DESIGN FOR INCLUSIVITY:
IDENTIFYING AND OVERCOMING
THE DESIGN AND SOCIAL BARRIERS
TO ADAPTIVE CLOTHING

by

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ABSTRACT

The purpose of this research is to identify and organize the design and social barriers of adaptive clothing in order to increase its market availability. Adaptive clothing are garments designed specifically for people living with disabilities, endeavoring to increase quality of life and independence. Despite the benefits, adaptive clothing is not widely available for purchase because very little house-hold-name brands sell it, typically only available online from small companies. This research is divided into two aims. The first aim facilitates the identification of the design barriers by designing and testing apparel, which addresses the clothing related needs of an individual living with Down syndrome. The second aim focuses on identifying the social barriers to adaptive clothing by identifying and organizing the descriptions of adaptive clothing perspectives within the context of disability, using the three models of disability. By identifying the design and social barriers, this research produces a novel approach to product design. The new practice, titled Design for Inclusivity, is an interdisciplinary research method, not only focusing on user-centered design to satisfy clothing related needs of people living with disabilities, but also creating inclusion by marketing to both people living with and without disabilities.
Chapter 1
IDENTIFYING KNOWN BARRIERS

1.1 Introduction

1.1.1 Research Context

The purpose of this research is to determine the barriers associated with adaptive clothing. Adaptive clothing is defined as clothing developed specifically for people living with disabilities (Na, 2007). As a result of their disability, this population may have physical and intellectual differences from the general population, causing not only difficulties finding appropriate clothing but also difficulties related to donning and doffing clothing (e.g., Carroll & Gross, 2010; Kabel, McBee-Black, & Dimka, 2016; Ward, 1958).

Difficulties finding clothing stem from the current standard practices of the fashion industry. Two methods can be used to produce a brand’s sizing standards. Traditionally, brands will use a fit model to develop a size. This singular person is measured to create one size and then that size is enlarged or shrunk to create other sizes (Workman, 1991). However, this standard industry practice has its faults because the model’s measurements may be representative of an “idealized” customer measurement, not the actual customers’ measurements (A. Liepke, personal communication, April 24, 2019). A second practice is to take large data sets and develop sizes based on the measurement averages (LaBat, 2007). This technique can
also cause issues because customers that fall outside of the average measurements will have difficulty fitting into the brand’s sizes.

People with physically different body shapes than a brand’s “average” may not fit into the brand’s clothes because the brand did not design the clothing to fit their body, especially people living with physical disabilities. Additionally, people with intellectual differences may not be able to manipulate common closures used on typical commercial clothing (Carroll & Kincade, 2007). Thus, people living with disabilities tend to be underrepresented in the fashion industry because (1) brands typically do not use them as fit models because they do not represent the “ideal” customer and (2) brands do not use their measurements to create averages for sizing development.

In an attempt to address the fit issue, brands have begun to develop size categories within their clothing brands (e.g., petite, curvy, long). Additionally, to address issues that people with intellectual difficulties may face, brands have started to produce adaptive clothing. Currently, only two nationally-known companies, Target and Tommy Hilfiger, provide adaptive clothing lines (Moniuszko, 2018). However, only Target provides the clothing line in-stores and online, contrary to Tommy Hilfiger which is only available online (Target, n.d.; Tommy Hilfiger, n.d.).

Another common characteristic of the adaptive clothing market is the limited styles provided. Excluding Target and Tommy, other online-based brands focus more on the functionality of the adaptive garment more so than the aesthetics of the adaptive garment, resulting in a “homemade” look (M.L. Hall, personal communication, April 10, 2019) or “institutionalized” feel (McBee-Black & Ha-Brookshire, 2018).
Because clothing is a nonverbal form of communication, it allows the wearer to create and express his/her identity in society (Roach-Higgins & Eicher, 1992). But, when people living with disabilities struggle to find appropriate clothing, their choices can be constrained by market availability. Thus, people living with disabilities will have restrictions on their personal expressiveness because of restrictions on their clothing style choices. Furthermore, Kabel, McBee-Black, and Dimka (2016) discovered that when a person living with a disability does not have appropriate clothing for a certain social situation, that person will choose to not participate in the social situation. Thus, people living with disabilities not only face design barriers, like fit and style limitations, when dressing, but also face social barriers, like expressive and situational limitations, when dressing.

1.1.2 Thesis Context

First, I will discuss the known design barriers that individuals living with disabilities face as well as the current fit and sizing practices of the fashion industry. Next, I will examine the social barriers individuals living with disabilities face, focusing on the perception of clothing and the perception of disabilities. Once the barriers are identified, I will then state and describe my research aims. I will conclude this chapter by describing the innovation of my research from previous research studies. Aim One and Aim Two will be explored in Chapter Two and Chapter Three, respectively. Finally, I will conclude my paper with a discussion in Chapter Four and a conclusion in Chapter Five.
1.2 Design Barriers

1.2.1 Down Syndrome

In the United States from 2004 to 2006, about 6,000 infants each year were born with Down syndrome (Parker et al., 2010). Down syndrome is the most diagnosed chromosomal condition, resulting from an extra copy of chromosome 21, or Trisomy 21. Trisomy will affect the development of a fetus’s brain and body, resulting in mental and physical challenges after birth (Cronk, Crocker, Pueschel, Shea, Zackai, Pickens, & Reed, 1988). Common physical traits of Down syndrome include (1) low muscle tone and loose joints (Patterson, 1987; Leshin, 2002), (2) vision issues (Patterson, 1987; Leshin, 2002), (3) small stature (Melville, Cooper, McGrother, Thorp, & Collacott, 2005; Patterson, 1987; Leshin, 2002), (4) short limbs (Jaswal & Jaswal, 1981), (5) typically overweight or obesity (Melville et al., 2005; Cronk et al., 1988) and (6) small hands and feet (Jaswal & Jaswal, 1981). Cognitive difficulties include: (1) placement on the autism spectrum (Capone, 2002), (2) development of obsessive-compulsive disorders (Patterson, 2002), and (3) less-developed motor functions (Latash, 2002; Leshin, 2002; Spanoá et al., 1999). As a direct result of these physical and cognitive characteristics, people living with Down syndrome will have atypical body shapes and greater dependency on caretakers than the general population. Both the body shape and the greater dependency will result in difficulties associated with finding appropriate clothing and donning and doffing the clothing, respectfully.

1.2.2 Current Fit and Sizing Practices of the Fashion Industry

A prevalent issue within the current fashion industry, amounting to an estimated $62.4 billion, is dissatisfaction with fit (Ilyashov, 2016). Clothing fit is how
the garment “conforms to the shape and size of the wearer” (Gupta, 2014, p. 34). Fit of a garment will produce a comfortable or uncomfortable experience as a direct result of a person’s movements. Fit also affects the appearance and performance of a garment (Gupta, 2014). In an effort to standardize commercial sizes to improve fit, various size categories and subcategories (e.g. juniors versus misses, regular versus curvy) have been developed (Faust, 2014). However, customers are still dissatisfied. According to a consumer survey conducted by Body Labs (Zaczkiewicz, 2016), 64% of all returns are due to incorrect fit.

This dissatisfaction originates because each company and brand uses its own methods to size and grade, not adhering to a national or international sizing standard (Faust, 2014). Grading is the enlarging or shrinking of an original size in order to develop other sizes (Bye, 1990). Furthermore, grading is based on unscientific assumptions (e.g. bodies grow at constant intervals, one size to another is constant or linear grades) to create larger or smaller sizes from the original (Gupta, 2014; Schofield & LaBat, 2005).

One standard industry practice for size development is to use a “fit model” (Workman, 1991). This singular person is used by a brand to develop one size. The model’s measurements are then graded, creating a variety of sizes for one garment. In addition to the grading challenges, brands may also experience incongruence between the fit model and their actual customers (Bougourd, 2007). The fit model may represent a brand’s “ideal” consumer but a brand’s ideal consumer is not always its actual customer, resulting in the production of sizes that their actual customers cannot fit into (A. Liepke, personal communication, April 24, 2019; Bougourd, 2007).
Another common practice is to collect anthropometric data (body measurements of a large sample population) to create a sizing standard (LaBat, 2007). Data are then analyzed to create groupings within the sample population. To ensure that the greatest amount of people is accommodated, outlier data is deleted (Gupta, 2014; Vinué, León, Alemany, & Ayala, 2014). By deleting outliers to create optimal market share, companies and brands exclude people that have atypical body shapes (e.g. people living with Down syndrome) when compared to the general population sample. Further, companies only aim to accommodate 65% - 80% of each sample population grouping (Gupta, 2014), leaving 20% - 35% of individuals from each sample population grouping underrepresented. From the beginning, the process of sizing standardization excludes atypical body shapes (outlier data) and marginalized sizes (20% - 35% of sample groupings) in order to accommodate the maximum amount of consumers (65% - 80% of sample groupings).

1.3 Social Barriers

1.3.1 Dress as a Social Norm

Dress is a form of visual communication, facilitating social interactions between the wearer and society. It establishes one’s own identities and selves and allows one to attribute identities to others (Roach-Higgins & Eicher, 1992). The formation of identities will differ depending upon the social situation and how people interpret dress in each situation. Workman and Freeburg (2000a) establish that societies have dress norms that specify how people should or should not look during certain social situations. Thus, dress is a form of communication but is interpreted within the context of social norms.
People living with disabilities are unable to meet social dress norms as a direct result of their appearance. “If an individual…has a physical disability, he or she would be unable to achieve the normative demands…even if he/she wanted to” (Workman & Freeburg, 2000b, p. 93). Further research has determined that “disability is the most salient information in the perception of persons with visible, physical disability” even over ethnicity and gender (Rohmer & Louvet, 2009, p. 80). Additionally, people living with disabilities do not always have the option to wear the clothing of their choice, usually as a result of accessibility, fit/comfort, or ease of dressing of the desired clothing (Kabel, McBee-Black & Dimka, 2016). Thus, people living with disabilities may have a compounded effect of not looking like the general population and also not dressing like the general population. This situation may cause barriers to social participation as a direct result of their appearance (Kabel, McBee-Black & Dimka, 2016).

1.3.2 Models of Disability

Many models of disability exist (e.g. Lamb, 2001; Llewellyn & Hogan, 2000; Swain & French, 2000). They are used to define the perceptions of disability. According to Llewellyn and Hogan (2000), disability models may generate an explanation but do not constitute an explanation. Thus, models are just replications of small samples and cannot be proven because they are not empirically tested (Llewellyn & Hogan, 2000). The following models of disability were developed through examinations of texts about disability and interviews with people living with disabilities.

The three main models of disability that this research will focus on are (1) Individual, (2) Social, and (3) Affirmative (ISA Models). Individual model of
disability (also referred to as medical, clinical and tragic model) explain the perspective of disability as a personal tragedy (Lamb, 2001; Llewellyn & Hogan, 2000; Swain & French, 2000). People see disability as an individual’s problem, after being diagnosed of a disease or disorder that is a lifetime ailment and has no cure (Lamb, 2001; Llewellyn & Hogan, 2000; Swain & French, 2000). The descriptive words of this model are very medically and individually driven. Next, emerged the Social model of disability (Oliver, 2013). Within the Social model, the context of disability is as a result of society’s environmental and attitudinal barriers and can only be solved through social action, rather than medical treatment (Lamb, 2001). Finally, the Affirmative model of disability emphasizes positive identity (Swain & French, 2000). Through both a positive individual and collective identity, disability can be seen as just an experience and everyone’s experiences create value in their lives (Swain & French, 2000).

Llewellyn and Hogan (2000) emphasize the importance of using the models holistically and that one model is not “more accurate” or “better” than the other. They conclude that the models should be used for research and understanding purposes, and should be chosen to match the context of each individual research project. However, this research will view disability as a fluid construct, not as siloed models. The definitions of the ISA Models will overlap and fluctuate, similar to a continuum.

1.4 Thesis Aims

This research has two primary aims. The first aim includes designing and testing apparel, which addresses the clothing related needs of an individual living with Down syndrome. Chapter Two explores this topic in further detail. The second aim is to identify and organize the perspectives of adaptive clothing descriptions.
within the construct of disability, using the three models of disability (ISA Models). Chapter Three investigates this aim in detail. In Chapter Four discusses a potential solution to the identified barriers. Finally, Chapter Five concludes with implications and future research.

1.5 Innovation

Innovation will stem from the research approach and population. Participatory Design processes have been previously used in the discipline of apparel design, mostly focusing on improving the environmental sustainability of a garment (e.g., Armstrong, Niinimäki, Lang, & Kujala, 2015; Aakko & Koskennurmi-Sivonen, 2013; Cramer, 2011; Sanders & Stappers, 2008). Participatory Design processes with people with cognitive disabilities are limited in scope, focusing on the development of technology and education, not clothing (e.g., Braddock, Rizzolo, Thompson, & Bell, 2014; Frauenberger, Good, & Keay-Bright, 2011). Thus, this research is innovative because it will design apparel in partnership with people from an underrepresented population: individuals living with Down syndrome.

Furthermore, this research goes one step further by not only identifying and evaluating clothing related needs and satisfaction of those needs but also the consumer preferences of the clothing produced. Previous research most often only discusses the development of garments in order to satisfy clothing related needs (e.g., Frescura, 1963; Rutledge, 2017; Stokes & Black, 2012; Menec, 1989) and only a few explore consumer acceptance. Most researchers focus on the perception of people living with disabilities (e.g., Rohmer & Louvet, 2009; Nisbett & Johnson, 1992) and perceptions of adaptive clothing (e.g., Feather, Martin, & Miller, 1979; Cosbey, 2001; Freeman, Kaiser, & Chandler, 1987).
Moreover, this research utilizes inclusive practices throughout, using inclusive research techniques within the research context and drawing from different research domains. The pool of participants is inclusive because participants are people living with and without disabilities. Also, inclusive design approaches through user-centered design and Participatory Design processes will be performed. Finally, this research aims to develop inclusive products by targeting marginalized and underrepresented market groupings but not excluding general population groupings. Therefore, this research presents a new construct: Designing for Inclusivity. Thus, the product research, product design, and product market are all purposefully designed to promote inclusion.
Chapter 2
DEFINING DESIGN BARRIERS

2.1 Introduction

Women living with Down syndrome may have physical and intellectual characteristics different from the general population. As a result of their low muscle tone (Patterson, 1987; Leshin, 2002) and reduced fine motor skills (Latash, 2002; Leshin, 2002; Spanoá et al., 1999), they may have difficulty manipulating fasteners on clothing, such as buttons and zippers. In addition, women living with Down syndrome may be proportionately different in height (Melville, Cooper, McGrother, Thorp, & Collacott, 2005; Patterson, 1987; Leshin, 2002) and weight (Casey, 2013) than the general population. These physical characteristics can cause challenges when trying to find appropriate clothing (Thoren, 1996). This study aims to design and test apparel, which addresses the clothing related needs of an individual living with Down syndrome. Through various interdisciplinary research methods, the participant’s clothing related needs will be identified, garments attempting to satisfy those needs will be constructed, and both the final garments and the Design Phase will be evaluated. This aim not only proposes to identify the barriers of adaptive clothing design but also to promote inclusion.
2.2 Methods

2.2.1 Theoretical Framework

The framework for this study is Design Thinking, an entrepreneurial approach to business development. Brown (2008) defines Design Thinking as “a discipline that uses the designer’s sensibility and methods to match people’s needs with what is technologically feasible and what a viable business strategy can convert into customer value and market opportunity” (p. 2). Design Thinking will take into consideration a person’s needs but will only satisfy those needs in a financially successful way. By ensuring financial success, the outcome for this research may go beyond just helping one participant and allow for a possible business venture, increasing market availability and reach in order to help other people that may have similar needs.

Design Thinking has three main stages, (1) empathy, (2) ideation, and (3) experimentation (Brown, 2008). Cultivating empathy for the end user will allow for a deeper and more meaningful understanding of the problem. The FEA² model (Hall & Lobo, 2017), an expanded version of the FEA Consumer Needs Model (Lamb & Kallal, 1992), will be used to organize the participant’s needs. The original FEA model described the Functional, Expressive, and Aesthetic Needs of an end user, allowing fashion designers a reference when developing clothing for individuals with special needs. See Figure 2.1 for a visual representation.
The Functional Needs of an end user include fit, mobility, comfort, protection, and donning/doffing. The Expressive Needs facilitate the establishment of identities and selves within society, producing different forms of self-expression for the end user. Expressive Needs also refer to the perceived opinion of one’s self or identity by others. The Aesthetic Needs are the physical, visual characteristics of a garment, including color, fabric, and garment type. The original model describes the three consumer needs to be fluid and not siloed (Lamb & Kallal, 1992). The FEA\textsuperscript{2} expands the original model’s definitions to include Accessibility Needs, depicted in Figure 2.2. These needs are described by the market price and market availability of a product (Hall & Lobo, 2017).
The ideation stage’s purpose of Design Thinking is to develop as many possible ideas in order to satisfy the end user’s needs (Brown, 2008). During this research’s Design Phase, the user-centered approach of Participatory Design is utilized to design clothing in collaboration with the participant in order to produce ideas that satisfy the participant’s needs. Participatory Design allows the end user and the designer to be co-creators, having equal influence over the garment design outcomes (Gronbaek, Grudin, Bodket, & Bannon, 1993). Further, exploration will reveal the participant’s current or alternative solutions to the clothing related needs, a practice from Design Thinking. Design Thinking emphasizes determining alternative solutions so that the designer can (1) learn what length the end user has already taken to fix
his/her problem and (2) use the current solutions to produce better, more efficient solutions. Participatory Design and alternative solution identification will allow the development of multiple, new ideas to solve the participant’s clothing related needs.

The final phase of Design Thinking is experimentation. During this phase the designer rapidly develops multiple prototypes, reporting to the end user after each iteration. During this final phase, the designer may revisit the first and second phase in order to collect new data to develop an appropriate outcome for the end user.

2.2.2 Research Design

A case study research design with three phases was utilized. Human Subject Research protocols were developed and approved by the University of Delaware Institutional Review Board before beginning. The Initial Interview Phase involved semi-structured interviews in order to determine the participant’s clothing related needs and current alternative solutions. The Design Phase employed the user-centered approach of Participatory Design. The Exit Interview Phase included semi-structured interviews to evaluate both the Participatory Design process and the final garments. Finally, the participant wear-tested the clothing during her typical daily routine in order to determine if the clothing successfully satisfied her needs.

2.2.2.1 Initial Interview Phase

During the Initial Interview Phase, the participant and her caregiver were interviewed separately. The expanded consumer need model, FEA² (Hall & Lobo, 2017) was used to identify and organize the participant’s clothing related needs. Alternative solutions were identified in order to align with the principles of Design Thinking (Brown, 2008). To ensure all clothing related needs were identified, the
participant’s caregiver was also interviewed. This second interview facilitated communication with the participant and provide insight into clothing related responsibilities held/not held by the participant, including clothing care and purchasing.

2.2.2.2 Design Phase

The Design Phase followed a traditional and industry-practiced collection development process (Seivewright & Sorger, 2017), while also employing the iterative Participatory Design process. This phase began with a clothing trend forecast specific to women’s wear, determining future trends in relation to the participant’s chosen product category (e.g., professional wear vs. active wear). Based on this forecast, the next step was to create a mood and color board for clothing style inspiration. The boards were presented to the participant, and concepts for garments were designed based on her preferences. Multiple garment illustrations were developed and presented to the participant. From these illustrations, the participant selected three ensembles. Throughout the Design Phase, the participant was consulted on design decisions such as color and fabric. Once the garments were constructed, the participant was given the ensembles in order to be wear-tested. Descriptive field notes documented the Design Phase.

2.2.2.3 Exit Interview Phase

During the exit interview, both the participant and her caregiver were interviewed after they had been able to test the clothing. The participant was interviewed separately from her caregiver, prompting her to describe each step of the
Design Phase. Then, both she and her caretaker were interviewed together to ensure that all clothing related needs were discussed.

Based on the participant’s experience during the Design Phase, she determined if the Participatory Design process promoted an inclusive atmosphere and equality in design decisions. Further, she also evaluated the clothing to conclude if her clothing related needs were met.

2.2.3 Participant

The participant of this research was an adult female living with Down syndrome between the age of 20 and 35 located in the Mid-Atlantic region of the United States.

2.2.4 Data Collection

Data collection was conducted through all three phases. In the Initial Interview Phase, the participant and her caregiver were interviewed separately and audio recorded. During the Design Phase, any data was recorded with detailed field notes and other visual aids, including photos, illustrations, and prototypes. These visuals acted as aids during the exit interviews. Finally, the Exit Interview Phase was two interviews, one with the participant only and one with both the participant and the caregiver. Both interviews were audio recorded and analyzed using qualitative methods.

2.2.5 Data Analysis

Data analysis was conducted on both the Initial Interview and Exit Interview phases. Audio recording was analyzed with qualitative research software, Nvivo, for keywords and phrases (Bazeley & Jackson, 2013). Grounded Theory methods were
used to structure the analysis process. Keywords and phrases were organically grouped into larger themes and categories. Three levels of coding were used: (1) descriptive and axial, (2) selective, and (3) theoretical. Each new level of coding allowed the researcher to compare and contrast findings while creating notes and memos to define those themes and categories (Corbin & Strauss, 1990). Final themes aligned with the FEA² model, identifying clothing related needs and potential satisfaction of the needs from the Design Phase. Further, satisfaction of the participant’s role in the Participatory Design process was evaluated. A coding protocol was developed to ensure accurate coding. The data was processed using two coders with a Cohen Kappa Coefficient of 0.4468 and inter-rater agreement of 92.4833%.

2.3 Results

My participant was chosen through community networks from both University of Delaware and the City of Newark, Delaware, United States. Laura is a woman in her late twenties/early thirties, working as a receptionist for Delaware State government. She also has Down syndrome and as a result of the physical and intellectual characteristics, she may have clothing related needs. Thus, after signing all IRB consent forms, a time and date were determined for the initial interviews. Results are presented in the form of the FEA² model and organized into the three phases of the research. However, it is important to note that the process was iterative and occurred concurrently, allowing data to be collected throughout all the processes.

2.3.1 Coding Results

Both the initial and exit interviews’ data was coding using NVivo coding software and Grounded Theory methods. The data were coded across three different
levels. To facilitate the first level of coding, the initial and exit interviews’ data were kept separate. Then, during the second and third level of coding, the two interview phases’ data were combined in order to create general themes across the data.

Category names, definitions, and reference amounts of the three levels of coding are represented in Tables 2.1, 2.2, and 2.3, respectively. The reference amounts column refers to the number of comments made by the participants for that particular category.
Table 2.1: Descriptive Coding Level

<table>
<thead>
<tr>
<th>Coding Level One</th>
<th></th>
<th>Reference Amounts</th>
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</thead>
<tbody>
<tr>
<td><strong>Initial Interview</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category/ Theme</td>
<td>Definition</td>
<td></td>
</tr>
<tr>
<td>Alternative Solutions</td>
<td>Actions being done or products being bought to help alleviate any problems Laura may hold</td>
<td>21</td>
</tr>
<tr>
<td>Clothing Preferences</td>
<td>What types of garments does Laura wear, What styles and other physical characteristics are like/not like</td>
<td>55</td>
</tr>
<tr>
<td>Clothing Related Needs</td>
<td>What are Laura's challenges or difficulties in relation to clothing and the act of dressing</td>
<td>51</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Exit Interview</th>
<th></th>
<th>Reference Amounts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category/ Theme</td>
<td>Definition</td>
<td></td>
</tr>
<tr>
<td>Alternative Solutions</td>
<td>Actions being done or products being bought to help alleviate any problems Laura may hold</td>
<td>23</td>
</tr>
<tr>
<td>Clothing Preferences</td>
<td>What types of garments does Laura wear, What styles and other physical characteristics are like/not like</td>
<td>20</td>
</tr>
<tr>
<td>Communication</td>
<td>Any communication difficulties or problems between Laura and interviewer</td>
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</tr>
<tr>
<td>Problems</td>
<td>What are Laura's problems, including clothing, physical and intellectual</td>
<td>28</td>
</tr>
<tr>
<td>Process</td>
<td>Any comments made about the design process or the experience in general</td>
<td>73</td>
</tr>
<tr>
<td>Shopping</td>
<td>Details about shopping preferences, habits, or interests</td>
<td>41</td>
</tr>
</tbody>
</table>
Table 2.2: Axial Coding Level

<table>
<thead>
<tr>
<th>Category/ Theme</th>
<th>Definition</th>
<th>Reference Amounts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Action to Solve Problem</td>
<td>What is the literal action being done to solve the problem, regardless of efficiency</td>
<td>27</td>
</tr>
<tr>
<td>Actual Solution to Problem</td>
<td>What is the physical item or product being used to solve the problem</td>
<td>17</td>
</tr>
<tr>
<td>Aesthetics</td>
<td>The physical characteristics of a garment in relation to color, garment type, etc.</td>
<td>52</td>
</tr>
<tr>
<td>Buying and Shopping</td>
<td>Details about buying or shopping preferences</td>
<td>79</td>
</tr>
<tr>
<td>Communication</td>
<td>Difficulties in communication</td>
<td>17</td>
</tr>
<tr>
<td>• Am I talking too Fast</td>
<td>Situations when the primary researcher was talking too fast for Laura's comprehension level.</td>
<td>2</td>
</tr>
<tr>
<td>• Miscommunication</td>
<td>Situations when Laura responded inaccurately, (e.g. off topic responses, inaudible responses)</td>
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</tr>
<tr>
<td>• Please Repeat</td>
<td>Situations when Laura asked primary researcher to repeat the question</td>
<td>1</td>
</tr>
<tr>
<td>• Repeating my Words</td>
<td>Situations when Laura would simply repeat the question as a statement</td>
<td>4</td>
</tr>
<tr>
<td>Function of Garment</td>
<td>Functional characteristics of the garment, including fit, comfort, etc.</td>
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</tr>
<tr>
<td>Garment Preferences</td>
<td>Details about the preferences of the style or type of garment</td>
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</tr>
<tr>
<td>Problems</td>
<td>Any problems Laura holds, including clothing related needs and physical characteristics</td>
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</tr>
<tr>
<td>Process Comments</td>
<td>Any comments relating to the development and design processes of the design phase</td>
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</tr>
<tr>
<td>Why the Solution is Better</td>
<td>Details about the solutions and why they are better than previous solutions</td>
<td>7</td>
</tr>
<tr>
<td>Work Stuff</td>
<td>Any comments or details surrounding work</td>
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Table 2.3: Selective Coding Level

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<th>Definition</th>
<th>Reference Amounts</th>
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</thead>
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<tr>
<td>Accessibility Needs</td>
<td>Details outlining any clothing related needs involving market availability, product price, and restrictions of shopping opportunities</td>
<td>135</td>
</tr>
<tr>
<td>Aesthetic Needs</td>
<td>Details revolving the physical characteristics of garments</td>
<td>161</td>
</tr>
<tr>
<td>Expressive Needs</td>
<td>Comments relating to social role, self identity, and clothing</td>
<td>72</td>
</tr>
<tr>
<td>Functional Needs</td>
<td>Descriptions about the functional elements of a garment, including donning/doffing, comfort, and fit</td>
<td>195</td>
</tr>
<tr>
<td>Other</td>
<td>Comments that did not fall into either of the above categories</td>
<td>119</td>
</tr>
</tbody>
</table>

2.3.2 Initial Interview Phase

For the initial interviews, Laura and her mother were interviewed separately. First, Laura was interviewed. Discussed topics included typical daily activities and associated challenges, clothing preferences, and current clothing options. Laura gave an account of her daily routines, including her typical outfit choices and job responsibilities. Some communication difficulties arose. As a result of her cognitive impairment, Laura had challenges responding to multiple questions at once and quickly stated questions. Laura also had difficulties expressing certain fashion items because she did not know the correct terminology (e.g., color blocking, jumpsuit, metallic). Thus, the interview techniques were modified, using visual social media, to help with understanding and expression. Laura’s mother was interviewed after Laura. This interview was to confirm and/or add any details about Laura’s life that were not brought up during Laura’s interview. The same topics from Laura’s initial interview
were covered, in addition to discussing buying and shopping habits and preferences, revealing any additional Accessibility Needs.

2.3.2.1 Functional Needs

2.3.2.1.1 Laura

To determine her Functional Needs, Laura was asked a series of questions focusing on any challenges she facing during her typical daily routine. Clothing proportion and comfort were discussed as well as closure manipulation. Laura agreed when asked if the length of pants and sleeves were too long. Further, she also discussed an issue of “flashing” people when bottoms are too short, stating:

And one of the things that my dad yells at me too, as well, is that I can't wear very short things around my dad.

But there are some times where I don't want to flash people as well as and their [skirts are] up to the knee.

Thus, Laura prefers her dresses “to the knee or close to a long dress, as well.” When discussing fit and comfort of shirts Laura stated:

I can wear with these kind of [t-shirts] that I'm wearing right now. Because you can just put [it] over your head. But with the kind of [button down] shirts that might fit you, can, tend to fit you and like all that, as well. When they design those kind of shirts, as well, it's also kind of a little tight, as well. And I think I've been ripping some kind of shirts.

In addition to shirts that are easy don and doff, Laura also confirmed that she would like to wear button-down shirts to work but only, “if they’re like big buttons, as well, and I could see them.” Laura also discussed her fit and comfort preferences with work pants, after being questioned about work pant styles and fit, she responded:
Some [work pants] are [tight around the ankle] but I do like loose
[around the thigh] pants…. I do like to let my thigh breathe a little bit,
so I do like loose then.

Further, when questioned about avoiding clothing because it have zippers and buttons,
Laura agreed, confirming the difficulty. She responded:

That does come up like a lot of times, of times I don't want, as well, to
zipper or button anything, as well, but. But also I do like to breathe, as
well, so I don't want to be tight from [mid-torso region] down.

Another problem Laura had was the position of buttons. She described the positioning
of buttons on some of her work shirts:

Some of them have buttons up the front…. But also, this problem that I
have with shirts though, as well. Some of the shirts put the buttons back
[at the nape of neck].

2.3.2.1.2 Mother

Laura’s mother summarized Laura’s Functional clothing related needs to be (1)
the proportion of clothing both in circumference and length and (2) the difficulty with
manipulating closures easily and independently. She also mentioned Laura’s challenge
with “flashing” people:

Because I noticed I put the skirt on her, I actually put it in Goodwill
because I think because she's a little heavier than last summer. It went
up in the back a little so she'd bend over. I'm sure you get the picture.

In addition to short clothing causing “flashing” situations, Laura’s mother described
other instances of clothing length difficulties when shopping:

It's just not compatible to her body…. Dresses too are really, I bought
dresses before where I thought they would go to her knee and when I
actually put them on her and they went like down [her mid calf]…. And
the sleeves of course for dresses, so I try to find three quarters sleeve
stuff for her. Like, I try and buy her tops now for the winter because
they have a lot of three quarter Fall things and that would be long on
her.
She also gave her opinion to explain why clothing doesn’t always fit Laura, describing it as a physical characteristic of Down syndrome:

Since [individuals living with Down syndrome are] not proportioned as a typical person, the clothing’s not proportional the way it should be.

So yeah, I think physically she is shaped funny. And typical sizes don't fit her typically. I think that's our biggest problem. I just can't go buy her a shirt or a pair of pants. Like I said I thought "Oh these look big enough and they stretch a little bit" and they just barely fit her and I'm like "Laura I thought I had a good pair of pants."

Laura’s mother gave additional challenges that Laura did not mention related to proportion and fit, describing another difficulty with shirts:

This part [of her chest, from the neck to the belly button] is a lot shorter than yours or mine. So any low cut things go down to [her nipple line] on her. We have to be careful about not buying V-necks and I try not to let her cleavage show too much. Plus, she's not very body aware.

Further, Laura’s mother described the fit issues associated with tights and stockings

Tights are really tough, they, to get them large enough to fit around [her waist] and they just, she gets elephant knees and elephant ankles because they're just too long, so tights are really tough.

Laura’s mother also confirmed that buttons and zippers created difficulty when donning and doffing because of her visual impairments and nerve desensitization associated with Down syndrome:

Yeah, the big buttons [she can do]. Those little shirt buttons, she can’t do. She might be able to do that if the holes were big enough. Because it's something to grab on to because she doesn't…. Laura can't. She has some depth perception problems. So she really can't look down. And so then she does it by feel a lot of time. She has a stigmatism, in her eyes not so much vision problems but…depth perception and some visual side visual things are distorted a little for her.

That's probably a big issue, is most of the time, I think kids with Down syndrome they're, since they are so hypotonic, they have very low
muscle tone. Their nerves are also under the mushy muscles so they can't feel.

2.3.2.2 Expressive Needs

2.3.2.2.1 Laura

Laura described her Expressive Needs in relation to her position at work. She agreed when asked if the dress code at work is business professional. Further, she described that:

There's no uniform that I have to follow. But I do have to, there's no uniform to follow, but I do have to wear something appropriate because it is a state building.

Laura also stated that she liked long dresses because she did not want to “flash” anyone. Despite her professional dress code, her favorite anytime outfit was:

Actually don't know why, but I’m think it's like a dress that was, [with a neckline that] comes down to [the bottom of the rib cage].

2.3.2.2.2 Mother

She also thought Laura’s Expressive Needs were rooted in her female co-workers’ attire. She believed that Laura wanted to wear dresses because the other women would wear dresses and skirts to the office, stating:

I think they all dress professionally because they are on the governor's floor. That's why she says she likes to wear dresses and skirts. Because, I think, that's what most of the women wear at work, especially in the summer.

However, when asked about Laura’s dress code for work, her mother described it as optional because Laura is in the background of the office team:

Well, she is out at the front desk for the governor's office. But it's his Wilmington office so they don't get as many visitors as they do down in Dover. Like I have in an emergency put on a Lula Roe flowered tights
and a long top and nobody's ever said anything to me about it. She's basically in the foreground (sic) so she's not really up, like she's in the front but they're talking to the receptionist she's just sitting there doing her work.

Laura’s mother also described Laura’s issue of “flashing” others, describing the reason in more detail:

Plus, she's not very body aware. So if something's like, you know how you and I would fix our stuff, she just gets up and walks and I'm like, “Laura your underwear's showing. Pull your shirt down.” [Laura’s coworkers] probably have said that to her.

2.3.2.3 Aesthetic Needs

2.3.2.3.1 Laura

Clothing preferences were also discussed in order to determine her Aesthetic Needs. Topics included favorite garment styles, favorite prints and colors, and preferred fabrics. Laura’s favorite garment style changed depending on the season:

I normally wear like…right around the fall and wintertime, is like pant and shirts, but in the spring and summer time, I wear like skirts and dresses.

Laura described herself as “I am a bright color girl, but a bright color girl from just from the simple side of that,” preferring “some…blue and greens maybe a little red.” In addition, Laura said, “I do like, I do like a little black and tan, maybe a little white in there, maybe off-white.” She also liked specific prints, “I do like cheetah or zebra…and Hawaiian floral.” Other fabric preferences included tulle, leather, lace and “flowy” fabrics. However, garment embellishments needed to be simple, “not actually like bedazzled, but I do like a little simple [beading] like.” Laura’s mother did not comment on Laura’s Aesthetic Needs.
2.3.2.4 Accessibility Needs

2.3.2.4.1 Laura

Laura has Accessibility Needs, as a result of her mother doing most of the shopping. Thus, she does not have the opportunity or access to buy clothing for herself. However, when discussing recent purchases and brands she stated:

There's this new company that I think came out of California that actually fits me…. It's called Lula Roe.

Laura wears that brand’s dresses to work. Further, Laura described a jacket/blazer style garment that she said she recently bought:

I did just bought (sic) a jacket, that kind of jacket. Not that long ago for the fall…. It's like a burnt gold or something.

Thus, Laura may have some purchasing power when buying her clothing.

2.3.2.4.2 Mother

Laura’s mother performed most of the shopping. Thus, Accessibility Needs were presented in more detail during conversations with the mother. She stated various clothing brands that she buys from for Laura, including Old Navy, J.C. Penny’s and Lula Roe. When questioned about Laura’s interests in shopping, her mother responded that Laura does not enjoy shopping or trying on clothes stating, “no, she will not try stuff on unless I force her to.”

2.3.3 Design Phase

Descriptive field notes were taken during the Design Phase in order to document the Development Stage and Design Stage. The Design Phase was an iterative and non-linear progression, involving constant prototyping and feedback.
Two concurrent goals were accomplished during this phase, (1) develop accurate fit of garments and (2) design aesthetically pleasing and expressive clothing.

2.3.3.1 Design Stage

The Design Stage occurred simultaneously with the Development Stage. First, current trends within the fashion industry were researched, a technique traditionally used by the fashion industry when developing clothing collections (Renfrew & Renfrew, 2016). Digital, visual platforms (e.g., WGSN, a fashion forecasting website) were used to collect data and graphics. Trends included prospective colors and cultural themes, influencing the women’s professional wear product category. Next, the research was presented to Laura in the form of mood/trend boards and an inspiration/color board. Figure 2.3 shows a modified version of the mood/trend boards.
Figure 2.3: Modified mood/trend boards
Current cultural trends included “people first” designing, “investing in imperfections” and “design doing,” all with the common trend of humans inspiring design. These themes created a parallel between the human-centered design and research methods used in this research and the themes of “people first” and “design doing.” Further, the theme of “investing in imperfections” helped promote this research’s aim of inclusivity and designing for unrepresented market segments.

Inspiration/color board evoked pictures of melting flowers, playing with the idea of distorting perfection to create new beauty. The colors were then drawn from the inspiration/color board pictures depicted in Figure 2.4.
Six ensembles were then designed, influenced by Laura’s clothing related needs, according to the Initial Interview Phase data. See figure 2.5 for presented potential ensembles. They were then presented to her, during which she chose three final ensembles: (1) a jacket and pant combo, (2) a skirt and button-down shirt pair, and (3) a dress. Using the original inspiration/color board, Laura chose each garment’s color.

Figure 2.4: Presented inspiration/color board
Fabric swatches were then sourced from an online distributor to determine if appropriate for final garment use. Once an adequate amount of appropriate fabric choices were collected by the primary researcher, they were presented in combination with fashion illustrations that mirrored Laura’s physical features. This visual display was to help Laura envision the potential fabric and color choices in relation to herself.
and the garments and also facilitate the creation of empathy by the primary researcher. Laura then chose the fabrics for the final ensembles. See figure 2.6 for fashion illustrations and final fabric choices.

Figure 2.6: Presented fashion illustrations and final fabric choices

To facilitate ease of dressing, white knit fabric was used in the shirt of both the first and second look and a swatch can be seen in the First Look of Figure 2.6. The fabric was chosen for its weight and stretch components but did not match Laura’s preferred
color. Thus, the primary researcher garment dyed both the t-shirt of the First Look and the button-up shirt of the Second Look to match Laura’s color preferences.

All these design decisions were made in-person by Laura, but also in the accompaniment of her mother. In addition to fabric, small notions (i.e., the buttons on the button-down shirt) needed to be picked out. Digital visuals were created to present the sourced notions to Laura. In order to expedite the design decision, the visuals were sent to her mother’s email because “[Laura] tends to rely on me, [the mother], a lot.”

2.3.3.2 Development Stage

To develop accurate fit, first, Laura’s measurements were taken. After measurements were recorded, foundational templates, or “slopers,” were drafted. Slopers are the basic foundational shape of any garment, which can then be manipulated to create various garment styles. A pant, bodice, and skirt sloper were drafted. Figure 2.7 and Figure 2.8 show the various iterations of the fronts and backs of the bodice and pant slopers, respectively.
Figure 2.7: Front and back bodice iterations
Figure 2.8: Front and back pant iterations
Using the slopers, inexpensive-fabric prototypes, also known as “toiles,” were constructed to test the accuracy of the measurements. Laura then tried on the first set of sloper toiles. However, they did not accurately fit, specifically in the shoulder/ armhole area of the bodice sloper toile (Figure 2.9) and the crotch and hip area of the pant sloper toile (Figure 2.10). Thus, the process began again, starting with new measurements. Alterations were made to the second set of sloper toiles to inform the third set. The third set of sloper toiles yielded an acceptable and comfortable fit in the pant, bodice, and skirt slopers. However, due to time and project constraints, an accurately-fitted pant sloper was never produced. This issue did not cause any challenges or dissatisfaction for the final pant because the final garment was a looser-style pant, contrary to the tight fit of a sloper.
Figure 2.9: Iterations of bodice sloper toile
Figure 2.10: Iterations in pant sloper toile
Once the sloper toiles were confirmed as acceptable and comfortable, patterns for the final garments could be drafted. Final garment toiles were then constructed, using inexpensive fabrics with similar qualities to the final fashion fabric. Only one fitting was needed in the final garment toiles. Alterations were needed to correct the length both at the shoulders of the tops and the hems of all the garments and the circumference size at the waist of all the garments. Figure 2.11 shows the alterations needed after the first fitting.

![Figure 2.11: Alterations needed after first final-garment toile fittings, highlighted in red](image-url)
Once final garment toiles were completed, construction of garments in the participant’s chosen, final fashion fabric began. The research team constructed six total garments, including (1) Pant/Jacket ensemble with a t-shirt, (2) Skirt/Button-up Shirt ensemble, and (3) Dress ensemble. Visuals of each final garment set can be seen in Figure 2.12.

Figure 2.12: Pant/Jacket ensemble, Skirt/Shirt ensemble, and Dress ensemble
Once the garments were complete, Laura had one final fitting in the final garments, requiring minimal alterations. One alteration was the color of the t-shirt. Laura wanted the final garment to be a cream or beige colored top, rather than the original off-white fabric (First Look in Figure 2.6). In addition, some of the garments needed front/back indicators, such as tags on the back inside waist and front pockets on the chest.

### 2.3.4 Exit Interview Phase

The Exit Interview Phase took place after the final garments were completed and Laura wore each outfit at least once. First, Laura was interviewed individually and then both Laura and her mother were interviewed together. By interviewing separately and then together, caregiver/dependent relationship and communication characteristics could be recorded.

During the exit interview with Laura, visual media from the Design Phase were used to create a chronological recreation of the design and fitting processes. See Figures 2.4 – 2.12 for examples. Prompts were given with each visual aid, however many of Laura’s responses were limited. Examples of limitations include single word answers like “yeah,” “right,” and “OK” and asking for the question to be repeated. Additionally, Laura’s mother gave examples of trying to influence Laura’s decision-making during the Design Phase, stating:

> We would have planned ‘Springy-er,’ (sic) I would have encouraged ‘Springy-er’ (sic) materials, I think, then what you picked.

Topics for both exit interviews included final clothing evaluation and Participatory Design process evaluation.
2.3.4.1 Functional Needs Assessment

As identified in the initial interview, Laura’s main Functional clothing related needs included inaccurate fit/proportion and donning/doffing difficulties. However, some unexpected Functional Needs arose during the exit interview including weather and seasonal appropriateness of the final ensembles.

2.3.4.1.1 Fit and Proportion

According to Laura’s mother, the jacket fitted better than previously bought commercial jackets:

The [jacket] sleeves fit her fine, so it's nice. You know, all of her other jackets, we have to, the sleeves are down [past her fingertips] on coats and we have to roll them up, so she has this big bulge around her wrist.

However, two issues arose, according to Laura, in relation to the fit of the skirt and the pants. The pant cuffs were too small and Laura was walking atypically as a result:

[The pants not fitting correctly] did not make me feel bad. But, but when you made things just a little tight around [the upper ankle/lower calf area], as well, I was walking funny, as well, and I don't want my mom to have that inspiration that it was something on me, as well.

In addition to the improper fit of the cuffs, the seams of the pants also revealed a new Functional Need. Upon inspection, in several spots, the side seam of the pants had “popped,” revealing holes in the seams. After pointing them out to Laura and her mother, Laura explained, “oh it's wait, yeah I'm at work, I do walk round a lot, as well, but I am all up and down like all day.” Her mother described further saying:

I think what you're seeing is she tends to, her feet don't like to dangle, so she tends to pull her feet up as she's sitting, so then that's putting a lot of strain [on the seams].

However, when asked if the pants are too tight and if she would like the seams taken out, Laura denied that they were too small. Furthermore, according to Laura, “the skirt
was a little too big” at the waist and needed to be made smaller. These fit and durability issues were resolved through minor alterations.

Laura expressed additional concerns in relation to the proportion of the garments when wearing them separately from the designed ensemble. Laura stated, “I've been wearing the shirt outside of the skirt [ensemble], as well, and it the skirt, as well, and it [the shirt] kind of comes up a little bit,” meaning, the button-down shirt is proportionately too short when worn with other bottoms outside the Skirt/Button-up Shirt ensemble.

Laura did note two concerns, occurring during the fitting sessions. She did not like the designated fitting area because of a lack of privacy when walking to the room, causing Laura to feel uncomfortable.

There's nothing I wouldn't change, change about [the Design Phase], as well, except for finding the right place to undress. And, you know, that one time, they're having a meeting back in that room I, I felt just a little bit uncomfortable.

Also, Laura commented on the length of the fitting sessions, agreeing that they could have been shorter saying, “you had to measure every length of me and pin it as well. I remember it, it did take like a couple of hours to do it all.”

### 2.3.4.1.2 Donning and Doffing

According to Laura, all the garments were easy to don and doff. However, when putting the dress on she stated:

I just have to make sure I'm not putting it on, it on when not, not checking it first before putting it on, with the trust of knowing which is the front or the back.

Thus, she must double check the front and back of the dress before wearing it in public to ensure that she is wearing it properly.
2.3.4.1.3 Weather and Season Appropriateness

Both Laura and her mother described the benefit of the jacket being made of a heavier material because the mother struggles when buying winter clothing for Laura:

It's only when you get into the winter. Winter, I think, is the hardest time to buy clothing…. Shorts are easier to buy for her in the summer and summer dresses are a little easier to buy. Winter is tough to buy clothing for.

According to the mother, “the jacket was gorgeous and it's so heavy she could, she wears it as [an outerwear] jacket, not as a suit jacket.” Furthermore, Laura also agreed saying, “Because you made [the] jacket a little heavy, as well, I do know that might just be like the fall and winter coat, as well.” Thus, the seasonal duality of the coat was an unexpected way to satisfy Laura’s weather-related Functional and Accessibility Needs, not previously discussed in the initial interview.

However, other weather and seasonal concerns arose, especially when Laura’s mother discussed the ensembles and the Design Phase:

You know I think the only thing…is just I think people would appreciate a timeline…. Only because a lot of stuff she picked out was last fall, and it's heavier stuff…. And now she's not going to be able to wear it…. So like the dress, I thought about putting it and I'm like, “well she probably can't wear that in the warm weather because…it’s heavy looking,” and the pants probably not too much longer because they’re a winter-type style.

The Design Phase began in the fall and the clothing was not finished until early spring, as a result, Laura did not have as great an opportunity to wear the fall-inspired clothing than if the ensembles were designed for the spring/summer season. Further concerns discussed the practicality of the skirt during the colder months:

I think the skirt, while it looks pretty, isn't useful to her right now, like, she might wear it in the summer…. But she, it's really hard to buy like stockings and tights for her…. So wearing a skirt in the winter is not practical…. Plus with, she has orthopedic issues with her feet and she
likes to have heavy socks on all the time…. So pants and stuff like that or are better for her in the winter.

Thus, Laura’s Expressive Needs (i.e., wearing garments like a dress in the winter) are restricted as a result of her Functional and Accessibility Needs (i.e., not finding appropriately fitted stockings).

2.3.4.2 Expressive Needs Assessment

Laura explained her Expressive Needs to be related to her wearing appropriate clothing both at work and at home, including not “flashing” anyone and professional work wear. Laura’s mother also confirmed that Laura wants to wear clothing similar to her co-workers. Thus, three professional-wear ensembles were designed for this research. Laura confirmed that the ensembles were appropriate for work by stating, “where I work, I have to wear stuff like this, [the pants from research].” After wearing the clothing to work, Laura described the comments her co-workers made about the ensembles. Comments included “cute,” “beautiful,” “smart,” “sweet,” and “cool.” Laura also described the Pant/Jacket ensemble as having a “conservative look” that others would like.

However, as a result of Laura’s Functional Needs when wearing the skirt (i.e. wearing heavy socks, wearing stockings in the winter), the mother described the Skirt/Button-up Shirt ensemble as “not professional looking,” specifically when Laura has to wear socks instead of stockings with it. The mother explained the challenge of the ensemble further:

With the dress, she could wear, legless, feetless tights and put boots on. With that blue skirt, it’s not kind of a boot kind of a thing…[the skirt is] a little fancier so other than [the challenge of finding similarly styled shoes], I think everything turned out good.
2.3.4.3  Aesthetic Needs Assessment

Aesthetic Needs were addressed during the Design Stage of the Design Phase by allowing Laura to decide aesthetic features of the garments, including garment styles, the color and fabric of the garments, and the notions of the garment (i.e., buttons). However, her choices could be seen as restricted because the primary researcher decided the options from which Laura chose. The purpose of this decision was to ensure that the garment materials had the appropriate characteristics. Garment styles were discussed in Functional Needs Assessment because of Laura’s mother’s opinion about the seasonal appropriateness of the ensembles.

Colors and fabrics were chosen by Laura, according to the inspiration/color board presented during the Design Phase. She positively responded to the final garment colors by saying, “I do know that some of these colors are some of my favorite colors to date.” She spoke about the material of the button-up shirt positively:

The thing that I like most about [the button-down shirt], as well, jeans is my go-to thing that I wear like every day, day, as well, so I was just thinking about that, the color jean would look really good in a shirt.

When asked about the final outcome of the Dress ensemble, Laura responded, “It did come out how I expected it to, as well, and I do know that purple is up there as one of my favorite colors, as well.” When questioned about the Pant/Jacket ensemble, Laura raised a concern, “the only thing is, well I saw the shirt, as well…as well, and you dyed it wrong.” During the Design Phase, Laura expressed that she wanted her t-shirt to be dyed to better match her pants. After the dying process, the t-shirt did not come out the intended color. To correct this error, the primary researcher had to re-dye the t-shirt a darker color, going against what Laura originally picked.
Further, button options for Laura to choose from were decided by the primary researcher based on the aesthetics of the final shirt fabrics. However, Laura made the final decision from those options.

2.3.4.4 Accessibility Needs Assessment

Laura’s Accessibility Needs were, in part, defined by her and her mother’s alternative solutions to Laura’s clothing related challenges. Market availability was identified by Laura’s mother’s need to buy three-quarter length sleeves and capris-style pants, showing the lack of options for Laura’s body shape:

So I do buy some of her stuff from Old Navy and Gap. She can wear a lot of their tops, especially spring and summer ones that are three-quarter sleeves or short sleeves.

I would wait…and try and find capris pants because I'm not good about hemming things or even taking them to get hemmed…So I tried to find capris but again you have to find certain lengths because if they're not quite long enough then they, they're too short on her and they look funny.

Also, Laura’s mother does most of the shopping stating, “[Laura is] not a great shopper. It's just easier for me [to go alone].” Further, her mother explained Laura’s lack of interest in shopping:

She doesn't like to shop…. No, she won't try things on. If we are shopping and I pick stuff up, she doesn't want to be bothered looking…. So she's not a shopper…. If she needs something, [she will] pick it out. But Laura tends to gravitate towards jeans and t-shirts. She doesn't pick out fancy stuff too often. If we're shopping and she sees a T-shirt she likes that has a cool logo on it or something, she’ll pick that up but otherwise I'm forcing her to pick stuff out.

However, when questioned about shopping, Laura responded:

I do like going to the store, like BJ’s or something like that…. I'm not saying that I don't like shopping for clothes, but also my dad is of the
same way as me though, as well. He likes to go in an out, as well, and [my mother is] the grazer, so yeah.

Laura’s opportunity to shop is limited further by her disability. Her mother stated:

And since, she doesn't really handle money well. She probably wouldn't shop without her mother or her sisters or somebody who [she] knew and could watch and pay for her stuff.

Thus, Laura’s buying is mediated by her family and friends that would ultimately decide to purchase a garment or not.

Additionally, Laura enjoyed being able to pick out the garment details for her ensembles, as a result of the Participatory Design process. She said:

For the very first time I did enjoy picking out my own colors from this [color] board because, because for the very first time, as well, it was my choice and not a parent choice, as well.

However, Laura brought up a challenge related to the Participatory Design process. She became overwhelmed as a result of the time restrictions and amount of options, stating, “it was hard like that because, yeah, so many options, but I did enjoy it as in three hours, as well.” Despite the large number of options, Laura did not want her options to be reduced:

Not exactly less options but you, I will say, less options, as well, it just got very overwhelming at times…. A lot of stuff was happening around [the room], as well, and I didn’t want to think a lot, as well…. I didn’t want to think a lot but, I didn’t want to think a lot, but, but I do want to think, Oh what. But. But I knew that I had to pick, like right away though.

She agreed when asked if giving her more time would have helped and potentially taking the samples home.
2.4 Discussion

Three main design challenges were discovered during this research, (1) Needs Determination, (2) Restrictive Communication, and (3) Experiential Knowledge. These themes increased the level of difficulty when designing and constructing the adaptive clothing ensembles. Needs Determination refers to the challenges that arose when trying to identify the participant’s needs throughout all three phases. Restrictive Communications refers to the challenges with both in-person and digital communication techniques when working with someone with an intellectual disability. Finally, Experiential Knowledge refers to the challenges that the primary researcher faced when designing the adaptive clothing ensembles. These three themes represent the design barriers this research aimed to identify. Also, the additional challenge of false or inaccurate responses from participants and co-workers, resulting from good-subject behavior or politeness, must be acknowledged. Table 2.4 summarizes the design barriers.
Table 2.4: Summary of Design Barriers

<table>
<thead>
<tr>
<th>Category/Subcategory</th>
<th>Definition</th>
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<td>Needs Determination</td>
<td>Challenges relating to determining the needs of a participant</td>
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<tr>
<td>• Expanded Definition of Needs</td>
<td>Addition of &quot;opportunity to shop&quot; to the Accessibility Need of the FEA^2 Consumer Needs Model</td>
</tr>
<tr>
<td>• Varying Interpretations of Needs</td>
<td>Needs interpretation can change depending on the speaker and the interpreter</td>
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<tr>
<td>• Others’ Mediation of Needs</td>
<td>Outside influences that affect a participant’s choices, usually limiting them.</td>
</tr>
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<td>Restrictive Communication</td>
<td>Communication challenges associated with determining needs during design phase</td>
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<td>• Laura and Primary Researcher</td>
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<tr>
<td>• Designing for Human Being</td>
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2.4.1 Needs Determination

2.4.1.1 Expanded Definition of Needs

The Needs Determination barrier refers to the challenges of determining a participant’s needs. The Functional, Expressive, Aesthetic, and Accessibility Consumer Needs Model was used to organize Laura’s clothing related needs, during the Initial Interview and Exit Interview phases. However, this research discovered an additional need, the opportunity to shop, which is not defined in the FEA or the FEA^2.
models. This opportunity to shop expands the definition of Accessibility in the FEA\textsuperscript{2} model, explaining that individuals may have a lack of opportunity to shop or buy their own clothing, creating a need. If one has limited access when buying his/her own clothing, his/her Expressive Needs can also be affected.

Laura and her mother gave evidence to support this expanded Accessibility definition. Laura explained that she enjoyed picking out the colors of the garments because for the first time, “it was her choice and not a parents’ choice.” She further explained that she “doesn’t not like shopping,” she just does not want to spend a lot of time shopping, contrary to her mother’s “grazing” style of shopping, unfortunately leading her mother’s to believe that Laura “is not a shopper” because she must “force her to pick out stuff.”

2.4.1.2 Varying Interpretation of Needs

Another difficulty contributing to the Needs Determination barrier is the process of interpreting an individual’s needs. Both Laura and her mother described Laura’s needs to the primary researcher. However, both Laura’s mother and the primary researcher had to interpret those needs. Despite Laura wanting a low-cut dress, her mother deemed showing cleavage as inappropriate, so an appropriate neckline was maintained on all the tops. Further, Laura wanted clothing without zippers or buttons, so the primary researcher designed a dress (1) with a modest neckline, which satisfied a Functional Need described by the mother, (2) with no closures, which satisfied a Functional Need of Laura’s and (3) with a hemline down to her knees, which satisfied an Aesthetic and Expressive Need of Laura’s. Thus, when addressing Laura’s needs, the primary researcher had to also take into consideration Laura’s mother’s interpretation of Laura’s needs.
Another example of multiple interpretations of needs includes the style of the skirt from the Skirt/Shirt ensemble. According to Laura, lace was a preferred fabric and the skirt a preferred silhouette and when shown together, Laura approved, resulting in the primary researcher using that fabric and that silhouette in order to satisfy an Aesthetic Need. Her mother discussed the skirt’s lack of practicality because the lace makes the skirt fancy and Laura must wear heavy socks, making the ensemble not fancy. So, when worn together, the socks made the Skirt/Shirt ensemble look “unprofessional.” Thus, Laura’s Aesthetic Needs changed depending upon if Laura or her mother were describing the needs and depending upon if her mother or the primary researcher were interpreting the needs.

2.4.1.3 Others’ Mediation of Needs

In the process of this research, Laura was influenced by others when making Aesthetic Needs decisions. During the Design Stage of the Design Phase, Laura was able to choose from a variety of options to fulfill her Aesthetic Needs (e.g. colors, fabrics, silhouettes). But, the primary researcher first sourced those options, creating a limitation of her options. Further, her mother revealed in the exit interview that she would have encouraged Laura to choose different fabrics and garment styles than originally picked. These two examples represent an outside mediation influencing Laura’s choices when trying to satisfy her own needs. Further, Laura’s Expressive Needs were limited when her mother revealed that Laura does not shop alone because “she doesn’t really handle money very well.” As a result, the ultimate decision to purchase clothing is not executed by Laura, but a friend or family member, further limiting her ability to create self-identities through clothing.
2.4.2 Restrictive Communication

The Restrictive Communication design barrier exists between both Laura and the primary researcher and Laura and her mother. Limitations of digital and in-person communication methods occurred.

2.4.2.1 Laura and Primary Researcher

As a result of Laura’s disability, her speaking and understanding can be slowed. She has a lisp and stutter, making it difficult to understand her words. Further, her sentences were not always easy to understand, because she would repeat words and phrases (i.e., “as well” or “I didn’t want to think a lot”) or use incorrect words (i.e., I don't want my mom to have that inspiration that it was something on me as well).

Further, Laura has never designed clothing before, resulting in a lack of knowledge when trying to describe her Aesthetic Needs. As described in the Results section, Laura did not know the meaning of “color block” nor “jumpsuit.” Thus, the most efficient way to elicit Laura’s needs was to have visual cues and physical options from which to choose.

After choosing the garments’ colors, Laura had the opportunity to see the colors together in an outfit as depicted in the personal ensemble illustrations, Figure 2.6. The illustrations were successfully used to help Laura envision the final ensembles and facilitate her choosing fabrics for the garments. She confirmed when asked if she was able to envision what the clothes were going to look like. She was also able to see and feel the fabrics before making the final decision. However, one problem occurred with this process, she became overwhelmed. She states in her exit interview that there were too many options and not enough time to choose, in addition
to many environmental distractions. However, she clearly stated that she did not want her options to be reduced, showing an interest in having various options. She just wanted more time to choose (e.g., if she took the options home with her). Thus despite being under pressure, giving Laura the opportunity to “shop,” successfully satisfied her Aesthetic and Accessibility Needs.

2.4.2.2 Laura and Her Mother

During the Design and Exit Interview phases, interesting caregiver/dependent interactions occurred. Throughout this research process, any interaction with Laura also included her mother. Participatory Design process was used to include Laura in the Design Stage of her final ensembles. However, her mother gave evidence that she was trying to influence Laura’s decision when the mother mentioned wanting “Springy-er (sic)” clothing. Another example of mother interference may have occurred when Laura was picking out the buttons for her button-up shirt. To facilitate timeliness and ease, the primary researcher emailed Laura’s mother with a digital display of potential button options from which Laura could pick. However, because the researcher was not present when the decision was made, she cannot ensure that it was Laura’s uninfluenced decision, reducing the effectiveness of the Participatory Design process.

Another communication theme arose between Laura and her mother: Laura’s mother would explain further what Laura was describing. One example of this situation occurred during the exit interview after the primary researcher noticed the seams of Laura’s pants had popped. Laura described the reason behind the seam pop as a result of her constantly moving, sitting down and standing up, while at work. However, her mother described the reason as being the position that Laura sits in all
day. This situation of varying explanations parallels the Needs Determination barrier of others’ mediation of needs. Thus, not only is Laura’s needs being mediated, but her interaction with others is also mediated, amplifying the difficulty when determining FEA² needs.

2.4.3 Experiential Knowledge

Experiential Knowledge is the third design barrier experienced during this research. It refers to the lack of information the primary researcher had when designing not only clothing for a human but also for an atypical body shape.

2.4.3.1 Designing for Human Being

Formal apparel design education uses mannequins to teach the different design techniques (e.g., Amaden-Crawford, 2012; Joesph-Armstrong, 2009). However, challenges arise when trying to transfer mannequin-made garments to a human body. Humans breath, move, and fluctuate in weight, mannequins do not. These human factors influence and even change the Development and Design stages. One example of how moving versus not moving affects garment design is the fit of Laura’s pants. The pants were designed according to Laura’s measurements, so while standing the pants fit her. However, once she started walking, the cuffs were too tight so it changed the way she walked, causing her mother to comment on her atypical walking pattern.

Further, Laura stated that the fitting sessions made her uncomfortable and were too long. This situation gives evidence of the primary researcher’s lack of experience when conducting fittings. The researcher did not take into account Laura’s personal wellbeing. Thus, the primary researcher was limited by her formal education and lack of experience when working with and designing for a human being.
2.4.3.2 Designing for Laura

Difficulties designing for Laura stemmed from two major themes, personal style and Down syndrome. Laura’s needs were difficult to determine. Intellectual limitations related to her cognitive disability, her caregiver’s mediation of needs, and her limited fashion knowledge made identifying Laura’s FEA\(^2\) needs challenging.

Laura’s physical characteristics also created challenges during the Development Stage of the Design Phase. Her atypical body shape led to atypically shaped slopers. See Figure 2.13 for comparison of Laura’s slopers and traditional slopers.
Figure 2.13: Comparison of Laura’s slopers and traditional slopers
As a result of these unfamiliar shapes, the primary researcher had difficulty creating an accurate fit. Further, when manipulating the slopers to create garment patterns, the predictability of design outcomes was challenging because of the atypical shapes. Thus, many iterations were needed during the Development Stage of the Design Phase to problem solve any design issues. The various iterations also resulted in alterations needed after the final garments were constructed (e.g., skirt size reduction).

Another unexpected challenge was created as a result of trying to satisfy Laura’s Functional Needs. The button-up shirt was too short to be worn with other garments outside of the designated ensemble. Laura described how the shirt would come up a little, exposing her belly, while she wore it with previously owned clothing. As a result, Laura’s expressiveness is limited again by her Accessibility Need (i.e., previously owned clothing) and Functional Need (i.e., protection from skin exposure).

Further, orientation issues were discussed in the Results section. As a result of creating clothing with no closures, the orientation of the garments on the body became difficult to determine. Thus, donning and doffing became easier in respect to closure manipulation, but also became more difficult because Laura did not know which was the front or the back of the garments. These situations show that although adaptive clothing can solve various needs of an individual, it can also create new needs.

2.5 Conclusion

The aim for this study was to design and test apparel, which addresses the clothing related needs of an individual living with Down syndrome. A multidisciplinary research method allowed the primary researcher to identify and address the clothing related needs of the participant. Laura and her mother enjoyed the
Participatory Design process used during the Design Phase. Laura summarized her experience as:

It was a really good, amazing, and surprising, like, experience, as well, and I’m glad I could be a part of this.

Laura’s mother described the experience:

It was a great process. We enjoyed coming and working with you…. I think Laura liked doing clothes this way…sitting here and pick[ing] it out, stuff and styles and all that, and I think she enjoyed that more [than traditional shopping].

Despite the success of the research outcomes, some limitations of the research design existed. This chapter’s research was a case study, focusing on one person with one disability. Thus, the population size is limiting.
Chapter 3
DEFINING SOCIAL BARRIERS

3.1 Adaptive Clothing and Models of Disability Evolution

Adaptive clothing is a fairly recent addition to the fashion industry. “Adaptive,” “functional,” and “design for disability” are labels all used to describe clothing designed for people living with disabilities and other impairments (Gupta, 2011; Na, 2007; Carroll, 2015). Adaptive clothing can be traced back to the early 1930s, where clothing began to be used as a rehabilitative tool (Carroll, 2015).

Then as World War II veterans began returning home from war with permanent injuries, records show that loved ones started adapting previously owned clothing to fit the physical needs of the vets (Williamson, 2019). This trend continued and popularized as years went on, as is evident with the increase in academic research of adaptive clothing and disability (e.g., Behrens, 1963; Bright, 1974; Cookman & Zimmerman, 1961; Feather, Martin, & Miller, 1979; Frescura, 1963; Gamwell & Joyce, 1966; Hall & Vignos, 1964; Hallenbeck, 1966; Moran, 1976; Rusk & Taylor, 1959; Wagner, Kunstader, & Shover, 1963; White & Dallas, 1977; Ward, 1958; Vocational, 1966). Despite the surge in recognition, the material published negatively described disability and people living with disabilities in a medical and individualistic way (e.g., Clothing for the mentally retarded; Functionally designed clothing and aids for chronically ill and disabled; Problems of clothing for the sick and disabled; Self-help fashions for the physically disabled child). This way of describing disability is the first model, the Individual model of disability, existing into the 1970s and 1980s.
Also during this time period, as disability and adaptive clothing research continued, medical pamphlets, books and flyers began being distributed with the aim of advising home sewer on how to adapt commercial clothing to an individual living with a disability (e.g., Bowar, 1977; Caddel, 1977; Hanselman & Friend, 1976; Hotte, 1979; Kernaleguen, 1978; Koester & Leber, 1984; Lamb, 1984; Meacham, 1987; Mead, 1980; Menec, 1989; Phipps, 1977; Schwab, & Sindelar, 1973; Yep, 1977; Yoder & Morgado, 1985). Additionally, academic researchers began recording adaptive clothing preferences and stating potential changes to ready-to-wear clothing (e.g., Atkins, 1980; Cone, 1984; Dallas & White, 1982; Forcense & Shannon, 1983; Liu & Hillers, 1983; MacDonald, 1980; Park, 1989; Reich & Ottens, 1991; Reich & Shannon, 1980; Rosenblad-Wallin, 1985; Thornton, 1990). This increase in published materials showed a deficit in the commercial availability of clothing for the disabled. In response to this commercial deficit of appropriate clothing, a new perspective formed, the Social model of disability. The foundation of the Social model is that disability is a construct of society, defined by built environmental and social norms (Oliver, 2013). Thus, a person is not disabled until society creates a restriction for that person. Take, for example, a man in a wheelchair is not disabled only until he cannot enter a building because it has no ramp. Thus, the building is an environmental restriction that defines the man’s difference to society’s norms of walking up stairs.

As society began to contextualize disability as defined by the Social model, changes ensued. During the eighties and continuing into the nineties, researchers began focusing on the psychological effects of clothing towards individuals living with disabilities, stressing the importance of choice, independence, and appearance (e.g., Freeman, Kaiser, & Chandler, 1987; Freeman, Kaiser, & Wingate, 1985;
Hoffman, 1979; Klopp, 1990; Lamb, 1993; Lamb, 2001; Liskey-Fitzwater & Moore, 1993; Wingate, Kaiser, & Freeman, 1986). In the 2000s, research started focusing on designing clothing for individuals with disabilities, not just adaptations of commercial clothing (e.g., Carroll & Gross, 2010; Carroll & Kincade, 2007; Chau, 2012; Kabel, 2016; Na, 2007; Rutledge, 2017; Stokes & Black, 2012). This change inspired a new perspective, the Affirmative model of disability. This model describes disability as a unique quality that makes a person special because of his/her differentness (Swain & French, 2000). Thus, everyone is special because everyone is different and disability is just a different life experience. Table 3.1 summarizes the three main models of disability.
Small adaptive clothing brands date back to the late 1970’s to early 1980’s with Buck and Buck and Silvert’s (Buck and Buck, n.d.; Silvert’s, n.d.). However, the appearance of these clothes can be described as “institutionalized,” focusing more on the function of the garment than its aesthetics and expressiveness (McBee-Black & Ha-Brookshire, 2018). Additional adaptive clothing brands continued to develop, usually as a result of an entrepreneurial-minded family member experiencing life as a caregiver (Carroll, 2015). However, these out-of-home clothing lines, although functional can look “homemade” in detail versus from a manufacturing company (M. L. Hall, personal communication, April 10, 2019).
3.2 Current Adaptive Clothing Trends

Only recently have popular retailers (e.g. Target, Tommy Hilfiger) started providing adaptive clothing to address the clothing related needs of consumers living with disabilities (Moniuszko, 2018). By providing adaptive clothing, these companies are trying to promote inclusivity by serving an underrepresented market segment (Carroll & Gross, 2010), attempting to break the environmental obstacles associated with the Social model of disability (Oliver, 2013). However, most adaptive clothing focuses only on the functional aspects of the garments, rather than the aesthetic elements, which aligns with the medical perspective of the Individual model of disability (Lamb, 2001). This functional focus leads to an institutional or homemade look, emphasizing the visual conspicuousness of the garment. The functional appearance of adaptive clothing also negatively highlights the physical differentness of a person with a visible disability, creating a feeling of further exclusion from the general population felt by people living with disabilities as a result of compounding their bodies’ differentness in addition to their clothing’s differentness. Thus, a stigma toward adaptive clothing is created because it may increase the salience of an individual’s disability (Wingate, Kaiser, & Freeman, 1986).

Moreover, people living without disabilities disregard adaptive clothing because it was not designed for them. Take, for example, a plus-size woman would not consider buying maternity clothing, even if they accurately fit her, simply because she was not pregnant. Thus, both people living with and without disabilities may not want to buy adaptive clothing.

This research will aim to identify and organize the descriptions of adaptive clothing perspectives within the context of disability, using the three models of disability. By identifying the adaptive clothing descriptions, this research can begin a
dialogue about disability and the stigma associated with adaptive clothing. The goal of this aim is to facilitate change in the fashion industry, allowing more fashionable adaptive clothing options to people living with disabilities by understanding their needs. In addition to potentially facilitating social change, increasing market reach by creating more palatable adaptive clothing for people living without disabilities.

3.3 Methods

3.3.1 Theoretical Framework

The three different models of disability (ISA Models) will be used to organize the final level of the data. The ISA Models represent different perceptions of disability and the disabled. The Individual model of disability describes perceptions of individuals living with disabilities as the individual holding a problem (Swain & French, 2000). Individuals may be described as “suffering from” a handicap or be defined by the disability. The Social model of disability describes disability as a social or environmental construct, meaning a building without a ramp defines a person in a wheelchair as disabled (Oliver, 2013). Finally, the Affirmative model of disability portrays people living with disabilities as being different but still normal. Everyone is different and those differences are what make us special (Swain & French, 2000). Table 3.1 summarizes the ISA Models.

Table 3.1 summarizes the ISA Models.

This research’s theoretical framework will be centered on Grounded Theory, developed by Glaser and Strauss (1967). “The procedures of Grounded Theory are designed to develop a well integrated set of concepts that provide a thorough theoretical explanation of social phenomena under study” (Corbin & Strauss, 1990, p. 5). Simply put, Grounded Theory discovers patterns within data; these reoccurring
patterns are systematically compared and then used to generate social theory. Three levels of coding exist within the Grounded Theory Method, (1) descriptive and axial, (2) selective, and (3) theoretical. Descriptive and axial coding allows researchers to organize and familiarize themselves with their data. During this level, key words and phrases are identified and categorized. Selective coding gives researchers the opportunity to compare and contrast their descriptive codes, creating a deeper and more meaningful relationship between category themes. Theoretical coding produces social theory through organic development of categories. Throughout the different levels of coding, researchers take notes and memos describing and defining their categories.

3.3.2 Research Design

Semi-structured interviews began after Human Subject Research protocols were developed and approved by University of Delaware Institutional Review Board. Three photos of a woman wearing the three ensembles from Chapter Two were shown. The interview participants were then prompted to “describe the photos.” The initial prompt was purposefully vague so that the interviewer did not influence the participants' responses. Then, once finished describing the first set of photos, three more photos were shown of a different woman wearing the same three Chapter Two ensembles. Participants were then prompted to “describe the differences between the photos.” Topics covered included fit, aesthetic preferences, and personal preferences. However, topics were not restricted to only those prompts.
3.3.3 Participants

3.3.3.1 Model Participants

The model participants being photographed consisted of the participant from Chapter Two, Laura, and an able-bodied woman with similar body measurements. Both model participants were photographed in the three ensembles developed in Chapter Two.

3.3.3.2 Interview Participants

Three different population groups interviewed included: (1) women living with Down syndrome between the ages of 20 – 35, (2) family caregivers and (3) able-bodied women between the ages of 20 – 35. There were at least five people in each grouping. These interview participants were selected from the local community, Mid-Atlantic region, United States.

3.3.4 Data Collection

All interviews were audio recorded. Depending on the interview participants’ relationship to Down syndrome, different models were shown first. Women in the able-bodied grouping were first shown the able-bodied model, then the model with Down syndrome. Women living with Down syndrome and their caregivers were first shown the model with Down syndrome, then the able-bodied model. Figure 3.1 represents the photos shown of the model with Down syndrome and Figure 3.2 represents the photos shown of the able-bodied model.
Figure 3.1: The three ensembles from Chapter Two modeled by participant with Down syndrome

Figure 3.2: Chapter Two ensembles modeled by able-bodied participant
3.3.5 Data Analysis

All interviews were audio recorded. Each interview was coded for key words and phrases using NVivo™, a qualitative data research software. The key words and phrases were reported according to themes and reference amounts. A coding protocol was created to ensure accurate coding. The data was processed using two coders with an inter-rater agreement of 96.506% and a Cohen Kappa Coefficient of 0.580.

3.4 Results

The interview participants were gathered through community ties and social media throughout the Mid-Atlantic region, United States. Five able-bodied women, five women living with Down syndrome and seven of family caretakers were interviewed. Caretakers included four mothers, two fathers, and a sister. The able-bodied model was also recruited using social media outlets and resided in Delaware, United States. She had similar bust and waist measurements but was taller than Laura.

Caretaker participants and participants living with Down syndrome began the interview by first describing the set of photos containing Laura. Topics discussed included descriptions of the clothing, particular features that stand out, and proportion (e.g., length, fit) of the garments. Then, the second set of photos, picturing the able-bodied model, was shown and participants were asked to describe any differences between the two sets of photos.

Similar prompts as the caretaker participants were given to the able-bodied participants. However, the first set of photos contained the able-bodied model and the second set of photos contained Laura, a reverse order from the caretaker participants.
3.4.1 Coding Results

The data for all three population-interview groups were coded using NVivo™ coding software and Grounded Theory methods. The data were coded across three levels, descriptive, axial, and selective. To facilitate the descriptive level of coding, the data for the three population groups were kept separate. Then during axial sorting and selective coding, the data for all groups were combined in order to create general themes across the data.

3.4.1.1 Descriptive Coding

To facilitate the descriptive level of coding, able-bodied participants’, participants’ living with Down syndrome, and caregiver participants’ data were coded separately. Researchers coded responses into two broad categories, “before” and “after.” The “before” category refers to clothing descriptions discussed before the reveal of the second model. The “after” category contains descriptions of differences between the two sets of photos after the second model was revealed. By keeping broad categories, the researchers were able to explore the data.

3.4.1.2 Axial Coding

As a result of the broad descriptive coding categories, researchers had to further sort the data via axial coding. Axial coding revealed thirteen categories. Coding categories, definitions, and reference amounts can be seen in Table 3.2. Interesting axial coding categories included (1) “clothing descriptions,” (2) “model descriptions,” (3) “mention of self,” (4) “mention of Down syndrome,” and (5) “on her/for her.”
Table 3.2: Axial Level Coding Summary

<table>
<thead>
<tr>
<th>Category/Theme</th>
<th>Definition</th>
<th>Reference Amounts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clothing Descriptions</td>
<td>Comments describing the physical appearance of the clothing, including aesthetics and fit</td>
<td>635</td>
</tr>
<tr>
<td>Giving Ownership</td>
<td>Comments that give ownership of the garment (e.g., her dress vs. the dress)</td>
<td>8</td>
</tr>
<tr>
<td>Good Subject Behavior</td>
<td>Comments that lead the researchers to believe participants are saying what they think the researchers want to hear</td>
<td>5</td>
</tr>
<tr>
<td>I Don't Know</td>
<td>Participant responses containing the phrase &quot;I don't know&quot;</td>
<td>35</td>
</tr>
<tr>
<td>I Don't Like</td>
<td>Participant responses containing the phrase &quot;I don't like&quot;</td>
<td>43</td>
</tr>
<tr>
<td>I Like</td>
<td>Participant responses containing the phrase &quot;I like&quot;</td>
<td>195</td>
</tr>
<tr>
<td>In My Opinion/I Think</td>
<td>Participant responses containing the phrase &quot;in my opinion&quot; or &quot;I think,&quot; typically referring to changes in the garments that would make the clothing &quot;better&quot; or &quot;more acceptable&quot;</td>
<td>173</td>
</tr>
<tr>
<td>Mention of DS</td>
<td>Any comments relating to Down syndrome. Also, caregiver participants referring to their daughters/sister and relating their daughter/sister to model with Down syndrome</td>
<td>95</td>
</tr>
<tr>
<td>Mention of Self</td>
<td>Responses when participants refer to themselves in relation to the clothing or the model</td>
<td>86</td>
</tr>
<tr>
<td>Model Descriptions</td>
<td>Any comments or descriptions about the models, including physical appearance and nonphysical characteristics. Also containing fit descriptions</td>
<td>279</td>
</tr>
<tr>
<td>On Her/For Her</td>
<td>Participant responses containing the phrase &quot;on her&quot; or &quot;for her&quot;</td>
<td>50</td>
</tr>
<tr>
<td>Parent Perspective</td>
<td>Descriptions containing clothing opinions in relation to being a parent</td>
<td>1</td>
</tr>
<tr>
<td>Photo/Jewelry</td>
<td>Any comments or responses describing jewelry worn by the models or difference in photo quality</td>
<td>43</td>
</tr>
</tbody>
</table>

“Clothing descriptions” category described the aesthetic characteristics of the garments, including color and garment type. An example depicting aesthetic characteristics includes a comment from a caretaker participant describing the first ensemble’s jacket being worn by Laura, “I think [the jacket’s] got a nice line, it’s simple, it looks tailored, not fussy, and it looks very appropriate.” This category also included descriptions of clothing fit. However, the primary researcher had difficulty defining fit because of its close relationship to the body, meaning fit is describing the
modification of the body by the clothes, but also the modification of the clothes by the body. One comment about Laura from an able-bodied participant is exampled below:

[The dress is] not like an A-line cut or something like that. It's just like a straight cut. And it doesn't like enhance her curves or it doesn't make sure the details of her waist and everything well and so it just looks as if something is put on the hanger it doesn't look something is put on a body.

Another example further exemplified the difficulty of separating details of the body and details of the garment when describing the second ensemble being worn by Laura:

I think [the button-down shirt] definitely because the shoulders look a little boxy, it doesn't look quite as form fitting. And it definitely looks a little oversized even though the rest of it fits her, a little bit, you know, fine.

As a result, clothing fit was coded into both the “clothing descriptions” category and the “model descriptions” category. “Model descriptions” category refers to comments made that described the model and her physical features. An example of a description from an able-bodied participant of the able-bodied model included:

Yeah I mean in general I think this is someone I feel who like tried to, like, put together a nice outfit but maybe had a couple missteps along the way.

A participant living with Down syndrome described Laura’s physical features instead of describing the clothing saying, “she looks so beautiful with her smile” and “she looks happy to me.”

“Mention of self” and “mention of Down syndrome” categories recorded when the participants discussed envisioning themselves wearing the clothing or caregivers related their daughters to wearing the clothing. Only the mother caregivers, as opposed to all caregivers (i.e. fathers and sister), compared their daughters clothing preferences
to the clothing in the photos or compared clothing challenges related to Down
syndrome to the clothing in the photos. Comments included:

As far as for [my daughter], [the jacket/pant ensemble is] a little, it
wouldn't be something she would prefer to wear. She’s more into, the
colors are not, she’s more black. She likes to wear black.

And that for us is a big issue, because of height. And getting things to
fit things properly. You know, as far as length goes…That’s another
big problem we have is sleeves. They never fit.

The “mention of self category” contained comments made by participants that
compared themselves to the clothing within the pictures, allowing the participant to
envision himself/herself wearing the clothing during his/her typical day. Most
common method of envisioning was to compare the clothing to typical events in their
daily lives, like going to work or hanging out with friends. One participant compared
the clothing in the picture to clothing she typically wears to work:

But it's still like I would not wear [the jacket/pant ensemble] if I am
working or if I'm working full time job at an industry. I'd probably not
wear that. This is more like a casual thing that I can do it like on like
maybe like a casual stuff, like maybe on Fridays when I go to work or
something.

Further, participants with Down syndrome related the clothing in the pictures to their
own clothing preferences:

Yeah I could wear [those] pants because not showing skin that much.

Yeah that’s how I wear my shirt.

I prefer to have [my shirt] down [further to my pants]…so I’m not
showing too much skin
“On her/for her” category contained descriptions of the clothing but only in relation to the model. Participants explicitly stated “on her” or “for her” in conjunction to clothing descriptions. Participants from all three population groups described the clothing using this method. Examples include:

I think it’s a great color for her.

I think it looks great on her.

But the thing is it's too short for her.

3.4.1.3 Selective Coding Phase One

The FEA\(^2\) model was used to code the selective level of this research. The same definitions of the FEA\(^2\) were used in this chapter as in Chapter Two with the addition of a fifth category, “other”. “Functional” comments of the adaptive clothing descriptions centered on topics related to (1) fit, coming from all three population groups:

The jacket fits her really nicely.

It fits her nice.

I think the jacket oversized.

and (2) comfort, coming from caregiver and able-bodied participants:

It looks very comfortable with the gathering on the bottom and everything

And also she seems a little uncomfortable with this [ensemble], because if you see, her sleeves or something, it's kind of like crumpled.

“Expressive” descriptions included opinions from all three participant groups on role satisfaction, describing if the clothing was appropriate for specific social situations:

Looks very good for like a career type thing.
Well that's a nice casual wear for work

She's going for maybe an interview or maybe she is in the corporate sector or something.

“Aesthetic” comments from all three participant groups focused on (1) sleeve and hem lengths:

Sleeve length is definitely good. Even the length overall of the shirt even. 

[The jacket sleeve] looks long [on Laura] and then short [on the second model].

I think [the dress is] a little short.

(2) preferences of fabric, color, and print:

[Jacket/pant ensemble] is a little bit unusual. You don’t see too many people wearing that particular outfit. I think the plaid kinda sets it apart.

Because I love the [red] color [of the jacket].

I do really like the color blocking of [the dress]. It creates like a nice shape of the garment.

and (3) an overall ensemble critique:

I think [the ensembles are] cool.

I think [the dress is] very stylish.

Just not a fan of the [shirt/skirt] outfit altogether.

“Accessibility” comments related to the participants’ inability to express themselves, creating a language barrier, either as a result from lack of fashion terminology or intellectual comprehension levels. Caregiver and able-bodied participants’ responses included phrases such as “I don’t know” and “I’m not sure,” usually in reference to why they liked/disliked a garment’s feature. “Accessibility” comments originating
from participants with Down syndrome depicted low comprehension levels when answering questions or repeating the primary researcher’s questions as statements.

In addition, caregiver participants also gave information alluding to market availability when trying to find their daughters appropriately fitted garments:

We run into this problem that [my daughter] likes really trendy stuff, but unfortunately due to her build…you can’t always fit into that mold…Even the plus size stuff, because her stature is different, the plus size doesn’t help…it’s a struggle, it’s a struggle.

We have to get [my daughter’s] pants, if we can, in petite, but then the issue is because she’s larger, then a lot of the times they’re not big enough in the waist so a lot of the time we end up buying the size that she needs [in the waist] and then just getting them hemmed. I mean they’re just like, she’s usually swimming in them.

These difficulties the caregivers face when shopping for clothing for their daughters translated to the current market’s lack of clothing that satisfies the clothing related needs of individuals living with Down syndrome.

The “other” category revealed an interesting trend. It recorded participant responses when discussing fit and clothing but was expressed in terms of the model’s body or by using nontraditional clothing adjectives:

I can’t tell whether, you know, they, I know it’s hard to accommodate somebody who’s a little heavier, but I and, I think it looks like they’re trying to make it look slimmer but it makes kinda makes her look fatter…

The participant discusses it but did not describe what it is, resulting in ambiguity in the meaning and making placement within an FEA\(^2\) categories difficult. Further, other difficulties with category placement occurred when participants used descriptions of the clothing but not with typical fashion adjectives, like “I would say the [Dress ensemble] on Laura looks more acceptable [than on the able-bodied model].” The
term *acceptable* is not a traditional word used to describe a single garment. In this case, the meaning of acceptable can only be understood when in the context of the models’ bodies. Thus, the topic (i.e. the dress or the body) being modified by *acceptable* is uncertain.

These responses emphasized the blurred line between “clothing descriptions” and “model descriptions” discovered in the axial coding level. It also recorded instances of determining blame or fault of poor fit, either by the model’s body or the clothing. Thus, further sorting of data was needed to accurately explore and present these new findings.

### 3.4.1.4 Selective Coding Phase Two

Once participants began describing the individual wearing the clothing, the ISA Models became a more appropriate human categorization tool than the FEA\(^2\) model that is used to describe clothing. The ISA Models were interpreted as being on a continuum. Thus, the perspectives of Individual models were on the far left, Affirmative descriptions were in the middle, and Social interpretations were on the far right. Figure 3.3 visually depicts and describes the continuum in more detail.
### 3.4.1.4.1 Individual

The “individual” category referred to participant responses that described the clothing pictured but by using the visible, physical features of a person. One theme that arose was that the subject of the sentence was a physical feature (e.g. the body as a whole, parts of the body, or distinctive features). The physical features determined if the interview participant liked or did not like the garments. Examples include:

For *someone with Down syndrome* … this is nice with the way it flows and everything.

That *somebody* should be *taller* in them. If it did that the whole thing might slenderize down.

I don’t think so, the only thing, the only think that bother me about this one, and it could just be *her build*, again, the flare out in the thigh. Yeah and I mean that could just be the style or it could be *her particular build*.

So if *I had such big arms* [as the model], I would not wear that.

So, I don't know, she just, the woman in the second [set of] photos looks like *she’s scrunched up* in the first two [ensembles].

But this [picture] *she* just looks uncomfortable.
Another theme arising from the “individual” category descriptions was the use of adjectives relating to the wearer when describing the clothing, meaning these descriptions could only be understood in the context of a person wearing the garments.

In this theme the clothing was the subject, contrary to the first theme:

She, the, you know, this two piece ensemble, its much more age appropriate

So from a skirt standpoint it looks like in the second model the lengths are a little more appropriate than the first model

But I think, I think this is a more appropriate size and length.

From this particular skirt, [it] looks like its more appropriate [in] length on the second model than the first [model].

But the top [set of photos] look very put together.

3.4.1.4.2 Social

The “social” category contained comments about the clothing by comparing the physical characteristics of the participant model to social norms of beauty. United States beauty culture glorifies slimness and sexual attractiveness of a woman (Kaiser, 1997). Some examples of adaptive clothing descriptions within the social descriptions category were:

And this one I think is good for, for her shape. I think just the pulling in the middle, kinda of helps, just looks, thinner and healthy.

I know maybe its suppose to make her look slimmer, but I don’t think it, I think it just calls attention to.

It just doesn’t do anything for her figure either, even though it comes in here, you know.

The way the pattern creates an hourglass silhouette almost, I'm sure to the eye that might create a slimming look. Conversely the first [ensemble], the flaring of the coat makes this person look wider than
they probably are. The middle [ensemble] is, I don’t know if its tapered in the middle or not, but I think that it creates a nice shape. It is the middle [ensemble] that I think makes the person more traditional, in shape.

Because it really shows off her, I don’t know, it really shows off her hips.

I think it’s slimming because of the cut… But, I think other than that, I think it’s, like I said, flattering because it is cut to make her look thin.

Also, I think that from what I know, the length of this particular dress is more in keeping with what is the standard, its shorter.

Another “social” category description revolved around the idea of role satisfaction. Some participants commented on the social situation that the ensembles portrayed (e.g., professional work wear, causal wear, going out wear). By relating the ensembles to a social situation, participants were able to describe the garments in further detail:

*Casual*, someone would put it on when they’re just hanging around.

Its just, I don’t know, Laura’s [ensemble], to me, looks more acceptable to wear like if you were wearing something like that to work, to me.

…To me, [it] looks like, again, maybe something [she would wear] if she was going out…

3.4.1.4.3 Affirmative

The “affirmative” category depicted different descriptions of the ensembles but without any influence from the models. Participant responses acknowledged the model but could separate the model from the clothing:

 Maybe there’s a little bit too much fabric in the back of Laura’s that it’s a little bit too bulky.

I like the hourglass kinda look to the third dress the color block look to the third dress.
I’m, I’m not crazy about the bare midriff look, particularly. And I just, I’m not crazy about that. But, it doesn’t look bad on her. And I think the jacket looks nice on her too.

I do think that the, it could fit nicer around the neckline maybe I don’t know if there's another button that's not buttoned or if it's just kind of where it ends but I think it maybe come up a little bit or be a little more structured I guess less relaxed right there.

3.5 Discussion

The challenges experienced by the primary researcher during the data analysis stage allude to the social barriers of adaptive clothing acceptance. Selective level coding categories were difficult to determine. The primary researcher expected participant responses to contain information about the adaptive clothing depicted in the pictures. These clothing descriptions would support the initial intention of using the FEA\(^2\) model to compare data between Chapter Two and Chapter Three. However, the models’ physical features were so closely entwined to the clothing descriptions that the FEA\(^2\) model would not accurately categorize participant responses. Thus, responses were interpreted into a new continuum made up of the ISA Models (see Figure 3.3).

The process of developing a new continuum from previously defined ideas (e.g., the ISA Models) provides an explanation to why the participants described the clothing in relation to the models’ bodies. Many interview participants did not have the communication skills to accurately describe the clothing, thus they used previously defined ideas to help them express their opinions. Many caregivers and able-bodied participants did not have the fashion vocabulary to define the specific features of the garments that they liked/disliked. When one participant discussed the geometric pattern of the dress she said, “and then I like that it's, there's, I guess, color blocking, is
that what it’s called?” Thus, interview participants began using socially constructed
definitions in order to properly express their opinions about the clothing. These social
definitions included the ideas of (1) slimness and flattery of the body and (2)
situational appropriateness of clothing.

3.5.1 Slimness and Flattery

The constant comparison of Laura and the able-bodied model to socially
constructed ideas of beauty occurred in the caregiver and able-bodied participant
groups. When the model was described as “slim,” “healthy,” or “thin,” participants
were describing the fit of the clothing positively. Negative comments about the fit of
the models’ clothing included:

- But I just think, I don’t know if it’s the stark contrast between the grey
  and the purple that makes, that draws your eye to the purple, which
  makes it look less shapely.

- Plus, again, it’s just not very flattering at all. Yeah I would just say,
  they’re very not flattering. I mean the dress, that’s just awful.

Both the positive and negative descriptions of the clothing support an idea of a
socially constructed definition of beauty: one that emphasizes a slim and attractive
physique. This ideal physique creates a social barrier for people living with
disabilities, because others will continually compare the disabled population to the
ideal body of the general population.

3.5.2 Situational Appropriateness of Clothing

The second social definition revolved around the concept of appropriateness.
All three participant groups described the ensembles as “appropriate” or
“inappropriate.” However, when describing the garments alone, this description does
not mean anything. It only can be understood in the context of the body or the individual:

And then I think where the shirt hits is also appropriate with it being high-waisted it doesn't look like it's a long flowing shirt, that's kind of coming down over top of the skirt.

So from a skirt standpoint it looks like in the second model the lengths are a little more appropriate than the first model

Appropriateness of the garments may originate from the idea of role satisfaction. According to the participants, some of the ensembles may be appropriate for work stating:

That would definitely that would be perfect to have a bunch of those for work.

Because a nice professional clothes for work.

And just the bottom one is going to her knee, which seems professionally more acceptable, to me, in a work culture.

Thus, the idea that these garments are professional wear was inferred by the interview participants. Then the participants, based on that inference, described the clothing as appropriate or not. This situation exposes a second social barrier for adaptive clothing acceptance: identification of social role. The interview participants are looking at the style of clothing, expecting a certain “role” or “identity” to be fulfilled (i.e. professional wear will be worn by a business woman), according to social standards. However, because of the physical appearance of the individual living with a disability, he/she may never fulfill that role because he/she does not compare to the ideal physique.
3.6 Conclusion

This research’s aim was to identify and organize the descriptions of adaptive clothing perspectives within the context of disability, using the three models of disability. The initial intention of this research was to catalog clothing descriptions, using the FEA\textsuperscript{2} model. However, participant responses went beyond just describing the clothing and began describing the model, validating the transfer from the FEA\textsuperscript{2} to the ISA model continuum and allowing successful organization of perspective descriptions through Grounded Theory methods.

Limitations of this chapter’s research arose. A small population sample limits the scope of the research. The participants were a convenience sample collected through social media and word of mouth. Thus, some participants knew Laura, which may have caused bias or inaccuracy in responses. Further, the difference in photo quality between the two photo sets also may have influenced participant responses when describing the clothing. Another limitation discovered during the interviews involved the order in which the models were presented to the participants. The first model shown, regardless of ability, set a “standard” fit of the clothing. Thus, participants viewing Laura first described the clothing on the able-bodied model as too small or tight of a fit. The participants that viewed the able-bodied model first, described liking both the short and long versions of the clothing.
Chapter 4

OVERCOMING DESIGN AND SOCIAL BARRIERS

4.1 Barriers Summary

4.1.1 Chapter Two

Chapter Two revealed the design barriers of adaptive clothing to be (1) Needs Determination, (2) Restrictive Communication and (3) Experiential Knowledge (see Table 2.4 for graphical representation).

Needs Determination identified the challenges that arose when trying to identify the participant’s needs throughout the three-phased research design. It explained the purpose of an expanded definition of Accessibility Needs, showing that an opportunity to shop can be a need for individuals living with disabilities. Further, the Design Phase of this research demonstrated the varying interpretations of an individual’s needs. The interpretation of a single person’s needs varied depending on if (1) the individual expressed his/her needs or if another expressed his/her needs and (2) who was interpreting the expressed needs (i.e., a designer or a caregiver). Needs Determination also identified the ability of others to restrict the clothing choices of an individual living with a disability, especially when buying clothing.

Restrictive Communication was the second barrier identified during Chapter Two. This barrier exists between the participant and the primary researcher and the participant and her mother. The participant’s cognitive disability and lack of fashion terminology both caused communication challenges during Chapter Two research.
Further, interactions with the participant and her mother depicted various situations in which the mother influenced the participant’s self-expression and communication.

The final design barrier discovered during Chapter Two research related to the experience of the primary researcher. Acting as a designer, the primary research noted her lack of experience when working with a human being and an atypical body shape.

4.1.2 Chapter Three

Chapter Three discovered the social barriers to adaptive clothing acceptance, (1) Constant Comparison and (2) Role Identification. Constant Comparison refers to the general population’s continual judgment of an individual with a disability’s physical appearance against the “ideal physique.” Role Identification refers to the perceived inability of an individual living with a disability to satisfy a social role, as a result of his/her physical appearance.

4.2 Overcoming The Barriers

Figure 4.1 visually depicts the process that an individual living with Down syndrome experiences when buying adaptive clothing. Each stage represents the barriers the individual will face when attempting to buy clothing. In this section, I will take the reader through the process, describing it in more detail, relating the identified barriers to the specific stages of the process and explaining the techniques used to overcome each barrier.
Figure 4.1: End-user adaptive clothing buying process

4.2.1 End User

The participant, Laura, is the ultimate end user of the adaptive clothing. So, she represents the end user in Figure 4.1. Her personal characteristics are the first barriers that were encountered. From Chapter Two, challenges faced when talking to Laura were described as (1) lisp and stutter, (2) repetition of words and phases, and (3) use of incorrect words. Thus, the formation of questions and the rapidity of questions
being asked changed after learning Laura’s difficulty with comprehension by creating a simpler and slower speech pattern.

Further, Laura did not have the fashion terminology knowledge to accurately express her Aesthetic Needs. Visual aids in different medias were used to create a nonverbal “language” with the purpose to facilitate Laura’s understanding of the unfamiliar terminology. This new form of verbal and visual communication reduced the Restrictive Communication barrier between Laura and the primary researcher.

4.2.2 Caregiver Mediation

The next stage of the buying process involves the caregiver and his/her influence upon the end user’s decision-making. Two barriers are experienced during this stage of the buying process, (1) Restrictive Communication, between Laura and her mother and (2) varying interpretations, during Needs Identification. Restrictive Communication became most prevalent during conversations, involving both Laura and her mother. Laura would answer a question and her mother would elaborate upon her answer but the responses were not always congruent. An excerpt depicting this situation includes, Laura stating:

Where I work I have to wear stuff like this, [a dress pant], as well, but when I'm home I can be comfortable in jeans and leggings, as well.

And her mother responding:

Yeah we wear, she wears leggings to work, but I have to make sure the tops long enough so that it looks appropriate for work.

Laura stated she has to wear dress pants to work and likes to wear leggings at home. However, her mother elaborated and said that Laura also wears leggings to work. This simple inconsistence between pants worn to work represents one of the challenges her mother created while the primary researcher was communicating with Laura.
Another challenge was the influence the mother had on Laura’s decisions of Functional and Aesthetic Needs, creating challenges when determining those needs. During the Design Stage of the Design Phase, Laura was presented various fabric options. Her mother swayed her decision making by responding negatively to the original fabric choice. The final garment was constructed in a fabric choice other than Laura’s original decision because of her mother’s influence. This situation gives example to the difficulty experienced when interpreting Laura’s needs due to the variations of choice between the caregiver and the end user.

However, by acknowledging the inconsistences between Laura and her mother’s responses and choices, the primary researcher was able to intervene. By either removing the mother physically from the conversation (i.e. offer her a guided tour with another lab member) or recognizing the influence and making note, (1) the varying interpretations during Needs Determination and (2) Restrictive Communication between Laura and her mother barriers could be taken away.

4.2.3 Social Norms

Social norms represent the next stage of the buying process an end user would encounter. Social norms are defined as the socially constructed standards of a society (Kaiser, 1997). Social norms influence how people interpret the dress and appearance of individuals, defining what is “normal” and/or “appropriate.” The barriers, (1) Constant Comparison and (2) Role Identification, discovered in Chapter Three support this notion, respectfully. Interview participants continually related the fit of the clothing on both models to the “ideal physique.” In one interview from Chapter 3, a participant stated:
I think, just, the pulling in the middle, kind of helps, just looks, thinner and healthy.

So the “ideal physique” defined by the interview participants’ comments was a thin woman, wearing figure-flattering clothing without any “bunching,” “buckling,” or “bulging.” Further, both models’ ensembles were deemed appropriate or inappropriate for work. One participant stated:

I don’t think that’s acceptable…the length on that one, to me, looks like, again maybe something if she was going out. But I wouldn’t wear something like that to work, but like I said, I know women do.

This situation supports the idea of identifying an individual’s role (i.e. a professional versus a party-goer) within society based on their clothing.

These two barriers may be difficult to overcome. The barriers are developed by the thoughts and opinions of a society, changing them will not happen quickly. Thus, the only way to overcome these social barriers is to identify the barrier and aim to remediate them.

4.2.4 Accessibility Needs Fulfillment

Accessibility is the next stage within the buying process. This stage depicts the personal and commercial challenges when an individual with a disability is trying to find clothing. Chapter Two discussed the personal challenges an individual faced when buying clothing, (1) others’ mediation during Needs Determination and (2) lack of opportunity to shop during Needs Determination. Laura’s mother described herself as the main shopper for Laura’s clothing, stating, “She doesn't like to shop.” However Laura disagreed saying:

Sometimes I do like to pick out my own stuff and all that, as well. Yes. Yes. Yes. But…I'm not saying that I don't like shopping for clothes, but also my dad is of the same way as me though, as well. He likes to go in an out, as well, and she's the grazer, so yeah.
This conversation depicts the lack of opportunity to shop that Laura encounters because for her mother, “it's just easier” shopping alone.

Further mediation by others can occur financially. Individuals with cognitive differences can be vulnerable when shopping alone. Laura’s mother stated:

And since, she doesn't really handle money well. She probably wouldn't shop without her mother or her sisters or somebody who knew and could watch and pay for her stuff.

Thus, Laura may pick out clothing that she likes but ultimately it is the buyer who will make the final decision, not Laura.

The commercial barriers that exist within the accessibility stage of buying refer to the availability and price of clothing on the market. Currently, Laura has Functional Needs that are not being satisfied by the available clothing on the market, forcing her to seek out solutions. One alternative solution to satisfy Laura’s Functional Needs was to alter and hem clothing, one that her mother did not like:

I'm not good about hemming things or even taking them to get hemmed. I'm not good at it and I realize she had pants sitting in her closet that she never wore because they needed to be hemmed.

Another potential solution would be to have clothing custom made to Laura’s measurements but again this method may be even more expensive than alterations. Thus, Laura’s mother attempts to find three-quarter sleeved shirts and capris pants for Laura to wear because they fit like regular sleeves and pants.

Similar to the social norms stage, overcoming this stage’s barriers maybe difficult, ultimately relying on caregivers and clothing brands to remedy the problem. To Laura, this research reduced the financial and commercial restrictions buy utilizing the Participatory Design process to create an opportunity to shop with limited restrictions. However, a large company cannot collaborate with a single individual to
produce clothing only for that individual. The process would be time consuming, expensive, and the clothing would be exclusive for that one individual. Companies must create economies of scale in order to develop affordable and profitable clothing. Thus, Participatory Design, in its purest form, would not yield a viable business.

4.2.5 Functional, Aesthetic and Expressive Needs Fulfillment

The final stage of this buying process addresses the challenges associated with the Functional, Aesthetic, and Expressive Needs of an individual living with a disability. The two barriers represented in this stage are (1) Experiential Knowledge of the designer and (2) varying interpretations during Needs Determination.

A designer needs Experiential Knowledge when designing clothing, especially when using nontraditional methods. Traditionally, clothing is designed through aesthetic inspiration, brought to three dimensions on a mannequin, and sized according to a fit model. This research created custom sized clothing in collaboration with an individual living with Down syndrome, creating design challenges for the primary researcher. The inspiration, conceptualization and sizing of the garments did not follow the traditional apparel industry process. Thus, to overcome this design barrier, this research’s Design Phase was cyclical, resulting in a multitude of iterations and variations.

Varying interpretations during Needs Determination barrier, appearing in caregiver mediation stage, also appears in this stage. During caregiver mediation stage, varying interpretations can be seen at a personal level, between dependent and caregiver. However, at this stage, varying interpretations is discussed at a commercial level, between a business and its customer. Thus, a company must identify and interpret the needs of its customers, paralleling the situation between the primary
researcher and Laura. The primary researcher created a barrier experienced by Laura because she had to interpret Laura’s needs but also the mother’s interpretation of Laura’s needs. Laura and her mother did not always have the same opinion about clothing. During the Initial Interview Phase, Laura expressed her want of a low-cut dress but her mother discussed “[having] to be careful about not buying V-necks [in order to] not let her cleavage show too much.” The Participatory Design process was one method that the primary researcher used to help reduce the restrictions set in place by the varying interpretations barrier.

Thus, through various techniques and nontraditional methods, the primary researcher was able to help reduce the barriers an individual living with Down syndrome would experience when buying clothing. Design for Inclusivity, an original research practice developed by the primary researcher, combines the different methods of overcoming the design and social barriers to adaptive clothing used in this research.
4.3 Design for Inclusivity

Design for Inclusivity is an interdisciplinary research approach, combining various forms of inquiry from diverse academic disciplines to facilitate the development of research plans. See Figure 4.2 for a visual depiction.

![Design for Inclusivity Model](image)

Figure 4.2: Design for Inclusivity Model
By using an interdisciplinary research approach, an inclusive atmosphere created. Design Thinking is the conceptual framework because of its focus on satisfying people’s needs within a viable business strategy (Brown, 2008). Researchers should focus on underrepresented populations because they will have the most unsatisfied needs. Further, by including different target markets, the idea of inclusivity is extended and the transferability of needs satisfaction is greatest (e.g., ergonomically designed products benefit people with arthritis, but also increase comfort for people without arthritis) (Roy, 2016). By increasing the transferability of needs satisfaction to multiple consumer populations, researchers will be posed to have commercially viable products after research, because of the large market share of the product, decreasing the design barrier associated with Accessibility Needs.

User-centered research approaches allow researchers to go directly to their end-user, learning about the problem and if other stakeholders are involved. By developing a detailed understanding of the situation, researchers will have the potential to create and test solutions that actually solve a real problem. User-centered approaches can also allow companies to understand their consumers’ needs by dialoging with them. The FEA$^2$ model and ISA Models Continuum can be used as a tool for researchers and companies trying to record consumer needs and social opinions of a specific population.

Hall and Lobo’s (2017) FEA$^2$ model, an expanded version of the Consumer Needs Model (Lamb & Kallal 1992), which highlights the Functional, Expressive, and Aesthetic clothing needs of users, with the additional component of Accessibility of products, can facilitate the design and development of a research product. This model, originating from the academic domain of Health Sciences and Fashion, will assess
clothing related needs and can evaluate satisfaction of those needs. Further, researchers may be able to adapt the model for products other than clothing. By incorporating the FEA$^2$ into the framework, it may facilitate in the identification, organization and evaluation of stakeholder needs.

The ISA Models Continuum will work similarly to the FEA$^2$ model. However, this user-centered approach can be used to identify the social norms associated with a product or population group. By having a reference model, researchers can organize opinions easier and understand better their customers’ and stakeholders’ cultural needs, rather than just physical needs with the FEA$^2$. Thus, the ISA Models Continuum can help the researchers acknowledge the social norms of a population, facilitating in the reduction of any social barriers.

Participatory Design extends the user-centered approach from just information collection to product development. This process, traditionally used in the domain of Disabilities Studies, allows researcher and end user to both become designers. Researcher and end-user will be co-creators, each having equal influence over the design of the product (Gronbaek, Grudin, Bodker, & Bannon, 1993). Thus, the two “designers” will shape the product according to the FEA$^2$ and ISA Models findings. By using this process, communication challenges associated with design barriers will be reduced and any stakeholder influence (i.e. caregiver mediation) can be acknowledged.

By creating this interdisciplinary research design, not only can researcher and companies create products that satisfy consumer needs, it can become a new inclusive standard. Researchers will include customers throughout the product development process, from conception research to final product design, a method not typically
practiced. When using this framework, researchers will not only be *practicing* but also *producing* Design for Inclusivity.
Chapter 5

IMPLICATIONS AND FUTURE RESEARCH

5.1 Implications

This research will expand the process of Participatory Design by working with an underrepresented population. This Participatory Design process can be described as inclusive product research. The successful utilization of inclusive product research from Aim One gives evidence toward the potential benefits of implementing inclusive product research within the fashion industry.

Also, it presents the benefits of Participatory Design in satisfying the clothing related needs of individuals with Down syndrome, overcoming the design barriers of adaptive clothing by providing an inclusive product design.

This research will also add to the limited body of knowledge relating to adaptive clothing and consumer preferences. By identifying the consumer preferences of adaptive clothing, researchers can then begin to understand the social barriers of adaptive clothing acceptance. Through identification and understanding, the barriers can then be challenged, resulting in a more inclusive product market.

This research also describes a new perspective of design, Design for Inclusivity. The simple purpose of Design for Inclusivity is to incorporate inclusion from conception to consumption of a product. It emphasizes the importance of inclusive product research practices so that no one group is underrepresented. It shows the importance of inclusive product design, so that anyone can wear what they want, when they want. Finally, it postulates an inclusive product market can be achieved.
through purposeful design and utilization of inclusive research practices and product designs.

Last, this research will also expand the perspectives of disability. Disability will not be seen as different models not based in fact but as an empirically tested construct. Each model of disability will be seen together, rather than separately, building and expanding on the construct of disability. For this reason, the construct of disability will have a foundation based in data, giving it more support than previous models.

5.2 Ideas for Future Research

Design for Inclusivity is a new framework, tested only in this research project. Thus, the framework must be tested again to prove efficacy. Other framework variations could use a different target population other than people living with Down syndrome and also use a different product category other than clothing. By the further testing and adaptation of the new framework, the process will create a better and more effective framework, while also promoting and expanding inclusivity each time it is tested.

Further, the ISA Models Continuum was developed during this research. Again, it must be tested, evaluated, and molded into the most accurate and advantageous form possible. Thus, future research could test its definitions and potential for identifying social norms across different cultures.

Although the design and social barriers to adaptive clothing were identified and methods were described to overcome the barriers, another barrier exists that must be identified, the commercial barrier. This research touched upon potential solutions for the design barriers, however these were used at a case study level. Financially,
companies cannot follow this exact research design. Thus, future research needs to
determine if commercial barriers exist by interviewing industry stakeholders. By
identifying any commercial barriers, the potential for adaptive clothing accessibility
will increase. Then, only after the full identification of all the barriers to adaptive
clothing, can the fashion industry began to be more inclusive.
REFERENCES


Buck and Buck. (n.d.). www.buckandbuck.com


Roy, E. (2016, August 16). When we design for disability, we all benefit [Video file]. Retrieved from https://www.youtube.com/watch?v=g2m97gPI70I


Silvert’s. (n.d.). www.silverts.com


Vocational Guidance Rehabilitation Services. (1966). Functionally designed clothing and aids for chronically ill and disabled. Chicago: VGRS.


Appendix A

CODING PROTOCOLS

A.1 Aim One Interview Protocols

Summary of Task: The goal of this task is to review, interpret, and document participant responses to an in-person interview. The participant is a woman struggling to find off-the-rack clothing that fits her body appropriately. Questions were open-ended and covered topics about clothing-related needs, her current alternatives, and clothing preferences.

We will categorize participant response using Nvivo software program. The program is available on the lab’s PCs.

1. Open NVivo 12 program on the desktop.
2. Write your full name and initials when prompted.
3. Open assigned file
   a. On the left hand side of the NVivo screen under “Recent Projects”
   b. If it is not available under “Recent Projects” click “Open Other Projects”
   c. Then find Initial Interview in the pop-up screen
4. Go to “Files” and find the interview you were assigned. Double click.
5. Review the Nodes
   a. Nodes are located on the left hand side of the NVivo screen, under the tab “Codes”
   b. First click on “Codes,” then “First Level”
   c. Each node will appear, these are the keywords or themes you will be looking for while coding the interview.
   d. To review each node, right click on it and go to “Node Properties.” Please review the description of each node.

NOTE: if you read something you think is interesting, useful, or important that is not covered by the existing nodes, please create a new node and code your selection. To create a new node: on the left hand side of the screen click the “Codes” tab, then the “Nodes” tab, then the “First Level” tab. Make sure you did not highlight any of the nodes on the right hand side of the screen. You can then (1) click create at the top of the screen in the tool bar OR (2) right click and select “New Node.” Then, name your node and include a description that explains what it means.
6. Review the interview interface
   a. On the right hand side of the NVivo screen is the raw interview data.
   b. At the top is the audio file
   c. At the bottom is the time-stamped interview transcription, including
      speaker, time stamp, and interview contents.

7. Review the interview contents
   a. Before coding anything, please read through the entire transcript at
      least once.
   b. You can play the audio as well. Simply press playback at the top in the
      tool bar.

8. To Code
   a. Start to read the interview with the nodes in mind. Each time you read a
      section related to the node, code it.
   b. To code, simply highlight the complete sentence containing the coding
      material, right click and select “Code.”
   c. A box will appear, please select the appropriate node for the coding
      material and click “OK” at the bottom of the box.
   d. You can code the same text in more than one node. If you think that a
      selected test fits in more than one node, you can code for each.

9. Annotation
   a. If you wish to link a question or comment to a certain word, phrase, or
      sentence simply right click and select “New Annotation.”

10. Memo
    a. If you wish to ask a question or comment in general, or your
        comment/question is too long, you can create a Memo. Simply locate
        “Notes” on the left hand side of the NVivo screen, highlight “Memos,”
        right click and select “New Memo.” Please include your name and also
        describe your question/comment in the description box. Click “OK.

After Coding is Complete – Coding Comparison Query

When coding is complete for each interview, we will have a coding meeting to discuss
the data, talk about coding, and compare results.

- We will use a negotiated agreement approach for assessing coder
  agreement. Coding results will be compared and disagreements discussed
  in an effort to gain insights and reconcile differences.

NOTE: Negotiation is an important part of the process – although the supervisor may
be more knowledgeable about the project, student coders can bring fresh ideas and
perspectives that are important.
- Inter-coder accuracy and agreement will be checked through a coding comparison query, part of the NVivo software package.
- Memos and/or annotation will be attached to any change made to the coding scheme, based on coding comparison, explaining the reason for the change.

Any differences or disagreements that cannot be resolved will be noted in statistical analysis, but will defer to the supervisor’s codes.

A.2 Aim Two Interview Protocol

Summary of Task: The goal of this task is to review, interpret, and document participant responses to in-person interviews. The participants are potential consumers of clothing, each with varying backgrounds. Participants were asked open-ended questions related to pictures of models wearing specific clothing. Questions included clothing preferences and opinions in relation to disability, plus-size fashion, inclusivity.

We will categorize participant response using Nvivo software program. The program is available on the lab’s PCs.

11. Open NVivo 12 program on the desktop.
12. Write your full name and initials when prompted.
13. Open Aim Two Interviews
   a. On the left hand side of the NVivo screen under “Recent Projects”
   b. If it is not available under “Recent Projects” click “Open Other Projects”
   c. Then find Aim Two Interviews in the pop-up screen
14. Review the Nodes
   a. Nodes are located on the left hand side of the NVivo screen, under the tab “Codes”
   b. First click on “Codes,” then the appropriate file. For example, if you are on the first level of coding choose the “First Level” file.
   c. Each node will appear; these are the keywords or themes you will be looking for while coding the interview.
   d. To review each node, right click on it and go to “Node Properties.”
      Please review the description of each node.

NOTE: if you read something you think is interesting, useful, or important that is not covered by the existing nodes, please create a new node and code your selection.

TO CREATE a new node: on the left hand side of the screen click the “Codes” tab, then the “Nodes” tab, then the appropriate level file. Make sure you did not highlight any of the nodes on the right hand side of the screen. You can then (1) click create at
the top of the screen in the tool bar OR (2) right click and select “New Node.” Then, name your node and include a description that explains what it means.

15. Go to “Files” and find the appropriate interview. You will be coding all 15 interviews. Double click the appropriate interview.
   a. NOTE: Interviews are titled with numbers, but first names are used in the interview transcription.

16. Review the interview interface
   a. On the right hand side of the NVivo screen is the raw interview data broken into two screens.
   b. At the top is the audio file
   c. At the bottom is the time-stamped interview transcription, including speaker, time stamp, and interview contents.

17. Review the interview contents
   a. Before coding anything, please read through the entire transcript at least once.
   b. You can play the audio as well. Simply press playback at the top in the tool bar.

18. To Code
   a. Start to read the interview with the nodes in mind. Each time you read a section related to the node, code it.
   b. To code, simply highlight the complete sentence containing the coding material, right click and select “Code.”
   c. A box will appear, please select the appropriate node for the coding material and click “OK” at the bottom of the box.
   d. You can code the same text in more than one node. If you think that a selected coding material fits in more than one node, you can code for each.

19. Annotation
   a. If you wish to link a question or comment to a certain word, phrase, or sentence simply right click and select “New Annotation.”

20. Memo
   a. If you wish to ask a question or comment in general, or your comment/question is too long, you can create a Memo. Simply locate “Notes” on the left hand side of the NVivo screen, highlight “Memos,” right click and select “New Memo.” Please include your name and also describe your question/comment in the description box. Click “OK.

After Coding is Complete – Coding Comparison Query
When coding is complete for each interview, we will have a coding meeting to discuss the data, talk about coding, and compare results.

- We will use a negotiated agreement approach for assessing coder agreement. Coding results will be compared and disagreements discussed in an effort to gain insights and reconcile differences.

NOTE: Negotiation is an important part of the process – although the supervisor may be more knowledgeable about the project, student coders can bring fresh ideas and perspectives that are important.

- Inter-coder accuracy and agreement will be checked through a coding comparison query, part of the NVivo software package.
- Memos and/or annotation will be attached to any change made to the coding scheme, based on coding comparison, explaining the reason for the change.

Any differences or disagreements that cannot be resolved will be noted in statistical analysis, but will defer to the supervisor’s codes.
Appendix B

INTERVIEW QUESTIONS

B.1 Aim One Initial Interview Questions

- So do you just tell me what you do when you first wake up?
- Where do you work?
- So what do you do while you're in the office?
- What do you normally wear?
- Are you allowed to wear other colors or is there like a uniform that you have to follow.
- So what type of shirts you wear? Do you were long sleeve? Do they have buttons up the front? For work.
- What, do you like patterns on your dresses? Like flowers or stripes or do you like just plain solid colors.
- Would you not wear clothes because you have things like a certain type of clothing because you have to get on a bus or that doesn't bother you?
- What's your favorite like any time outfit.
- Do you know any other specific issues that you have? Or like things that, when you see it on an outfit you don't want to wear that outfit. So like, if an outfit has a zipper, like “oh I can't wear this” because I can't use a zipper, is that, does it ever come up?
- Any issues with shirts?
- What's your favorite color, clothing wise?
- What are your favorite colors or prints?
B.2 Aim One Exit Interview Questions

- Do you buy more online?
- Like in the office she said it was more like a professional business wear. So is anything like discouraged? She said she likes bright colors but like would that be discouraged in the building?
- Is there any way I can like contact Laura, or should I always go through you?
- So do you ever go shopping like do you ever bring Laura shopping? Does she like trying on the clothes?

B.3 Aim Two Interview Questions

- Please describe the photos.
- Is there any details that you like or you don't like about the clothes?
- If you can describe the differences between the first set and the second set.
- So which would you say looks better. The first model or the second?
- And then are there any other differences you see between the photos?
Appendix C

INSTITUTIONAL REVIEW BOARD CONSENT FORMS
C.1 Aim One Consent Forms

C.1.1 Interview Consent Form
INFORMED CONSENT TO PARTICIPATE IN RESEARCH

Title of Project: Interviewing Individuals with Motor or Sensory Impairment About Challenges with Daily Activities

Principal Investigator(s): Martha L. Hall, MS & Michele A. Lobo, PT, PhD

You and/or the person in your care are being invited to participate in a research study. This consent form tells you about the study including its purpose, what you will be asked to do if you decide to take part, and the risks and benefits of being in the study. Please read the information below and ask us any questions you may have before you decide whether or not you agree to participate.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to better understand the functional challenges faced by individuals with motor and/or sensory impairment during daily activities. Challenges could be related to personal care, independence, or social activities.

You and/or the person in your care will be one of approximately fifty participants in this study. You are being asked to participate because either you or someone in your care has a motor and/or sensory impairment. To participate you and/or the person in your care must not be confined to a prison, hospital, or in acute rehabilitative care. You must also be able and willing to be interviewed by a researcher.

WHAT WILL YOU BE ASKED TO DO?

As part of this study you will be asked to answer a short series of questions. These questions will be regarding (1) challenges with typical daily activities, (2) use of devices related to assistance with daily activities, and (3) current challenges and preferences related to clothing. Challenges with daily activities could be in terms of personal self-care, interacting with objects, activities promoting independence, or the ability to engage in social activities. Challenges with typical clothing could be ease of dress/undressing, comfort, fit, appearance, and/or functionality. You have the right to refuse to answer any question(s) during the interview.

You will have an initial contact with the researcher by phone, email, Skype or in person to discuss your preference for interview setting. Interviews can take place at the University of Delaware, in a residence, or at a selected location, depending on your availability and preference. You and/or the person in your care will be asked a short series of questions with opportunities for further discussion or follow-up questions, if necessary. The interview should last approximately 30 minutes.

The interviewer will be member of our research team and may be accompanied by an undergraduate student or other member of our lab. You or the person in your care may decline the presence of additional personnel if preferred at the initial contact. We will audio record the interview for transcription purposes.

If you and/or the person in your care participate in this study, the total time commitment will be less than one hour, including the initial contact.

Participant’s Initials
WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

Possible risks of participating in this research study include feeling uncomfortable describing your impairment, daily challenges, device use, and/or clothing preferences. To minimize this risk, interview questions are worded broadly and may answer the questions according to the comfort level of the participant. You and/or the person in your care may also refuse to answer any question(s).

WHAT IF YOU ARE INJURED DURING YOUR PARTICIPATION IN THE STUDY?

There is no risk of injury during participation in the study other than those one would encounter in daily life.

WHAT ARE THE POTENTIAL BENEFITS?

You and/or the person in your care will not benefit directly from taking part in this study. However, the knowledge gained from this study may contribute to our understanding of the needs of individuals with motor and/or sensory impairment. Information from this study may be used to guide future research projects and programs.

NEW INFORMATION THAT COULD AFFECT YOUR PARTICIPATION:

During the course of this study we may learn new information that could be important to you and/or the person in your care. This may include information that could cause you and/or the person in your care to change your mind about participating in the study. We will notify you as soon as possible if any new information becomes available.

HOW WILL CONFIDENTIALITY BE MAINTAINED? WHO MAY KNOW THAT YOU PARTICIPATED IN THIS RESEARCH?

Participants' identity will be kept confidential. The confidentiality of participant records will be protected to the extent permitted by law. Research records may be viewed by the University of Delaware Institutional Review Board, which is a committee formally designated to approve, monitor, and review biomedical and behavioral research involving humans. Records relating to this research will be kept for at least three years after the research study has been completed.

To maintain your confidentiality, participants will be assigned a numerical code within the study for ID purposes. Interview data will be stored electronically on password-protected computers in a locked lab. A list linking participants' IDs with their names will be kept in a secure database file that is password-protected and stored in a password-protected computer in a locked lab. Paper data will be stored in a locked cabinet in a lockable lab. Data will be kept indefinitely but at least for five years after the study ends.

We also must let you know that if during your participation, and/or the participation of the person in your care, in this study our research team was to observe or suspect, in good faith, child abuse or neglect, we are required by Delaware state law obligates us to file a report to the appropriate officials.

Page 2 of 5

Participant's Initials
USE OF DATA COLLECTED FROM YOU IN FUTURE RESEARCH:

The research data we will be collecting from you and/or the person in your care during participation in this study may be useful in other research studies in the future. Your choice about future use of your data will have no impact on participation in this research study. Do we have your permission to use in future studies data collected from you and/or the person in your care? Please write your initials next to your preferred choice.

☐ YES  ☐ NO

WILL THERE BE ANY COSTS TO YOU FOR PARTICIPATING IN THIS RESEARCH?

The only associated cost with participating in this study is travel cost if you choose to have the interview occur at the University of Delaware. There are no fees associated with parking for study participants.

WILL YOU RECEIVE ANY COMPENSATION FOR PARTICIPATION?

You and/or the person in your care will not receive any monetary compensation for participating in this study.

DO YOU HAVE TO TAKE PART IN THIS STUDY?

Taking part in this research study is entirely voluntary. You and/or the person in your care do not have to participate in this research. If you choose to take part, you have the right to stop at any time. If you and/or the person in your care decide not to participate or if you decide to stop taking part in the research at a later date, there will be no penalty or loss of benefits to which you are otherwise entitled. A decision to stop participation, or not to participate, will not influence current or future relationships with the University of Delaware.

If, at any time, you and/or the person in your care decide to end participation in this research study, please inform our research team by telling the investigator.

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Participant's Initials
WHO SHOULD YOU CALL IF YOU HAVE QUESTIONS OR CONCERNS?

If there are any questions about this study, please contact the Principal Investigators, Martha L. Hall at 302-831-8666 or mlucinda@udel.edu or Michele A. Lobo, at 302-831-8526 or malobo@udel.edu.

If there are any questions or concerns about your rights as a research participant, you may contact the University of Delaware Institutional Review Board at irb-research@udel.edu or (302) 831-2137.

CONSENT FOR ADULT INVOLVEMENT OR PARENT INVOLVEMENT

Your signature on this form means that: 1) you are at least 18 years old; 2) you have read and understand the information given in this form; 3) you have asked any questions you have about the research and the questions have been answered to your satisfaction; and 4) you accept the terms in the form and volunteer to participate in the study. You will be given a copy of this form to keep.

Patricia Kelly
Printed Name of Participant

Patricia Kelly
Signature of Participant

9/13/18
Date

Person Obtaining Consent
(Person Obtaining Consent)

Date

CONSENT FOR CHILD INVOLVEMENT (IF APPLICABLE)

You are making a decision whether or not to have your child participate in this study. Your signature indicates that you have read the information provided above and decided to allow your child to participate.

(Printed Name of Parent/Guardian) (Signature of Parent/Guardian) (Date)

Person Obtaining Consent
(Person Obtaining Consent)

Date

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Participant’s Initials
CONSENT FOR ADULTS WITH CAREGIVER INVOLVEMENT (IF APPLICABLE)

You are making a decision whether or not to have an adult under your care participate in this study. Your signature indicates that you have read the information provided above and decided to allow the adult under your care participate.

(Patricia Kelly) (Patricia Kelly) 9/13/18
(Printed Name of Caregiver) (Signature of Caregiver) (Date)

Person Obtaining Consent Person Obtaining Consent Date
(PRINTED NAME) (SIGNATURE)

OPTIONAL CONSENT TO BE CONTACTED FOR FUTURE STUDIES:

Do we have your permission to contact you regarding participation in future studies? Please write your initials next to your preferred choice.

YES

NO

OPTIONAL CONSENT FOR AUDIO RECORDING TO BE SHARED WITH EDUCATIONAL AUDIENCES:

Do we have your permission to share portions of your audio-recorded interview with educational audiences? Please write your initials next to your preferred choice.

YES

NO

Page 5 of 5
Participant’s Initials
C.1.2 Interview Assent Form
ASSENT TO PARTICIPATE IN RESEARCH FOR TEENAGE CHILD

Title of Project: Interviewing Individuals with Motor or Sensory Impairment About Challenges with Daily Activities

Investigator(s): Martha L. Hall, MS & Michele A. Lobo, PT, PhD

I am asking if you want to be part of a research study. This form tells you what the study is about, what you will be asked to do if you want to be in the study, and the possible bad and good things about this study. Please read this paper and ask us any questions you have.

WHAT IS THE PURPOSE OF THIS STUDY?

This research study is being done to better understand the challenges experienced every day by people with physical disabilities or special needs.

We are asking you if you want to be in it because you or someone who helps take care of you told us that you have difficulty with one or more of your daily activities. We are looking for a total of fifty people to be in this study.

WHAT WILL YOU BE ASKED TO DO?

If you want to participate we will ask you to talk with us to tell us about any difficulty you have with your daily activities, such as dressing for school, using things like hairbrushes or eating utensils, or going to social events. We will be asking you about whether you use devices to help you each day, and what you like or don’t like about the devices. We will also be asking you about clothing options and your opinions about clothing and style.

We can meet with you at a place you and your family decide is most convenient and comfortable for you. This might be at your house or at the University of Delaware. When we meet, we will ask you a series of questions. You do not have to answer all the questions, or answer any question you do not want to answer. The questions will take about one half hour. We will sound record our discussion so we can correctly remember all of your comments. You get to decide and write at the end of this form whether you think it is okay for us to share parts of the sound recording with students and other people who want to learn about our work.

WHAT ARE THE POSSIBLE BAD THINGS ABOUT THIS RESEARCH?

We do not think that participating in this research will make you uncomfortable or hurt you. If you are shy, you can ask a family member to help you respond to questions. If you are uncomfortable answering any questions, you do not have to answer.

Participant’s Initials: [Signature]
WHAT ARE THE POTENTIAL GOOD THINGS ABOUT THIS RESEARCH?

You will not directly benefit from being in the study. However, we hope to learn new things during this study that would help us better understand the needs of people who have challenges with daily activities. This study will help guide future projects that might help people.

WHO MAY KNOW THAT YOU PARTICIPATED IN THIS RESEARCH?

Leaders of our research team will know you participated in this research. This includes the people who meet with you to ask you questions and may include a person or two who work in the lab. These people will not tell others about your participation. Throughout the study, anyone besides these few people who sees or hears your answers during the interview will not know they are from you. You will be assigned a number and they will only know that information belongs to the person with that number.

WILL YOU RECEIVE ANY COMPENSATION FOR PARTICIPATION?

There is no compensation for participating in the study.

CAN YOU CHANGE YOUR MIND ABOUT BEING IN THE STUDY?

You do not have to say yes. Taking part in this research study is up to you. If you choose to take part, you can change your mind and stop at any time. If you decide not to participate or if you decide to stop taking part in the research later, nothing bad will happen to you and no one will be upset with you. If, at any time, you decide to stop please let us know by telling one of the researchers. During this study we may learn new things that could be important to you and we will let you know and check if you still want to be in the study.

WHO SHOULD YOU CALL IF YOU HAVE QUESTIONS OR CONCERNS?

If you have any questions about this study, please tell Martha Hall at (302) 831-8666 or mlucianda@udel.edu or Michele Lobo at (302) 831-8526 or maloo@udel.edu.

If you have any questions or concerns about your rights as a research participant, you may contact the University of Delaware Institutional Review Board at irb-research@udel.edu or (302) 831-2137.

If you want to participate, and we have answered all of your questions about it, please sign below.

Laura Kell
Signature of Participant
01/31/18
Date

Person Obtaining Consent
(PRINTED NAME)

Person Obtaining Consent
(SIGNATURE)

[Signature]
Participant’s Initials

Page 2 of 3
OPTIONAL CONSENT FOR SOUND RECORDING TO BE SHARED WITH EDUCATIONAL AUDIENCES:

Do you agree to share portions of your sound-recorded interview with educational audiences? Please write your initials next to your preferred choice.

✓ YES       NO

Page 3 of 3  Participant's Initials LMK
C.1.3 Design Consent Form
INFORMED CONSENT TO PARTICIPATE IN RESEARCH

Title of Project: Clothing Design for Individuals with Adaptive Clothing Needs

Principal Investigator(s): Michele Lobo, PT, PhD, Martha Hall, MS

You are being invited to participate in a research study. This consent form tells you about the study including its purpose, what you will be asked to do if you decide to take part, and the risks and benefits of being in the study. Please read the information below and ask us any questions you may have before you decide whether or not you agree to participate.

It is important you know that in order to participate in this project, you must agree to allow us to share the photographs and videos we take during the study for scientific and educational purposes, such as in journal publications and conference and class presentations.

WHAT IS THE PURPOSE OF THIS STUDY?
Clothing available for purchase may not target the needs of people with disabilities. The purpose of this study is for our team of fashion and rehabilitation professionals to work with participants to identify their key clothing needs and then design clothing that addresses one of those needs. The needs can relate to ease of dressing, fit, function, and/or appearance.

You will be one of approximately 40 participants in this study. You are being asked to participate because you have an identified disability and may have clothing needs that are not met by commercial clothing options. To participate: 1) you must not be in a hospital, prison, or an acute rehabilitative facility and you should not have open wounds, 2) you must agree to allow us to take photos and videos of you throughout the study and to share these photos and videos for publications, presentations, and other educational purposes, understanding that your facial features may be seen, 3) you must have physical and/or sensory needs that result in unique needs for clothing, and 4) you must have a clothing need that our team believes we have the resources to successfully meet. If you are pregnant and would like to participate in this study, you must provide us a note from your doctor stating that it is safe for you to participate.

WHAT WILL YOU BE ASKED TO DO?
If you take part in this study, you will first be asked to engage with the team to identify your clothing needs and to help design potential solutions for one key need. You can engage with our team through a medium of your preference, such as phone, Skype, or email. We will also obtain measurements from you. Depending on the clothing desired, the measurements will vary but could include measures such as height, weight, and arm length and circumference. Depending on your comfort level, our researchers can take these measurements or our

Participant's Initials
researchers can instruct you or someone you are comfortable with to take these measurements. Our initial engagement should require about 1-1½ hours.

You will then be asked to take part in 2-10 fittings lasting about 1-2 hours each over the course of 1-3 months. In most cases, 2-4 fittings will allow us to fabricate your clothing; but more complex clothing may require up to 10 fittings to allow for appropriate adjustments. At each fitting, photos and videos will be used to document how you are able to move in different positions you assume throughout your day. We will check with you before we take photos or videos to be sure you feel ready and comfortable for them. You can decide where you would like fittings to take place, for instance at our safe and comfortable space at the STAR campus at the University of Delaware or at your home.

When we have completed your clothing, you will keep it and we will contact you monthly for 3 months for your feedback on how often you have used the clothing and for your thoughts on how/whether it fits within your real life and ways you might suggest we improve it. These follow-up sessions can take place via a medium of your preference, such as phone, Skype, or email and will last about 30 minutes.

If you participate in this study, the total time commitment will be between 5 and 24 hours across 4-6 months. This will include time to complete a medical history questionnaire and questionnaires to gather information about your clothing preferences and your perceptions of the clothing we design.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?
One possible risk of participating in this research study is that you might feel uncomfortable having one of our team members take your body measurements. To maximize your comfort, we will offer you the opportunity to take your own measurements or to have a person you are comfortable with take the measurements and write them down to hand to the research team.

A second possible risk of participating in this research study is that you might feel uncomfortable changing your clothing around our team. To maximize your comfort, we will allow you to choose locations for fittings. In our research space, you can change in a private curtained changing area and we can exit the larger room at your request.

A third possible risk if you have movement or balance impairments, is that you could fail when changing clothing. To minimize this risk, we will ask you about the level of assistance, support, and supervision you typically require for safe dressing and we will ensure that same level of assistance, support, and supervision is provided to you during our fittings.

A fourth possible risk is that if the clothing fits poorly, it could rub your skin and cause redness or blistering. To minimize this risk, we ask that you report any
discomfort associated with wearing the clothing to us and we can try to fix the fit. If we cannot fix the fit, we will recommend that you discontinue wear of the clothing.

WHAT ARE THE POTENTIAL BENEFITS?
One potential benefit is that you will be active in the process of designing your own clothing that may meet your needs in ways that typical clothing may not.

Another potential benefit is that you will keep the final clothing at the end of the design process.

In addition, the design that emerges from your participation in this study may be beneficial for other people with similar clothing needs and we will work to make the design available to the broader community.

HOW WILL CONFIDENTIALITY BE MAINTAINED? WHO MAY KNOW THAT YOU PARTICIPATED IN THIS RESEARCH?
The results of this study may be presented and published. You will have the option below to select whether you would like to be mentioned by name as being an active member of the design team or whether you would like your identity to remain confidential, or only known to the research team. Because the designs that emerge from this study will be individualized solutions, we will likely report the results at the level of the individual. This could include your direct quotes and descriptions of your design process and results. You will remain confidential unless you select on this consent that you would like to be recognized.

If you select on this document that you would like your identity kept confidential, the confidentiality of your records will be protected to the extent permitted by law. Your research records may be viewed by the University of Delaware Institutional Review Board, which is a committee formally designated to approve, monitor, and review biomedical and behavioral research involving humans. Records relating to this research will be kept for at least five years after the research study has been completed. After 5 years, your name will be erased from paper and electronic data records.

To maintain confidentiality of data, data associated with your design will be identified using a numerical code that is assigned as your ID. A list linking participants’ IDs with their names will be kept in a secure database file that is password protected and stored on a password-protected computer in a locked lab. Electronic data files will be encrypted and stored on password-protected computers or on external hard drives that are stored in lockable cabinets in a lockable lab. Paper data will be stored in a lockable cabinet in a lockable lab. Data will be kept indefinitely but at least for 5 years after the study ends.
We must also let you know that if the primary participant is a child and during your participation in this study our research team was to observe or suspect, in good faith, child abuse or neglect, Delaware state law requires us to file a report to the appropriate officials.

WILL THERE BE ANY COSTS TO YOU FOR PARTICIPATING IN THIS RESEARCH?
The only associated cost with participating in this study is travel cost if you choose to have the fittings occur at the University of Delaware. There are no fees associated with parking for study participants.

WILL YOU RECEIVE ANY COMPENSATION FOR PARTICIPATION?
You will not receive any monetary compensation for participating in this study but you will receive the clothing we design and create for you.

DO YOU HAVE TO TAKE PART IN THIS STUDY?
Taking part in this research study is entirely voluntary. You do not have to participate in this research. If you choose to take part, you have the right to stop at any time. If you decide not to participate or if you decide to stop taking part in the research at a later date, there will be no penalty or loss of benefits to which you are otherwise entitled. Your decision to stop participation, or not to participate, will not influence current or future relationships with the University of Delaware.

The researchers may choose to terminate your participation in this study if, despite our team’s best efforts, we cannot create a design that addresses your needs.

If, at any time, you decide to end your participation in this research study, please inform our research team by telling the investigator.

WHO SHOULD YOU CALL IF YOU HAVE QUESTIONS OR CONCERNS?
If you have any questions about this study, please contact the Principal Investigators, Michele Lobo, at (302) 831-8526 or malobo@udel.edu, or Martha Hall, at (302) 831-3214 or mihucinda@udel.edu.

If you have any questions or concerns about your rights as a research participant, you may contact the University of Delaware Institutional Review Board at hsrc-research@udel.edu or (302) 831-2137.
CONSENT FOR ADULT INVOLVEMENT OR PARENT INVOLVEMENT

Your signature on this form means that: 1) you are at least 18 years old; 2) you have read and understand the information given in this form; 3) you have asked any questions you have about the research and the questions have been answered to your satisfaction; 4) you accept the terms in the form and volunteer to participate in the study; and 5) you voluntarily give permission to the researchers in this study to use videos and photographs of you and/or your child collected as part of this research study for educational purposes, including journal publications, conference presentations, and lectures, understanding that your facial features and/or those of your child will not be masked and may be seen but no identifying information beyond that contained in the videos and photos will be provided to educational/scientific audiences if you choose below to not be identified by name. You will be given a copy of this form to keep.

Note: This is the section you will sign if you consent to participate in this study as an adult or if you consent to participate in this study as a parent along with your child as the primary participant.

\[\text{Printed Name of Participant}\]  \[\text{Signature of Participant}\]  \[9/13/18\]  \[Date\]

\[\text{Printed Name of Person Obtaining Consent}\]  \[\text{Signature of Person Obtaining Consent}\]  \[\text{Date}\]

\[\text{Participant’s Initials}\]
CONSENT FOR CHILD INVOLVEMENT (IF APPLICABLE)

If you are making a decision whether or not to have your child participate in this study, your signature below indicates that you have read the information provided above and have decided to allow your child to participate and that you voluntarily give permission to the researchers in this study to use videos and photographs of your child collected as part of this research study for educational purposes, including journal publications, conference presentations, and lectures, understanding that your child’s facial features will not be masked and may be seen but no identifying information beyond that contained in the videos and photos will be provided to educational/scientific audiences if you choose below to not have your child identified by name.

Printed Name of Parent/Guardian   Signature of Parent/Guardian   Date

The following consents are optional, meaning you can still participate in the study regardless of your choices below. If at any point throughout the research process, you would like to change your preferences for these optional consents, please inform the researchers and you can complete a Change of Optional Request Form to reflect your new preferences.

OPTIONAL CONSENT TO HAVE YOUR NAME IDENTIFIED AS PART OF THE DESIGN TEAM - ADULT

Because we anticipate that you will play an active role in the design process, please let us know if you would like to be identified by name when we list the members of the design team, such as in publications, on-line, and at speaking events. Please write your initials next to your preferred choice.

_____ YES  _____ NO

Participant’s Initials

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OPTIONAL CONSENT TO HAVE YOUR NAME IDENTIFIED AS PART OF THE DESIGN TEAM - CHILD

Because we anticipate that your child will play an active role in the design process, please let us know if you would like your child to be identified by name when we list the members of the design team, such as in publications, on-line, and at speaking events. Please write your initials next to your preferred choice.

[ ] YES [ ] NO

OPTIONAL CONSENT FOR PHOTOS AND VIDEOS TO BE SHARED FOR COMMUNITY OUTREACH

A key purpose of this research is to design solutions that not only help the participants but may be useful to others with similar needs. This will be done through means such as educational brochures, do-it-yourself manuals, and on-line tutorials. Please write your initials next to your preferred choice.

[ ] YES, you can share the photos and videos unaltered

[ ] YES, but I prefer you share the photos and videos with faces masked

[ ] NO, I prefer you not share photos and videos for these purposes.

OPTIONAL CONSENT TO BE CONTACTED FOR FUTURE STUDIES

Do we have your permission to contact you regarding participation in future studies? Please write your initials next to your preferred choice.

[ ] YES [ ] NO

OPTIONAL CONSENT TO BE CONTACTED FOR POTENTIAL PARTICIPATION IN EDUCATIONAL AND COMMUNITY EVENTS

Do we have your permission to contact you to invite you to participate in educational and community events where we highlight the designs that emerge from this study. Please write your initials next to your preferred choice.

[ ] YES [ ] NO

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Participant's Initials [Signature]
C.1.4 Design Assent Form
ASSENT TO PARTICIPATE IN RESEARCH

Title of Project: Clothing Design for Individuals with Adaptive Clothing Needs

Investigator(s): Michele Lobo, PT, PhD, Martha Hall, MS

I am asking if you want to be part of a research study. This form tells you what the study is about, what you will be asked to do if you want to be in the study, and the possible bad and good things about this study. Please read this paper and ask us any questions you have.

It is important to know that to participate in this research you must agree to let us take photos and videos of you at our visits and to let us share these with other scientists, teachers, and students.

WHAT IS THE PURPOSE OF THIS STUDY?
This research study is to see if we can work with you to design and make you some clothing that works better for you than the clothing you can find at typical stores. We want to make some clothing for you that is easy to put on and take off, fits well, is comfortable, and looks good to you.

We are asking you if you want to be in the study because you or someone you know has told us typical clothing does not always best meet your needs. We are looking for a total of 40 people to be in this study.

WHAT WILL YOU BE ASKED TO DO?
If you want to participate, we will ask you to talk with us to tell us what you do and do not like about your clothing. We will also ask that you let us or someone you know measure you so we know what size to make your clothing. We will decide together what is most bothersome to you about your clothing and we will work to try to make clothing that solves this problem and that looks and feels nice for you. We will do this by meeting 2-10 times for ½ to 2 hours each time over 1-3 months. We can meet at a place you and your family decide is most convenient and comfortable for you. This might be at your house or at our studio at the University of Delaware. When we meet, you can try on the clothing to see how you like it. We will make any needed changes and meet again until the clothing fits you well. Then you will get to keep the clothing and we will contact you to see if you use it and what you think of it.

WHAT ARE THE POSSIBLE BAD THINGS ABOUT THIS RESEARCH?
You may feel shy or uncomfortable giving us your body measurements or changing your clothes in this study. If you have trouble balancing, you could get hurt if you fall down when you are changing. We will work to keep you safe and comfortable by having you choose who will take your measurements, having you change clothing in a private area, and by making sure you have someone to help you change if you need that help.

Page 1 of 3
Participant’s Initials LMK
WHAT ARE THE POTENTIAL GOOD THINGS ABOUT THIS RESEARCH?
Potential good things about this research are that you will get to keep the clothing you help us design and that we will hopefully create clothing ideas that will also help other people.

WHO MAY KNOW THAT YOU PARTICIPATED IN THIS RESEARCH?
You can decide who will know that you were in this study by telling us below. If you prefer other people not know, only our research team will know. If you prefer people know you participated and helped design your clothing ideas, you can choose for us to share your name as a member of your design team.

We will take pictures and video of you during our meetings so we can see how the clothing fits and how you move when wearing the clothing. We will share these pictures and video with other people when we talk about this research.

We also must let you know that if you tell us that someone has done or is doing bad things to you or other children, we will tell people who can help.

WILL YOU RECEIVE ANY COMPENSATION FOR PARTICIPATION?
As a thank you for participation, you will get to keep the clothing we make you.

CAN YOU CHANGE YOUR MIND ABOUT BEING IN THE STUDY?
You do not have to say yes to being in this study. Taking part in this research is up to you. If you choose to take part, you can change your mind and stop at any time. If you decide not to participate or if you decide to stop taking part in the research later, nothing bad will happen to you and no one will be upset with you. If, at any time, you decide to stop, please let us know by telling one of the researchers.

Page 2 of 3
Participant’s Initials
WHO SHOULD YOU CALL IF YOU HAVE QUESTIONS OR CONCERNS?

If you have any questions about this study, please ask Michele Lobo at (302) 831-8526 or malobo@udel.edu or Martha Hall at (302) 831-3214 or mlucinda@udel.edu.

If you have any questions or concerns about your rights as a research participant, you may contact the University of Delaware Institutional Review Board at (302)831-2137 or harb-research@udel.edu.

If you want to participate in the research and we have answered all of your questions about it, please sign your name below.

<table>
<thead>
<tr>
<th>Printed Name of Participant</th>
<th>Signature of Participant</th>
<th>Date</th>
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<tbody>
<tr>
<td>Laura Kelly</td>
<td>Laura Ken</td>
<td>9/13/18</td>
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<th>Printed Name of Person Obtaining Consent</th>
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C.2 Aim Two Consent Forms

C.2.1 Consent Form for Able-Bodied and Caregiver Participants
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Study: Interviewing individuals about wearable products and/or devices preferences and perspectives.

Principal Investigator(s): Martha L. Hall, PhD

KEY INFORMATION

Important aspects of the study you should know about first:

- **Purpose**: The purpose of this study is to better understand consumer and industry preferences and perspectives of wearable products, including clothing and assistive devices.
- **Procedures**: If you choose to participate, you will be asked to participate in an in-person interview session at a location convenient to you.
- **Duration**: This will take about 30 minutes to complete.
- **Risks**: The main risk or discomfort from this research is you may be uncomfortable sharing your opinions.
- **Benefits**: There are no direct benefits from participating in this study.
- **Alternatives**: There are no known alternatives available to you other than not taking part in this study.
- **Costs and Compensation**: If you decide to participate there will be no additional cost to you.
- **Participation**: Taking part or not in this research study is your decision. You can decide to participate and then change your mind at any point

Please carefully read the entire document. You can ask any questions you may have before deciding if you want to participate.

You are being invited to participate in a research study. This consent form tells you about the study including its purpose, what you will be asked to do if you decide to take part, and the risks and benefits of being in the study. Please read the information below and ask us any questions you may have before you decide whether or not you want to participate.

**PURPOSE OF THE STUDY**
The purpose of this study is to better understand consumer and industry preferences and perspectives of wearable products, including clothing and assistive devices.

WHO IS BEING ASKED TO PARTICIPATE?

You will be one of approximately 150 participants in this study.

You are being asked to participate because you have experience relating to wearable products and/or devices. Experience can include production and manufacturing knowledge, experience in usage, or professional care knowledge. To participate you cannot be confined to a prison, hospital, or in acute rehabilitative care. You must also be able and willing to be interviewed by a researcher.

PROCEDURES: WHAT WILL YOU BE ASKED TO DO?

As part of this study you will be asked to answer a short series of questions. These questions will be regarding 1) preferences toward wearable products and/or devices 2) perspectives of using wearable products and/or devices. Preferences can include frequency of use, style comparison, or strengths and weakness of wearable products and/or devices. Perspectives can include attitudes toward wearable products and/or devices. You have the right to refuse to answer any question(s) during the interview.

You will have an initial contact with the researcher by phone, email, video call, or in person to discuss your preference for interview setting. Interviews can take place at the University of Delaware, in a residence, or at a selected location, depending on your availability and preference. You will be asked a short series of questions with opportunities for further discussion or follow-up questions, if necessary. The interview should last approximately 30 minutes.

The interviewer will be a member of our research team and may be accompanied by an undergraduate student or other member of our lab. You may decline the presence of additional personnel if preferred at the initial contact. We will audio record the interview for transcription purposes.

If you participate in this study, the total time commitment will be less than one hour, including initial contact. There are no known alternatives available to you other than not taking part in this study.

WHAT ARE POSSIBLE RISKS AND DISCOMFORTS?

Possible risks of participating in this research study include feeling uncomfortable when answering questions about wearables and devices perceptions and perspectives. To minimize this risk, interview questions are worded broadly and you may answer the questions according to your comfort level. You may also refuse to answer any question(s).
There is no risk of physical injury during participation in the study other than those one would encounter in daily life.

WHAT ARE POTENTIAL BENEFITS FROM THE STUDY?

You will not benefit directly from taking part in this study. However, the knowledge gained from this study may contribute to our understanding of perceptions and perspective of wearables and devices. Information from this study may be used to guide future research projects and programs.

NEW FINDINGS THAT COULD AFFECT YOUR PARTICIPATION

During the course of this study, we may learn new important information. This may include information that could cause you to change your mind about participating in the study. If any new important information becomes available while you are a participant we will let you know.

CONFIDENTIALITY: WHO MAY KNOW THAT YOU PARTICIPATED IN THIS RESEARCH?

Participants' identity will be kept confidential. The confidentiality of participant records will be protected to the extent permitted by law. Research records may be viewed by the University of Delaware Institutional Review Board, which is a committee formally designated to approve, monitor, and review biomedical and behavioral research involving humans. Records relating to this research will be kept for at least three years after the research study has been completed.

To maintain your confidentiality, participants will be assigned a numerical code within the study for ID purposes. Interview data will be stored electronically on password-protected computers in a locked lab. A list linking participants' IDs with their names will be kept in a secure database file that is password-protected and stored in a password-protected computer in a locked lab. Paper data will be stored in a locked cabinet in a locked lab. Data will be kept indefinitely but at least for five years after the study ends.

We also must let you know that if during your participation in this study our research team was to observe or suspect, in good faith, child abuse or neglect, we are required by Delaware state law to file a report with the appropriate officials.

The confidentiality of your records will be protected to the extent permitted by law. Your research records may be viewed by the University of Delaware Institutional Review Board, which is a committee formally designated to approve, monitor, and review biomedical and behavioral research involving humans. Records relating to this research will be kept for at least three years after the research study has been completed.

COSTS AND COMPENSATION

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I/C Form Rev. 01/2019
The only associated cost with participating in this study is travel cost if you choose to have the interview occur at the University of Delaware. There are no fees associated with parking for study participants.

You will not receive any monetary compensation for participating in this study.

**DO YOU HAVE TO TAKE PART IN THIS STUDY?**

Taking part in this research study is your decision. You do not have to participate in this research. If you choose to take part, you have the right to stop at any time. If you decide later not to participate, or if you decide to stop taking part in the research, there will be no penalty or loss of benefits to which you are otherwise entitled. Your decision to stop participation, or not to participate, will not influence current or future relationships with the University of Delaware.

**INSTITUTIONAL REVIEW BOARD**

This research study has been reviewed and approved by the University of Delaware Institutional Review Board (UD IRB). If you have any questions or concerns about your rights as a research participant, you may contact the UD IRB at hrsb.research@udel.edu or (302) 831-2137.

**CONTACT INFORMATION**

If you have any questions about the purpose, procedures, or any other issues related to this research study you may contact the Principal Investigator Martha L. Hall, at (302) 831-3935 or mlucinda@udel.edu.
CONSENT TO PARTICIPATE IN THE RESEARCH STUDY:

I have read and understood the information in this form and I agree to participate in the study. I am 18 years of age or older. I have been given the opportunity to ask any questions I had and those questions have been answered to my satisfaction. I understand that I will be given a copy of this form for my records.

Catherine Canill
Printed Name of Participant
(PRINTED NAME)

Signature of Participant
(SIGNATURE)

3/20/19
Date

Person Obtaining Consent
(PRINTED NAME)

Person Obtaining Consent
(SIGNATURE)

OPTIONAL CONSENT TO BE CONTACTED FOR FUTURE STUDIES:

Do we have your permission to contact you regarding participation in future studies? If you agree to being contacted in the future, we will keep your contact information. Please write your initials next to your preferred choice.

C T C YES NO
C.2.2 Consent Form for Participants Living with Down syndrome
INFORMED CONSENT TO PARTICIPATE IN RESEARCH

Title of Project: Interviewing Individuals with Motor or Sensory Impairment About Challenges with Daily Activities

Principal Investigator(s): Martha L. Hall, MS & Michele A. Lobo, PT, PhD

You and/or the person in your care are being invited to participate in a research study. This consent form tells you about the study including its purpose, what you will be asked to do if you decide to take part, and the risks and benefits of being in the study. Please read the information below and ask us any questions you may have before you decide whether or not you agree to participate.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to better understand the functional challenges faced by individuals with motor and/or sensory impairment during daily activities. Challenges could be related to personal care, independence, or social activities.

You and/or the person in your care will be one of approximately fifty participants in this study. You are being asked to participate because either you or someone in your care has a motor and/or sensory impairment. To participate you and/or the person in your care must not be confined to a prison, hospital, or in acute rehabilitative care. You must also be able and willing to be interviewed by a researcher.

WHAT WILL YOU BE ASKED TO DO?

As part of this study you will be asked to answer a short series of questions. These questions will be regarding (1) challenges with typical daily activities, (2) use of devices related to assistance with daily activities, and (3) current challenges and preferences related to clothing. Challenges with daily activities could be in terms of personal self-care, interacting with objects, activities promoting independence, or the ability to engage in social activities. Challenges with typical clothing could be ease of dress/undressing, comfort, fit, appearance, and/or functionality. You have the right to refuse to answer any question(s) during the interview.

You will have an initial contact with the researcher by phone, email, Skype or in person to discuss your preference for interview setting. Interviews can take place at the University of Delaware, in a residence, or at a selected location, depending on your availability and preference. You and/or the person in your care will be asked a short series of questions with opportunities for further discussion or follow-up questions, if necessary. The interview should last approximately 30 minutes.

The interviewer will be member of our research team and may be accompanied by an undergraduate student or other member of our lab. You or the person in your care may decline the presence of additional personnel if preferred at the initial contact. We will audio record the interview for transcription purposes.

If you and/or the person in your care participate in this study, the total time commitment will be less than one hour, including the initial contact.

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Participant's Initials
WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

Possible risks of participating in this research study include feeling uncomfortable describing your impairment, daily challenges, device use, and/or clothing preferences. To minimize this risk, interview questions are worded broadly and may answer the questions according to the comfort level of the participant. You and/or the person in your care may also refuse to answer any question(s).

WHAT IF YOU ARE INJURED DURING YOUR PARTICIPATION IN THE STUDY?

There is no risk of injury during participation in the study other than those one would encounter in daily life.

WHAT ARE THE POTENTIAL BENEFITS?

You and/or the person in your care will not benefit directly from taking part in this study. However, the knowledge gained from this study may contribute to our understanding of the needs of individuals with motor and/or sensory impairment. Information from this study may be used to guide future research projects and programs.

NEW INFORMATION THAT COULD AFFECT YOUR PARTICIPATION:

During the course of this study we may learn new information that could be important to you and/or the person in your care. This may include information that could cause you and/or the person in your care to change your mind about participating in the study. We will notify you as soon as possible if any new information becomes available.

HOW WILL CONFIDENTIALITY BE MAINTAINED? WHO MAY KNOW THAT YOU PARTICIPATED IN THIS RESEARCH?

Participants' identity will be kept confidential. The confidentiality of participant records will be protected to the extent permitted by law. Research records may be viewed by the University of Delaware Institutional Review Board, which is a committee formally designated to approve, monitor, and review biomedical and behavioral research involving humans. Records relating to this research will be kept for at least three years after the research study has been completed.

To maintain your confidentiality, participants will be assigned a numerical code within the study for ID purposes. Interview data will be stored electronically on password-protected computers in a locked lab. A list linking participants' IDs with their names will be kept in a secure database file that is password-protected and stored in a password-protected computer in a locked lab. Paper data will be stored in a locked cabinet in a lockable lab. Data will be kept indefinitely but at least for five years after the study ends.

We also must let you know that if during your participation, and/or the participation of the person in your care, in this study our research team was to observe or suspect, in good faith, child abuse or neglect, we are required by Delaware state law obligates us to file a report to the appropriate officials.

Page 2 of 5

Participant's Initials: [Signature]
USE OF DATA COLLECTED FROM YOU IN FUTURE RESEARCH:

The research data we will be collecting from you and/or the person in your care during participation in this study may be useful in other research studies in the future. Your choice about future use of your data will have no impact on participation in this research study. Do we have your permission to use in future studies data collected from you and/or the person in your care? Please write your initials next to your preferred choice.

✓ YES  ____ NO

WILL THERE BE ANY COSTS TO YOU FOR PARTICIPATING IN THIS RESEARCH?

The only associated cost with participating in this study is travel cost if you choose to have the interview occur at the University of Delaware. There are no fees associated with parking for study participants.

WILL YOU RECEIVE ANY COMPENSATION FOR PARTICIPATION?

You and/or the person in your care will not receive any monetary compensation for participating in this study.

DO YOU HAVE TO TAKE PART IN THIS STUDY?

Taking part in this research study is entirely voluntary. You and/or the person in your care do not have to participate in this research. If you choose to take part, you have the right to stop at any time. If you and/or the person in your care decide not to participate or if you decide to stop taking part in the research at a later date, there will be no penalty or loss of benefits to which you are otherwise entitled. A decision to stop participation, or not to participate, will not influence current or future relationships with the University of Delaware.

If, at any time, you and/or the person in your care decide to end participation in this research study, please inform our research team by telling the investigator.
WHO SHOULD YOU CALL IF YOU HAVE QUESTIONS OR CONCERNS?

If there are any questions about this study, please contact the Principal Investigators, Martha L. Hall at 302-831-8666 or mlucinda@udel.edu or Michele A. Lobo, at 302-831-8526 or malobo@udel.edu.

If there are any questions or concerns about your rights as a research participant, you may contact the University of Delaware Institutional Review Board at hsrc-research@udel.edu or (302) 831-2137.

CONSENT FOR ADULT INVOLVEMENT OR PARENT INVOLVEMENT

Your signature on this form means that: 1) you are at least 18 years old; 2) you have read and understand the information given in this form; 3) you have asked any questions you have about the research and the questions have been answered to your satisfaction; and 4) you accept the terms in the form and volunteer to participate in the study. You will be given a copy of this form to keep.

Printed Name of Participant ______________________ Signature of Participant ______________________ Date __________

Person Obtaining Consent ______________________ Person Obtaining Consent ______________________ Date __________

(PRINTED NAME) ______________________ (SIGNATURE) ______________________

CONSENT FOR CHILD INVOLVEMENT (IF APPLICABLE)

You are making a decision whether or not to have your child participate in this study. Your signature indicates that you have read the information provided above and decided to allow your child to participate.

Gwynn Gibbons for Rebecca Gibbons 3/18/19

(Printed Name of Parent/Guardian) ______________________ (Signature of Parent/Guardian) ______________________ (Date) __________

Person Obtaining Consent ______________________ Person Obtaining Consent ______________________ Date __________

(PRINTED NAME) ______________________ (SIGNATURE) ______________________

Participant's Initials __________
CONSENT FOR ADULTS WITH CAREGIVER INVOLVEMENT (IF APPLICABLE)

You are making a decision whether or not to have an adult under your care participate in this study. Your signature indicates that you have read the information provided above and decided to allow the adult under your care participate.

(Printed Name of Caregiver)  (Signature of Caregiver)  (Date)

Person Obtaining Consent  Person Obtaining Consent  Date
(PRINTED NAME)  (SIGNATURE)

OPTIONAL CONSENT TO BE CONTACTED FOR FUTURE STUDIES:

Do we have your permission to contact you regarding participation in future studies? Please write your initials next to your preferred choice.

✓ YES  ● NO

OPTIONAL CONSENT FOR AUDIO RECORDING TO BE SHARED WITH EDUCATIONAL AUDIENCES:

Do we have your permission to share portions of your audio-recorded interview with educational audiences? Please write your initials next to your preferred choice.

✓ YES  ● NO

Participant’s Initials  

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