PLAY IMAGINED: ENABLING CHILDREN THROUGH EXPLORATIONS INTO CREATIVE PARTICIPATORY DESIGN METHODS

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

> MASTERS OF APPLIED ART in Design

EMILY CARR UNIVERSITY OF ART + DESIGN Vancouver, British Columbia

2009

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ABSTRACT

This thesis essay and accompanying project explore the use of a generative toolkit designed to involve children with disabilities in the design process. A generative toolkit includes an assemblage of visual materials including several pages of word stickers, carefully selected images, basic shapes, coloured paper and a space on which to arrange them. This thesis is part of a larger ongoing study involving collaboration with children to design a play space in the therapy department at Sunny Hill Health Centre for Children in Vancouver, BC. Discussed are the modifications to the toolkit and iterative testing, to determine the function and accessibility of the components. The insights of this study come from recognizing the collaboration between two seemingly different disciplines, industrial design and occupational therapy.

Adults often underestimate the ability of a child or youth to meaningfully contribute to decision-making and research. This may lead to the design of objects and environments that reflect more of an adults' view of the world, rather than acknowledging the valuable perspectives that children have to offer. While involving children with disabilities in research activities may present challenges, efforts to empower them and provide a measure of control over their physical world can contribute to their sense of well-being. Input from children with disabilities can contribute valuable insight to inform the design of products and environments that are meaningful and relevant for them.

Building on Sanders and Stappers' (2008) approach to co-design and generative toolkits, this essay offers a listing of practical suggestions for research and design teams who wish to bring the input of children with disabilities into the design process. The findings consider the World Health Organization's International Classification of Function, Disability and Health framework, the practical and ethical issues involved when researching with children and youth with disabilities. The research can be extended to develop inclusive toolkits for adults with physical and cognitive limitations, and the elderly. The results could contribute to the increased quality of products for independent living, multi-sensory, communication and positioning and mobility equipment. Additional applications include the design of healthcare education programs, services, knowledge transfer materials, and adaptations to the built environment for accessibility. Implications also involve the area of designing for social impact, including international health, where communication may be limited due to physical, cognitive, social and cultural factors. This study, which employs concepts from the sociology of childhood, theory of affordances, person-centered practice, and sensory integration, illustrates that the toolkit is a valuable, creative and visual method with application for children with disabilities in participatory design.

KEY WORDS

Co-design, co-creation, generative tools, toolkit, design research, universal design, inclusive design, participatory research methods, participatory design, creative research methods, people-centered design, industrial design, occupational therapy, affordances, sociology of childhood, International Classification of Function, Disability and Health.

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PREFACE

As early as I can remember I was influenced by my parents' backgrounds, their interests in science and art, and their resourcefulness; they are bricoleurs of sorts. My parents were constantly inventing, patenting and making everything from homemade dollhouses, blue jeans, to a fish smoker made from an old fridge, and a 'Weed-screen' to prevent weeds from growing in the garden. It is their influences that have led to my creative interests, career as an occupational therapist (OT) and current Master's Degree of Applied Arts in Design.

When I decided to pursue my Master's Degree at Emily Carr University, it felt like a natural progression from my personal, professional and practical interests. Before coming to Emily Carr I practiced occupational therapy for eight years. Working at Sunny Hill Health Care for Children in Vancouver, I assessed children's feeding abilities, prescribed and designed specialized equipment for children with disabilities (such as custom seats for wheelchairs). I began to see the potential for design to make a difference in the healthcare setting. As an occupational therapist I felt limited in my practical skills and ability to translate these opportunities into a tangible form. Through exploring the design process, research methods and applied skills, I hoped to extend my practice as an occupational therapist.

My course of study in design at Emily Carr has had a significant impact on my way of thinking, observing, and working. Design research has shifted my perspective from hoping for somewhat of a career change, to reflecting on my position as an occupational therapist practicing design research. The notion that visualization through creative methods can support, deepen and enrich my practice as an OT has been a significant realization for me. My training as an occupational therapist does not have to be left behind to embrace design; to the contrary, the use of design methods has the potential to greatly enrich my OT practice. The past two years of research have resulted in an acknowledgement of my background and a discovery of the connections between industrial design and OT that I previously had not been fully cognizant of. Creativity has been rediscovered and validated in my practice through design research.

ACKNOWLEDGEMENTS

During the past two years a number of people have shared their time, ideas and knowledge with me, creating a supportive research community. These collaborations have both challenged and enriched the way that I think and practice in research and design. I would like to extend my gratitude to the many people who have contributed to this process.

First, I wish to thank my husband Matt for his incredible support and for keeping my life balanced outside of this thesis; my family for their encouragement, and the young designers Julian, Sidney and Adam. I am deeply grateful to my faculty advisor Louise St. Pierre from Emily Carr University, whose guidance, encouragement and patience was integral to my research and the writing of this thesis. Her philosophy of education and her experience in interaction design, medical assistive design and designing for children, have been invaluable influences for me. I also thank her for mentoring a student not formally trained in industrial design, and supporting me throughout this process of learning.

My appreciation goes to Liz Sanders, whose work this thesis is largely founded on, for providing her comments and ideas. I would also like to thank my colleagues in the design stream of the Masters of Applied Arts (MAA) program at Emily Carr University - Kara, Joanna, and Rok, together with students from previous and subsequent years, for your support and sharing your exemplary work as research designers. To my colleagues in the visual arts and media streams of the MAA program, I thank you for lively interdisciplinary discussions that helped me to broaden my view of art and design.

My appreciation goes to the many other outstanding individuals in the Emily Carr community. I thank you for sharing your support, inspiration, and encouragement over the past two years - Ron Burnett, Monique Fouquet, Renee Van Halm, Rob Inskter, Dawn Whitworth, Deb Shackelton, Paul Mazzucca, Charles Dobson, Jim Budd, Sharon Romero and Bonne Zabolotney. I also thank Karolle Wall for her insight and support toward the content and form of this thesis essay.

I would also like to recognize Lori Roxborough, at Sunny Hill Health Centre for Children in Vancouver, for being instrumental in the play space study, and for providing support and guidance for my research project. To my exceptional colleagues at Sunny Hill, I say thank you for your encouragement and assistance in the project. I am extremely grateful to Anna Vouladakis for her commendable industrial design mentorship and support.

Finally, I would like to acknowledge the number of others who offered their mentorship, time and comments throughout my studies. They are, Niki Dun - Design for Development, Alida Lindsley -Whirlwind Wheelchair International, Alice Osborne - thinkpublic - UK; from the Healthcare, Technology and Place Network (HCTP) at the University of Toronto: Annmarie Adams - McGill University, Patricia McKeever - University of Toronto, and Pascale Lehoux - University of Montreal.

DEDICATION

This thesis research is dedicated to the children, families and health care providers at Sunny Hill Health Centre for Children in Vancouver, British Columbia, Canada, whose enthusiasm and creativity provided the inspiration, material and support for this research. I also dedicate this thesis to my parents, Christina and Peter Sawrenko, their creativity, inventiveness, and work in health care have led me down the path I am on today. Grown-ups never understand anything by themselves, and it is exhausting for children to have to provide explanations over and over again.

- Antoine De Saint-Exupéry, The Little Prince

INVITATION

If you are a dreamer, come in, If you are a dreamer, a wisher, a liar, A hope-er, a pray-er, a magic bean buyer... If you-re a pretender, come sit by my fire For we have some flax-golden tales to spin. Come in! Come in!

- Shel Silverstein, Where the Sidewalk Ends

PART ONE - A PRIMER

CHAPTER I: INTRODUCTION

The main objective of this thesis is to review a series of explorations involving the design and use of a set of creative research methods, known as a toolkit, with children with disabilities. Disability in this essay is defined broadly using the World Health Organisation's Classification of Function where "disability serves as an umbrella term for impairments, activity limitations or participation restrictions" (World Health Organisation, n.d., introduction page). The use of the toolkit is part of a larger participatory design study, aimed at involving children in design process to design a play space in the therapy department of Sunny Hill. Sunny Hill is a rehabilitation centre that is affiliated with British Columbia Children's Hospital and provides specialized health services to for children and youth with disabilities from birth to their nineteenth birthday, with:

- Complex developmental needs. These children may have difficulties with language, cognitive and motor abilities. They may also have difficulty with sensory, social and, or emotional development.

- Conditions primarily affecting physical or motor development, including cerebral palsy, children who are non-verbal, children who have difficulty swallowing, children who require mobility assistance, children with visual impairments, or children who need adaptive recreation.

- Identified inpatient needs, such as orthopedic post-operative needs and acute brain injury rehabilitation. (Sunny Hill, n.d.)

This research has provided a unique opportunity to combine participatory design techniques with the perspective of occupational therapy (OT). It aims to contribute knowledge in design and OT by offering further understanding of the use of the toolkit as a research method with children with disabilities, making new connections between OT and industrial design, and working in underresearched areas; for example, the participatory design of healthcare spaces involving children with





Figure 1. Examples of typical materials in a generative toolkit, 2001, by permission ¹.

disabilities. This research captures new evidence and explores the value of the toolkit as a research method in pediatric healthcare.

Much of contemporary design practice in the area of human factors ³ focuses on end-users' participation in the design process. There is an emphasis on collaborative, creative and meaningful activities toward the design of products that meet peoples' needs. Co-design and generative toolkits are two examples which exemplify this perspective. In participatory design with adults, generative toolkits have shown to be a valuable method for allowing the creative expression of people's current experiences and thoughts to generate new ideas (Sanders & William, 2001). In this thesis co-design is defined as the collaboration between children, their parents, and the researcher, or author (Sanders & William, 2001). Creative research methods employed in the study include tasks such as drawing,

collage ⁴, photography, and building models. A generative toolkit is described as an assemblage of ambiguous visual materials including several pages of word stickers, carefully selected images,

basic shapes, coloured paper and a space on which to arrange them (Sanders & WIlliam, 2001) (see Figure 1). In this essay, the use of the term 'toolkit' will be synonymous with 'generative toolkit'.

Ambiguous materials are items that have the potential for many interpretations and meanings by the participant; they are more abstract than concrete in nature. Gaver, Beaver and Benford (2002) state that in design, ambiguity can be an opportunity for people to interpret situations about their own context; this can lead to deeper, more personal relationships with systems or objects.

1.1 OCCUPATIONAL THERAPY - A HOLISTIC FOUNDATION

Occupational therapists bring a unique skill-set and holistic perspective that have the potential to enrich participatory design. Likewise, the design process and research methods have much to offer occupational therapy. Both disciplines have the potential to enrich the other, and to push their practice and research further.

This section introduces my background as an occupational therapist and my opportunity to engage in design research, factors which position me as a hybrid research designer. Tony Dunne defines a hybrid designer as a person who embodies the characteristics of an artist, engineer, designer, and thinker (as cited in "Perimeters, Boundaries and Borders", 2008). Liz Sanders also discusses the notion of the hybrid designer in her article the 'New Landscapes of Design" (Sanders & Stappers, 2008), wherein she asks, "Who are the new hybrid research-designers?" (p16). In responding to Sanders' question, I propose that OTs have the potential to be hybrid researcher designers. Finally, Schon (1983) acknowledges a range of professions in the arts and sciences that engage in creative problem solving. Similarly, I have begun to recognize the connection between OT and design through the iterative process of reflection and action.

Occupational therapy engages in a holistic approach to knowing, thinking and interacting with people. It can be described as a humanities based profession that is both an art and a science, as well as a practice that is productive and creative in its work (Kronenberg, Algado, & Pollard, 2005). OT is focused on the ability to enable people to participate independently in everyday,

meaningful activities which are specific to each person and might include things such as sharing a meal, taking care of pets, or tending a garden (Kronenberg et al., 2005). Similar to the design process, OT practice uses a multi-staged, iterative approach that is often described as a continuous loop; goals and objectives are defined, actions are taken and reflected upon, goals and objectives are then redefined, and the cycle begins again. One difference perhaps, is the client-centered model that guides OT practice.

In OT practice, the term 'client' refers to the end user, whereas in design, it refers to an intermediary between the designer and the end user. The term 'client-centered' in OT practice is equivalent to user, human or people-centered in design circles, and is rooted in Carl Rogers' theory of the same name in psychology. In client-centered practice, the goals and needs of the client are paramount. For the purposes of this paper, the term 'client' refers to the end user. Participatory design and co-design research are beginning to bring the designer closer to the end user. I have come to recognize that many of the tenets of occupational therapy practice resonate with the current perspective of human centered, participatory design. These include the use of methods that are participatory, creative, capacity building, people centered and inclusive. Keeping this in mind, the research explores how designers can work more closely with the end user, particularly in healthcare design where sensitivity and empathy are paramount.

As an OT, my role is often that of a facilitator, educator and advocate. OTs regard people as the experts of their own experiences and recognize "each of us as a spiritual being that is trying to construct meaning in our life" (Kronenberg et al., 2005, p.155). This acknowledgement has led to a greater level of understanding and empathy toward the children and families that I work with. It is through my work, that I began to ask, could I, as an occupational therapist, listen more deeply and empathically to the needs of children and families? Could I be fun and creative in my interactions as a health professional, with colleagues, children and families? And, could positioning and mobility equipment be both functional and delightful? This thesis addresses all but the last question.

In my previous work at Sunny Hill, I collaborated with children, youth, their families, community therapists, and technicians to design and build adaptive positioning and mobility

equipment (e.g. custom seating for wheelchairs and bed positioners). Throughout this process, in cases where oral communication was ineffective or impossible, I tended to use gestures to communicate design parameters; for example where a child required support, or how big an element of the system needed to be. Reliance on gestures alone would often result in miscommunication, leading to many iterations of the design and equipment trials. In many cases, the process became long and arduous for the child and their family. At this time, I was unaware of how helpful a simple sketch or visual model would be in communicating my ideas to children, youth, families and colleagues. I have learned that the visualization of information is integral to designers, as expressed in the use of visual research, sketches, models and prototypes. The value of visualizing information and research has been a significant discovery in my studies at Emily Carr.

While this thesis is influenced by my practice as an occupational therapist, it is primarily informed by participatory design, qualitative research methods and human centered practices in industrial design. My training as an occupational therapist has provided me with an awareness of how activity or occupation such as 'keeping busy through the hands' can facilitate healing, health and well-being. The engagement of a person in activity provides a greater understanding of their context, thoughts and feelings. This has led to my awareness of the potential for the toolkit to enable the articulation of tacit knowledge for children and their parents in the design process, in the healthcare setting.

1.2 OBJECTIVES

The intent of the project is to meaningfully involve children with disabilities in design research through the use of child-friendly, creative visually engaging media, or materials that focus on their strengths. In this thesis, child-friendly research methods refer to an approach that is understandable from a child's perspective. This can include play and media that are familiar to children (e.g. comics, arts and crafts materials) (Berglund, 2008). Ideally these methods are determined by the children themselves for how they would like to participate in the research. Child-friendly research methods are also attentive to children's levels of energy, exhaustion, frustration, or

interest in completing tasks (Berglund, 2008). This thesis project is exploratory and hypothesis generating versus hypothesis testing. Questions guiding the research have been prioritized and are:

- 1. Can the toolkit facilitate or augment non-verbal communication?
- 2. Does using the toolkit encourage empathy for the participants, and foster a deeper understanding of the children for the author?
- 3. Can toolkits be a complementary method for occupational therapists, other healthcare providers, and researchers in healthcare?
- 4. Do toolkits encourage the articulation of participants' needs, hopes, fears and desires?
- 5. What toolkit materials are most successful for children in terms of ease of use, adaptability, flexibility, level of engagement, and the ability to facilitate the expression of imagination, creativity, fun, opinions and ideas?
- 6. Is the toolkit easier for children to engage with than traditional methods such as interviews, surveys and questionnaires?

CHAPTER II: BACKGROUND RESEARCH

Primary influences have included literature on play and art therapy, human geography, sociology, pedagogical approaches (e.g. Froebel, Montessori and Friere), design and architecture involving the use of participatory, creative activities with children in the design process (Dudek, 2001, 2006; Hemming, 2008; Malchiodi, 1999; McCarthy, 2008; Spencer & Blades, 2006; Rasmussen, 2004, West, 1992). The design of the toolkit is based on Liz Sander's generative toolkits and guided by James J. Gibson's theory of affordances, Carl Roger's theory of client-centered practice, the sociology of childhood and Jane Ayres' theory of sensory integration (Case-Smith, 1996; Greene & Hogan, 2005; Kytta, 2003; Spencer & Blades, 2006; West, 1992).

Sanders and Stappers (2008) argue that "all people are creative, but not all people are designers" (p. 12). They state that there are four levels of creativity that people engage in throughout their daily activities (Sanders & Stappers, 2008). An individual's level of engagement varies based on their knowledge and curiosity. In addition, a person's level of commitment is related to their physical, cognitive function, and contextual factors. Sanders and Stappers' (2008) levels of creativity directly relate to using creative methods in participatory design. Further, Louridas (1999) discusses design as a human activity that "impinges on the human condition in general" (p. 15). He also writes on the notion of "unselfconscious design...which is design without designers", and guided by tradition and ritual (Louridas, 1999, p. 8). If creativity and design are inherent activities to us as human beings, how might a child design a space to play if given creative materials and tools to envision their ideas? And, would tradition and ritual be reflected in their creations?

Table 1

Four levels of creativity

| Level | Туре | Motivated by | Purpose | Example |
|-------|----------|-------------------------------|--------------------------|--------------------------------|
| 4 | Creating | Inspiration | 'express my creativity' | Dreaming up a new dish |
| 3 | Making | Asserting my ability or skill | 'make with my own hands' | Cooking with a recipe |
| 2 | Adapting | Appropriation | 'make things my own' | Embellishing a ready-made meal |
| 1 | Doing | Productivity | 'getting something done' | Organising my herbs and spices |

Note. The table is from "Co-creation and the new landscapes of design" by Sanders, E.B. -N. & Stappers, P.J., 2008, p. 12. Copyright 2008 by Taylor and Francis. Reprinted with permission.

2.1 PARTICIPATORY DESIGN

Although the larger play space project incorporates both participatory action research (PAR) and participatory design approaches, this thesis essay focuses primarily on the participatory design aspect involving the use of the toolkit. The combination of PAR and participatory design has allowed me to draw on the strengths of each framework to support the design challenges within the project, and encourage participants to openly contribute throughout the research. Although these two approaches are similar in their participatory nature, they are different in their goals and methods (Foth & Axup, 2006).

Participatory design aims to produce practical and realistic designs through frequent collaboration with stakeholders (i.e. end users, researchers, developers, workers and management) using informal "ethnographic and in-situ methods" (Foth & Axup, 2006, p.2). This might include questionnaires, observations, surveys, creative workshops and focus groups. In addition, while it is acknowledged that alternative approaches exist in participatory design such as role-play, bodystorming, prototyping and simulations, generative toolkits are well suited to children with a range of physical and cognitive abilities in the early stages of the design process. (Buchenau and Suri, 2000; Ehn and Kyng as cited in Wardip-Fruin and Montfort, 2003; Ireland as cited in Laurel and

Lunenfeld, 2003; Moggridge, 2006; O'Grady and O'Grady, 2006; Oulasvirta, Kankainen, Kurvinen, 2003). In this project, it is important for the children to generate a number of ideas quickly, easily and successfully in the early stages of the design process. The toolkit is a participatory design method aimed at developing practical and appropriate solutions through engaging, creative visual materials that focus on each child's strengths. The toolkit also allows for activities to be adapted to meet a wide range of needs. Whereas, methods such as bodystorming may be less inclusive and effective for children with limitations in mobility due to the emphasis on large body movements.

Participatory design enables participants to collaborate and contribute to the research process to "ensure it is authentic, useful, fair, ethical, and relevant" (Foth & Axup, 2006 p.1) and can also serve to bridge the gap between the research activities and real life practices (Foth & Axup, 2006). In this project, the combination of participatory action research and participatory design methods allowed for the inclusion of both design and qualitative research approaches, which had both practical and ethical benefits. Ethically, this combination allowed for a framework that was congruent with the hospital ethics committee, addressed the intentions for the study to actively involve children throughout the design research process, respect children's autonomy, and maintain a child centered approach that views children as informants rather than objects of research (Cappello, 2005).

Current examples of individuals and organizations (among many others) practicing creative participatory design methods include the work of Liz Sanders, Bill Gaver, IDEO, the Design Council and thinkpublic in the UK. In their work, creative methods such as drawing, collage and photography are employed to enable people to communicate their hopes and fears toward the design of products, healthcare environments, policies, systems and services.

Participatory action research (PAR) endeavours to generate change and knowledge through the empowerment of individuals or groups (Veale as cited in Greene & Hogan, 2005). PAR includes cycles of collaborative planning and information sharing, action, observing and reflection (Creswell, 2003, 2006; Foth & Axup, 2006; Kemmis and McTaggart as cited in Denzin and Lincoln, 2005; Swann, 2002; Trentham and Cockburn ctd. in Kronenberg, Salvador & Pollard, 2005). PAR also

acknowledges the collective knowledge, or perspectives of lived experiences within groups of people.

PAR resonates with OT philosophy, practice and values including client-centeredness, reflection and a holistic point of view. Assessments in OT practice typically involve interviews, questionnaires, standardized tests, and observations. OTs often include creative art based activities, play and role-playing in both the assessment and intervention stages of their practice. However, the aim of these activities is commonly therapeutic rather than a primary method to explore an individual's goals, ideas and opinions. Participatory design methods support PAR to "foster a kind of 'playfulness' about action", while creating "opportunities for participants to adopt a thoughtful but highly exploratory view of what to do" (Kemmis and McTaggart as cited in Denzin and Lincoln, 2005, p. 580).

2.2 THE IMPORTANCE OF INCLUDING CHILDREN IN PARTICIPATORY DESIGN

Contemporary research, theory and policy support childrens' abilities and rights to share ideas, be acknowledged and have the opportunity to influence change (Darbyshire, MacDougall & Scholler, 2005). The UN Convention for the Rights of the Child encourages the inclusion of children in decision making, adults' recognition of their ability to make decisions and the use of creative activities to communicate with children (United Nations [UN], 1990). Addressing children, the convention states:

All adults should do what is best for you. When adults make decisions, they should think about how their decisions will affect children; You have the right to give your opinion, and for adults to listen and take it seriously; You have the right to find out things and share what you think with others, by talking, drawing, writing or in any other way unless it harms or offends other people. (UN, 1990).

The toolkit promotes these articles of the convention in its design and in the methodology surrounding its use.

Involving children and youth throughout the design process is important when creating objects, environments, systems and services that are meaningful and relevant to them. Thomas and O'Kane (1998) also argue that by providing children and youth with a sense of control using child-friendly methods, research would not only be more relevant and meaningful, but also more reliable and valid. The creative activities and materials included in the toolkit are inherently child-friendly, provide a sense of autonomy, and an opportunity for the participant to meaningfully contribute to the design process.

Adults often underestimate the ability for a child or youth to meaningfully contribute to decision making and research (Darbyshire et al., 2005; Greene & Hogan, 2005; Hart, 1992; Qvortrup et al. as cited in Dudeck, 2005), leading to the design of objects and environments that reflect more of an adults' view of the world (Druin, 1999; Greene & Hogan, 2005; Guha, Druin, Chipman, Fails, Simms & Farber, 2005). While involving children with disabilities in research activities may present challenges, efforts to empower them and provide a measure of control over their physical world can contribute to their sense of well-being.

Including children in the design process honours that they have their own perspectives to offer. The use of the toolkit has the potential to empower childrens' abilities to make decisions and avoids trivializing the importance of their unique ideas and opinions. This can result in expressive and imaginative designs that best meet their needs and offer a sense of increased understanding, awareness and empathy for the designer.

2.3 THEORY RELATED TO CHILDREN'S PARTICIPATION

The theoretical framework for this thesis includes ideas from J.J. Gibson's theory of affordances, Carl Rogers' theory of client centered practice, the sociology of childhood and Jane Aryes' theory of sensory integration (Case-Smith, 1996; Kytta, 2003; Dudek, 2001, 2006; Spencer & Blades, 2006; West, 1992). Two conceptual frameworks are referred to; the Ludic Model (Ferland, 2005) and the World Health Organization's (WHO), International Classification of Function, Disability

and Health for Children and Youth (ICF-CY) (World Health Organization, [WHO], n.d.). These theories and conceptual frameworks are discussed below in the context of their impact on this study.

Gibson's Theory of Affordances considers the range of opportunities perceived by a person through interacting with objects in their environment and the environment itself. As an example, a table "affords sitting at or on, two behaviours with very different goals" (Kytta as cited in Spencer & Blades, 2006, p. 177). In this thesis, affordance theory is related to the interactions with the toolkit materials, the children's ability to participate in the activity, and their response to the research environment. For a child with a disability, objects and environments have different affordances compared to children without limitations. For instance, a playground may be seen as a positive place of social interaction, or, on the other hand, may be perceived as a place of exclusion for a child who is unable to use the equipment due to environmental and social barriers. As well, children often perceive the places designed and chosen for them by adults differently than originally intended by adults (Rasmussen, 2004). For example, for a child, a table may be a secret hiding place or a fort, whereas an adult may have intended it to be used for drawing, playing, or eating.

Affordance theory also considers the social, cultural and emotional factors associated with the physical features of the environment and the person (Kytta as cited in Spencer & Blades, 2006). This holistic point of view supports a social model of disability, regarding disability as a social and political matter, which results from an individual's interaction with their environment, rather than a medical issue occurring within the person (Clover, 2005). The same perspective on disability is also reflected in the International Classification of Function and Disability for Children and Youth (ICF-CY) (WHO, n.d.).

The ICF-CY serves as a conceptual framework to view children's functional abilities and participation. It is based on the adult model, the ICF-D (WHO, n.d.). The ICF framework empowers people through collaboration and encourages the use of common language to foster a neutral or positive view of disability and understanding, as well as communication across disciplines (WHO, n.d.). It encompasses a biopsychosocial perspective reaching beyond an exclusively medical or biological dysfunction. As a classification tool it can be used to provide a common framework,

bridging differences related to space, time, and discipline (WHO, n.d.). The ICF framework could work well as a point of departure for designers researching and practicing in universal design ⁵ or inclusive design ⁶, and medical assistive design. In design, the ICF has been referred to in Gielen's (2005) article involving an approach to designing play objects with children with disabilities. The ICF categories consist of:

1) Function and Disability

- a. Body, structure, and function (i.e. anatomy, physiology, psychology, sensory)
- b. Activities and participation (i.e. communication, mobility, socialization)

2) Contextual Factors

- Environmental factors (i.e. products, technology, inclusiveness, social and emotional support)
- b. Personal factors (i.e. age, gender, social and cultural background, experiences) (WHO, n.d.)

Hogan addresses, and attempts to reconcile tensions that exist between the differing approaches of developmental psychology and sociology concerning research with children (as cited in Greene & Hogan, 2005). He or she criticizes developmental psychology approaches for assuming that children develop in a standard and predictable way, and argues that developmental psychology emphasizes adult values and perspectives, considers children as unreliable, and views them as 'objects', rather than participants (Hogan as cited in Greene & Hogan, 2005).

Alternatively, the sociology of childhood suggests that children are involved social actors and agents (Clover, 2005; Skelton, 2008), and supports their inclusion and ability to contribute to issues related to their families, communities and to research (Clover, 2005; Davies 2007). Carl Rogers' theory of client centered practice also addresses autonomy and self-governance. His theory of client-centered practice provides a humanistic approach to therapy, and an alternative to behavioural and psychoanalytical approaches (West, 1992). Rogers' theory acknowledges that each person is motivated toward growth and self-actualization (West, 1992). The sociology of childhood and Rogers' theory of client-centered practice are important in supporting children's autonomy, inclusion, and participation in research.

The Ludic Model is a framework that considers the participation of children in relation to their play skills. As such, it seemed to be an appropriate lens with which to view children's play and their interactions with the environment at Sunny Hill and the toolkit. The model considers sensory, motor, cognitive, emotional and social domains, and encourages an attitude toward spontaneous and undirected play (i.e. ludic) in children, that stimulates their curiosity, pleasure, imagination, and problem solving skills (Ferland, 2005). The Ludic model also encourages children to be involved in the decision-making process (Ferland, 2005), further supporting the notion of client or child-centeredness.

Jane Ayres theory of sensory integration addresses children's participation from a sensory, motor perspective. Ayres, an OT with training in neuroscience and educational psychology, posited that sensory integration is a neurological process involving the organization of sensory information received from a person's surroundings, influencing the body's ability to function effectively within his or her environment (Case-Smith, 1996). Ayres' theory contributes to understanding the relationship between the brain, sensory information and behaviour. Children can be either over or under responsive to certain stimuli. For example, low light, 'heavy' work (pushing, pulling, kneading), deep pressure and warmth are characteristics that can be calming, while light touch, and scratchy materials might be noxious, and strong scents, or spinning may be alerting, or arousing. In the toolkit, certain materials and activities can afford different sensory responses. These responses can affect a child's ability to interact with and participate in the toolkit activity and the research environment.

2.4 CHALLENGES OF ENGAGING IN RESEARCH WITH CHILDREN

There are ethical and practical challenges to engaging in research with children. Greene and Hill (as cited in Greene & Hogan, 2005) argue that a complete understanding of children's experiences cannot be accomplished due to the nature of their responses in research situations. For

example, children often want to please versus tell the truth, they go between reality and the imagined, respond better to open ended versus closed questions, and have a tendency to answer 'no' when they do not understand a question (Greene & Hill as cited in Greene & Hogan, 2005). Greene & Hill suggest that researchers can strive at best, to acknowledge the strengths and limitations of the information children provide, be sensitive to the challenges of doing research with children, and account for this in their methodology (as cited in Greene & Hogan, 2005).

A primary concern of engaging in research with children is the power imbalance that is present between the adult researcher(s) and the child (Mishna, Antle & Regehr, 2004). The literature reflects the significance of this issue and describes ways that the researcher can account for this in their work. This includes being mindful of the nuances of a child's behaviour indicating they may no longer wish to participate in the research. Additional practices consist of using research materials, methods and forms of communication that are child-friendly, inclusive, and "in tune with children's ways of seeing and relating to their world" (Hart, 1992; Hemming, 2008; Mishna et al., 2004; Thomas & O'Kane, 1998, p. 337). In therapy, it has been suggested that play and art provide a "non-threatening and developmentally appropriate" means of communication for children (Malchiodi, 1999, p. 22). Therefore, creative media may have the potential to level the power imbalance that can occur in research with children.

A practical challenge of engaging in research with children is related to their attention span. Holt, Weightman, Allsop, Levesley, Preston and Bhakta (2007) state that children often have a maximum attention span of 30-45 minutes, which may limit their ability to engage in conversations. One suggestion to maintain children's interest and focus is to provide opportunities for 'free' and unstructured activities, such as free drawing, in the methodology (Veale as cited in Greene & Hogan, 2005). Children also need to be given enough time to complete tasks and give responses in research methods (Greene & Hogan, 2005); they cannot be rushed. They may also need frequent breaks to address fatigue, frustration or boredom. Finally, although Darbyshire et al. (2005) found that offering a range of activities contributed to a greater awareness of children's experiences, they raise the

important question of whether using multiple methods in qualitative research with children leads to deeper understanding or contributes to increased stress.

2.5 CREATIVE PARTICIPATORY DESIGN METHODS WITH CHILDREN

Creative research methods are well-suited to engage children, encourage perspectives, feelings, and give information that might influence decision making in the design process. Creative methods in participatory design have been used extensively with children in the design of toys, schools, playgrounds, healthcare environments and technology (Aprile & Keyson, 2008; Baek & Kee, 2008; Berglund, 2008; Druin, 1999, 2001; Dudek, 2005; Erikson, 2000; Fast & Kejellin, 2001; Guha et al., 2005; Kelly, Mazzone, Horton & Read, 2006; McCuskey Shepley, 2000; Simpson, 2007; Spencer & Blades, 2006; Van der Helm, Taxea, Druin, Stringer, Harris & Fitzpatrick, 2006; van Rijn & Stappers, 2007). Various creative approaches in the design of technology and environments have developed, that involve children through Cooperative Inquiry (Druin, 1999; Laughnan, 2004), and the Mosaic Approach, respectively (Clark as cited in Dudek, 2005; Greene & Hogan, 2005).

Children have been described as being able to engage with, and communicate using creative activities such as storytelling, drawing, music, and building, more successfully than adults (Griffiths & Corr, 2007; Thomas & O'Kane, 1998). Hanington (2003) also writes that working with visual and creative research materials in design research is likely to be preferred by participants versus completing a written survey or participating in an interview. Druin (2002) adds that, for children, "traditional research methods of surveys and written tests can be difficult or stressful to negotiate; they may be frustrated with the lack of control or uninterested in the activities" (p. 19-20).

The use of creative modalities provide children with a sense of control and self-efficacy, as well as help to develop skills in decision-making (Malchiodi, 1999). Art in children's play, is one of the few activities that result in the creation of a tangible object. Therefore, the drawings and models that they create become "important, not only for communication of feelings and experiences, but also as a visible and external record of the self" (Malchiodi, 1999, p.17).

Creative approaches commonly used with children have involved storytelling in combination with low tech prototyping methods using familiar arts and crafts materials. For example, white and coloured paper, cardboard, pens, pencils, crayons, string, markers, glue, scissors, tape, play dough, and balloons (Druin, 1999). These materials allow the expression of ideas through drawing, worksheets, building three-dimensional models ("Garden City Park", n.d.; Guha et al. 2004). Technology, such as digital cameras, cell phones, geographic information systems (GIS) mapping, laptops, have also been used as research tools to capture photographs or audio recordings (Berglund, 2008; Druin, 1999; Light et al., 2007). In hindsight, the plethora of possibilities is overwhelming for the author. Key to gaining useful insight from all of these activities is encouraging the child or youth to share the story behind their choices and decisions, thus reducing the likelihood of false interpretations and assumptions of the researcher. Insights generated through creative methods benefit design projects through the establishment of goals that are meaningful and relevant to the children who will ultimately be using the products, systems and services.

2.6 THE USE OF CREATIVE METHODS FOR CHILDREN WITH DISABILITIES

Although specific techniques have been developed to engage children in the design process (Holt et al., 2007), there is limited literature describing participatory design with children with disabilities (Gielen, 2005; van Rijn, 2007; van Rijn & Stappers, 2007). There are even fewer writings that include collaborative design using creative activities and approaches directly with children with disabilities (Buckley, Fennell & Figueiredo, 2005; Holt et al., 2007). Instead, due to the common perception that children with disabilities are unable to effectively communicate their needs, and, or the challenges for researchers communicating with these children, interviews and creative research tools are often limited to their parents, caregivers or peers (Light et al., 2007; Lu Liu, 2007; Prellwitz & Skar, 2007; van Rijn, 2007; van Rijn & Stappers, 2007). Descriptions of toolkits used in designing with children with disabilities is also minimal. Buckley et al. (2005) used drawing, collage, model building, and augmentative communication approaches in their workshop session with youth with disabilities, however they do not describe if, and how, they adapted the activities for accessibility.

Thomas and O'Kane (1998) drew from techniques used in international community development known as Participatory Rural Appraisal (PRA). Activities such as drawing were used together with communities with low literacy levels to facilitate communication. In this situation, the use of creative methods enabled people to share their ideas and opinions without feeling pressured or 'put on the spot' as they might in an interview (Thomas & O'Kane, 1998). Bingley and Milligan (2007) further argue that creative workshop sessions encourage participants who may be less expressive in "focus group sessions or interviews to actively contribute" (p. 295). This is an important consideration when speaking with children and their families about sensitive or difficult issues. Creative activities may have the potential to break down the power imbalances that occur when working with children and in healthcare, when a professional and, or researcher is seen as 'the expert'. This leads to the question of whether creative tools can facilitate communication, empathy and understanding, all of which have increased importance when working with children with different abilities.

Similar to Thomas & O'Kane's (1998) study, one of the objectives for the toolkits in the research is to provide a "repertoire of verbal and non-verbal techniques that can be adapted to the needs and preferences of the child" (p. 343). Play is a form of non-verbal communication (McCarthy, 2008). Play involving creative activities then provides a common language or idiom for clients, designers, researchers and therapists. This common language facilitates communication and provides a level basis for which problem solving can take place (Foque & Lammineur, 1995). This is particularly relevant for children who may have limitations in spoken communication and experience difficulties expressing their thoughts, feelings and ideas. Malchiodi (1999) states that

Art is believed to be a visual language for children and a developmentally appropriate form of communication, especially for young children who may not have the cognitive abilities to express themselves with words. The creative process of art making is not only an integral part of human growth and development, but is particularly important as a means for problem-solving, improvisation, and spontaneous expression for children. (p.16)

Further, McCarthy argues that movement is also "the primary mode of communication for young children" to share feelings and needs (McCarthy, 2008, p. 46). This can certainly be observed in infants and toddlers who are at the pre-verbal stage in their communication. In addition, as humans, "50-90% of communication occurs on a non-verbal level" (p. 46), and we have tendency to believe body expressions over spoken language when the two contradict each other. This raises the question of whether creative activities involving different kinds of movement can facilitate communication in participatory design. Finally, since the use of creative materials also decreases the level of cognitive demand involved in brainstorming (Druin, 1999), this naturally increases the opportunity for individuals with cognitive limitations to participate in the design process.

CHAPTER III: METHODOLOGY

The following chapter provides a summary of the research methodology (see Table 2). A combination of methods were chosen to gain a richer understanding from the children's perspectives. Along with Sanders' and William's (2001) approach to using toolkits in design research, ethnographic observations took place preceding the creative workshop sessions. At the time of writing this thesis, four observations and three initial workshop sessions were completed with the children, youth, and their families.

3.1 ETHICS AND INFORMED CONSENT

The play space study was approved by the research ethics board of British Columbia Children's Hospital (including Sunny Hill Health Centre for Children), the Behavioural Research Ethics Board of the University of British Columbia, and the Emily Carr University Ethics Committee. For children and parents whom English is not their primary language, an approved translator through British Columbia's Children and Women's Hospital was available. Participants were free to request that voice or video-recording be stopped at any time and were free to leave at any point during the workshop sessions or withdraw from the study. In maintaining confidentiality, identifying features of the participants have been removed from this thesis and pseudonyms have been used throughout the essay. Informed consent forms were completed with the parents, guardians, and assent forms completed with the children and youth, for both the participants of the play space study and the pilot testers. The informed consent and assent forms for the study can be found in Appendix A.

3.2 INITIATING THE PROJECT

Besides providing the children and families with information and consent forms for the study, child-friendly invitations were given to the participants. The invitation gave therapists an easy way to obtain participant contact information, while offering a small and engaging 'take away' for the children and families.



Figure 2. Invitation to Participate

Before the observations and workshops, I brainstormed and mind-mapped my expectations and assumptions for the sessions. This reflexivity was an essential element of my research, allowing me to consider my role as an enquirer, my assumptions about childhood, disability, function and creativity. Greene and Hogan (2005) comment that the reflexivity of the researcher is an important factor in increasing awareness throughout the research process. Along with taking into account the effect of my presence on

the research, I engaged in what Donald Schon refers to as

reflection-in-action (Schon, 1983). Following each research activity I considered what I had learned, and how I had applied previous knowledge related to my background as an OT to specific situations. These reflections increased the awareness of my own "tacit knowledge" (Schon, 1983, p. 53), and would be applied toward the next research activity.

3.3 PARTICIPANTS

Four parent-child pairs who receive outpatient therapy services through the Positioning and Mobility Team at Sunny Hill volunteered to take part in the study. The children and youth are between six and nineteen years of age, mixed gender, cultural, ethnic and socioeconomic backgrounds, and have physical and, or cognitive limitations. Three of the participants use wheelchairs as their primary means of mobility; one child also uses a walker, and another uses a power wheelchair in addition to their manual wheelchairs. Two of the four participants have limitations in fine motor skills, two of the children have limitations in speech and communication, and three of the participants have cognitive limitations. All four of the children are able to demonstrate a reliable yes or no response and make a choice between a preferred and nonpreferred activity.

3.4 RESEARCH METHODS

Table 2

Research Methods

| Method | Description |
|-----------------------------|---|
| A. Ethnographic Observation | Initial meeting where the researcher introduces themselves, the project, and observes the participant in the therapy department. |
| B. Primer Activities | First activity taken by the participant, involving two tasks (camera and worksheet) with the goal of encouraging the participants to begin to pay attention to the research topic during their day to day activities. |
| C. Pilot Testing | To determine which objects and activities might be most successful during the workshop sessions and make revisions accordingly with a group of pilot testers. |
| D. Workshop Session | Creative workshop session using the toolkit with the participants in their home or school environment. |
| E. Analysis of Data | Typically takes place after the workshop sessions have been transcribed. Data analysis is not part of this thesis research, and will occur in the future stages of the play space study. |

A. ETHNOGRAPHIC OBSERVATION

The observation sessions were guided by the Ludic Model, a conceptual framework and model of practice used in OT. The model provides a framework for viewing children's play holistically, focusing on the needs of children and their families. Detailed field notes were taken by the author, combining the framework of the Ludic Model with any additional information observed during the session. IDEO's Design for Social Impact field guide was also used to document the author's observations following the field ethnography and the workshop sessions (IDEO, 2009). The ethnographic observations complemented the workshop sessions and provided valuable information related to the children, their siblings, parents' and, or caregivers' "behaviour, beliefs, and preferences" in the environment of the therapy department (Ireland as cited in Laurel and Lunenfeld, 2003, p.26).

B. PRIMER ACTIVITIES

Primer activities can often "enhance the quality" of the following workshop session (Sanders & WIliam, 2001, p.4), and are also known as sensitization (Sleeswijk, Stappers & Van Der Lugt, 2005) or immersion activities (Sanders & William, 2001). Examples include taking a camera home, completing a workbook or mapping a 'day-in-the-life'.

These activities are different from the tasks included in Probes, created by Bill Gaver (Gaver, Boucher, Pennington & Walker, 2004). The purpose of the primer activity is solely to stimulate the participant to start noticing the research topic in their everyday life, and not to measure participant's responses. Whereas, Probes are a series of activities sent out to people in the early stages of the design process to be a source inspiration for the designer; their goal is to help the designer develop a sense of empathy toward the user through providing "clues about their lives" (Sleeswjik et al., 2005, p.8). Also, while Probes might contribute to new concepts, they do not involve people generating specific ideas in the same way a toolkit does.

The participants were given a camera and a worksheet as primer activities, with the goal of increasing the child's awareness of play in preparation to further discuss ideas for the play space during the workshop session (see Figure 3). The worksheet asked the participants to place a sticker on an image of a tree each time they played, 'to make the tree come alive'. The disposable camera invited the children to take pictures of the therapy department at Sunny Hill. The purpose of the camera activity was to provide a view of the therapy department from the children's perspectives. Children were asked to take pictures that corresponded to the following statements printed on the back of the camera:

- 1. This is my favourite
- 2. I like this the least
- 3. This is where I wait the longest
- 4. This is where I spend the most time
- 5. I would like more of this

The participants had twenty-four exposures in the camera to use; they were provided with verbal instructions on how to use the camera and encouraged to take as many or as few photos as they wished. The photos would be developed and the content discussed with the children at the next workshop session.



Figure 3. Primer activities, camera and worksheet

C. PILOT TESTING

Sanders and William (2001) state that it is invaluable for designers to engage in the steps of brainstorming, pilot testing and refinement before producing the final toolkit. Therefore, pilot testing took place between each workshop session with each test focused on a specific variable of the toolkit (e.g. image, symbol or material choices). Testing before each workshop session was also necessary because the participants were so varied in their abilities, requiring customization of each toolkit.

The pilot sessions took place with consistent group of three children - James age four, Alex age six and Sarah age ten*, who were unfamiliar with the environment of Sunny Hill. Due to difficulties with recruitment, the testers did not have physical or cognitive limitations, and their context required them to participate as a group of two or three. These

^{*} All childrens' names have been changed to maintain anonymity.

circumstances are acknowledged as a limitation of the pilot tests as it would have been favourable to have a one to one pilot testing sessions with children with different abilities. Despite this, the participants provided a child-perspective toward the toolkit activity. The pilot testers were informed of the purpose of their involvement, given a scenario with which to guide the session, and a brief set of instructions. Pilot testing occurred prior to each workshop session, resulting in three pilot test sessions in total.

D. WORKSHOP SESSIONS

In design, the toolkit attempts to bridge the gap between the researcher and the users. This allows for a greater understanding of user needs and enables them to contribute to the design process. The workshop session involves working with the toolkit, which typically consists of a variety of materials to allow people to create maps, drawings, collage, models, stories, storyboards, or plans (Sleeswijk et al., 2005). For the play space study, a combination of two and three-dimensional collage materials seemed most appropriate to enable participants with a range of physical and cognitive needs to participate in the toolkit activity. Creative methods (drawing, collage) and approaches suited to children were chosen, such as using open-ended questions, narratives, and visual prompts (dolls, games, pictures) (Greene & Hogan, 2005). Using a range of materials and activities met the diverse and individual needs of each participant.

The ambiguous and visual nature of the toolkit materials is paramount in encouraging people's memories, feelings, and expression of ideas through random exploration (Sanders & William, 2001). The ambiguous characteristics of the information presented in the images and forms of the toolkit aimed to encourage engaging, thoughtprovoking ideas and designs from the participants (Gaver et al., 2002). Typical materials may include cutout images and words from magazines, paper die-cuts, simple wooden shapes and craft materials. These basic items can easily be found in a craft store, are not too designed or manufactured, do not carry any intrinsic importance or value, and do not elicit a right or wrong response. In repeated conversations with the Emily Carr University Design Faculty, Liz Sanders has stressed the importance of the materials being uncontrived. By using familiar materials, she argues that people feel more confident and comfortable engaging in the activities, and this in turn makes it easier for them to access their intuition.

The workshop sessions were video and audio recorded by the author and transcribed afterward. Video recording provided a means to observe children's nonverbal communication (gestures, behaviours) that could not be documented in audio recording or photography. Photos were also taken of the children's work during the sessions and notable discoveries throughout the design process. Following each session I reflected on the successes, challenges and discoveries during the session through journalling, sketching, mind-mapping and revisiting the background research (visual precedents and written literature). These reflections informed the next iteration of the toolkit.

PART TWO - THE TOOLKIT EXPLORATIONS

CHAPTER IV: RESULTS

4.1 TOOLKIT #1 - THE ALPHA TOOLKIT

Danielle, a seven year old girl, participated in the workshop session with the alpha toolkit. Danielle has complex developmental needs resulting in difficulties with language, cognition and motor abilities. Danielle uses both a walker and manual wheelchair for mobility.

Alpha Toolkit Observation

During the observation session the author observed Danielle's ability to communicate using short sentences and choice making, as well as her ability to draw and print using a regular pencil. This information led to certain activity and material choices for the toolkit that are discussed later in this section. As the session progressed, her father spoke about the need for accessible play spaces in public areas such as parks and schools. He shared his frustration with the decreased accessibility of the majority of playground equipment resulting in Danielle not being able to play with her peers. During the observation the need for engaging activities for Danielle's younger sibling, who attended the appointment with her, was noted as well.

Alpha Toolkit Primer Activities

Danielle chose not to engage in the camera activity which may have been related to the level of engagement required of her during her appointment. She completed the worksheet at home prior to the first workshop session.

Alpha Toolkit Pilot Test

My objective was to create a toolkit that would provide a range of meaningful tools to allow for creativity, flexibility and adaptability. Specifically, my intent was for the alpha toolkit to:

- Be easy to use and accessible to a range of physical and cognitive abilities
- Be fun and engaging
- Contain open-ended, highly visual, ambiguous and familiar materials
- Allow for access to creativity, imagination and the expression of ideas
- Allow for adaptability of activities
- Allow for ideas to emerge quickly

Liz Sanders' suggestion that children have a tendency to be either "builders or pretenders", was used as a jumping off point to guide my initial material and activity choices for the toolkit (L. Sanders, personal communication, January 17, 2009). For instance, a child who is offered a set of blocks might choose to build a tower or wall, while a different child may choose to use the blocks to represent a "tea set and have a party for their stuffed animals" (L. Sanders, personal communication, January 17, 2009). She emphasized that the tendency to be a builder or pretender is not gender related and it is important for the components to be kept to basic forms that allow for open-endedness in their use (L. Sanders, personal communication, January 17, 2009).

The pilot toolkit consisted of a cardboard model of a room with three adjustable walls, small wooden people, small three-dimensional cardboard blocks that could be drawn on, wooden blocks in basic shapes, blue and yellow coloured poster board, stickers of facial emotions, Post-it Notes of different colours and shapes (square, house, flower), crayons, markers, fabric (felt, fuzzy and shiny), scissors, glue stick, coloured pipe cleaners and pom poms.

The cardboard model was similar to a dollhouse and provided an opportunity for the participants to engage in imaginary, fantasy or pretend play. This is also known as symbolic play, where children use one object to represent another, an ability that emerges around two years developmental age (Case-Smith, 1996; Woolley and Wellman, 1993). Pretend play has been viewed as a form of problem solving, and is a "marker of a child's ability to use symbols to represent objects and events" (Barton and Wolery, 2008, p. 109).



Figure 4. Pilot test of the alpha toolkit.

Pilot testers James, Alex, and Sarah, tested the alpha toolkit. There was an incredibly high level of energy and activity during the workshop session; it was challenging to maintain the testers' focus on creating a play space in a children's hospital. There was a high level of interest in playing with certain materials separately, rather than combining them to create a collage. Of particular interest was the prism plastic and highly textured materials (e.g. clear plastic bubbles, thin cork). The prism plastic created a distorted, rainbow like effect when looking through it, which James was fascinated with. Besides the excitement over the materials, the pilot testers were hesitant to begin the task of designing a play space despite my initial explanation. I was uncertain if this was related to their unfamiliarity with Sunny Hill.

I observed that the children would draw on the cardboard room walls without prompting, but not on the cardboard blocks. Alex drew a large TV monitor for playing cartoons on one of the walls while Sarah and James used the Post-it notes to place a series of round and star shaped windows along the adjoining wall. Sarah built soft chairs for the small figurines using pom poms, and created a small desk for drawing. With encouragement to draw on the blocks, Alex drew wheels to create a rolling bed, and laid down a 'sleeping' figurine. He said that he wanted a dog to be in the hospital, and after not finding a material to suite this request, used one of his own toys. The floors quickly became covered in soft, brightly covered felt material. I noticed that quick and easy materials such as Post-its and stickers were popular and easy for the children to use. Alternatively, using scissors to cut out an image or material seemed to take their attention away from the collage activity and onto the task of cutting. Following the pilot test, the toolkit was further refined. I realized that images and a childfriendly alternative to a sticker list of keywords (as is often done in adult toolkit exercises), were needed to provide the participants with more cognitively accessible materials. A calming activity was also required to temper the high level of energy during the session, and maintain the children's attention. I also planned to provide scenarios that the children could imagine and take part in. I wondered if this would allow them to feel less hesitant toward the activity. For example, I could have said 'Imagine your favourite place with all of your favourite things', 'Imagine what the play space could be', 'imagine what would make it easier for you to spend all day at the hospital?', 'imagine how you might make a boring place into a happy place?'. I also thought about Thomas & O'Kane's example of asking 'if you had a magic wand, what would you change or add to your environment?'. Refinements were made to decrease possible associations with a particular quality of a material. This included providing white poster board instead of coloured to avoid decisions being made based on the colour of the paper (e.g. blue for water, green for grass). My objectives for the next iteration of the alpha toolkit were to:

- Increase the ease of use
- Provide child-sized materials
- Provide a calming activity
- Provide images and a child-friendly alternative to a sticker list of words
- Provide more generic materials

The next iteration, included images, a smaller cardboard model, small wooden people, a smaller piece of white poster board, cutout picture communication symbols (PCS), scissors, markers, crayons, small basic shapes, pipe cleaners, small fabric and textured squares (mirrored, bumpy, shiny, fuzzy), coloured paper in triangular and rectangular shapes with perforations to allow for an easy



Figure 5. Finger crayons and triangular markers.

alternative to cutting (i.e. tearing), wooden blocks, coloured play dough and a glue stick. I included both regular crayons and markers, as well as finger crayons and wide triangular shaped markers to accommodate for decreased fine motor skills (i.e. decreased dexterity, grip).

Movements (e.g. climbing, hiding) and childhood fantasy (e.g. castles, dinosaurs), together with Mark Dudek's (2001) groupings of children's archetypal spaces (i.e. winding paths, views through, climbing spaces, hiding or secret spaces high ridges, caves, promontories), guided my image choices. A range of concrete and abstract images of varying aesthetic qualities were included. I avoided pictures of specific pieces of furniture, equipment or toys, for concern that a participant might choose that image based on their hope for an identical object rather than gleaning a general 'idea'. This led to an assemblage of images that included children playing dress-up, a range of outdoor views and settings, themes of childhood fantasy, symmetrical, regular and geometric patterns, as well as textures.

Jane Ayres' theory of sensory integration led me to consider how specific characteristics of activities and materials might be perceived by a child's sense of touch, smell, vision, hearing and taste. Understanding that kneading, pushing and pulling activities are somewhat calming or grounding, I decided to add playdough to the tookit as a material and activity, because it affords calming actions (e.g. kneading, pulling).



Figure 6. Picture Communication Symbols (PCS)

The pilot test illustrated the need for an alternative to the sticker list of words that are commonly used in the adult toolkit. Picture communication symbols, that are often used in assistive and augmentative communication (AAC) were chosen to meet this need. AAC uses alternative methods that build on an individual's current communication skills (Brown, 2006). This thesis focuses

generally on the potential for AAC methods to be included in the toolkit activity, rather than providing an in depth study of the use of picture communication symbols. AAC is a specific area of expertise that primarily involves speech and language pathology, and can include OT as well. For a child with physical or cognitive disability, AAC can provide an effective method for them to communicate, and decrease frustrations between themselves and those they are communicating with (Brown, 2006). AAC can include sign language, gestures, visual communication material - symbols, graphics, pictures, and speech devices (Brown, 2006). The graphics and accompanying text used in picture communication symbols provide an alternative and representational means of communication. Although different sets of graphic symbols have been developed for AAC, picture communication symbols (PCS) were chosen because they are the most widely used symbols and offer a combination of graphics representing sign language, symbols and objects (Brown, 2006). The software program Board Maker, available through Mayer Johnson, is commonly used to acquire PCS'.

The pilot session also led to the contemplation of how affordances relate to visual perception, cognition and physical abilities. For example, the size, weight and shape of objects, as well as surfaces that support building without the use of scissors and glue (e.g. Velcro, magnets and perforated paper), afford different levels of access for a range of physical abilities. As well, a vertical rather than horizontal surface, high contrast images and text have different affordances for visual perception.

Alpha Toolkit Workshop Session

My objective for Danielle was to enable her to articulate her needs and hopes for a play space in the therapy department using the creative toolkit. Danielle's physical abilities resulted in certain constraints in the design of the toolkit. This included keeping the toolkit components proportional to the size of her body, ensuring the activities and materials accommodated for her physical and cognitive limitations, and emphasized her strengths. With matching the materials to her fine motor abilities, she was able to pick up, hold and manipulate a range of items (e.g. pens, crayons, markers, scissors). The design criteria for Danielle's toolkit included:

- Materials proportional in size to the dimensions of her body (e.g. hands)

- Use of picture communication symbols and images for an augmentative and alternative means of communication
- Providing a range of familiar craft materials fabrics, textures, small foam shapes, wooden blocks, pipe cleaners, playdough, wooden dolls, paper, glue, scissors, markers, crayons

During the workshop session I discovered that offering a wide range of materials seemed to be distracting for Danielle. At times she seemed more interested in the actual materials, rather than designing her ideal play space. As well, cutting out images was time consuming for Danielle and focused her attention on this task. In future sessions, I would need to reduce the number of materials and images to the most effective ones to decrease distractions and increase interest and attention.



Figure 7. Alpha toolkit session with Danielle.

Despite efforts to use appropriate sized elements in the toolkit, the cardboard room and poster board were still too large for Danielle to manoeuvre. Nevertheless, the activity was engaging for her. When I used the dolls to pretend that we were at Sunny Hill, Danielle's face lit up and she pretended along with me. Danielle made seats out of blocks for sitting and standing on, and playdough pillows for the dolls to rest their heads while they napped. Through creating a scenario and offering an opportunity to pretend and play, I was able to engage Danielle in a conversation comfortably, without using interviews or surveys. Due to Danielle's limitations in spoken communication I discovered she was better at communicating with me through choice-making. During the session I would frequently ask Danielle what she had made and why, by presenting her with choices. I let her story guide me in interpreting what she had created. When she created a series of round circles, using pipe cleaners, and pasted them to the wall, I offered a series of choices, two at a time, to determine her intent. She shared that the circles were images on the wall, whereas I had assumed that they might be mirrors or windows. Likewise, when she chose an image of a winding path and another of a grassy ridge, I wondered if she wanted a similar path indoors or to bring nature inside. Instead, she told me, simply, that she liked to play outside. We continued this way throughout the session, her, freely exploring and building, and me, sharing in her creative works while asking questions using choices. Overall, I felt that by the end of the session, the alpha toolkit had augmented Danielle's ability to communicate with me in a fun and engaging way. The success of including imaginary play and choice making in this session could influence the approach taken in future research design projects involving children with disability.

4.2 TOOLKIT #2 - THE SKINNY TOOLKIT

The second toolkit, referred to as the skinny toolkit, was refined based on my experience with Danielle from the previous session and piloted again. The the skinny toolkit was to be used with Michael, a sixteen year old youth. Michael has a degenerative genetic condition resulting in limitations in mobility and strength of his lower limbs, shoulders, arms, in reaching and grip strength. Michael uses a power wheelchair as his primary mobility.

The refined criteria of the skinny toolkit was designed to:

- Further increase the ease of use
- Increase the accessibility of the materials and activities
- Delimit choice of activities and materials with decreased task demands to maintain focus on the goal of the toolkit

- Address the notion of reusability of the toolkit components, allowing the basic components to be reused with future participants, when appropriate

My realization that too many materials were distracting to the children prompted me to focus on the most effective and efficient items. This resulted in the evolution of a very 'skinny' toolkit. The skinny toolkit contained Playdough, images and picture symbols placed onto foamcore with magnetic backing, markers, a cardboard room with magnetic whiteboard paint, small wooden people, and plain paper.

By increasing the toolkit's ease of use, I addressed the need to maintain the participant's attention on the larger goal of the toolkit rather than the details of construction (e.g. cutting and pasting). I explored materials that allowed for objects to stick without using glue, such as Velcro, felt, magnets, and stickers. I tested magnetic paint combined with erasable whiteboard paint. Magnets eliminated the need for glue and stickers and the whiteboard paint allowed for free drawing on the floor and wall surfaces of the cardboard room. Since the images could easily be erased, the cardboard room could be reused.

Images, picture symbols, basic shapes and texture swatches were placed on a foamcore backing and decreased in size (approximately $2 \frac{1}{2}$ " x $2 \frac{1}{2}$ ") to afford easier grasping for a whole hand grasp and smaller hands. I considered having a knob placed in the centre of each piece, but decided that this would limit access only to those with certain fine motor abilities (pincer grasp). I contemplated placing small magnets on the feet of the wooden dolls to allow them to stand easily, but was concerned that this might lead to over-designing the toolkit.

During this stage of refinement, while reflecting on Sanders' emphasis of using materials that are open-ended and ambiguous (Sanders & William, 2001), I discovered a tension between providing child-friendly activities that were inclusive, and over-designing the toolkit, to the point where it might be less familiar and approachable. I became curious whether, in making the toolkit accessible, if some of the open-endedness and approachability of the materials would be lost. In future sessions I hoped to explore whether certain materials could meet both of these needs.

Skinny Toolkit Observation

Michael, similar to Danielle, was very busy working with the Sunny Hill team during his appointment. During the observation I gained insight into Michael's physical abilities and capacity for communication. Michael has limitations in his fine motor skills related to decreased strength and mobility. He is excellent at telling stories.

Skinny Toolkit Primer Activities

I presented Michael with the primer activities during the observation session. It occurred to me then that placing stickers on a page is not necessarily age appropriate for a teenager, and that this activity would need to be reconsidered for an older child or youth. When invited to take photographs with the camera, Michael seemed shy and chose not to take pictures of the therapy department.

Skinny Toolkit Pilot Test

In this pilot session I wanted to determine the effectiveness of using picture symbols, and the level of comfort toward the magnetic white board surface. Considering my first pilot test, I decided that having two pilot testers instead of three would lower the energy level. Testers Alex and Sarah were brought back for this pilot test. I presented them with the materials and a set of instructions. Alex and Sarah were given a scenario "If you had a magic wand, what would your ideal school be like?". I hoped that this scenario would be easier to relate to than the previous hospital story. Sarah and Alex were excited to engage in this challenge, and immediately set-out to design their ideal school. Overall, they appeared to be comfortable engaging with the whiteboard surface and the magnets.

Alex and Sarah used the picture symbols to communicate feelings, ideas and wishes for their design. Sarah placed the happy face picture symbol on one of the walls to express what mood she wanted the students to feel at school. The computer picture symbol was used literally to create a computer workstation in combination with the playdough as a stand. Sarah exclaimed, "and here

is a calendar on the wall so that they can see their schedule" as she drew a small rectangle containing a typical weekly grid. She also arranged a series of picture symbols on the adjoining wall to create a visual schedule for 'music class', 'outside' and 'activities'. Sarah shared, "these circles are a path for them to walk on, on the floor, these numbers and shapes too...". Alex commented, "they need a roof on their school", and a "disco ball!", as he placed one of his own glittery balls on top of a playdough container. Alex was especially adventurous in using his own toys to add to the model when lacking an object or material to express his needs.

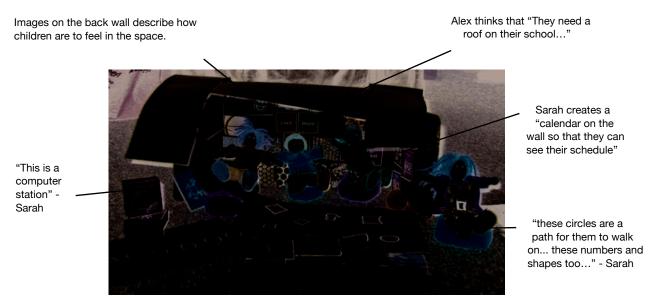


Figure 8. The Skinny Toolkit pilot test with Sarah and Alex.

Through observing the pilot session I decided that certain items could be brought back into the repertoire of activities, such as perforated coloured paper and poster board for the floor surface. Mirrored surfaces seemed to be popular, although this presented another tension. How does one provide visually stimulating materials while avoiding distraction? In the alpha tookit pilot test, the prism plastic was so inviting to look through, that James became preoccupied. However, in this pilot test, the same material did not have the same affordance when presented in a much smaller size and glued to foamcore. Thus, changing the presentation of a material (e.g. size, shape, orientation), changes its affordances.

Skinny Toolkit Workshop Session



Along with the materials included following refinement and pilot testing, I chose to use a figure that did not resemble a doll, in an attempt to make the toolkit more age appropriate. Michael and I met at his school for the workshop session in a quiet room in one of his classrooms. He chose to use his wheelchair tray surface for working with the toolkit. The session began with the 'magic wand scenario' and a description of the materials available in the toolkit.

Figure 9. The components of the skinny toolkit in the box lid.

Michael engaged with the toolkit quickly and easily, working with the majority of the materials to build objects on the walls,

floor and 'ceiling' of the model. He chose not to use the markers or the playdough. In working with the large number of small foamcore squares, I realized a container was needed to present Michael with the squares all at once. In looking around the room, I quickly appropriated a lid to a board game as a holding container. Once the squares were in the box lid, Michael could look through them quickly and easily, then make his selection. He was able to pick up the small foamcore squares easily and place them within the model. This adaptation allowed for his ideas to emerge quickly by accommodating for his functional mobility in his arms and hands. The smaller size of the model was advantageous due to his physical abilities and the smaller working surface of his wheelchair tray.

Throughout the session Michael was very insightful, and openly told a story about how his experiences at Sunny Hill related to his choices. He thought of activities and objects for himself, as well as for other children. He commented "well, for me I don't really need a play space, I don't get bored, but the younger kids might". Michael placed pictures and objects lower down on the walls so that they would be accessible to most children, as he placed different fabrics and bumpy textures on the walls he said, "and I think that having panels that are interesting to touch would be nice for some of the kids, and they could be lower down so that they could reach them"..."the mirrors too



Figure 10. Skinny Toolkit workshop session with Michael.

would be lower". At the end of the session, Michael exclaimed, "I didn't think I would have so many ideas!".

Michael's ideas included having an entrance way into the play space that was "like a tent, with dogs, fish and plants". While arranging the picture symbols in a row to reflect each idea, he said "I know there is a quiet room outside of the therapy department, but I think it would be good to have a room inside the department when you could go to lay down and take a rest, watch TV or read". Michael also requested having different patterns and colours on the floor. He built an activity centre "for things like drawing" on one side of the room, and a computer and music centre on the other side of the room, "where you could choose what type of music you wanted to listen to" and "it would play quietly overhead like in the grocery store". Opposite walls had identical mirrors that were framed with colourful triangles because "this makes them more interesting". Michael also wanted star and circular shaped windows. Similar to the pilot group, he seemed to use the picture symbols for literal representations of objects (computer, TV, Video, music) and activities. In one instance he used the picture symbol for 'outside' to reflect the existing skylight in the department. I wondered whether these items were too literal, and could be leading the participants choices. In the pilot group, before having the picture symbols, Alex drew a TV using the markers. Now, with the picture

symbols, Michael didn't have to. Perhaps having basic shapes, even outlines of shapes, and limiting picture symbols to verbs, adjectives and emotions, would be more open-ended.

"This is the window that you sometimes see in the ceiling at Sunny Hill"

Michael thinks "that having panels that are interesting to touch would be nice for some of the kids, and they could be lower down so that they could reach them"

"There could be patterns and colours on the floor"

The entrance way into the play space would be "like a tent, with dogs, fish and plants"



"The mirrors too would be lower"

Michael thinks that star and circle shaped windows would be more interesting.

"This is a computer station, where you could choose what type of music you wanted to listen to"..."it would play quietly overhead like in the grocery store"

"I know there is a quiet room outside of the therapy department, but I think it would be good to have a room inside the department when you could go to lay down and take a rest, watch TV or read"

Figure 11. "I didn't think I would have so many ideas!" - Michael

The materials of the skinny toolkit proved to have a greater degree of accessibility and decreased task demands. The use of the magnets and lightweight foamcore components were both easier to use and reuse. I wondered whether Michael's physical limitations had influenced his choice of materials, and if this had implications for other children. Although Michael did not engage with either the drawing materials or the playdough, I felt that these materials were still relevant for participants with different interests and abilities. Overall, the skinny toolkit allowed for Michael to share a large number of ideas quickly and easily.

4.3 TOOLKIT #3 - THE KINESTHETIC TOOLKIT

In reflecting upon the successes and challenges of the skinny toolkit, I focused on developing the three-dimensional and sensory characteristics of the materials, and revisiting the choice of picture symbols. Although playdough provided a flexible media for the participants to construct objects, when it is not a preferred material, participants are limited to using geometrical shapes. Therefore, opportunities were needed to allow for flexible components that could be combined in a number of ways. Existing children's activities that reflect this flexibility include Lego, Tinker-toys, and basic wooden blocks.

The next participant, Sam, was seven years old and very movement oriented. His parents described him as enjoying, and being most engaged in, activities that use large body movements (e.g. video games, riding a bicycle, building). His needs were different from the two previous participants as he did not have functional limitations in his mobility requiring the use of equipment such as a wheelchair. I considered creating a life-sized toolkit for him to embody his ideas. The notion of embodied cognition is supported throughout the field of cognitive science in the areas of "artificial intelligence, psychology, cognitive neuroscience, linguistics and philosophy" (Goldman and de Vignemont, 2009, p. 154). Embodied cognition posits that mental representations in bodily forms contribute to the process of learning and understanding through thought, experience, and the senses (Goldman and de Vignemont, 2009; Clark, 1997). Bodily forms include stimuli produced within the body, movements, moods, feelings, and attitudes. Clark (1997) also argues that embodied cognition is best distinguished by "non-computational and non-representational ideas and explanatory schemes" (p. 148).

This is similar to Nigel Frost's system of introducing young people to the creative design process using large three-dimensional models of famous architectural buildings, structures and spaces (Dudek, 2005). As a teacher-architect, Frost created a system which focused on empowering children using "kinesthetic language" involving large, whole body movements and "simple, tactile materials" (Dudek, 2005, p. 120).

The notion of kinesthetic awareness is frequently considered in sensory integration therapy and in education. For example, when working on printing, a child might be instructed to use their entire body to 'draw' and 'form' the letters of the alphabet, or draw in different textures such as sand, clay, or rice using their finger. The objectives of providing kinesthetic awareness are to increase concentration, motivation and motor memory. My objective with Sam was focused on increasing his motivation and concentration, rather than his memory for certain movements.

The aim of providing an embodied experience for Sam was to meet his sensory need for movement and provide an engaging experience through an arrangement that would lead to the understanding and description of his needs in a space. I wondered whether a life-size toolkit would be more interesting and motivating for him, compared to the smaller scale toolkit I had been using. The refined criteria for Sam's kinesthetic toolkit was designed to:

- Provide opportunities for large body movements lifting, carrying, reaching, drawing
- Provide larger scale materials consistent with previous toolkit revisions perforated paper, images, pictures symbols, two and three-dimensional shapes and textures
- Provide a greater range of ambiguous two and three-dimensional shapes to allow for a range of combinations when building
- Limit picture symbols to verbs, adjectives, emotions, and avoid the use of objects (e.g. computer, TV)

I brainstormed ideas including a large cardboard room or paper on the walls and floor surfaces to draw on, two and three-dimensional textures and shapes to place on the walls and the floors, building with cardboard boxes, and foam shapes. Many of the refinements of the smaller scale toolkit could be applied to the kinesthetic toolkit such as, images and picture symbols, perforated paper, stickers, two and three-dimensional shapes (square, circle, triangle), and textures. The two-dimensional images of textures could be replaced with 'tactile equivalents' using fabric, sand, sawdust, straw, etc. The kinesthetic toolkit contained a large scale cardboard room, craft paper for the floor, cardboard shapes (triangle and square) covered in craft paper, plain white foam shapes - sphere, stars, eggs, cones, markers, images and picture symbols with perforations, precut coloured paper shapes (triangle, square, circle), masking tape, and a piece of silver metallic paper.

Kinesthetic Toolkit Observation

During the observation session I observed that Sam's preference for movement oriented activities as he was incredibly active during his appointment. This necessitated his appointment taking place in an enclosed space where he was safe to run and move around. Sam chose to play with the Wii video game while he waited during his appointment. His parents shared that Sam loves interactive computer and video games, science, math, and drawing with a partner - which he can do up to fifteen minutes maximum. He is able to make choices, is familiar with picture communication symbols, and uses single words to communicate.

Kinesthetic Toolkit Primer Activities

Sam's parents also reported that he "isn't much of a sticker or playdough guy". Therefore the worksheet was not a successful activity for Sam, nor was the camera due to his attention span.

Kinesthetic Toolkit Pilot Test

All three pilot testers, Sarah, James, and Alex, explored the kinesthetic toolkit. The goal for this pilot test was to determine the overall size of the toolkit components and level of engagement by the children. Similar to the first pilot session, this trial was very high energy. This was likely related to having all three testers involved at once, as well as the inherent affordances of the kinesthetic toolkit. This time the testers were asked what they would like to build in the space, rather than the author presenting them with a



Figure 12. The high energy kinesthetic toolkit pilot test.

scenario. The pilot testers chose to build a classroom again. The pilot session revealed how the

affordances of the toolkit changes when scale is increased. The larger size of the kinesthetic toolkit demanded action. The children had to walk around the walls, stand, or kneel, rather than sit quietly at a table.

There was no hesitation toward engaging with the components. Sarah, the eldest of the three pilot testers, quickly went to work constructing a small 'play house' using the cardboard square and triangle. She drew windows and doors on the walls of the house and decorated the roof with coloured paper. She drew the alphabet on the wall, and a calendar beneath. Sarah used the precut circles to create numbers on the floor. The metallic paper was hung as a mirror on the side wall with a portrait of a person drawn on. Alex drew a rainbow with a happy face on the main wall. He interacted with the cardboard boxes and exclaimed "I am wrapping a present!". When asked who the present was for and if he wanted presents at school, he said "it is to this guy" as he gestured to the marks he had made on the 'present' indicating the recipient's name. His present seemed to be inspired by his own experiences, memories and associations related to the affordances of the object. Similarly, Alex drew a pattern on one of the foam balls to make a 'soccer ball'. He continued to place the soccer ball on top of a long tube to create a "soccer trophy for the classroom". James being the youngest of the three pilot testers, was much more interested in using the components for imaginary play unrelated to the task of creating a classroom. Besides his chronological age, he had not attended elementary school yet, and it may have been difficult for him to understand the context of the activity. For James, the foam ball quickly became a baseball, the long cardboard tube a bat, and the foam cones a large pair of ears. This time, none of the testers chose to use the images or pictures symbols.

The larger scale of the materials in the kinesthetic toolkit allowed for a different level of imaginary play compared to the smaller scale toolkits, particularly for the younger pilot testers. For James and Alex, the scale of the components stimulated imaginary play outside of the initial goal of the toolkit. I wondered if the 'life-sized' characteristics had placed too much emphasis on the three-dimensional objects. Sarah, on the other hand, was able to stay focused on the original task. The larger size of the toolkit did not appear to overwhelm her. There are many factors that could have



Figure 13. Sarah drawing her alphabet and calendar, and James holding Alex's soccer trophy.

contributed to the pilot testers different perceptions toward the kinesthetic toolkit. Among them could have been age, personal experience, gender, interests, level of attention and physical size (for James the cardboard house was much larger than for Sarah, the eldest).

Practically, working with the larger toolkit was a bit unwieldy. The larger shape of the cardboard walls and 'blocks' made this iteration difficult to transport. Following the pilot session the overall size of the cardboard blocks and room were decreased to make them slightly more manageable for transportation. A few of the foam shapes that afforded 'throwing' were left out (i.e. foam star and egg shapes), tactile forms were added, and the images and picture symbols were printed onto sticker paper with perforations to increase the ease of use.

Kinesthetic Toolkit Workshop Session

I met Sam at his home for the kinesthetic toolkit session. Sam's toolkit included the cardboard room and blocks, foam shapes - sphere and cone, precut coloured and metallic paper shapes and post-it notes (square, triangle, rectangle), images and picture symbols printed on sticker paper and perforated, markers, crayons, tape, and tactile squares with textures that were fuzzy, rough, bumpy, stringy, soft, striped, woven and smooth. Sam was given the scenario "Imagine if you could have anything in a play space at Sunny Hill, what would it be?", and introduced to the toolkit materials.

This workshop session lasted just under thirty minutes, which is longer than the author anticipated Sam would allow, given his attention span. Unfortunately the session was not videotaped or photographed because Sam was very distracted by the video and digital cameras. It was anticipated that documentation using the cameras would limit his ability to participate in the toolkit activity. Sam has decreased spoken communication, he is able to express yes, or no, and can make choices. He also uses short phrases (two to three words) to communicate.

Sam was wearing a toy shield and sword, which he played with throughout the session. His parent asked him several times to first work with me, then play with his sword, but Sam was adamant to do both activities together. Although this made the session challenging, I tried to think of ways to maintain his attention on the toolkit activity. I began by offering him a choice of materials to work with first; he chose the images. Presenting two sheets of pictures at a time, Sam would choose the image he wanted. I then demonstrated how to tear it away using the perforations, and peel back the sticker paper. Following my demonstration, he focused his attention back to playing with his sword and moving it through the air. I had an idea, and proposed that he 'cut' out his chosen sticker using his sword. This brought his attention back onto the toolkit activity. We worked this way through the images and tactile squares. Sam, first choosing an image or texture, 'cutting' it away with his sword, then placing it on the wall. Sam chose a brightly coloured parrot, an astronaut, a house, a person playing the drums and textures that were smooth, woven and bumpy. In choosing the textures, he paused to touch each one. The multi-sensory characteristics seemed to briefly hold his attention. Each time Sam chose an image I asked him about it. When he chose an image of a person playing the drums, I asked him if he liked music, he said 'no', I then asked him if he wanted music at Sunny Hill, and he said 'yes'. Sam's limited verbal language made it challenging to use open-ended questions with him.

Sam was offered all the materials of the toolkit. He briefly used the markers, making a few marks on the main wall of the cardboard room. Overall, he did not seem interested in the coloured and metallic paper shapes. For Sam, the size of the toolkit was a positive characteristic because he was able to move around. The toolkit provided opportunities for Sam to play another game of his

own when he became disinterested in the toolkit. While this made it more challenging for the author, I think it might have made the session less frustrating for Sam because he was able to move freely, and take breaks as he needed without having to get up from a chair and table, and then return to the toolkit activity when ready.

Communicating with Sam was very challenging due to his decreased attention span and ability to orally communicate with me. While he was familiar with picture communication symbols, he did not use them spontaneously during the session. It was difficult to know if he fully understood the goal of the toolkit activity and why he chose the images and textures that he did. Intuitively, I felt that he might have had something more to say about his choices, and I was very curious what that might have been. I found myself relying on my observations of Sam's behaviour to understand his needs. I understood his increased distraction as a clue that he was finished with our session. When I asked him, using gestures, if he 'was finished', he said 'yes'.

While the outcome of the session was quite different from my expectations, the findings provided valuable insights. The need for flexibility when engaging in research with children was strongly emphasized. Flexibility was required in the use of the materials and in my approach. The materials were adapted from previous iterations of the toolkit to suit Sam's physical and cognitive needs. Flexibility in my approach was challenged in the workshop session, where I needed to quickly adapt my manner of working with him to one that complemented his interests and strengths. In retrospect the use of a scenario could have been emphasized more. I could have engaged Sam in an imaginary story revolving around his shield and sword that perhaps included nobles, knights, and warriors that were 'designing a play space in their castle'. I wondered whether the connection between an imaginary story and the truth of designing a play space at Sunny Hill would have been too abstract for him. This session illustrated the need for a greater understanding of how to communicate with children like Sam in design research. In this particular case, the opinion of a speech and language pathologist and an art, or play therapist may have been beneficial.

CHAPTER V: DISCUSSION

5.1 INTERPRETATION OF RESULTS

The objective of this thesis was to explore the design and use of a set of creative methods, or toolkits, with children with disabilities. The following insights reflect my experience as an occupational therapist, together with the knowledge I have gained in participatory design methods. They reflect the holistic approach of OT, coupled with the visual and functional perspective of design. It should be noted that these viewpoints are by no means mutually exclusive; they exist along a shared continuum, allowing for resonance between the two disciplines. Throughout the research, I have found myself becoming somewhat of a bricoleur; one who makes use of the available items at hand, and where the use of these materials reflect past experiences, skills, and knowledge (Louridas, 1999). The outcome of the toolkit sessions have created a structure for designers, researchers and therapists.

This essay reviews the experiences of participants using the toolkits, and offers practical suggestions based on what was most successful in the workshop sessions. Components were considered for ease of use, adaptability, flexibility, level of engagement, ability to facilitate the expression of imagination, creativity, fun, opinions and ideas. Suggestions include ideas for accessible toolkit materials, and for facilitating communication with children with physical and cognitive limitations.

To provide a framework for understanding and further application of this study's findings, the observations made during the toolkit sessions can be viewed within the International Classification of Function (ICF) (WHO, n.d.). The ICF combined with the theoretical framework of this thesis, led to suggestions that respond to the ICF categories (see Tables 3 and 4)

The toolkits deepened my sense of empathy and understanding toward the participants. Observation sessions allowed for a greater appreciation of each participants' abilities and needs. This helped to determine the limits of the toolkit materials, and choose items and activities that best supported each participant. This delimiting resulted in a process of creating an adaptable, inclusive toolkit with the potential to be used by a greater number of people regardless of age, gender or ability.

The initial observation sessions with the child, parent or caregiver and their therapist at Sunny Hill were invaluable for fostering rapport, trust, and empathy. Overall, I found that an initial meeting 'broke the ice' for the following workshop sessions between the child, parent or caregiver and the author. Through observation, I was able to learn about the participants' physical and cognitive abilities and preferences. I also gained insight into their communication styles. The Ludic Model (Ferland, 2005) guided my observations holistically and prompted me to observe specific areas related to play that I otherwise might have missed. Occasionally, stories emerged from the parents during the observation session about the child's preferences and abilities. These stories together with my observations and field notes, led to the customization of each participant's toolkit.

Generally, the children chose not to engage in the camera activity. This could have been related to the overall complexity of the task, that they were too busy during their appointment time, had limited attention span, or were too shy to engage in the exercise within the environment of Sunny Hill. Alternatively, the majority of children completed the worksheet activity. This may be because the worksheet was done at home and did not require extra time at the appointment to complete.

The toolkit sessions complemented the information gained from the initial observation sessions, and enabled the participants to actively contribute to the research. For Danielle, she was able to convey her ideas through imaginary play and choice making, rather than being involved in an interview or questionnaire, which would have been challenging given her ability to communicate using speech. In Michael's case, he was surprised at how many ideas he was able to generate by building his ideal play space using the toolkit. Michael's experience supports Liz Sanders' philosophy that using generative toolkits allow for a greater number and variety of ideas to arise than participants are unable to expressly state (i.e. tacit knowledge) (Sanders and William, 2001). Even for Sam, the toolkit potentially provided a less frustrating, more active and explorative way for him to participate in the design process.

The full-size kinesthetic toolkit is significantly different from the earlier toolkits and presents a different scale of representation through the body rather than a model. While both sizes allow for pretend play, the question of required skill level and desired outcomes arose. How does the capacity for children to engage in imaginary play compare to the idea of using models to represent a situation, as a learned design skill? How do children's understanding of representational relations of knowing and imagining affect the outcomes and quality of the information they provide through the toolkit? Woolley and Wellman (1993) would argue that children younger that eighteen months may not be able to 'pretend' and that their imagination is closely linked to reality, making imagining through a model more difficult and unreliable.

Being mindful of the above, the author wonders which situations the kinesthetic toolkit might be most successful. As it affords a high degree of activity, the kinesthetic toolkit may be suited to children who need to be active, rather than those who need a more calming or grounding type of toolkit to help maintain their attention to participate. When used with children who use mobility equipment such as a walker or a manual or power wheelchair, the larger scale might be easier to engage with, and afford a greater understanding of one's movement and position in the environment. The kinesthetic toolkit is similar to a mock-up, and could offer an experience of how something might be. This could be helpful when planning home renovations to increase accessibility, or in determining how a piece of equipment, such as a wheelchair, might fit through a particular sized doorway, or move about within a room. The decision to use a small or large scale toolkit might be driven by both the unique needs of the participant combined with desired outcomes or goals. For example, the smaller toolkit may be better suited in the early brainstorming and generative stages of the design process, while the larger toolkit is better for experiencing and 'trying out' prototypes in the later phases. This is an area that requires further exploration.

The examples presented in this thesis illustrate that toolkits have the potential to be successful with children with disabilities, as well as adults, when the materials are customized to meet their individual needs and goals. A summary of each child's unique needs and abilities related to their toolkit can be found on the following pages.

Table 3

| Summary of Participant Toolkit | S | | |
|--|--|--|--|
| Toolkit #1 - The Alpha Toolkit | | | |
| ICF Category | Danielle | Toolkit Challenge | Solution |
| 1. Function and disability | | | |
| a. Body structures and function i.e. human anatomy and body functions mental functions, sensory functions, voice and speech functions | Danielle has smaller physical dimensions | To provide materials that are proportional to her size. | Smaller sized: - Model - Materials such a scissors, crayon glues, craft materials |
| | Limitations in verbal speech | To provide a means of communication. | Use of Picture Communication Symbols (PCS') through Mayer Johnson. |
| | | | Focusing on verb adjectives and emotions rather than objects (i.e. TV) |
| | Limitations in cognition | To provide inclusive task demands. | Allow enough time for research activities |
| | | | Allow twice as lor for a response following a question or reque |
| b. Activities and Participation i.e. mobility, talking, and social interactions, communication, social life! | Limitations in communication | | Present choices to facilitate communication |

| ICF Category | Danielle | Toolkit Challenge | Solution |
|--|--|--|---|
| 2. Contextual factors | | | |
| a. Environmental factors i.e. attitudinal (encouragement, inclusiveness, social [emotional and physical support, communication] and physical | Inclusiveness | To have a supportive and inclusive attitude and | Informal location for the workshop sessions (e.g. home) |
| (products, technology, services, aids) | | approach. | Use informal language (avoid design jargon) |
| | | | Sit in a position or at a level that is comfortable for Danielle |
| | | | Have a participatory mind- set (rather than an expert driven mind- set) during the sessions |
| b. Personal factors i.e. age, gender, social background, education, experience, character style | Danielle likes 'pretend play' | To provide opportunities for imaginary play. | Dollhouse' model of the therapy department |
| | | | Use of a scenario: "If you had a magic wand…" |
| | Danielle is seven years old and in grade one | To provide familiar, materials that complement her age and experiences. | Familiar arts and crafts materials: craft paper, pipe cleaners, fabric, shapes, textures, stickers |
| | | To provide open-ended, ambiguous materials | Reference to Mark Dudek's archetypal children's spaces; basic shapes and colours |

| Toolkit #2 - The Skinny Toolkit | | | |
|--|--|---|---|
| ICF Category | Michael | Toolkit Challenge | Solution |
| 1.Function and disability | | | |
| a. Body structures and function i.e. human anatomy and body functions mental functions, sensory functions, voice and speech functions | Limitations in fine motor skills: grasp, strength and range of movement in shoulders, arms and hands | To provide materials that allow for independent building and creating. | Smaller sized model to allow for easy reaching and grasping and allow the model to fit on his wheelchair tray surface |
| | | | Images with perforated edges so that cutting and the use of scissors is not required |
| | | | Use of magnetic surface for the model walls and components to allow for building without glue |
| | | | Lightweight components to allow for easy grasping |
| b. Activities and Participation i.e. mobility, talking, and social interactions, communication, social life! | Limitations in fine motor skills: grasp, strength and range of movement in shoulders, arms and hands | To provide an alternative to writing text and drawing pictures. | Use of Picture Communication Symbols |
| | Limitations in mobility | Materials that allow for maximum participation | Smaller sized model to fit on wheelchair tray surface |
| | | | Using a box to hold and present all of the images and component 'tiles' at once |

| ICF Category | Michael | Toolkit Challenge | Solution |
|---|---|---|---|
| 2.Contextual factors | | | |
| a. Environmental factors i.e. attitudinal (encouragement, inclusiveness, social [emotional and physical support, communication] and physical (products, technology, services, aids) | Inclusiveness | To have a supportive and inclusive attitude and approach. | Use informal language (avoid design jargon) |
| | | To have a supportive and inclusive attitude and approach. | Sitting at the same level that is comfortable for Michael |
| | | | Have a participatory mind- set (rather than an expert driven mind- set) during the sessions |
| | Michael asks for help with certain tasks when needed | Provide graded physical support for tasks when needed to enable as much independence as possible. | Completing tasks together i.e. pulling on one side of the perforated images while he pulls on the other |
| | Michael is a very good story-teller | Providing opportunities for narratives and listening | Use of a scenario: "If you had a magic wand…" |
| | Michael is sixteen years old and in grade eleven | To provide familiar, materials that complement his age and experiences | Using a drawn figure of a person rather than a doll; provide age appropriate primer activities (colouring activity vs. a 'scavenger hunt') |
| | | | Familiar arts and crafts materials: craft paper, pipe cleaners, fabric, shapes, textures, stickers |

| ICF Category | Michael | Toolkit Challenge | Solution |
|--|--|--|--|
| 2.Contextual factors | | | |
| b. Personal factors i.e. age, gender, social background, education, experience, character style | Michael is sixteen years old and in grade eleven | To provide open-ended, ambiguous materials. | Reference to Mark Dudek's archetypal children's spaces; basic shapes and colours |
| | Michael is shy | To provide a comfortable research environment | Informal, private and safe location for the workshop sessions (e.g. Quiet room in his classroom at school) |

Toolkit #3 - The Kinesthetic Toolkit

| ICF Category | Sam | Toolkit Challenge | Solution |
|--|--|---|--|
| 1.Function and disability | | | |
| a. Body structures and function i.e. human anatomy and body functions mental functions, sensory functions, voice and speech functions | Sam enjoys activities that involve movement (bike riding, building, Wii) | To provide materials that enable him to embody his ideas. | Larger, life-sized model with large, basic shapes and paper on the floor for drawing |
| | | | Provide materials and components that allow for large body movements |
| | Limitations in verbal speech | To provide an alternative means of communication. | Use of Picture Communication Symbols (PCS') through Mayer Johnson |
| | | | Focusing on verbs, adjectives and emotions rather than objects (i.e. TV) |

| ICF Category | Sam | Toolkit Challenge | Solution |
|---|------------------------------|---|--|
| 1.Function and disability | | | |
| a. Body structures and function i.e. human anatomy and body functions mental functions, sensory functions, voice and speech functions | Limitations in attention | To provide interesting, meaningful and engaging activities. | Present a scenario that is meaningful and matches his interests. |
| | | | Allow for flexibility during the session. |
| | | | Provides images on stickers with perforations for quick application (no scissors or glue required). |
| | | | Provide multi- sensory components to increase attention and focus - tactile, sound, sight, smell. |
| b. Activities and Participation i.e. mobility, talking, and social interactions, communication, social life! | Limitations in communication | | Present choices to facilitate communication |
| | | | Include picture communication symbols |
| 2.Contextual factors | | | |
| a. Environmental factors i.e. attitudinal (encouragement, inclusiveness, social [emotional and physical support, communication] and physical (products, technology, services, aids) | Inclusiveness | To have a supportive and inclusive attitude and approach. | Informal location for the workshop sessions (e.g. home) |
| | | | Use informal language (avoid design jargon) |

| ICF Category | Sam | Toolkit Challenge | Solution |
|--|--|---|---|
| 2.Contextual factors | | | |
| b. Personal factors i.e. age, gender, social background, education, experience, character style | Sam is seven years old and in grade one. | To provide familiar, materials that complement developmental level and experiences. | Familiar arts and crafts materials: craft paper, pipe cleaners, fabric, shapes, textures, stickers |
| | | To provide open-ended, ambiguous materials. | Reference to Mark Dudek's archetypal children's spaces; basic shapes and colours |
| | | | Picture Communication Symbols |

Note. The ICF categories from are the World Health Organization. (n.d.). The International Classification of Function,

Disability and Health. Retrieved on February 24, 2009, from http://www.who.int/classifications/icf/en/

This research has led to an understanding of the physical, sensory, and cognitive demands and affordances of the toolkit materials. For example, the sensory affordances of playdough are calming, while the kinesthetic toolkit provides a stimulating activity. These observations begin to build a menu of possibilities that can be tailored to individual children. A summary of the adaptations to the toolkit materials, corresponding to individual needs (e.g. fine motor, sensory, cognitive and perceptual abilities) and the literature can be found in Table 4.

Table 4

Practical Suggestions for Inclusive Toolkits in Participatory Design with Children

| ICF Category | Toolkit Activity | Suggestion |
|--|--|--|
| 1.Function and disability | | |
| a. Body structures and function i.e. human anatomy and body functions mental functions, sensory functions, voice and speech functions | Planning | Meet children at their level of function (reading skills, vision, cognition, physical abilities). |
| | | Provide materials that are proportional to the size of the child. |
| Limitations in speech | Stickers of words and phrases | Picture communication symbols (focus on verbs, adjectives, emotions). |
| Limitations in fine motor abilities | Collage activity (i.e. scissors, glue, stickers, images, paper, simple shapes) | Print images, shapes and picture symbols on sticker sheets with perforations between each item to allow for tearing rather than using scissors. |
| | | Use magnets, Velcro, stickers or felt, rather than glue. |
| Limited grasp | | Place images and textures on a raised lightweight surface for easier grasping (foamcore or balsa wood). |
| | | Offer wider diameter drawing utensils (e.g. wider crayons, finger crayons, triangular shaped markers). |
| | | Foam pipe insulation can also be placed over drawing utensils to increase their diameter. |
| | Collage activity (i.e. scissors, glue, stickers, images, paper, simple shapes) | Offer stamps or 'bingo blotters' as an alternative to drawing |
| Visual impairment | | A vertical slanted surface can be physically and visually easier to work with. |

| ICF Category | Toolkit Activity | Suggestion |
|--|--------------------------|--|
| 1.Function and disability | | |
| a. Body structures and function i.e. human anatomy and body functions mental functions, sensory functions, voice and speech functions | Images and words | Incorporating braille |
| Visual impairment | | High contrast images and text (black and white, sans serif font, avoid using coloured paper or type) |
| | | Consider a hierarchy for visual material to augment communication; beginning with a tangible object, to a photo of the tangible object, to a picture symbol, graphic, or icon |
| | | When children are learning to use a visual communication system, they ma work through this progression |
| | | Tangible objects allow children to discern items by touch |
| | Primer activities | Audio journal rather than written |
| Sensory motor needs | 3D building materials | Multi-sensory materials that stimulate the senses (tactile, olfactory, auditory, gustatory, temperature, kinesthesia, vestibular) e.g. clay, water play, sand play, finger painting. |
| | | The kinesthetic toolkit and Nigel Frost's approach - use simple materials and involve large body movements |
| | | Placing paper on wall and floor surface to allow for large body movements when drawing |
| b. Activities and Participation i.e. mobility, talking, and social interactions, communication, social life! | Workshop sessions | Allow for a response time that is twice as long as you would usually |
| | | Allow enough time for research activitie |
| | | Kinesthetic toolkit allows for free movement |

| ICF Category | Toolkit Activity | Suggestion |
|---|----------------------|---|
| 1.Function and disability | | |
| b. Activities and Participation i.e. mobility, talking, and social interactions, communication, social life! | Workshop sessions | Present choices to facilitate communication |
| | | Allow for breaks and free play activities |
| | | Delimit the number of materials to increase attention and focus |
| | | Non-directive approach in the workshop session |
| | | Provide open ended questions |
| 2.Contextual factors | | |
| a. Environmental factors i.e. attitudinal (encouragement, inclusiveness, social [emotional and physical support, | | Initial observation session to build rapport and an appreciation of the child's strengths and abilities |
| communication] and physical (products, technology, services, aids) | | Informal location for the workshop sessions (e.g. home, school or outdoors) |
| | | Have a participatory, client-centered mindset toward children and their families |
| | | Use informal language rather than jargon |
| | | Sit in a position or at a level that is comfortable for the child |
| | | Provide basic and familiar materials that can easily be found in a craft store, and are familiar to children. (e.g. crayons, markers, colouring, sticker and workbooks, paper, basic shapes, blocks, figures and small dolls). |
| | | Choose materials that complement the child's age, experiences and level of function, (i.e. consider reading skills, past experiences, fluency) |

| ICF Category | Toolkit Activity | Suggestion |
|--|----------------------|---|
| b. Personal factors i.e. age, gender, social background, education, experience, character style | Workshop sessions | Use scenarios, low-tech prototypes and mock-ups to 'imagine how something could be', and generate ideas quickly and easily (e.g. 'if you had a magic wand') |
| | | Provide open-ended, ambiguous materials |

Note. The ICF categories from are the World Health Organization. (n.d.). *The International Classification of Function, Disability and Health.* Retrieved on February 24, 2009, from http://www.who.int/classifications/icf/en/

5.2 RELATIONSHIP OF FINDINGS TO THE LITERATURE AND THEORY

The literature and theoretical framework have guided the suggestions provided in tables 3 and 4 with the goal of increasing children's abilities to participate in the toolkit activities and contribute to research. On embodiment, (including Gibson's theory of affordances and Heidegger's work) Clark (1997) argues that embodied action "includes all cases in which body and local environment appear as elements in extended problem solving activity" (p. 171). This presents a reevaluation of the decision to use a small versus large scale toolkit that is based on both the unique needs of the participant combined with desired outcomes or goals related to the stages of the design process.

While this research supports the sociology of childhood, it also acknowledges that valuable details can be lost if certain aspects of development are not taken into account. In particular, the notion of 'developmentally appropriate activities' is relevant to the toolkit materials and activities. In this thesis, it is understood that all children develop differently (trajectories and abilities), and that standard expectations of child development are often not possible. Developmental differences were accounted for in the toolkit activities and materials to reflect the temporality that exists throughout an individual's life (e.g. the perspectives of a teenager versus a seven year old are very different). The toolkit components were chosen primarily to support the child's functions and context, versus

developmental expectations (as might be considered from a therapeutic perspective). Having a deeper understanding of a child's context led to the creation of a toolkit that was more relevant and accessible to them.

In terms of family centered practice, having an initial session to meet and observe the child and their family was advantageous in planning the materials for the toolkit, as well as in fostering rapport with the child and their family. Sensitivity toward the demands placed on children and families is important, particularly when a member of the family has a disability. By considering the specific needs of each participant, activities and materials could be thoughtfully chosen that were responsive to individual needs, and make the best use of the workshop time together. For example, the larger scale kinesthetic toolkit was more suitable to Sam's physical needs than the smaller toolkit, and made our time together productive.

The findings illustrate that while it is important to ask open-ended questions with children, a child with limitations in spoken communication might find it easier to communicate through choicemaking. Similar to Greene and Hogan (2005) it was also observed that in-depth conversations are sometimes difficult with children in research situations, due to decreased attention span. In the research, attention span appeared to be related to both environmental factors (e.g. number of participants), personal factors and physical functioning. It is important to be patient and allow for shorter sessions, and breaks. For children with physical and or cognitive limitations, it is especially important to provide enough time for them to respond to questions and requests. This supports Greene and Hogan's (2005) recommendation to allow children with enough time in research situations.

All the workshop sessions took place outside of a clinical setting, This was advantageous as it is much easier for a child to express his, her ideas when they at home, school or in an outdoor play environment rather than a laboratory or clinic (Druin, 1999; Greene & Hogan, 2005). Michael's self-consciousness in taking photographs in the therapy department (as part of the primer activities), may have been related to this factor.

The author agrees with Druin (1999) that the use of basic art supplies comes naturally to both adults and children. The results illustrate that this may have been conducive to placing the author and the child on an equal basis, thereby breaking down the power differential, a common challenge when engaging in research with children (Greene and Hogan, 2005).

5.3 RELATIONSHIP OF FINDINGS TO PRACTICE

The approach of using toolkits with children with disabilities in design research is one which has other potential applications in healthcare. This research highlights the relevance of using creative methods as a complement to traditional approaches such as interviews, questionnaires, observations and surveys. The toolkit explorations have provided an example of how researchers can use this method with children with disabilities toward the design of the built environment.

While traditional research methods are valuable and necessary in certain situations, researchers might find that creative methods are well-suited to children's needs, and provide an engaging alternative when involving children in decision making. For the participants in this study, the toolkits enabled me to listen more deeply and empathically to their needs while also being fun and creative in my interactions.

In using the toolkits, I employed what Sanders refers to as a 'participatory mind-set' in working with the children and youth. This mind-set involves designing together with people (Sanders, 2006). The opposite is the 'expert mindset' where designers are more focused on "designing for people using specialized skills and expertise" (Sanders, 2006, p.5). The notion of a participatory mindset strongly resonates with client centered practice. The toolkits fostered a participatory mindset in the design process and brought me closer to the same level as the children, thus decreasing their perception of me as the 'expert' researcher.

5.4 LIMITATIONS

Due to time limitations, a more in depth examination of the experience of children with disabilities and their parents in using a co-designing approach involving the toolkit was not possible.

As well, the review of the workshop sessions and their implications for the design of a future play space are not included in this thesis. The analysis of ideas and findings of the play space research will occur in the later stages of the larger participatory action research study.

The limitations of the pilot tests are acknowledged; ideally one to one sessions would have taken place with children with a range of abilities. While it appeared easier for both older children and those with a higher level of functional spoken communication to share their ideas with the author, the extent to which the toolkit facilitates or augments non-verbal communication could be further explored for children like Sam and Danielle. The area of assistive and augmentative communication (AAC) is a specialized field. It was outside the scope of this thesis to engage in an in-depth exploration for the how AAC might influence the participation for children with disabilities in the toolkit activity.

5.5 FUTURE RESEARCH

While this essay contributes to the understanding of creative research methods in pediatric disability studies, further research focused on refining the use of the toolkit could be explored including large versus smaller scale toolkits with children. In this project, the children were able to participate in the workshop sessions independent of parent or caregiver support. While this was an overall success, there are some children who may require assistance from another person to participate in the toolkit activity. In these cases, how the activities and materials are perceived by parents or caregivers might need to be considered. How do we create a toolkit that satisfies the needs of both an adult and a child?

In considering Louridas (1999) idea of unselfconscious design, the author asks - how do children and parents design in their everyday lives (and environments) to increase the ease of daily routines and activities? What could we learn from them as designers and healthcare practitioners? What is our understanding of children and parents' needs and desires for medical equipment, systems and services compared to their own perceptions? And how can this information lead to innovative, meaningful and relevant designs?

In acknowledging that children with disabilities' have their own unique experiences within the world, a research opportunity might involve exploring how ideas for a play environment differ for children with disabilities, compared to children without physical or cognitive limitations. This research could inform inclusive designs for all children in healthcare and community settings. For instance, a child who uses a wheelchair might request an image on the floor that is textured to allow for vibration when driving overtop, whereas this sensory feedback might not be as meaningful to for a child who is ambulatory.

Furthermore, participatory design and healthcare research involving collaboration between both industrial designers and OTs in the design of inclusive toolkits could be studied further. This might include working together with speech and language pathologists to address assistive and augmentative communication methods. It may also involve work with play or art therapists and cognitive psychologists to provide insight into creative approaches and in the interpretation of the children's artifacts. Opportunities might involve collaboration beginning in undergraduate and graduate levels of education, through to industry partnerships between education, design and healthcare institutions and organizations. Future research efforts might also explore the use of visual materials and creative methods in OT research and practice, not only as a means to provide patient information and assessment, but throughout the assessment and intervention process.

The International Classification of Function, Disability and Health (ICF) framework has been introduced in this essay as a means to provide a common language and foster a neutral or positive view of disability between occupational therapy and design (WHO, 2001). Further studies addressing the use of the ICF within inclusive ⁸ and medical assistive design practices may be advantageous to designers when working across disciplinary boundaries. This framework can foster communication and support the empowerment of end-users. The ICF is potentially significant in the design of policy and service development, as well as the growing area of designing for social impact⁹. The ICF could provide a holistic framework toward design research, further contributing to deeper contextual understanding, and significant designs.

The knowledge gained from this research has potential applications for pediatric occupational therapy, designing for children with disabilities, and populations such as the elderly, adults with physical and cognitive disabilities, and individuals with mental health issues. Potential design research opportunities include:

- Designing for children with autism, where communication is often a challenge
- Design of products such as aids for independent living, multi-sensory equipment for children, and positioning and mobility equipment
- Decisions related to choice of rehabilitation equipment and planning renovations to the built environment for increased accessibility (home, community, school) to help individuals decide on particular modifications, such as doorway width, the height of countertops, light switches and electrical sockets
- Design of knowledge transfer materials for children and their families, that are child and family friendly
- Health education and service design
- Design for social impact ⁷, including international health, where communication may be limited due to social and cultural factors, along with physical and cognitive elements.

Finally, Liz Sanders states that "co-design as it is practiced and discussed today takes on quite different manifestations, depending upon the expertise and mindsets of its practitioners" (Sanders & Stappers, 2008, p. 8). Knowing that the success of the toolkit sessions are dependent on the skill of the facilitator, this research further emphasizes the level of awareness required for a researcher using creative methods with children with disabilities. What are effective methods of knowledge transfer to build capacity toward inclusive participatory design methods in the design community?

5.6 IMPLICATIONS

This thesis essay is an effort to address the need for further research in using creative methods in research with children with disabilities, for both occupational therapists and designers.

The toolkit is a valuable creative and visual method that has potential for use in pediatric occupational therapy and design practices, as well as in research. This series of explorations has revealed that the toolkit has the potential to be easy for children to engage with. Further, the use of creative materials increases the opportunity for individuals with physical and cognitive limitations to participate in the design process, and contributes to overcoming the power imbalances that are common when engaging in research with children. This was apparent for both Danielle and Michael, in their abilities to articulate their needs, hopes, and desires for the play space.

For designers, this essay provides a summary of key points for consideration when using creative research methods with children with different abilities. Occupational therapists are provided with insight into how participatory design methods can support the sharing of ideas through creative, visual materials. Both disciplines are supported in encouraging a sense of empathy and contextual understanding, in their practices, toward individuals for whom their skills and services affect.

The insights of this thesis come from recognizing how the collaboration between two seemingly different disciplines, industrial design and occupational therapy, has contributed to the research involving the direct involvement of children with disabilities in the design process. The quality of the information provided from the workshop sessions will be useful to designers and researchers. This work will hopefully lead to an increased comfort level for researchers using participatory design methods with individuals with a range of abilities and has provided ideas for future research initiatives that support participation, creativity, autonomy and empowerment of children with different abilities.

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APPENDIX A

INFORMED CONSENT AND ASSENT FORMS



INFORMATION AND CONSENT FORM For Parents/Guardians of Children

Co-designing play spaces in the therapy department at Sunny Hill

Principal Investigator: Lori Roxborough, M.Sc., OT/PT, Telephone # 604-453-8302

| Co-Investigators: | Louise St. Pierre, B.F.A. (Honours) Industrial Design Telephone # 604-844-3800 extension 2826 |
|-------------------|---|
| | Jen Sawrenko, B.Sc.OT, M.A.A. Design Candidate, OT, Also study co-ordinator Telephone # 604-844-3800 Email: jsawrenko@eciad.ca |

To: Parents/guardians

Introduction:

Your child is being invited to participate in this study because s/he resides in the Lower Mainland and are currently receiving seating or therapy services from Sunny Hill Health Centre.

Participation is Voluntary:

Your child's participation in this project is entirely voluntary. Before you decide, it is important for you to understand what our research involves. This consent form explains the study in detail; it tells you why the research is being done, what will happen during the study and the possible benefits, risks and discomforts.

If you and your child wish to participate in this study, you will be asked to sign this consent form, and you will receive a copy of your signed consent form. You are still free to withdraw at any time and without giving any reasons for the decision.

Who is Conducting the Study?

This research project is part of a thesis requirement for the Master's of Applied Arts in Design graduate degree program at the Emily Carr University of Art and Design (formerly the Emily Carr Institute). This study is being conducted by researchers from the Emily Carr University of Art and Design and Sunny Hill Health Centre for Children. Sunny Hill Health Centre for Children (Sunny Hill) is part of Children's and Women's Health Centre of British Columbia.

Background:

Co-designing is used by designers in an attempt to gain an understanding of the issues that are important to the individuals they are designing for. This method involves the use of creative activities such as drawing, collage and building of models. Previous studies have shown that this method is easy to use and enables individuals to communicate their needs through a means other than speaking and writing. This method has not yet been used for children with disabilities and their parents.

What is the Purpose of this Study?

The purpose of this study is to explore the use of co-designing methods for children with disabilities and in healthcare. The study is focused on designing play spaces or play objects for, and with children in the therapy department of Sunny Hill.

Who Can Participate in the Study?

Children and youth between the ages of 6-18 years of age who live in the Lower Mainland, are able to make choices between two items (preferred and non-preferred) and have a consistent yes/no response.

Who Should Not Participate in the Study?

Children or youths who will be moving out of the Lower Mainland in the next six months.

What Does the Study Involve?

The study will be taking place at Sunny Hill Health Centre and, or within your home, whichever is most convenient. The information you provide will be used to design play spaces and objects in the therapy department of Sunny Hill. During the designing of these spaces and objects you and your child will be asked to provide your feedback and ideas. The first visit will involve an observation of your child playing during an already scheduled positioning and mobility appointment at Sunny Hill the time is dependent on your appointment, it may be as short as 30 minutes and a maximum of one hour. The observation will be guided using the Ludic Model.

The Ludic Model is a play assessment used by occupational therapists to find out what children like to do, what they can do, how they do activities, how they react to activities and what their special difficulties are. You will also be asked to complete a workbook on the same topic that will include activities such as drawing and photography. The workbook will take less than 1 hour to complete over several days. On the second visit, the researcher will pick up the workbook and you and your child will be asked to do a creative collage activity and a model making activity. This session will take a maximum of 1 hour 15 minutes. During the third visit, the researchers will share initial design ideas for the play spaces or objects with you and your child and ask you about your experience using creative activities and co-designing, which will take up to one hour. During the visits, with your consent, you and your child will be photographed, video and audio-taped, to help the researchers remember the information you provide.

If You Decide to Participate in this Study:

Before the First Visit

A research coordinator will contact you to answer your questions and co-ordinate the first visit.

First Study Visit

You will meet with the researcher at Sunny Hill during your scheduled positioning and mobility appointment, where the researcher will review the consent form with you and your child. Questions and concerns about the study will be addressed and you will be asked to sign the consent form. You will be given a copy of your signed consent form. The study researcher will observe your child playing during your appointment using the Ludic Model, and provide you with a workbook to complete. It is anticipated that this visit will take a maximum of one hour depending on the length of your scheduled appointment. The workbook will take you less than one hour to complete over several days.

Second Study Visit

The same study researcher will meet you at Sunny Hill or at your home (wherever is more convenient). They will have prepared a creative activity for you and your child to complete involving collage, drawing, and building models, they will also collect the workbook from you. This visit will take approximately 1 hour and 15 minutes.

Third Study Visit

The same researcher will meet you at Sunny Hill or your home. The researcher will show you and your child drawings and models for the play spaces and objects based on the information you and other children and parents have provided. The researcher will ask for your input into the design and ask you questions about your experience using creative activities and co-designing. This visit will take a maximum of 1 hour.

What Are My Responsibilities?

You and your child are asked to participate in one observation session, and attend 2 workshop sessions, which will be scheduled between September 2008 and December 2008. The total amount of time you will be asked to contribute is a maximum of 4 hours and 15 minutes including all sessions and the workbook. If for any reason you are unable to attend, please notify the researchers at 604-453-8302.

What Are the Possible Harms and Side Effects of Participating?

There are no known risks to this assessment, nor should there be any cause for discomfort during the creative activities.

What Are the Benefits of Participating in this Study?

There are no direct benefits to your child from taking part in this study.

The information you provide will contribute to the design of play spaces and objects in the therapy department of Sunny Hill. If the use of co-design methods is positive, it may be used in the future to assist therapists, families and children with disabilities in making design decisions (for example specialized equipment or home renovations).

What if New Information Becomes Available That May Affect My Decision to Participate?

If new information arises during the research study that may affect you/your child's willingness to participate, you will be advised of this information.

What Happens if I Decide to Withdraw My Consent to Participate?

You and your child's participation in this study are entirely voluntary. You or your child may decline to enter this study or withdraw from the study at any time without any consequences to your continuing services at Sunny Hill Health Centre for Children.

What Happens if Something Goes Wrong?

You do not waive any of you or your child's legal rights by signing this consent form.

After the Study is Finished

If you are interested in the results of the study you may ask the researchers to notify you when the study results are available. The specific information related to your child's participation in this study will be kept confidential. Once the study is completed the data will be kept at Sunny Hill Health Centre for Children for 5 years in a secured, locked cabinet (including video and audio recordings and digital photographs). 5 years following the completion of the study, all data will be destroyed.

Will My Taking Part in this Study Be Kept Confidential?

You and your child's confidentiality will be respected. No information that discloses your child's identity will be released or published without your specific consent to the disclosure. However, research records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of Health Canada, and the UBC Research Ethics Board for the purpose of monitoring the research. However, <u>no records which identify your child by name or initials will be allowed to leave the investigators' offices</u>. All documents, audio and videotapes resulting from this study will be identified by only a code number and kept in a locked filing cabinet by the study co-coordinator.

Who Do I Contact If I Have Questions About the Study During My Participation?

If you have any questions or desire further information about this study before or during participation, you can contact the study coordinator Jen Sawrenko at #604-844-3800 or the principal investigator Lori Roxborough at #604-453-8302.

Who Do I Contact If I Have Questions or Concerns About My Rights as a Subject During the Study?

If you have any concerns about your rights as a research subject or your experience while participating in this study, contact the "Research Subject Information Line in the University of British Columbia Office of Research Services" at telephone #604-822-8598.

Subject Consent to Participate

The parent(s)/guardian(s) and the investigator are satisfied that the information contained in this consent form was explained to the child to the extent that he/she is able to understand it, that all questions have been answered, and that the child assents to participating in the research.

- I have read and understood the subject information and consent form.
 I have had sufficient time to consider the information provided and to ask for
- advice if necessary.
- _____ I have had the opportunity to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that results will be used for scientific objectives; results may be inclued in presentations about the project and as part of the Emily Carr University Graduation show, and written thesis requirement for the Masters of Applied Arts Program.
- _____ I understand that my child's participation in this study is voluntary and that my child is completely free to refuse to participate or to withdraw from this study at any time without changing in any way the quality of care that my child receive(s).
- _____ I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- _____ I understand that there is no guarantee that this study will provide any benefits to my child.
- _____ I have read this form and freely consent to participate in this study.
- _____ I have been told that I will receive a dated and signed copy of this form.

| Printed Name of Subject | Signature of Subject | Date |
|---|--|------|
| Printed Name of Parent/Guardian | Signature of Parent/Guardian | Date |
| Printed Name of Witness | Signature of Witness | Date |
| Printed Name Principal Investigator | Signature Principal Investigator | Date |
| Printed Name of Translator (if applicable) | Signature of Translator (if applicable) | Date |
| | | |

Language of Translation (if applicable)



ASSENT FORM

Co-designing play spaces in the therapy department at Sunny Hill

What is this study about?

This study will find out whether the creative activities (drawing, collage, photography) can be used to design play spaces and objects in the therapy department at Sunny Hill.

Who is doing this study?

Therapists and researchers at Sunny Hill Health Centre for Children and Emily Carr University (formerly the Emily Carr Institute of Art and Design) are doing this study. Sunny Hill Health Centre provides therapy services to children throughout British Columbia and learns about new ways of treating children by doing research.

Why is this study being done?

Children with disabilities often find it difficult to tell people what they like by talking and writing. Using creative activities might make it easier to share ideas and thoughts. New methods are needed to help therapists communicate with children and their parents to decide on the design of equipment and adaptations that would work the best for them. This study will explore the use of these creative, imaginative methods.

What will you be asked to do?

You will come to Sunny Hill or be visited in your home, three times over six months for about 1 hour each time. During the visits, you will be asked about what your favourite play activities are and why, and participate in creative activities to help design play spaces and objects in the therapy department at Sunny Hill. Activities include taking pictures, drawing, and collage or cut and pasting. You will also be asked to provide input into the design of the spaces and objects as they are built. During the visits you will be video and audio taped to help the researchers remember the information that you give them.

Does any of this hurt?

No, none of the activities will cause pain. If there are things that you cannot do, or do not want to do that is okay.

Is there anything that might help you?

There isn't a benefit to you but the study might help other children in the future because therapists will be able to use creative activities with the children that they see as well.

Do you have to do this?

You don't have to be in this study if you don't want to. If you do decide to be in the study you can withdraw at any time and no one will be upset with you. No matter what you decide, you will still be able to get any of the services you get now.

Will information about you be kept private?

All information collected about you for this study will be kept private and your name will not be used on any study records. When the study is finished the researchers will write a report about what is learned. The report will not include your name or that you were in the study.

What if you have questions?

You should talk to your parent about the study and ask them any questions you have before you decide. During the study you can ask the researchers questions too.

Yes, I would like to be in this study

Printed Name of Child

Signature of Child

Date

SUNNY HILL HEALTH CENTRE FOR CHILDREN VANCOUVER, B.C.

VIDEO/AUDIO/PHOTO CONSENT FORM

Co-designing play spaces in the therapy department at Sunny Hill

The 2 workshop sessions with you/your child will involve creativity-based research tools such as collage, photographs, 3-Dimensional modeling (using Velcro models and playdough) and drawing activities as data gathering methods. Sessions will be audio and video recorded, transcribed and photographs taken of the collages, models, drawings made. The video data will also provide information on non-verbal communication such as gestures and expressions, that cannot be captured using only audio-recording. The video and audio recordings will be reviewed only by the study researchers and the information provided will be written down and compared with other participant responses to provide an explanation of the how the study participants envision the future design of the play spaces at Sunny Hill and their experience using the co-designing process.

Only the principal and co-investigators of the research project will have access to any video, audio recordings and photographs taken of you/your child during the research. All information provided during the workshop sessions, including video and audio recordings, and photographs will be identified only by code number and kept in a locked filing cabinet or password encrypted, secure computer for the duration of the research study. You/your child will not be identified by name in any reports of the completed study. Any quotes from audio or video recordings used in reports, presentations, or papers will not use your/your child's real names. Those not participating in the study will not be videotaped during the documentation.

Once the study is completed the data will be kept at Sunny Hill Health Centre for Children for 5 years in a secured, locked cabinet (including video and audio recordings and digital photographs). 5 years following the completion of the study, all data will be destroyed.

| l, | | |
|--|-------------------------------------|------------------|
| (Name | e of Parent/Guardian), | |
| hereby authorize the co-investigate Photographs Video tapes Audio tapes | ors Louise St. Pierre and Jen Sawr | enko to take: |
| during the 2 workshop sessions | | |
| of the for the purpose of: Research (data gathering ar other | nd analysis of findings) | of Child) during |
| | | |
| Signature of Parent/Guardian | Relationship to Child | |
| Witness | Date | |
| I agree to the capture, editing, pro | duction, duplication and conditiona | al distribution |

of content for a limited time at the discretion of Sunny Hill Health Centre for Children. I may withdraw my consent at any time. Enabling Children: Explorations into Creative Design Research Methods with Children with Disabilities

PILOT TESTER INFORMATION AND CONSENT

Principal Investigator: JEN GELLIS Emily Carr: 604-844-3800 Cell: 778-888-3855 Email: jengellis@gmail.com

Masters of Applied Arts in Design (MAA) Emily Carr University of Art and Design

INTRODUCTION AND INVITATION

I would like to invite you to be part of a research project that I am conducting. This project is part of the requirement for a Masters of Applied Arts Degree in Design, at Emily Carr University of Art and Design. My name is Jen Gellis and my credentials with Emily Carr University can be established by calling Dr. Monique Fouquet, Vice-President of Academic at 604-844-3865.

YOUR PARTICIPATION IS VOLUNTARY

Take time to read the following information carefully, for it will tell you why the research is being done, what will happen to you during the study and the possible benefits of being in the study.

WHO IS CONDUCTING THE STUDY?

The Principal Investigator is the sole person conducting and investigating this study.

BACKGROUND

This study is part of a larger participatory action research study at Sunny Hill Health Centre for Children. The study at Sunny Hill involves collaboration with children with disabilities, parents, caregivers and healthcare providers to design a play space in the therapy department. Pilot testing is an important step in planning the creative methods used in the creative sessions with the participants of the play space study.

WHAT ARE THE GOALS OF THIS STUDY?

The goals of this study are to understand:

- The use of creative research methods with children with disabilities
- Whether creative methods facilitate or augment non-verbal communication
- If the toolkit facilitates empathy and understanding for researchers
- Whether toolkits can be a complementary method for occupational therapists, other healthcare providers, and researchers in healthcare
- If there are certain criteria and considerations, that are important when utilizing a toolkit in research with children with different abilities

WHAT DOES THIS STUDY INVOLVE?

You will be involved in four sessions that involve the pilot testing of a set of creative methods, know as a toolkit. The sessions will last from 30 minutes to an hour maximum. During the session you will be asked to engage in creative activities such as drawing, building models and collage. You can choose to take part in one or more of the pilot tests.

WHAT ARE THE BENEFITS AND COSTS OF PARTICIPATING IN THIS STUDY?

While there are no direct benefits of you participating in this study, we hope that the information learned from this project can be applied or benefit the use of creative methods with children in design research with children.

AFTER THE STUDY IS FINISHED

A copy of the final essay will be published. A copy will be housed at the Emily Carr Institute of Art and Design, available through the library and online through the Emily Carr Institute of Art and Design Databases and the Theses Canada portal and will be publicly accessible. Access and distribution will be unrestricted.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

No information that discloses your identity will be released or published without your specific consent. Your names will not be used in this study. You will be identified by pseudonyms only. Information will be stored on one single computer with encrypted access. All paper documents will be stored in a safe and secured filing system. All data will be destroyed one year from the date that the study is completed deleting of all computer files including back-ups and shredding of all paper documents), unless consent is given by you.

WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?

If you have any questions or desire further information about this study before or during participation, you can contact Principal Investigator: Jen Gellis at 778-888-3855, jengellis@gmail.com or Emily Carr representative Dr. Monique Fouquet, Vice-President of Academic at 604-844-3865.

CONSENT TO PARTICIPATE

| I have read and understood the subject information and consent form. |
|---|
| I have had sufficient time to consider the information provided and to ask for advice if |
| necessary. |
| I have had the opportunity to ask questions and have had satisfactory responses to my |
| questions. |
| I understand that all of the information collected will be kept confidential and that results will be used for scientific objectives; results may be included in presentations about the project and as part of the Emily Carr University Graduation show, and written thesis requirement for the Masters of Applied Arts Program. |
| I understand that my child's participation in this study is voluntary and that my child is completely free to refuse to participate or to withdraw from this study at any time. |
| I understand that I am not waiving any of my legal rights as a result of signing this consent |
| form. |
| I understand that there is no guarantee that this study will provide any benefits to my child. |
| I have read this form and freely consent to participate in this study. |
| I have been told that I will receive a dated and signed copy of this form. |
| |

SIGNATURES

| Printed name of participant | | |
|--|--|------|
| Signature | | Date |
| Printed name of parent/guardian | | |
| Signature | | Date |
| Printed name of witness | | |
| Signature _ | | Date |
| Printed name of principal investigator | | |
| Signature | | Date |

Enabling Children: Explorations into Creative Design Research Methods with Children with Disabilities

ASSENT FORM

I have had the opportunity to read the consent form, to ask questions about my participation in this research, and to discuss my participation with my parents/guardians. All my questions have been answered. I understand that I may withdraw from this research at any time, and that this will not interfere with the availability to me of other health care. I have received a copy of this consent form. I assent to participate in this study.

Printed Name of Child/Youth

Signature of Child/Youth

Date

FOOTNOTES

1. *Note.* The images are from "Harnessing people's creativity: ideation and expression through visual communication" by Sanders, E.B.-N. and William, C.T., 2001, pp. 5, 8, 9. Copyright 2001 by Elizabeth Sanders. Reprinted with permission.

2. *Note.* The table is from "Co-creation and the new landscapes of design" by Sanders, E.B. -N. & Stappers, P.J., 2008, p. 12. Copyright 2008 by Taylor and Francis. Reprinted with permission.

3. Human factors, also known as ergonomics, "is a discipline which is concerned with designing according to human needs; theory, principles, data and methods are applied to design in order to optimize human well-being and overall system performance". Retrieved on February 24, 2009, from http://www.iea.cc/browse.php?contID=what_is_ergonomics

4. Collage is defined in the Oxford online dictionary as "a form of art in which various materials such as photographs and pieces of paper or fabric are arranged and stuck to a backing to create a composition" ("Oxford Online Dictionary", n.d.).

5. Universal design is defined as "The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design." There are seven principles of universal design: equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort and size and space for approach and use. The term universal design originated in the United States. Retrieved on February 24, 2009, from

http://www.design.ncsu.edu/cud/about_ud/udprinciplestext.htm

6. Inclusive design, although similar to universal design, originated in the United Kingdom and is reported to better reflect the context and values of the UK than universal design, and implies that there is not one universal solution for the needs of all people. Instead, inclusive design is defined as "a process that results in inclusive products or environments which can be used by everyone regardless of age, gender or disability." Retrieved on February 24, 2009, from http://www.cebe.cf.ac.uk/learning/sig/inclusive/whatisinc.pdf

7. Design for social impact is defined by IDEO as using design tools to create significant social change and "address global social issues such as poverty, health, water, economic empowerment, environmental activism, and the need for basic services. Design for social impact seeks to incite transformational change in under-served, underrepresented, and disadvantaged communities." Retrieved February 25, 2009, from http://www.ideo.com/thinking/focus/social-impact/