

**Bespoke Design Meets Systems at Scale:
A Design Study with Judy Heumann**

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B.S. Mechanical Engineering
Olin College of Engineering, 2016

Submitted to the System Design and Management Program
in partial fulfillment of the requirements for the degree of
MASTER OF SCIENCE IN ENGINEERING AND MANAGEMENT
at the
MASSACHUSETTS INSTITUTE OF TECHNOLOGY
June 2023

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Abstract

This thesis documents a bespoke design process for disability; it also establishes its relevance to population-scale systems in caregiving and health technology spaces. As people with disabilities are the largest minority group and one of the most underrepresented in the world, it is crucial to recognize these unique challenges and address them through inclusive design practices. To do so, the study explores the sleep needs of Judy Heumann, a wheelchair user with evolving medical needs for assistive technology, and a world-renowned civil rights activist on disability inclusion. Heumann's daily sleep routine involved thirty minutes of building an intricate elevation device to support her lower body. If any part of the device was not properly tuned to her comfort levels, Heumann was unable to sleep. The study utilizes design thinking methodologies to deliver a working prototype that meets her functional needs and alleviates recurring pain points. The final thesis deliverable is a bespoke prototype for Heumann, integrating concepts from biomedical technologies and custom home adaptations. The prototype resembles an intuitive-origami-like setup including adjustable and collapsible features for comfort and travel. By using a design-for-one framework, the final prototype meets Heumann's material sleep needs and simultaneously reveals common pain points in systems where caregiving and health technology meet.

Concurrent to prototyping, the research expanded to other wheelchair users to investigate their overlapping and unique needs. Interviews revealed insightful latent needs and accompanying systems upstream and outside of the product context. This includes the economics and supply of human staffing while evaluating where smart home technology is heading. The aim of the thesis is to provide hybrid insights that blend technology and human services, where technology alleviates tedious burdens, and humans can be empowered in areas of connection and agency.

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Motivation

The motivation for this study is the stories of creative self-determination by people whose needs were not met or represented. There are countless stories of triumphant ad-hoc solutions and others of helpless frustrations arising from systemic crises like the current national shortage of caregivers. It is important to highlight these stories and recognize where systems design and engineering innovators can help.

Heumann's autobiography *Being Heumann: An Unrepentant Memoir of a Disability Activist* remarks how legislation intended for the disability community, is now universally beneficial - like curb-cuts and elevators. Many of these challenges are personal and systemic, yet established design frameworks cater to one or the other. As a current System Design and Management (SDM) student who was also trained in design thinking practices, I found an unexpected gap between these camps – one geared toward complex sociotechnical systems and the other in human-centered product design. There are great advantages applying either independently; however this thesis required a deep ethnographic and transdisciplinary approach. While looking closely at one user and her complex artifacts and systems, this thesis suggests approaches and analysis for wider-scale application.

Acknowledgement

I would like to express my sincere gratitude to my thesis advisors Professor Sara Hendren and Professor Warren Seering for their guidance, support, and invaluable feedback throughout the entire research process. Sara, your class, Investigating Normal 9 years ago at Olin College of Engineering, has played a pivotal role in shaping my understanding of disability, and I cannot thank you enough for thinking of me for this project. Your continued work in this field inspires me, and I am forever grateful for your support. Warren, I want to express my sincere gratitude for your unwavering support throughout the course of this thesis. Your keen insights and thoughtful feedback have been invaluable to me, and your encouragement has been a source of motivation throughout the process. Thank you for being an exceptional advisor and for sharing your expertise with me.

I would also like to express my deep appreciation to my mentor, Chris Hinojosa. Your invaluable insights and advice throughout the thesis have played a pivotal role in shaping my work. I am truly grateful for your support and for consistently challenging me to think critically and deeply. Your mentorship has not only contributed to my professional growth but has also had a profound impact on my personal development.

I would also like to express my gratitude to the Boston Center for Independent Living (BCIL). I am thankful to Bill Henning for connecting me to the wheelchair using community at BCIL and for his tireless efforts in advancing equity and inclusion. I would also like to thank Tony Hu and Andy MacInnis for welcoming me into the Integrated Design and Management (IDM) studio space and supporting me throughout the build phase during IAP. Furthermore, I'd like to thank my SDM community for their unwavering support throughout my time at MIT.

I extend my sincere appreciation to my friends and family for their support, love, and encouragement throughout this journey. Special thanks to Carmen de la Sierra Cauley for being my companion as we finished our theses, to Kevin Liao for assisting me in resolving LaTeX bugs, and to Miriam Riad for her valuable editing contributions. And to my parents and sister, thank you for your unconditional love, prayers, and being my biggest cheerleaders.

Lastly, I want to thank the late Judy Heumann, her husband Jorge, her cook Martha, and her assistants Kelila and Kylie. The opportunity to dream, create, and collaborate with all of you has been an extraordinary privilege. I am grateful for the trust you placed in me and for welcoming me into your home.

Thank you all for your contributions, support, and belief in me. This thesis would not have been possible without each and every one of you.

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Act I - Design for Judy Heumann

1.1 Meet Judy Heumann, Mother of Disability Rights

Judy Heumann was a world-renowned disability rights activist who committed her life advocating for the civil rights of the disability community. She was also a post-polio wheelchair user with little mobility in her legs and moderate mobility above her torso. Growing up in a world without ADA (Americans with Disability Act), Heumann navigated a world void of curb cuts and building ramps with pervasive social stigmas that limited her schooling and vocational options. Her career highlights include suing the U.S. Board of Education [9], spearheading Section 504 legislation [2], and special advising to the President of the United States. Please refer to Heumann's autobiography *Being Heumann – An Unrepentant Memoir of a Disability Rights Activist* [7] or www.judithheumann.com to learn more.

After seven months of collaboration, Judy unexpectedly passed away. She is sorely missed.



Figure 1-1 - Portrait of the late Judy Heumann

1.2 A Setup of People, Parts, and their Interactions

Early summer of 2022, I was introduced to Judy by my undergraduate professor from Olin College of Engineering, Professor Sara Hendren. At the time, Judy was 74 years old and had developed a sleeping routine that involved raising her legs with a pyramid of soft goods involving dozens of towels, pillows, and blankets that she had collected over the years (Figure 1-2). Its original design intent was to improve blood flow after sitting in a wheelchair all day; however, Judy's sleep setup had become increasingly intricate over the years, as her changing needs required further material specificity and nuanced tunings.

Building the setup required careful configuring and positioning of each item based on Judy's instructions and feedback, taking up to thirty minutes on a good day. However, there were frequent variations in the routine, like when training a new assistant, adjusting to a hotel room, or even adapting to temperature differences. Judy's set of parameters for feeling comfortable was constantly changing, making the setup process inefficient and in need of streamlining to accommodate these variations. Furthermore, the setup did not fit into a standard check-in suitcase during travel. As a frequent traveler, Judy would have to sacrifice half of the setup and rely on hotel towels to fill the gaps. Therefore, she sought out support in streamlining the setup while addressing these pain points.



Figure 1-2 - Judy Heumann's Setup of 33 pillows, blankets, and towels

1.2.1 The Current Setup

I visited Judy at her home in Washington, DC on October 20, 2023, to interview her and gain a better understanding of her setup. We chatted for an hour about the history of her setup before spending the next two hours observing her routine. Although the setup appeared complex at first, as Judy explained each step, we were able to break it down into four main parts, completed in chronological order: Staging, Baseline Elevation, Comfort Elevation, and Micro-Adjustment.

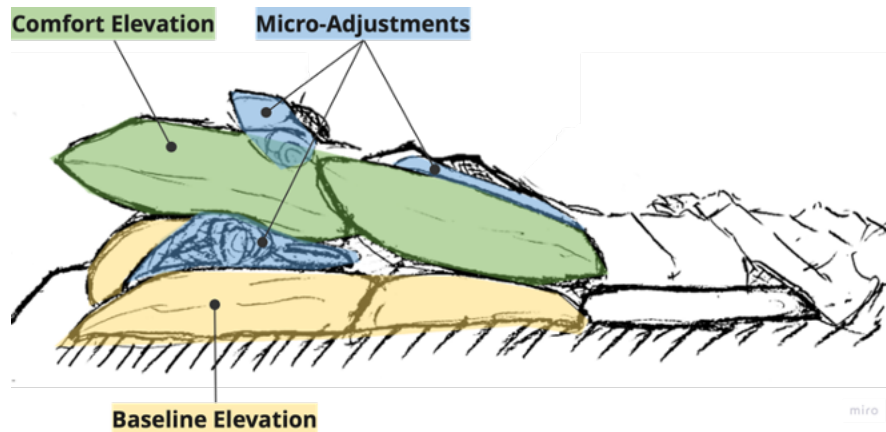


Figure 1-3 - Abstracted Setup Modules

Staging During this stage, attendants are instructed by Judy to clear the bed of any household items while she positions her wheelchair in front of the bed for transfer. This stage is particularly precarious because transferring requires careful coordination to maintain Judy's balance and prevent any accidents.

Baseline Elevation During this stage, attendants are instructed to lay pillows, similar in color and stiffness that act as the setup's foundation.

Comfort Elevation During this stage, attendants add layers of pillows and blankets over the baseline pillows. These additional pieces further elevate Judy's legs and provide a soft and supportive surface for her skin to rest on.

Micro-Adjustments During this stage, attendants insert flattened hand towels throughout the setup, providing slight elevation. Towels are also tightly rolled and inserted under Comfort pillows to support overall structure.

The full representative interview observing the setup, capturing frame-by-frame steps, can be found in Appendix A.

1.2.2 Observation Analysis

After observing and transcribing each step in the process, it was important to further analyze the observations by quantifying areas with and without Judy's intervention. These metrics represent the difficulty of each step as well as the level of feedback needed at each stage. This was done by counting intervening action words given by Judy and tasks done without shown in Figure 1-4. Additionally, Figure 1-5 visually represents the clusters of tasks done in sequence as well.

Staging

- 1) She **instructs** her two assistants, Kylie and Kelila, to clear the bed of any household items like the remote or her husband's belongings.
- 2) Judy precisely **positions** her wheelchair to be optimally **pulled** onto her bed.
- 3) Judy **instructs** her assistants to lift her feet then proceeds to drive wheelchair into bed.
- 4) She **removes** her glasses and her wheelchair add-ons, **unbuckles** her seatbelt, and **instructs** to remove her sandals. All to prepare for wheelchair transfer.
- 5) Kylie **climbs** onto the bed to securely grip Judy's calves while Kelila keeps her upper body balanced and supported.
- 6) Synchronously, Judy's assistants **transfer** her from wheelchair to bed. Her position is adjusted as Judy is pivoted.

Note – What makes it hard is the softness of the bed. The softer it is, the traction we don't get. The firmer, the more slippery. Opposite of drag.

There's a lot of variability.

Baseline Elevation

- 1) Judy is slowly **laid flat** along her side of the bed.
- 2) Judy **asks** Kylie to close the bedroom door to open closet door.
- 3) Judy **asks** to pull out 2 red pillows.
- 4) Judy **instructs** to place pillow with plastic wrap [P-THIGHS1] underneath and between knee and hips.
- 5) Kylie **holds up** Judy's calves and Kelila **places** pillow right under her thighs, **butting up** against her bottom.
- 6) Judy **asks** to put other red pillow [P-CALVES] up against first pillow and under her calves.
- 7) Kelila walks into closet and pulls out another set of pillows.
- 8) Kelila **pushes** blue pillow [P-RHIP] partially under right hip to elevate hip, support right elbow, and keep right shoulder aligned.
- 9) Judy **asks** Kelila to pick up her right arm to place on [P-RHIP].
- 10) Kelila **places** beige pillow under left hip. Judy notes, "Move hips to be as straight as possible".

Note – When sitting, Judy leans to the right all the time. There's a lot of pressure. Needs more support on right side to give a lift.

Figure 1-4 - Partial analysis of observations. Yellow highlights instructions given by Judy and grey highlights tasks performed without instruction or done on her own. Complete analyzed observations can be found in Appendix B.

As a result, there was a total of 65 completed tasks where Staging and Baseline Elevation (BE) comprised of 33% of the tasks, Comfort Elevation (CE) comprised of 42% and Micro-Adjustments (MA) comprised of 20%. Interestingly, the lowest percentage of Judy's intervention is shown in the MA stage, which made up 67% of the total tasks. Though CE required the highest amount of intervention, CE only comprised of 12 tasks compared to 44 in MA. What's important to note is that up until CE, Judy's two business assistants were building the setup and weren't as familiar

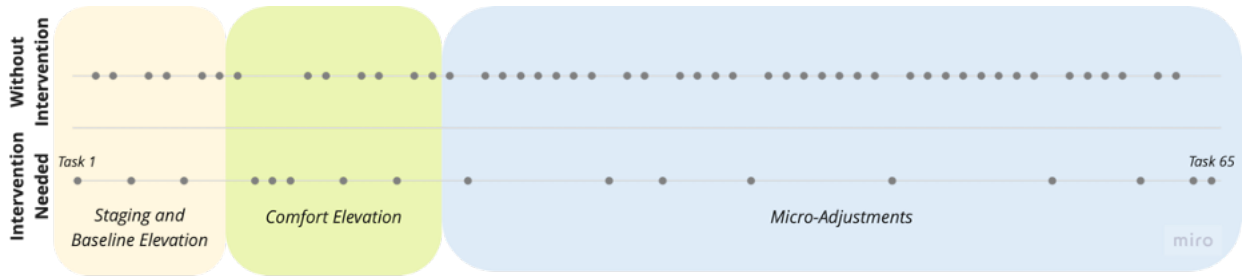


Figure 1-5 - Visual representation of tasks completed chronologically identified with or without intervention

with home protocols. During the MA stage, Judy's experienced live-in cook, was called in and took over. And as expected, Judy's intervention levels dipped despite the density of tasks. The data suggests that her first two assistants didn't have as much experience, so Judy had to intervene more frequently. Therefore, there is a clear need for ease of training in the new setup.

	Staging & Baseline Elevation	Comfort Elevation	Micro-Adjustments	<i>Sum</i>
Intervention Needed	3	5	9	17
Tasks Without Intervention	6	7	35	48
<i>Sums</i>	9	12	44	65
% of Intervention	33%	42%	20%	26%

Figure 1-6 - Count of tasks performed with and without intervention for each setup module

1.2.3 Needs Analysis

A part of observation is investigating the explicit unmet needs requested by the user but also finding latent needs and values that aren't as apparent. It is important to confirm and inquire about the existing solution while also teasing out unspoken practices.

As such, Judy's needs can be categorized into four major buckets: Utility, Comfort, Relief and Proactive Care shown in Figure 1-7. These categories are distinct but also overlap in context. For example, Judy's toes must be cleared and not touch anything. This is purely a function of sensational comfort than to proactively manage her health or find relief from previously accumulated tension. Furthermore, it is important to distinguish between her physiological needs and setup needs.

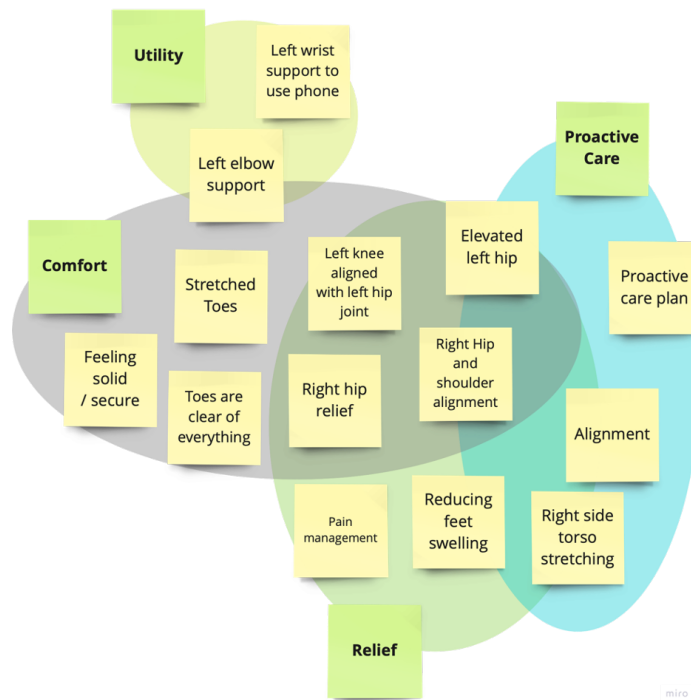


Figure 1-7 - Diagram of Judy's Needs Categorized by Utility, Comfort, Proactive Care, and Relief

After understanding Judy's needs, it was also important to understand the functionality and utility of the setup. Figure 1-9 shows an exploded, top view of the setup, annotated. Each part was then assigned a label, description, function, keywords, and

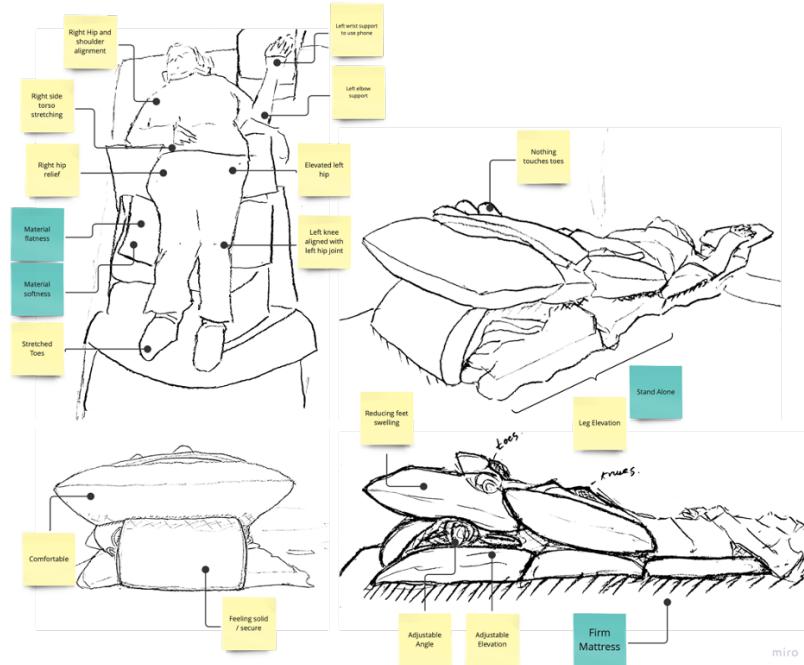


Figure 1-8 - Judy's needs mapped to her body and setup

utility score shown in Appendix C. The scores were empirically given based on interviews* and observations. By dissecting each part and their interrelation to each other, I'm able to understand the net delivered value rather than the pure mechanics of the current setup.



Figure 1-9 - Annotated parts of exploded setup

*Interviews are described in 1.4.1

1.3 The Current Market for Overnight Incline

Scale is often the goal in standard product design and development practices. Generally, the framework involves market gap research, development and testing, and mass distribution. It is a well-tested and refined model that has significantly contributed to daily efficiency and value. However, design for scale is a core principle in DFM, or design for manufacturing, which is driven by financial margins. Though many products are intended to meet needs, this ideal becomes expendable to keep DFM costs low. The reality is that average-based products do not meet the needs of all people, particularly those living with disability. For example, products on the market do not consider the body's need to incline overnight. According to Judy, many products miss the mark and feels like they “have never been tested.”

Durable Medical Equipment (DME) is one category where products, meant for a categorical need, miss the mark. Some examples of DMEs include wheelchairs, walkers, alternating pressure mattresses, positioning wedges, and BiPap machines. They are designed to be durable and reliable but not always adjustable or necessarily comfortable. Bennett, a physical therapist for In-Home Orthopedic and Home Care, mentioned that DMEs are not made for asymmetrical bodies. In other words, DMEs are not mindful of our body's inevitable changing condition rather driven by a clinical framework on what's deemed medically necessary.

Products for Elevation On my first visit, we tested two products for feedback. Unsurprisingly, products marketed for leg elevation, swelling reduction, alignment* – all of Judy's needs – were highly uncomfortable for Judy (shown in Figure 1-10). Judy knees rolled outward causing misalignment and eventual discomfort. As shown, the product was too big for Judy's legs and did not provide the support she needed.

*<https://www.amazon.com/LightEase-Post-Surgery-Elevation-Elevating-Sleeping/dp/B087TR1X4R/?redirectFromSmile=1>



Figure 1-10 - Testing off the shelf elevation pillow

Products for Portability Portability was also a critical design characteristic. Since Judy travelled for a third of the year, ease of packing and assembly was important to consider. Therefore, we tested an inflatable wedge pillow[†] shown in Figure 1-11. However the setup felt insecure and unsupported. We attempted to supplement the product with her original set of pillows but it still felt too “wiggly.” Judy also noted that these products were probably designed for temporary relief and may not have been tested overnight.



Figure 1-11 - Testing off the shelf inflatable pillow

[†]<https://www.amazon.com/Elevation-Inflatable-Sleeping-Circulation-improving/dp/B09NVX6YSL/?redirectFromSmile=1&th=1>

Products for Modularity Other products include modules* to attach wedges as needed. However, material selection turned out to be a vital feature for Judy, and many products were homogeneously too soft or too stiff, sinking her legs or causing discomfort. She needed a material configuration that were both soft for skin contact and durable for leg support.

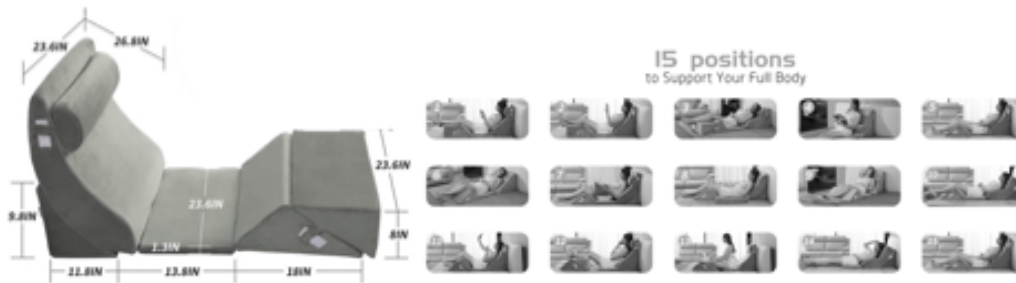


Figure 1-12 - Off the shelf bed wedge pillow set for post-surgery relief

Products for Active Relief Another corner of the market is a bed that dynamically changes pressure to prevent bed sores. Alternating pressure mattresses is seen as a good solution because the user can control pressure levels and inflation cycles throughout the night. Additionally, alternating pressures (Figure 1-13 promote circulation in bodies with limited mobility while alleviating overnight aid. However underlying issues like cost, access and stigma make product adoption difficult. The alternating pressure mattress from Vive Health* is upwards of \$499.99 with a 1-year warranty. In an interview, Dianna, a quadriplegic wheelchair user, told me her alternating mattress lasted only a few years before it was too difficult and expensive to repair. She’s currently using a static air mattress while having her personal care attendant turn her throughout the night. Access is also an issue because alternating mattresses were designed for hospital settings, making them bulky and unfit for homes. Furthermore, because it is primarily used in hospitals, it is tagged with medical stigma – something many in the disability community try to detach from. Another interview with Franklin, also a wheelchair user, wouldn’t use it because he doesn’t

*<https://www.amazon.com/Qirroboni-Orthopedic-Adjustable-Pillows-Comfortable/dp/B09KBLGYLL?th=1>

*<https://www.rehabmart.com/product/alternating-pressure-mattress-vive-health-50209.html>

want to be portrayed as a patient.



Figure 1-13 - Off the shelf alternating pressure mattress with 16 programmable air chambers to prevent bed sores

Though products on the market addresses key needs, there is a lot of room for improvement. As human bodies are complex systems that consist of complex set of needs, the solution is rarely singular. That's the case for Judy – her body is an interconnected system needing alignment, relief, and comfort. And each piece of hardware in her current setup play in concert with each other – spatially and materially to deliver a spectrum of functional use.

1.4 Qualitative Research

1.4.1 The Lives and Sleep Experiences of Six Wheelchair Users

In addition to designing for Judy’s needs, it was also important to expand the research frame and interview other wheelchair users. Through the help of the Boston Center of Independent Living, I conducted 1-hour interviews with six wheelchair users to discuss their sleep experiences. The goal of these interviews was not to deliver prototypes but to relate their experiences with Judy’s. With their permission, I’ve synthesized what they’ve shared in Figure 1-14. The interviews can be distilled into five personas:

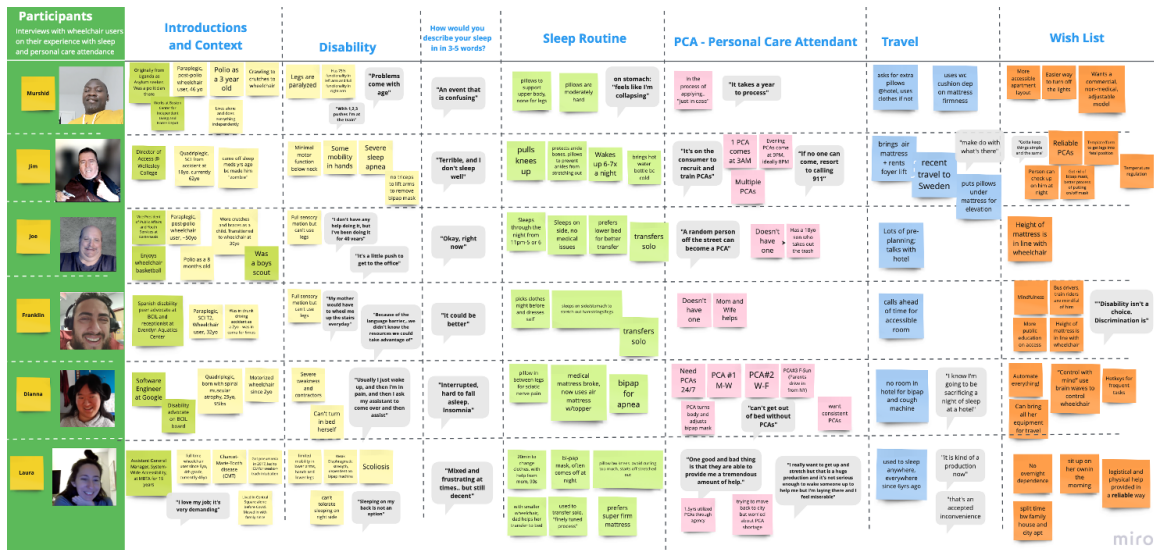


Figure 1-14 - Interview notes organized by context, disability, sleep routine, experience with PCAs, travel, and wish list

The Hesitant Traveler The hesitant traveler may have attempted to travel in previous years but have had poor experiences from the lack of accessible facilities or traveling constraints. Now they may not think it’s worth the hassle. If they must travel, they have an exhaustive checklist packing necessary equipment and chargers, calling ahead to ensure hotel rooms are accessible and spacious for gear accommodation, and notifying airlines of fragile equipment during transport and flight. They also need to plan out scheduling and logistics for their PCAs as well. Some travelers may have the means to hire PCAs for the entire trip, but most rely on friends and

family travelling with them which can be a pain-point in delivered care.

The Uninformed Newcomer The uninformed newcomer can be an immigrant or a state transplant unaware of available resources provided by the state. Sometimes the newcomer can get by without resources, given their level of autonomy, or can depend on friends for help. Many times, the newcomer is overwhelmed by the process in applying for benefits because of the time involved and requirements constantly checked by the agency.

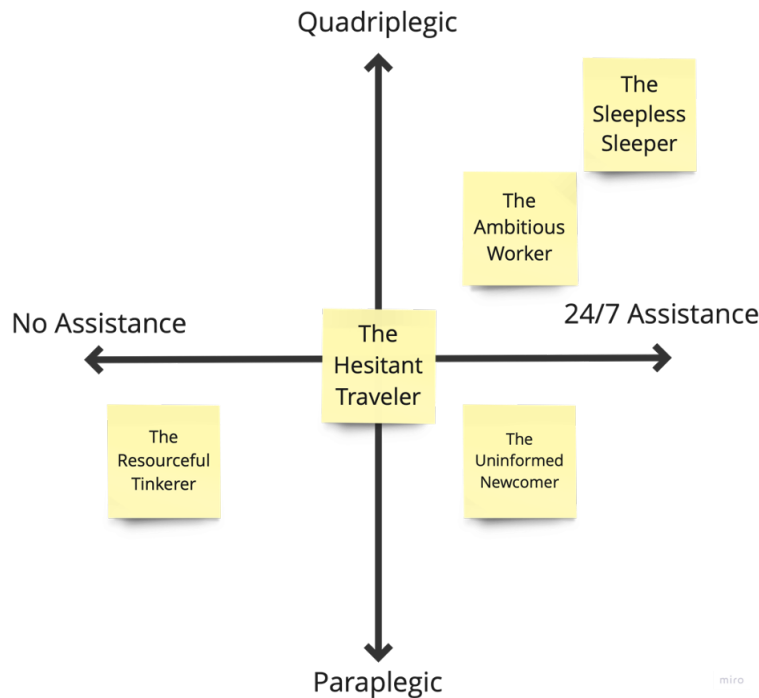


Figure 1-15 - Map of mobility and assistance.[†]

The Ambitious Worker The ambitious worker is a high performer and has many accomplishments at their place of work. They desire to be known by their performance but are also very involved in advocacy and pushing for accessibility in the workplace. The ambitious worker often has high needs and are accompanied by their PCAs nearly everywhere they go.

The Sleepless Sleeper The sleepless sleeper requires regular overnight assistance, often for body turning to avoid bed sores. Other times, they need assistance adjusting

[†]Note built personas and their mobility map placements are intended to reflect use cases from interviews and do not represent all disability populations.

their BiPAP or CPAP masks to breathe properly. They are often laying in discomfort in the middle of the night while waiting for their PCA to come. If their PCA is available during an emergency, the sleepless sleeper calls their neighbors or 911, if life-threatening.

The Resourceful Tinkerer The resourceful tinkerer adapts wherever they go. They can perform daily tasks on their own and don't like asking for help, even family. Whenever they travel, they makeshift their environment to fit their needs and aren't afraid to ask for what they need. Upgraded assistive gear isn't at the top of their wish list; rather, desires the public to be more mindful and aware of people with disabilities.

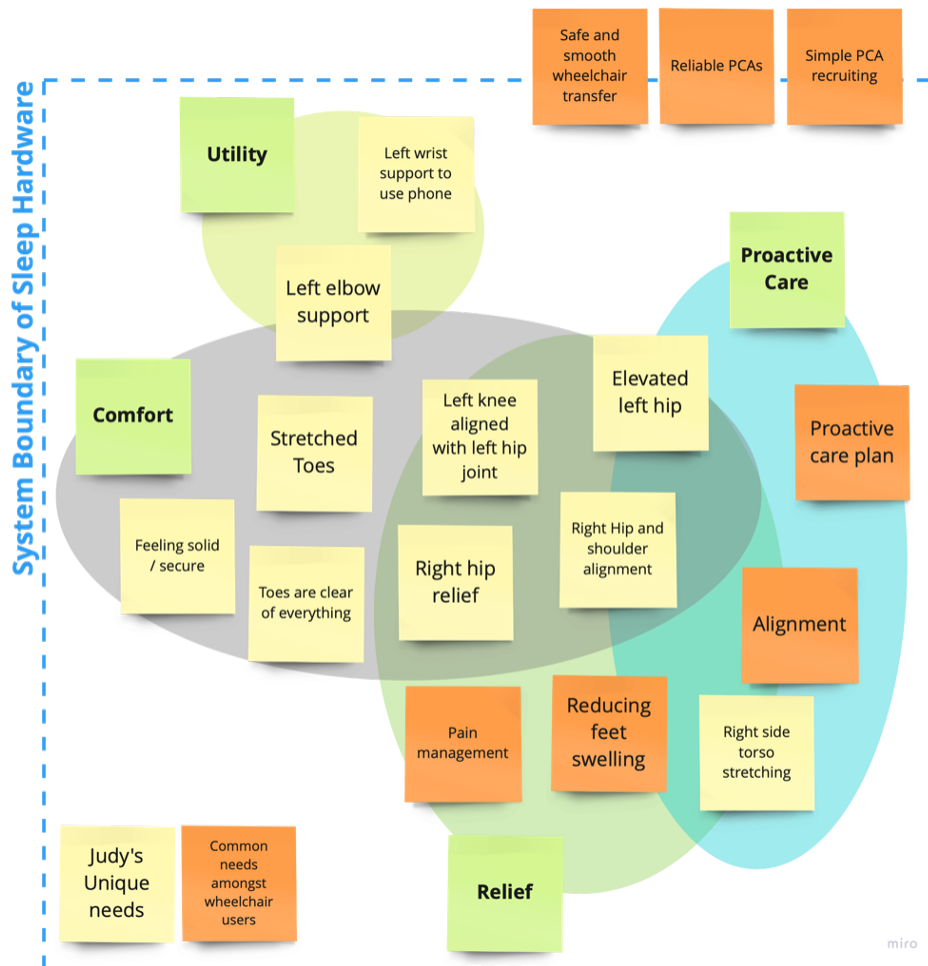


Figure 1-16 - Diagram of unique and common needs amongst wheelchair users

The map in Figure 1-15 reflects where personas lie across the spectrum of mobility

and needed assistance. Furthermore, when connecting common themes from interviews to Judy's diagram of needs in Figure 1-7, we discover her apparent set of needs extend beyond the system boundary of pure hardware shown in Figure 1-16. Judy and the interviewed wheelchair users all require a unique setup to meet their needs, some simple and others more involved. At the same time, themes like pain management, feet swelling, alignment and proactive care are consistent across users. The prevailing themes however laid on the fence of the system boundary. Wheelchair transfers and PCA management were dominant pain points that highly influence quality of sleep and daily routines. Therefore, systems to address these prevalent hurdles are needed.

1.4.2 The Sleep Experiences of Eight Engineers

Sleep is a universal experience, always on time and vital to human health. After chatting with wheelchair users, I further investigated the sleep experience, but this time for eight engineers who do not use wheelchairs and are able-bodied. This study was conducted through an afternoon design workshop where we gathered around tables pushed together in a studio at MIT. With little context, I started with a couple of questions, "Can you describe your sleep?" then, "Can you draw your sleep experience?"

What resulted were varied responses of peaceful and miserable experiences. On one hand, Person A drew their experience like a campfire, peaceful and waking up with the sun. Person C and H also drew themselves within and as a box, falling into deep asleep and cannot be bothered, like they're on another planet. Similarly, Person F's jumbled thoughts flatline when it's time to sleep. On the other hand, Person B is wide awake and Person D's thoughts get louder and harder to turn off at the precipice of sleeping. And lastly, there were experiences that seemed more materially dependent than psychological. Person G drew their room, organized, to ease into their sleeping routine and Person H is shown turning in bed, trying to get comfortable.

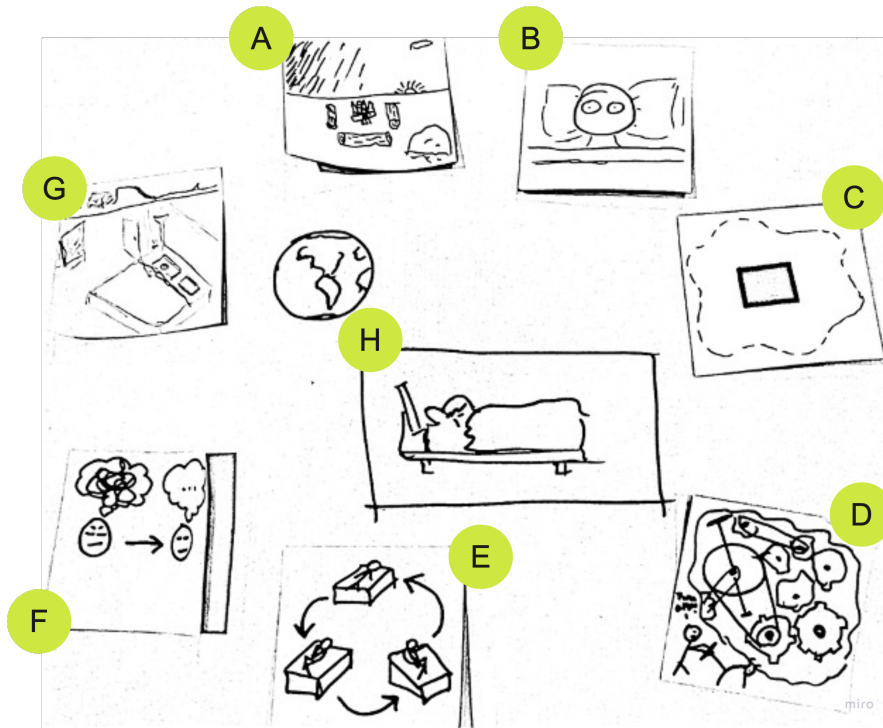


Figure 1-17 - Sketched Sleep Experiences of Engineers

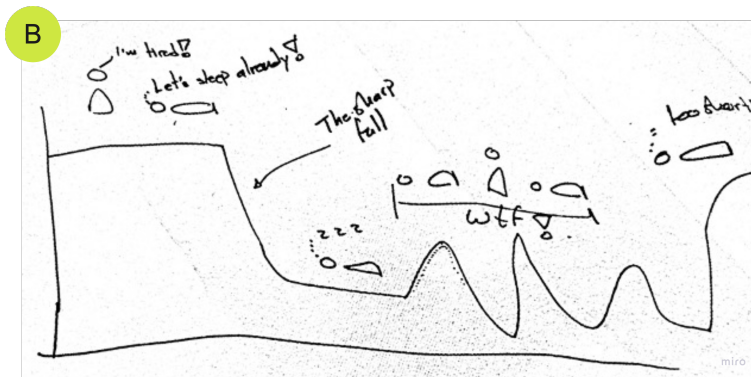


Figure 1-18 - Person B's Sketched Sleep Duty Cycle

By no means does the qualitative research reflect the entire sleep experience; however it offers key insights suggesting that it is a complex problem tied to the lack of products and services for the disability community and the prevailing mental health challenges keeping people, with and without disabilities, up at night.

1.5 Accompanying Systems in Caregiving and the Economics of Human Staffing

The vision of the smart home is meant to ease home operations and routines, possibly automating them. Practical use cases include assisting the aging population, those in rehabilitation or those navigating chronic realities. With the current shortage in caregiving personnel [13], there is a rise in caregiving robotics like Stevie, a Socially Assistive Robot [11] that provides companionship and medication reminders or Robear, a lifting “care” robot [15] that transfers patients. There are more commercial solutions like Voice Assistants like Alexa or Google Home that can seamlessly open window blinds and turn on lights. But what is often missing with automated protocols is flexibility and understanding the nuances in differentiated needs, not to mention affordability.

In today’s climate, the pursuit for full automation within caregiving may be due to the shortage of personal care attendants (PCA) and more significantly the systems supporting them. Applying for, recruiting for, and retaining PCAs are consistent challenges noted by interviewees and covered by national news over the years [14]. To receive state funds for a PCA, the consumer must be on MassHealth, a joint state and federal program offering Medicaid and Children’s Health Insurance Program (CHIP). The consumer then needs to in contact with a Personal Care Management agency who determines their eligibility and analyzes daily living needs for appropriate services like activities for daily living (ADL) or instrumental activities of daily living (IADL). ADLs include mobility, dressing, bathing/grooming, toileting, eating, taking medication, and passive range of motion exercises. IADLs include laundry, cooking, shopping, housekeeping, and meal preparation. The agency then sends an occupational therapist or nurse for evaluation and reports to MassHealth on the number of hours/week the PCA is approved for. Then it is the consumer or surrogate’s responsibility to recruit, hire and train PCAs. However because of the shortage, consumers have had to default to public ad posts or friends and family instead of finding trained professionals.

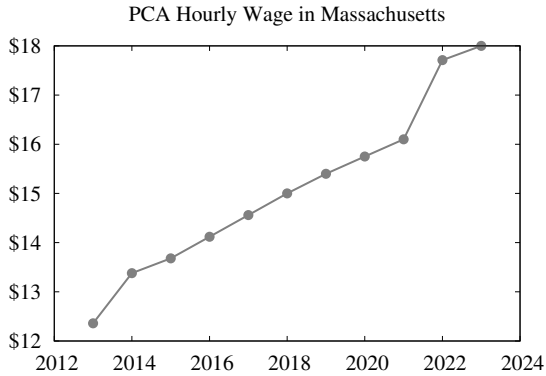


Figure 1-19 - PCA hourly wage in MA from 2013 to 2023 [12] [6]

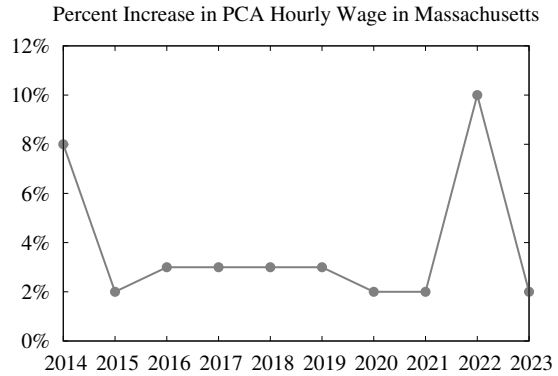


Figure 1-20 - Percent increase from previous year's hourly in MA from 2013 to 2023

The PCA wage is negotiated by 1199SEIU, a healthcare union in the United States, while the consumers are represented by the PCA Quality Home Care Workforce Council [3]. In the state of Massachusetts, there has been a steady increase of at least 2% to most recently a 10% wage increase. As of April 1, 2023, the PCA wage in Massachusetts is \$18 an hour [1]. In such a precarious staffing context, the role of new technologies and their deployment by skilled caregivers is shifting. What new blends of human care and designed tools will be optimal for wellbeing in the future?

Act II: Building for One, Sketching for Many

2.1 Design and Dream to Delight

2.1.1 Problem Decomposition and Clarification

After user visits, research, and observation, the following stages focused on problem clarification and idea generation involving functional decomposition, individual and collective brainstorming, and codesigning with Judy. Each phase cyclically diverged and converged on ideas which were tested through iterative sketching and prototyping.

Problem decomposition is defined as the breakdown of a broad problem statement into smaller parts. The goal is to understand its sub-problems, making the problem more approachable. This includes decomposing the problem into Level 1 and Level 2 parts. “Two down, One Up” is a common principle in System Architecture [4] that states that the “goodness of a decomposition Level 1 cannot be evaluated until the next level down has been populated and the relationships identified.”

By decomposing the setup functionality, we can abstract them into primary players, operands, and processes. This is reflected in the functional diagram shown in Figure 2-1. It is important to note The Consumer and the Setup are within system boundaries for this design study whereas components outside the boundary are drivers affecting the consumer experience and setup and are not controlled for. The full system diagram includes the following components:

- The Consumer*: the consumer is any person with a disability using assistive technology.
- The Setup: the assembled hardware that supports the consumer’s body for relief and comfort.

*According to Mass.Gov, the PCA consumer (the person receiving PCA services) is defined as the employer of the PCA, and is fully responsible for recruiting, hiring, scheduling, training, and, if necessary, firing PCAs

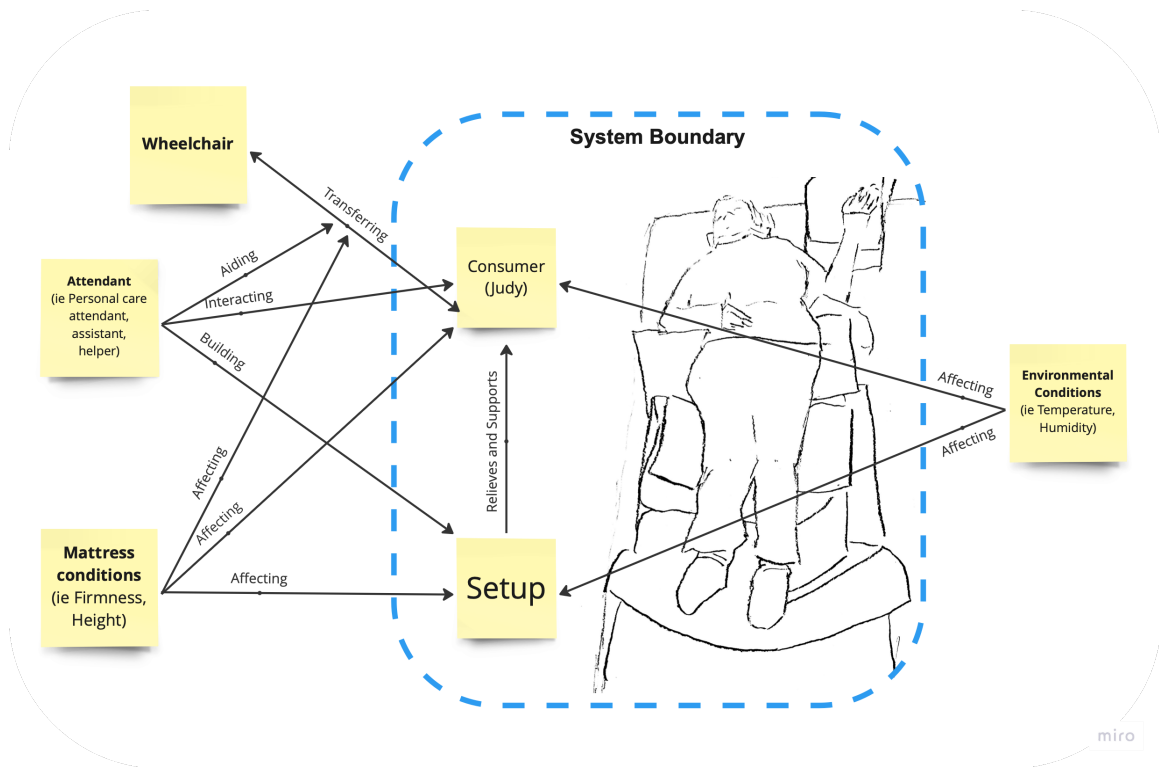


Figure 2-1 - Functional Diagram including elements within and outside system boundary

- The Wheelchair: the wheelchair is an integral part of the user’s daily life and routine including sleeping rituals. While in the wheelchair, Judy positions herself in front of the bed and her attendant transfers her onto the bed safely and smoothly.
- The Attendant*: The attendant interacts with Judy by assisting in wheelchair transfer and setup build. The attendant can be one or both of her executive assistants, her live-in cook, or a hired personal care attendant (PCA).
- Environmental Conditions: conditions like room temperature or humidity can affect Judy’s sleeping comfort. For example, if it’s too hot, Judy may pull her blanket which inadvertently destabilizes and collapses the setup.
- Mattress Conditions: conditions like firmness and height can affect the wheelchair transfer process because the wheelchair seat and mattress planes should be col-linear for smooth transfer. Likewise, firmness is also important. If too soft, the

*A PCA is a person recruited by the Consumer and physically assists in performing ADLs (activities of daily living) and IADLs (instrumental activities of daily living)

increased mattress drag causes Judy to sink, requiring more force to transfer and making the process more precarious.

2.1.2 Setup Needs

After breaking down the problem and understanding product gaps in relation to Judy's needs, we can identify product needs and generate concepts shown in Figure 2-2. Judy highly rated and emphasized Comfortable and Intuitive in the list given. The following lists the rationale behind each need:

- Comfortable: Setup needs to be comfortable or else Judy won't get quality sleep. This is a critical yet difficult requirement as it requires tight feedback on how Judy's feeling for the day.
- Intuitive: Currently the setup takes over thirty minutes to build. The setup needs to be intuitive for seasoned and new attendants, requiring little training.
- Simple: Setup needs to be simple to use and simple to repair. Affordance is especially important as new attendants are unfamiliar with the routine and setup.
- Reliable: Since the product will be used at a daily frequency, it must perform reliably during use and storage.
- Durable: Setup needs to be durable for travel.
- Adjustable & Repeatable: Judy's conditions daily vary so her setup needs to be adjustable to match her comfort level. Setup parameters should be repeatable to maintain consistent comfort levels or protocols for proactive care.
- Customized: Related to comfortable, the setup needs to be catered to Judy's bodily needs.
- Travel friendly: Setup needs to fit within a check-in suitcase.
- Collapsible: Setup needs to collapse for quick and easy transfer.
- Modular: Setup needs to be modular to address comfort variability.
- Relieving: Setup needs to relieve Judy's body as overnight incline is a form of therapy.

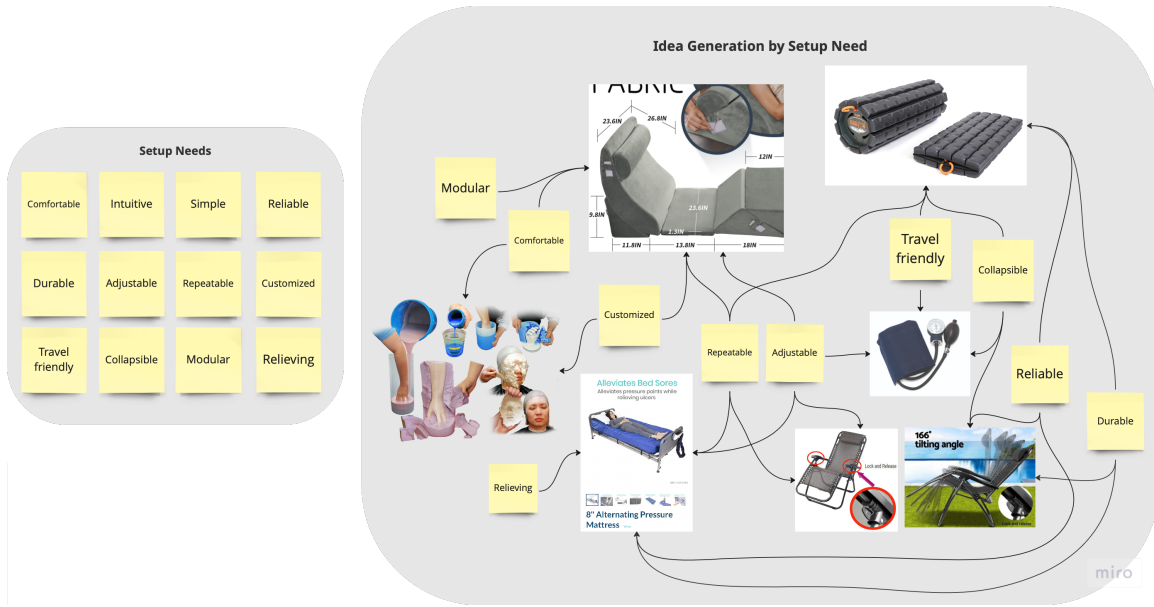


Figure 2-2 - Ideas by Setup Need

2.1.3 Concept Exploration

During ideation, Judy and I brainstormed tech-inspired solutions. I posed the question, “What is your dream setup?” to her. And as we dreamed up ideas, questions exploring what automated care could look like and whether the smart home is the ideal solution also weaved in and out of ideation. The Wired article, *The New Frontier of Prosthetics? Tech for Independent Living* by Sara Hendren, [10] further investigates this idea and cites Judy’s distinction of self-determination and self-sufficiency, a dichotomy between authentic agency of making one’s own decisions around care, and autonomy to complete tasks alone. Hendren highlights Judy’s argument that solo living is not a robust definition of independence.

One avenue in practicing self-determination is through one’s data. By utilizing wearable and biosensor technology, the user can make decisions based on the generated data while improving communication efficiency and efficacy. For example, one identified pain point was the steep training curve in building the setup not just for new attendants but current ones including family and friends. This was evident in my visit observing the routine. The burden was on Judy to share her needs every night to train the attendant and adjust the setup parameters if she needed it. Otherwise,

she would get bad sleep, accumulating exhaustion, stress, and pain.



Figure 2-3 - Ideas for process

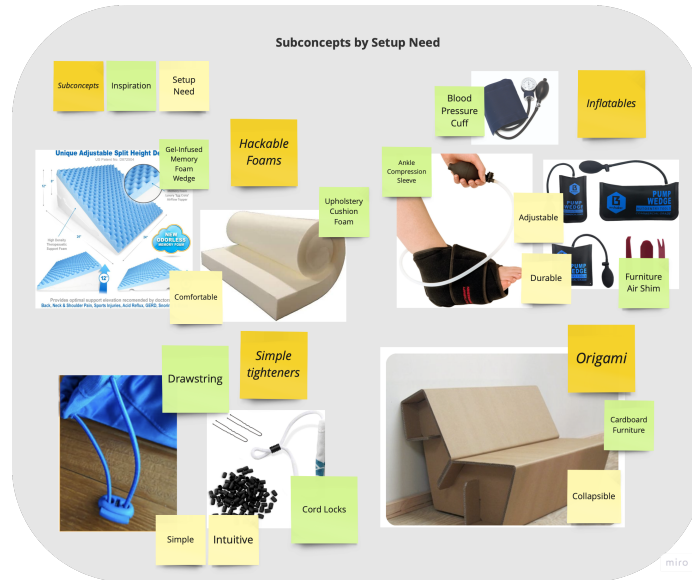


Figure 2-4 - Ideas by subconcepts

There was a high need for alternatives to communicate her needs that were also reliable and repeatable. This inspired ideas in current wearable technology shown in Figure 2-3. The idea was to track Judy's overnight physiology including heart

rate, movement, sleep cycles, providing resolution and perspective. For example, the Whoop band* or Oura ring† are common wearables that, among many features, can track sleep stages and pinpoint when the user is awake, in deep sleep and in between. We thought to collect Judy’s sleep data, observe her sleep stages and experiment with setup parameters to improve sleep quality. The data can also help precisely determine PCA scheduling, specifically when the attendant should check in throughout the night. Judy mentioned she didn’t want to wake up her attendant in the middle of night. But perhaps if scheduling was prescribed and referenced from data for regular overnight adjustments in setup, temperature, etc, the burden to self-report would be mitigated.

Furthermore, ideating around setup needs also sparked inspiration and concepts. For example, though the alternating pressure mattress is reliable, durable, repeatable, adjustable, and relieving, it is not comfortable, travel friendly or simple to use. As mentioned in Act 1.3, the high cost and stigma attached to DMEs also make it difficult for adoption despite the benefits. Its pressure alternating functionality, however, offers high value that could be adapted into a comfortable and simple design. Adjacent concepts include portable inflation and pressure devices including blood pressure cuffs and ankle compression straps shown in Figure 2-4. The setup also needed to be portable and collapsible. Inspired ideas included a flattening foam roller* to origami furniture made of cardboard†, a trending solution for sustainable adaptations.

*<https://www.whoop.com>

†<https://ouraring.com>

*<https://www.amazon.com/Brazyn-Trek-Foam-Roller-Collapsible/dp/B07GXYFG88>

†<https://www.chairigami.com/product-page/cardboard-sofa>

2.2 Modeling an Asymmetric Body

As Judy was in another state, it was critical to capture her body measurements and build a baseline model to design around. During my first visit on October, I took multi-view photos of Judy's setup including a ruler for calibration shown in Figure 2-5. However, also shown, the set of pillows had obstructed body features so by stitching together side, top and front views, I was able to estimate general dimensions and their parametric relation to each other shown in Figure 2-7. It was important to capture photos at consistent planes for consistent blending. Figure 2-6 shows a recreated isometric view of the setup using 3 still images.



Figure 2-5 - Left and Right Side Views with Measuring Tool



Figure 2-6 - Stitched 3D Image from Stills

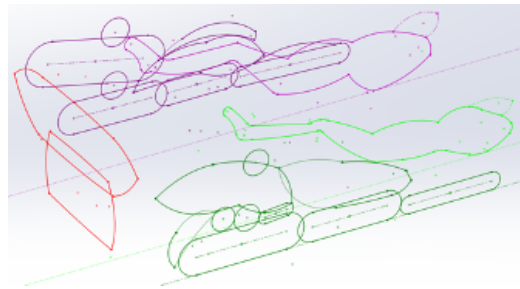


Figure 2-7 - Abstracted Sketch of Setup and Body

It is important to note that the model was not meant to be an accurate body model but a representation to reference. Ideally, user testing is done frequently but given the distance and access, a digital representation was needed. The goal in modeling was to understand the relationships between critical joints and features identified during interviews and problem decomposition. This would be regarded as hard requirements

driving the new designs. This modeling phase was meant to be a quick and iterative stage because the new setup would require adjusting to accommodate Judy's varying body conditions. The model helped baseline range of motion and tolerances.

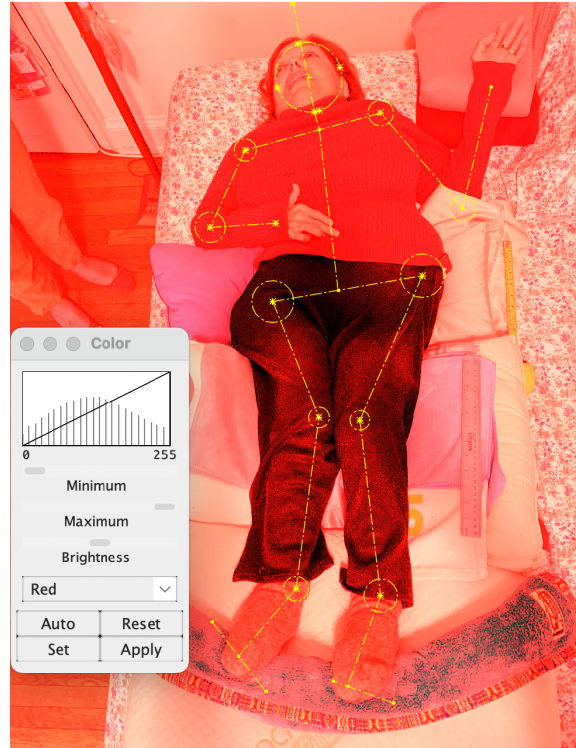


Figure 2-8 - Abstracted Body Joints

Furthermore, through various vision image processing programs like Image J* and SolidWorks sketch tools, Judy's joints were estimated and mapped, shown in Figure 2-8. It was important at this stage to review the analysis with Judy to confirm that these markers looked right to her. From there, abstractions of her body outline and critical joints were built, shown in Figures 2-9 and 2-10. The green and purple outlines capture the silhouette differences between her left and right side. The blue axes reflect where her toes, knees, hips elbows, shoulders lay in the image. And Figure 2-11 shows the abstract model body to reference in the design work.

*ImageJ - <https://fiji.sc>

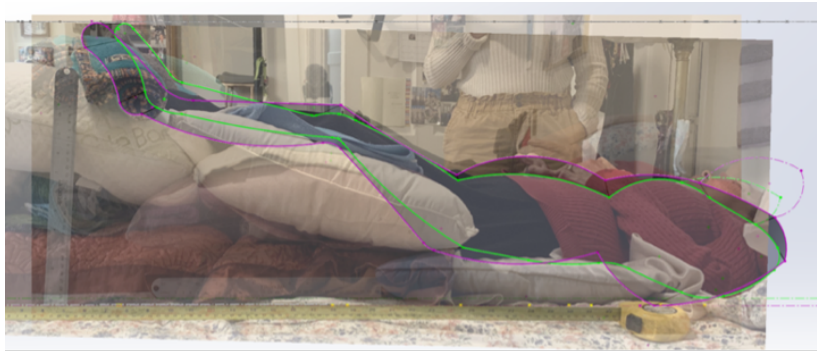


Figure 2-9 - Sketched Outline of Body

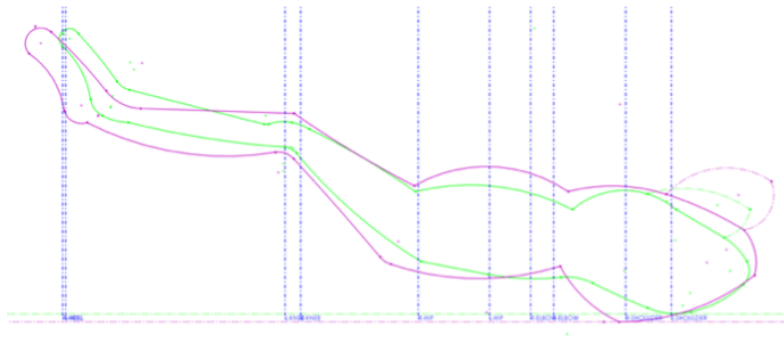


Figure 2-10 - Abstracted Sketch of Body

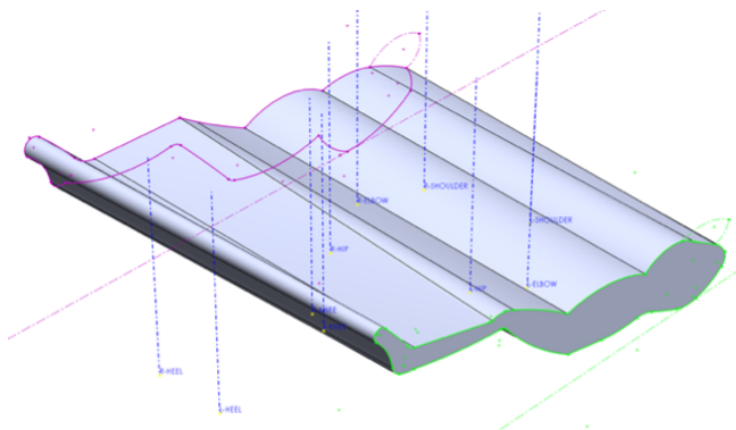


Figure 2-11 - Model of Critical Body Joints and Body Abstraction Extrusion

2.3 The Bespoke Prototype and its Interactive Parts

2.3.1 Prototyping the Prototype

The month of January 2023 was dedicated for agile prototyping and iterations to deliver the first prototype by February 3, 2023.

As mentioned in Act 1.2.1, the parts making up the setup can be categorized into 3 modules: Baseline Elevation, Comfort Elevation, or Micro-Adjustments. Determining structural designs within the Baseline Elevation module was an important first step because the setup was built like a pyramid, where each layer was built on top of each other.

Week to Prototype	Baseline Elevation aka "Baseline"	Comfort Elevation aka "Comfort"	Micro-Adjustments
Week 1	V0	-	-
Week 2	V1	V0	V0
Week 3	V2, V2.5	V1	V1
Week 4	V3	V1.5	-

Figure 2-12 - Schedule to Prototype

Version 0 of Baseline Elevation was a quick prototype to understand cardboard geometry, tolerances, tolerance stack-up, and manufacturability – noting thickness, consistency, and durability. It was also important at this stage to determine laser-cutting parameters that can cut through the cardboard without burning it. Figure 2-13 shows the initial sketches, inspired by origami furniture. The idea was to mimic foldable sheets wrapped around a central truss. More sketches found in Appendix E.

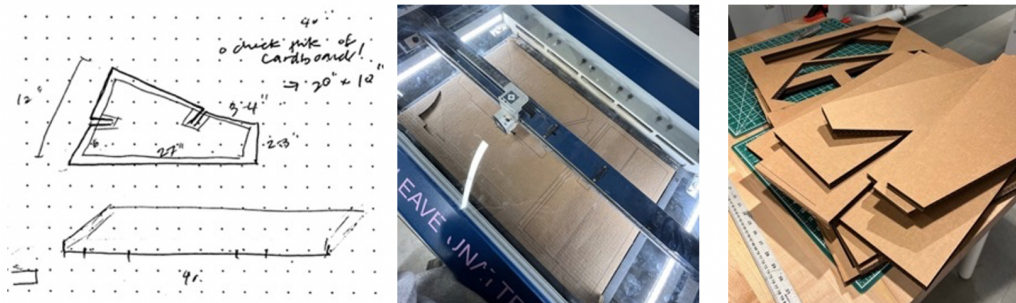


Figure 2-13 - Sketch to Build Using Laser-cutter

This first prototype shown in Figure 2-16 was a combination of planned execution and ad hoc hacks. For example, the overall dimensions including width, height and angle were predetermined and referenced from the 3D model body shown in Figures 2-8 and 2-11. However, cardboard tolerance stack-up was not accounted for, resulting in many re-cutting and re-taping. The next version of Baseline Elevation (V2) would account for tolerances with improved structural integrity with ease of build in mind. The goal was to quickly test and fail ideas for quick iterations.

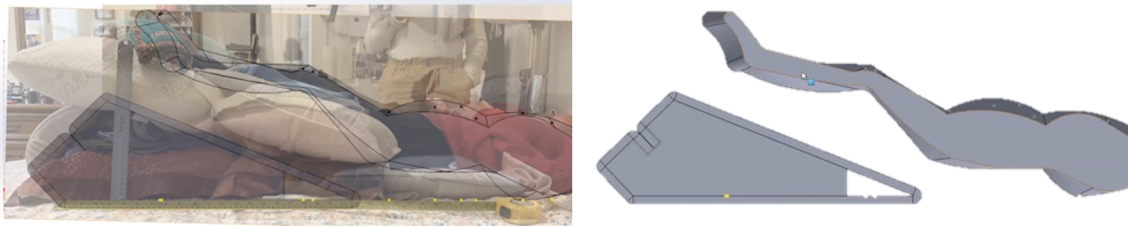


Figure 2-14 - Model of Baseline Elevation V0

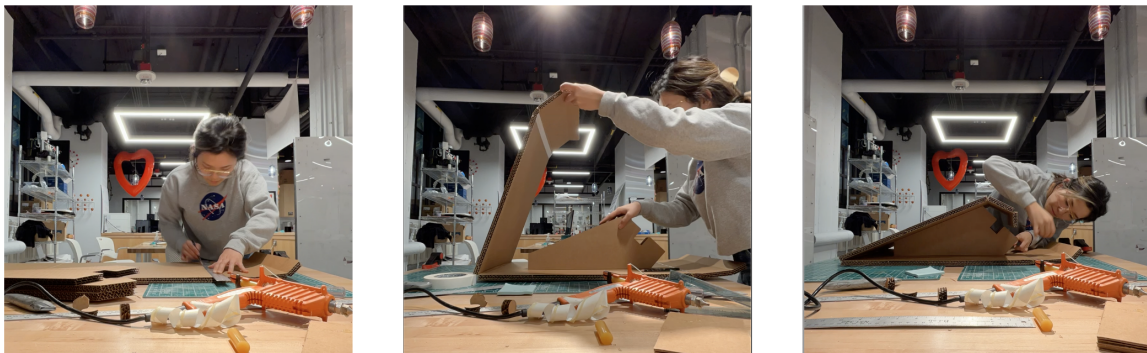


Figure 2-15 - Process Fabricating Baseline Elevation V0



Figure 2-16 - Baseline Elevation V0

The next stage was to retrofit an off-the-shelf elevating foam to fit over the Baseline Elevation module. Figure 2-17 shows the reshaping process to fit over the baseline geometry. The goal was to characterize the foam's performance and manufacturability while determining its shape for optimal compression and comfort during incline.



Figure 2-17 - Process of Fabricating Comfort Elevation V0 A) Trace cardboard outline onto foam B) Manually cut out cavity C) Smooth out face

Integration of Baseline V1 and Comfort V0 is shown in Figure 2-18. Baseline V1 proved to be durable and collapsible while being simple enough to setup, only requiring a couple of steps to build shown in Figure 2-19.



Figure 2-18 - Baseline V1 and Comfort V0 Integration

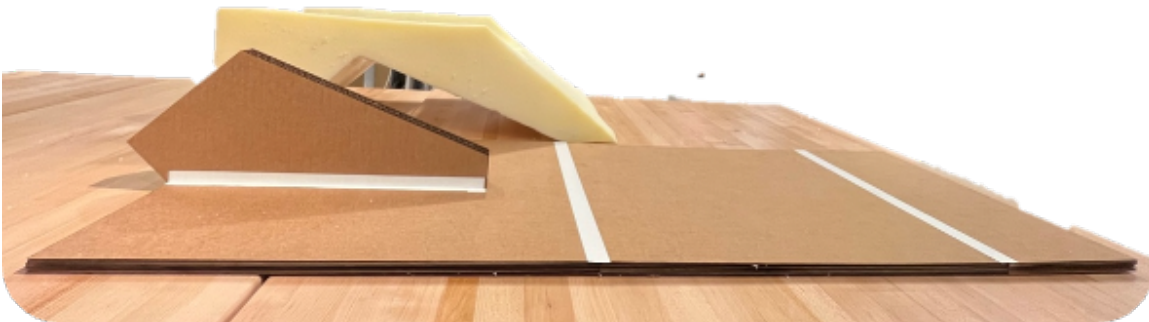


Figure 2-19 - Semi-Flattened Baseline Elevation V1

With the lessons learned from the first prototypes, the next stage was to incorporate the Micro-Adjustments module into the design shown in Figure 2-20. The primary form that proved to allow for incremental, repeatable, and easy adjusting was through valved inflatable shims, using a manual pump*. Originally used to squeeze in between narrow cracks and lift heavy furniture like refrigerators and cabinets, the inflatable shims can displace centimeters at a time while holding up to 500 pounds. To accommodate for these inflatables, pockets were strategically designed into Baseline V2 to elevate specific planes of the body. For example, the first inflatable is placed right under the thighs to adjust the height of the knees. The second is placed under the calves to adjust the height of the heels. And the third inflatable is placed at the tail to hold the position of the feet's soles.



Figure 2-20 - Baseline Elevation V2 and Micro-Adjustments V0

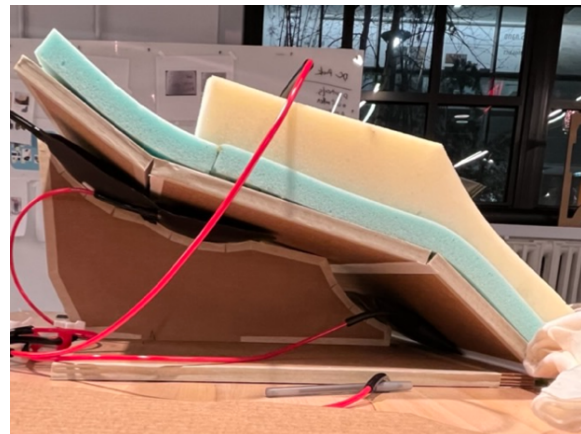


Figure 2-21 - Baseline Elevation V2.5, Comfort V1, and Micro-Adjustments V1

This prototype doubled in part count to include more functionality but still only required a couple of steps to set up. Baseline V2 was quickly tested and found the back truss could not support any load as it would slip out of place therefore it was combined with the central truss shown in Figure 2-21 as Baseline V2.5. This Figure also includes other modules including foams for Comfort and pneumatics for Micro-Adjustments.

When constructing V1 of the Comfort Elevation module, the foam from V0 was

*<https://www.amazon.com/Commercial-Inflatable-Professional-Leveling-Alignment/dp/B08G4S6L5K>

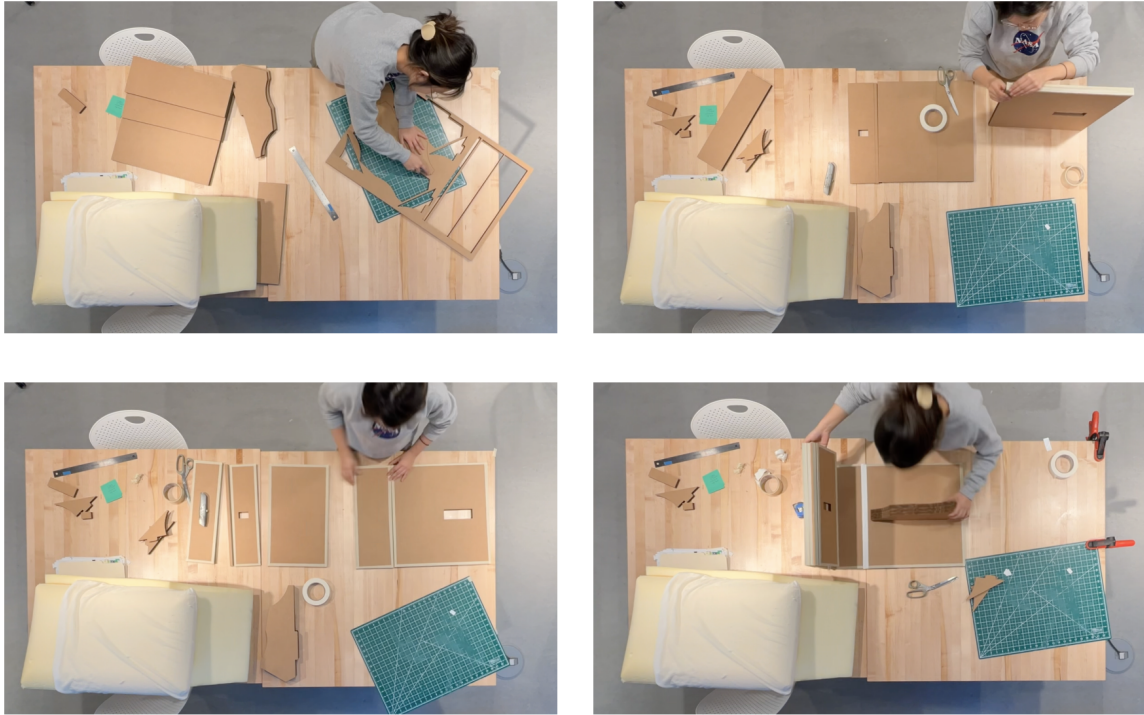


Figure 2-22 - Process photos building prototype. Left to Right: A) Laser-cut parts removed from stock cardboard B) Mask edges of each piece to improve structural integrity C) Assemble pieces and construct hinges D) Fold into final state

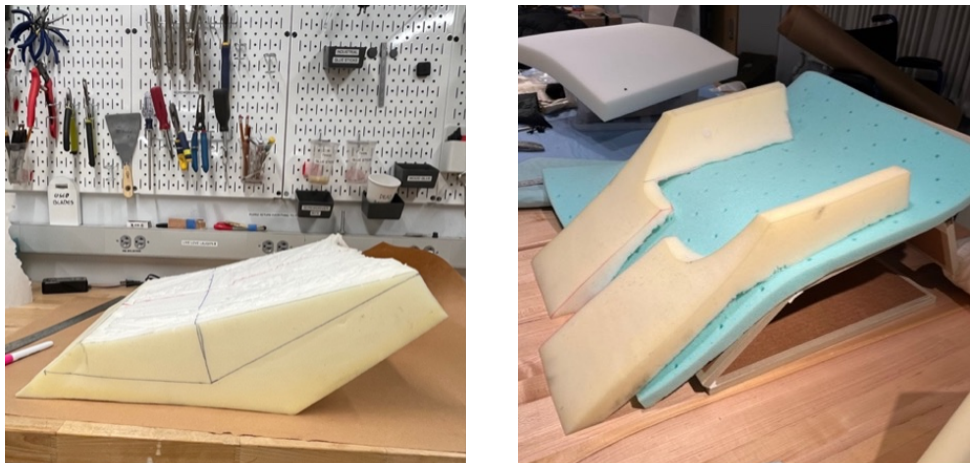


Figure 2-23 - Comfort Elevation V1

further trimmed and empirically tested on myself. Additionally, I added a blue polyester foam[‡] layer embedded with cooling gel beads to act as a thermal sink and circulate accumulated heat. Comfort V1 proved to be uncomfortable unfortunately.

[‡]<https://www.amazon.com/LUXELIFT-Wedge-Pillow-Sleeping-Adjustable/dp/B07GL2CPYT>

The foam was too dense and didn't compress around the legs for a snug fit. Therefore, for Comfort V2, I cut down a memory foam pillow[†] meant for these conditions. Figure 2-24 shows the individual pieces, cut and glued, as well as showing sewed covers.



Figure 2-24 - Comfort Elevation V2 with and without sewed covers

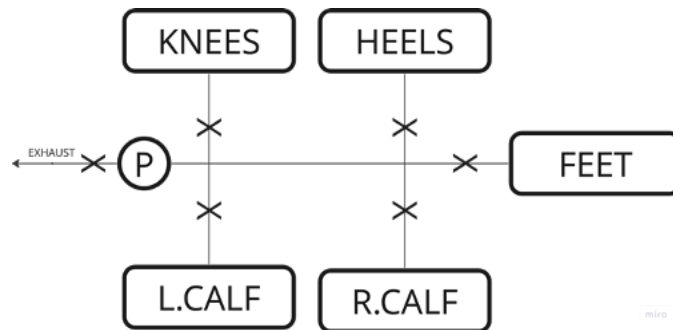


Figure 2-25 - Schematics of Pneumatics Controlling Micro-Adjustments Module

And finally Micro-Adjustments used off the shelf parts from McMaster including manual valves* and a single manual pump. Figure 2-25 shows the pneumatic schematic controlling adjustments for the heights of the knees and heels, the holding position of the feet soles, and the securing rails of the left and right thighs. Expected displacement is shown in blue arrows in Figure 2-26 and Figure 2-27.

[†]<https://www.tempurpillows.com/shop-pillows/symphony-pillow/v/1381/>

*Valve - <https://www.mcmaster.com/2824N11/>



Figure 2-26 - Direction of Displacement on Calves

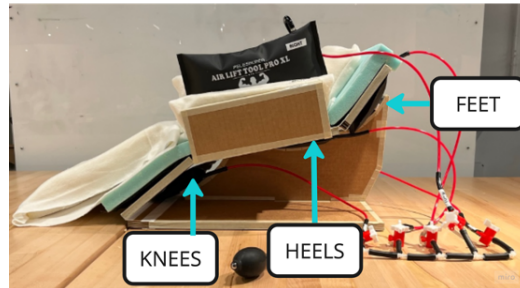


Figure 2-27 - Direction of Displacement on Knees, Heels, and Feet

2.3.2 The Final Specs

The final prototype is made up of 3 modules where Comfort Elevation consists of five pieces, Baseline Elevation two pieces and Micro-Adjustments, one, where parts are counted by their connectedness. Notably, the collapsible cardboard pieces are made of 9 pieces but constructed to be one part and can only be built in one way. The goal in keeping parts together limits confusion allowing easier training to build the setup quickly and effectively. Each system of modules is shown in Figure 2-30. Final prototyping costs are shown in Figure 2-29.

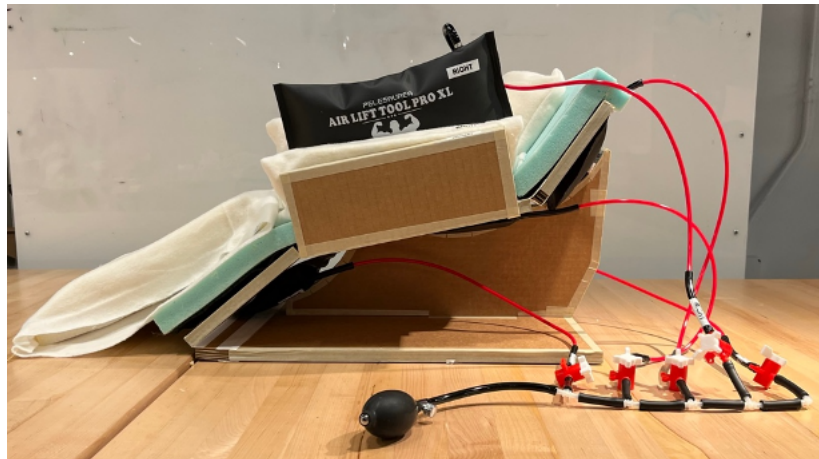


Figure 2-28 - Final Prototype

Module	Parts	Description	Supplier	Cost Per Part	Qty	Total Cost
Baseline	1	Triple-Ply Cardboard	MIT Shop	-	-	-
	2	Masking Tape	MIT Shop	-	-	-
	3	Non-Slip Anti Slip Rubber	Amazon	\$ 14.49	1	\$ 14.49
Comfort	4	Tempur-Pedic Memory Foam Symphony Pillow	Amazon	\$ 60.99	1	\$ 60.99
	5	Open-Cell Foam for circulation	Amazon	\$ 47.90	1	\$ 47.90
Micro-Adjustments	6	Large Commercial Grade Air Wedge, Pack of 2	Amazon	\$ 19.99	3	\$ 59.97
	7	Manual Valves, PN: 2824N11	McMaster	\$ 11.37	5	\$ 56.85
	8	Firm Tubing 25', PN: 5648K19	McMaster	\$ 10.55	1	\$ 10.55
	9	Tubing Fitting, Tee, Pack of 10	McMaster	\$ 12.82	1	\$ 12.82
	10	Plastic Quick-Turn Tube Coupling, Pack of 10	McMaster	\$ 5.61	1	\$ 5.61
Prototyping Costs						\$ 269.18

Figure 2-29 - Prototyping Costs

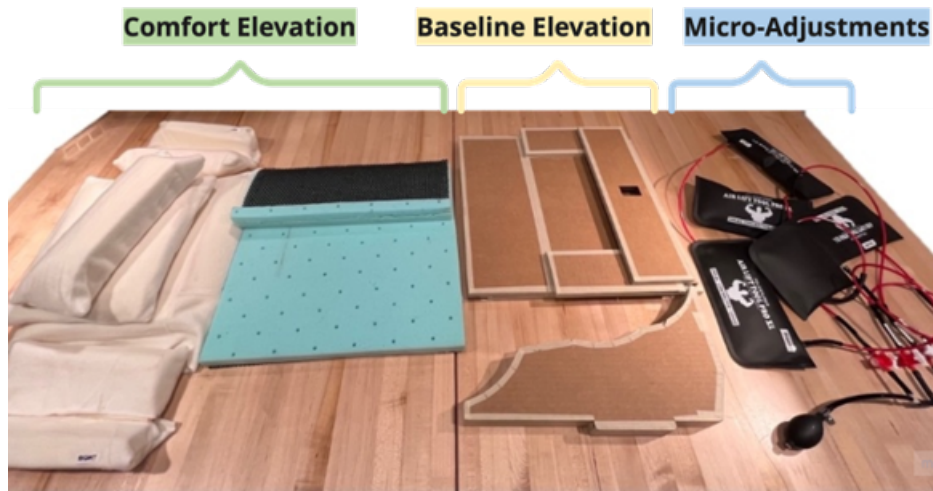


Figure 2-30 - Prototype Modules Laid-Out

2.3.3 Alpha Testing and Feedback

On February 3rd, 2023, I travelled to DC with a suitcase full of hardware. We spent 3 hours testing the prototype while also playing with configurations based on feedback. Before pulling out the hardware, I showed Judy and her assistants a video of the setup being built to prime and set mental models. Also, since Judy is laying during the actual build, it was important to visibly show the new and same features of the setup because Judy will ultimately be giving instructions every night.



Figure 2-31 - Testing Alpha Prototype



Figure 2-32 - Front View of Alpha Prototype



Figure 2-33 - Top View of Alpha Prototype

After showing a video on how to assemble the setup and its design principles, we pulled out the hardware for testing. Initial feedback included:

- Good height and elevation
- Materials were comfortable
- Cushioned rails along calves didn't reach her at all even with the inflatables fully pumped
- Tail of setup was too far – supporting cushion didn't support feet soles



Figure 2-34 - Views of Trying Different Configurations with Judy and assistant

Modifications from Feedback

- Bottom pillow needs to extend outward more
- One hinge broke off. Hinges need to be more robust and reinforced
- Additional cushion for foot soles

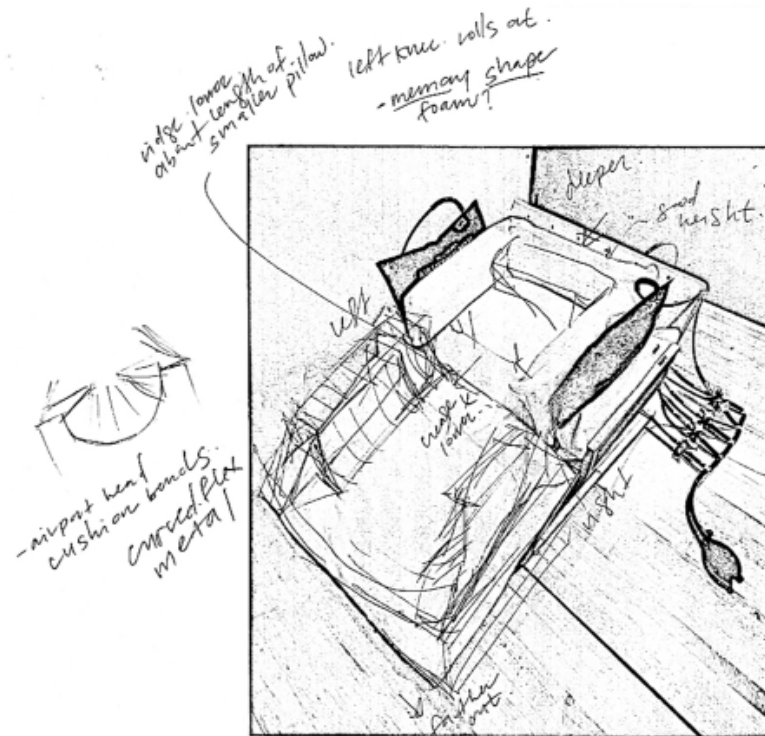


Figure 2-35 - Field Notes During Visit

- Move cushion crease down about 2 inches
- One fabric along legs, no seams/crack
- Include bag on both sides
- Double cushion under thighs
- Flexible gooseneck to cradle thighs †

2.4 March 4, 2023

One month after testing the alpha prototype, Judy passed away on March 3rd, 2023.

V2 sketches drawn before then can be found in Appendix E.

† <https://www.mcmaster.com/products/flexible-goosenecks/>

Act III: Legacy

Judy's lifetime spanned pivotal moments in time, from a world without the Americans with Disabilities Act (ADA), to a world that fought for it, and finally to a world shifting because of it. To fully appreciate its historical significance, it is essential to understand the context in which these events took place. In particular, the eugenics movement, which promoted the idea of "Fitter Families" and "Better Babies" through selective breeding, was a dark and fatal era that justified sterilization and genocide as means of promoting humanity's betterment throughout the 19th and 20th century. It evangelized the pure and desirable genes and radicalized the survival of the fittest notion by ridding the "feeble-minded" [5]. The decline of the movement came at the revelation of World War II atrocities that implemented similar practices and policies during the Holocaust. Through emerging genetic research, its scientific bases for selective breeding were also debunked and found to be inaccurate and oversimplified. In fact, it was found that many mental disabilities and human behaviors are shaped by their environment than genetic make-up [8].

Judy was born into a loving Jewish family in 1947 in Philadelphia, PA and raised in Brooklyn, NY. She contracted polio as an infant and lived with disabilities for the rest of her life. Although I can't fully know her experiences living with the stigma and prejudices of residual eugenics ideals, her autobiographies and our conversations shed some light on them. One example of this was early on when the thesis was initially titled "A Case Study with Judy Heumann," with the intention of using the common conventions of case studies as tools to analyze specific companies or events. However, Judy made it clear that she did not want to be labeled as a "case." Specifically, a medical case to be cured or fixed. Thankfully a lesson learned at the start of the project, it was important to continuously check assumptions and be mindful of context cues throughout the design process.

Though the prototype was designed and fitted for Judy, this design research examines an artifact within a system of caregiving that is commonplace. The need for skilled caregivers, products that are intuitive, comfortable, adjustable, and accessible invites designers and engineers to see technologies embedded in dynamic systems of

personal care attendants and medical liaisons. At the same time, the prototype was intentionally built with accessible materials, like three-ply cardboard, a ubiquitous and sustainable material that is easy to acquire and iterate with. This along with repurposed off the shelf products came close to the setup Judy needed. Judy’s exact design may not be scaled and commercialized as such. But the process of adaptation—research, tinkering, and above all, understanding linkages between technology and caregiving—is what scales. The approach, more than the object, is transferable.

Narrative, language, and the products we create have the power to either reinforce or dismantle systemic social barriers. Unfortunately, the needs of the disability community are often overlooked in the design of technology and services. As technologists, we have a responsibility to bridge this gap. In his book *Fables and Futures – Biotechnology, Disability, and the Stories We Tell Ourselves*, George Estreich emphasizes the pivotal role that technology advancements and regulations play in either furthering or reducing the divide between the vulnerable and the powerful. It’s crucial that we prioritize equity in the narratives that dominate the conversation around technology and policy. By doing so, we can ensure that our innovations benefit everyone, not just a privileged few [5].

Judy once said, “. . . ‘disability culture’ is really just a term for a culture that has learned to value the humanity in all people, without dismissing anyone for looking, thinking, believing, or acting differently.” [7] The legacy she leaves behind is the revelation of one’s agency and value, of all people. Even the genesis of this project reflects exactly that – where Judy did not conform to what was given but took action to find what she needed.

May our post-ADA generation shake norms, design for change, and build for equitable systems, keeping Judy’s spirit alive.

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Appendix A - Representative

Interview

The following figures outlines all sixty-four frames required to build Judy's setup.

A) Staging

1. She instructs her two assistants, Kylie and Kelila, to clear the bed of any household items like the remote or her husband's belongings.



2. Judy precisely positions her wheelchair to be optimally pulled onto her bed.
3. Judy instructs her assistants to lift her feet then proceeds to drive wheelchair into bed
4. She removes her glasses and her wheelchair add-ons, unbuckles her seatbelt, and instructs to remove her sandals. All to prepare for wheelchair transfer.
5. Kylie climbs onto the bed to securely grip Judy's calves while Kelila keeps her upper body balanced and supported.
6. Synchronously, Judy's assistants transfer her from wheelchair to bed. Her position is adjusted as Judy is pivoted. *Note: What makes it hard is the softness of the bed. The softer it is, the traction we don't get. The firmer, the more slippery. Opposite of drag. There's a lot of variability.*
7. Judy is slowly laid flat along her side of the bed.

B) Baseline Elevation

1. Judy asks Kylie to close the bedroom door to open closet door
2. Judy asks to pull out 2 red pillows

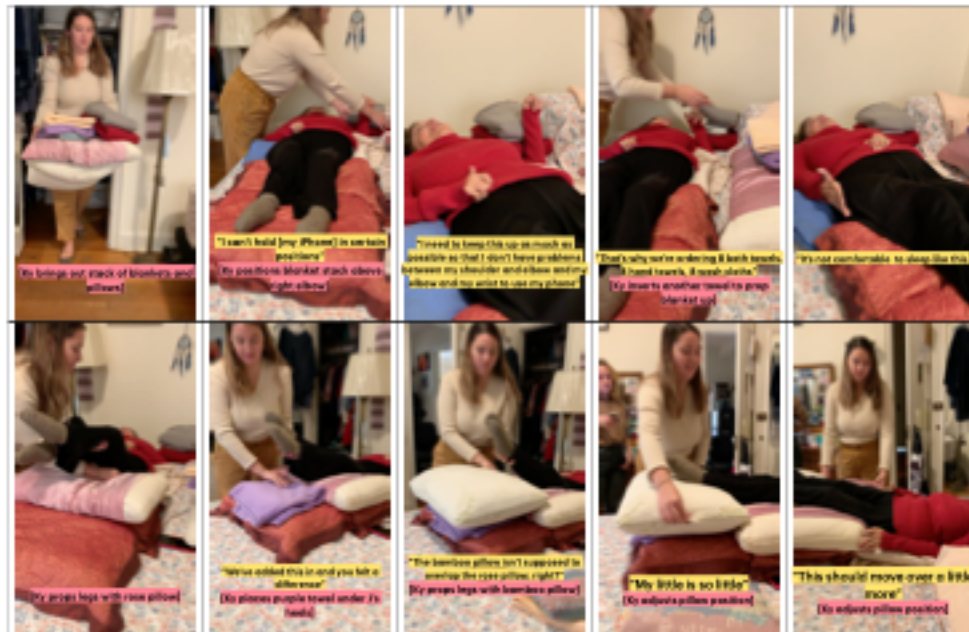


3. Judy instructs to place pillow with plastic wrap [P-THIGHS1] underneath and between knee and hips
4. Kylie holds up Judy's calves and Kelila places pillow right beneath her thighs, butting up against her bottom
5. Judy asks to put other red pillow [P-CALVES] up against first pillow underneath her calves and ankles
6. Kelila walks into closet and pulls out another set of pillows

7. Kelila pushes blue pillow [P-RHIP] partially underneath right hip to elevate hip, support right elbow, and keep right shoulder aligned
8. Judy asks Kelila to pick up her right arm to place on [P-RHIP]
9. Kelila places beige pillow under left hip - "Move hips to be as straight as possible"
10. When sitting, Judy leans to the right all the time. There's a lot of pressure. Needs more support on right side to give a lift.
11. "99.99% of the time heats up and under the neck"
12. Kylie places beaded neck pill [P-NECK] underneath her neck
13. Judy emphasizes importance of mattress firmness and pillow flatness *Compares princess and the pea with pillow beads*

C) Comfort Elevation

1. Kylie brings up neat stack of folded blankets and pillows
2. Judy asks to bring red and grey blanket where left hand is a. Usually uses hotel towels (red and grey stay at home) b. Blankets are folded squarely
3. Kylie puts stack B-LARM1 AND B-LARM2



4. Kylie adds another white towel T-LARM2 in between red and grey towels
5. Judy emphasizes she wants to reduce swelling in feet. Wears compression socks
 - a. Does a lot on the prevention side
6. Kylie tucks rose pillow [P-THIGHS2] under Judy's knees into thighs, on top of red pillows
7. *Optional: Kylie grabs stack of towels. Adds purple loosely-squaredly folded towel [T-HEELS1] under heel, against rose pillow, on top of second red pillow.*
8. Kylie grabs big bamboo memory pillow and places under heel of legs a. Bamboo pillow should not be on top of rose pillow
9. Kylie adjusts pillows to straighten her hips

D) Micro-Adjustments

1. Judy points to two stacks of towels on top of jewelry box
2. Kelila grabs stacks of towels on the right. There are 3 substacks within each stack



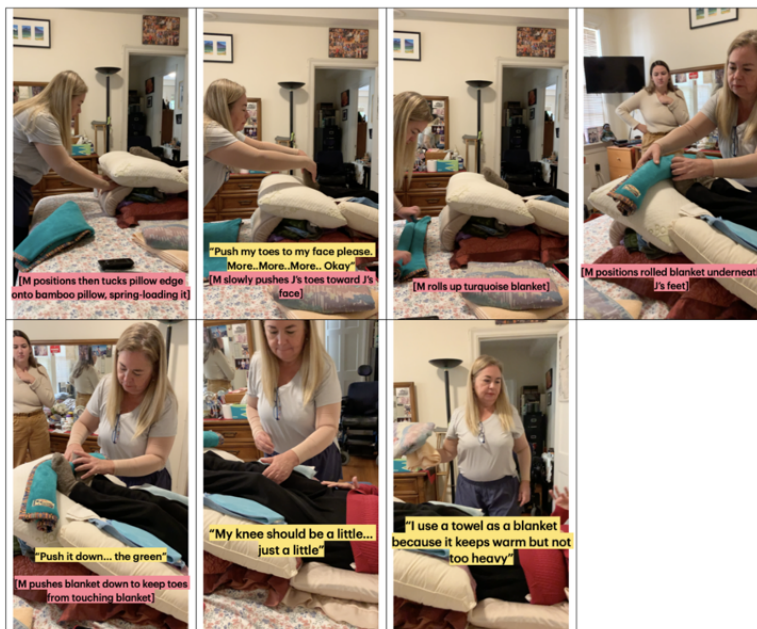
3. Kelila grabs bottom right stack (3 folded towels: red [T-KNEE1], black [T-KNEE2] and dark grey [T-KNEE3]). Judy begins rolling towels then calls for Martha.

4. Martha tightly rolls red and black towels then holds between arm and chest. Then she tightly rolls dark grey towel which appears to be larger. Both rolls equal a similar diameter
5. Martha grabs second stack of towels, flattens them then lifts Judy's right leg and tucks towels under thigh
6. Judy asks Martha to pull towel down toward bed pointing her fingers down
7. Martha grabs 3rd stack of towels, folds in halves into each other then makes tight roll
8. Martha grabs stack for left side and repeats



9. Martha repeated rolls towels and tucks into left side, under the rose pillow, outside the centerline of left knee, pats the rose pillow down
10. Judy asks to move feet. Martha looks intently at Judy, lifts up her feet and adjusts. Finishes with a nod
11. Martha grabs second stack of flat towels, flattens them out. With her other hand, lifts Judy's left leg upward, then carefully lays the towels, ironing out

- any wrinkles, then with both hands puts her leg back down
12. Judy asks her to pull the towels toward the window then to pull her leg toward Martha – adjusting her pelvis position
 13. Martha flattens, folds and tightly rolls final stack and tucks under left corner under bamboo pillow to support left foot
 14. Judy asks Martha to push her toes to her face. Increasing asks for more pressure to straighten feet and toes
 15. Martha rolls turquoise blanket and places underneath her foot – keeping her feet upright
 16. Judy asks Martha to push blanket down to avoid touching toes
 17. Judy asks to pull right knee outward a little



On Toes
 "It's an irritation. If my toes aren't touching anything, it's best."

On blanket

- Uses a towel to avoid overheating and to easily pull off if too hot
- If blanket is too heavy, it'll collapse the setup

miro

Appendix B - Observation Analysis

Staging

- 1) She **instructs** her two assistants, Kylie and Kelila, to clear the bed of any household items like the remote or her husband's belongings.
- 2) Judy precisely **positions** her wheelchair to be optimally **pulled** onto her bed.
- 3) Judy **instructs** her assistants to lift her feet then proceeds to drive wheelchair into bed.
- 4) She **removes** her glasses and her wheelchair add-ons, **unbuckles** her seatbelt, and **instructs** to remove her sandals. All to prepare for wheelchair transfer.
- 5) Kylie **climbs** onto the bed to securely grip Judy's calves while Kelila keeps her upper body balanced and supported.
- 6) Synchronously, Judy's assistants **transfer** her from wheelchair to bed. Her position is adjusted as Judy is pivoted.

Note – What makes it hard is the softness of the bed. The softer it is, the traction we don't get. The firmer, the more slippery. Opposite of drag.

There's a lot of variability.

Baseline Elevation

- 1) Judy is slowly **laid flat** along her side of the bed.
- 2) Judy **asks** Kylie to close the bedroom door to open closet door.
- 3) Judy **asks** to pull out 2 red pillows.
- 4) Judy **instructs** to place pillow with plastic wrap [P-THIGHS1] underneath and between knee and hips.
- 5) Kylie **holds up** Judy's calves and Kelila **places** pillow right under her thighs, butting up against her bottom.
- 6) Judy **asks** to put other red pillow [P-CALVES] up against first pillow and under her calves.
- 7) Kelila **walks** into closet and pulls out another set of pillows.
- 8) Kelila **pushes** blue pillow [P-RHIP] partially under right hip to elevate hip, support right elbow, and keep right shoulder aligned.
- 9) Judy **asks** Kelila to pick up her right arm to place on [P-RHIP].
- 10) Kelila **places** beige pillow under left hip. Judy notes, "Move hips to be as straight as possible".
Note – When sitting, Judy leans to the right all the time. There's a lot of pressure. Needs more support on right side to give a lift.
- 11) [optional] **Heats up** neck pillow [P-NECK] and places under the neck. |
Note – Judy emphasizes importance of mattress firmness and pillow flatness. And compares herself to the princess and the pea.

Comfort Elevation

- 1) Kylie **brings up** neat stack of folded blankets and pillows.
- 2) Judy **asks** to place red and grey blanket under left hand.
Note: When travelling, uses hotel towels and blankets are always folded squarely.
- 3) Kylie **adds** another white towel T-LARM2 in between red and grey towels.
- 4) Judy **emphasizes** she wants to reduce swelling in feet and wears compression socks to bed.
- 5) Kylie **tucks** rose pillow [P-THIGHS2] under Judy's knees into thighs, on top of red pillows.
- 6) [optional] Kylie **grabs** stack of towels. **Adds** purple loosely-squarely folded towel [T-HEELS1] under heel, against rose pillow, on top of second red pillow.
- 7) Kylie **grabs** big bamboo memory pillow and **places** under heel of legs.
Note – Bamboo pillow should not be on top of rose pillow.
- 8) Kylie **adjusts** pillows to straighten her hips.

Micro-Adjustments

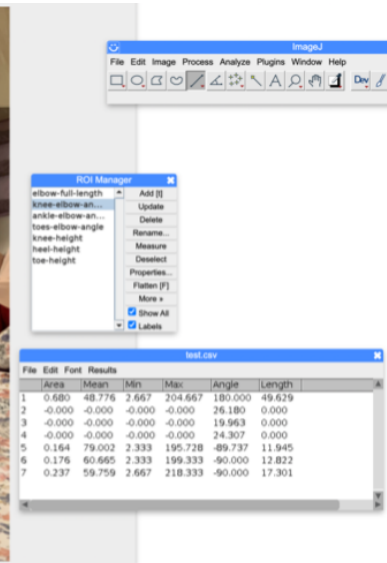
- 1) Judy **points** to two piles of towels on top of jewelry box.
- 2) Kelila **grabs** stack of top towels on the right.
Note – There are 3 stacks within each pile.
- 3) Kelila **grabs** bottom right stack (3 folded towels – red [T-KNEE1], black [T-KNEE2] and dark grey [T-KNEE3]). Judy begins rolling towels. Judy **calls** for Martha.
- 4) Martha **tightly rolls** red and black towels then holds between arm and chest. Then she **tightly rolls** dark grey towel which appears to be larger.
Both rolls have similar diameter.
- 5) Martha **grabs** second stack of towels, **flattens** them then lifts Judy's right leg and tucks towels under thigh.
- 6) Judy **asks** Martha to pull towel down toward bed pointing her fingers down.
- 7) Martha **grabs** 3rd stack of towels, **folds** in halves into each other then **makes** tight roll.
- 8) Martha **grabs** stack for left side and repeats
- 9) Martha **repeatedly rolls** towels and **tucks** into left side, under the rose pillow, outside the centerline of left knee, **pats** the rose pillow down.
- 10) Judy **asks** to move feet. Martha **looks** intently at Judy, **lifts** her feet, and **adjusts**. Finishes with a nod.
- 11) Martha **grabs** second stack of flat towels, **flattens** them out. With her other hand, **lifts** Judy's left leg upward, then carefully **lays** the towels, ironing out any wrinkles, then with both hands **puts** her leg back down.
- 12) Judy **asks** her to pull the towels toward the window then to pull her leg toward Martha – adjusting her pelvis position.
- 13) Martha **flattens**, **folds** and **tightly rolls** final stack and **tucks** under left corner under bamboo pillow to support left foot.
- 14) Judy **asks** Martha to push her toes to her face. Increasingly asks for more pressure to straighten feet and toes.
- 15) Martha **rolls** turquoise blanket and **places** underneath her foot – keeping her feet upright.
- 16) Judy **asks** Martha to push blanket down to avoid touching toes.
- 17) Judy **asks** to pull right knee outward a little.

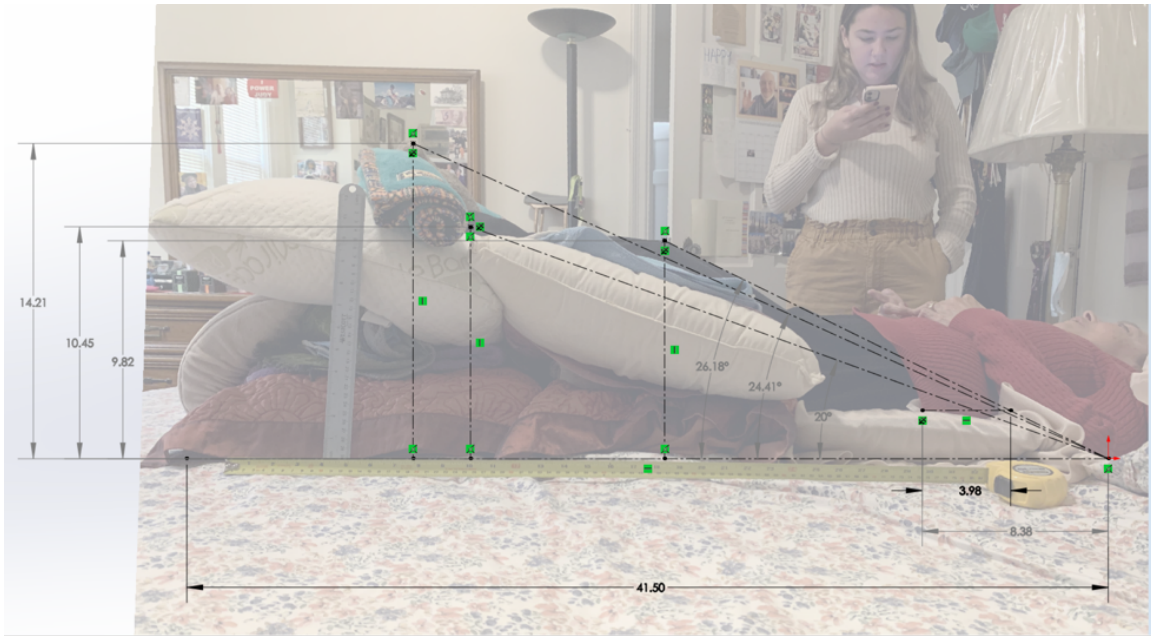
Figure B-1 - Observation annotations. Yellow highlights instructions given by Judy and grey highlights tasks performed without instruction

Appendix C - Setup Part List

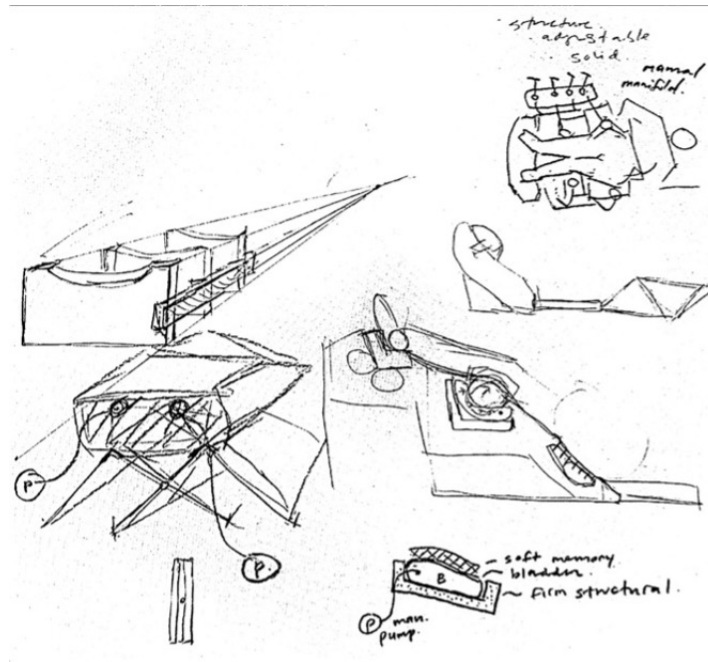
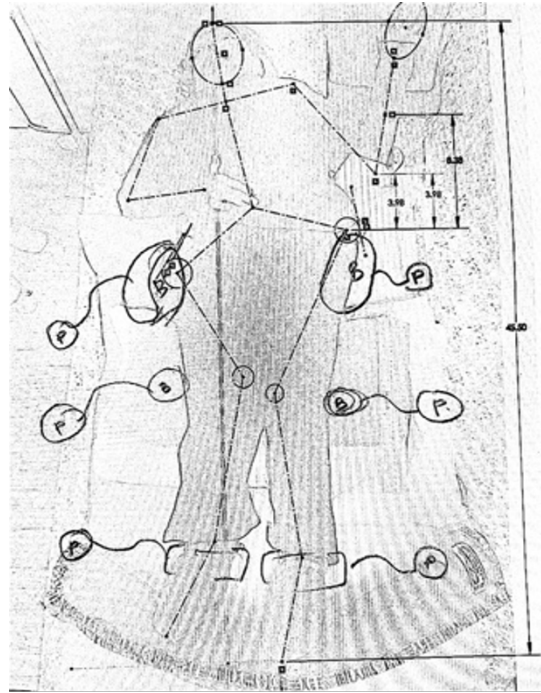
<i>Label</i>	<i>Item Description</i>	<i>Function</i>	<i>Functional Keyword</i>	<i>Utility Score</i>
<i>P-RHIP</i>	Right Hip Blue Pillow	Elevates right hip “a little bit”, Supports Right elbow Keep right shoulder aligned with hip Lifts and Stretches torso	Alignment	4
<i>P-LHIP</i>	Left Hip Beige Pillow	Elevate left hip, “Not the Same” for left elbow	Elevation	4
<i>P-THIGHS2</i>	Rose pillow	Elevates thighs and knees	Elevation	4
<i>P-HEELS2</i>	Big bamboo memory pillow	Supports heels	Elevation	4
<i>P-THIGHS1</i>	Red Pillow with Plastic Wrap	Supports bottom of hip and thighs	Elevation	3
<i>P-CALVES</i>	Red Pillow without Plastic Wrap	Supports calves and ankles	Elevation	3
<i>T-RKNEE1</i>	Rolled Small red towel – roll 1	Supports and prevents knee from rolling outward	Alignment	3
<i>T-RKNEE2</i>	Rolled Small black towel – roll 1	Supports and prevents knee from rolling outward	Alignment	3
<i>T-LKNEE1</i>	Rolled Small dark green towel – roll 1	Supports and prevents knee from rolling outward	Alignment	3
<i>T-LKNEE1</i>	Rolled Small white towel – roll 1	Supports and prevents knee from rolling outward	Alignment	3
<i>B-LARM1</i>	Left arm support grey blanket	Supports shoulder to elbow and forearm to wrist to use phone otherwise, folding arm into chest position hurts forearm and shoulder	Support	2
<i>B-LARM2</i>	Left arm support red blanket	Supports shoulder to elbow and forearm to wrist to use phone otherwise, folding arm into chest position hurts forearm and shoulder	Support	2
<i>T-LARM3</i>	Left arm support small elevation towel	Supports shoulder to elbow and forearm to wrist to use phone otherwise, folding arm into chest position hurts forearm and shoulder	Support	2
<i>T-RTHIGH1</i>	Flat Small white towel 1	Slightly elevates right thigh	Elevation	2
<i>T-RTHIGH2</i>	Flat Small white towel 2	Slightly elevates right thigh	Elevation	2
<i>T-RTHIGH3</i>	Flat small blue towel 3	Slightly elevates right thigh and provides comfortable skin-interface	Elevation	2
<i>T-RTOE1</i>	Folded and rolled towel 1	Slightly adjust angle	Adjustment	2
<i>T-RTOE2</i>	Folded and rolled towel 2	Slightly adjust angle	Adjustment	2
<i>T-RTOE3</i>	Folded and rolled towel 3	Slightly adjust angle	Adjustment	2
<i>T-RTOE4</i>	Folded and rolled towel 4	Slightly adjust angle	Adjustment	2
<i>T-RTOE5</i>	Folded and rolled towel 5	Slightly adjust angle	Adjustment	2
<i>T-LTHIGH1</i>	Flat Small white towel 1	Slightly elevates left thigh	Elevation	2
<i>T-LTHIGH2</i>	Flat Small white towel 2	Slightly elevates left thigh	Elevation	2
<i>T-LTHIGH3</i>	Flat small blue towel 3	Slight elevates left thigh and provides comfortable skin-interface	Elevation	2
<i>T-LTOE1</i>	Folded and rolled towel 1	Slightly adjust angle	Adjustment	2
<i>T-LTOE2</i>	Folded and rolled towel 2	Slightly adjust angle	Adjustment	2
<i>T-LTOE3</i>	Folded and rolled towel 3	Slightly adjust angle	Adjustment	2
<i>T-LTOE4</i>	Folded and rolled towel 4	Slightly adjust angle	Adjustment	2
<i>T-LTOE5</i>	Folded and rolled towel 5	Slightly adjust angle	Adjustment	2
<i>B-FEET</i>	Blue turquoise blanket	Support feet soles	Support	2
<i>P-FEET</i>	Beige wedge pillow	Supports setup	Support	2
<i>P-NECK</i>	Beaded, heat safe, Neck Pillow	Supports neck. Heats up in microwave 99.99% of the time at home. Depends on hotel	Support	1
<i>T-HEELS1</i>	Squarely folded purple towel	Elevates heels	Elevation	1

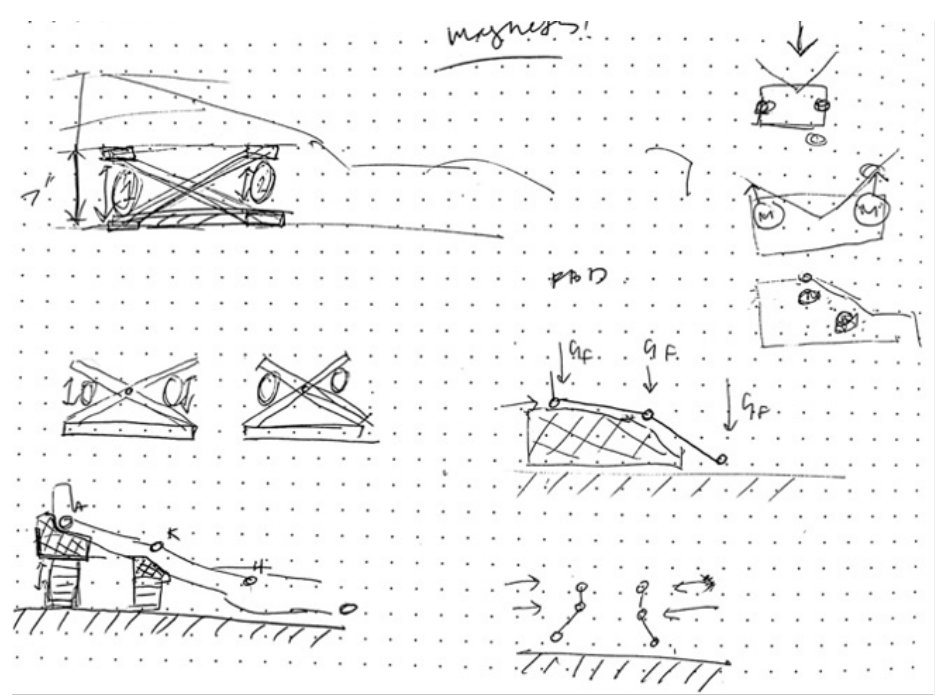
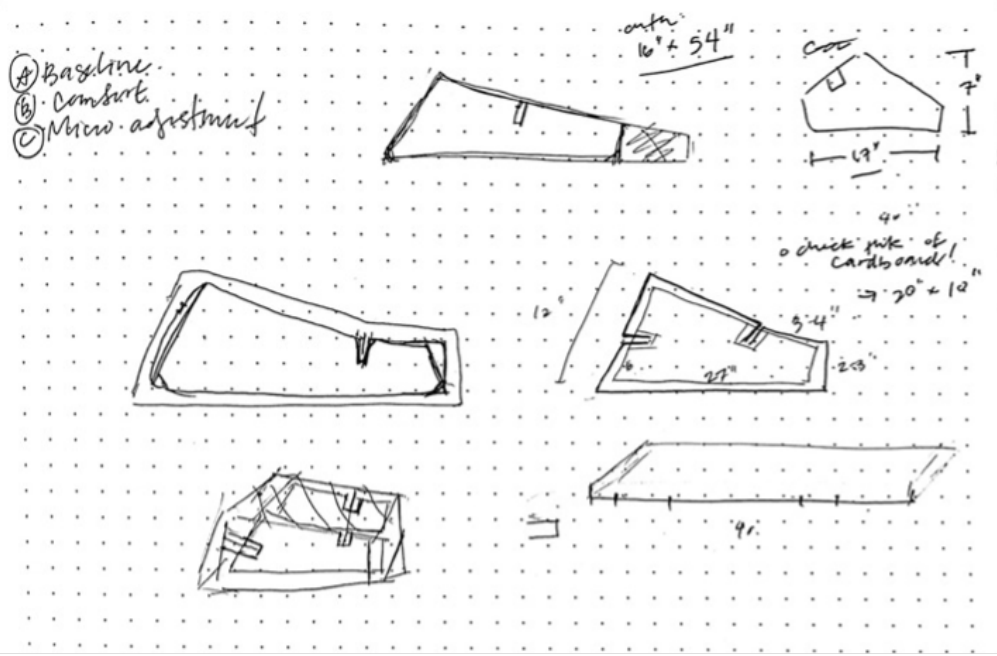
Appendix D - Imaging Processing





Appendix E - Sketches of Initial Prototypes





Appendix F - Prototype Iterations

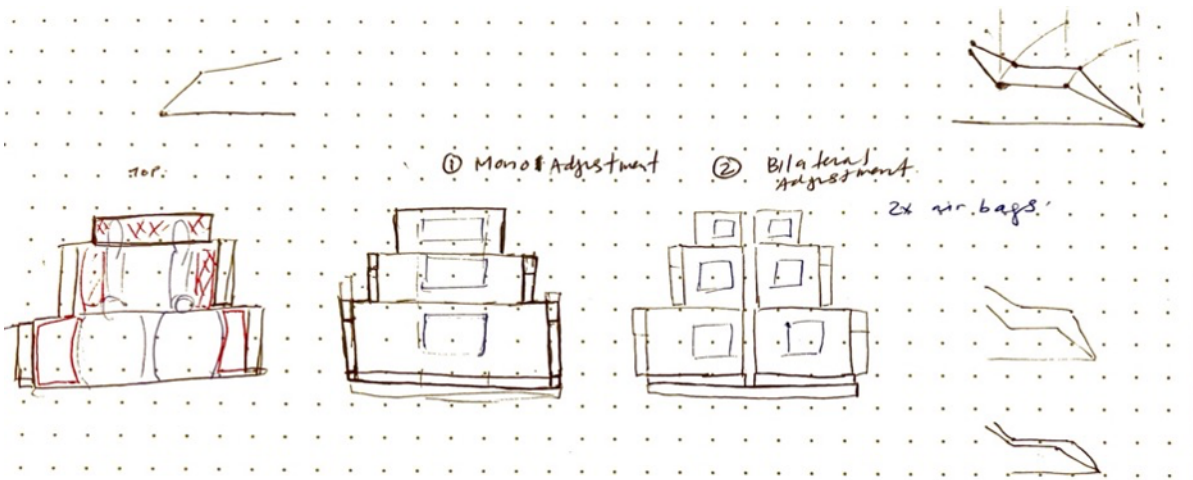


Figure F-1 - Prototype Iterations



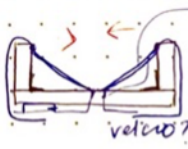
Figure F-2 - Prototype Collapsed and Fitted within Check-In Suitcase

Appendix G - Sketches of Bespoke Prototype V2



cradle. drape/hammock?

Hinges. durable.



fabric, will partially
suspend & stretch?
- will collapse legs.
need reactionary
force.

- will need lots of
give.
very small tension

- better cap?

- redundancy tightening.

