EMPOWERMENT of PEOPLE OF ALL ABILITIES
Katarzyna (Kasia) Matlak
2017
A thesis presented in partial fulfillment of the requirements for the degree of Master in Industrial Design in the Department of Industrial Design at the Rhode Island School of Design, Providence, Rhode Island

Claudia Rebola,
Associate Professor Dept. of Industrial Design,
Full-time Faculty Advisor

Emily Rothschild,
Adjunct Faculty Dept. of Industrial Design,
Part-time Faculty Advisor

Diana Wagner,
Wyss Institute, Sr. Functional Apparel Designer,
External Advisor
To my parents,
who gave me all that I am.
I want to acknowledge the Fulbright Commission for supporting my studies at RISD.

All the people at RISD who have taught me, inspired me, and will keep on influencing me after graduation, especially:

Michael Lye
Lindsay French
Claudia Rebola
Emily Rothschild
Charlie Cannon
Andy Law
Tom Weiss
Ayako Takase
Paolo Cardini
Tim Maly
Scott Geiger

Also to, my extraordinary classmates, for teaching me something new every day.
DECLARATION
We assume a particular set of human abilities to be normal. In this way, we construct abnormalities. Every day, we fail to notice the whole picture. In this way, we create walls (mostly unintentionally). Our environment is a range of obstacles. All of us experience them. We can choose to design around them. We should challenge everything we know and facilitate inclusiveness. If we create the world with open eyes, we can make it better. By addressing the needs of the masses, we address our needs. If we make, build and represent looking at the most minor or oppressed individual, we will be able to do it right. The thing that makes us all the same is that we are all different. Unique. We are all able and unable. Variable.
ABSTRACT
Exploring empowerment for people of all abilities to help build a more accessible future.
Can design take part in providing inclusiveness?
Can objects empower?

For my thesis, I sought ways to redefine disability, by focusing on people with lower limb amputations. I focused on the most troublesome part of their daily interaction with a prosthesis, which is a socket. My primary concern was to improve the experience with it, as it is where prosthesis attaches to the body. I looked at disability, prosthetics, body image, identity, and loss. After an amputation surgery, people experience a grief that is comparable to the loss of a loved one. Historically, some people deal with grief by creating and performing rituals. Those rituals have proved to be helpful; therefore I am creating a care tool-kit that facilitates acceptance.

I have talked with several people with amputations, as well as physicians, prosthetists and peer visitors from amputee support groups. Through my research process, I began to understand the challenges and opportunities to facilitate empowerment. I divided my actions into four types of empowerment: control of the action, acceptance of one's current state, elimination of social biases and access to resources. I address these four areas of empowerment through design of a system of support that contains important resources and a care tool-kit. The kit embedded with tools for healing rituals that help an individual gain acceptance when dealing with grief. In the Declaration I communicate that disability happens between human and environment — which can be physical or social. It is necessary to initiate social change by promoting a new outlook in society as we all have various abilities and we all are #variable. Empowerment of people of all abilities is focusing on embracing atypical strengths and to alter the perception of disability. The goal is to promote accessibility and design for people of all abilities. Good design should take into account diverse audiences. If you design for those for whom the activity is difficult and make it easy you design well for everyone.
# CONTENT

| I | Introduction | 1 |
|   | Context glossary | 2 |
|   | Current situation | 4 |
|   | Empowerment | 10 |

| II | Having control over life | 20 |
|    | Providing acceptance | 28 |
|    | Access to resources | 32 |
|    | Redefining disability | 36 |

| III | Process | 42 |
|     | Conclusion | 50 |
|     | References | 54 |
INTRODUCTION

I love walking. When I walk, when I run, when I’m in a rush I feel most alive. It might have started when I was a child — I cannot remember clearly but I remember the time I realized that people are weird for getting places so slow — when you can run everywhere. In Poland, we would say "zywe srebro" which describes an extremely active child. A change in the way I move would alter my personality and character, moving fast made me feel accomplished, careless (even when running late) and simply happy. It changes the way I speak and act, I always feel the need to be efficient - when I act differently I am nostalgic, miserable or feel guilty for being lazy. It's more therapeutic than anything else that I know, staying busy keeps me sane (unless I no longer have time left between going to bed and waking up). Imagining living without the ability to move freely petrifies me. While talking with amputees what prostheses are for them most often I hear "independence" and that is why I am so interested in prosthetics and assistive technologies. What I appreciate in design is an ability to help people — to improve their lives. The best kind of improvements that have happened in our lives are the ones we implement and ignite by ourselves. It is called empowerment.
Accessible design

“...is a design process in which the needs of people with disabilities are specifically considered.” ¹

Adjusting process

it is coming to peace with loss and life change after an amputation surgery.

Behavior change

it is a research-based consultative process for addressing knowledge, attitudes and practices. It provides relevant information and motivation through well-defined strategies, using a mix of media channels and participatory methods. Behavior change strategies focus on the individual as a locus of change. ²

Biases

it is a prejudice in favor of or against one thing, person, or group compared with another, usually in a way considered to be unfair.

Bionics

it is the study of mechanical systems that function like living organisms or parts of living organisms

Body

it is a priori form that is a necessary precondition for understanding the world beyond mind and matter. (According to Immanuel Kant (1724–1804)) ³

Body image / Acceptance

it is a personal and subjective outlook of self that influences a process of acceptance. “Sometimes body image plays a central role in adjusting process, and other times it is secondary to more global adjustments in self concept (e.g., form nondisable to disable, independant to semi-depen-dant, employed to unemploied, etc.). These more fundamental changes in self-concept may take precedence over changes in body image, and body image changes may not be fully integrated until these other issues are addressed. In other case, a focus on the tangible changes in appearance may serve as adversion away from less tangible and more anxiety-provoking concerns about one’s changed role or purpose in life.” ⁴

Disabilities

it is “(f)or each major body system, impairments considered severe enough to prevent an individual from doing any gainful activity.” ⁵

Grieving process

it is a process experienced by people after losing a limb, similar to the grieving process after losing a loved one.

Healing ritual

“...can help restore a sense of balance to life. [They] empower people emotionally, mentally, and spiritually.” ⁶
Identity
it "is never a priori, nor a finished product; it is only ever the problematic process of access to an image of totality.” 7

Mobility
it is a privilege.

Objects
it can be empowering when they give people an ability to make their life better.

Peer visitor
is an experienced amputee from local Association volunteering to help others.

Phantom limb pain
it is pain that is affecting the limb which is no longer there.

Prosthesis
is device that assist people to perform human abilities. It is an empowering device. It is independence, equality and adjustment.

Prosthetic socket
is an interface between the prosthesis and a human's body. Because of this relation, it is the area that requires the most attention when relating to comfort.

Residual limb
it is a part of the limb left after an amputation surgery.

Self-esteem
it is an “independent aspect, which is not affected by lower-limb amputation. However, self-esteem is influenced significantly by phantom pain sensation.” 8

Self-help
it is a constant checking of your skin condition. “One sore can set you back for a weeks (months if it get infected).” 9

Society
it is a body of individuals living as members of a community. 10

Trauma
is mostly associated with unexpected and abrupt limb loss. However, all amputees agrees that regardless of the circumstance amputation surgery is always traumatic.

Universal design
“...is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.” Ron Mace 11

Usable design
is an “effectiveness, efficiency, and satisfaction with which a specified set of users can achieve a specified set of tasks in a particular environment.” 1

Self-help
it is a constant checking of your skin condition. “One sore can set you back for a weeks (months if it get infected).” 9

Society
it is a body of individuals living as members of a community. 10
The benefits of prostheses for a person with limb loss are evident. They are guaranteed a return of mobility, and independence as well as standing posture, which — compared to a sitting in a wheelchair — changes their perspective on the world for the person using it as well as their social interactions.

Influences of the prostheses go beyond the physical. Psychologically, the relation between the prosthetic and body is incredibly complex. In her book *Phantom Limbs*, Cassandra S. Crawford uses the term of “Tran-scendent prosthetization” to explain the relation of body and mind that become evident when the person uses the prostheses. It is not only about the physicality of the body, it is about the relation of an object with the phantom limb described by Crawford as a “ghostly appendage.” Phantom sensations, which can be painful and strong, are often a reenactment of trauma, its cause might be neurological or psychological, in some cases emphasize the pleasure feeling. Those create an uncanny presence of the body part which no longer exists. Moreover, it can reenact the pain and sensations related to the trauma of injuring it. In this sense, the artificial limb may become not only a “new limb” but also provide an alternative interpretation for the brain of the body’s wholeness which helps it deal with neurological phenomena such as phantom pains.

A lower limb prosthesis is extremely demanding on the body, especially the prosthetic socket because it is an interface between the body and prostheses. Despite advances in technology, a prosthetic socket continue to cause users discomfort. Changes in the shape of the body, in weight, sweat and even time of day make a perfect fit for the socket an impossible task. Currently, to help fine tune the connection between changing residual limb and neutral prosthetic socket, thin ply socks are used to add thickness and ensure a snug fit. Some users may end up
wearing as many as 13 layers of ply socks over the course of the day to manage the fit. Which mostly indicates the need for the new socket; however, each application is unique based on the personal physiognomy of the particular user.

Depending on the reason for amputation, the reaction to prostheses is different. When the surgery happened as a result of a chronic disease or as a prevention from a life-threatening condition, it tends to be more acceptable. When someone loses the limb as a price for their life, they see the value and purpose in the tragedy. When I interviewed people in Vietnam, those who lost their limbs during the Vietnam or Cambodian War, had a peaceful understanding of the reason, and their adjustment and grieving processes have been easier. They valued being alive, the same happens to people who lost their limb to cancer. In both cases tragedy occurred earlier, the amputation become part of their recovery process. The war as a tragedy has not consumed the life, it has taken something and caused injuries but let them live. Parallel to cancer treatment it has been stopped by amputation in this way it has helped people survive. Despite feeling the loss, they have a logical reason for it, understanding, which can help them to adjust to lost.

In contrast, in case of the unexpected and sudden limb loss, the reaction and recovery process is much more challenging. The most common question asked by the new amputees in this context is, “Why, why me?”. When at the same time it is also the worst question to ask because there's no answer. When dealing with such tremendous trauma the amputee must relay on those closest to them. Otherwise those — family and friends have no idea how to help and how to navigate the situation to be sensitive, supportive and motivational. Amputees tend to establish a strong bond with their prosthetists, because they understand and are able to provide advice.
Depending on the circumstances of the amputation, a person may or may not have time to get used to the idea of losing the limb.

**PLANNED**
If the amputation was planned as a result of diagnosis, as a consequence of disease or prevention of a life-threatening illness such as cancer, the patient has time to talk with an experienced amputee and see what living with prosthesis looks like. This conversation is important because it helps have a realistic expectation of what is going to happened next. In this situation the patient wakes up after surgery with some understanding of what their new life will look like.

**UNEXPECTED**
If the reason was unexpected and sudden, like a motorbike accident, there was no time before the surgery for understanding, to speak with anyone or to learn about their new life as an amputee. In this situation, the person wakes up after surgery in shock and falls into denial which makes the recovery process much more difficult.
Coming back home, an amputee loses the “umbrella of care” which existed in the hospital or during rehab. They also face new challenges with readjusting to the familiar space. Moreover, family and friends often don’t know how to help, because they can’t understand.

Established trust and bonds between patient and prosthetist — as valuable as it is — can become more important for an amputee than a right fit.

Leaving the hospital in this scenario is not easy.
WHAT IS EMPOWERMENT?

Empowerment

it is “the process of becoming stronger and more confident, especially in controlling one’s life and claiming one’s rights.” 13

Dictionary

“Empowerment is the process of increasing the capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes. Central to this process are actions which both build individual and collective assets, and improve the efficiency and fairness of the organizational and institutional context which govern the use of these assets.” 13

World Bank

World Bank also identifies its areas of practise as:

- Access to information
- Inclusion and participation
- Accountability
- Local organization capacity

In order to better understand empowerment I surveyed people asking: What is empowerment? I have been asking people around me to tell me the stories about their moments of empowerment.
“The first time I make a stand for myself to someone who offended me.”

Anqi

“For some reasons, finishing some long distance runnings such as half-marathon makes me feel empowered. I trained myself a lot in order to get better record, and then I broke my personal record. I was exhausted, but felt very satisfied and then this satisfaction made me feel I can run another half right now.”

Jerry

“Working out at gym is the most powerful time. Feeling my biceps from “marshmallow” to firm and strong empowered me physically and mentally.”

Anqi

“I was in a great disappointment of myself for not achieving any success, making any big fortune, not being famous. When I hike to the top of the mountain, and watched landscape of the great earth, I felt the tiny and fragile of human being comparing to the whole universe, and I realized the essential meaning of life is that I should be happy. Afterwards, I felt more calm and peace.”

Anonymous

“Spinning makes me feel empowered because I push my body and you get to a point in each class where it doesn’t feel so hard anymore even though you are really tired.”

Alyssa
What objects empower you? What objects makes you feel less able?

As a designer I was trying to figure out how objects can be empowering. Can objects facilitate the process of gaining control or evoke feelings of being strong and confident?

"Whenever I was in a negative mood, reading a book that gave me a new perspective of the problem I was facing empowers me."

Anqi

"I wear heels to be taller for vain reasons but also for confidence. Like when I used to meet with clients or go on a job interview I feel that I look really young or childish unless I am wearing heels. Not in a sexy heel or anything, it is really more about the height. Also, my feet are really small so if you can see how small they are (in flats, for example) I think it makes me look young and inexperienced. I worry the client won't take me seriously or the job might not give me a good offer."

Alyssa

"Tools. When I build something or cut some material and it is all done just right I feel empowered."

Tim

"Climbing shoes, they greatly improve my ability to climb. Rope, saves me from death and allows me to try and try again. Pen and paper, allows me to translate my thoughts/ideas. Car, it takes me places I need to go."

Court
**First stage**
My class experiment consisted of 3 parts.

The first one was about recognizing objects from everyday life that made people feel more or less empowered. (Photo 1)

Second part was about recognizing what kind of empowering qualities are presented in objects. (Photo 2) Objects that I choose for the second stage of this experiment were based on my primary assumptions from a previously conducted e-mail survey about the empowering objects. They were ordinary things related to active lifestyle, body image, utilitarian objects and those that require some basic skills.

Lastly, I asked participating classmates to modify those objects to enhance their empowering qualities. (Photo 3)
Second stage

Following the first stage I asked people on the street to organize selected objects on scale from empowering to disabled. I have chosen objects that my classmates used during the first part of experiment. After I asked them to add their own object to the group.

Based on the responses I realized that objects have a very specific and subjective influence on people - which is based on their experiences, character, and environment. (Photo 4)
As a last stage, I participated in the New England Amputee Association (NEAA) meeting in Clinton, Massachusetts. I asked participating people what objects they feel are empowering and which are limiting. Some of their answers were not objects despite being asked specifically for those. (Photo 5)

An additional question was about their prostheses. I asked what they like and don't like about their prostheses hoping to understand how it might relate to empowerment. Their relationship with this object is very instrumental, it is good, as long as it performed correctly. Understanding the pain points with prostheses was crucial for my thesis development. (Photo 6)
Surveys and experiments helped me identify the qualities of empowerment and establish 4 areas of practice that I would address in my project.
AREAS OF EMPOWERMENT

HAVING CONTROL OVER LIFE

PROVIDING ACCEPTANCE

ACCESS TO RESOURCES

REDEFINING DISABILITY
HAVING CONTROL OVER LIFE

Being in charge, feeling like taking care of several tasks and completing them is one of the most empowering actions that people do in their life. It is motivating; it brings them up to speed, it adds purpose, and a feeling of accomplishment, especially if these are activities that are related to what the person loves to do.

After an amputation surgery the patient stays in the hospital rehab center until reaching a feeling of comfort and safety with some sort of assistive technology whether it is a wheelchair, walker or crutches. This level of support is part of the obligatory good practice that is crucial for patient wellbeing. While I was working in Vietnam, I met a young boy who lost his leg in a motorbike accident. He was fitted with prosthesis in the Red Cross hospital in Ho Chi Minh; however his home and school were in the rural Vietnamese area. (Photo 7, 8) In this hospital, patients are staying until they learn how to use their prosthetic and restore mobility. There are two rooms with multiple beds, one for women, one for men. All newly fitted amputees stay there, they support themselves and spending time together. At the time when I talked to the boy it was one of his last days there, and he was reluctant to leave. He prefer to stay in the hospital, because at his school he would be the only one with an artificial leg. All other men at this hospital were at least twice his age, but they become his best friends because they could relate to one another.
In my work, I wanted to expand on this boy’s experience, by providing tools and resources that can be introduced to the patient by doctors and physical therapists; but that can also continue to provide the support after patients are discharged. While attending the amputation association meetings, participants had a common opinion that getting out of the hospital is like leaving the bubble which has been offering stability. Going back home after rehab introduces not only new challenges but also takes away this support that was giving the feeling of stability. My goal is to introduce tools that can help balance the range of difficulties, experiences, as well as daily care. Taking care of the skin on a residual limb is important in order to maintain an active lifestyle, and prevent complications.

To design an effective kit, with the necessary tools, I paid close attention to the order of care activities, as well as the steps that each amputee must go through.
I have understood that at the beginning, tools are different and that those actions need to be performed with caution. Over time, these activities become easier meaning the kit needs to adapt to the changing context within which it is used. It is also necessary that it can facilitate tools which will always be part of this new routine. (Photo 9, 12)
As an addition to the physical kit, I designed a digital platform to facilitate regular self-reports and ease connection with the prosthetist but, also to provide an option for sharing the notes and photos about the condition of the skin. (Photo 10,11) EMPEER is an application which is a digital extension of the kit. It gives space for daily notes about fit, feelings, and rehabilitation accomplishment. Option for voice recording makes it easy to document more complex information. App gives an easy way to share notes, recordings, and photos with a peer visitor as well as with a prosthetist. It also link the notes with weather, which helps track how atmospheric changes influence the fit of the socket.
In the beginning, the kit functions as a mat for performing the care routine in the seated position on a bed or the floor.

The pocket on the right provides storage for a shrinker, bandages, and surgical tape which would be used during the first stage of care.

The middle section is for regular check-ups. It has a compartment with a mirror, measuring tape, notebook, and voice recorder.

The left side has a soft towel mitten for drying the residual limb but also to provide the best way to desensitize the wound. There is also a pocket for the brochures with practical information.
The kit can also be hung.

When the kit is hanging, it can be fully open or partly zipped which creates a shelf, to give an extra surface while being used in the bathroom.

A partly closed kit also creates a privacy space when someone does not want to show their leg to others that might be in the same space.
The major part of empowerment is an ability to help yourself. To have the feeling of wholeness and acceptance towards own mind, situation, and body. It is about adjustments and feeling at peace with current situation.

The grieving process after losing a limb affects most amputees and may result in neglectful care of the residual limb which can lead to interruption in the healing and infections. I identified an opportunity with a prosthetic socket experience to improve the relationship between the amputee and their new body. To highlight this opportunity, I sought to create a link between taking care of the residual limb and establishing the ritual necessary to care of yourself.

Introducing habit of care right after amputation, not just before fitting with prosthesis for people who went thought traumatic limb loss and are facing the grieving process to help them gain an acceptance. I find this work important because those who haven't experienced all stages of the grieving process never properly accept themselves as an amputees which leads to a tendency to isolate themselves, which can be dangerous.

Rituals as a tool for dealing with grief cas have a various associations. There are plenty of established healing rituals related to religion, spirituality and culture. I choose to focus on enhance the routine by providing the right tools and experience to transform it into a ritual of
healing and acceptance.

Despite having three dimensional form; my kit unzips to a flat mat that contain organized tools in a functional order, provides a working surface and encourages keeping a self-report journal which can either be a notebook, voice recording or platform entry. Moreover, tools are redesigned to serve the purpose of building a better relationship with their own body. A towel in the form of a mitten adds a layer of intimacy into drying the residual limb along with providing a safe and easy tool to desensitize post amputation wounds. The form of the kit, intentionally does not resembles medial equipment. (Photo 13–15)
ACCESS TO RESOURCES

One of the most striking research insights for me was discovering that I already know more than some amputees. Despite the ubiquity of information, amputees are not highly informed — whether it is someone who has just undergone surgery or someone with a couple years’-long experience with a prosthesis.

Prosthetist as a primary source of information often does not inform the patient enough and does not encourage them to form communities within Amputee Associations. Some say it is because the danger of exchanging experiences with their fit and socket technology raise the threat of competition among doctors. The relationship between patient and prosthetist is very complicated. It comes to the point when the personal connection is more important for the patient than a proper fit. From the beginning, prosthetist have been the primary point of contact for answers and encouragement. A critical aspect of an amputee’s life. They might feel like they owe them for helping them walk again. This idea is not wrong — their relationship is crucial, feeling comfortable and safe is beneficial; however, often it may become something more like the toxic relationship. The ones who are involved do not see that it become a problem. Some amputees think that this is what they need to live with, and there is no better way.” Quite often, there are better ways to provide the right fit just not provided by one particular prosthetist.

Navigating this environment is particularly challenging because it is evident that most prosthetists care for the wellbeing of their patients and their work is an invaluable part of the amputee experience. However, I believe that the accumulation of professional support ought to transfer on to the peer visitor, who is trained to aid with this transition and has no interest in this relation, and at the same time is the person with the best expertise.

Talking with people who have experienced limb loss made me realize that they have expressed various perspectives on their abilities. Some realize they would have to adjust and that they can still do most if not all, that they want. It takes longer to figure out because they would have to modify their previous routines. People I met are perfect examples of that: Rose who is the founder of the New England Amputee Association which works on educating and bringing amputees together. Patricia who at the age of 19 lost a leg was helping others in the Rehab within a couple months even though she was still going through physical therapy. Robin who despite her motor accident keeps on driving her Harley and many more.

Unfortunately, people often react differently — they assume their life changed in such a profound way that their understanding of their remaining ability shatters and grows out of proportion. They set limitations
on themselves believing they can’t do anything they did previously and they are not hopeful of improvement. This kind of thinking is not only incorrect, but is dangerous and impedes their healing. It can lead to depression, which can cause lack of care and exacerbates other problems. Within my work I addressed those issues by facilitating a support system based on the contact with a peer visitor. This professional connection provides the knowledge needed by people with prostheses. Building the system that connects pertinent information to the patient is necessary before the surgery, if not available than, shortly after. Connecting Amputee Associations to local hospitals and building the network would work to a benefit of both, with an emphasis on the patient. Access to information and support from another amputee before the surgery or shortly after helps build realistic expectations, which are essential to deal with changes and to adjust after. This conversation will be one of the most important in their recovery process. When family and friends are not able to motivate a person to get over their loss, they need objective and evident proof that their life changed but is not worse.

“She knows what she says. She is not just somebody feeding me some information.” 

Linda

“When he came in we were just talking about different things, support groups etc. But we were just talking how is it feeling form somebody who has already gone through, it is like... yeah my life is not over I can continue doing things, and we actually talked about one of his trips where he went to one of the hotels and swimming (...) and he enjoy it and that helped me see that (he) is able to do that.” 

John

“...thank you for getting so many folks to come to the meeting and to share their experiences. Barb and I were blown away. It was great to meet so many folks who have dealt with amputation and moved beyond it, getting back to and enjoying life.”

Glenn
Each new amputee or someone whose amputation has been planed or suggested has access to a peer visitor. An experienced amputee who has expertise and knowledge can help and assist during the transition. This kind of pairing provides a much needed support system, as well as, access to information for the user.
After leaving the hospital their relationship with this peer continues, to avoid the feeling of hopelessness when faced with new challenges related to being on their own such as changing and adapting to their homes as well as dealing with grief. There are things that the majority of new amputees are trying to hide from family and friends as they don't want to be a burden and show weaknesses. Within the system, there is also a way to contact prosthetist in case of an emergency or significant changes of the residual limb.
REDEFINING DISABILITY

People with amputations are considered "disable." Wearing this kind of label is strongly related to identity; however people that I talked with said: "I don't consider myself disable, I am unable."

Everyone's identity shapes in a different way — we are being born with a particular set of "tools" — characteristics — we have our bodies with all their abilities and limitations. To perform beyond our congenial abilities, we invent an assistance and use technology. When we dive, we use scuba, to fly we use planes or parachutes. What helps us in those cases are our assistive technologies. Something that is peculiar is the way we call people who have been born without the limbs — congenital amputee. This nomenclature suggests they have had an amputation surgery, whereas in fact they have been born in the way which differs from what society perceive to be normal. Despite the fact that for them this is the body which is theirs and how it always looked. Without the influence of the environment they would have never thought they were abnormal. In those cases introduction to a prostheses seems unnatural — the embodiment of "norm" created by people who reflect on themselves as right — whole. In this scenario, it is a social environment which imposes specific abilities in this way creating disability. The disability which is not a human definition but societies of environments.

During one of the Amputee Association meeting that I participated in, I witnessed a fascinate conversation about disability and gender. The woman started a lively monologue about how much easier it is for men to accept amputation than for woman. She said that women are deeply disturbed by this change of their appearance. Her main goal is to hide a prosthesis and this became dominant agenda for her choice of clothing. Other woman in the meeting agreed, however also said that with time this become less of a problem. As an response to that statement, one of the present man told an anecdote how after fitting with prosthesis he went with his daughter who uses a wheelchair to the mall and was amused observing people react on them. This has to do a lot with personal perception of body image and self-esteem which is so much related with identity and accepting current state.
Disability is an interpretation of an impairment in a specific context. Any sort of discrimination has to do with the social perception of impairment. There are different ways to think about differences. When The Convention for People with Disabilities is changing the way we should interpret the law and guides us towards better understanding, of people whose lives might be different than ours. It emphasizes the importance of participation – “Nothing about us- without us” – and eliminating the labels, because as much as we would think about this- we are all the same and we are all completely different from each other, whether it’s job, interests, fears, skin color, gender, impairment etc. “we have the right to be the same when differences diminish us. We have the right to be different when sameness uncharacterized us”. 

Redefining disability is related to changing ones outlook on it, by promoting this progressive definition, changing existing visual language- like Sara Hendren ( Photo 16), and providing the guidelines to work with like my Variable Declaration.
Looking at the contrast between the synonyms of the word disable and Instagram posts of people with lower limb amputations is a great example of how inaccurate this word is.

<table>
<thead>
<tr>
<th>Disability synonyms</th>
</tr>
</thead>
<tbody>
<tr>
<td>aliment</td>
</tr>
<tr>
<td>defect</td>
</tr>
<tr>
<td>impairment</td>
</tr>
<tr>
<td>infirmity</td>
</tr>
<tr>
<td>injury</td>
</tr>
<tr>
<td>affliction</td>
</tr>
<tr>
<td>detriment</td>
</tr>
<tr>
<td>disqualification</td>
</tr>
<tr>
<td>drawback</td>
</tr>
<tr>
<td>inability</td>
</tr>
<tr>
<td>incapacity</td>
</tr>
<tr>
<td>incompetency</td>
</tr>
<tr>
<td>inexperience</td>
</tr>
<tr>
<td>invalidity</td>
</tr>
<tr>
<td>lack</td>
</tr>
<tr>
<td>unfitness</td>
</tr>
<tr>
<td>weakness</td>
</tr>
<tr>
<td>disablement</td>
</tr>
<tr>
<td>disorder</td>
</tr>
<tr>
<td>handicap</td>
</tr>
</tbody>
</table>

According to:
merriam-webster.com
thesaurus.com
Starting my thesis I focused on general research. I was working on understanding the complexity of the problem.

I started looking at the problems of people with lower limb prostheses at the beginning of my grad school. I have soon identified the prosthetic socket is the point of most potential within the spectrum of life quality.

I have been wanting to design the ideal, adjustable socket that would empower people by making their life so much easier and more comfortable. After talking with many people: amputees, prosthetists, physicians,
and psychologist, I came to understanding that solution might not be feasible — at least not for me during the time of my school.

People’s residual limbs are extremely different and their volume changes extremely frequently. It depends on physiognomy, activity and even time of a day. This made me realize that improving the design of current socket, would only be better for a limited time and for one person. That made me rethink the project, what can I do that would be more beneficial for people using prostheses.

I looked at the adjustment process, grief, acceptance, and image of self. Amputation introduce numerous changes and seems like a complete life transition. People experiencing it do not had proper tools and are not given any directions, they need to look for information by themselves. The Amputee Associations have recognized this problem and are training peer visitors to help facilitate information — which is also a mission of the Amputee Coalition.

**Amputee Coalition of America**

is a nonprofit organization based in Manassas, Virginia, United States of America. ACA’s mission is to reach out to people with limb loss and empower them through education, support and advocacy. 16
ECOSYSTEM

- New amputee
- Transition
- Adjusting
- Identity change
- Depression
- Grief
During summer before my thesis year I traveled to Vietnam to research the situation of people with prosthetic legs in local hospitals and clinics. I conducted interviews (Photos 32 – 34) and made observations which informed my thesis topic. I have been asking patients about their experiences with artificial legs, their relationship to this and experiences with it. The whole trip was eye opening for me, it showed me how fascinating and ingenious people who I am designing for are. I realized that what my work as a designer should be about change for better, providing improvements and being cautious on the context of my projects.
Photo 28 - home made prosthesis, utilized while waiting on leg from Red Cross.
Contextual interviews were evident in my process. I have been meeting with people for coffee and chatting to understand their life. Despite always having prepared set of questions each interview was different because my emphasize was primary on facilitating conversation, in which way I believe I was able to learn more.

I have conducted heavy secondary research, I was reading books, magazines, scientific journals, look at popular websites, and social media.

On one of the meetings I asked my users to address the “Thank you” note to their assistive technology to identify their relation with that object.

I participated in several Amputee Association meetings, sometimes just observing and listening to what they were talking about, hand what their perception of world looks like.
Talking with some people on the phone was an interesting and challenging task. It gave me an opportunity to ask specific questions.

During one of an Amputee Association meetings I asked participants to write down the schedule of a typical day with an emphasize on the objects and how they interact with them to understand if they are introducing the barriers or are helpful.

I was conducting experiments to understand forms of empowerment.

When I decided on designing the kit I asked one of my user to co-create it with me, together we identified what should be in the kit and what qualities should it have.
CONCLUSION

EMPOWERMENT

- TAKING CARE OF RESIDUAL LIMP
  - FUNCTIONAL KIT
  - PROVIDING INFORMATION
    - ACCESS TO RESOURCES
    - SYSTEM DESIGN + PLATFORM
- DEALING WITH GRIEF
  - PROVIDING ACCEPTANCE
  - REDEFINING DISABILITY
- HAVING CONTROL OVER LIFE
- RITUAL WITHIN THE KIT
- DECLARATION
SOLUTION

I decided to take on the space of emotional empowerment for people with lower limb amputation, by designing a kit that would provide the functional tools and necessary information for taking care of the residual limb as well as facilitate healing ritual aiming towards acceptance. The kit would be inherently involved in the system of support provided for a new amputee. Connecting local Amputee Associations with the hospitals, providing the hub of information and the option for caregivers to determine their role and show their care by providing the kit. One that doesn't look stigmatizing- currently all the care solutions for people with amputation are a medical tool, which only reminds people of their conditions. I want to make the appropriate tool kit that would correspond with their everyday life. Because taking care of yourself is not a medical requirement- it is a part of their routine. Routine which is crucial for the general well being influencing quality of life.
REFERENCES

Referred

16 “Amputee Coalition.” Resources and news for amputees, amputation, limb loss, caregivers and healthcare providers. N.p., n.d.

Other

Devlieger, Patrick et al. Rethinking Disability. World Perspective in
culture and society. antwerp, belgium: garant publishers, 2016
freud, sigmund. civilization and its discontents. new york: w.w. norton, 1962.
jain, s. s. “the prosthetic imagination: enabling and disabling the prosthesis trope.” science, technology & human values 24, no. 1 (1999): 31-54.
mattlin, ben. “cure me? no, thanks.” the new york times. the new york times, 22 mar. 2017. web. 6 may 2017.
video: from limb loss to limitless... (2013, july 16). retrieved may 07, 2017, from https://youtu.be/kt55a4dDWAw

magazines:
inmotion,
amplitude,
Katarzyna (Kasia) Matlak
Rhode Island School of Design
Master of Industrial Design 2017

kasiamatlak.com
kasia.matlak@gmail.com