

# Imagine

S  
C  
H  
O  
O  
L  
  
O  
F  
  
P  
U  
B  
L  
I  
C  
  
H  
E  
A  
L  
T  
H



BROWN



# Imagine

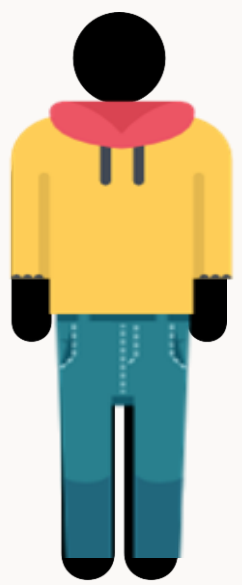


BROWN

S  
C  
H  
O  
O  
L  
O  
F  
P  
U  
B  
L  
I  
C  
H  
E  
A  
L  
T  
H



# People With Disabilities (PWDs)



BROWN



# Marginalized Consumers: Exploring Disability, Body Image, and Clothing Consumption



Presentation by Krystal Sarcone

BROWN



# Introduction

## Focus Area

- “Adaptive Attire”
  - A.K.A.
    - Disability Clothing
    - Adaptive Apparel

## Essentially:

- Modified for easier use
- Initial design intentional



BROWN



# Inspiration

1. Personal Experience
2. Background in Clinical Research in Orthopedics.

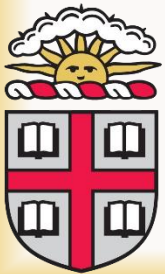
## Specialty Deformity

- Scoliosis
- Wheel-Chairs
- Missing Limbs
- Dwarfism
- Other Genetic Abnormalities



BROWN





BROWN



# Observations



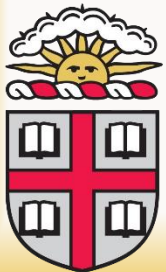


# Goals and Process

## Qualitative Course Project Master's Thesis for MPH

### Objectives for this project:

- Formative Research
- Gain Insight & Qualitative Data to Back Observations



BROWN

---



# Selection Criteria / Target Population

3 Major Categories of Body Modifiers

Significant  
Deformity



Wheelchair  
Users



Amputees



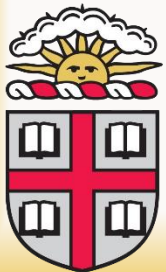
BROWN



# Thesis Eligibility

Eligibility to participate in the interviews met the following criteria:

- English proficiency, enough to feel comfortable conducting the interview in English;
- Access and the ability to conduct the interview via phone, skype, in-person, or text-chat-platform;
- 18 years of age
- Have a body modifier that falls into one of four major categories:
  - Currently diagnosed or have visible and significant anatomical curvature such as severe scoliosis;
  - Be a wheelchair user;
  - Has had any major amputation, includes all foot and above or below elbow or knee;
  - Self-identifies as having a condition or ailment (chronic or acute) that impacts their personal engagement with clothing consumption and use



BROWN



# Developing Interview Guide

## Grand Tour Questions:

### 1) Why don't we begin with you sharing how you think about clothing?

*-What feelings come up when thinking about, planning for, or wearing different styles of clothing such as casual/every day wear, cocktail party, formal occasions, business meeting etc.*

*-In your own words, what would you say you're looking for in clothing? What qualities or attributes are preferred or necessary?*

*--What about comfort? Access? Style? Fit? Function? Ability to put on or take off?*

### 2) Tell me how you go about getting clothing?

*-Where do you do most of your clothing shopping?*

*--What makes online shopping easier/harder?*

*-You did(not) mention tailoring?*

*--Do you have your clothing tailored? If so, by who/where?*

*--What sort of additional expenses arise with needing clothing altered?*

*-I would love to hear more about certain brands or stores you prefer?*

*--What is it about that brand/store that better meets your preferences?*



BROWN



# Recruitment

1. Personal Network + Referrals & Snowball Effect
2. Social Media & National Organizations
3. Institution Listserv

Looking for Interviewees

Sarcone, Krystal <krystal\_sarcone@brown.edu>  
to GSBB-L

Apr 18 (7 days ago)

Dear GSBB,

I am doing a qualitative project for my master's program regarding what I call "adaptive attire." Essentially I am interested to gain insight on what limitations and challenges are faced by people with non-mainstream body shapes, which includes amputees, individuals in wheelchairs and even those with significant deformity.

My inspiration and interest originated during my work for a medical nonprofit in which I engaged with hundreds of kids with severe spine curvatures and genetic abnormalities. Many of them were in wheelchairs, had an extremely short stature, or were missing limbs. As I thought more about how they used or avoided certain clothing options and seemed limited by what was typically available in the industry of clothing, my thoughts extended to amputees.

Right now I am conducting interviews with people to gain insight to something I only have observational and anecdotal information on. The interview could be in person or over the phone and may take between 45 min to an hour. Additionally, though data is collected and the interview is recorded, all data is de-identified and recordings are destroyed after being transcribed.

Please feel free to contact me directly if you are, or know someone, that may be interested!

Thanks!



BROWN

## Adaptive Attire

Does clothes shopping stir up frustration?



Do you wish you had more fashionable options that fit your body?



Do manikins fall short of representing your figure?



Approx 45min

## Share Your Story

Graduate Student Looking For Interviewees!

100% Confidential

Contact: Krystal Sarcone

Email: AdaptiveAttire@Brown.Edu

Tele: (914) 960-0522

Conducted over the phone!



# Interviews

	Participant 1	Participant 2	Participant 3
<b>Recruited</b>	Social Media- Amputee Coalition of America Facebook Group	Personal Network	Brown University Graduate Listserv
<b>Body Variance</b>	“Short R Arm” Since Birth	Bilateral leg Amputee. 1 AK* & 1BK** Since Jan 2015	Left Leg Amputee At Hip. Since 7 years old.
<b>Age &amp; Gender</b>	25   female	32   female	50   female
<b>Via</b>	Phone	Phone	In-Person
<b>Length</b>	32min	36min	28min

\*Above-Knee  
\*\*Below Knee



BROWN

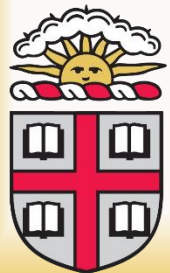


# Thesis Research Table 1

**Table 1.** Characteristics of participants in the sample (n=20).

<b>Characteristic</b>	<b>Number</b>
<b><i>Country of Residence</i></b>	
USA	17
United Kingdom	2
Burkina Faso	1
<b><i>Gender</i></b>	
Female	15
Male	5
<b><i>Age</i></b>	
18-29	8
30-45	4
45+	8
<b><i>Disability</i></b>	
Wheelchair User	12
Amputee	3
Scoliosis	3
Other	2
<b><i>Recruited Via</i></b>	
Social Media	10
Personal Network	5
Referral/Snowball	4
Listserv	1
<b><i>Method of Interview</i></b>	
Phone	13
Video Chat	5
Text Chat	1
In-Person	1


- April 2016 until January 2017.
- Interviews were conducted in the English language.
- 17 and 71 minutes

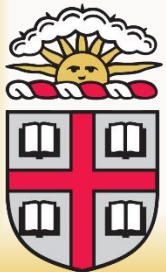


BROWN



# Analysis

- Transcribed Interviews
- Coded in NVivo 
- Assessed for Prevailing Themes
- Maintained Audit Trail



BROWN

---

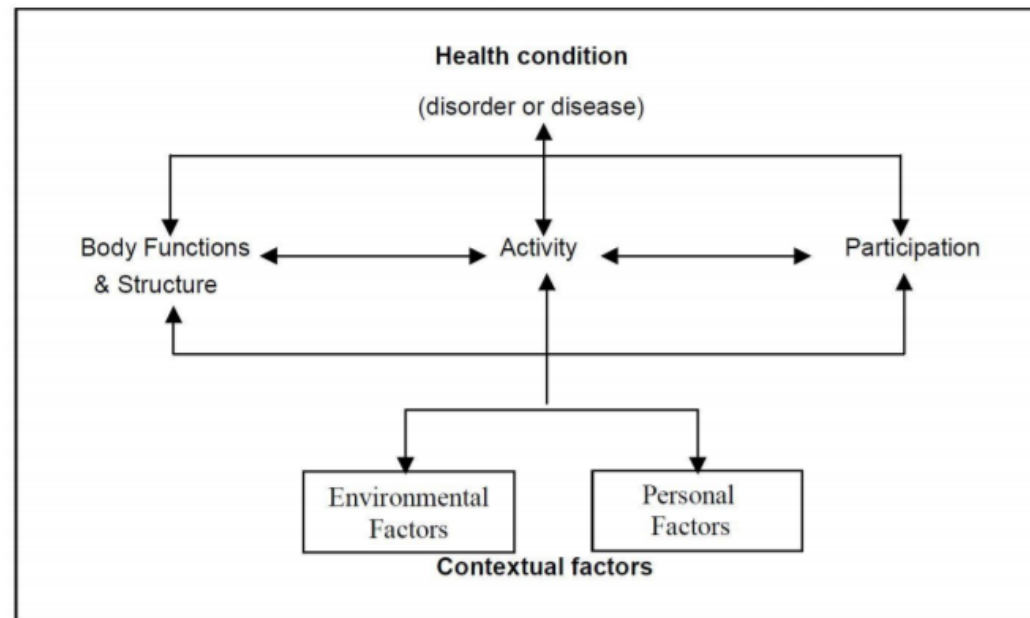




# Theoretical Framework

- Medical Model
- Social Model
- ICF

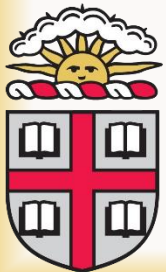
**Illustration 1:** Interactions between the components of ICF (WHO, 2002 p. 9)



## Theme 1: Participants express disappointment in the style, availability and pricing options of current adaptive attire available

Zoe (all names are pseudonyms), a community activist, thinks about footwear with her prosthetic feet in mind. She even mentions that her old shoes (prior to her recent bilateral lower limb amputation) do not fit her prosthetic feet. The following quote reveals additional frustration of design and style with adaptive footwear:

- *“They make diabetic-like shoes for people to wear, for like amputees or anybody that has any kind of muscular issue or whatever, but those are really ugly. They’re bulky and they’re ugly and they don’t go with anything, they clash with every single thing you want to wear. It doesn’t look good with anything. It’s like why would I just want those? I don’t just want those. I want to wear whatever I want to wear on my feet.”*



BROWN



*Theme 1a: Participants share that they want inclusive designs to be integrated with current clothing brands and venues*

In commenting on the universal applicability of adaptive attire, Roberta, diagnosed with cerebral palsy and a wheelchair user, also talks about the stigma associated with disability, and the branding of adaptive attire.

- “I just wish that they could make it more adaptable, more without it being labeled as “adaptive clothing.” I mean, even able-bodied people probably struggle with some of these issues, so it would be useful. There's so many stigmas.”*



BROWN

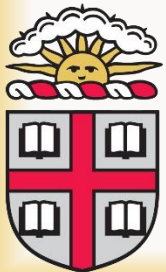
---



*Theme 3a: Participants desire clothing that meets their functional needs*

Clyde, a scuba diving aficionado and wheelchair user, speaks to a different functional need from his clothing. Cautious of injury, zipper placement, and inseam lengths factor into his clothing selection and purchase.

- *“In clothing, one thing I am conscious of [is] am I going to be able to catheterize myself and if I’m not able to pull them down far enough to either to catheterize, that’s something that I’d be conscious of. I would definitely take clothes back if they’re going to do that. So when I’m looking at it, I have to make sure if it’s a zipper, that when I pull my penis out or something I’m not going to be cutting myself on zippers or pinching the body, or cutting myself every step.*



BROWN

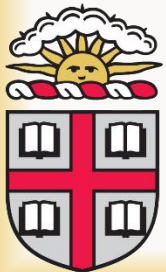
---



## *Theme 3b: Functional clothing is a mediator for autonomy*

Michael, a wheelchair user with hand dexterity limitations, also shares his experience choosing clothing by considering if he'll be able to manage with it on his own, and how that plays a role in his decision making process.

- *“When I am looking at clothing ... I'm thinking what is gonna be the easiest for me to deal with by myself. Which for me entails that I'm normally looking for something, like you said, with elastic waistband and sometimes I really like the joggers cause they got the elastic around the ankles. That way my pants aren't like getting wrapped up in my shoes or possibly in my wheels or things like that.... Because sometimes it will hinder me, like, especially if it's like, using the bathroom, or dealing with it myself, and then it would require me laying out [rather than] just being able to fix it in my chair.”*



BROWN



## Skipped Themes

**Theme 2:** In addition to disability-related needs and challenges, participants also reported clothing frustrations unrelated to attributes of their disability, e.g. Shoulders & Tall

**Theme 3:** Clothing plays an intimate role with all three aspects of the International Classification of Functioning, Disability and Health (ICF)

### Activity and Participation

- Theme 3c: “Fitting in” is a major concern for PWDs
- Theme 3d: The professional environment creates additional clothing challenges

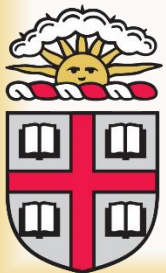
### Contextual Factors

#### *Environmental Factors*

- Theme 3e: Return policies are deciding variables for PWD apparel consumption
- Theme 3f: PWDs do not encounter truly accessible retail environments

#### *Personal Factors*

- Theme 3g: PWDs use clothing as a major way to convey aspects of identity
- Theme 3h: Participants report positive body image

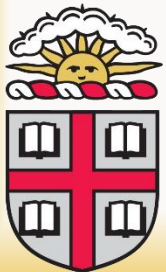


BROWN



# Limitations

- Sampling Methods, e.g. social media heavy
- Diversity of Sample
  - (-) Gender Balance
  - (-) Diagnosis/Disability
- Language
  - English Only
- Recall Bias



BROWN



# Discussion & Recommendations

- Further **qualitative and quantitative** research on adaptive attire
- Further research regarding use and preference for **non-prosthetic solutions**.
- Beyond **disability inclusivity** in fashion week... offer adaptive apparel for **current brands**.
- **Private sector** solutions.



BROWN





# Final Thoughts

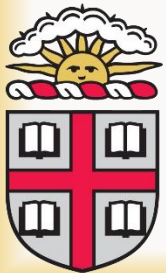
- Innovative, cost-effective, and simple modifications and designs are not only feasible but are:
  - 1) a prerequisite for societal engagement;
  - 2) critical to the opportunity to dress the part and invest in one's body image;
  - 3) central to participation in normalcy, and;
  - 4) long overdue for the largest minority population in the USA.

Today's clothing market of ready-made apparel fails to meet the needs of all its consumers. In some respects, this is an understandable challenge. However, with ample research, technological advances in garment design and construction, and the mere diversity of our global population, the perpetual exclusion of adaptive apparel in the clothing market facilitates the continued marginalization of millions of consumers.



BROWN





BROWN

