.0, 77.3] | 60.7 | 86.0 (13.3) | [78.9, 93.1] | 87.9 |
| Incorrect (%) | 10.3 (14.3) | [3.2, 17.4] | 7.1 | 13.6 (13.2) | [6.5, 20.6] | 12.1 |
| Not named (%) | 26.0 (29.6) | [11.4, 40.7] | 7.1 | 0.4 (1.8) | [-0-5, 1.4] | 0.0 |
| Attributes [b] | 1.02 (0.59) | [0.7, 1.3] | 0.84 | 1.74 (0.64) | [1.41, 2.07] | 1.57 |
| Specificity | | | | | | |
| Initial | 2.29 (0.74) | [1.93, 2.66] | 2.38 | 3.27 (0.47) | [3.03, 3.51] | 3.31 |
| Final | 2.64 (0.76) | [2.26, 3.01] | 2.76 | 3.48 (0.44) | [3.25, 3.70] | 3.65 |
| Partner contributions | | | | | | |
| Style of partner | 3.16 (0.67) | [2.83, 3.49] | 3.00 | 3.00 (0.15) | [2.92, 3.08] | 3.00 |
| Parent | 3.22 (0.91) | [2.73, 3.70] | 3.00 | 3.00 (0) | [3.00, 3.00] | 3.00 |
| Peer | 2.91 (0.93) | [2.41, 3.40] | 3.00 | 3.02 (0.21) | [2.90, 3.14] | 3.00 |
| Professional | 3.28 (0.86) | [2.85, 3.71] | 3.00 | 3.00 (0) | [3.00, 3.00] | 3.00 |
| Help average per task | 5.10 (3.70) | [3.26, 6.95] | 3.90 | 0.62 (0.60) | [0.31, 0.93] | 0.50 |
| Parent | 6.16 (9.75) | [0.96, 11.35] | 2.38 | 0.07 (0.19) | [-0.10, 0.24] | 0.00 |
| Peer | 4.41 (5.07) | [1.70, 7.11] | 3.25 | 0.45 (0.47) | [0.18, 0.73] | 0.50 |
| Professional | 5.28 (5.45) | [2.57, 7.99] | 4.00 | 0.93 (0.78) | [0.36-1.49] | 0.69 |
| Element chosen (%) | 83.2 (24.4) | [71.1-95.4] | 96.6 | 99.5 (1.4) | [98.8-1.00] | 100.0 |

*Note.* [a]Objects were calculated for doll and necklace tasks only (AC group *n* = 227; SN group *n* = 198); it was not required to say: *domino* or *block* for the remaining tasks; [b]Number 1 represents the best possible score.

Table 9

*Relationships Between Success Variables and Children's Age, their Functioning Levels, Time, Misunderstandings, Attributes, Specificity, Partner style and Help Provided.*

Aided communicators (N=18)

| | Age | GMFCS | MACS | CFCS | VC | NR | Time | Mis | Att | ISp | FSp | PStyle | Help |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Solved | .55* | -.24 | -.12 | -.66** | .36 | .51* | -.14 | -.16 | .36 | .73** | .67** | -.25 | -.22 |
| Errors | -.38 | .33 | .23 | .74** | -.39 | -.67** | .35 | .29 | -.34 | -.70** | -.65** | .11 | .17 |

*Note.* GMFCS = Gross Motor Function Classification System; MACS = Manual Abilities Classification System; CFCS = Communication Function Classification System; VC = verbal comprehension (results from TROG); NR = non-verbal reasoning (results from Raven/KiBIT); Mis = misunderstandings; Att = attributes; ISp = initial specificity; FSp = final specificity; PStyle = partner style

Spearman Rho's correlation, two-tailed

*$p < 0.05$

**$p < 0.01$

Figure 1

*Examples of Interactions of Children with Peers*

Child (C) from NS group and peer (P). Task: Domino 1.
Time without interruptions: 41 sec.

C: *So there are 3 dominos and they are arranged horizontally. And there is one that has one side with 1 dot and another with 4 dots. The one dot is facing to the left. And then beside that is a double 6 domino and they are touching. And then next domino has 3 on one side and 1 on the other and 3 is touching.*
P: ((gets the dominoes and looks down at dominoes while arranging them))
C: *Okay, here we go.*

---

Child (C) who uses PCS on a speech generating device, accessed with two switches, and peer (P). Task: Doll 2.
Time without interruptions: 615 sec.

C: *"Yellow"*
P*: Is it this yellow shirt?*
C: *Yeah,* "*brown"*
P: *I am just trying to put his arms in* ((puts on the shirt)); *was it brown pants?*
C: *Yeah*
P: *There is just a brown bag. There is blue pants. I do not see any brown pants. There is no brown pants. Is this what you mean?* ((picks up the khaki pants))
C: *Yeah, "brown"* (pause)
P: ((puts the pants on))
C: "*Brown"*
P: *Is it brown bag?*
C: *Yeah*
P: *How about sweater? There is a green sweater here. It matches* ((puts bag across the right way))
C: *"Shoes"*
P: *What kind of shoes? The only shoes here are these brown shoes. Or maybe these slippers?* ((points to slippers))
C: *"Blue"*
P: *I don't know. Because this are blue, this are half blue and this are sort of blue. What kind?* ((points to different slippers looking at C))
C: ((nods))
P: *There is a hat* ((looks at remaining pieces at the table and C))
C: ((looks away))
P: *Boy this doll looks so cute.*

Figure 2

*Examples of Interactions of Children with Teachers*

Child (C) using Bliss on a speech generating device, accesses it with switches and teacher (T). Researcher (R) also present in room. Task: Making a necklace 2.
Time without interruptions: 1100 sec

*T:* *Can you tell me how I should put the pearls on the string?*
C: *WHITE*
T: *Yeah*
C: *YELLOW*
T: *Did you mean yellow?*
C: ((nods))
T: *Two yellows. Can you tell me a bit more?*
---
C: *BIG*
T: *The big yellow one is the first one, yes.* ((puts yellow cube on string)) *That is okay, you can continue with the next*
C: *SMALL*
T: *A small, m::*
C: *BLUE*
T: *It has blue color, yes.*
C: *SQUARE*
T: *Then I will take this one. Like this, now I am read for the next.* ((puts small blue square on string))
C: *THANKS*
T: ((looks at C and smiles))
C: *GOOD-BYE*
T: ((looks at C questioningly))
C: *GOOD-BYE*
T: ((looks at C questioningly))
C: *NO*
T: *No? Did I do wrong?*
C: ((nods))
T: ((removes small blue square from string))
T: *But it shall be a small blue one?*
C: ((smiles at T))
T: *There are two small blue ones. You have told me that it should be a small blue shape. Now you must tell me something about what it looks like*
C: *M::* (pause for several minutes) *ah::*
R: *Can you tell us if you lack words. Do you?*
C: ((nods))
R: *Are you lacking the word you are searching for?*
C: ((nods))

R: *Then T can help you with that one.*
T: *The star or the triangle?*
C: ((looks at triangle))
T: *Triangle?*
C: ((nods))
T: *Correct?*
C: *Ah::*
T: *Yes* ((puts small blue triangle on the string))
R: *Then there is one more*
T: *Yes. Then we take the next one.*
C: *BLUE*
T: *Blue shape once more, yes.*
C: *GREEN*
T: *Was it green you meant?*
C: ((makes some movements))
T: *Yes*
--
C: *BIG*
T: *A big green one. And then I have three big ones here*
--
C: *ROUND*
T: *Then I take the round one* ((picks up green cylinder))
C: ((shakes head))
T: *Wrong?*
C: ((nods))
T: *This one?* ((lifts green oval shape up for C to see))
C: ((nods))
T: *Then it is this one. Like this? Are you happy with it?*

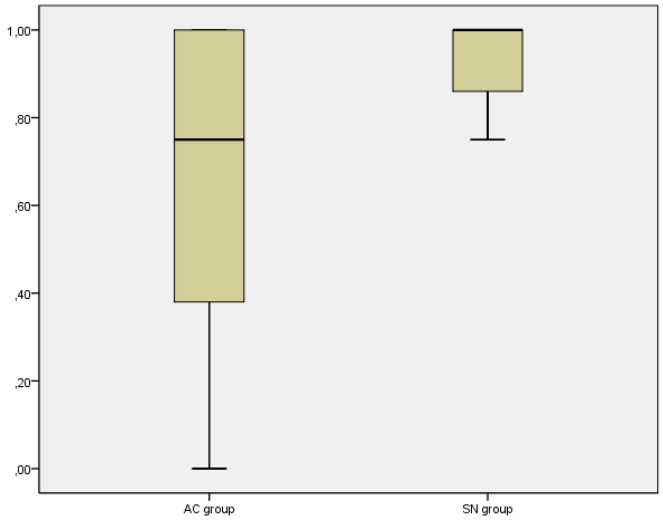
---

Child (C) from NS group and teacher (T). (Same age and sex as the child who uses communication aid). Task: Making a necklace 1.
Time without interruptions: 55 sec

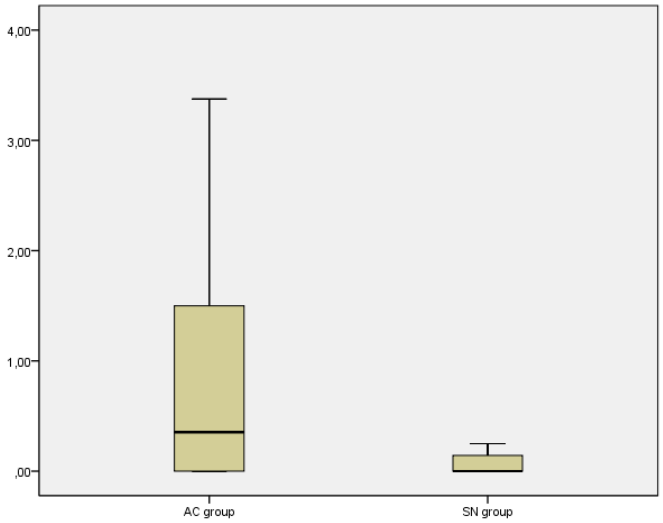
C: *Uh first there is a red star.*
T: *M::* ((picks up red star and puts it on the string))
C: *And then there is a green square.*
T: ((picks up green square and puts it on the string))
C: *Then there is a red uh, like rounding.*
T: ((picks up red cylinder and puts it on the string))
C: *Yes*

Figure 3

*Data Distribution for Success Variables for AC and SN Groups: Average Number of Solved Tasks and Average Number of errors, per task.*




**Average Number of Solved Tasks**

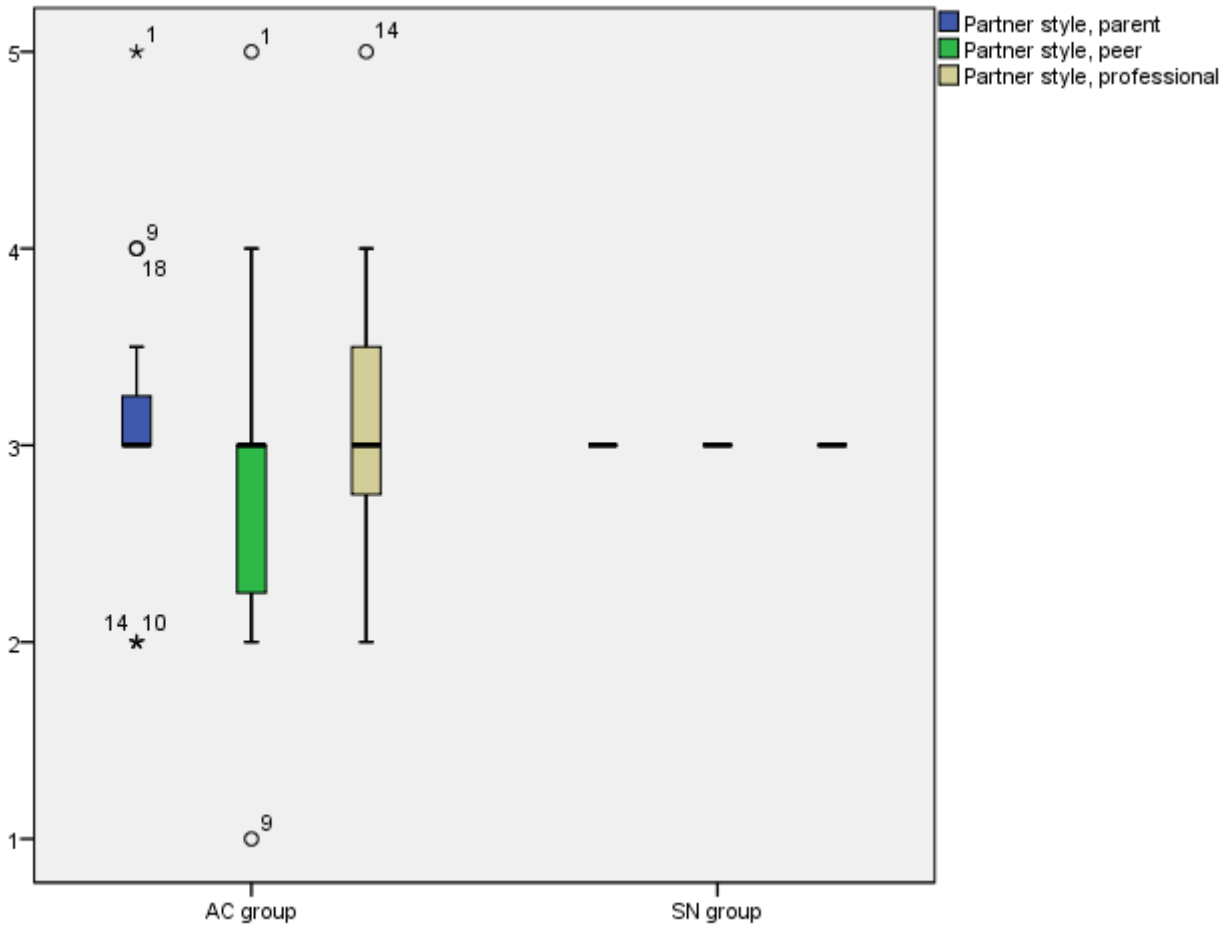



**Average Number of Errors**

*Note.* The figure shows a large variability within AC group and small variability in SN group; no outliers in both groups.

Figure 4

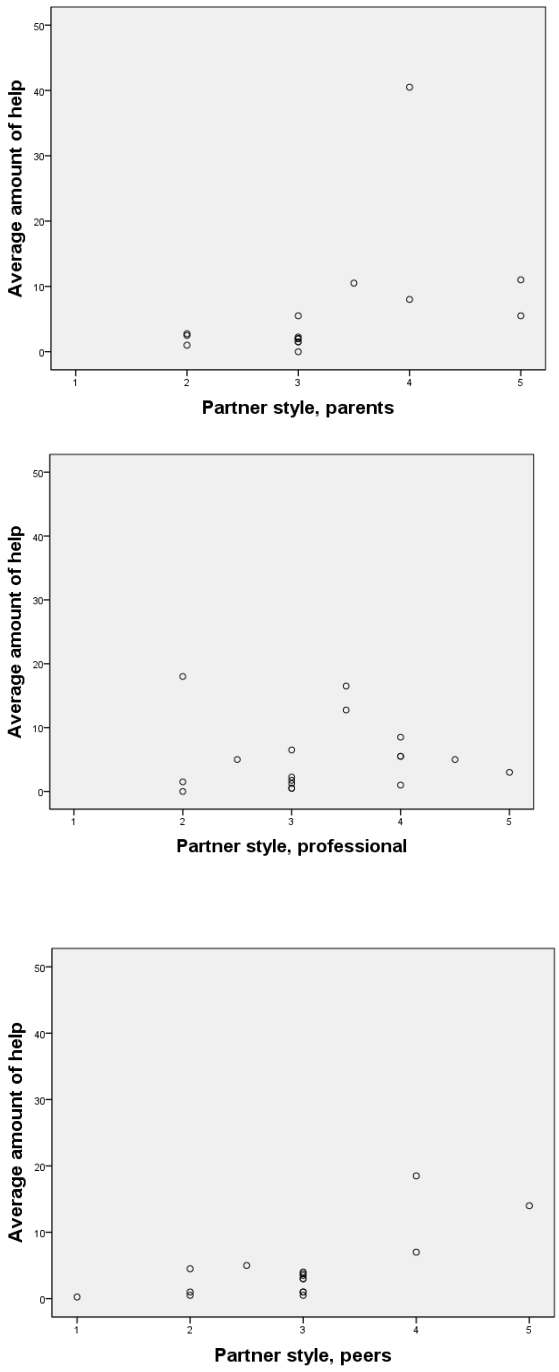
*Data Distribution for Partner Style of Parents, Peers and Professionals in AC and SN groups*




*Note.* While middle of the data set (median) are similar in both groups and for all partners, there is a large variability within the AC group and there are individual partners that differ from the group (outliers); this is not observed in SN group.

Figure 5

*The Relationship Between Amount of Help Given on Average, Per task, and Partner Style; for Parents, Professionals and Peers in the AC group*



## Chapter Four

## Title of Paper: An Integrated Model of Social Environment and Social Context for Pediatric Rehabilitation

Authors: Beata Batorowicz, Gillian King, Lipi Mishra, Cheryl Missiuna. Complete citation: Batorowicz, B., King, G., Mishra, L., & Lee, & Missiuna, C. (submitted). An Integrated Model of Social Environment and Social Context for Pediatric Rehabilitation. *Disability and Rehabilitation.*

### Abstract

This article considers the conceptualization and operationalization of "social environment" and "social context" with implications for research and practice with children and youth with impairments. We first discuss social environment and social context as constructs important for understanding interaction between external environmental qualities and the individual's experience. The article considers existing conceptualizations within psychological and sociological bodies of literature, research using these concepts, current developmental theories and issues in the understanding of environment and participation within rehabilitation science. We then describe a model that integrates a person-focused perspective with an environment-focused perspective and that outlines the mechanisms through which children/youth and social environment interact and transact. Finally, we consider the implications of the proposed model for research and clinical practice. This conceptual model directs researchers and practitioners towards interventions that will address the mechanisms of child-environment interaction and that will build capacity within both children and their social environments, including families, peers groups and communities.

*Health is created and lived by people within the settings of their everyday life; where they learn, work, play, and love [1, p.2].*

### *Conceptions of Disability Resulting from Person-Environment Interaction*

With increasing awareness that disability is the outcome of person-environment interaction, rehabilitation science researchers have discussed the importance of environmental influences on people's health and well-being. Many frameworks and models, especially within occupational therapy, have attempted to explain the complexity of the relationship between person and environment [2-5]. Despite these important contributions, relatively little attention has been given to the social aspects of child/youth* environments, particularly in relation to their influence on child development [6, 7].

The International Classification of Functioning Disability and Health (ICF) [8] proposes that disability is the result of the interaction between impairments and environment; however, it does not specify the mechanisms through which people and environments interact [9]. Similarly, other social disability models that explain disability as caused by the person-environment interaction, such as The Disablement Model [9], or Iva Lie's Gap Model [10], do not explicate the processes by which people affect their environments and environments affect people. Although the social model of disability describes how the organization of society affects the person and disability (i.e., disability is constructed through social environmental barriers like attitudes, supports, information, physical accessibility of buildings) [11], it does not explain how individuals affect their

social environments and the reciprocal nature of this interaction. In this article, we propose an integrated model of social environment and social context that outlines mechanisms through which people and environments interact and transact over time. Interaction needs to be distinguished from transaction. Interaction indicates a mutual or reciprocal action or dependency whereas transaction means that 'one element changes the usual activity of another, either quantitatively by increasing or decreasing the usual level or qualitatively by eliciting or initiating a new response' [34](p. 24).

Next, we discuss the importance of the social environment to child development and health-related outcomes, and the need to clarify the concepts of social environment and context.

*The Need for a Model Clarifying Concepts of Social Environment and Social Context*

It has been widely accepted that the social environment is an essential contributor to children's health and that it may facilitate or diminish health-enhancing experiences and development [12, 13]. Children experience their world as an environment of relationships, and relationships engage children in the human community in ways that help them define who they are, what they can become, and how and why they are important to other people [14-16].

Although we understand that variability in the quality of children's social environments contributes to different experiences that affect children's development and functioning [4, 6, 17, 18], little is known about mechanisms through which specific environmental characteristics and qualities facilitate or limit the meaningful experiences

of children with impairments [7, 19], experiences that lead to long-term social, emotional and competency-related benefits [4].

Despite prevailing recognition of the important role of the social environment, there is no clear conceptualization of it in the context of pediatric rehabilitation. The disciplines of sociology and psychology have a long tradition of researching social environment and context in relation to human behavior [20-23], but there are no generally accepted definitions of these concepts. The terms 'environment' and 'context' are used often interchangeably [24, 25]; the two terms are combined (e.g., 'social contextual environment') [26]; and many authors define social environment and context by listing the elements of interest to them. Such approaches lack specificity and clarity [27, 28].

Similarly, within health and rehabilitation science, the notions of social environment and social context are often implicit. Given the complexity of measuring environmental factors in relation to human health and disability [6], clarifying the concepts of social environment and social context can help us to understand how they can be studied. Measurable units of analysis are required to help researchers and clinicians evaluate specific aspects of children's social environments and social contexts and design appropriate environmental-level interventions.

We propose that '*social environment*' refers to broad objective socio-physical structures (people and institutions) with unidirectional (top-down) influences on people, whereas '*social context'* refers to the subjective experience of individuals regarding the places, activities, people, and objects where the person-environment interaction occurs. Reciprocal influences are therefore possible for individuals and environments – through

social context. The reciprocity between the social environment and social context includes thus bottom-up influences, which are the individuals' reactions, actions and responses to the top-down influences that shape the nature and qualities of the contextual elements that people encounter and experience.

This understanding of social context as the subjective experience of the objective environment (a) is based on a conceptual review of the literature from the fields of sociology and psychology, and (b) *integrates* person-focused perspectives and environment-focused perspectives. Furthermore, it is influenced by (a) the positive youth development literature which indicates that we can influence in positive ways the human's developmental trajectory by aligning the potentials for positive change of youth and environments; and (b) ICF framework of person-environment interaction [8] as key to understanding health and disability, [43-45]. Within the view of social context being proposed, the participation of children in typical childhood activities and settings is understood as a contextualized experience which, over time, contributes to development of competence, belonging and self-understanding [4, 46].

Understanding key social environmental and social contextual factors and the intricacies of how these factors interact with each other over time has important implications for the design of services for children with impairments.

*Article Objective*

The purpose of this article is to propose an integrated model of social environment and social context and discuss its implications for pediatric rehabilitation. It was our intent to develop a model that does not support any one paradigm and that has the

capacity to provide equal attention to the individual and to the environments in which children live and function, play and learn [29].

## *An Integrated Model of Social Environment and Social Context*

### *Overview of the Model*

The Integrated Model of Social Environment and Social Context is both person-focused and environment-focused. The intent of the model is to describe the nature of the relationship between the social environment and social context, illustrating the structures and mechanisms that link people to social environments. Figure 1 portrays the Integrated Model. Its horizontal structure represents social context as five key elements: *people, place, activity, objects,* and *time* (discussed below). The vertical structure illustrates the units of social environment consisting of *individuals, family, groups/networks, organizations/institutions,* and *neighbourhoods/communities*, all of which are embedded within macro *cultural, economic, historical, political, social* and *technological* circumstances and processes. The environment affects children through the availability and provision of opportunities, supports, and resources represented in the model by an arrow pointing downwards [4, 30]. Children affect the social environment (e.g., family, organizations) through their choices, active engagement and collaborations in various settings and activities in which they interact with people and objects (illustrated by the arrow pointing upwards) [27, 31]. Together, both arrows represent the ongoing reciprocity of influences. The child is situated in the middle of the contextual elements to

illustrate the interaction of the elements in creating the child's social experience as the child is a 'meaning maker'.

*Insert figure 1 about here*

The model illustrates how people, place, activity, objects and time are all aspects that are experienced, which are important to the processes that emerge and which are affected by the top-down processes emanating from the social environment. The utility of the model lays in its explanation of the transaction between individuals and social environments as mediated through meaning derived from experience, which is afforded by social settings.

In the following sections, we explain the theoretical foundations of the model, distinguish between 'social environment' and 'social context' and then describe the model in detail.

*Theoretical Foundations*

Following the bio-psycho-socio-ecological approaches of Bronfenbrenner [32] and Sameroff [33] we take the view that the ongoing interaction/transaction between attributes of child and social environment is important to understanding long-term developmental benefits and is a critical mediating factor in development and health.

Transaction suggests plasticity of both the environment and the individual as they engage in change and it signifies the dynamic relationship of people with the aspects of the external world [15, 29]. Both the individual child and social environment change with time due to transactions that occur between them as children actively negotiate their social settings [34]. This thinking reflects a shift from a mechanistic world view to a

systemic-organic world view in which environments, like individuals, interact with each other and affect each other [32, 33, 35]. This view calls for integrative and relational models, measures, and designs that help capture the changing relations between the individual and the environment [36]. An integrative framework that provides equal attention to the individual and to environments is beneficial to understand aspects of social environment in relation to child health and disability [35].

Our approach integrates various viewpoints and is (a) interactional/transactional, (b) ecological/environmental, (c) functional/experiential, (d) relational, and (e) health and development-focused. First, the model is *interactional* on the social contextual level (among the elements) but transactional between social environment (reciprocal pathways of influence) and social context (meaning a person accrues). Development and change are neither a function of the individual alone nor a function of the social environment – they are products of the combination of environmental characteristics and child's experience [15, 29, 33, 35].

Second, the model is *ecological/environmental* as it focuses on both children within social environments and on the social environments [37-39], and it combines individual and environmentally-focused perspectives. An ecological perspective emphasizes environmental factors as playing the major role in child development, and proposes the existence of spheres (or systems) of environmental influence on the person [37, 38]. Environment-focused perspectives consider social phenomena, groups, communities and social organizations, as well as the interactions, functions, and patterns within them [22, 40].

Third, the model is *functional/experiential* as it integrates an 'outside-in' view – looking at the individual from the outside – with an 'inside-out' view – looking at the external world from the perspective of an individual. The outside-in view represents a functional perspective that considers the environment as an external force that is a source of demands and expectations, providing conditions that facilitate or inhibit a person's performance and/or competence. Thus, this perspective views the social environment as an arena for action with opportunities, supports, and resources [4, 8, 10]. The inside-out view represents the *phenomenological* perspective that highlights the importance of the meaning of an experience to a person, suggesting that social context should be understood and studied from the individual's perspective [41].

Fourth, the model is *relational* [33] because it considers a child in relation to people and the wider community where the child lives and it draws attention to changing relations among different social environmental units, which are interconnected (e.g., family, school and children's rehabilitation centre). Lastly, the model focuses on *healthy child development* and building *healthy environments* for all children, not just children with impairments.

In rehabilitation science, the ecological approach has been widely accepted; however, not much attention has been given to children's actual experiences of particular environments, including social relationships. We propose that capacity building as a rehabilitation intervention should reflect not only the capacity for function [1], but also the building of capacity for development and change within both children themselves and their social environments. A conceptual framework based on a clearer understanding of

the transaction between environmental and experiential aspects could be useful for designing interventions that optimize children's social participation and long-term social, competency-related, and psychological-emotional benefits [4].

*Distinction Between Social Environment and Social Context*

There are various conceptual propositions of social environment and/or social context, either individually-based or society-based, depending on disciplinary traditions and theoretical viewpoints (person-focused or environment-focused traditions). Despite the lack of uniformity in use of the terms and conceptual viewpoints, similar elements and mechanisms are discussed by many authors. These similarities formed the basis of our model of social environment and social context that integrates both sociological and psychological perspectives.

We propose that environment is external to the individual and context is related to people's experiences. '*Social environment'* is a broad concept involving specific geographical, cultural, and institutional location and reflecting a conception that includes both physical and social dimensions. It describes aspects of the physical environment configured by human social processes [47, 48]. Social environment is based on location, and both physical and social structures (e.g., families, groups, and organizations) [47, 49].

*'Social context'* is conceptualized as the experienced (perceived and understood/interpreted by the people) aspects of the social environment [22, 50, 51]. Context thus refers to inferred meaning, which is linked to norms, scripts, and tacit knowledge of social expectations [50, 51]. Social context refers to people's relationships or connections with others within shared activities or places [52-55]. 'Social

environment' has its effects on people through 'social context' (i.e., the subjective experiences of the individual within their proximal settings).

This means that a child is embedded in a certain social environment [32] and is active [15] – he/she 'meets' that social environment as a series of places, people, activities, and objects situated in time. Thus the opportunities that are provided to enter into interactions with places, people, activities and objects are important. Furthermore, how these opportunities are experienced by a child will depend on the qualities of the places, people, objects, and activities (e.g., supports that enable meaningful experiences) as well as child's personal factors (e.g., preferences, interests, goals, beliefs), and how these transact over time. Ensuring optimal environmental qualities may not always guarantee positive experiences for an individual child [4, 57]. However, without opportunities, supports, and resources, children are not likely to have meaningful experiences of doing, belonging, and understanding self and others, experiences that over time may contribute to long term benefits in both children and social environment [46].

In the sections that follow, notions from both environmental and contextual perspectives are combined to describe an integrated model for pediatric rehabilitation.

*Description of Elements of Social Context*

As shown in Figure 1, social context is comprised of five elements: *place, activity, people, objects* and *time.* All elements interact with one another and all together (i.e., combined) create a contextualized experience. If we consider a child attending a reading program at the local library (i.e., activity setting), the setting of the library, the reading activity itself, the organization of the program, the timing of the session, the books that

the child reads, the tools or resources that are used to help them to read, and the adults and other children in the program, all matter to this child's experience.

Social context at any given point in time is influenced by past experiences and their meaning and by future goals. For example, a child who uses a communication aid may not want to go back to the library if the child felt that, in the past, people ignored his communication attempts and spoke only to his mother. However, for this child it might be more important to go again to the library, because his classmates will be there and there might be an opportunity to talk to them.

*People.* This element is comprised of individuals and their characteristics. It involves the individuals with whom a child interacts [53, 58, 59]. It also involves adults and peers who are present in the child's life [49, 60] and who may participate in selecting activities and places or in organizing the child's time. Adults and peers may include familiar and unfamiliar people, media, virtual characters, or imaginary others, who are not physically present but who may influence the mind of the child (e.g., a librarian, other children participating in the program, a character from a book).

*Place.* The notion of 'place' signifies location as a social phenomenon through its emotional significance and physical and symbolic importance [4, 61]. Place combines the natural world with human history, activities, and aspirations. It helps with forming relationships between people and enables the exchange of information [28, 62]. Place may include a child's typical activity settings, physical space or the virtual space where the child spends time (e.g., a library, the setting where the child accesses an e-book virtually).

*Activity.* Activity refers to what the child does and what is happening around the child. Activities matter to children, are important parts of their lives, and provide developmental context [43, 63, 64]. The field of occupational therapy has a long tradition of drawing attention to contextualized activities/tasks/occupations as central to a child's functioning, learning and well being [65]. Activities provide opportunities for social interaction [58]. The activities in which a child participates may be organized or not, solitary or group-based (e.g., a book club).

*Objects.* Objects have both symbolic (representational) and instrumental significance. Objects are used in the everyday actions and social exchanges of people and they are also considered to be the cognitive artifacts through which people interact with their environment [66, 67]. Objects may include the toys with which a child plays, educational tools, or technology used by youth (e.g., an e-book that is read aloud by a computer).

*Time.* There are different meanings of time. In the model, one is the point in time and the other refers to a process-oriented view ('over time'). Social context is rooted in the 'here and now' as interactions with environment occur at a specific time [28]. What we do, with whom, with what, and where is related to the temporal dimension. People may select the activities (or occupations) they engage in, who they meet, or where they go based on the time at which they occur, as well as past experiences and/or future goals (e.g., attending a book reading at the library). The second meaning of time, 'over time', refers to how the other four elements of social context change over time [28]. For example, a child may only have access to seasonal organized leisure programs (e.g., summer camps).

*Social Environment: Its Units of Analysis*

Despite some minor variations in the literature, similar primary units of social analysis have been identified by many authors. These consist of the individuals, family, group/network, institution/organization, and neighbourhood/community, as well as macro social forces involving cultural, economic, historical, political, social and technological processes [40, 68-70]. All these are codependent and they all together are important to understand the child's social context.

*Model Relationships and Mechanisms*

The model shows how the social environmental and contextual components are interconnected, both horizontally and vertically. Horizontal patterns in the model refer to interactions of contextual elements [50, 53] – namely, *interactions* among people, activities, places, objects and time. Within sociological literature, vertical patterns link different social units to one another (e.g., families to community) [47, 71, 72, 73]. In our model we unpack these links and propose the bi-directional mechanisms connecting across the environmental levels. For example, policy will regulate an educational setting for a child with impairments (segregated or integrated), which in turn, influences who the child's classmates are (top-down). On the social contextual level this may affect developing friendships (meaning accrued from the here and now and symbolic influences of understandings of the social units). However, the child may have peers in the neighborhood who play with him after school. Similarly, there may be lack of government funding for (a) an assistive device that the child needs, however a local organizations may raise funds to help family; or (b) a library, which will restrict

purchasing books, however, people from the local community may donate books to the library, thus affecting available resources.

The above examples illustrate that it is important to consider both vertical and horizontal connections together to understand children's every day experiences and social environments over time (see Table 1). The environmental units are thus connected for individuals through their actual experiences (afforded by opportunities), their perceptions and understanding based on their daily experiences and meaning derived from experience [15, 74], social context is thus fundamental – where it all comes together.

Table 1 presents examples of social context elements with respect to different environmental units of analysis. Figure 1 shows the relationships.

*Insert table 1 about here*

The processes in the model are represented by broad environmental socio-cultural processes and the processes through which children and the micro social environment affect each other. The social environment and people engage and affect each other through reciprocal processes that represent ongoing interactions that contribute to certain outcomes (individual and environmental) [30, 9]. In our model, we propose that environmental processes affecting children, families, and communities involve the nature and quality of available *opportunities, supports and resources* [40, 26]; where each social unit affords the opportunities, supports and resources for the units below (cascading effect). For example, the opportunities to participate with other children at school and after school, to be with peers, to engage in activities in meaningful ways, to interact with familiar and unfamiliar adults and peers, to spend time in a meaningful way, and to have

choices about friends and activities. Provision of supports may involve the social, emotional, and practical assistance of other people (their behavior) or of the place (design and set-up related to accessibility). Resources may include the influence of materials such as *funding* for schools and rehabilitation centres, *people* (e.g., teacher to student ratio; qualifications and skills of therapists) and *services* (What is available? How easy are services to access? Are there waitlists?).

In terms of the processes that emerge in response to experienced (perceived, understood and interpreted) opportunities, resources and supports and through which individuals affect their social environment, the literature points to individual or group actions such as choice and decision-making, active engagement, self-expression, advocacy, or collaboration, partnership and coalition building [24, 27, 60]. Although the specific terms used by authors may differ, they refer to coordinated action/behavior and the *exercise of choice*. Therefore, the integrated model posits three key processes through which individuals affect their social environment: choice, active engagement, and collaboration. *Choice* refers to their intrinsic motivation in relation to social settings; choosing activities, places, time, objects, and people; making choices as to entry into them and within them [4, 31]. Choice is not only instrumental (e.g., selecting activities or objects) but also, and most importantly, it means autonomous decision-making and control, being in charge, and having a say in things [75].

Engagement has been defined as the physical or behavioral (e.g., attendance), cognitive (e.g., expectations, beliefs) and emotional involvement [76] and meaningful engagement has been identified as a key process that drives development and change

[15]. Deriving meaning and a sense of purpose directs actions [15; 29; 34]. How the individual explains experience, in turn, motivates him/her to create new experiences [15]. For example, a child may choose how to spend time not by selecting an activity but rather by who will be there; 'hanging out' may be meaningful to that child to derive a sense of belonging.

Social involvement has been defined as (a) presence (e.g., a child without disabilities attends a performance where children in wheelchairs dance), (b) encounter (e.g., a child who uses a communication aid meets a stranger who is asking him for directions), and (c) participation (e.g., children with impairments playing together with their peers from the neighborhood) [77]. Although Clifford Simplican and colleagues [77] suggest that only participation matters to social inclusion, our model suggests that all above may be important because it is the meaning derived from *all* three types of involvement by *all* involved that needs to be considered if we are concerned with building capacity within *both* children and our social environments (i.e., both perspectives). Subsequently, we propose that *active engagement* within places and activities and with objects and people has a reciprocal effects on the social environment. For example, if the child in the library see a child using a communication aid talking to the librarian, he/she may perceive this child as a potential conversation partner.

*Collaboration* refers to how individuals form relationships/partnerships/alliances and act together to influence the issues that affect them [27, 78]. The term conveys the idea of sharing and implies joint action that is oriented toward a common goal [79]. The community development literature indicates that communities cannot change unless

people are actively involved in issues that affect their lives [27]. For example, collaboration could refer to groups of people – families, service providers, representatives of community agencies – taking initiative and meeting together to develop inclusive community programs or to change policy according to their own needs and priorities.

Opportunity structures, supports and resources are *afforded* by environments and they may or may not support genuine involvement (e.g., there is an opportunity for parents to join a research project concerning their child, but a parent may be not be motivated to participate in such a group). The processes of opportunities, supports and resources elicit certain responses from a child, which in turn affect others involved. The child's presence and what the child does contribute to particular experiences of *all involved.* For example, the staff can change the program to provide a better experience for children with disabilities, rather than just end the program. However, such a choice needs to be afforded by the institution where the staff is employed.

Key to understanding transaction is process of change, which refers to the covert and overt actions and experiences that individuals engage in [15; 29]. Because meaning is derived from both the qualities of places, people, objects, activities and from the sense a child makes of the experiences and actions [46], the desired positive change will more likely occur if there are opportunities, support and resources that enable a child's meaningful experiences of doing, belonging and understanding [4]. Our model concerns not only personal change (within a child), but also interpersonal, and organizational change and proposes how one set of processes (opportunities, resources, and supports) affects the other (choice, active engagement and collaboration) across time. Figure 1

represents the social context situated in ‘now’ and the ‘over time’ aspect is depicted by the arrow pointing towards the healthy development of children and healthy social environment.

Children, by pursuing their goals via processes of choice, active engagement, and collaboration within the environmental constraints, opportunities, resources and supports available in their social settings, influence and create the social structures of their local environments. Consequently, the social environment continues to change, children change and their contexts change [40, 80].

*Discussion*

This article has proposed a model of the social environment and social context that is grounded in current developmental theories and integrates person-focused and environment-focused perspectives, and developmental literature that emphasizes the importance of experience on development [1, 43, 64]. The model provides simultaneous attention to children, to the social environment and to their transaction.

To our knowledge there are no models that *integrate* the perspectives of social environment with how individuals experience it, and describe processes of child-environment transaction with direct relevance to rehabilitation science. Our model emphasizes the importance of focusing simultaneously on both the development of children and the changes that might be occurring in their social environments.

The proposed model aligns well with current conceptual propositions that underscore the importance of transdisciplinary views of human development and function and that combine the dialectics of nature and nurture [29, 35]. Our model responds to the call to:

'create new frameworks that do not privilege any one method or any one paradigm (…) and to provide equal attention to the individual and to the environments in which individuals find themselves across time' [35] (p.287-288); and to integrate the opportunity structures from sociology and the intent and meaning-making constructs from anthropology and psychology [29]. Opportunities for experiences that have meaning are at the heart of the developmental process [15]. Attending to children's and families' subjective experiences of objective environmental qualities and processes could have predictive power for understanding individual differences [29] and also may help us to better understand how to prevent long term disability.

The proposed model points to the importance of experience and meaning. Recently, more attention has been given in the rehabilitation literature to subjective experience [81] and the meaning derived from participation in activity settings [57], recognizing that *competency* and *performance* are not always sufficient when considering children's health. Experiences can be either developmentally supportive or inhibiting; they can shape and reinforce values, goals, activity interests and choices, skill development, exploration and creative expression, and may nurture interpersonal relationship building [15, 31, 82, 83]. Meaningful experiences have been linked to *optimal* environments, which have certain opportunity-related, social and physical-aesthetic qualities [31].

Furthermore, the model has implications for building children's capacity and the capacity of social environments, as it proposes two sets of transactional processes by which capacity develops. The model is congruent with the recent health promotion and prevention literature, which directs attention to changing social environments through

intra-personal, inter-personal and community-level interventions that are designed to prevent disability (e.g., secondary physical or mental health issues for children with impairments) [4, 6, 83]. The social environment becomes the direct focus of rehabilitation intervention as it can provide affordances (i.e., opportunities, supports, and resources) for children and families that ensure growth-enhancing and health promotion experiences (e.g., before the child who uses graphic symbols for communication begins to attend a new school, all students at this school receive education about different ways people can communicate and how to support such interactions).

Considering environments functionally encourages a focus on the doing or performance aspects of the environment. Considering how different aspects of the environment are actually experienced, though, encourages a focus on how the child's mind is shaping environmental perceptions and future experiences [15, 74]. It is important to combine perspectives and study environments in both ways – functionally and experientially.

*Implications for Pediatric Rehabilitation*

This paper presents a model that can help researchers and practitioners to 'unpack' the complexity of how individuals and social environments are linked over time. In particular, we focus on children and youth, because developmental and long-term thinking has been missing from some functionally-based rehabilitation propositions and service delivery models. A functional perspective may suggest a goal oriented, relatively static solution (e.g., provision of graphic symbols for a child to communicate in a classroom) and does not necessarily reflect the dynamic nature of child-environment

transaction, which calls for solutions that extend beyond the particular child-environment context and may affect developmental trajectory (e.g., building capacity within the school and in the community to support meaningful experiences of children who communicate using graphic symbols). Such an approach suggests that interventions (even if they are brought about by policy) all ultimately end up being about changing the proximal social context. People can do something upstream (e.g., health promotion efforts) but ultimately, for change to happen, things need to change on the 'here and now' level.

The model can be applied to different situations involving the social context and the child's experience of it. Any issue relevant to developmental outcomes could be approached from a broad perspective with the model as a guide to looking at objective and subjective features/factors. There are measures that can help to assess the 'objective' environmental qualities and youth's 'subjective' experiences of activity settings [46]. Evaluating these aspects can assist to link youth's experiences to specific characteristics of the environment [57] and may ultimately contribute to the design of appropriate environmental-level interventions. Understanding individual experiences can help to identify how therapeutic and community programs may promote child-specific outcomes and family well-being.

To afford children with impairments with positive experiences, the model points to building capacity within all levels of the social environment - from child, family, peer groups/networks to organizations/institutions and community. Possible capacity building interventions are directed at providing opportunities, supports, and resources in relation to places, people, objects, time, and activities, within families, schools, and communities.

For example, the provision of particular resources in public places may enable children's interaction with others in meaningful ways [84] and creating and supporting natural opportunities in which children with communication impairments interact with their peers in their neighborhood could have an effect on all participating children (e.g., peers' attitudes towards children with impairments) [85]. Developing interventions together with children, families and community providers to educate and share information may build children's, families' and community capacity [84, 86, 87]. By providing opportunities, resources and supports that foster choice, active engagement and collaboration over time, rehabilitation services may affect social environments and children's experiences in desirable ways.

*Limitations of the Model*

This work has a number of limitations. First, we need to clarify that our work focused on the description of aspects of the social environment and important elements of social context and key environmental and contextual processes, showing how they work together in a reciprocal fashion; however, not how they affect specific rehabilitation outcomes. A need for this type of description and clarification has been identified in recent literature [6, 22, 40]. The trans-disciplinary integration of conceptual literature about social environment and context can be criticized for oversimplification from any single disciplinary perspective. Our stance considers multiple viewpoints not as competing alternatives; rather, we propose that the social environment and social context is best understood from multiple viewpoints [33]. The model needs to be used and assessed critically before we can draw any conclusions about the relative importance of

the elements and relationships that have been described. We suggest that the model may not be only specific to children and could have broader application. However, developmental issues are particularly important to rehabilitation services with children with disabilities.

Future research may examine changes in the quality of children's experiences over time as the outcome of specific environment-focused interventions. Longitudinal studies could help to determine how specific intervention programs directed at capacity-building within social environments have effects on children. By studying the complex mechanisms of child-social environment transaction, we may gain important insights into how to facilitate development and desired health outcomes and how to design the best services to support children and families.

### *Conclusion*

This article has described an integrated model that outlines the key elements of social environment and social context, and highlights the mechanisms of child-environment transaction. The utility of this model lies in understanding: a) social context as a subjective situated experience of activity, place, objects, people, and time; b) the bi-directional sets of processes through which children/youth and the social environment affect each other; and c) the dynamic nature of social context and environment. This model may assist researchers and practitioners to identify and study key factors that may enhance the capacity of both children and their environments, viewed through the social processes that lead to healthy development of children and to the creation of health promoting environments. We hope that this article contributes to providing conceptual

tools and language to practitioners, policy-makers, and researchers about how it might be possible to understand the lived experience of childhood – children's social context. The model provides a step towards an increased understanding of the connection between environments and functioning of children and could help researchers and clinicians to consider the multiple pathways through which disability may be prevented.

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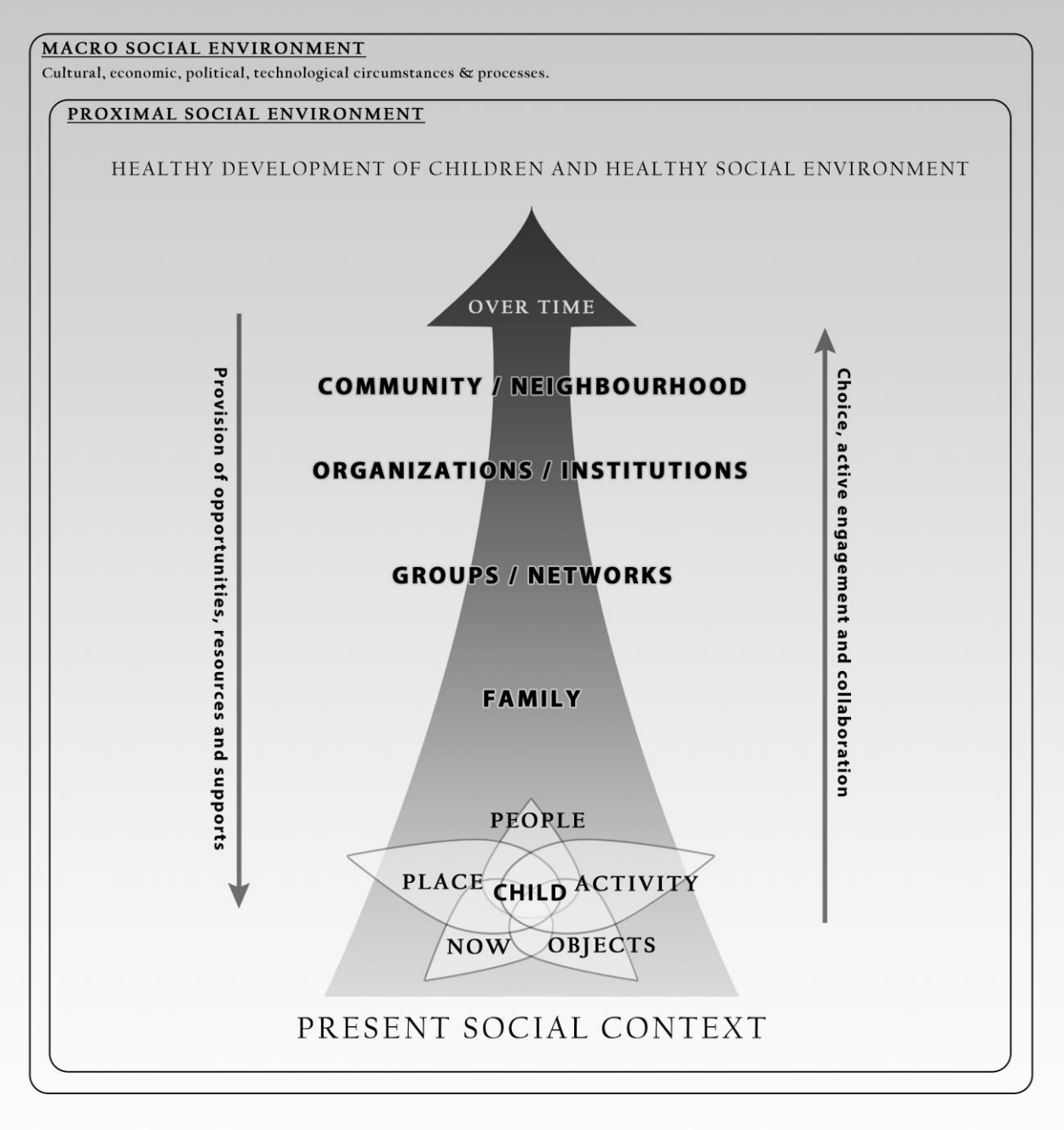
Table 1. Examples of the intersection between the social context and the social environment.

| **Social Context** | **Social Environment** | | | | | |
|---|---|---|---|---|---|---|
| | **Child** | **Family** | **Group/network** | **Organization/ institution** | **Community / neighbourhood** | **Macro** |
| **People (who)** | Child's characteristics | Parents and siblings and their characteristics<br>Availability of extended family | Friends / peer groups, sport teams and their characteristics | Personnel at school – teachers, educational assistants, therapists and their characteristics | People with whom child interacts after school, beside family and their characteristics | Cultural rules for social interaction with peers, adults or strangers |
| **Place (where)** | Where the child goes and spends time (e.g., grandmother's house) | Where the family lives<br>Where the family goes | Where the child participates in after school activities (e.g., community library) | School the child attends<br>When things are happening at school | The geographical area of the neighbourhood (e.g., safety) | Economic circumstances |
| **Activity (what)** | What the child does during the week; typical activities | How the family spends time<br>Activity preferences and habits (e.g., planned, structured | What peers do and if they attend organized structured events | After school activities organized by school | Activities available in the local library; What children in the neighbourhood do on the weekend | What culture accepts as an age appropriate activity |
| **Objects (with what?)** | Toys, books, technology, any other material resources that child has | Material resources available at home (e.g., toys, educational, computers) | What peers play with; playground equipment | What therapy materials are available in the children's centre<br>What material resources are at school | What books are available in the local library | Meaning attached to objects; cultural values as to which objects are appropriate, healthy or safe in relation to various situations |
| **Time (when, how long)** | How the child spends time (e.g., reading at home) | How the family spends time (e.g., structured vs. unstructured activities; planned activities) | If peers and friends attend organized structured events | Waiting list for services<br>When things are happening at school (e.g., if parents can attend) | What kids in the neighbourhood do on the weekends | Cultural values as to what time is appropriate, healthy or safe in relation to various situations |

Figure 1

*The Integrated Model of Social Environment and Social Context*



# Chapter Five: Discussion

The purpose of this dissertation was to explore the social context, participation and goal-oriented communicative interactions of the expressive group of children who use AAC – children characterised by a significant gap between their comprehension and expressive skills. This work was intended to improve our understanding of the processes that may contribute to the success of interventions with this specific group of children. This chapter first provides an overview of the findings, then outlines the contribution of the thesis to the AAC field specifically, then its overall conceptual contribution, placing the findings within the context of the interdisciplinary literature. Research implications of the findings are included throughout. Finally, the AAC clinical implications and limitations of the overall thesis are described.

## Overview of Findings

Chapter One synthesizes the empirical evidence outlining the need to support children's meaningful experiences within their social context and to support children's development. In addition, this review emphasises the need to better understand the construct of social context and the processes by which children and social environments influence one another. Through a review of the emerging evidence of social context and participation of children who use AAC, these multiple issues are apparent and highlight the profound challenge for these children to be active and in control. This chapter underscores our limited understanding of the social context and participation of these

children, especially from their own and their parents' perspectives, as well as the need to enable the child's active role within typical childhood activities.

The following two chapters (Two and Three) represent the next step towards increasing our knowledge of social context and social participation of children from the expressive group. These studies were conducted with the goal of informing clinical intervention, first to gain a unique account of children's voices, as well as their parents' views, and then to help uncover children's communicative abilities.

Chapter Two describes a qualitative research study in which 8 children and 8 parents participated separately in interviews, discussing their lived experiences in relation to children's social contexts, social participation and relationships with others. From the parents' and children's accounts we learn about the discrepancy between a child who wants to be with others, to be involved and take part, and how these wishes are not often supported by institutions or individuals in the child's environment (e.g., people not having time to interact, restrictive policies, lack of access to communication aids). This study enhanced our understanding of the lived experience of this understudied group of children, highlighted the importance of their perspective, and identified the need for further research in the area of social participation and potential need for changes in service provision, so children can be meaningfully involved in childhood activities.

Chapter Three describes a research study in which 35 children (18 who used AAC and 17 typically-developing) were videotaped during 238 construction play interactions with their peers, parents and teachers. The play activity was structured in such a way that the children with motor impairments who could not physically manipulate toy objects

were still able to lead play by using a communication aid. This study identified the success of children using AAC in carrying out an active role in construction play with others through communication, and also highlighted some differences between these children and their typically developing peers. Findings also pointed to a potential lack of opportunities or experiences within daily play contexts in which children with AAC are not dominated by others.

Chapter Four proposes a model of social environment and social context that integrates current developmental theories with health promotion and positive youth development literature. The purpose of this model is to help elucidate the ongoing child environment interaction within a given social activity setting (i.e., social context) and between the child and larger units of the environment (family, group, etc.) and also to illustrate how environmental intervention focusing on providing opportunities, supports and resources for meaningful experiences can contribute to children's long-term health and developmental benefits. The analytical units proposed in the model need to be further tested.

**Contribution to AAC**

The contribution of this dissertation for the expressive group of children using AAC specifically lies in highlighting: (a) the crucial role of communication aids, which allow children to interact and demonstrate their language and communicative abilities, given the opportunity; (b) the social interaction challenges attributed to communication partners' control over social situations, especially lack of time, willingness to engage in interaction,

and familiarity with children using AAC; (c) communication as children's strength related to the overall social participation; and (d) the need to support everyday meaningful participation experiences across multiple activity settings, providing opportunities for active engagement and autonomous communication within the context of childhood activities.

This dissertation adds to the emerging body of work about the social context, participation and communicative interactions of school-age children who use AAC. Studies involving children using AAC have typically considered a range of children who use some form of AAC (i.e., a heterogeneous group in various aspects of their functioning or diagnostic groups); it is unique to study only the group of children who have high receptive abilities. This approach allowed us to learn about the achievements and challenges specific to these children, who are very limited in terms of their motor abilities but have cognitive skills similar to their peers. Studies with similar populations of children are currently being conducted in 16 countries, in an effort to learn more about their language development and communication (von Tetzchner et al., 2015).

In the following sections, I discuss the specific contributions to current AAC knowledge in the areas of social context, social and communicative participation, and goal-oriented communicative interactions, along with the research implications of the findings.

***Social Context, Social and Communicative Participation***

Since this dissertation research began, studies from other countries have reported that children using AAC: (a) had restricted out-of-school activity participation, (b) had restricted social participation and interaction with peers, (c) had limited locations for activity engagement; (d) participated in activities close to home; and (e) took part in passive recreational activities (Clarke et al., 2011; 2012; Raghavendra, Virgo, Olsson, Connell, & Lane, 2011; Raghavendra, Olsson, Sampson, McInerney, & Connell, 2012; Thirumanickam, Raghavendra, & Olsson, 2011). Clarke and colleagues (2011; 2012) also found that the perceived effectiveness of the communication aid was not related to the level of participation and that the child's emotional functioning and family impact were predictors of out-of school participation, suggesting an influence of the social context. Evaluating only levels of participation (higher or lower) as done in the above studies is difficult to interpret, because more participation is not necessary better. Thus quality of social participation may be better appraised by considering an individual's experience (King, Rigby, Batorowicz, 2013).

The study in Chapter Two adds a unique contribution to this recent body of literature, in that the children were actually interviewed and thereby provided insight about their social context and participation experiences. Other than the ongoing study by von Tetzchner and colleagues, only one study has directly interviewed school-aged children using AAC about their out-of-school activity settings and participation experiences (Gibson et al., 2014). In this study, a newly developed measure of self-reported

experiences (King et al., 2014a) was used in conjunction with face-to-face interviews, followed up by questions sent via email.

Children with cerebral palsy in general, similarly to children in the study described in Chapter Two, indicated that doing lots of things was important to them; however, that doing was not related to level of independence but to engagement in activities, which children considered important to them (Kramer & Hammel, 2011).

The findings of the study described in Chapter Two emphasize the significance of communication and communication aids, especially electronic devices, to children's overall social participation and interaction. When parents of children who use AAC were interviewed about their parenting experiences, they also indicated that communication and communication aids were critical factors in their children's experiences (Marshall & Goldbart (2008). This echoes findings of Trembath and colleagues (2010) and Blackstone and colleagues (2007) who reported that communication played a pivotal role in determining social experiences of adults using AAC.

Similar to work by many authors (e.g., Kent-Walsh & McNaughton, 2005; von Tetzchner & Martinsen, 2000), the current study noted the dominance of communication partners as well as a lack of ongoing access to reliable communication aids. However, the dominance of the communication partner was related not only to turn-taking and occupying the time, but most of all to control. The positive experience of control (i.e., being in charge) was emphasised by more than 600 children with disabilities as a key to supporting their participation (Eriksson & Granlund, 2004). In the current study it was the communication partner who controlled entry into a social situation, the interaction, its

length and the departure from the situation, often despite the child's protests. Thus, a child is left to rely not only on communication aids which might not be working, might break down, might not be available, or might lack the appropriate vocabulary needed to say what the child wants to say (Kent-Walsh & McNaughton, 2005; Smith, Murray, von Tetzchner, & Langan., 2010), but is also dependent on the willingness of others to engage in age-appropriate interaction with a child who uses AAC. These frustrations all became apparent in the analysis of the child transcripts. The lack of willingness of other people to engage in communicative interaction with adults who use AAC was observed by Smith and Murray (2011) with regard to service providers.

Consequently, one may ask if the reported notion of passivity and lack of initiation in children using AAC (Finke & Quinn, 2012; Salminen, Petrie, & Ryan, 2004) might reflect the reaction of children to specific people (i.e., there are 'two kinds of people') and the choices that they make, based on prior experience. Similarly, adults who use AAC reported dichotomous social experiences with other people (i.e., 'wonderful' or 'hell') (Trembath, Balandin, Stancliffe, & Togher, 2010). Choice and control are instrumental to children's wellness and quality of life (Prilleltensky, Nelson, & Peirson, 2001), and positive experiences may erase negative ones as new meanings are developed (Seligman & Csikszentmihalyi, 2000).

Issues of time seemed to be prevalent throughout the dissertation findings and it is also a recurring topic in the AAC literature (Kent-Walsh & McNaughton, 2005; Smith et al., 2010; von Tetzchner & Martinsen, 2000). The study in Chapter Three indicates that it took children using AAC, on average, 5 times longer than their peers to complete the

goal-oriented interaction. Although not all of this could be attributed purely to communication time, it may be assumed that even thinking about vocabulary and where to find a word within the communication device is related to communication for these children. From the qualitative study described in Chapter Two, we learned that time was the major barrier to children's social interactions with others. Other studies have reported the slow pace of communication using AAC; however, this has often been attributed to a child's abilities or limitations of technology (Fager, Bardach, Russell, & Higginbotham, 2012; Fager, Beukelman, Fried-Oken, Jakob, & Baker, 2012). The current study shifts the focus to the communication partners who do not take the time to engage in interaction with the child who uses AAC. Similar observations were made by Trembath and colleagues (2010), who noted that successful interaction of adults who use AAC occurred when partners allowed them sufficient time to get the message across.

Multiple studies on social networks indicate that, beyond family members, professionals interact most frequently with children using AAC (Beukelman & Mirenda, 2013; Blackstone et al., 2007). Professionals within current service delivery models (e.g., consultative) may not be supported to take time to interact directly with a child who uses AAC, as already noted in the case of adults (Smith & Murray, 2011); instead, they may talk to parents or educational assistants about the child. Furthermore, parents in the current study talked about the lack of community programs that were suitable for their child to attend and identified a need for more experiences outside of the home.

The model proposed in Chapter Four, with its bidirectional influences between an individual and the social environment, would suggest a dependency that may be created

within the system as parents seemed to wait for things to be organized by therapists and did not feel that they had an opportunity to influence the situation. Furthermore, because the social environmental levels are connected transactionally, as proposed in Chapter Four, it may be that the sense of lack of control experiences in the child is linked to control experiences within the family and affected by the lack of opportunity and support structures. A lack of adequate support structures was found in studies that explored experiences of adults who use AAC (Hodge, 2007; Smith & Connolly, 2008) and the development of a coordinated system of support was suggested (i.e., policy across education, health and social services).

In the study in Chapter Two, especially concerning is a general lack of peers in the child's social context, despite parents' efforts to arrange time for their children to be together with peers. This is not a new concern (e.g., Clarke & Kirton, 2003) and recent studies reported that peers were considered to be helpers of children who used AAC (e.g., Raghavendra et al., 2012), rather than assuming a more 'equal' role during activities. It was also found that although children who used AAC had more interactions with adults in comparison to children without disabilities, they reported lower levels of meaningful engagement (King et al., 2014b). Chapter Two also highlights the importance for children to attend the same activity settings over time (e.g., programs with peers). This may help children to develop lasting connections and possibly friendships with peers. O'Keefe and colleagues (2007) found that adults using AAC identified building and maintaining friendships as one of the key principles of AAC research.

Although much emphasis has been placed on people's attitudes as a social environmental barrier (e.g., Light & McNaughton, 2014; Beukelman & Mirenda, 2013), the study described in Chapter Two suggested that lack of knowledge and intimidation might also be issues. McCarthy and Light (2005) found that people had more positive attitudes towards individuals using AAC if they had previous experience with people with disabilities. A need to educate society about AAC has been identified in other studies in which parents of children using AAC were interviewed, regardless of the topic of the study (Dattilo et al., 2008; Marshall & Goldbart, 2008; McNaughton et al., 2008).

### *Goal-oriented Communicative Interaction*

Chapter Three's unique contribution is its description of: (a) a method to involve children in structured play with others, breaking the dominance of communication partners and creating conditions for autonomous communication; (b) a method of analysis and coding of the goal-oriented interaction; (c) the achievements of a group of children using AAC when they were 'in charge' of a play situation collaborating with the communication partner to solve tasks; and (d) the challenges these children had, in comparison with their peers. Children in this study were willing to exert tremendous effort to interact with familiar partners, were engaged and, although they had less success than their peers, could do well when given the opportunity and time. Sundqvist and colleagues (2010) also found that three girls who used aided communication could control the conversational interaction and that adults provided less opportunities than peers

during conversation. No differences between communication partners were found in the current study, possibly due to the nature of the goal-oriented interaction.

While Chapter Three highlights children's achievements, it also reveals group differences between children using AAC and children naturally speaking and suggests larger variation within the AAC group. The variability in children's cognitive functioning is worth noting and emphasises the importance of using adapted cognitive assessment (Schiørbeck & Stadskleiv, 2008) in the design and methodology of studies with this population. Cognitive assessment is not routinely done because standardized tests cannot be used. However, the recent studies pointing to perceptual and learning challenges for children with cerebral palsy in general (Jenks, Lieshout, Maathuis, Keus, & Gorter 2006) and for children who use AAC specifically (Binger & Light., 2008) suggest that these issues should be addressed. Results of this study call for the thorough assessment of non-verbal reasoning, which in both groups correlated significantly with communicative success. The work conducted in this chapter underscores the necessity of including detailed descriptions of children using AAC, with emphasis on their motor, cognitive, and language skills, and details of the aided systems (e.g., graphic, orthographic, combination). A general need for more information regarding the characteristics of children using AAC has been also noted by other researchers (e.g., in Schlosser, 2003).

While we know from previous studies that children who use AAC rely heavily on answering yes-no binary questions and co-construction of messages with their communication partners (Smith, 2003; von Tetzchner & Martinsen, 1996), our results now extend the knowledge to situations where communication partners do not have the

context information and need to rely on the child's language and communicative abilities and problem solving. The predictable or known content of interactions has been often discussed as supporting children's communication and lack of shared content as an additional challenge for children using AAC (e.g., Light & McNaughton, 2014). However, from the results of the study presented in Chapter Three, one could argue that children from the expressive group can communicate autonomously and problem solve, given the opportunity and time.

The developmental benefits of social play and the general lack of information about social play of children using AAC have been discussed in Chapter Three. Parents of children using AAC identified both the importance and the lack of opportunities for their children to be involved in play activities (McNaughton et al., 2008). The AAC field needs methods and strategies to engage children meaningfully in play activity contexts with their peers, giving children control and a more equal role. Encouraging a child with severe movement and communication impairments to become more active within age-appropriate activities has been a challenge noted previously; however, this has typically been in relation to the physical operation of communication aids, switch-adapted toys or message selection methods (e.g., Cook & Polgar, 2008; Higginbotham, Shane, Russell, & Caves, 2007). While adapting activities is often described in the occupational therapy literature, the focus has been on physical independence (e.g., see Case-Smith & O'Brien, 2010). However, *doing* may be accomplished in various ways, capitalizing on children's strengths, as described in this study, which exemplifies doing via language and

communication. The study in Chapter Three supports a need for integrating disciplinary perspectives (Batorowicz & Shepherd, 2008; 2011).

The goal-oriented interaction could be considered to be related to the functional perspective, however, this method as implemented in the current study – within the settings where children would typically engage in construction play (i.e., home and school) – can be viewed as specific design of an activity setting to bring about particular benefits of language development, as done previously in studies in community psychology and occupational therapy (e.g., Segal & Hinojosa, 2006). The activity adaptations described in this dissertation may be useful for clinical assessment purposes, as well as for intervention. Referential communication tasks have been discussed in language acquisition literature in relation to the communicative acts in which two speakers exchange information such as giving directions or telling stories based on pictures (Yule, 1997). Such tasks offer a natural opportunity to elicit autonomous communication (Clark, 1992) and, when used within the context of children's play activity, they can be motivating and fun for all children involved. In the future, the procedures and tasks developed within this study may provide a useful template to analyse goal-oriented communicative interactions. This template could be expanded to include the details of paralinguistic interaction to gain full understanding of the multimodal communication.

In previous studies (e.g., Angelo, 2000; Bailey, Parette, Stoner, Angel, & Carroll, 2006) as well as in the study described in Chapter Two, parents of children who use AAC expressed their wish for children to be more autonomous communicators. Adults using

AAC reported their autonomous communication as one of the key factors to successful social participation (Trembath et al., 2010). Language and augmentative and alternative communication provide a chance for children to be active in the world and to develop autonomy. Particularly for children with severe motor impairments, goal-oriented communication in general may have profound importance, which extends beyond communication and into all aspects of life – doing, choice and control, and decision making (see Collier & Self, 2010). Kramer and colleagues (2011) found that children with disabilities had a desire to direct decisions regarding specific supports and accommodations for them. A need for establishing greater independence and intelligibility of communication, which requires linguistic skills, has been also noted by Light & McNaugthon (2014) because of the possibilities offered by social media and the increased demands for the development of literacy skills to enable access to information technologies and social media (Williams, Beukelman, & Ullman, 2012).

Future studies should measure the significance of the experiences for children, after they had participated in similar types of activities. This may provide insights into the meaning derived from participation and could be compared to other activity settings in which children are more passive or just observe what is going on around them. Furthermore, the self-reported experiences could be linked to the specific opportunities provided within each activity setting. Appropriate measures are now available that will allow for this type of data collection (see King, et al., 2014a and King et al., 2014c).

**Conceptual Contribution**

This dissertation (Chapter Four) makes a conceptual contribution beyond the population of children who use AAC and is relevant to all children, by (a) defining social context and social environment; and (b) suggesting the specific units of analysis, namely five interacting contextual elements and two sets of transactional processes. This chapter brings together concepts from psychology, sociology, rehabilitation science, positive youth development and health promotion literature and integrates the following ideas (a) everyday activities and occupations as pathways to development, health and well-being (e.g., Law, Petrenchik, Ziviani & King, 2006; Petrenchik & King, 2011; Townsend & Polatajko, 2007); (b) importance of active engagement (e.g., Granlund, 2013), choice and control (Prilleltensky et al., 2001) and meaning in daily activities/occupations (e.g., Hammell, 2004); (c) subjective aspects of participation and the need for self-reports (e.g., King et al., 2013; Raghavendra, 2013); (d) linking opportunity structures to positive psychosocial outcomes (e.g., Gorter et al., 2014); (e) activity settings as units of analysis relevant to rehabilitation science (King et al., 2014d); (f) key role of family (e.g., Raina et al., 2005; Rosenbaum, 2007; Rosenbaum & Stewart, 2007; Rosenbaum & Gorter, 2012) and community (e.g., King, 2004) in intervention; and (g) participation-based interventions (e.g., Batorowicz, McDougall, & Shepherd, 2006; Palisano et al., 2012).

The conceptual model proposed in Chapter Four attempts to unpack the complexity of child-social environment transaction and to relate key concepts/elements to each other. Although transactional models are not new (e.g., Sameroff, 1975; Law et al., 1996), the contribution of the current model lies in its identification of the reciprocal mechanisms of

influence. This implies not only a deterministic approach (top-down influences), and not only pragmatic (bottom-up), but both, where the child actively negotiates and seeks meaningful experiences within supports and constraints provided within activity settings by their own action, which contributes to both their own development and to changing various units of the social environment.

Within the literature on typical child development, child-parent relationships and teacher-parent relationships have been examined, and more recently so have the multilevel transactional relationships (child-parent-culture) (Bornstein, 2009). However, the emphasis has been on risk rather than supportive factors (Sameroff, 2010) and the unidirectional or top-down processes of linking social institutions to individuals (e.g., the neighborhood effects literature; Sampson, Morenoff, & Gamon-Rowley, 2002) with minimal attention to reciprocity of interaction and the upward processes of how individuals affect environments. This dissertation, similar to the positive youth development literature (e.g., Lerner, 2002; Mahoney, Larson & Eccles, 2005), concerns aspects supporting children's development and understands health as a multifaceted construct, comprised of mutually intertwined physical and psychosocial factors (Prilleltensky et al., 2001).

As shown in this thesis, it is worth noting that, despite multiple challenges, and lack of opportunity to engage in typical activities, most children do progress in language development. Although there is an implicit conjecture that the development process can be influenced through the manipulation of external factors (Smith, 2003), other explanations are possible. In contrast to a constructivist position (e.g., Piaget, 1977)

which views the environment as essential to development, a nativist position (e.g., Chomsky, 1972) suggests that the path of developmental change is predetermined (i.e., innate and constrained). This thesis would actually support the bio-psycho-socio-ecological approach and unified theory of development (e.g., Bronfenbrenner, 2005; Sameroff, 2010), suggesting that it is a combination of factors that are responsible for change and progress, including factors both external and internal to the individual. Further investigation of the phenomenon of development in the absence of optimal experiences is warranted; as suggested in Chapter Four, future studies could consider how the 'outside' and 'inside' factors transact over time.

Chapter Two and Three findings address particular aspects of the proposed model. Specifically, the qualitative study provides insights about the children's and parents' experiences, their subjective perceptions, understanding, and interpretation of the child's social settings and communicative and social interactions within these settings (i.e., multiple social contexts). The quantitative study informs us about children and their communication partner's interaction in a very specific activity setting, in which certain opportunities, resources and supports are provided/assumed (i.e., structure and activity adaptation, time, communication aids and toys). The next stage of research of this model could focus on determining - if a specific opportunity is provided as intervention – the way in which this links with the child's perception of that experience and their communicative outcomes.

**Putting Development Back into AAC**

> *Development depends on experience and learning gained from the unique perspective of child in the midstream of becoming a person. The child actively seeks meaningful experiences relevant to her current needs and interests and makes pragmatic sense of what she encounters in the world, in close relation with adults who care for, support, and guide her.* Nelson, p. 11.

Evidence suggests that children with disabilities experience similar developmental trajectories to their peers without disabilities – through positive and developmentally appropriate life experiences (Gorter et al., 2014). However, a developmental approach is often forgotten in interventions that consider assistive technology solutions for the here and now – to meet a current and specific need. As noted by Light & McNaughton (2013; 2015), the field of AAC has been overtaken recently by high technology that offers many opportunities, but there is also a danger of forgetting the person. As this dissertation highlighted, a growing child needs ongoing meaningful experiences with others to develop competencies, a sense of belonging, friendships, skills, self-efficacy and self-determination.

The model proposed in Chapter Four could help guide the design of studies within the AAC field, taking into consideration the subjective aspects of an individual's experience. The model and the other literature now emphasize building capacity within social environments, creating developmentally favourable environments, supporting social interactions with peers in a variety of settings, freedom of expression and choice, and communication, and the opportunity to develop a sense of belonging and connections with others (Bazyk, 2011; King et al., 2013a; Petrenchik, King & Batorowicz, 2011;

Gorter et al., 2014). Longitudinal studies are required to better understand developmental outcomes over the life course and how person-environment factors contribute to change.

**Clinical Implications**

There are several clinical implications inherent in this work. There seems to be a discrepancy between the accepted social models of practice and actual practice in AAC where communication aids are often "prescribed' (Batorowicz & Shepherd, 2008) and clinical work focuses on technology much more than on social interaction and social context (Light & McNaughton, 2013). Current service delivery models may match AAC technology to the child and offer training about how to operate the device and program messages (Light & McNaughton, 2013), but little time is left to focus on supporting the child's actual participation in different social settings, especially outside of school (Batorowicz, McDougall, & Shepherd, 2006).

If a child is just seen in a children's treatment centre, therapists may lack a comprehensive picture of their social context, outside of their observations within their practice setting. However, the review of qualitative research with children and youth with disabilities showed that children had meaningful experiences when services were individualized to the unique needs and strengths of children within their various life circumstances (Kramer, Olsen, Mermelstein, Balcells, & Liljenquist, 2012).

Within the context of the proposed model (Chapter Four) the question remains: How can we create service delivery programs that transform our communities, giving all children and their parents, voices, choices and ways to meaningfully engage? First, this

work suggests environmental intervention by providing ongoing opportunities, supports and resources for children to participate and engage actively in a range of social activity settings, at school and in the community. Second, we need to take the time to ask children and parents directly about the meaning of those experiences to ensure that children and parents perceive opportunities, resources and supports present in the social setting as facilitating development, so that interventions can have the intended effects. Third, for children who use AAC, this dissertation highlights the need for more opportunities (a) to be involved together with other individuals who use AAC as well as with their typically developing peers; (b) to support relationship-building through participation in activities and programs with the same peers over time – allowing deeper connections to develop; and (c) to have the time to provide autonomous and precise communication.

Martinsen and von Tetzchner (1996) pointed out that we need different interventions for different language groups and the expressive group of children has unique needs – they do not necessarily require support for comprehension, but need experiences in all kinds of childhood situations and settings. This dissertation emphasises family and client-centred practice in AAC (King, Batorowicz, & Shepherd, 2008), pointing to supporting the active participation of children within their families and communities in accordance with their own interests and goals.

Chapter Four, like the health promotion and prevention literature (e.g., Bazyk, 2011; Wagemakers, Vaandrager, Koelen, & Saan, 2010) and a recent review on developmental trajectories of individuals with disabilities (Gorter et al., 2014), points to shared responsibility of families, communities and institutions/government in creating and

providing appropriate social environments, emphasising opportunities for children who use AAC to have choice and voice, to meaningfully engage in typical childhood activities in their neighbourhoods and have a say in things that are important to them.

**Limitations of this Research**

The limitations of each study are described in the manuscripts, while the limitations of the thesis as a whole are discussed here. The findings are specific to the expressive group of children who use aided communication (i.e., children showing a large gap between comprehension and expressive skills, who use AAC). The sample was small and heterogeneous and the study design ran concurrently. For the empirical studies, recruitment was limited by the small population size available in the province. Judgment of children's cognitive abilities was dependent upon therapists and teachers and made recruitment difficult. The data collection process was extremely slow due to the pace of interaction documented in both studies. Therefore, the conceptual model and the two empirical studies were developed in parallel, one informing another, which could be considered a strength or a limitation.

**Summary**

This thesis has explored the social context, participation and goal-oriented communicative interactions of children aged 5 to 15 who have severe motor and communication impairments and use communication aids. The unique finding of this dissertation is the emerging picture of a social child, who is capable of interacting with

others, who can adapt to different communication partners and potentially repair communication breakdowns, but who often lacks opportunities and experiences to demonstrate and use their abilities; they desire to be with peers, to interact with unfamiliar people, and to interact with other people who use AAC.

This work promotes the importance of a developmental approach and child-social environment transaction as a theoretical framework for pediatric rehabilitation. Furthermore, it suggests that further research and interventions focus on providing opportunities for participation and autonomous communication within typical childhood activity settings, rather than just provision of communication aids. It proposes interventions that address the contextual elements needed to support an active child, who expresses his/her voice, makes choices and is allowed to play – wishes captured at the beginning in the poem written by Whitney.

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