Report

Living in Limb-o

re-imagining the world as if it was built keeping in mind individuals with limb loss & difference

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Photo courtesy of workshop participant 1

Significance of the Project

Of the 332 million people in the US, 2.1 million (as of 2017 according to the Amputee Coalition) live with limb loss or limb difference and a whopping 28.1 million are at-risk of amputation. This number is expected to balloon to 3.6 million by 2050 (Zieger-Graham et al., 2008). Every year, approximately 1 in 1,900 babies born in the U.S. are born with a congenital limb difference. In addition to daily life struggles, they live and function in a world predominantly designed for the non-disabled masses.

Living in Limb-o re-imagines the world as if it was built keeping in mind individuals with limb loss, limb difference or limb deficiency. This should help pave the way for normalising conversation around this topic and reduce stigma. Moreover, it will help raise awareness and convert those without limb loss or difference into allies.

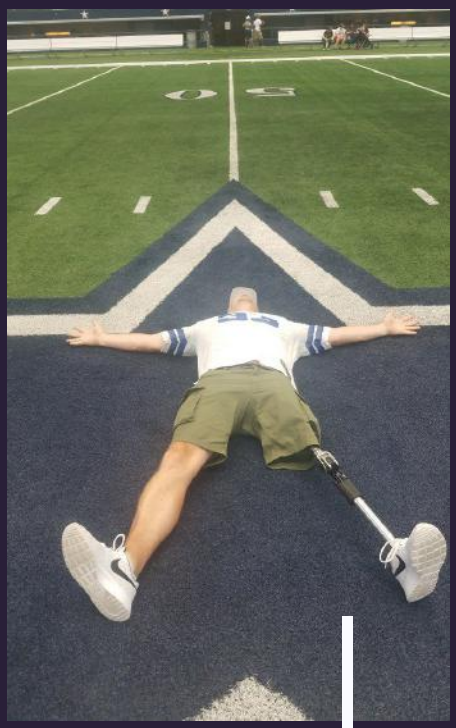
By starting a dialogue, individuals without limb loss or difference can act as allies to help repair and renew our deficit society.

Inspiration for the Project

This project was inspired by an Instagram video posted by Josh Sundquist, a paralympian based in California, whose left leg was amputated at age nine. In the video, he recounts how he found his "sole mate" (an amputee on the opposite leg) in the same city who shares his shoe size and preference. Since meeting online in 2011, Josh and Stephen have been splitting shoes.

Watching this video was an eye-opening experience. Despite being a designer and self-proclaimed empath, I had never given this a thought, a conundrum staring me right in my face. Individuals with lower limb loss might need a single shoe but have to buy two because that is the default.

Vision Statement



Photos courtesy of workshop participant 1

The anticipated outcome is two-fold: help those with limb loss and sensitise those without.

This project started off with an idea to build (yet another) app to match individuals with limb loss or difference so they could find others like themselves nearby to swap shoes with. Secondary research unearthed a much more complex and disconcerting state of affairs. What started as an app design project soon pivoted into a re-imagination exercise. It is rooted in Maxine Greene's *Social Imagination*, which is both a call for action and an artful movement (***Guyotte, 2018***). *Living in Limb-o* is tackling a systemic issue. Hence, it does not propose a single design but a series of design concepts.

Photo courtesy of workshop participant 1

Stage I

Cover of Sara Hendren's *What Can a Body Do? How We Meet the Built World*

This stage was focused on exploring the design space and framing the issue at hand appropriately. "*What can a body do? How we meet the built world*" by Sara Hendren was pivotal to the direction this project took. Full of life stories of people experiencing the built world in different ways, it helps one look at our bodies with a "new and productive strangeness".

Drawing on Maxine Greene's *Social Imagination* and the maker movement, design concepts were developed based on personal accounts from individuals with limb loss or difference. These fictional concepts should be treated as "probes" to help us envision and re-build our deficit society.

Process

Step 01

Research

Secondary research including literature review, social media & online forum

Step 02

Insights

Insight-driven analysis and recognition of patterns and themes from collected data

Step 03

Concepts

Interrogative design concept development based on firsthand personal accounts

SDCDCKF

Should Do:
Inclusivity / Social Normalisation

Can Do:
Social Change / Promote Awareness / Question Status Quo / Redirective Practice

Can Know:
Collections / Existing assistive products & technologies / Existing workarounds & hacks

Forms:
Interrogative Design Concepts following Co-Design ideation workshop

PERCEPTION
"They need our help" or "They have overcome their disability"

CONCEPTION
"We all have problems but it is what we make of them."

Predispositions

1. One expects to find mostly negative and depressing information online while searching for terms like “quadriplegics”, “amputees”.
2. People might avoid concerning themselves with such topics anticipating strong emotional reactions.
3. When media outlets report on advancements in prosthetic technology, they focus on delivering a feel-good “technology rescue” narrative about individuals “overcoming” their disabilities.
4. Individuals with disabilities are somehow “less than” those without disabilities or need prosthesis to be “whole” again.
5. Those who spend time with an individual with a disability are doing so for charitable reasons.

1. HCI's Response to Stigma

The approach is inspired by the journey from LGB to LGBTQIA+. This controversial social issue has evolved over the years and is still an ongoing process, i.e. an unfinished journey. It started off as a movement in the 1990's with a select few activists speaking up against the social stigma attached to the Lesbian, Gay and Bisexual minority community. It was characterised by the reclamation of slurs in a heteronormative society unaccepting of the the LGB community. The 2010's saw the LGB being brought to the mainstream thanks to professional pronouns being adopted, portrayal in television and film, and representation on social media. Today, with added support and more perceived acceptance, LGB has expanded into LGBTQIA+ accepting and embracing others in this ever-evolving acronym.

1990's

STIGMA

Source: Wikimedia Commons

2010's

MAINSTREAM

Source: Atishi Batra

2020's

LGBTQIA+

Source: Atishi Batra

A parallel can be drawn between the LGBTQIA+ movement and the inclusivity movement. Additionally, one can see a transcendence from real world to the digital world. For instance, professional pronouns on networking sites and standardised accessibility guidelines for web design.

HCI has a role to play in addressing stigma attached to social issues and empowering stigmatised populations (Maestre et al., 2018; Maestre et al., 2021). The project aims to normalise conversation around limb loss or difference, treatment of the community as "one of us" and removing stigma attached to them via interrogative design. We need to take this issue from a matter of accessibility to inclusivity to normalisation, from "Typical vs Disabled" to "Typical + Disabled" to "There is no typical" (Hendren, 2020).

2. Use and Perception of Prosthesis

"They like us best with bionic arms and legs... It would be an affront to ask the hearing to learn sign language. Instead they wish for us to lose our language, abandon our culture and consider ourselves cured."

- Jillian W.

"If I'm at a restaurant and want to cut a steak, and I go to do it with my little arm, everyone's gonna stare at me or offer to help. But if I do it with my prosthesis, Nobody. Says. Anything."

- Angel G.

"Prosthetic arm technology is still so limited that I become more disabled when I wear one."

- Britt Y.

99% Invisible is a podcast that talks about "the unnoticed architecture and design that shapes our world". The episode released on July 27, 2021 covers "the lows of high tech" following the story of Britt Young, who was one of the youngest children in the country in the early 1990s to get a myoelectric arm. She talks about her off-again-on-again relationship with prosthesis.

She has had firsthand experience with both functional and cosmetic prosthesis. During high school, she used the latter to avoid stares, whereas at a later stage in life, she switched to shiny, glittery ones to stand out and ride the wave of cyborgism. She noticed that others around her didn't feel the need to offer to help her with daily tasks if she was wearing a prosthesis. "A lot of people with limb differences can do tasks better with no prosthesis at all because they've developed their own adaptations."

However, she rightly pointed out that the tendency of designers and engineers is to create the newest and the coolest new technology to erase their disability. While, perhaps, they should be focusing on designing a world that can accommodate people with different types of bodies and abilities. That would negate the need for adaptations and making the "disabled" whole again. Ultimately, she resorted to using an activity-specific device which is a type of socket with swappable attachments in lieu of the latest, multi-articulating myoelectric prosthesis. The latter came with its own assemblage of issues like lack of access, expense, weight, discomfort, cumbersome operation while cycling through multiple grip options and so on.



"Cyborgs are having a moment" | Source

According to Cain et al. (2021), there is a "need to reframe amputation from its historical image as "loss" to that of a procedure with the ability to maintain or even increase function".

In many of the accounts, using prosthetics is actually an expensive, cumbersome and uncomfortable affair. Some of them decide to forego it after having tried it because their hacks work better and quicker than prosthetics. But others cling to prosthetics despite the discomfort because they don't want to attract attention or avoid stares. More for social acceptance than personal enhancement.

I can almost equate it to somebody getting a breast enhancement surgery, living with it for a while and then deciding to go back to their natural form because they don't care anymore what people think or want to set an example for their daughter.

3. Conception of a "Normal" Body

One of my biggest drivers throughout the process, especially the pivot, was Sara Hendren's *What Can a Body Do? How We Meet the Built World*. The overarching message that Sara is trying to convey is that "people wouldn't make such a huge deal out of disability if they saw their own bodies as getting and receiving help when they need it. We are all receiving help in one form or the other. Prosthetics are considered assistive technology but so are mobile phones. Perhaps a better term would be adaptive technology.

Instead of looking to fix a body, we should be attempting to make the body and the environment meet differently. The medical model of disability is that the body is the location of impairment and the individual bears the responsibility for it. Whereas, a more constructive perspective is the social model of disability, whereby the interaction between the conditions of the body and shapes of the world makes disability into a lived experience. Hence, it is a matter of concern not only for the individual in question but the society as a whole. In order to reduce friction and this selective disharmony between world and body, we need to "look at our bodies with a new and productive strangeness". Today the idea of a normal body is ubiquitous and mundane but 1840 was in fact the first time 'normal' was used to describe a body. Before that it was a technical term. This attachment of meaning is what brings about the accompanying stigma and stereotypes.

According to John Heskett, design should address Utility and Significance. Combining this with Maxine Greene's concept of Social Imagination sums up our approach to this project, "What if questions" made by design.

In addition to mobility issues, self-image and social acceptance emerged as recurring themes

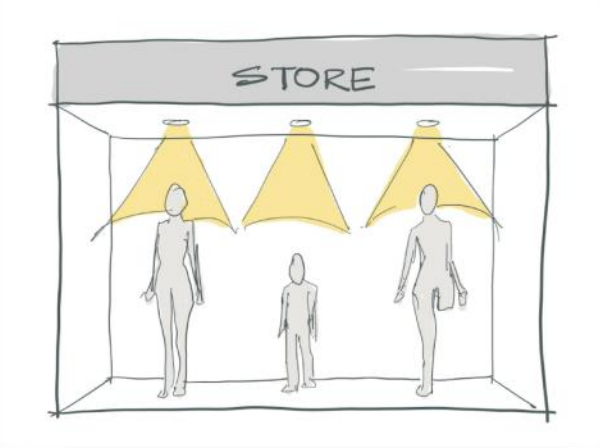
Based on findings from the literature review, several themes have emerged which will act as the starting point for the next step in the process, concept development.

Literature review indicates that individuals with limb loss or difference tend to be bothered more by their social environment than any physical limitation they may experience. Therefore, limb loss or difference can not and should not be considered an individual issue. Instead, it is and should be addressed as a systemic social concern, a mismatch between the physical body and the built environment. Of all the themes, the following need further probing during the one-on-one workshops in order to fully understand the context:

1. Self-image, perception and representation of and by individuals with limb loss or difference.
2. Use of prosthesis for social acceptance rather than personal enhancement.

Photo courtesy of Visme

What if we could see different body types in public displays?



Sketch by Atishi Batra

"One of the things that I think is most important about a disability perspective is to make life work. To make things fit between body and world.

You change the environment, not the body. You change the environment, not the person."

(Microsoft, n.d.)

Should Do:
Inclusivity / Embracing diversity

Can Do:
Disrupt / Promote awareness

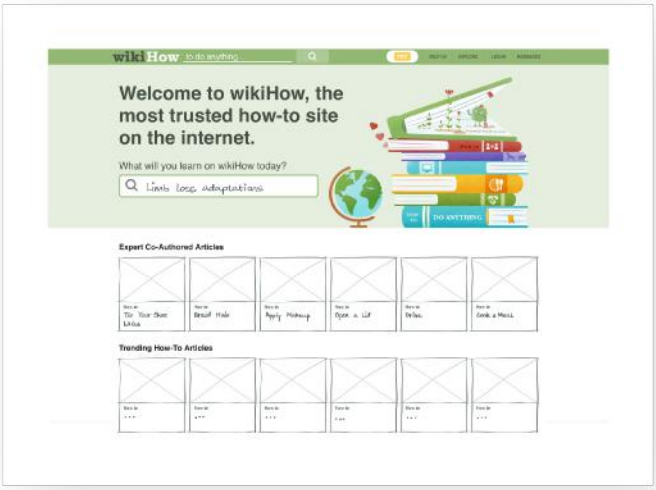
Can Know:
Collections / Diverse body types

Forms:
Installation / Storefront displays

The body positive mannequins ensure everybody else, those without limb loss or difference, can still see it represented around them. Imagine a girl with limb loss seeing a mannequin just like her in the display making her feel represented, accounted for and included. Now imagine a little girl without limb loss looking at such a mannequin. It will hopefully be the start of a healthy conversation with her parents about people who don't look like her but are still "just like her".

This falls in the category of modifying / adapting existing artifacts to help raise awareness amongst those without limb loss or difference.

What if we could learn from others' experiences?



Sketch by Atishi Batra

"Each thing I found either by just cruising around on the internet or somebody telling me about it. I keep thinking that there must be other things out there that would make something easier for me but I don't always know what it is."

(Hendren, 2020)

Should Do:
Connecting people / Sharing

Can Do:
Connect / Promote awareness

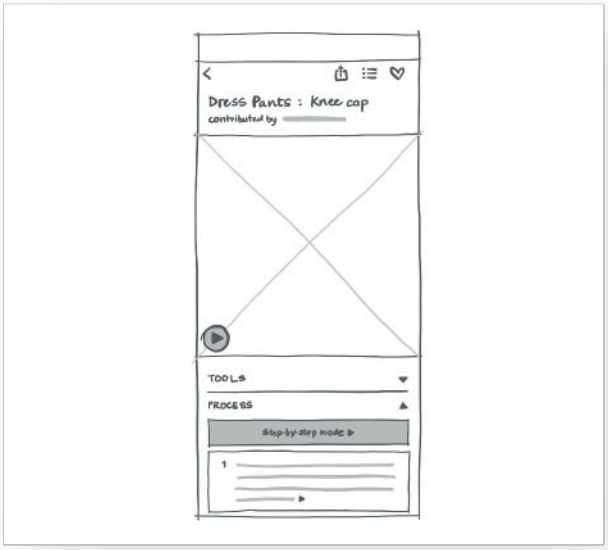
Can Know:
Collections / Personal adaptations

Forms:
Website / wikiHow section

A wikiHow section for recent amputees is inspired by research findings. Recovery time (both physically and emotionally) depends on whether it was congenital or induced, need-based or forced, and so on. Someone who lost their limb at age 2 only knows life a certain way. However, for someone who gets amputation at a later stage in life, it is harder to get accustomed because they need to unlearn, relearn and adapt how they've lived their lives thus far.
Instead of creating a separate website dedicated to this, I propose using wikiHow in order to also promote awareness amongst those without limb loss or difference.

This falls in the category of modifying / adapting existing artifacts to help those with limb loss or difference.

What if we could adopt 'recipes' that have worked for others?



Sketch by Atishi Batra

"First time I went out for birthday drinks after my amputation ... I discovered that the extra socket around my knee meant that none of my smart trousers fitted nicely.

You end up having to try to explain the intricacies of amputation to a doorman who doesn't care, just because they have got a 'no shorts rule' and trousers aren't practical."

(Day et al, 2019)

Should Do:
Personal Growth / Self-sufficiency

Can Do:
Disrupt / Redirective practice

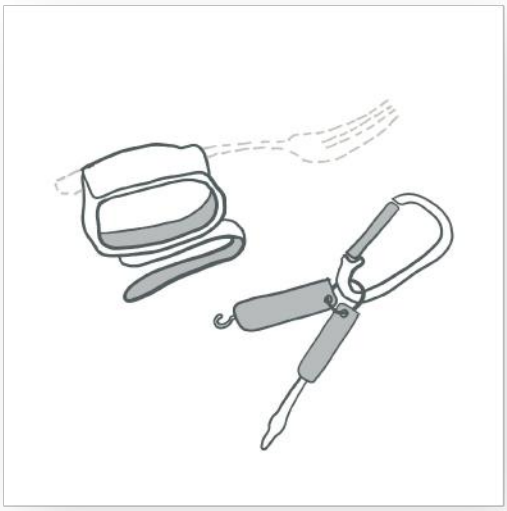
Can Know:
Collections / Clothing adaptations

Forms:
Mobile app / DIY videos

Fashion choices are a big part of self-expression (i.e. fashion sense) and social participation (i.e.uniforms, dress codes, etc.). I equate an individual with upper limb loss wearing a shirt with a dangling empty sleeve to a fashion-conscious individual wearing an ill-fitted suit. Being able to modify and adapt clothing to your body type is an empowering concept and can lead to positive feelings and enhanced confidence about self in any individual, irrespective of limb loss or not. This app teaches individuals to modify their own clothes following easy steps that have worked for others.

This falls in the category of creating new artifacts to help those with limb loss or difference.

What if we could have easier access to adaptive tools?



Sketch by Atishi Batra

> "*Instead of tuning a grip pattern for the myoelectric arm to open a drawer in her kitchen, Cyndi uses the gross motor grasping function she has to pull on the loop of cable tie attached to the handle. ... What Cyndi needs is not a single miraculous replacement limb but a whole panoply of these extensions, where the work is distributed among multiple objects. ...*"
>
> (Hendren, 2020)

Should Do:
Inclusivity / Self-sufficiency

Can Do:
Organise / Forced connection

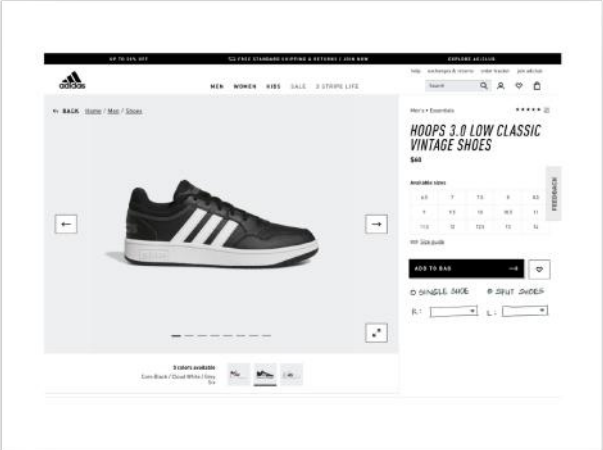
Can Know:
Collections / Adaptive artifacts

Forms:
Physical / Multi-tool

'Swiss Army knife' of adaptive tools, i.e. handy multi-utility tools are inspired by Cindy's collection of inexpensive adaptations around her home to mould her environment to her needs. Taking this idea forward, what if she was traveling? How does she work in or adapt an unfamiliar environment? Hence, the idea of portable adaptive tools that can help her when she's not at home surrounded by her adaptations.

This falls in the category of modifying / adapting existing artifacts to help those with limb loss or difference.

What if we could tailor our purchasing to our specific needs?



Sketch by Atishi Batra

"*Six Flags - It's not that I wasn't capable but that I wasn't allowed on certain rides ... I lost my leg when I was 2 so this is what I've grown up with and I've been on these rides before.... It kind of pissed me off because I love roller coasters. It was taken away!*"

- Participant 1

Should Do:
Inclusivity / Embracing diversity

Can Do:
Disrupt / Redirective practice

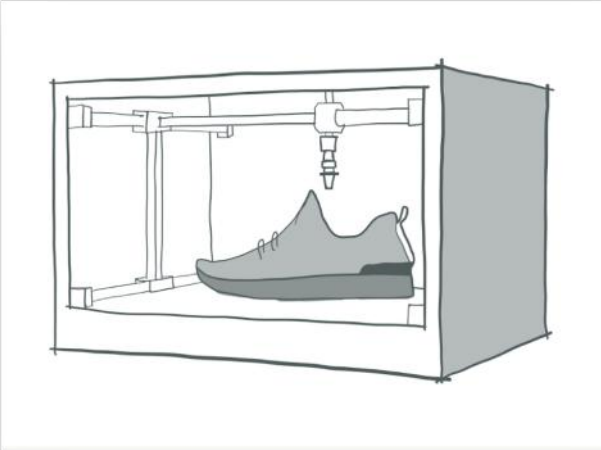
Can Know:
Needs / Adaptation needs

Forms:
Websites / Add-on functionality

After spending half a day contacting the customer support for every major shoe brand. I gave up on finding a single shoe or split pair purchasing program (except Nordstrom's limited variety and Nike's One Shoe A Year Program). Why can't corporates let customers buy single shoes or split pairs? There are plenty of defective shoes for them to be able to spare singles. Even if it turns into a logistical issue (which it shouldn't), there is plenty of marketing and PR glory to be had for the first brand to jump on the bandwagon of including the option to add this functionality to their online stores.

This falls in the category of modifying / adapting existing artifacts to help those with limb loss or difference.

What if we could 3D print any accessory we wanted?



Sketch by Atishi Batra

> *"For me, I just do it for game shoes. I want a single shoe because I don't wear my prosthetic when I'm playing wheelchair basketball. Some of them can get scuffed up so I'm walking around with one shoe that looks almost brand new and one that's all messed up."*
>
> - Participant 1

Should Do:
Inclusivity / Self-sufficiency

Can Do:
Disrupt / Redirective practice

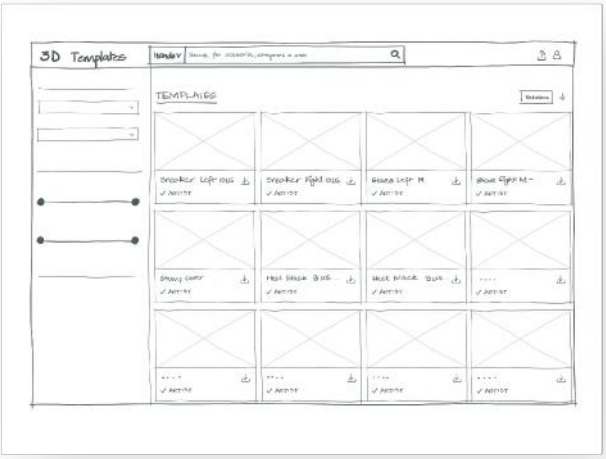
Can Know:
Needs / Adaptation needs

Forms:
Service / 3D printing capabilities

The default is to buy shoes in pairs, one for our left foot and the other for our right foot. But what if we don't need two? I could have a single foot or could have different sizes on both feet. Instead of having to buy two and waste/donate/exchange one, there is now the option to 3D print a single or split shoe per your exact specifications.

This falls in the category of modifying / adapting existing artifacts to help those with limb loss or difference.

What if we could download pre-set 3D printing templates?



Sketch by Atishi Batra

"I have tested out a 3D printed socket. I live to see the day when prosthetics no longer require added effort and adapting the gesture of walking."

(Day et al, 2019)

Should Do:
Inclusivity / Sharing

Can Do:
Organise / Scaffold behaviours

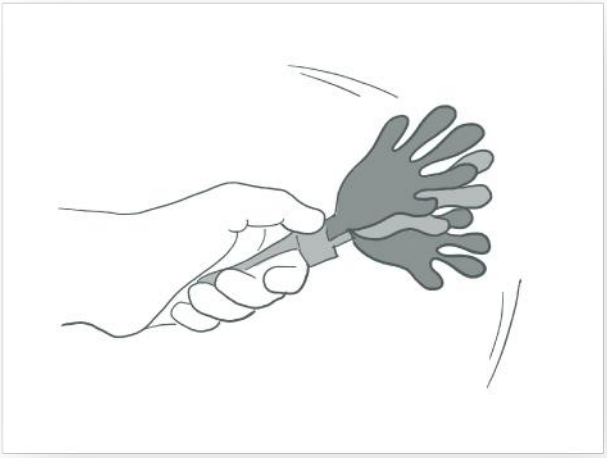
Can Know:
Measurements / Sizes & materials

Forms:
Website / Library of templates

Just like one buys a pair of shoes online, one downloads a 3D printing template of a "10 US left sneaker", for instance. This gives individuals the freedom to download, customise and print their single shoe or split pair. Instead of having to buy two and waste/donate/exchange one, they get access to exactly what they need when they need it.

This falls in the category of creating new artifacts to help those with limb loss or difference.

What if we could use everyday objects in a renewed way?



Sketch by Atishi Batra

> *"(with a myoelectric arm) He found that he could clap his hands together in applause along with the other attendees for the first time since he was 14. That was a big deal, being able not only to reach or grasp or carry, but to participate in a social ritual, using the reciprocity of his palms in an everyday gesture that he had only distantly remembered."*
>
> (Hendren, 2020)

Should Do:
Inclusivity / Social participation

Can Do:
Disrupt / Redirective practice

Can Know:
Collections / Needs & objects

Forms:
Physical / Reframed usage

Everyday objects can be adapted and reframed to resolve issues that may not be resolved by more complicated conceptions. One such example is a toy clapper being used to mimic the act of clapping. An individual with an upper limb loss and no prosthesis may feel just a tiny bit more included and part of the crowd when they're able to clap with them at the end of a performance, for instance. It's just a matter of using a little creativity and thinking outside the box.

This falls in the category of using existing artifacts in new ways to help those with limb loss or difference.

Photo courtesy of workshop participant 1

Stage II

This stage was focused on understanding the lived experiences of individuals with limb loss or difference. Analysing conversations and the underlying patterns helped establish social values that are important to the target group. Understanding what's important also helps highlight what's missing.

An essential part of this exercise was to build a good rapport with the participant and not make it feel like yet another interview. Instead of treating them as an information source and assumption validator, they get to play a more central role and feel part of the design process. A lot of visual aids were used to act as stimulants such that it encourages them to share their embodied experiences.

Process

Step 01

Research

Primary research including photo collection and design ideation workshop

Step 02

Insights

In-depth analysis and recognition of patterns and themes from collected data

Step 03

Social Values

Conception of strategies based on conversation with workshop participant

1. Workshop : Designing and Conducting

Inspired by Greenbaum & Madsen (1993), the workshop was divided into three sections: *Storytelling*, *Critique* and *Fantasy*.

Storytelling: with the help of visual aids, the participant tells stories of their everyday living.

Critique: with the help of photo collages, the participant assesses what is satisfactory or problematic about the perception and representation of limb loss or difference.

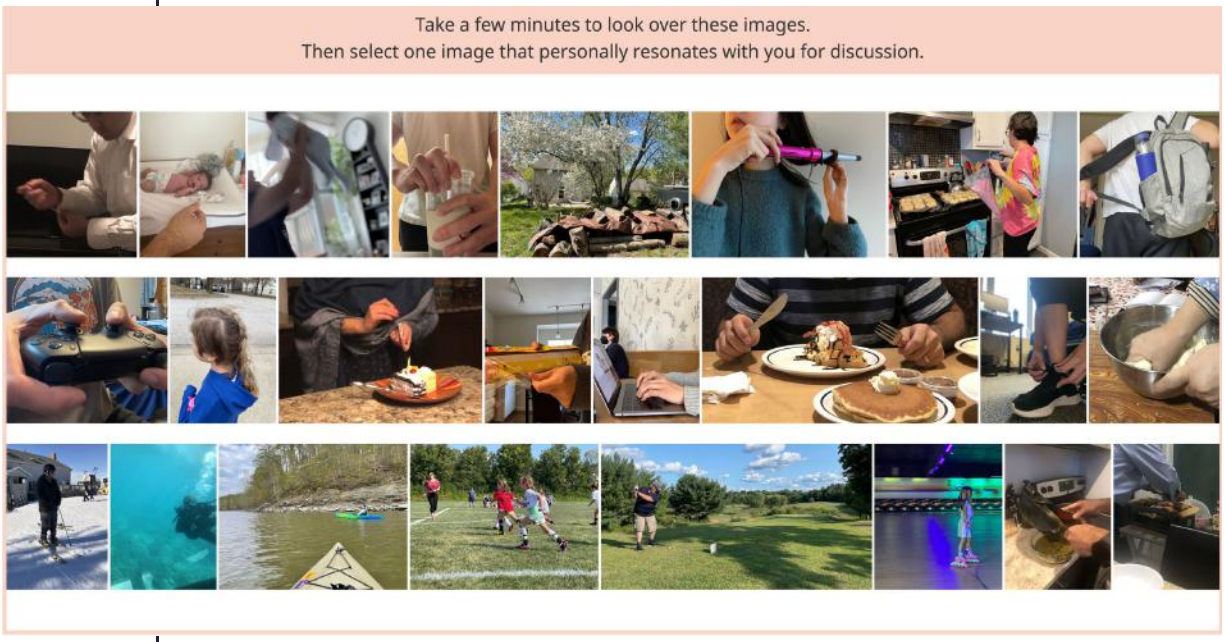
Fantasy: with the help of concept design sketches, the participant is encouraged to imagine and express what-ifs.

1.1 Storytelling

"*You go out anywhere and others call you an inspiration. Yes and no. I know if I'm going on a treadmill and they go 'if you can do it, so can I' then ok. But you know in everyday life, 'no, I'm not inspiring. I'm just on my way to the bar'.*"

- Participant 1

The *Storytelling* section aims to help establish context and encourages participants to share their lived experiences. The visual aids help trigger memories of situations they might've been in or emotions they might've felt in the past. To be fair and empathetic, equal emphasis is placed on challenges they've faced and overcome.
As an experiment in perception, individuals without any limb loss or difference were asked to share photos of everyday actions that they thought required both hands and legs. These photos were then showed to the workshop participants.



Screenshot from workshop : *Storytelling* section

To my surprise and delight, the participant went through each activity depicted by a photo and mentioned he could or has been able to do everything listed and then some. In fact, having been a car salesman at some point, he had also taught himself how to drive stick (i.e. a manual car) despite having lost a lower limb. In fact, he used this as a selling tactic telling potential buyers if he could drive a stick then so could they.

Additionally, existing innovative adaptations created by or for individuals with different needs were shared, prompting them to share some of their own personal adaptations.

Screenshots from workshop : *Storytelling* section

"It's not that I wasn't able but I wasn't allowed to ride certain rides. I lost my leg when I was two so this is what I've grown up with. I've gone to Six Flags all my life and all of a sudden there are all these parameters. ... It was taken away from me."

- Participant 1

When asked about the last time they couldn't do something because of their limb loss, to my surprise, the participant spoke about their recent experience at theme parks. As a roller coaster enthusiast and a long-time regular theme park visitor, he was taken aback during one of his visits to Six Flags a few years ago. There was a new clause in the rules of one of his favourite rides that prohibited anyone with missing limbs or with prosthetics from riding.

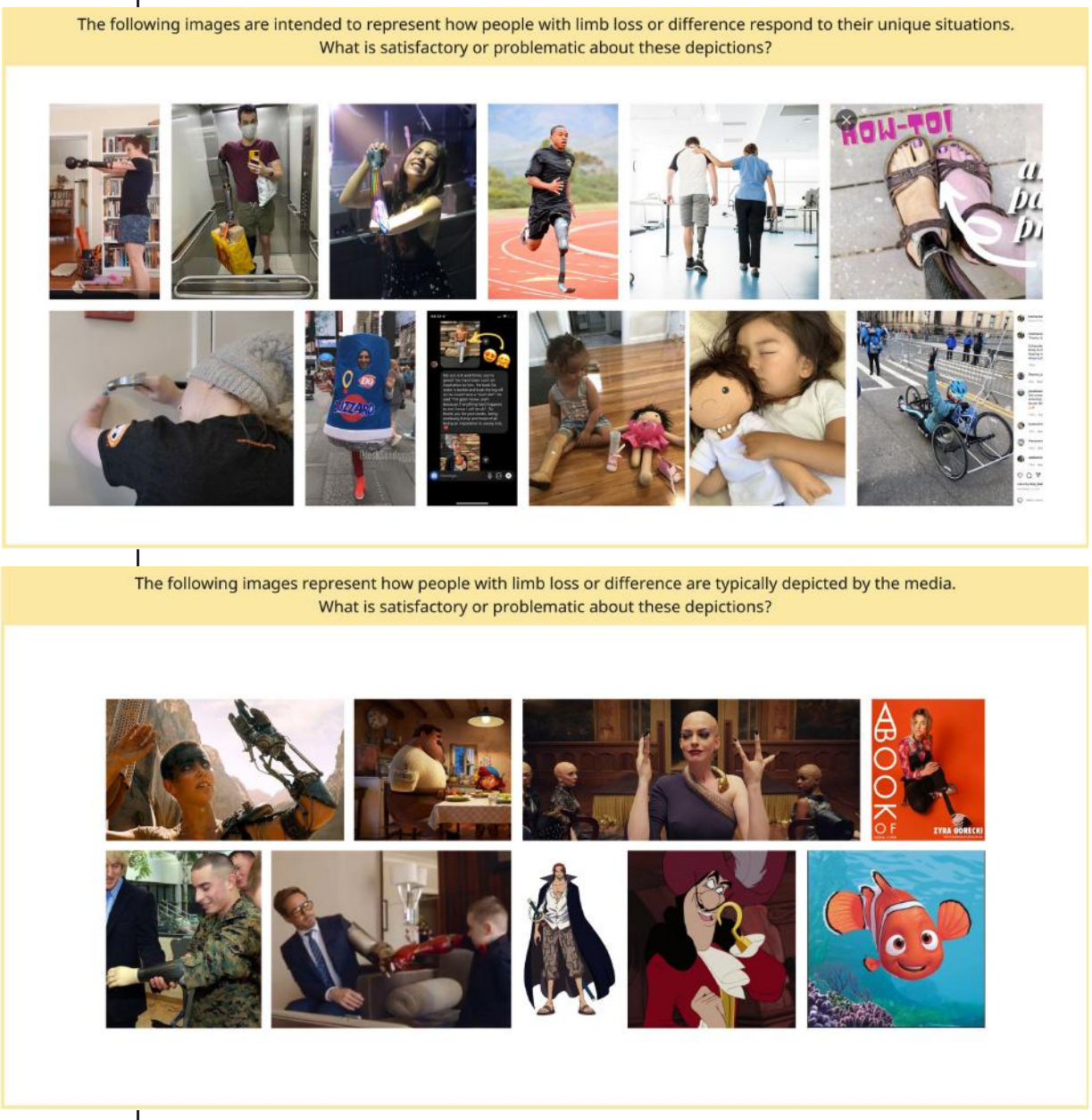
The *Storytelling* section truly helped the participant open up and share their embodied experiences. The visual aids reduced awkward silences that usually follow "tell me about a time" questions.

1.2 Critique

"Inspiration porn refers to the objectification of people with disabilities in media, which serves the purpose of making consumers, people with no disabilities, feel good."

The *Critique* section is focussed on shedding more light on the participant's perspective on the perception and representation of individuals with limb loss or difference. This not only pertains to their own self-image and self-projection but also the perception of others and representation in media and the entertainment industry.

Photo collages were split into real life and reel life so as to nudge them to speak from personal experiences but also voice opinions about how they are represented in media. The latter was included due to a term I came across in my research, *inspiration porn*, which was coined by late disability activist, Stella Young in a TED talk.



Screenshots from workshop : *Critique* section

1.3 Fantasy

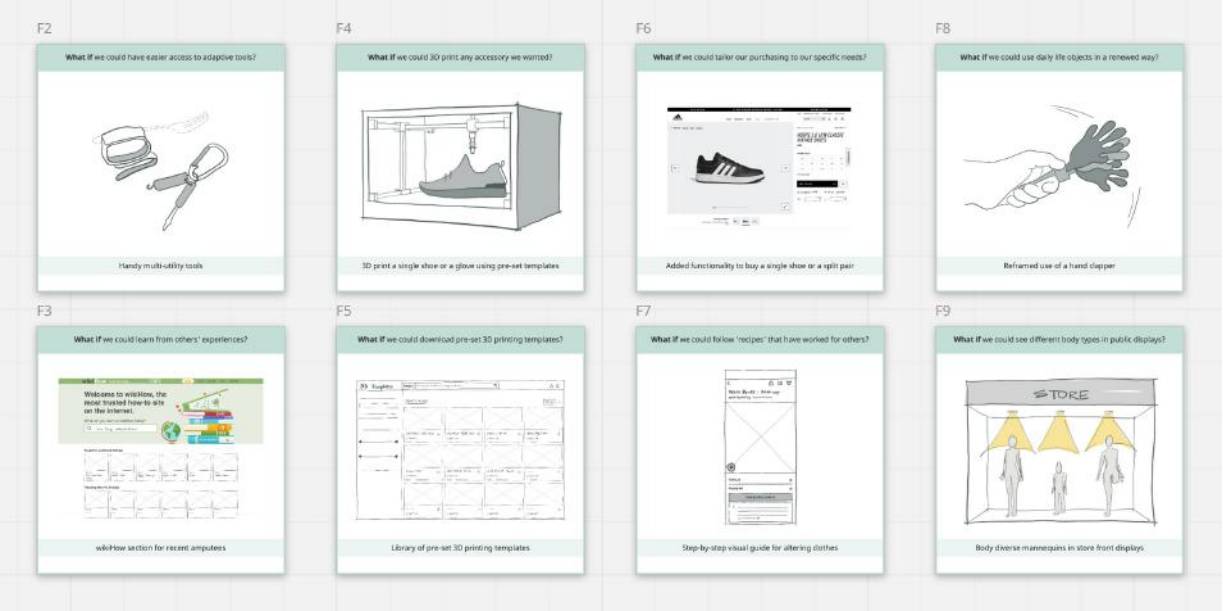
Responses from the *Critique* section helped set the tone for the final section, *Fantasy*. It slowly brought us from topics ingrained in reality and everyday life to nice-to -haves. This further allowed them to let their imagination loose and think beyond what is readily available. The idea was for them to think of larger than life concepts, tangible or otherwise, that they would like to see implemented in their lifetime, irrespective of feasibility and viability at the present time.

The interrogative design concepts developed at the end of Stage 1 were shared in order to get firsthand feedback from participants and perhaps ways in which they would expand on these ideas. Empathy is an important tool for a designer to create something but at times, it isn't enough. Embodied experiences can help someone engineer a design that no one else would've been able to conceive of because they are the ones who truly understand what it is they're going through and their needs.

As in Cindy's case, she adapted her own environment through informal engineering. There were adaptations that she came up with for issues that her prosthetist could not help resolve, despite his 42 years of experience. The lesson here is that co-design and participative design is the way forward. We need to include individuals with limb loss or difference early on and frequently. They need a say in the process and design because they are the true experts of their lived and embodied experiences.
The participant jumped on board with much enthusiasm and contributed an idea to be added to the collection of concepts.

"*Sometimes household objects lead to better solutions than anything I can do, with my 42 years of experience, and thinking I'm a genius at everything,I know I don't have all the answers. I need my patients to jump in and help me. This is when we're most successful.*"

- Greig Martino, Prosthetist
(Engineering at Home, 2009)



Screenshots from workshop : *Fantasy* section

Cause, duration and context of limb loss or difference plays a big role in coping, adapting and living with it

One conversation with an individual with lower limb loss was a treasure trove of information insights. Due to the project duration and other reasons discussed in the reflection, only one participant could be recruited in time for this project's deadline. In the future, given the chance, I would like to continue the dialogue and speak to more individuals and learn from them in order to take this initiative forward so that something comes of it.

Assumptions were pushed aside and what's truly important came to the surface. One might think the solution lies in tangible artifacts like advanced prosthesis. Sometimes, it does. But, most of the times, it's the intangible that can truly help fix this feeling of not 'fitting it'.

1. Everyone has a different sort or degree of limb loss or difference. What works for one may not work for another.
2. Those who go through amputation later in life find it far more challenging than those with congenital conditions or early life amputations since they require unlearning.

Photo courtesy of Visme

Based on the insights and takeaways from the one-on-one workshop, the following recurring social values were identified as paramount:

1. **Empowerment & Ownership**
   sense of control over one's life, claim to their rights as humans first and the moral or natural right over their own body
2. **Self-Expression & Freedom**
   conveying who they are and being perceived, based on their words, acts or emotions, without interference or disdain
3. **Collective Intelligence & Exchange**
   contributing to and learning from a shared pool of others' efforts, experiences and lessons, without having to reinvent the wheel
4. **Social Perception & Engagement**
   treating everyone like humans first, reframing social cues to reflect that and including them in society as equals (not less, not more)

These are by no means exhaustive or ubiquitous. Instead, they should be treated as reminders to designers and non-designers alike. These are highly valued by individuals with limb loss or difference and, as such, should be important to all of us as a society. Each concept embodies one or more of these social values.

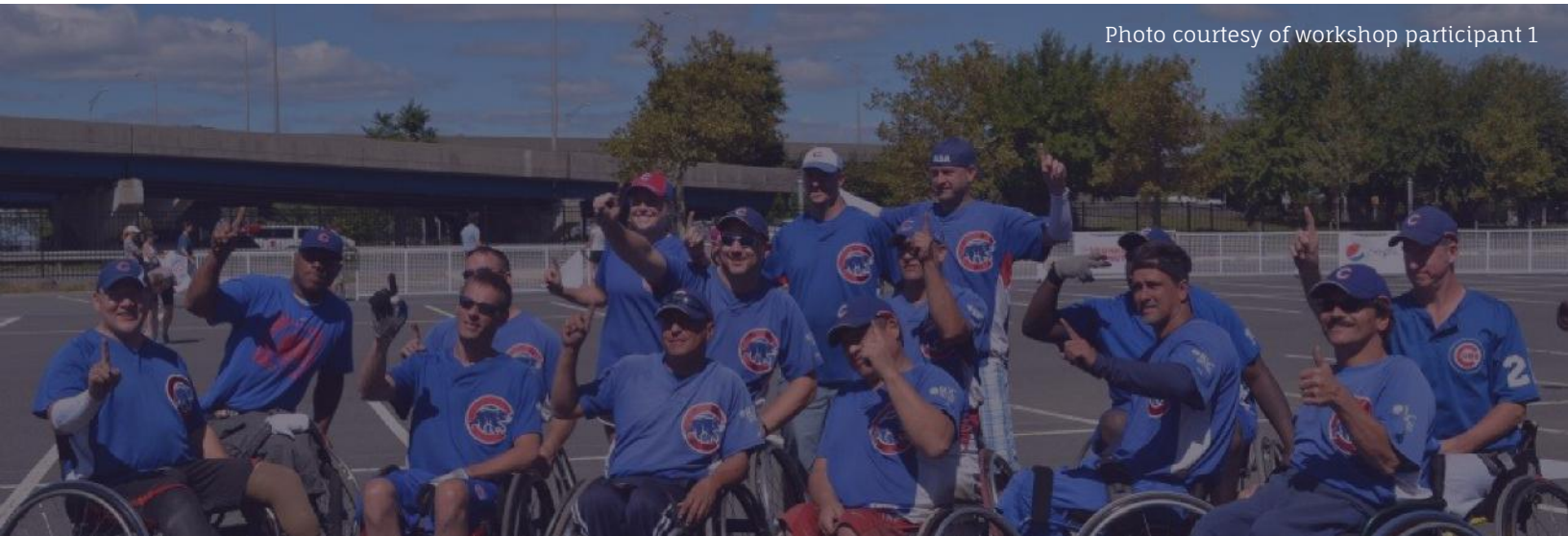


Photo courtesy of workshop participant 1

Reflection

Photo courtesy of workshop participant 1

It is an ongoing, never-ending process. Small changes all around us will eventually lead to big change.

One of the biggest challenges I faced during the process was recruitment for user research. Access to target groups, reaching out and building a rapport remotely was a daunting task and seemed almost impossible. However, thanks to the Office of Disability Services came through and introduced me to someone with lower limb loss. Although the capstone project can definitely be completed in a single semester, condensing the user research phase is challenging and can throw the project plan off-course. Having a contingency plan helps and will remain high on my priority list.

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Stakeholder Map