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Swimwear: Needs Assessment and Prototype Development for Special Needs Children

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SWIMWEAR: NEEDS ASSESSMENT AND PROTOTYPE DEVELOPMENT FOR SPECIAL NEEDS CHILDREN

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Abstract

Children with complex medical issues often require a placement of a tube known as a central venous line in their major artery. The insertion prohibits such individuals from experiencing the physical and psychological benefits of water activities. This qualitative and quantitative study examined the swimwear needs of children fitted with a central venous line based on a user analysis using Lamb and Kallal's (1992) Functional Expressive Aesthetic Consumer Needs Model of design attributes. The study was conducted in 3 phases: user analysis, design development, and field-testing. User analysis results revealed that the 7 participants (4 parents, 3 children) rated function as the most important design attribute, followed equally by expressive and aesthetic elements. The second phase produced a prototype that incorporated participants' needs and preferences. Field testing concluded that the prototype fulfilled expressive and aesthetic needs but only partially fulfilled functional needs.

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Dedication

This thesis is dedicated to all children with disabilities and to the parents and child participants who inspired me during my research endeavours.

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Chapter 1: Introduction

Background and Nature of the Problem

As the renowned theoretical physicist and author Stephen Hawking reminds us, "We have a moral duty to remove barriers to participation and to invest sufficient funds and expertise to unlock the vast potential of people with disabilities" (as cited in World Health Organization [WHO], 2011, p. 3). Children with disabilities face many environmental and social challenges every day, all of which have the potential to negatively affect their psychological functioning.

Statistics Canada's (2008) *Participation and Activity Limitation Survey 2006* defined disability as "an activity limitation or participation restriction experienced by an individual as a result of physical or mental conditions or health problems" (Definition of Disability section, para. 1). This definition is based on the WHO's (2012) International Classification of Functioning (ICF) framework, which in turn defines disability as the relationship between body structure and functions, daily activities, and social participation in context. Conditions associated with disabilities include those affecting hearing, seeing, speech, mobility, dexterity, learning, delay development, psychological health, cognitive abilities, and general well-being. In addition, it is recognized that activity limitations can impede health, overall self-esteem, and quality of life for individuals affected.

According to Statistics Canada (2008), approximately 3.7% of Canadian children under the age of 15 have two or more disabilities that limit physical activity in one way or another. The WHO's (2008) *The Global Burden of Disease: 2004 update* report estimated that 95 million children 0 to 14 years of age (or 5.1%) have some form of disability and 13 million (or .07%) have "severe disabilities" like blindness, Down syndrome, quadriplegia, severe depression, and active psychosis. As stated in the WHO's (2012) ICF framework, disability is a

multidimensional concept, the definition of which depends on inter-related factors, including physical, social, and psychological issues, and as such the term "disability" is difficult to define precisely.

For any child, with or without disabilities, physical activity promotes fitness, endurance, coordination, and self-esteem. Physical activities such as sports provide children with attainable goals that further enhance their sense of accomplishment and their self-esteem. Recreational activities provide children, especially those with disabilities, an opportunity to participate in a broader social community. Dumas and Francesconi (2001) suggested that participation in aquatic activities is beneficial for children with physical disabilities, particularly those who have limited mobility, as water offers much needed stimulation (educational, social, recreational, and therapeutic). Pool facilities are a common fixture in both rehabilitation and community centres where they are used to foster social participation in a meaningful group activity (Christie, 1985). However, some children with physical disabilities associated with medical conditions that limit mobility—such as cerebral palsy, Down's syndrome, acquired brain injury, spinal injury, spinal bifida, chronic illness, and chromosome disorders—require long-term intravenous therapy provided through a central venous line or catheter (Levi & O'Rourke, 2002). A central venous line or catheter is a long, soft, thin, hollow tube that is inserted into a large vein (blood vessel) usually in the neck, upper chest, leg, or arm (Fahy & Sockrider, 2007), which is used to administer intravenous therapy, such as fluids, medications, blood products, or total parenteral nutrition (Revel-Vilk, 2006). Total parenteral nutrition involves feeding of a high-calorie, high-protein fluid directly into the bloodstream (Levi & O'Rourke, 2002). It is important to note that any tube (catheter) inserted into the body creates the risk of bacteria entering the bloodstream

through the opening in the skin; therefore, the area of insertion must be kept absolutely dry to prevent possible infections (Eggimann & Pittet, 2002).

A central venous tube impacts children's participation in everyday activities, specifically, exclusion from aquatic activities and aqua therapy that could enhance their physical and psychological well-being. An aquatic environment enables children with mobility disabilities to be more active. Aquatic activities promote social interactions with therapists and other children, thus creating and fostering greater self-esteem and elevating quality of life (Getz, Hutzler, & Vermeer, 2007).

Purpose

The Canadian Institutes of Health Research (CIHR) and Bloorview Research Institute advocated health, well-being, participation, quality of life, and social inclusion for children with physical and cognitive disabilities in "Bright Futures for Kids with Disabilities" (CIHR, 2009). Unfortunately, children with mobility issues who are fitted with a central venous line find it difficult, if not impossible, to achieve these goals.

This research aims to determine functional swimwear needs in order to develop and execute prototypes for children with physical disabilities fitted with a central venous line. The study used the Functional Expressive Aesthetic (FEA) consumer needs model framework to establish a better understanding of swimwear needs and preferences for this group of individuals. Research questions included:

- Based on Lamb and Kallal's (1992) functional, expressive, and aesthetic principles, in the category of swimwear, what are the functional, expressive and aesthetic needs of children (fitted with a central venous line) and their primary caregivers?

- When selecting swimwear for these children, how are functional, expressive, and aesthetic design attributes prioritized?
- What fabrics and designs are preferred by this group of children?

The availability of function-specific swimwear may provide this group of children an opportunity to participate in the aquatic activities or aquatic therapy that can enhance their overall health, self-esteem, and quality of life The WHO Quality of Life Project (1997, p. 1) defines “quality of life” as “individuals’ perceptions of their position in life in the context of the culture and value system in which they live, in relation to their goals, expectations, standards, and concerns” (p. 1).

Chapter 2: Literature Review

Children with disabilities who are fitted with a central venous line require specific design attributes that address their unique and individual needs. The physical, psychological, and social benefits of participation in aquatic activities is universally acknowledged and it is encouraged by government, schools, and the community. The literature review includes research studies dealing with disability, appearance, self-esteem, clothing concerns, physical and psychological benefits of aquatics, user needs, and fabric.

Appearance and Self-Esteem

Parkes and McCusker (2008) have argued that there is sufficient evidence to conclude that children with disabilities are at increased risk for psychological problems. These children who rely on others in the pursuit of their daily activities may experience frustration, depression, and low self-esteem. Furthermore, the inability to control his or her body properly creates feelings of helplessness in the child, which leads to more frustration and depression. As this group of children matures, the physical self becomes a central concern and the image of the physical self influences a person's self-concept and feelings of self-worth (Magill & Hurlbut, 1986). Human beings develop their first sense of self from their own bodies. Lawrence (1991) suggested that impairment to one's body and body image can be extremely frustrating and discouraging, with possible negative impact on an individual's emotional stability.

Wolman, Resnick, Harris, and Blum's (1994) extensive study encompassing 3,000 participants further supports the conclusion that disability can have a negative effect on body image. Slade (1994) defined body image as, "a loose mental representation of body, shape, size and form which is influenced by societal, cultural, individual and biological factors" (p. 502).

Slade argues that "Affect and cognition together determine body image which, in turn, determines body esteem" (p. 497). People's understanding of "who they are" is based in part upon their physical abilities. As an individual matures, his or her physical sense of self expands and incorporates the social environment. Self-perception comes to depend in part on the views of others within the social circle (Chase & Quinn, 2003).

Festinger (1954) found that people use social comparison not only to evaluate their opinions and abilities, but also to manage emotions and maintain self-esteem. Festinger also postulated that an evaluation of one's ability is influenced by comparison to others, and one's self-esteem is based on the opinions others have of one's abilities. The opinions of others influence one's own opinions of one's abilities. Furthermore, it has been found that self-esteem levels are highly correlated with quality of life (Emerson, 1985).

Numerous studies have shown that physical disabilities are viewed negatively in our society (Longmore, 2003; Stone, 1995; Taleporos & McCabe, 2001). Negative societal attitudes towards individuals with disabilities influence both their self-perception and their self-esteem. Overall, individuals with physical disabilities face greater than average challenges to their self-esteem (Taleporos & McCabe, 2001).

Body image, which Rudd and Lennon (2001) define as our mental image of our body, affects our cognitive functioning and mental health. Entwistle (2000) argued that "the body constitutes the environment of the self, and is inseparable from the self" (p. 6). Self-image correlates directly to body image or the body. She further argued that clothing is one of the means by which identity is portrayed: "The right clothes make individuals look their best and feel at ease in their bodies" (p. 7). Clothing prepares an individual for the social world, making the individual appropriate, acceptable, respectable, and even desirable.

Clothing Concerns

Kernaleguen (1978) argued that "clothing is important to the physical, social, and psychological well-being of physically disabled individuals" (p. 2). Clothing that is comfortable and promotes safety fulfills physical needs while clothing that is aesthetically pleasing fulfills both social and psychological needs. Looking attractive promotes positive self-esteem and elicits positive response from others, which, in turn, elevates self-esteem. Looking attractive and conforming in appearance to one's peer group are the two major factors to be considered in the design of clothing for the special needs population (Feather, Martin, & Miller, 1979; Hoffman, 1979; Kernaleguen, 1978).

Much has been written on clothing for special needs individuals (Cookman & Zimmerman, 1961; Forbes, 1971; Hoffman, 1979; Kernaleguen, 1978; McKay, 1986; Thornton, 1990; Watkins, 1995). The literature includes discussion of adaptive clothing and made-to-measure clothing as well as clothing for the elderly, clothing for persons with limited mobility, and clothing for persons with assistance devices (Bower, 2009b; Cookman & Zimmerman, 1961; Forbes, 1971; Hoffman, 1979; Kernaleguen, 1978; McKay, 1986; Thornton, 1990; Watkins, 1995).

Website-based research investigated online stores (Mini-Miracles, Special Clothes, Epiphany Designs, and Easy Access Clothing) that sell clothing for special needs, and it was found that most of the stores sold clothing geared towards sleep wear, outdoor wear (coats, ponchos, and jackets), daywear (pants, shirts, shorts, and dresses), and continence swimwear. Dry Pro™ sells a waterproof ostomy protector that enables children and adults with an ostomy to swim, shower, and bathe. (Ostomy refers to a surgically created opening, usually in the abdomen, for the discharge of waste.) As with the insertion site of a central venous line, the area

must be kept absolutely dry. The Dry Pro™ ostomy protector is made of durable, high quality, surgical latex that promotes a watertight vacuum seal. The device is circular and to be worn around the waist.

The combination of literature and product research revealed a void in function-specific swimwear that addresses the needs of children with physical disabilities fitted with a central venous line.

Benefits of Aquatics

The benefits of aquatics, both physical and psychological, are well documented. Schilling (1993) posited that the benefits of aquatic exercise and/or activity are multiple and range from physical to psychological in nature. She outlined the experiences of persons with disabilities, mostly affecting mobility, in relation to aquatics. The buoyancy of water negates the effect of gravity by supporting joints, which gives persons with limited mobility increased movement and flexibility. The opportunity for increased movement due to water's buoyancy leads to improved cardiovascular function and muscle strength. Broach and Dattilo (1996) argued that participating in aquatic activities and aqua therapy improved circulation, mobility, strength, coordination, range of motion, pulmonary function, sensory perception and spatial awareness, muscular and vascular endurance, relaxation, and decreased pain and bone loss in people with disabilities associated with spinal cord injuries, orthopaedic impairments, cerebral palsy, acquired brain injuries, developmental disability, and autism.

Kraus and Crew (as cited in Broach & Datillo, 1996) also claim that persons with physical disabilities experience a difficult time negotiating land activities. However, in an aquatic environment, the buoyancy of water permits this group of individuals to hold their bodies up themselves so that they can attain simple movements that can lead to an improvement in their

physical well-being. The water also provides resistance that can improve the muscle strength of individuals in this group (Betrand, 2004). The gentle flow of water also enhances the experience of individuals with sensory deficits resulting from their physical disabilities, and the warmth of the water relaxes tense muscles. Lepore, Gayle, and Stevens (2007) argue that sensory stimulation from aquatic activity is particularly useful for persons with disabilities. Water stimulates the epidermis and improves the sense of balance as well as those of hearing and vision.

Dumas and Francesconi's (2001) annotated bibliography on aquatic therapy in paediatrics summarized published articles that relate to the use of aquatic therapy as an intervention for children and adolescents with physical disabilities (neuromuscular and musculoskeletal) in the rehabilitation literature from 1979-1999. The authors reported that the trend of rehabilitation literature is towards evidence-based practices, and the articles reviewed involve research reports, case reports, and accounts of clinical practices, suggesting that children with physical disabilities such as cerebral palsy, spinal muscular atrophy, neurological dysfunction, deaf-blindness, spinal cord injury, chronic pain, and orthopaedic injuries gain physiological benefits from aquatic activities.

In a recent study, Retarekar (2008) researched the effects of aquatic aerobic exercise on endurance, functional mobility, and participation in a child with cerebral palsy. The study resulted in preliminary evidence on the effectiveness of aquatics for the improvement of function in the participant. However, because of the limitations of her study—single subject design, the therapists who measured the outcome variables were the same ones who were treating the child, hence possible conflict of interest, and no testing in aquatic and land environment was carried

out at a constant work load—she suggested further research is required involving a larger sample size in order that generalizations might properly be made.

In addition to physical improvements, aquatics also have psychological benefits. The sensation of water relaxes the body, which leads to improved mood as well as a decrease in anxiety and depression (Broach & Datillo, 1996). Water allows children with limited mobility to move more easily. The ease of movement bolsters confidence and gives participants a sense of accomplishment that leads to greater self-esteem. In general, children enjoy showing off their accomplishments to their parents, peers, and friends (Skinner & Thomson, 2008). However, children with physical disabilities have few opportunities to do so. As well, participants in aquatic activities come to feel more comfortable and confident in their bodies and develop a positive view of their physical selves. Furthermore, fun, relaxation, and activity without assistive devices improve their self-esteem (Broach & Dattilo, 1996).

Kowalchuk and Crompton (2009) supported the notion that social participation has benefits for children with disabilities. Social participation refers to relationships with family members, peers, community members, local institutions and society as a whole. Social participation promotes social well-being, which is essential to the overall health and quality of life of all children. Unfortunately, children with disabilities are often socially isolated, which leads to a lower level of social and emotional well-being. Montie and Abery (2011) stated, "The more children with disabilities are included, the greater options for social relationships and expanded circles of friends. And increased inclusion is also associated with higher expectations for learning and social interaction" (p. 2). Social interaction allows people to connect with others (social), and to know, understand, and experience one's feelings (emotional), which are two

essential ingredients of a quality life. Social experiences allow children with disabilities to engage more fully in living and to develop healthy lifestyles (Montie & Abery, 2011).

Hoffer, McKeown, and Heyne (2011) postulated that social interaction in an activity arena improves the quality of life of individuals with disabilities. The quality of life benefits include socialization with peers, improved communication skills, the development of friendships, increased leisure skills, and enhanced self-esteem and self-confidence.

User Needs

Rosenblad-Wallin (1985) argued that "user-oriented product development has proved to be complementary to conventional methods. It should be applied to products whose functional properties are of great importance". The starting point is the user and the user's situation. In her view, the objective of a product is to combine functional and symbolic values. She states that the functional value of clothing offers protection and comfort while the symbolic value of the clothing provides an opportunity for personal expression and influenced how the wearer is perceived by other people. Rosenblad-Wallin (1985) viewed protection as a principle that addresses the climatic domain and comfort as the relationship between the body and clothing. These body/clothing relationships are: the moderating of heat and cold, ease of movement, weight/load, fit, pressure on the body, friction applied against the body, tactility and static electricity. All of these encompass the comfort spectrum. She also argues that only the ultimate user can subscribe to their needs (Rosenblad-Wallin, 1985).

Disability and the FEA model. Lamb and Kallal (1992) developed a consumer needs model that incorporates functional, expressive, and aesthetic considerations. Functional needs included protection, mobility comfort (easy on and off), as well as fit and thermal comfort (balance of temperature). Expressive needs included the symbolic or communicative messages

that the garment conveys and possibly denotes the wearers' identity. Aesthetics needs addressed design principles of line, form, colour, texture, and pattern to create a visually pleasing design that consumers would find attractive.

Lamb and Kallal's (1992) FEA model is displayed as a concentric circle diagram with the target consumer at the centre. The incorporation of demographics, psychographics, physical characteristics, activities, and preferences is essential to identifying the target consumer. Lamb and Kallal underscored the importance of the needs of the target consumer and argued that needs analysis must be done before a design process can even begin. Culture sits at the second circle surrounding the target consumer. For Lamb and Kallal, "culture acts as a mediator or filter between the intended users of apparel and their requirements or desires in their apparel items" (p. 43). Kaiser (1990) explained that all human behaviour, including that involved in the choice of dress, takes place within a cultural context. Cultural foundations play an important role in an individual's decisions regarding clothing choice and mode of dress.

The third circle gives examples of functional, expressive, and aesthetic design considerations while the outermost circle names each of the FEA elements. The two-way arrows between function, expression, and aesthetic indicate that these design considerations are interconnected, although Lamb and Kallal (1992) described them separately and noted "they are interrelated in different ways for different target consumers" (p. 43).

Lamb and Kallal (1992) suggested that apparel designers need to consider these three elements in the design stage, the stage at which the consumer's wants and needs can be addressed through innovative and novel designs. The inclusion of the three elements gives the designer a better understanding of the target consumer's wants, needs, and preferences. The success of several design projects (e.g., Bye & Hakala, 2005; Emerich, 2011) supports Lamb and

Kallal's conceptual framework of defining the intended user and the use of the FEA consumer model for designing functional clothing. Functional clothing or functional fashion consists of garments specially designed for specific needs or utility. For example, Dr. Dava Newman's "BioSuit" is designed for space exploration of the moon or Mars and working in an orbital space station (Bradley, 2008). Elizabeth Bye and Lyndsie Hakala designed women's sailing apparel that addresses environmental protection, maintains health and safety, and improves women's sailing efficiency. Lamb and Kallal described three of their function specific projects. The projects included a figure skating costume, cleaning room garments, and an ensemble for a teenager with spina bifida. The functional elements described in these studies include fit, mobility, comfort, protection, and ease of donning and removal (Bye & Hakala, 2005; Lamb & Kallal, 1992). The expressive elements include status, self-esteem, body appearance, and group identity, and aesthetic elements include visual elements (line, colour, shape, texture, space, form) applied to design principles (unity, point, balance, movement, symmetry, and rhythm/pattern). People with special needs want clothing that is both attractive and socially acceptable on bodies that may be seen as different from the norm in shape, surfaces, or motion (Lamb & Kallal, 1992).

Functional needs. The first functional need is protection from environmental elements. This is a mandatory requirement for children with or without disability. For children fitted with a central venous line who want to participate in water activities and therapy, waterproof fabrics are essential. Waterproof (i.e., impermeable) fabric is completely resistant to water (Fan & Hunter, 2009).

The second functional need is mobility comfort (easy on and off). For anyone requiring assistance dressing, the quicker the process can be performed the better, as it reduces the wearer's period of dependence on the assistive dresser, and thus the discomfort associated with

being dependent on others (Turnbull & Ruston, 1985). Fastening systems are one of the most significant features in the design of functional clothing. The length and location of the fastening-system openings are critical, as they affect comfort, possible interference with the central venous line, and the ability to dress with ease. The garment should be fairly easy to put on and take off with minimal discomfort for the participant and/or assistive dressers.

The third functional need is fit. The garment should be the correct size, fit easily, and not restrict movement (Kernaleguen, 1978). Fit may be challenging to achieve due to irregular body shape caused by impeded growth. For example, the ribcage may be extended while the neck is shortened. Loose clothing can easily accommodate this challenge. However, power mesh fabrics may compress the body, concealing the irregular shape as well as medical devices such as a central venous line, resulting in body shape that appears the same as those without a central venous line.

The fourth functional need is thermal comfort (balance). The interaction of body, clothing, and the environment contributes to the thermal balance of the body. Watkins (1995) defines thermal balance as the ability to keep the body temperature at a safe level with the influence of the surrounding environment. Various factors that help the body to balance heat gain and heat loss (thermal regulation) include conduction, convection, radiation, and evaporation as well as the body`s chemical processes and its metabolism. Metabolism includes all of the chemical and physical reactions that occur in the body; the body uses metabolism to balance the heat equation (Watkins, 1995). Numerous factors affect the body`s metabolism. They include height and weight ratio, thyroid disease, fat to body ratio, amount of food consumption, and physical activities that produce heat energy (Watkins, 1995). For individuals with disabilities, limited mobility leads to a decrease in physical activity, thereby creating a thermal imbalance or

a decrease in heat energy in these individuals' bodies. For those with a central venous line, food consumption is problematic. Therefore, their thermal balance is further compromised.

Expressive needs. Expressive needs "relate to the communicative, symbolic aspects of dress "(Lamb & Kallal, 1992 p. 43). Clothing communicates messages about the wearer (Damhorst, 1990) and represents "a mixture of social and cultural values and sign systems" (Dant 1999, p. 107). This supposition is prevalent in sociological and symbiotic discourses. Theorists such as Simmel, Davis, and Saussure agreed in some way that clothing performs a non-verbal form of communicative function. Barnard (1996) defines non-verbal communication as "one that does not use spoken or written words" (p. 29).

Saussure (1974) used the theory of semiology to explain the symbolic aspect of dress. Saussure defined semiology as a "science that studies the life of signs within society" (p. 16). Saussure believed humans do not communicate directly and instead use one thing to stand for or represent something else, and Saussure called this concept "sign," which comprises two parts: signified and signifier. Signifier is the physical part of the sign while signified is the mental concept to which the signifier refers (Saussure, 1974, pp. 65-67). Barnard (1996) asserts that humans use "clothing as a signifier "(p. 81). Barnard provides an example of clothing as signifier: a man's collar worn open and without a tie signifies casualness and informality, while the same collar worn closed and with a tie signifies formality and smartness (p. 82).

George Simmel (1957) asserts that clothing sends messages of the wearer's social status and societal values and is also a product of class distinction. During medieval times, the wealthy donned clothing made of the finest fabric such as silk and adorned with jewels, while the lower classes wore clothes made of the cheapest fabrics such as undyed blanket cloth with no adornments—and often were barefoot (Wilson, 1987, p. 22). In short, clothing may differentiate

social status: “Clothing unites those of a social class and segregates them from another (Simmel, 1957, p. 541). Simmel (1971) argues that clothing operates in a dichotomy; people appear to need to be social and individual at the same time, and clothing “depends upon the conflict between adaptation to society and individual departure from its demands” (p. 295).

Davis (1992) pointed out that it has become something of a cliché to say “clothes make a statement” (p. 3). He proposed that clothing communicates through codes. However, he qualifies his views by stating fashion does not communicate through codes in a well-defined structure like cryptography, defined as the science or study of techniques of secret writing, especially code and cipher systems, methods, and the like (“Cryptography,” n.d.). Rather, it communicates through less defined “quasi codes.” He observed there were several additional distinguishing features to this code. The first feature is context-dependency. Davis noted that the manner in which this code is communicated in fashion is dependent on the external social environment in which it is presented—a good example of this being that most western cultures would associate black as formal and often worn during somber occasions such as funerals. For the Chinese, however, white is the appropriate dress code for funeral gatherings.

Another feature of fashion coding is signifier–signified dependence—the “signifier” being the wearer or person doing the communicating and the “signified” being the viewer or receiver of the intended communication. For example, Davis (1992) observed that fashion is communicated differently between two individuals who are similarly fashion conscious as opposed to between a fashion conscious person and someone who is fashion indifferent.

Lastly, Davis (1992) argued that clothing communication is often undercoded. Undercoding is the result of lack of reliable and conventional interpretation rules. Fashion codes

can be motivated by aesthetics and therefore do not necessarily comply with conventional sign codes charts and road signs that are employed in everyday communication.

Such theorists argued that clothing functions as a message, code, and sign which express an individual's social and/or economic status (or worth), and societal/cultural values and identity. Lamb and Kallal (1992) argue that individuals with special needs want their functional clothing to be appealing and "not convey a stigmatized image" (p. 42). The term "stigma" refers to "any persistent trait of any individual or group that evokes negative or punitive responses. Thus, disabling conditions are stigmatizing to the extent that they evoke negative or punitive responses" (Susman, 1994, p.16). Goffman (1963) explains that stigma is associated with the notion of deviance, or deviation from prevalent or valued norms. Deviance occurs only if the attributes or acts are perceived to be different from the prevalent or valued norm; norm, in turn, is "a shared belief that a person ought to behave in a certain way a certain time" (Stafford & Scott, 1986, p. 81).

Clothing communicates message about the wearer's identity and identity may be stigmatized; therefore, clothing may also be stigmatized. How others perceive us is very important to the way we dress. Kernaleguen (1978) asserts that functional clothing must provide the wearer with an "appearance comparable to that of others with whom she/he interacts in his everyday activities, in that the wearer will be dressed in clothing which is currently popular in style and does not single out the wearer in any way" (p. 4). By imitating peer image and "what they wear," individuals with disabilties gain social acceptance, thus enhancing self-concept and promoting self-esteem (Hoffman, 1979).

Aesthetic needs. Aesthetic needs address the human desire for beauty (Lamb & Kallal, 1992). "The function of beauty is to lift the human spirit. Just as people respond to the aesthetic

stimulation of a beautiful sunset, a flower, or a work of art, so do they respond to the aesthetic stimulation of attractive clothing" (Hoffman, 1979, p. 36). For individuals with disabilities, attractive clothing can provide aesthetic stimulation that may lift their spirits and enhance their personal worth (Hoffman, 1979). Beautiful clothing may elicit positive responses from peers, thus furthering social inclusion.

The elements used to produce attractive clothing involve the design principles of colour, shape, line, form, texture, and pattern. In addition to the above aesthetic attributes, Kernaleguen (1978, p. 4) asserts that it is desirable that clothing designs for individuals with disabilities should conceal their disability as much as possible or at least attract no attention to it. Attractive clothing encourages children with physical disabilities to participate in social activities in an aquatic environment and contributes to their general well-being. Participation with others promotes social interaction, thus further increasing self-esteem and quality of life.

Function-specific clothing presents multiple concerns and possible conflicting design considerations; the designers must pair each design consideration (functional, expressive, and aesthetic) in order to determine relative importance. For example: clothing designed for military activities and protection against hazards presents conflicting requirements, as ballistics protection adds weight and decreases mobility and thermal comfort, thus fatiguing the wearer (Shanley, Slaten, & Shanley, 1993).

Fabric

Functional specific swimwear requires the need waterproof fabrics. Neoprene, Latex, PVC (polyvinyl chlorine) and PUL fulfilled this need.

Neoprene is a synthetic rubber material designed to be abrasion-resistant, waterproof, flexible, and buoyant. It is mainly incorporated into household products, protective gear,

assistive gear, medical braces, pet collars, and trek gear. One of its most popular uses is in the structure of a wetsuit. In wetsuits, neoprene traps the water between the wetsuit and the wearer's skin. Neoprene also prevents heat loss in cool water (Pereira, Anand, Rajendran, & Wood, 2007).

Latex is a synthetic or natural latex fabric, contrived to be water resistant, lightweight, thin, and flexible. Latex is used in many types of clothing. Due to the flexibility and thinness of the fabric, most latex garments made are skin tight ("Latex Fabric," 2012).

PVC or polyvinyl chloride is a thermoplastic made of 57% chlorine (derived from industrial grade salt) and 43% carbon (derived primarily from petroleum) (PVC Europe, n.d., para. 4). PVC is available in rigid and flexible forms, both durable and lightweight. It is waterproof and resistant to some chemicals. The functional qualities of PVC make it a great material for protective clothing outdoors (PVC Europe, n.d.).

PUL combines polyester and polyurethane together to form a fabric that is two sided. Polyurethane is laminated to a 70 denier interlock fabric producing a fabric that possesses the following properties: waterproof, breathable, moderate stretch, hypoallergenic, lint free, and abrasion resistant. This speciality fabric targets the baby product market ("PUL Fabric," 2012).

Chapter 3: Methodology

Lamb and Kallal's (1992) conceptual theoretical framework was used to define the intended user following the FEA model (p. 42). The seven-step design process proposed by Koberg and Bagnall (2003) was used for the development of a prototype that addresses the swimwear needs of children with impeded mobility fitted with a central venous line.

Method and Procedure

Quantitative and qualitative data were collected to gain in-depth knowledge of the specific swimwear needs of children fitted with a central venous line (as described by the children themselves or by their caregivers). This study comprises three phases. Phase I consisted of interviews with children and/or their primary caregivers. Information regarding socio-economic status (SES), age range, family status, level of attained education, current employment status, and income was collected with a demographics questionnaire. In Phase II, the researcher investigated fabrics, and analyzed data collected from Phase I to create swimwear ideation designs. The design that fulfils the participants' needs and preferences was fabricated into a prototype. Phase III consisted of field testing the prototype with each child participant in a pool facility.

With the approval of the Ryerson Ethics Board (Appendix A), Phase I began with a user-needs analysis conducted through personal interviews (n=9) with children and/or primary caregivers and two medical professionals. A nurse from a renowned children's hospital recruited participants. Selection criteria were specific, that being two girls and two boys, ages 6-10 with a varied spectrum of mobility fitted with a central venous line. The purposive sampling was drawn from the children with whom the nurse worked on a daily or monthly basis. The nurse approached potential candidates and discussed the study. The interested eligible candidates were

verbally introduced to the study by the recruiting nurse. A project description and consent forms (Appendix B) were printed and sent home with eligible participants for review. Since sampling was purposive, only four initial requests were made; recruitment continued until the sample population was attained. After receiving the completed consent forms, the researcher conducted a demographic questionnaire through e-mail followed by personal interview.

The personal interview included participatory observation as well as measuring of each individual child. Parents and the children were presented with interview questions focused on the primary caregiver and child's functional, expressive and aesthetic needs for swimwear. Likewise, both parent and child were asked about their swimwear preferences and clothing attributes that were important to them. Participants were also asked to describe an account of their daily routine. Participatory observation can help the researcher gain insight into both physical and psychological needs of the target consumer by becoming familiar with the environment. Observations were recorded in a journal. Children's measurements were collected to ensure correct swimwear fit.

Interviews were audio-recorded and transcribed. To ensure confidentiality, study participants were assigned an identification code. Participants were assured that quotations and excerpts from data collected would be used and labelled with pseudonyms. Interview transcripts were read, analyzed, and highlighted to locate themes related to the research questions. The answers to the questions were categorized into functional, expressive, and aesthetic groups. Interview transcripts were read several times and themes were further subdivided and consolidated.

In Phase II, fabric options were investigated through Internet-based online retailers as well as visiting local retail store. Ideation sketches were created based on the analyzed data

collected from Phase I. The design that fulfils the participants' needs and preferences was fabricated into a prototype. Design considerations were based on the participants' needs analysis. In addition, the researcher reviewed websites that sell similar garments so that the prototype is comparable to garments worn by children without the central venous line. Although the study group comprised girls and boys alike, gender-specific prototypes except the use of colour are not required since there is relatively little gender anatomical difference in this age group. Prior to field-testing, several processes to ensure fabric and construction quality were executed. Firstly, water permeability was tested by running water onto the prototype for several minutes. Secondly, the garment was stretched to determine its flexibility and elasticity. Thirdly, the closures were assessed for their application. Zippers were evaluated and Velcro hook and loop tape were analyzed. Finally, seams were stretched to confirm the sealing property.

In Phase III, the prototype was field tested on the four participants in an aquatic facility. Prior to field testing, the swimwear prototype was delivered to the participants at a location of their choice, providing an opportunity to try on the prototype prior to field testing. The researcher guided participants or assistive dressers as to how to put on the swimwear to confirm the fit. Photographs of key areas of the garments on the participants were taken. This included a full-length front view and back view of the prototype to establish the fit and design aesthetic on the body. The researcher inspected the neckline and the arm and leg openings to verify a snug fit and the fastening system was tested to determine ease of use. Upon finalizing fit, the researcher arranged with the participants to field test the prototype in an aquatic facility. Before the field testing in the pool, a folded paper towel was taped on the tube site as an extra layer of protection as well as a checkpoint for possible water contamination. To ensure validity, a field test procedure was created and used with each participant. The children began by stepping in the

shallow end and then proceeding slowly to the deep end. The suit was checked at 2 minute intervals over a period of 10 minutes. If the suit became wet before 10 minutes had passed, the field test was suspended and the participant was advised to exit the pool immediately. Field testing in the water allowed the researcher to observe the effectiveness of the prototype in its intended environment. For future reference and analysis, photographs and videotape of the participants (with their consent) were taken during the field study sessions.

An informal interview following the field test collected relevant feedback related to function, expression, and design aesthetics, which was then used to refine the prototype for future studies.

Chapter 4: Results, Analysis, and Discussion

Nine interviews (*n*=9) were conducted with four parents, three children, and two medical professionals. The results are divided into three phases. The first is the demographic questionnaire data (parents), the second is the interview data, and the third is the prototype evaluation data following field testing. Transcripts were examined and interpreted to formulate the necessary attributes required to develop a prototype garment. Attributes were based on functional, expressive, and aesthetics category needs outlined in Lamb and Kallal's (1992) FEA model.

Phase I

Demographic questionnaire. Demographic information is presented in Table 1. All of the parent participants (100%) lived with their partners. The majority of fathers (75%) attended university or college and (25%) attended high school. Most mothers (75%) attended high school while one (25%) had a university degree. All four fathers (100%) have full-time jobs; one mother (25%) was employed full-time, one (25%) worked part-time, and two (50%) were unemployed. Most families (50%) preferred not to disclosed their income, one of the families (25%) had an income between $15,000-$20,000, and the other (25%) indicated income between $50,000-$100,000. Most children (50%) were 7 years old, one (25%) was 6 years old, and the other (25%) was 10 years old. All children (100%) were fitted with a central venous line, in addition to the central venous line they were also fitted with gastrostomy (G) tubes and jejunostomy (J) tubes (tubes with bags attached, inserted into their abdomens). The G-tubes and J-tubes ensure children get additional fluids and calories they need to thrive.

Table 1

Participant Demographics (Parents n=4)

Household status				
	Married/living with partner			4
	Living alone with child/children			0
	Living with friends/relatives			0
	None of the above			0
Educational status				
	Father		Mother	
	High school	1	High school	3
	College	1	College	0
	University	2	University	1
	Post-Graduate	0	Post-Graduate	0
Current employment status				
	Father		Mother	
	Full- time	4	Full-time	1
	Part-time	0	Part-time	1
	Not currently employed	0	Not currently employed	2
Annual household income				
	$10,000-$14,999			0
	$15,000-$20,000			1
	$20,000-$30,000			0
	$30,000-$50,000			0
	$50,000-$100,000			1
	$100,000+			0
	Prefer not to answer			2
Describe the nature of your child's disability/name of child's disability and brief description of the condition				
	Short bowel syndrome or short gut (small intestinal track)			1
	Gastroschisis (intestine form outside of the abdominal wall)			1
	Intestinal failure due to Pseudo bowel obstruction and Gastroparesis (a disorder affecting the nerves and muscles of the stomach, resulting in a paralyzed stomach that cannot perform its normal function)			1
	Cerebral Palsy			1
Onset of disability or age or first diagnosis				
	Birth			3
	Age 4			1
Does your children need special aides or equipment for mobility				
	Yes			1
	No			2
	Sometimes			1
Child's gender				
	Male			2
	Female			2
Child's age				
	Age 6			2
	Age 7			1
	Age 10			1

The majority (50%) of the participants was independently mobile, one (25%) required assistive aid, and one (25%) required assistive aid occasionally. The children (100%) had a variety of medical conditions including the following: Gastroschisis (intestine formed outside the abdominal wall), Short Gut Syndrome, liver failure, intestinal failure, pseudo bowel obstruction, post-thrombotic clot syndrome (blood clots easily), cerebral palsy, and developmental delay. Most children (75%) were diagnosed at birth and one (25%) was diagnosed at age 4.

Personal interviews. Interviews took place at the participants' homes, commencing with a brief summary of each of the children's medical conditions and treatments. Questions focused on daily routines and medical devices affecting their clothing choice, preferred swimwear attributes, and purchase intentions.

Function. The garments' function criteria encompass protection and safety, as well as mobility (easy on and off).

***Protection and safety*.** The fitting of a central venous line impacts the participants' priority in choosing swimwear. This choice is dictated by the need of water protection and tube entanglement. The need of water protection correlates to the seriousness of infection that can occur if water gets into the tube site. Most of the participants mentioned that the fear of infection prevented their children from participating in pool activities: "Infections are inconvenient in the best case, but infections can further complicate my daughter's health. Her illness has already kept her away from school and her friends for seven months."

Infection can affect the family members' lives. One of the participants recounted an incident during a vacation in the previous year in which her child fell over on his side. This seemingly uneventful incident for most families not having to care for a physically disabled child caused insurmountable stress for her and her family. She proceeded to explain how important it

is to mitigate surprise events and went on to explain the importance of keeping the central venous line dry.

> The central venous line is inserted into a major artery. If the line gets wet or dirty, my child will suffer from a blood infection and the hospital stay can lasts from 1 to 3 months. My child will also miss schooling and social interaction with other children.

She ended by saying, "I would be so happy if my child can enjoy the water without me fearing severe infection."

In addition to water protection, the parent participants and the two medical professional also commented on accidental line detachment or dislodgement. The detachment of the line can lead to air embolism or the forming of an obstruction of the line which may lead to potential morbidity and mortality ("Venous Air Embolism," 2012).

Mobility (easy on and off). The majority of the parent participants agreed that easy on and off is a lower priority so long as the child or the parent can put it on. However, when the question of easy on and off was presented to these three child participants, they all answered "it didn't matter" as long as they looked good. In contrast to non-disabled children who may prioritize the importance of easy on and off because their products needs are easily satisfied by the abundance and availability of mass consumer oriented products, this is not the case for these special needs children. Their priorities are clearly different.

Fit. Several interpretations of fit materialized through the four interviews. The medical professionals believe fit is related to safety or possible infections. The prototype should fit the body in order to protect this group of individuals from water seepage. Participants accredit fit as the relationship between body and garment. One of the participants dresses frequently in loose fitting garments made primarily of stretch material. Her mother feels that the shape and stretchy

material accommodates and hides her child's protruding abdomen. By disguising her body shape in a loose fitting garment, her projected image is comparable to those of her peers.

Thermal comfort (balance). All four participants agreed that temperature is not an issue for their children but cold affects one of the participants more than the others. Her mother claims that "her child love swimming so much, it didn't matter if she was cold." The most important issue stressed by all four participants was that their children can swim without the fear of infections.

Appearance (expressive and aesthetics). Medical devices and medical conditions altered the participants' bodies and affect their appearance. The image or appearance of the physical self influences a person's self-concept and feeling of self worth (Magill & Hurlbut, 1986). Concealment plays an important role in the appearance and image management of this group of individuals.

> If the medical device is showing, then you got a lot of people enquiring. These enquiries are not so much from the kids in his school, they know him but other kids would say "what's that? What's that"? Children have that natural curiosity, they don't mean to, but this natural tendency unfortunately makes my son very uncomfortable. He doesn't know what to say?
>
> I look for clothing that have ruffles that goes across the body, the ruffles disguises her protruding abdomen.

For the participant who required a wheelchair, his appearance is utmost important.

> Because my child uses a wheelchair, he has a disability. We want to make sure that he looks good all the time. Looking good is very important. I particular think that is true if they have things that their peers would identity as different and undesirable. It important

for us to help them compensate style wise in assist them in fitting with their peers. I make sure his clothes are always clean and pressed and highly fashionable and stylish. I make sure he is dressed up in higher end, not necessary fancy clothes. Again, he doesn't wear clothes that have a rip in the knee or are stained. My son drools, I make sure the clothes don't change color. We just try to protect and enhance his image through his clothing as much as possible".

We avoid clothing that shows his line, it is important that my child dresses in clothing he can feel good about himself.

The image these children project can affect their social and emotional well-being. Festinger (1954) postulated that an evaluation of one's ability is influenced by comparison to others, and one's self-esteem is based on the opinions others have of one's abilities. The opinions of others influence one's own opinions of one's abilities. The desire and need to belong or blend in is clearly indicated by the participant's verbatim comments.

Needs and preferences. Clothing is an important part of our daily lives and contributes to our physical, social and psychological needs (Kernaleguen, 1978). Clothing that is specially designed for the disabled allows the child to be independent in dressing and fulfills the alternative needs of comfort and safety. The satisfaction gained by the ability to independently perform activities will enhance pride and self-esteem, a congruent part of psychological well being (Kernaleguen, 1978).

The data from the interview led the researcher to conclude that function is the most important need for swimwear for the participants. However, expressive and aesthetic needs ranked equally. The participants mentioned that colour is both an expressive and aesthetic element and the role of gender emerged unexpectedly from these discussions. Female

participants preferred feminine colours such as purple and pink and the males preferred blues and greens. The data analysis also confirmed that all three attributes must be considered in tandem for development of specific needs garments. Table 2 shows the garment attributes categorized under functional, expressive and aethetic needs.

Table 2

Garment Attributes

Design criteria	Garment attributes
Functional needs	
Protection	Waterproofing
Mobility (easy on and off)	Zipper closure, stretchy fabric.
Fit	Fitted to body shape and concealment of medical tubes
Thermal comfort	Laminated two-layer fabric.
Expressive needs	
Self-esteem	Flattering to the body. Concealment of medical tubes. Comparable to other children
Gender appropriate	Distinguish between boys and girls (design and colour attributes)
Aesthetic needs	
Fit in with others	Current colors, styles and fabrics
Age appropriate	Design and color attributes
Gender appropriate	Design and color attributes

Phase II

Design process and prototype. The design criteria and garment attributes shown in Table 2 guided the researcher to develop ideation sketches and pick a design best suited for children fitted with a central venous line. The central venous line site led the researcher to

choose a one piece, short-sleeve and short-leg suit that covers from neck to mid-thigh. The one-piece design provides coverage for the insertion site as well as circumventing possible water seepage around the waist area. The added flap at the back closure and rubber sealant around the neck, arm, and leg openings adds extra protection from water seepage. For additional water protection, the researcher added a rubberized vest that covers the insertion site.

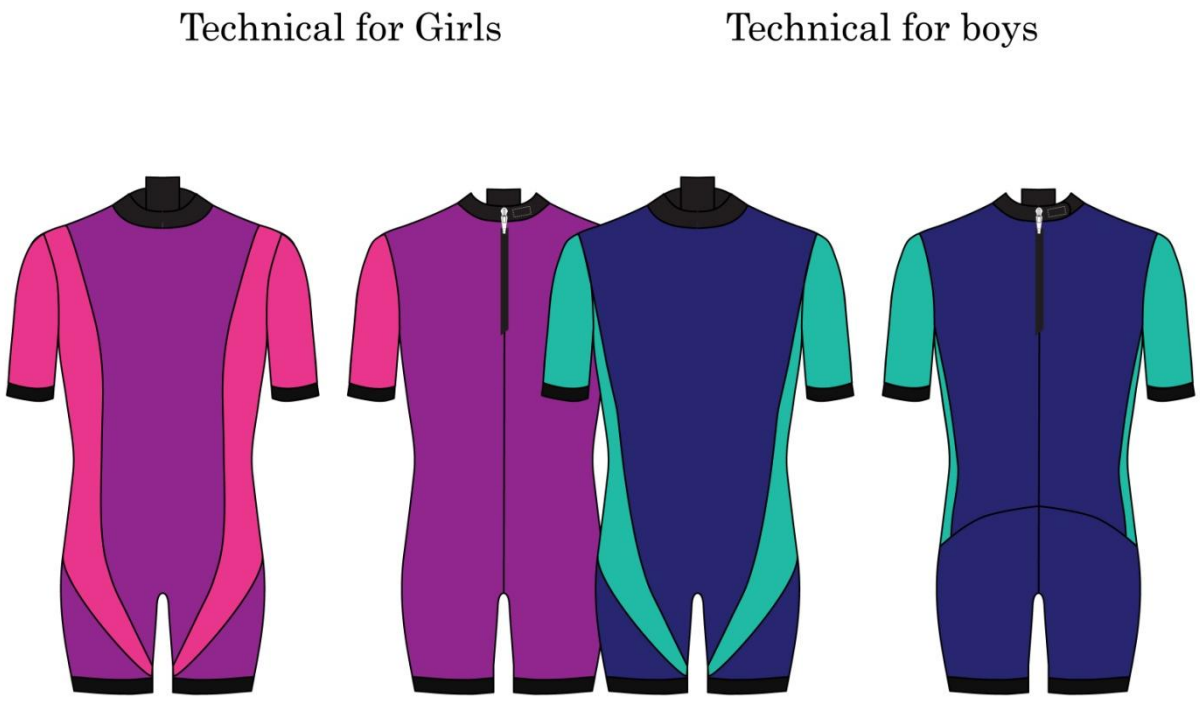

Figure 1. Prototype design.

The functional needs and expressive needs listed in Table 2 support the use of Neoprene for the entire suit. Neoprene possesses the following properties: waterproof, smooth, soft, durable, and easy to clean. Neoprene also provides stretch and compression at the same time. The compression property conceals the medical tube and the stretch property provides comfort. The expressive and aesthetic needs directed the design and colour attributes. The one-piece and

form-fitting design conceals the medical devices and projects a flattering body shape. Also, the design of the one-piece swimwear is similar to those of a wetsuit, therefore projecting an image that allows the participant to fit in with other children.

The age of the participants (6-10 years old) led the researcher to conclude that the shape of the garment can be used for both girls and boys. However, the participants' colour preferences distinguish their gender difference. As previously stated, the girls chose pink and purple while the boys chose blue and green. The researcher reviewed several websites and aquatics stores and came up with several design patterns. The design pattern on the girls' suits comprise curvy feminine lines while the boys' suits have straighter masculine lines.

Phase III

Field-testing results and prototype evaluation. Participatory observation allowed the researcher an intimate view of the participants' reactions prior to and during the field-testing stage from putting on the prototype to the participants' first steps into the water. A video camera captured this journey and recorded the prototype's functional, expressive, and aesthetic attributes as seen by the participants' and the researcher's lens. The field testing phase comprised two parts: before pool and pool activity.

***Before pool*.** The Participants had an opportunity to try on the prototype prior to field testing to verify the function of easy on and off and fit. The sealant around all possible seepage sites combined with the additional rubber back flap impeded the ease of mobility. The body-hugging fit of the prototype further complicated the putting on and off function. All four children needed assistance in dressing. The participants struggled with the first attempt. However, after several attempts, the participants became more proficient and were able to put on the prototype

within 5 minutes. The additional back flap also made the operation of the zipper difficult. The zipper got snagged on the flap several times and necessitated an additional 2 minutes to dress.

The participants' other medical tubes also presented a challenge. The tubes were pulled and tangled, causing some discomfort to the participants while putting on the prototype. The assistive dressers helped by holding down the tubes while dressing the participants. The extra vest also helped to contain all three medical devices, resulting in less snagging and tugging of the tubes. At the end of the fitting phase, the parents agreed that the difficulty of putting on and off outweighs the opportunity for their children to participate and enjoy water activities. The time required for putting on and off didn't matter. Although the prototype was tight fitting, the stretch property of the fabric allowed the participants to move their bodies freely. The participants also pointed out that the fabric felt smooth against the skin and was very comfortable. Subsequently, the children proceeded to test the functional need of water protection in a pool environment.

Pool. Two of the field tests took place in private pools while two took place in the rehabilitation pool at a renowned children's hospital. The temperature of the private pools and the hospital pool differed. The private pools provided an ability to change the temperature as needed while the hospital pool is subject to the regulation of a rehabilitation facility. This difference in temperature presented no challenges to the participants. However, the hospital pool contained a higher level of chlorine than the private pools. The concentration of chlorine may affect the integrity of the fabric.

The prototype was checked for water migration at the 2-minute mark as a precautionary measure. All four participants revealed that the suit remained dry when half of the body was submerged. But as soon as the participants ventured into the deep end, two of the participants' site sustained water seepage at the 10-minute mark, while one got wet at the 2-minute mark and

the remaining participant's tube site stayed dry until the end of the testing time. As the participants swam around the pool, the researcher observed that pockets of air were trapped, creating a balloon effect on the body that provided a semi-flotation aid. At the end of the 10-minute test, the researcher observed that the suit came off easily. Water provided a slippery surface that allowed the swimwear to simply slide off the body. However, the rubber sealant around the sleeves and the legs of the swimwear required a slight tugging.

Upon initial inspection of the prototype, the researcher found that all four suits were totally wet except for the sleeves. By analyzing the water migration pattern on the prototype, the researcher and the participants concluded that the water migrated from the neck area and the back zipper of the suit to the rest of the body. Furthermore, the vest provided no additional water protection for the majority of the participants but did protect the site for one of the participants. The preliminary test revealed conflicting objectives between the functional need of water permeability versus easy on and off.

Prototype Evaluation

An interview followed the field-testing. The researcher asked the parent and child participants to rate the prototype based on the design criteria and garment attributes listed in Table 2. The evaluations reflect the functional, expressive, and aesthetic attributes in the FEA Consumer Needs Model (Lamb & Kallal, 1992) and are parallel to the results in the field-testing phase.

Functional needs. The pool testing revealed that the prototype provided moderate to no protection from water seepage. Half of the participants experienced moderate success while half of the participants experienced failure. The participants indicated that the prototype fulfilled the functional need of fit, thermal comfort, and garment quality. All four parents liked the fit of the

garment which concealed the medical devices and enhanced body shape, particularly the body shape of one of the participants. One of the participants mentioned that the shape of the garment made her child's tubes and protruding stomach invisible. All four participants made no comment on thermal comfort but did agree that the fabric of the prototype felt soft and smooth as well as comfortable when worn.

Expressive needs and aesthetic needs. All of the participants agreed that the style of the prototype suited their children's age group and gender appropriateness and will help the children fit into their peer groups. The colours distinguish the boys from the girls, making the children feel positive about their gender image.

The participants also commented that the fabric and fit of the suit compresses the body, thus concealing the medical devices and the body shape. By concealing the medical devices and body shape, the participants felt that their children's appearance became comparable to those without the medical apparatus and would allow their children to fit in their peer group. The design lines of the prototype created an attractive silhouette for both girls and boys. The colours used reflect the current fashion colors of swimwear worn by children without medical devices. The image of this group of children appeared the same as those without medical devices, thereby creating a sense of belonging. The feeling of belonging elevates their self-esteem and promotes their well-being.

The prototype fulfilled the participants' expressive and aesthetic needs. The participants were happy about how their children looked (aesthetic need) as well as how others viewed their children's appearance (expressive need).

Chapter 5: Significance, Assumptions, Scope and Limitations, and Future Direction

This research provided a better understanding of required swimwear design attributes for children with physical disabilities fitted with a central venous line. Results from the field study provided information about the performance, fabric suitability, and practicality in design for the participants. Discussion with parents, children, and health care professionals further supported the use of Lamb's and Kallal's (1992) FEA model for the design criteria categories. These categories were translated into garment attributes leading to the development of a prototype. The prototype design combined functional, expressive, and aesthetic needs attributes to provide health, safety, self-confidence, and attractiveness to the wearer.

As expected, the participants rated functional garment needs as their primary concern. While expressive and aesthetic garment needs may be taken for granted by children who do not have to cope with special needs, possibly because mass market products are readily available to satisfy their needs, the same cannot be said for this study group. Children with special needs want to appear like those in their peer group. Acceptance and inclusion were clearly on top of their wish list. Colour choice related to gender emerged in both expressive and aesthetic garment considerations. Girls preferred pinks and purples while the boys preferred blues and greens.

Significance

Previous research looked at apparel for children with special needs and found that swimwear for children fitted with a central venous line did not exist. This research provided insight into the clothing considerations for this special group of individuals. Although the population is small, a prominent doctor and a rehabilitation nurse at a renowned hospital commented that it is important for all children to experience water activities, providing them

with physical and psychological benefits. The physical and psychological benefits of water activities affect not only the child but also the family unit.

Participatory observation provided an insight of what a family unit experiences when caring for a child with a physical disability fitted with a central venous line. The constant care and unknown prognosis of their child places great strain on the family unit. The researcher visited one of the participants after the initial interview to check on her health status. Her parent exclaimed that the family is exhausted, but she wouldn't have it any other way. The family unit is not the only one that cares for this group of children. After interviewing one of the parents, the parent and the researcher drove to her child's school to take measurements for the swimwear. The visit to the school revealed that the school's mandate was to provide social interaction for the child. Her child got wheeled around in a stand-up wheelchair so he can participate in daily activities with other children. The researcher realized how difficult it would be for this group of individuals to keep up their spirit, emotional strength, and energy to endure other obstacles that may present themselves in the future.

This study also provides functional specific clothing manufacturers insight into what children fitted with a central venous line are specifically looking for in their swimwear as well as their everyday garments. Clothing designers are shown the significance of functional, expressive, and aesthetics considerations. Perhaps more importantly, this study reaffirms the need and benefits of a methodological approach to needs identification and analysis in order to deduce a suitable product design, as generalities in design without proper needs analysis are inevitably flawed.

The research revealed that although mobility is not an issue for some of the children fitted with a ventral venous line, physical disability as defined by the *Participation and*

Limitation Survey 2006 (Statistics Canada, 2008) still exists for this group of individuals; unable to attend school and to participate in certain sports and other daily activities, all fall under the definition of physical disability. These disabilities will eventually lead to exclusion and isolation for this group of children which may be the greatest disability experienced by the children and a challenge to be internalized by their parents, families, and caregivers.

Children with physical disabilities face many challenges every day. The swimsuit provides a positive self-reflection with a social context that potentially could increase the quality of life of these children.

While the premise and focus of this study is to identify the needs of a specially designed and fitted swimsuit for special needs children, it was difficult not to digress into the emotional needs of this study group. The significant reality is that these needs are often comingled and indistinguishable, at least from the perspective of these children and their caregivers.

Assumptions, Scope, and Limitations

Assumptions. This study made two assumptions: (a) that function-specific swimwear for children with disabilities fitted with a central venous line is not currently available, and (b) that both females and males will identify similar elements, as outlined in Lamb and Kallal's (1992) FEA consumer needs model, as necessary for their function-specific swimwear.

Scope and limitations. The scope and limitations of this study were as follows:

- The cost of producing the prototypes limited the field testing to four participants. Preliminary estimates were that each prototype would cost a total of $500 (this figure includes fabric, trims, and labour). Budget constraints dictated that only four could be produced.

- The data collection phase of the study involved only four children (two male and two female, between the ages of 6-12) with a varied spectrum of mobility issues and who are fitted with a central venous line; four parents; and two medical professionals. Due to the sensitive nature of the subject of disabilities in young children, recruitment of participants was done gently and as unobtrusively as possible. Recruitment focused on arriving at a representative sample, not a large one. It was felt that the sample could provide information adequate to the development of a prototype. However, because the sample is small, further study would need to be done before a final design or set of designs appropriate to the target population could be developed.
- Due to monetary and time limitations, this study used fabric and trims currently available to consumers and manufacturers of swimwear. In order to develop a waterproof fabric for function-specific swimwear for children with a central line inserted, the researcher would have had to work with a technical textile designer in a large size firm. Only a large textile firm would be in the position to invest the money and time that is required to develop a new fabric, and because such a fabric might not have broad commercial appeal, no private firm would be interested in making the necessary investment. Most companies would provide sample yardage when requested to do so by a university.
- The researcher had limited knowledge of waterproof swimwear; she had to rely on the wetsuit manufacturer's knowledge and skills in making appropriate swimwear to fulfil the requirements for waterproof garments.
- Geographic distance prevented the researcher from investigating other potential manufacturers. The manufacturer used in this study had limited equipment and could only produced neoprene garments.

- Geographic barrier limited the location of the prototype fitting. The initial prototype needed to be tried on in the manufacturer's facility.
- The researcher had limited knowledge of children's disabilities (both physical and psychological). The researcher had to rely on the literature about children with disabilities initially, as she did not have prior field experience with this population.
- Field testing presented a challenge. The accessibility of pools may hinder the results of the prototype. Hospital pools contain a high concentration of chlorine while private pools contain very little. The concentration of chlorine may alter the integrity of the fabric as well as the construction applications. In addition, the fear of infection allows minimal testing time. Further testing for a longer period of time in a pool is recommended.

Future Direction

The presence of a prominent doctor, five staff nurses, and a physiotherapist at the field testing of one of the participants indicated their commitment and support for research in the area of clothing for children with special needs. This study exposed an opportunity and future research possibilities within the medical community. It is hoped that the results of this project will reach the medical and fashion community, resulting in collaboration between these two disciplines that may eventually lead to the development of other clothing for children with special needs. If we as a society can advance this important and overlooked area and address the needs of this small group of children, we would reach another milestone towards a socially responsible social welfare state.

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Appendix A

Ryerson Ethics Board Approval Letter

RYERSON UNIVERSITY
RESEARCH ETHICS BOARD

To: Pui Yee Chau
Faculty of Communicaton and Design, The School of Fashion

Re: REB 2011-372: Swimwear: Needs Assessment and Prototype Development for Special Needs Children

Date: February 23, 2012

Dear Pui Yee Chau,

The review of your protocol REB File REB 2011-372 is now complete. The project has been approved for a one year period. Please note that before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required.

This approval may be extended after one year upon request. Please be advised that if the project is not renewed, approval will expire and no more research involving humans may take place. If this is a funded project, access to research funds may also be affected.

Please note that REB approval policies require that you adhere strictly to the protocol as last reviewed by the REB and that any modifications must be approved by the Board before they can be implemented. Adverse or unexpected events must be reported to the REB as soon as possible with an indication from the Principal Investigator as to how, in the view of the Principal Investigator, these events affect the continuation of the protocol.

Finally, if research subjects are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research.

Please quote your REB file number (REB 2011-372) on future correspondence.

Congratulations and best of luck in conducting your research.

Nancy Walton, Ph.D.
Chair, Research Ethics Board

Appendix B

Assent and Consent Forms

Assent Form

Water fun: A Field Test of swimwear for children with special needs fitted with a central venous line

Ryerson Principle Investigator: P.Y. Chau, Graduate student, Ryerson University, School of Fashion
Supervisor: Lucia Dell'Agnese

We are asking your parents and you if you would like to work with us to help make you a bathing suit so you can go swimming safely with your pic line.

This is called a research study because we are testing things out to see how they work. We are doing this to help make you a good and safe bathing suit and also so that we can make good and safe bathing suits for other kids just like you, who have pic lines and can then go in the water safely.

What will happen?

We will ask your parents if it's okay that you do this with us first. Your parent will be there the whole time and is okay with whatever you decide about doing this.

First, we'll talk to your parent about what you like to wear in the pool so we can make something you'll like to wear when swimming. Then we'll take some measurements to see how big you are so that the bathing suit we make will fit. You'll be measured with your clothes on and it's just like getting measured to see what size you are.

You will then get to test out a new swimsuit, made just for you, in a pool with your parent and one of us. We will ask you a few questions about how you like it. We will take a few pictures of you with a camera that won't show your face to help us make other bathing suits that are good for other kids.

You will get to keep the swimsuit when we're all done.

Are there good things and bad things about the study?

The good thing is that we hope that you and other kids like you can go into a pool without worrying about your pic line.

The bad thing might be that when we test the bathing suit out in the pool, some water might come into the suit and we may take you out of the pool fast. You may be scared about water coming in but your parent will be there at the pool to help make sure it's all okay.

Who will know about what I did in the study?

The only people would know is the researcher, and your parent. Your parent has said it's okay that you do this but if you don't want to, or change your mind, no one will be upset or angry. It's okay to do this, but only if you want to. You can talk to your parent about this.

If we feel you might be really sick, we may have to talk about it with your parent and doctor.

If you want to do this, please put your special mark or sign your name on the line below. That will mean you're okay with:

-having your parent talk to us about what you like to wear;
-getting measured so that the bathing suit will fit;
-having a bathing suit made for you;
-testing it out with your parent in a pool that you know;
-being okay with having some pictures of you taken without your face showing.

Remember, it's okay to change your mind or ask any questions about things you aren't sure about.

_____
Signature or Special Mark

_____
Child's Name
(Please Print)

_____ _____
Signature of Participant or Parent/ Guardian Date

Child Consent Form

Water fun: A Field Test of swimwear for children with special needs fitted with a central venous line

Investigator(s):

P.Y. Chau Graduate student, Ryerson University, School of Fashion
416-979-5000 x6443 or pychau@ryerson.ca

Supervisor:
Lucia Dell'Agnese (supervisor), Ryerson University, School of Fashion
416-979-5000X 7172 or ldellagn@ryerson.ca

Why are we doing this study?

We are doing this so that you, and other kids like you who have a pic line, can go play in the water safely.

What will happen during the study?

We will ask your parents or you questions about what you like to wear in the pool. You or your parents' answers will help us to make a swimsuit that we hope you would like to wear in the pool.

You will then get to test out a new swimsuit, made for you, in a pool with your parent and a researcher. We'll ask you a few more questions about whether you like the swimsuit, or what you'd like to change about it.

You get to keep the swimsuit that will be made for you at the end of this study.

Are there good things and bad things about the study?

The good thing is that you and other children like you can go into a pool without worrying about your pic line.

The bad thing is that when we test the swimsuit out in the pool, some water might come into the suit and we may take you out of the pool fast. You may be scared about water coming in but your parent will be there at the pool to help make sure that doesn't happen.

Who will know about what I did in the study?

The only people would know is the researcher, and your parent(s).
If we feel your health may be in danger, we may have to talk about it with your doctor.

Can I decide if I want to be in the study?

Nobody will be angry or upset if you do not want to be in the study. We are talking to your parent/legal guardians about the study and you should talk to them about it too.

Consent:

By signing this form, I agree that:

1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private except as described to me.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I agree, or consent, to take part in this study.

Printed Name of Subject & Age	Subject's signature & date
Printed Name of person who explained consent & date	Signature of Person who explained consent
Printed Witness' name (if the subject/legal guardian does not read English)	Witness' signature & date

If you have any questions about this study, please call P.Y Chau at 416-979-5000 X6443 or e-mail pychau@ryerson.ca

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at 416-813-5718.