

~~DON'T~~ **PLAY WITH FOOD**

CREATING A STRESS-FREE HOME ENVIRONMENT
FOR TUBE-FED CHILDREN

by Nicole Wiesner

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the requirements for the degree of
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DEDICATION

To my parents, Mijal and Andy, and to my brother Daniel.

For your unconditional love and support, infinite patience, and for the ever present reminder to dust yourself off when you fall down. I am so grateful for the trust and freedom you have given me.

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CONTENTS

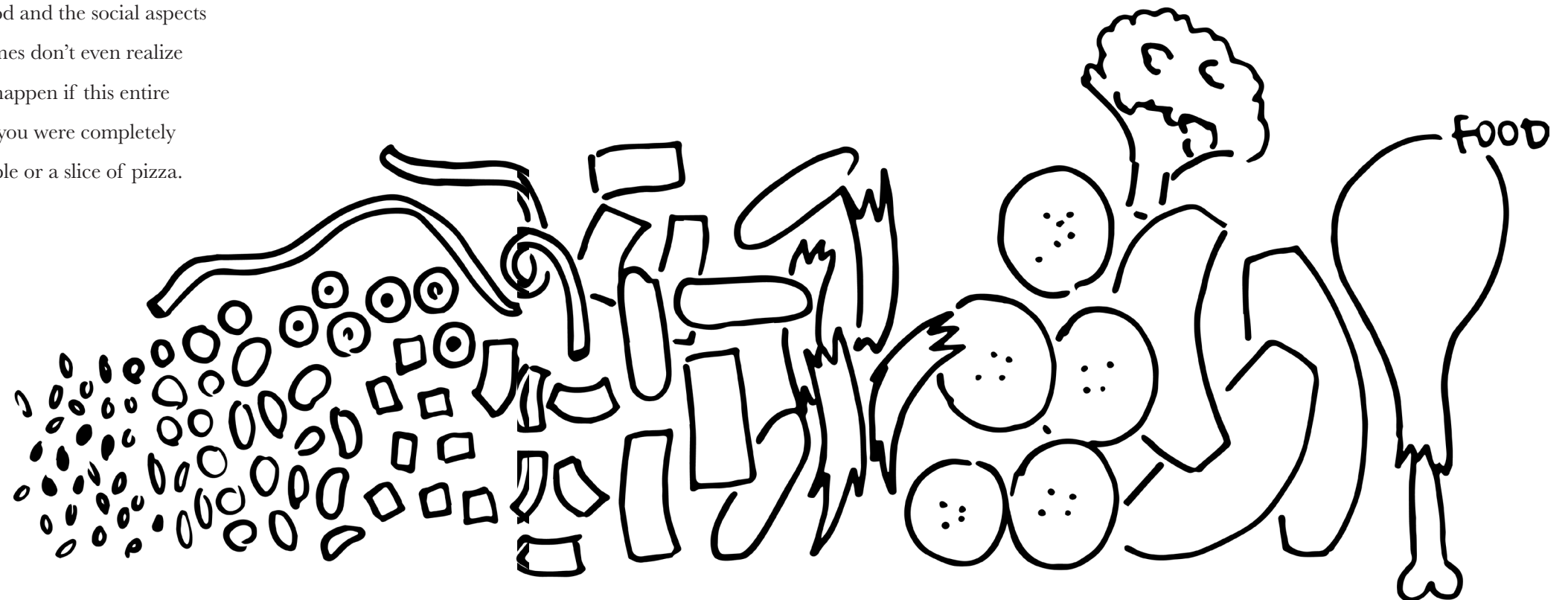
	PREFACE	vi			
1	INTRODUCTION Thesis Statement	1	4	DESIGN Playcemat Tubie Doll Tubie Book	35
2	DISCOVER Tube Feeding in Infants and Children Child Healthcare Network Tube Weaning Methodologies	7			
3	DEVELOP Designing for Intimacy Design Criteria	27	5	CONCLUDE	87
				BIBLIOGRAPHY	90
				APPENDIX	94

PREFACE

Food is an essential part of our everyday life. It isn't just a matter of nutrition, but it also serves as a social experience. We plan our work days around meals, gather with our friends and families around dinner tables, and even have entire holidays dedicated to food and drink. We have surrounded ourselves with food and the social aspects that come with it, so much so that we oftentimes don't even realize how important food is. Imagine what would happen if this entire concept of food were somehow destroyed; if you were completely unable to associate your connection to an apple or a slice of pizza.

This is the case for tube-fed children.

Tube-fed children are kids born with medical conditions that impede them to swallow and digest food. Typically, they have physical malformations, such as cleft palate and abnormalities in the digestive tract, that make it difficult, or even impossible, to swallow causing them to have reflux and vomit consistently. Fortunately, thanks to modern day medical technology, they are able to survive by receiving all or part of their nutrition through a feeding tube directly into their digestive tract. The only problem is that they cannot eat for a period of time until their medical conditions are resolved. Since these children have never ingested food orally, they develop food aversions. In order to wean them off effectively from these tubes and integrate them fully into society they must undergo therapy for extended periods of time, from months up to several years. My thesis is dedicated to designing and creating products that will help these tube-fed children through this therapy and overcome their food aversion.



1

INTRODUCTION



I have always been amazed by the complexity of the human body. Our anatomies are hardwired to know everything about our inner processes in order to react according to what happens in different areas of the body. More impressive, though, is that our bodies are able to do so all without the mind making any conscious decisions on how to react or why. The body is a multi-layered circuit system with intricate connections, where any force applied has a chain reaction somewhere else that affects the entire system. As a mechanical engineer training to become an industrial designer, problem solving fuels my rational engineering brain, while making things feel beautiful feeds my designer's mind. Medical design is where my skills, knowledge, and interests intersect. Medical design embraces my design agenda: to be able to understand the "big picture" and the effects of making changes in said system to find the optimal solution to a problem, by balancing functionality without losing aesthetic qualities while using innovative technology that improves people's lives.

While working in medical design studio, we were given the task to redesign or come up with idea related to the healthcare industry. I chose to redesign a feeding tube. You might ask: "Why did you choose to redesign a feeding tube out of so many different medical products?" Due to my fascination with food and digestion. I knew I was going to choose a project related to the gut. I remember when I first learned about the gastrointestinal system in biology class and felt a deep admiration

towards the mechanics and chemical balances of the gut. Our intestines process everything we consume to extract what is valuable to the body and discard what is not. Whatever we eat directly affects our energy levels, performance, and even how consistently and comfortably we get a bowel movements.

I started with what I know: Crohn's disease, an immune related disease that causes bowel inflammation, specifically to the colon and small intestine, and affects the entire digestive system from the mouth to the anus. My mother was diagnosed with Crohn's after she gave birth to my younger brother almost twenty-five years ago. Fortunately, she does not have an extreme case of Crohn's and has not needed surgery, but still struggles with the illness since a cure does not exist. In some cases, patients with Crohn's disease have to undergo different surgeries to remove their rectum, anus, and parts of their colon (colostomy) or their entire colon (ileostomy), and their digestive system is diverted into a visible opening on the abdomen (known as a stoma) where a colostomy bag is placed to collect the waste that the body normally produces.

As comfortable as I am talking about feces, I did not want to work on an entire product that directly relates to human waste, such as a colostomy bag. I instead decided on a product that focused more on the entrance rather than the exit: feeding tubes. Similar to stomas, they are surgically created at the beginning of the gastrointestinal tract to provide nutrition to the body. The most common conditions that require patients to tube feed include failure to thrive, inability to swallow, neurologic or neuromuscular disorders, anatomical malformations of the mouth and esophagus, different types of cancer, and digestive disorders. Patients that need feeding tubes cannot obtain nutrition by mouth, are unable to swallow, or require additional temporary or permanent supplementation.

The temporary tubes that are placed through the nose and esophagus (called nasogastric, nasoduodenal, and nasojejunal) are very commonly used in intensive care units for critically ill patients with eating disorders or dementia. For a

more long-term or permanent solution, feeding tubes, such as gastrostomy (G-), gastrojejunostomy (GJ-), and jejunostomy (J-) tubes, are inserted directly into the stomach through the abdomen. These types of tubes can extend from the body into a catheter-like tube or a low-profile “button” with detachable tubes for feeding. The two most common retention mechanisms used to secure G/GJ/J-tubes to the stoma are bumpers and balloons, both located inside of the body under the stoma. The former is a thick and rigid disc-like shape that can only be removed through an endoscopy, while the latter can be replaced by deflating the balloon. For simplicity, I grouped the G/GJ/J-tubes into G-tubes since they look very similar from a design perspective. The retention mechanisms are the same and outside appearances are very similar (GJ-tubes have three openings instead of two and have an extended tube on the inside portion).

Through my research I found that many issues arise while using the G-tube: clogging, pulling and tugging, leaking, material decay, and balloon rupture. Clogging and material decay are inevitable – although its effects can be mitigated through proper tube upkeep – since the tubes are very thin and the silicone or polyurethane need to be biocompatible. The two most prevalent issues were rupturing of the retention balloon and pulling on the button. These problems led me to design a more low-profile exterior that is aesthetically pleasing and change the retention mechanism into an anchor-like mushroom cage that was previously used in a medical procedure I found during my research.

Since I enjoyed the project and saw a lot of potential in it, I decided to continue exploring feeding tubes, more specifically, the patients and their experience with the tubes. What caught my attention was that some of these children, after many surgical procedures and therapy, regained the skills to swallow and potentially have their tubes removed. However, they had difficulty learning to eat due to trauma and oral aversions. This issue is so common that there are therapists and institutions, such as No Tube in Austria, several children’s hospitals in the United States, and centers for pediatric feeding disorders around the world, that specialize in helping

these children and their families wean from the tube.

The more I read, the more I empathized with these children and their families. The feeding tube is what keeps them alive, but their lives are still limited. Once the tube is removed they are able to regain control of their bodies and their lives. This thesis brief explains my research findings and analyses on tube fed children and the design opportunities where I developed a set of products to aid in this transition.

THESIS STATEMENT

Through a systems design approach, the interactions and relationships in the tube fed child’s network can be changed to improve their family’s dynamics and overall health. I will explain the current situation of the tube fed child and their surroundings, and speculate ways to improve or shift it. By developing criteria to evaluate the proposed designs for my thesis, I will be able to find the appropriate solution to this situation. The goal of this thesis project is to help, through design, both parents and children in weaning from the tube.



2

DISCOVER

TUBE FEEDING IN INFANTS AND CHILDREN

There are many infants that have problems eating during growth in the first few weeks of their lives. Some babies are born preterm or post term and have minor complications and may need temporary feeding tubes to sustain their health. Long term feeding tubes are used only in severe cases where the child is diagnosed with failure to thrive, dysphagia (difficulty swallowing), GERD (gastroesophageal reflux disease), including any neurological disease that affects the newborn's motor skills, such as Down syndrome and cerebral palsy, and structural malformations in the chest, lungs, heart, and digestive tract.

Enteral fed infants and children rely on these tubes for most or all of their nutrition. Due to their inability to swallow, constant nausea, and problems with digestion, the only way to nourish them is to place a feeding tube to gain weight. Initially, nasogastric tubes are used and, depending on the severity of the case, they transition to PEG/J tubes after a few months of use. Depending on the case, disease, and physical state, the infants and children continue to rely on the tube for nourishment and to support the required caloric intake based on their age. However, many

research articles show that long-term tube feeding can be detrimental to the children's health and psychological development (McHattie; Strauss *et al*; Dunitz-Scheer *et al*). The term tube dependence was coined by Dr. Marguerite Dunitz-Scheer "as an unintended result of long-term tube feeding in infants and young children." (Dunitz-Scheer 210) Despite the resolution of the initial issues that caused eating refusal before tube feeding, the child loses the motivation and willingness to eat mainly due to a complete disconnect with hunger. (Dunitz-Scheer). Many pediatricians do not acknowledge the condition of tube dependency, and simply expect the babies to magically "turn it around" and start eating, despite the tube's interference. Tube dependency also affects the caregiver's routine and anxiety levels since they have to dedicate more time, even resign from their positions at work, to the health and development of the child (Duniz, Trojovsky, *et al* 99). Therefore, it is critical to tube wean these infants and children: gradually transition them from tube feeding to oral feeding. Similar to weaning from breastfeeding, infants and children slowly transition from exclusively receiving nutrition through the feeding tube to eating liquid and solid foods of various textures and flavors.



Is it absolutely necessary to immediately place a feeding tube in non-extreme cases? Take for example Stella's situation, where surgery was not necessary and she still had the motor skills and neurological abilities to swallow. Many changes can be implemented in order to nourish the baby, such as feeding her more slowly, changing positions during feeding, or rocking her to different movements and rhythms, but not immediately feed her with a tube. Parents can work with nutritionists and lactation consultants, or even try out recommendations from their friends and family before resorting to a quick fix. In Lilly's case, her parents "decided to get a g-tube for her so [they] could take her home from the hospital and continue helping her learn to eat on her own timeframe" (*Lilly's Wean*). Placing a G-tube on Lilly, which has many

side effects including making a hole through her abdominal wall, is mentioned so casually by her mother on her blog *Lilly's Wean*. This rush to solve the medical condition (and the immediate condition, not necessarily the deep-rooted condition, which requires long-term care) is prevalent in American health care. When I get sick, my healthcare provider prescribes medicines that suppress the symptoms I have instead of prescribing rest and letting the body heal itself.

My brother, Daniel, also had feeding issues when he was a newborn. Because he had pyloric stenosis – a narrowing of the sphincter, or opening, between the stomach and the duodenum (the beginning of the small intestine) –, he vomited as soon as he finished eating, especially if he ate too fast. Since the doctor recommended to feed him more slowly, my mother gathered all the patience she could muster and calmly fed Daniel. Sometimes it worked; other times Daniel regurgitated and had to change methods again. Daniel was never tube fed and gained weight slowly, but was always a healthy boy. He is now tall and lean, and always has a big appetite even though he feels full quickly after starting to eat a meal. Learning from this, what if tube feeding can be prevented in non-extreme cases, such as Daniel's? How can pediatricians and nutritionists apply long term methodologies instead of quick fix solutions that affect the child's future?

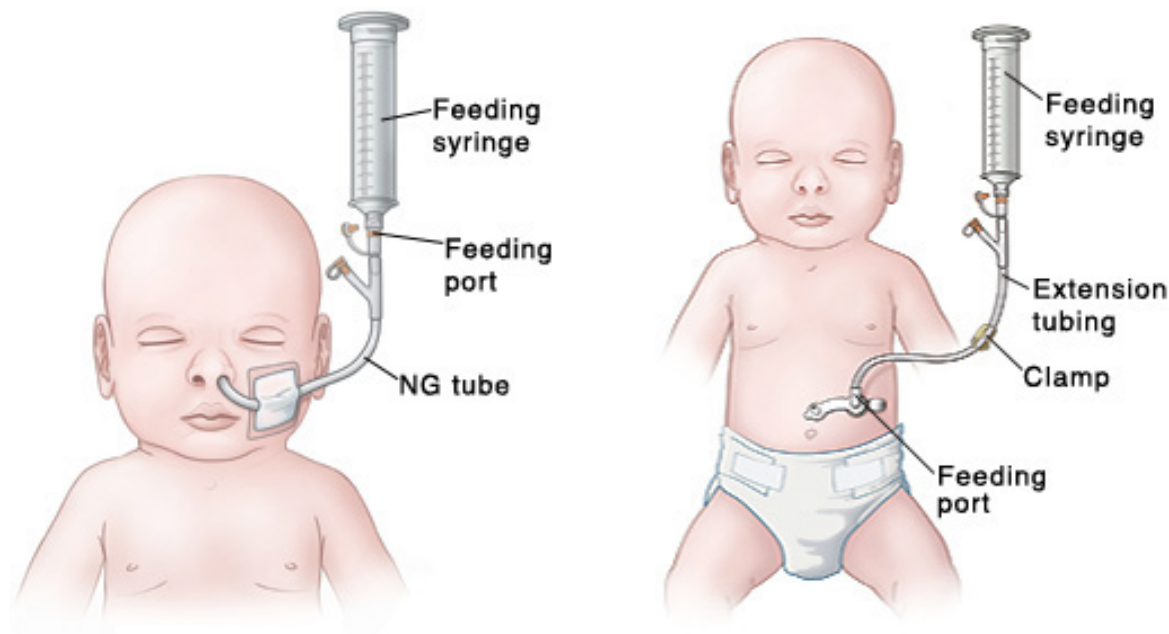


FIGURE 1.1 Diagrams of a child with a nasogastric tube (*left*) and a percutaneous endoscopic gastrostomy tube (*right*). (Fairview Health Library)

CHILD HEALTHCARE NETWORK

"IT TAKES A VILLAGE TO RAISE A CHILD"

For a child to grow in a society, several groups and individuals support her aside from the members in her immediate family. Healthcare professionals assure the child is in good medical conditions, neighbors and teachers educate her, and the surrounding community aid in her social development. For these groups and individuals to help raise a child for efficiently, they have to bypass or work through the child's parents, making the network surrounding the child parent-centric and not child-centric as perceived initially.

The strongest connection and the most important in the child healthcare network is the parent-child relationship, therefore taking into account the entire family dynamics will be critical when designing for the tube fed child and her family.

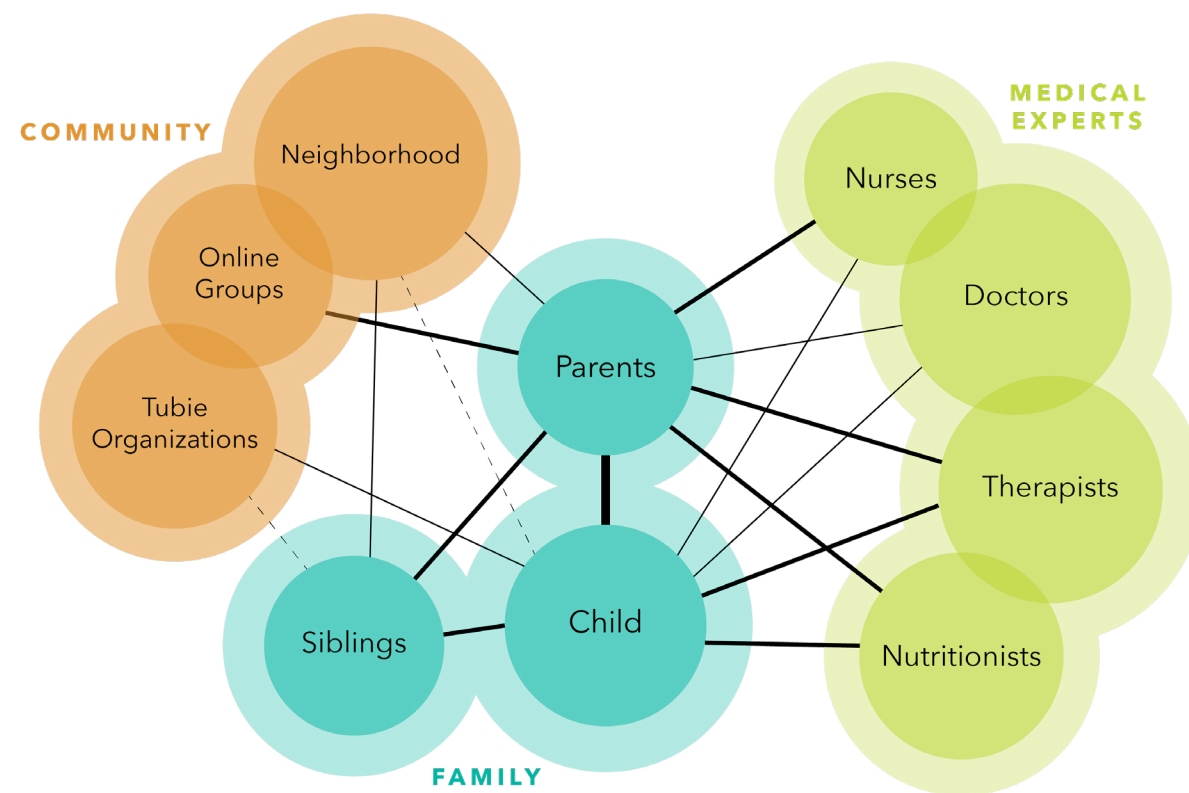


FIGURE 1.2 Child healthcare network.

THE FEEDING TUBE

Adding the feeding tube in the parent-child connection affects the relationship between the child and her parents. When Stella had her tube placed, her relationship to her mother was interrupted as she could not enjoy moments of intimacy that she had become accustomed to during breast and bottle feeding. While placing the feeding tube on Stella several times, Amber and Cody had to endure difficult experiences by seeming to hurt their daughter as she gushed and squirmed due to discomfort. Here, the tube as a mediator acts as a barrier: it has an effect in the rest of the network by changing the parent-child relationship, creating stress for the parents, stagnating the child's developmental stages, and limiting connections to the larger community.

But a mediator also has the capacity to strengthen, or even create new connections, instead of hindering existing ones. By telling her story through her blog *The Life and Times of Stella*, Amber met mothers that were going through similar experiences with their newborns, and shared their stories as well. The online community is filled with mommy blogs and forums where mothers from all over the world can have a conversation with other women who are going through similar experiences and support each other. This connection would not be possible without websites and the Internet as a mediator.

PARENT ----- CHILD

PARENT --- TUBE --- CHILD

TUBE FED CHILD

Newborn, infant, baby, child, and toddler – all used to designate a young human being. In order to create consistency and clarity, I defined these terms based on general findings and opinions since there was not a clear definition for each one. I established structure in relation to the age child's age: *newborn* is used when an offspring is less than a month old; *infant* is used when the child is less than twelve months old; *baby* or *toddler* is a child that is younger than two years; and *child* is younger than thirteen years old. In this paper, I will use *child* or *baby* interchangeably, and in the cases where I use *newborn* or *infant*, I am referring to the specific definitions described above to immediately identify the age of the subject.

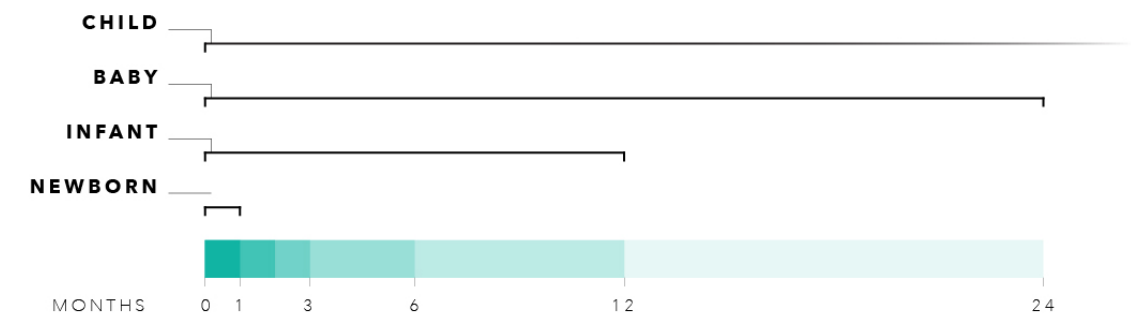
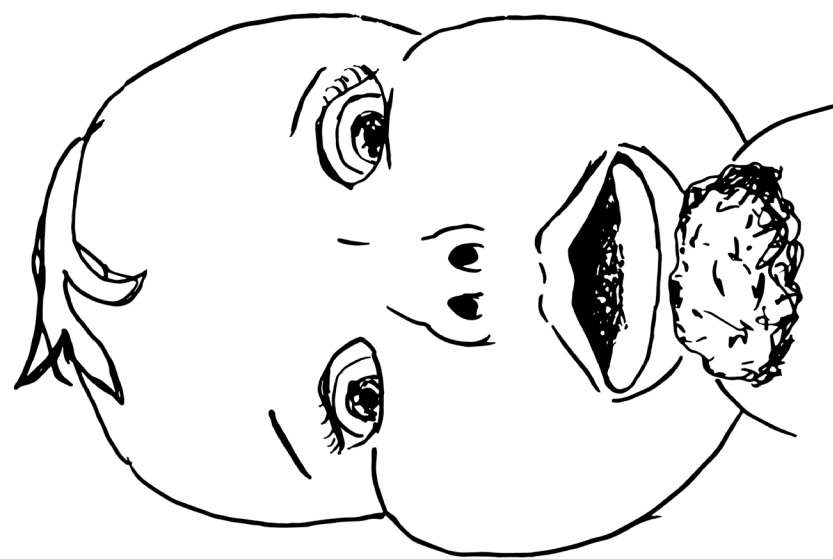
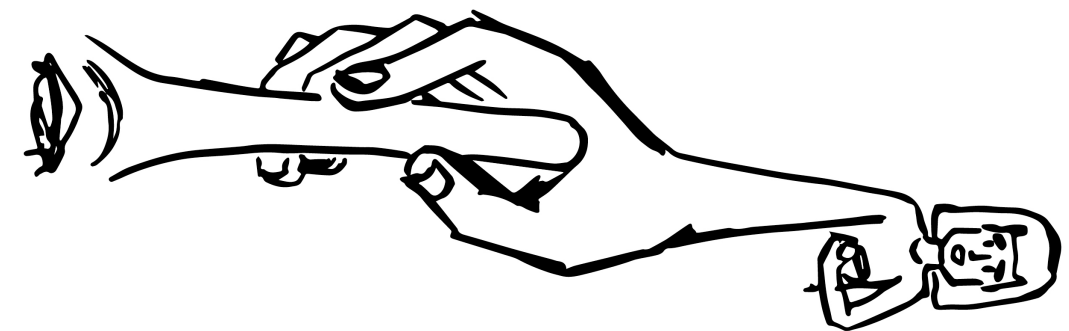


FIGURE 1.3 *above* Defining the age relationship between the terms Newborn, Infant, Baby, and Child.

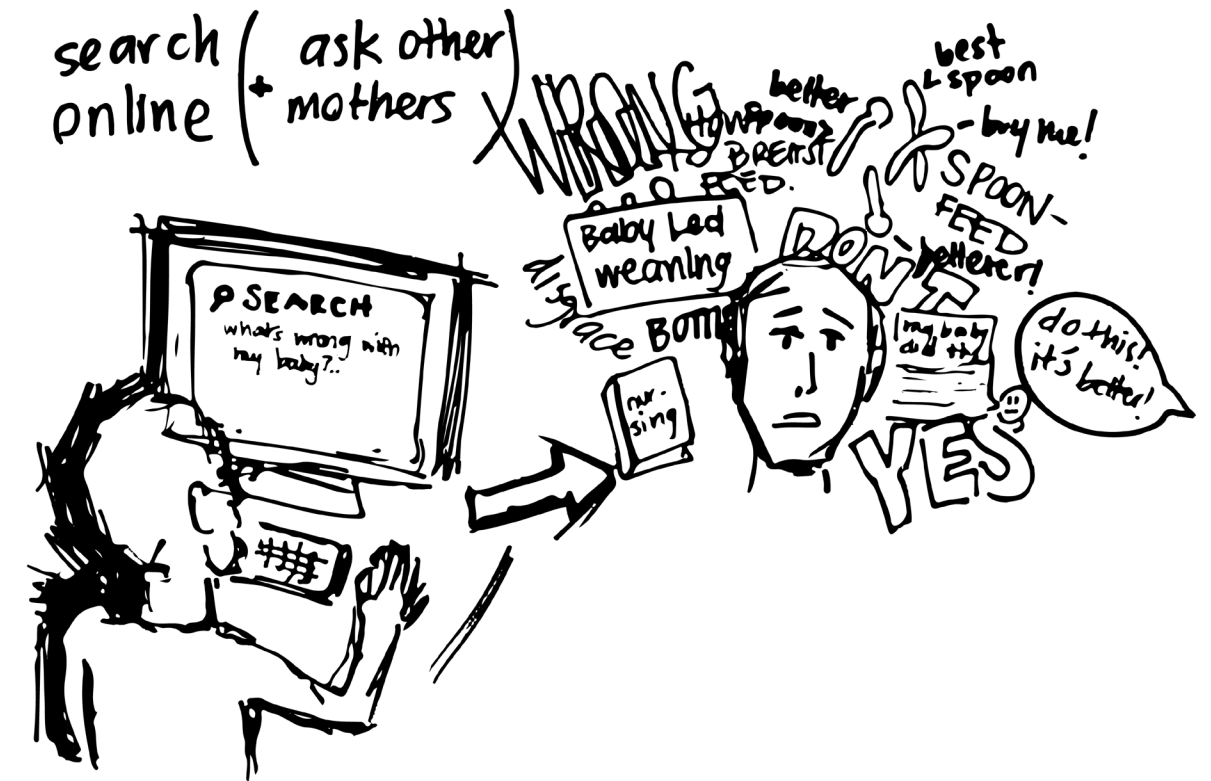
FIGURE 1.4 *below* How is the child's feeding experience different from parent's point of view? What does the child feel while being spoon-fed?



PARENTS

Parents often suffer postpartum depression, post-traumatic stress disorder, and overall anxiety and it is overlooked since they focus on their children and work more than on themselves. Parenting is already a challenge, but there are immediate effects after any complication – children are neglected, family relationships are broken, or financial problems ensue. How can parents learn to manage their mental health conditions while not being detrimental to their child or family dynamics?

After reading Stella's tube weaning memoir on *The Life and Times of Stella*, I noticed that Amber repeatedly conveyed antagonistic feelings as she documented her daughter's story – she was happy when she shared with Stella but sad when her daughter kept losing weight. Even though Amber found comfort in knowing that they are doing everything in their power in the pursuit to help Stella prosper, she occasionally expressed her angst and frustration in not being able to feed her daughter. On December 9th, 2008, Amber wrote: "When Stella began to stop eating, so did I. [...] Anxiety made it impossible to keep food down." After many ups and downs, Amber realized that she was neglecting her physical and mental health, which in turn affected Stella negatively. By changing her habits and paying more attention to her health – by going to a therapist just for her –, Amber felt better and in turn improved Stella's health.



MEDICAL EXPERTS

THERAPISTS, NUTRITIONISTS, LACTATION
CONSULTANTS

Occupational therapists are an important emotional and educational support to the parents by helping them understand their child's cues and improving the social interactions between them. They also explain typical child development and its stages, what they mean for their child to achieve certain skills – when she should be rolling on their belly, for instance –, and what the parents can do to aid in this growth. Each therapist has his/her recommendations to sustain the child's growth or try to solve problems that are impeding the child's development.

After interviewing many feeding therapists and a lactation consultant, I gained a more intimate insight to the weaning process. Each therapist works in similar environments but they approach the therapy differently and their programs vary from one another. I go into more detail about each feeding therapy methodology in the next section.

TUBE WEANING METHODOLOGIES

As aforementioned, it is critical to tube wean babies and children that have been tube-fed for extended periods of time. To tube wean is to gradually transition them from tube feeding to oral feeding. Similar to weaning from breastfeeding, infants and children slowly transition to solid foods of various textures and flavors from liquid breast milk or formula delivered through the tube. The main feeding therapies used to tube wean children are: mealtime focus (Morris, *New Visions*), Sequential Oral Sensory (SOS) approach (Toomey & Associates), Applied Behavioral Analysis (ABA), Baby Led Weaning (BLW), and hunger-based approach.

The No Tube Team at Graz Clinic in Austria, Dr. Markus Wilken in Germany, Seattle's Children's Hospital, Center for Pediatric Feeding Disorders in St. Mary's Hospital for Children in New York, and Spectrum Pediatrics in Virginia have focused specifically in implementing one or a combination of these methodologies and formed tube-weaning programs. I focused specifically in No Tube's Graz Model and the SOS approach developed by Dr. Kay Toomey.

at No Tube. During play picnics, children freely interact with food are not pressured to eat any specific amount in order to develop their “capacity for autonomous food exploration and food-regulation intake” (Beckenbach 96).

THE GRAZ MODEL

A group of doctors and therapists in the Graz Medical University in Austria have developed a diagnostic system, called the Graz Model or DC:0-3R, that specifies feeding disorders and developmental delays in infants and children associated to long term tube feeding. After completing the program, children can have the feeding tubes removed if their weight has stabilized upon returning home and they have fully transitioned to oral feeding (Dunitz-Scheer *et al*). The core ideology of the Graz Model is to trigger children to eat by allowing them to feel hunger and to interact freely with food. The children need to feel hungry to want to eat, so it is important to drastically reduce tube feeding even though they will lose some weight at the beginning of the weaning process, which requires constant non-invasive monitoring of the child’s medical condition.

In order to be accepted into the No Tube program, the medical condition that caused the child to depend on enteral feeding must be resolved and then the child must pass their assessment, similar to common swallow tests performed in the United States. Different medical experts, such as physiotherapists, occupational therapists, speech language pathologists, and psychotherapists for parents, support families during the time the child participates in the No Tube program. One of the most important activities is the daily play picnics implemented in the Eating School

STAGES OF TUBE DEPENDENCY

Stage 1. The child depends 100% on tube feeding for nourishment and shows indifference or aversion to any visual or tactile stimulation from edibles. In some cases, the anticipation of any feeding experience can provoke negative and anxious reactions. Children in this stage “cannot eat, have never learnt to eat, and do not want to eat by mouth as long as full tube feeding is continued”. They have a neutral or sometimes positive connection to their tube feeding routine and show adversity to any change.

Stage 2. Tube dependency decreases to >80%. The child shows some interest in food and oral stimulation; yet still depend on their tube for all of their nutrition. There is an increase in play and curiosity with food; the child may enjoy touching, grasping, and tasting food.

Stage 3. Oral feedings occur once to twice a day by “bottle, spoon, or cup” and tube dependency is around 60%.

Stage 4. Tube feeding supports 50% of the child's calorie intake, which is provided at night while the child is sleeping so that he/she thinks of him/herself as an eating child during the day.

Stage 5. The child's calorie intake increases to 70-90% orally, with occasional supplemental feeding while the child is sleeping.

Stage 6. The final stage is to completely tube wean the child and depend entirely on oral feeding for all of his/her caloric intake.

No Tube has been very transparent with their work and process and has successfully weaned several thousands of infants and children during the past 25 years, with success rates of >90% (Dunitz-Scheer *et al*; *No Tube Website*). Their two week long Eating School program costs EUR 8,320, without including accommodations and transportation, and can only be completed by attending their facilities in Austria. Since it is difficult for families to travel, No Tube has also developed an online program and network, called Netcoaching, which supports their methodologies and aids other families that cannot afford to travel but would invest in the program for about half the cost of the Eating School (*No Tube Website*).



SOS FEEDING THERAPY

SOS, or Sequential Oral Sensory, Feeding Approach uses “play based therapy techniques and positive reinforcement” (SOS Website) to address problematic feeding behaviors, such as oral aversions in children with physical or neurological developmental issues.

I interviewed feeding therapists, Iliana Rotkopf and Alison Jackowitz, both of which work with children younger than three years, and gained the following insights:

- They work in areas that look like regular feeding environments, such as a kitchen or a dining room.
- When tube fed children are allowed to become hungry, they became immediately interested in the food.
- Incorporating tokens or reinforcements throughout mealtime and therapy increases the child's engagement with the food.
- Different textures in physical products are engaging for the children, but there is a fine line with over-stimulating them with too many textures. The same goes with saturated and bright colors.
- Feeding therapy takes time and has a lot of ups and downs. One must trust the process.

3

DEVELOP

DESIGNING FOR INTIMACY

How will I evaluate precedents to affect the aesthetics, form, material, and color? Since I am designing for children and their parents are the ones with purchasing power, I need to design a product that evokes trust in the parents yet is appealing for the kids to use and play with. Essentially, I am designing for two.

In *Our Aesthetic Categories*, Sianne Ngai describes cute as a “response to our perception of the vulnerability in an object”. A baby is vulnerable; therefore we find it cute. Cuteness is a reaction that is hardwired into our brains as humans. We find babies cute because of our evolutionary instinct to take care of our offspring since “attending to them closely makes good Darwinian sense.” (Angier). This is similar to our preference for sweet foods and our perception of “sexiness”, two other evolved instincts that cater to our ancestors’ needs: survival and reproduction of the human race. We have a sweet tooth because we prefer high-energy foods, even if it was designed for fruit and not candy. In his TED talk, Denis Dennet explains why we have such preferences by reusing Nikolaas Tinbergen’s definition of supernormal

stimuli. In Tinbergen’s studies, gull chicks responded strongly to a larger orange spot on the gulls’ beaks compared to the average sized spot, making it a supernormal stimuli (Dennet 0:04:47-05:25). Therefore, for example, a supernormal stimulus to cuteness is a baby panda; to sweet is a decadent chocolate cake; and to sexy is a woman in a Victoria’s Secret ad.

According to Dennet, if babies looked differently, we would still find them adorable (0-05:47-59). Because babies are the way they are and look the way they look, we find them cute – not the other way around. These baby-like features were first described by Konrad Lorenz as babyiness or das Kinderschema in a variety of young mammals that evoke nurture and caretaking from adults (Winston 123). The set of physical characteristics range from “(a) large head relative to body size, rounded head; (b) large, protruding forehead; (c) large eyes relative to face, eyes below midline of head; (d) rounded, protruding cheeks; (e) rounded body shape; and (f) soft, elastic body surfaces.” (Winston 124) In the article The Cute Factor, Natalie Angier states how humans quickly regard as cute “the young of virtually every mammalian species”, such as “woolly bear caterpillars, a bobbing balloon, a big round rock stacked on a smaller rock, a colon, a hyphen and a close parenthesis typed in succession.” (Angier) Essentially, humans deem cute everything that remotely resembles a baby, including inanimate objects with rounded, furry, and squishy features or baby-like movements. Because this definition of cuteness is so generalized, humans take almost everything as cute. It is important to differentiate cuteness from beauty, “emphasizing rounded over sculptured, soft over refined, clumsy over quick” (Angier). Beauty demands admiration and awe while cuteness evokes affection and care.

Designing the head proportionately larger than the body and the eyes larger relative to the face adds a cuteness factor to a character. To make an object cuter is to make it rounder, blob-like, and squishy. Softening an object’s features will make it seem cuter, but making it more so augments its vulnerability. Just like a baby is weak and defenseless, something that is inherently weak evokes the desire to nurture followed

by a sense of manipulation that challenges our initial reaction, since the subject feels that it is being deceived (Ngai 24). This negative, secondary feeling of deception is caused by our quickness in reacting to something cute, which “seems to invite what Denis Dutton calls ‘the sense of cheapness ... and the feeling of being manipulated or taken for a sucker that leads many to reject cuteness as low or shallow.’” (Ngai 25) What about things that seem to be safe but are not? Where seemingly adorable characters – killer teddy bears, evil clowns, and cunning bunnies – take advantage of people’s susceptibility to cuteness and loss of the ability to think critically.



CREATING TRUST THROUGH CUTE DESIGN

There is a fine line between the initial positive feeling of cuteness and the negative secondary feeling deception where it is dangerous to be positioned regarding baby products. Betrayal creates mistrust, which eradicates the confidence in purchasing an infant toy. When taking cuteness into the formal aspect of my design, I must assure to evoke an affective response without creating the sense of cheapness or manipulation. Then again, what if I explore the boundaries of cute design for babies by playing with evil while still creating trust, just as Pixar Animation achieved with Monsters, Inc.?

All in all, I am designing for parents and children alike. The design principle lies in the sweet spot between evoking affection in the parents, designing for trust, and creating a joyful experience for the child.

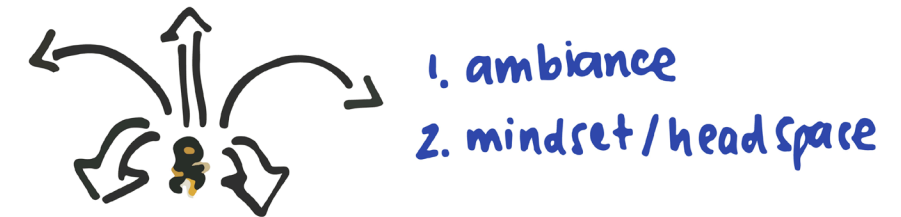
SAFE + ENDEARING = DESIGN FOR TRUST

DESIGN CRITERIA

Having completed this research, I have found that the tube weaning process has two main stakeholders: the tube-fed child and their parents. They engage in a vicious circle, where the parents pressure the child to eat and the child does not eat due to their oral aversion. None of the parties are to blame, but the way to break to cycle is by reducing stress in the home environment aside from participating in feeding therapy. Therefore, I am left with the final question:

*HOW CAN WE UTILIZE DESIGN
TO TRANSITION FEEDING THERAPY
PRACTICES INTO THE HOME
ENVIRONMENT CONTINUING THE
TUBE WEANING PROCESS WITH
CHILDREN THAT HAVE BEEN TUBE FED
SINCE BIRTH?*

how to design a PLAYFUL ENVIRONMENT?



Additionally, if applying play picnics and its exploratory environment is healthy for the child and the parents, how can I design that physical space and emotional state at home?

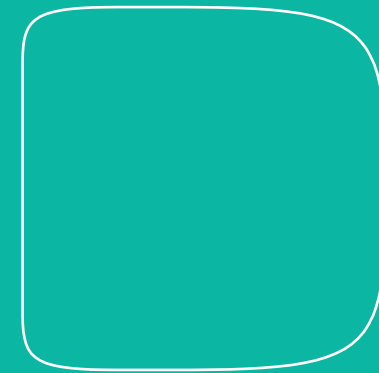
My design seeks to answer this problem in a number of ways:

- By **educating** the parents about their children's point of view and maintaining a physically and mentally healthy environment for their family.
- Implement a **playful** design to inherently reduce stress and anxiety to ease the weaning process at home.
- Be **engaging** so that the children want to interact with it, yet do not get distracted with over-stimulating textures and colors.
- Maintaining **inclusivity** not only during the mealtime and at the dinner table, but also by assessing the diversity of all tube fed children.
- Creating **representation** among the tube fed children by allowing them to feel **identified** by other tube fed children, characters, and role models.

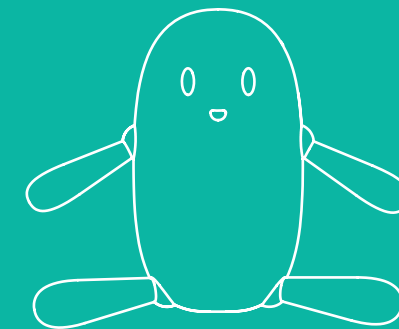
4

DESIGN

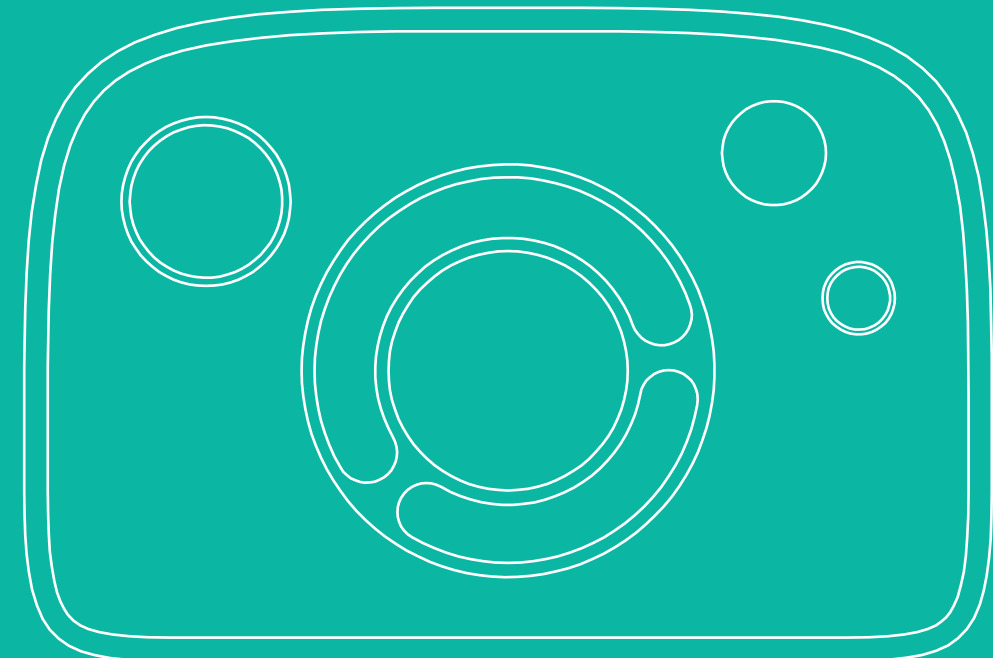
TUBIE BOOK



TUBIE DOLL



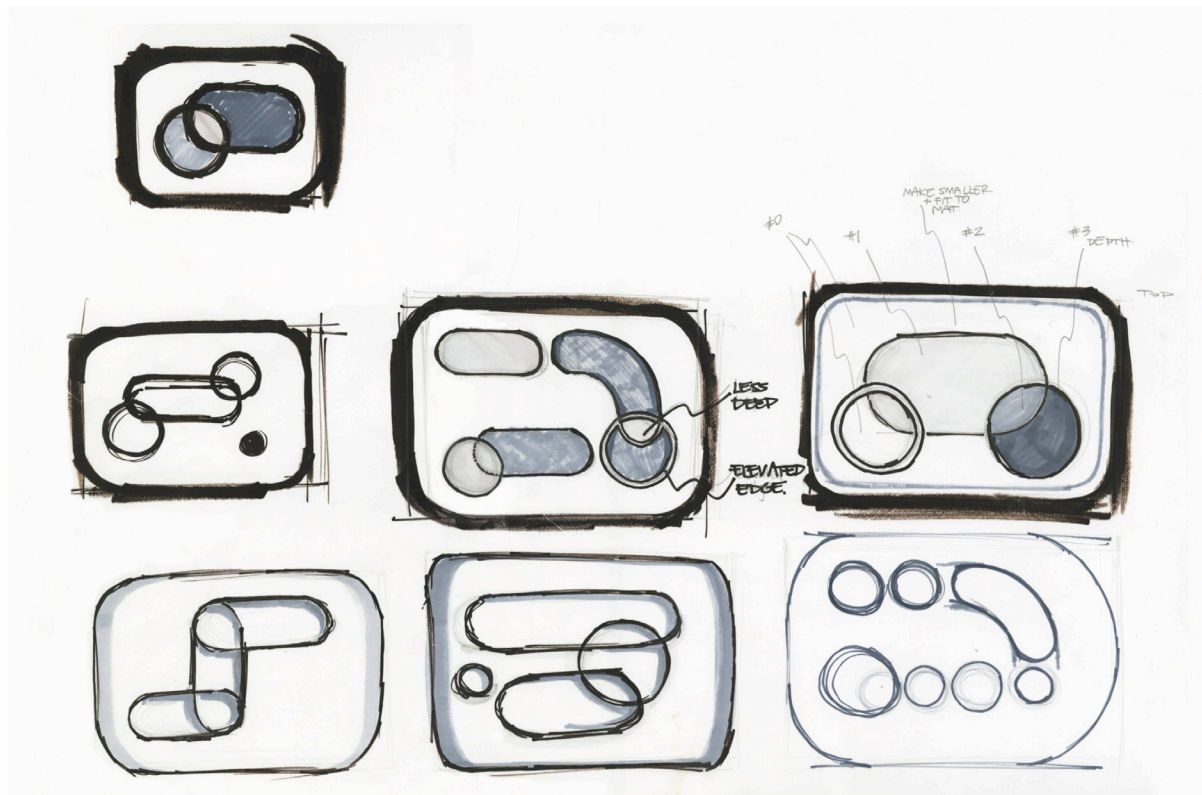
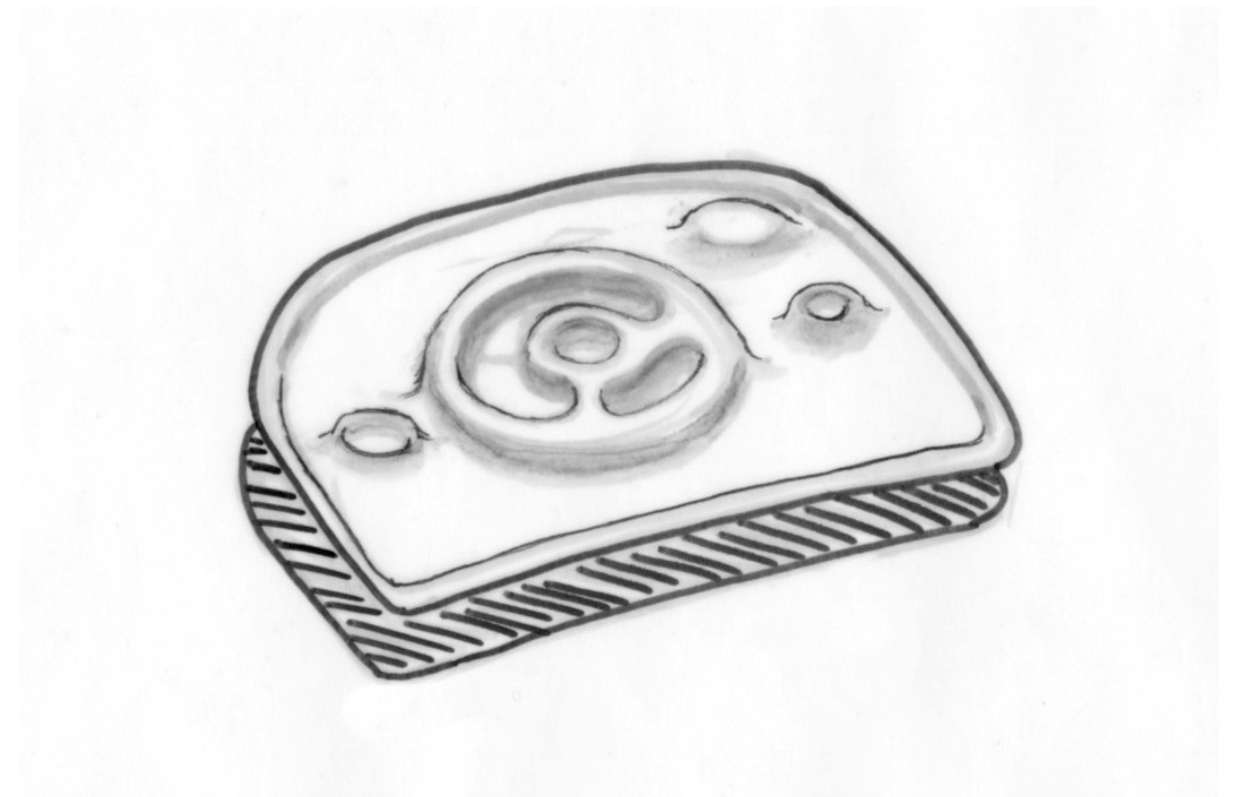
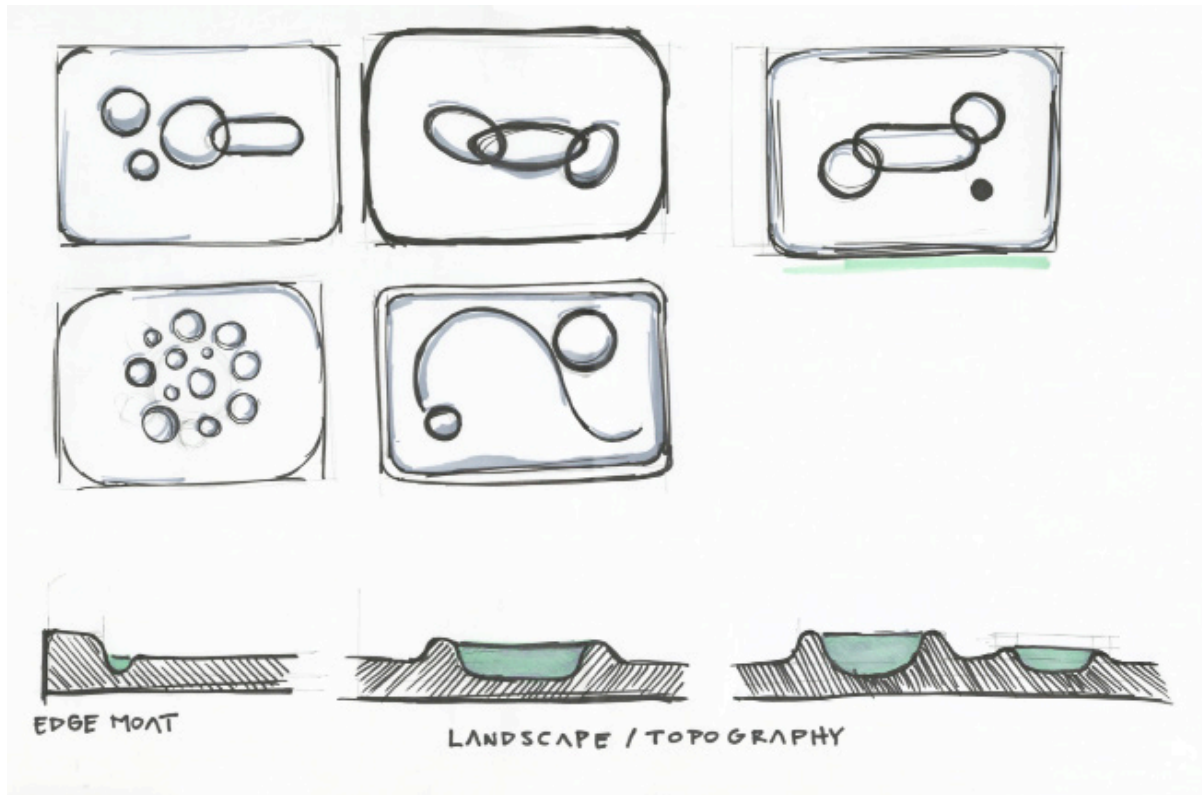
PLA(Y)CE MAT



PLA(Y)CEMAT



The Playcemat creates a playful eating environment to permit free interaction with food, reminding parents to allow their child to do so - no matter the amount of food eaten or messy consequences.

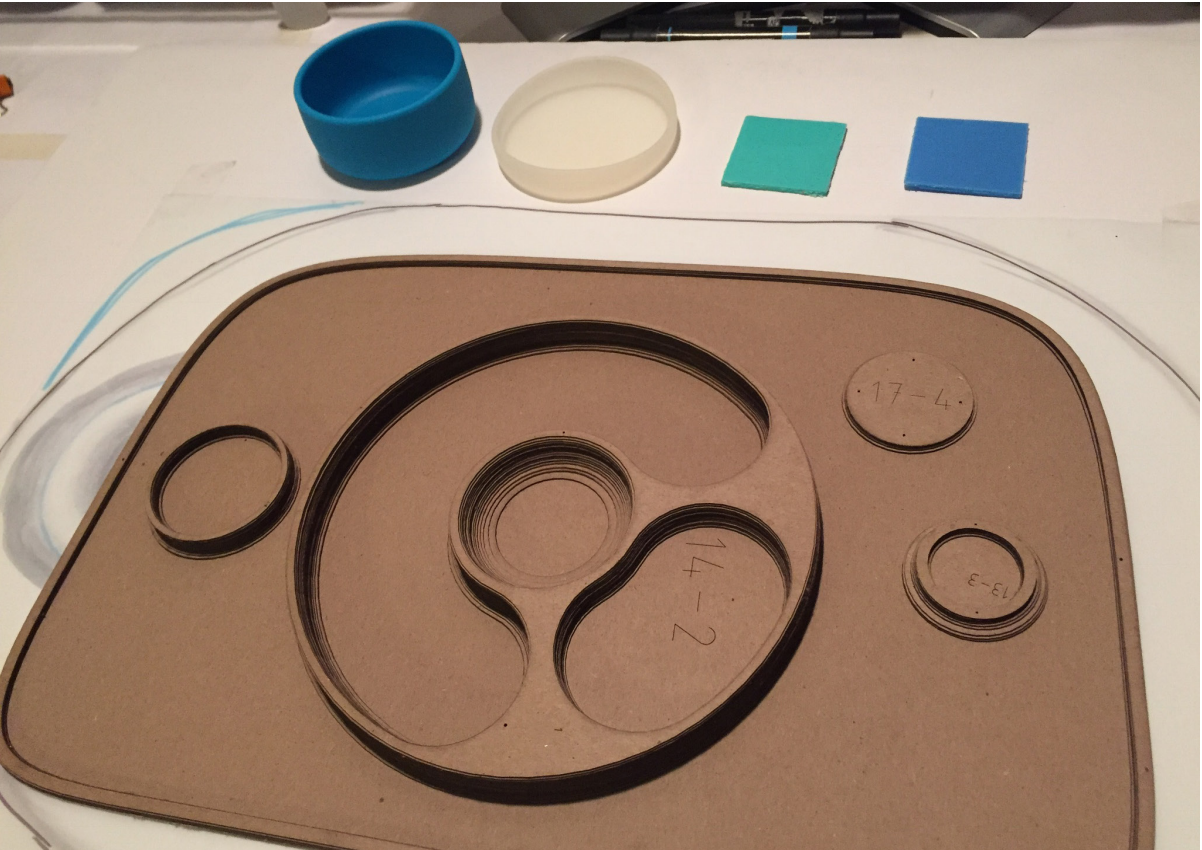
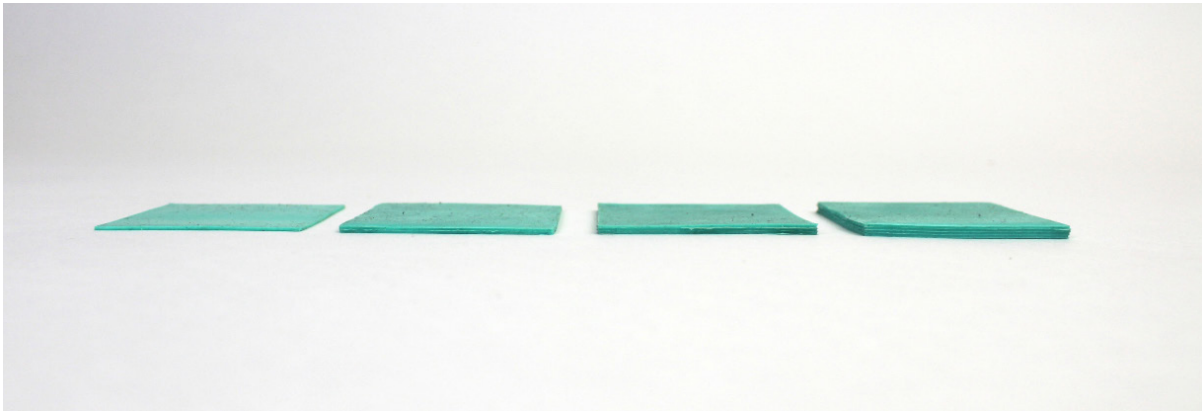
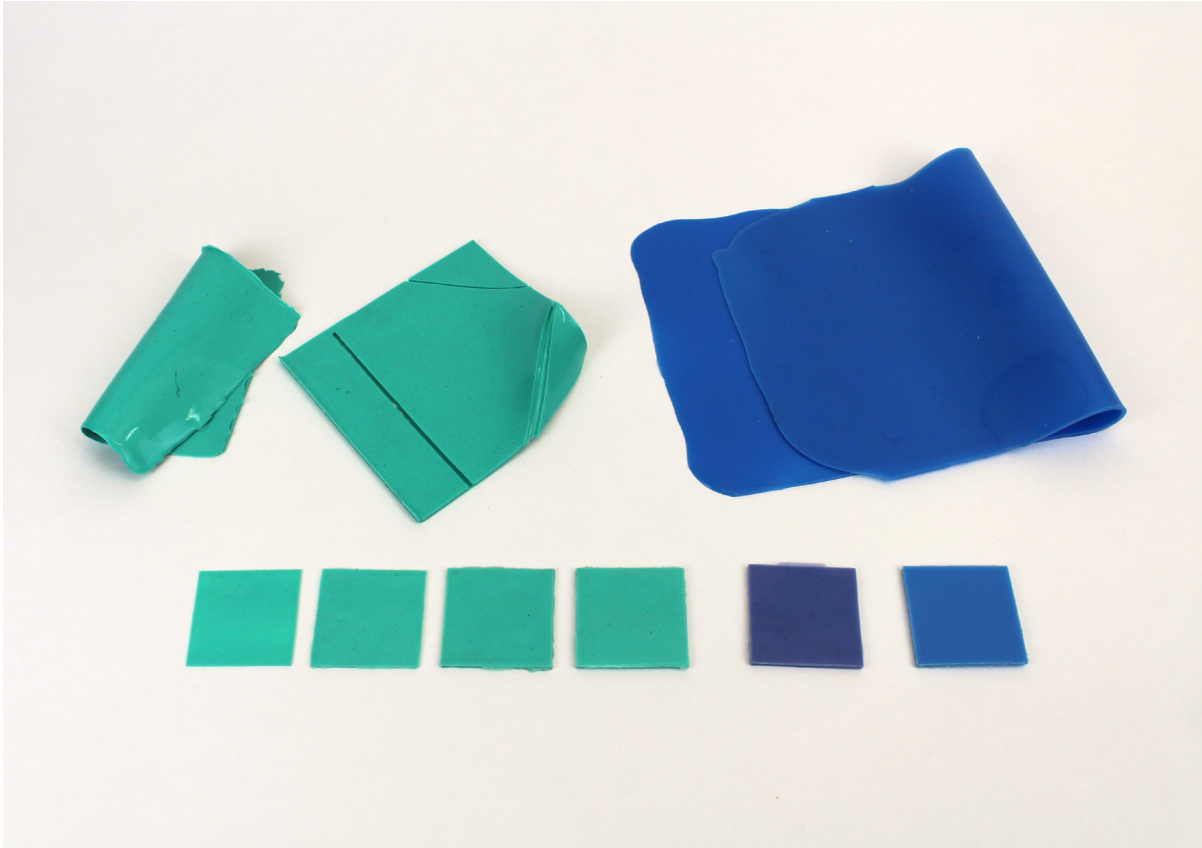
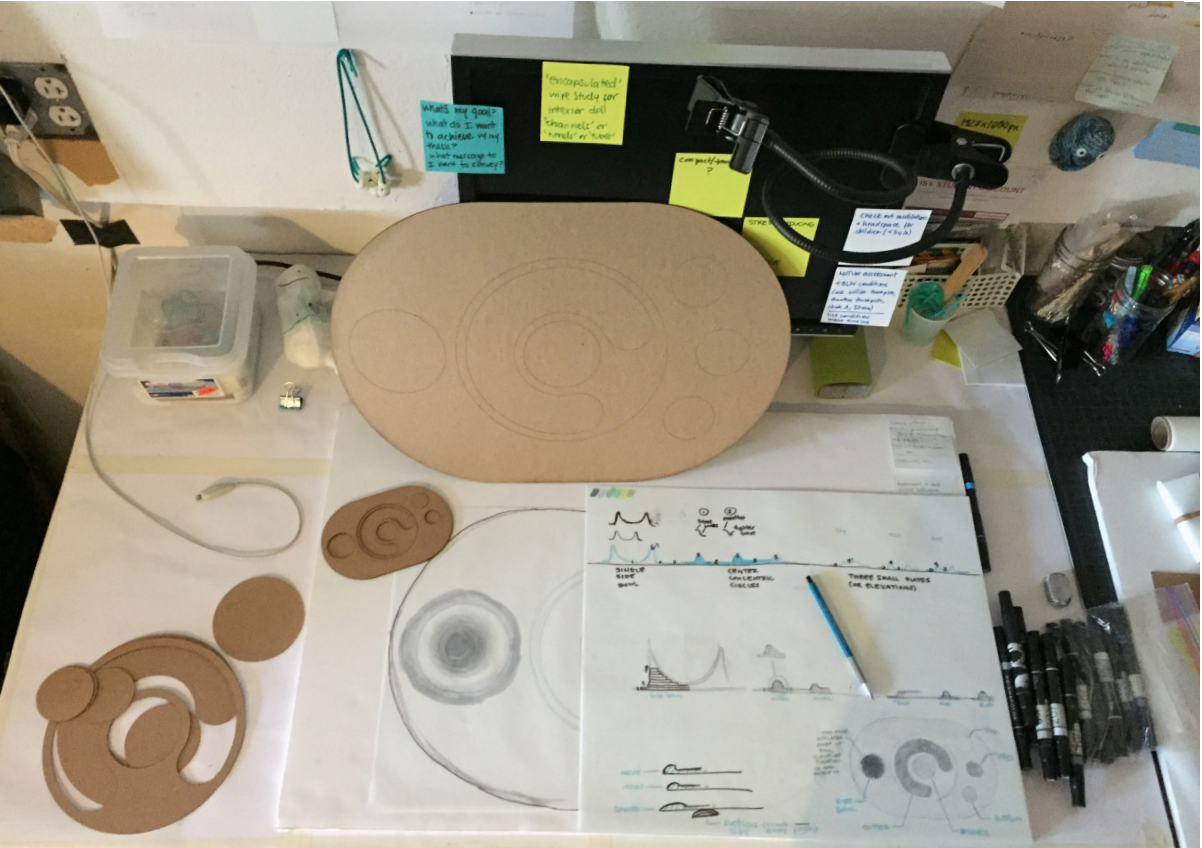


PROTOTYPES

What is the most appropriate layout? Why is this the most appropriate design? I consistently asked myself these questions while going through many iterations and trying out different layouts to select the most suitable layout. I started with small 1/4 scale models first and, after scaling up to full size, I made changes accordingly, such as making the thickness of the mat thinner and scaling down the overall size .

I also tested out different thicknesses and silicone shore hardnesses to get a better feel for the final prototype. If the material is too soft and thin, it will feel too delicate and therefore cause the parents or therapists to consider the placemat unreliable.

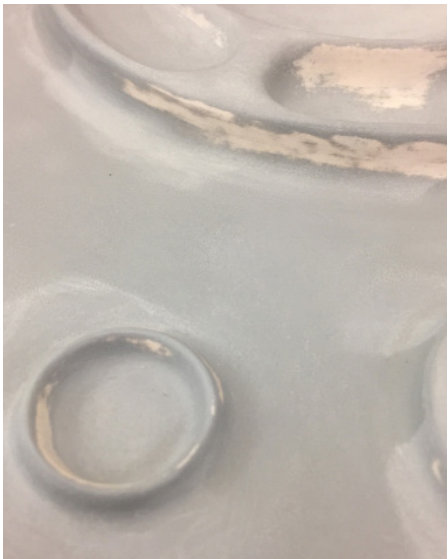
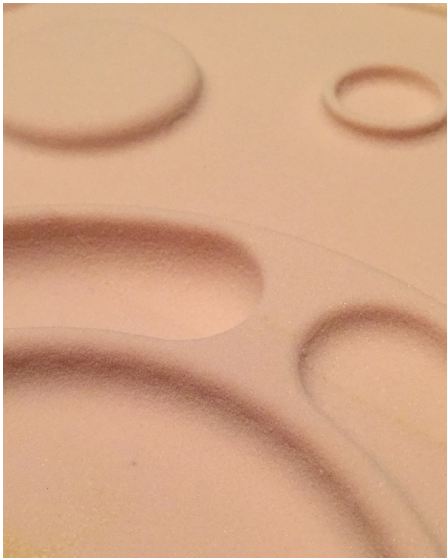


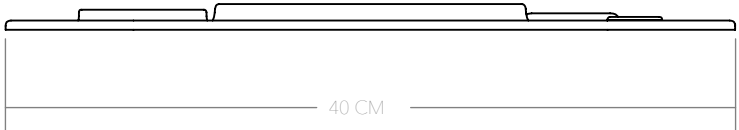
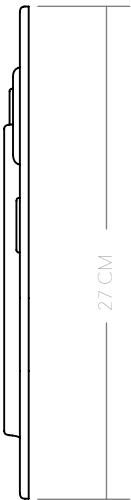
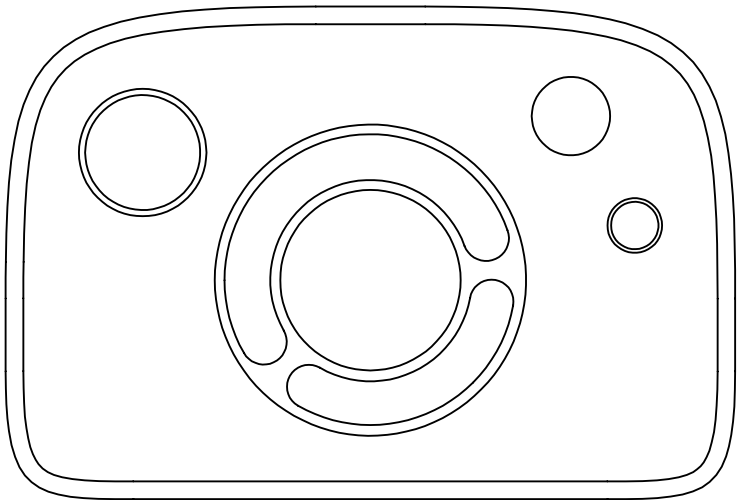
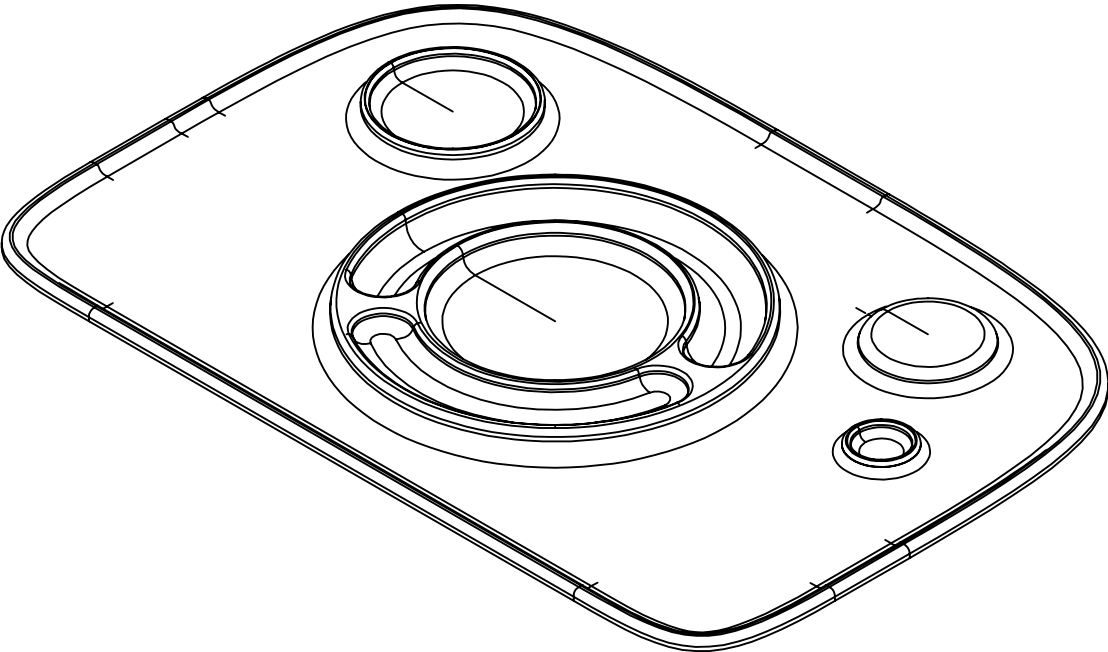


MAKING OF PLA(Y)CEMAT

After finalizing the design of the place mat, I made the positive, which became the mold of the mold, using high density corafoam and a CNC milling machine. After treating the positive mold with several layers of resin and paint, I cast the mold of the place mat out of plaster. Finally, I cast the final place mat using a two part silicone, which I dyed myself to find the desired color. The blue-green and yellow-orange hues were deliberately chosen to be gender neutral yet still remain vibrant to attract the child's attention.





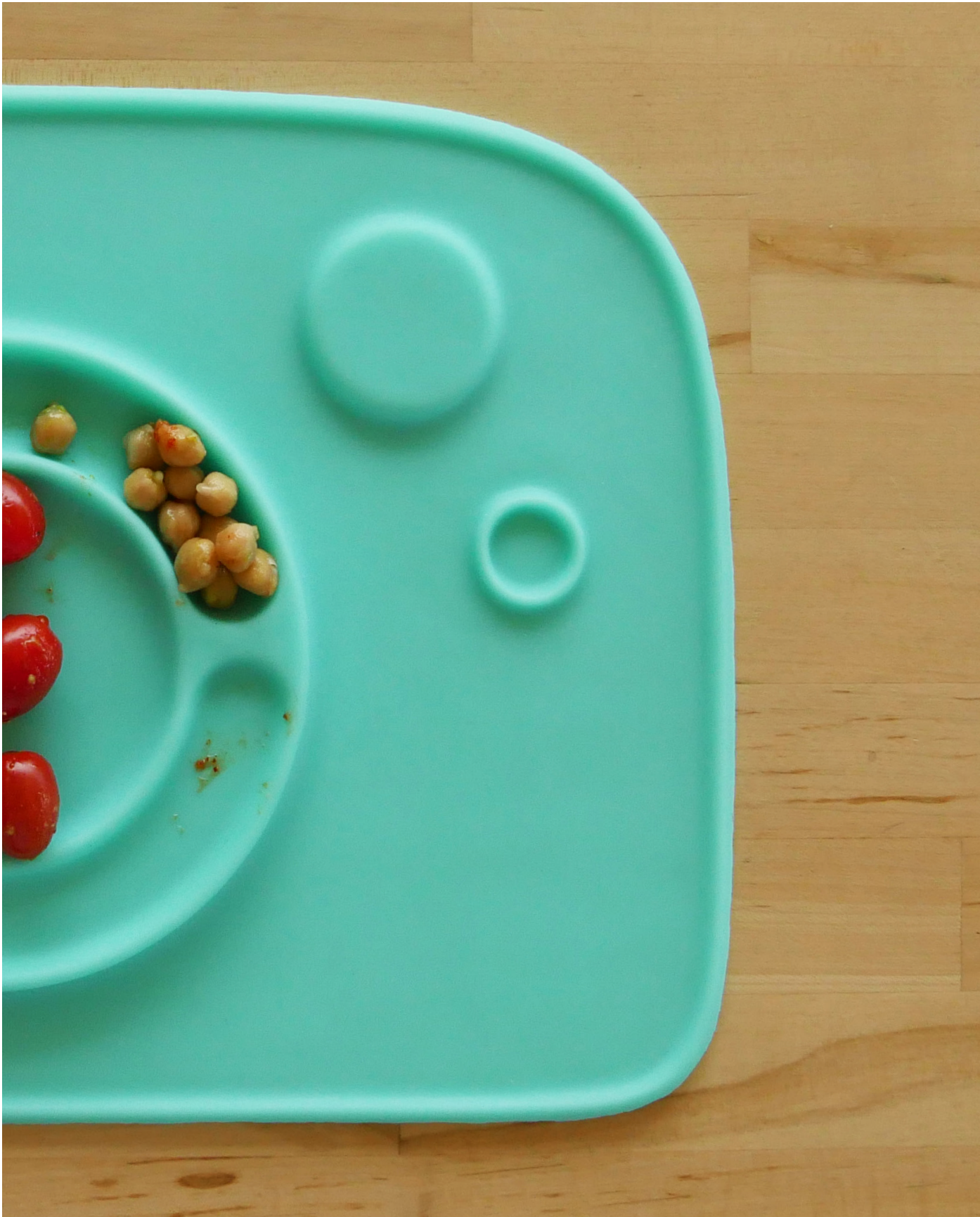




PLAYCEMAT FEATURES

The Playcemat was designed to be able to suction to virtually any flat surface, as long as the surface is not too textured. If a child were to pull on the elevated ridges, she would not be able to throw the Playcemat off the table. To remove the Playcemat's suction from the table, one must simply lift any of the mat's edges.





FURTHER DEVELOPMENT

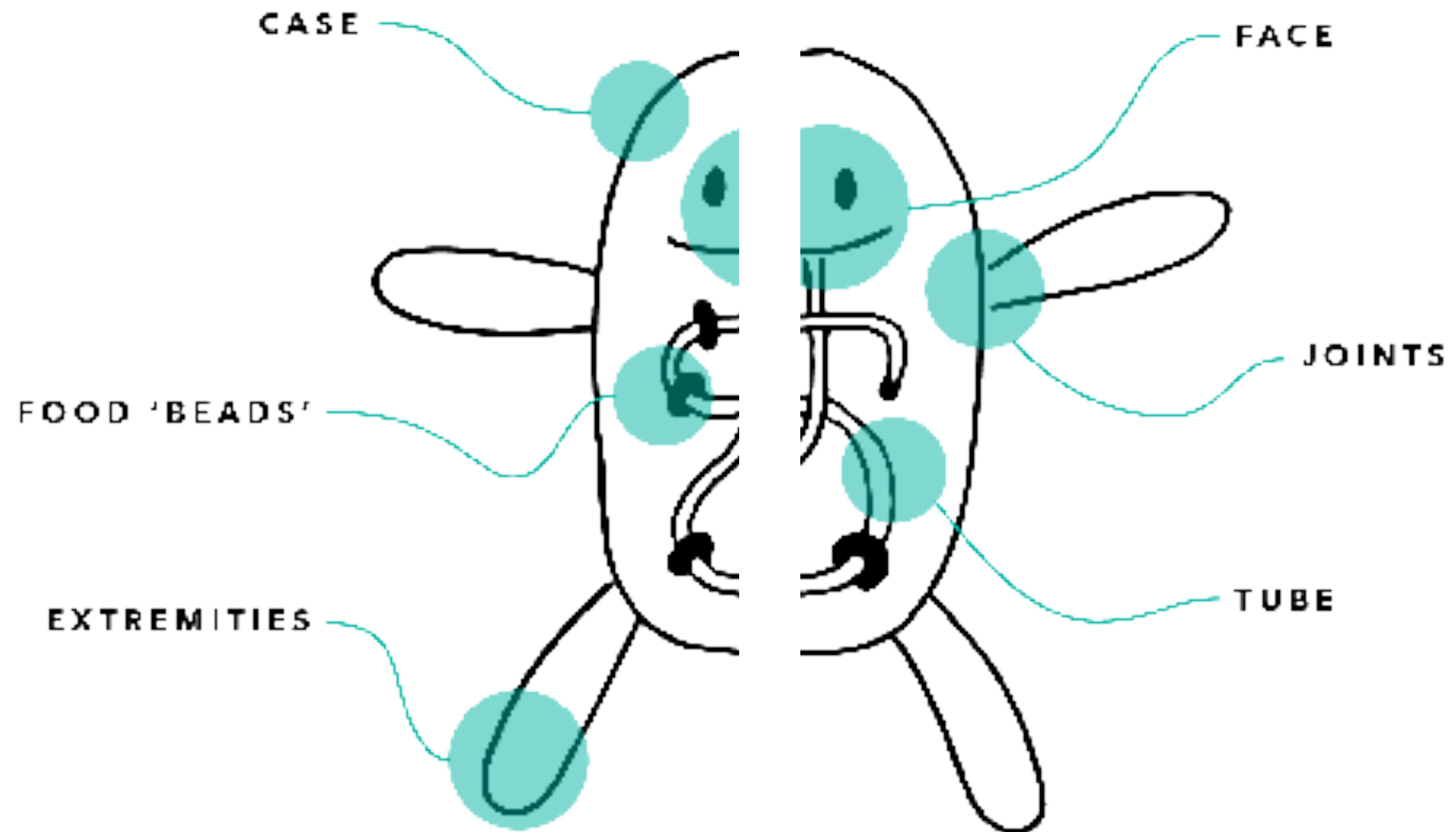
To continue developing the design, I made a set of small bowls that can be used as the child grows and requires larger meals. The bowls could be designed to perfectly fit into the Playcemat's elevations so that they would also be affected by the suction strength and impede the child to throw the bowls on the floor.

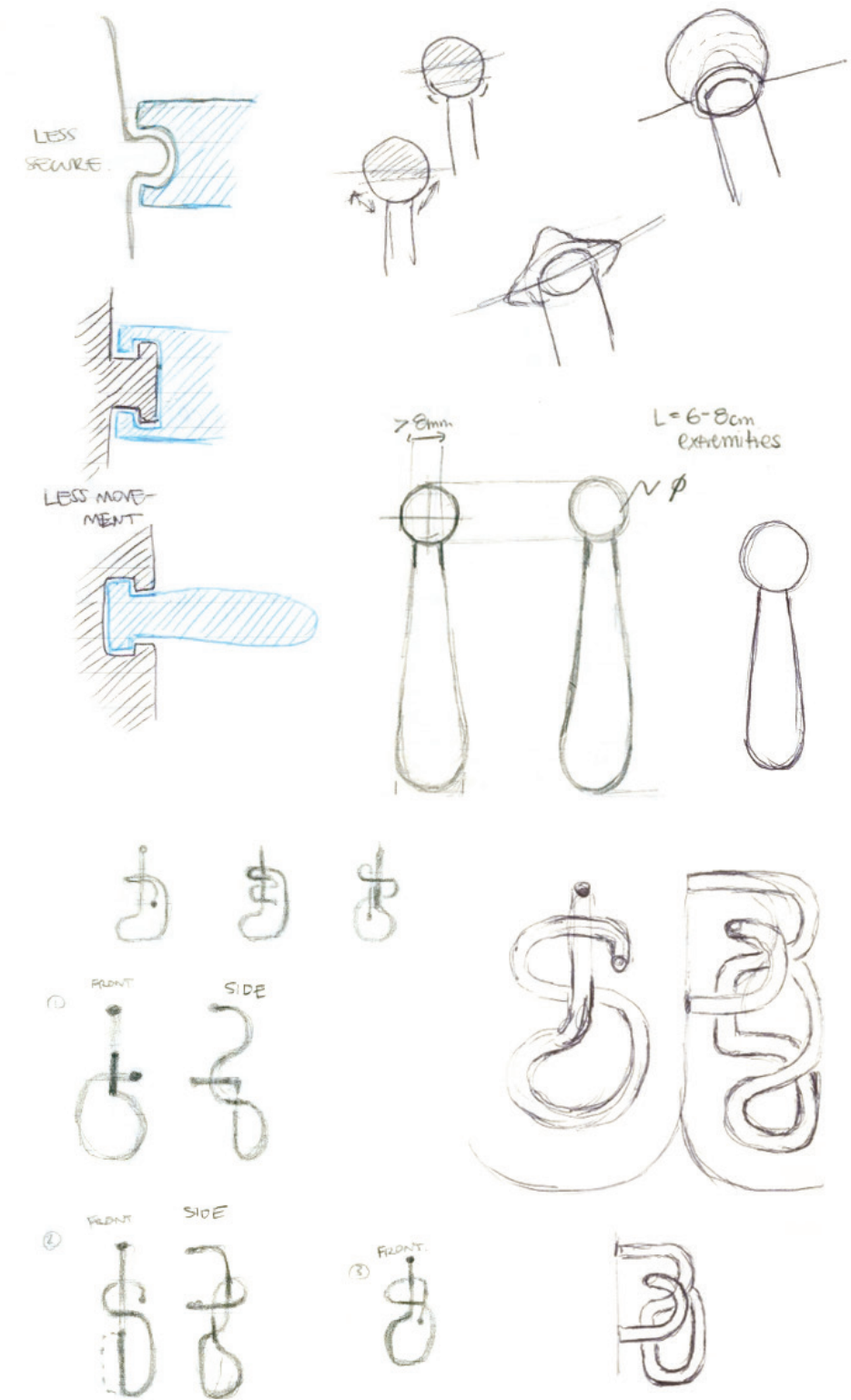
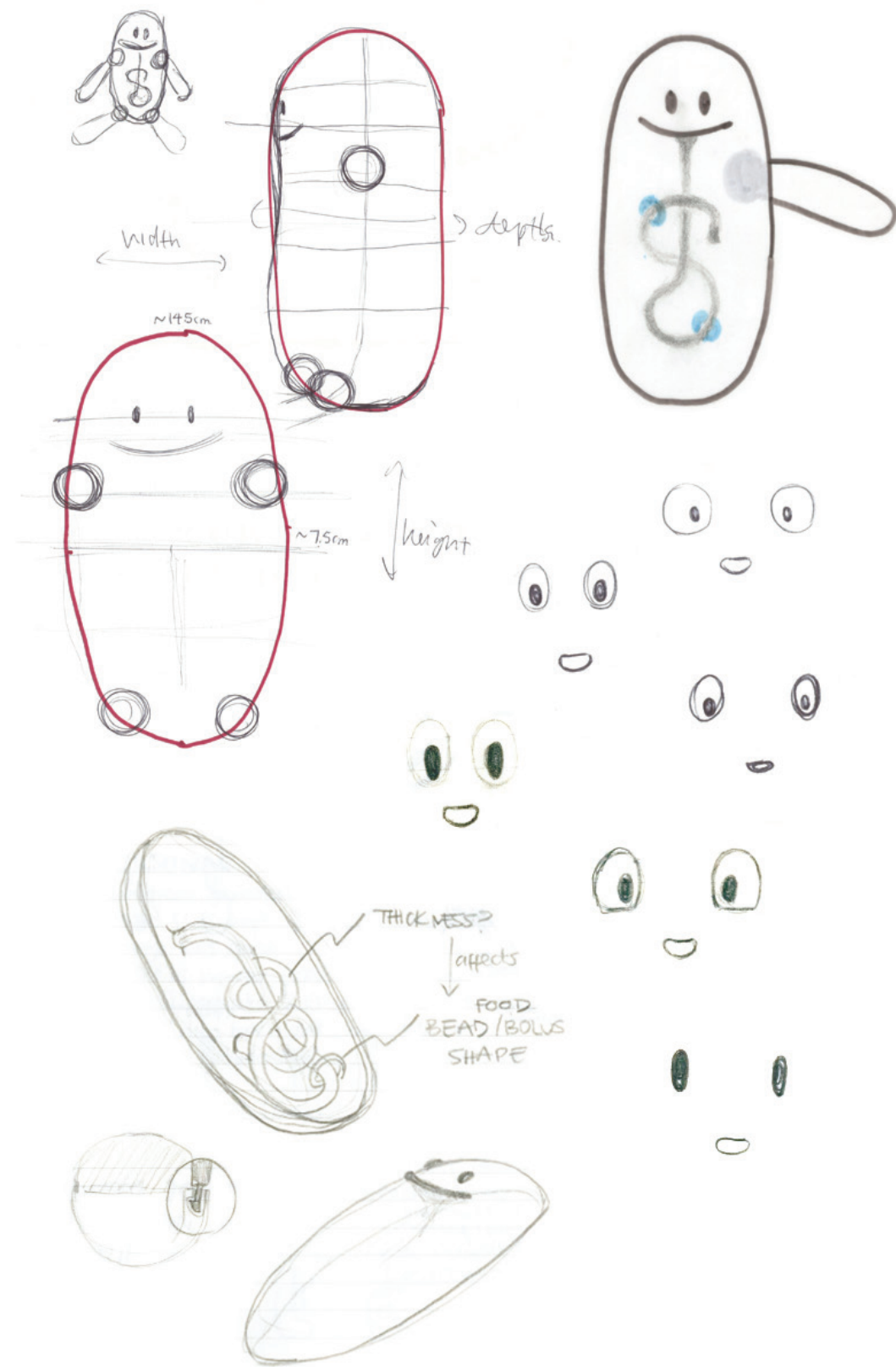


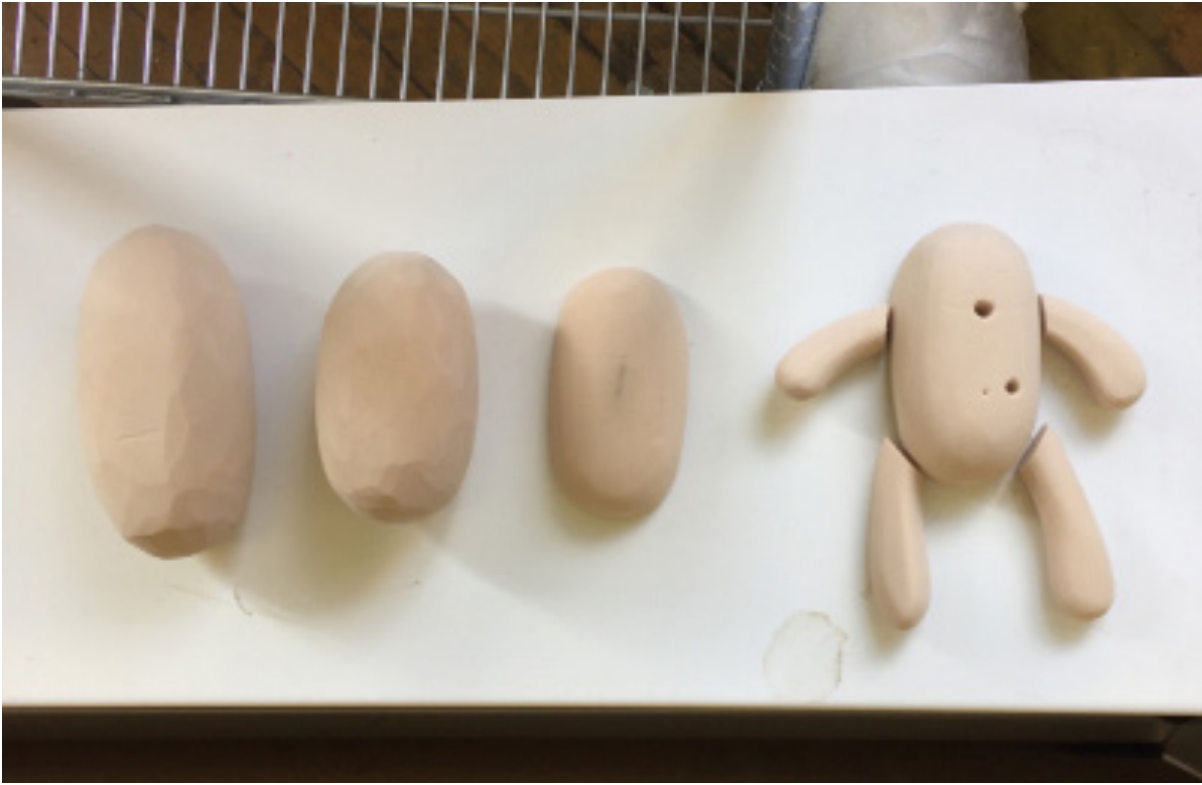
TUBIE DOLL

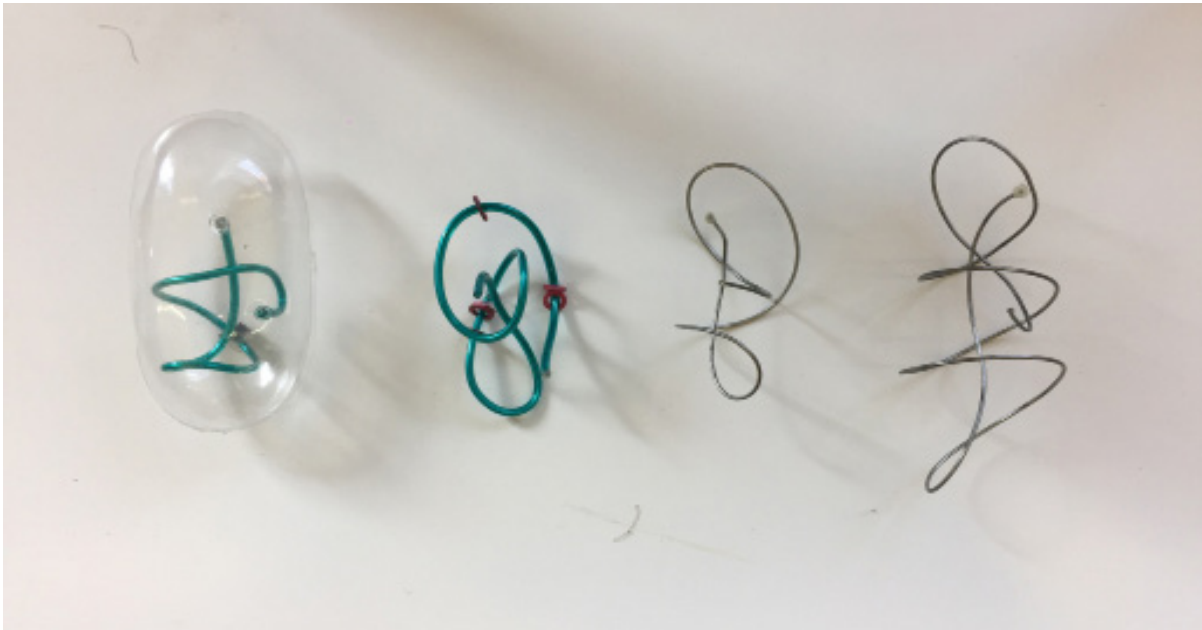
Tube fed children just want to be like other children and want a sense of belonging, many mothers sew onto their children's dolls old feeding tubes and tubie pads. They find tutorials on Feeding Tube Awareness Foundation website and *Feeding Raya* blog. I designed the Tubie doll because there is a need to have dolls that are more representative of the variety of children in the world, not just tube fed, but other children with disabilities that feel left out. Dolls are also used during feeding therapy and can aid the occupational therapist and speech language pathologist.

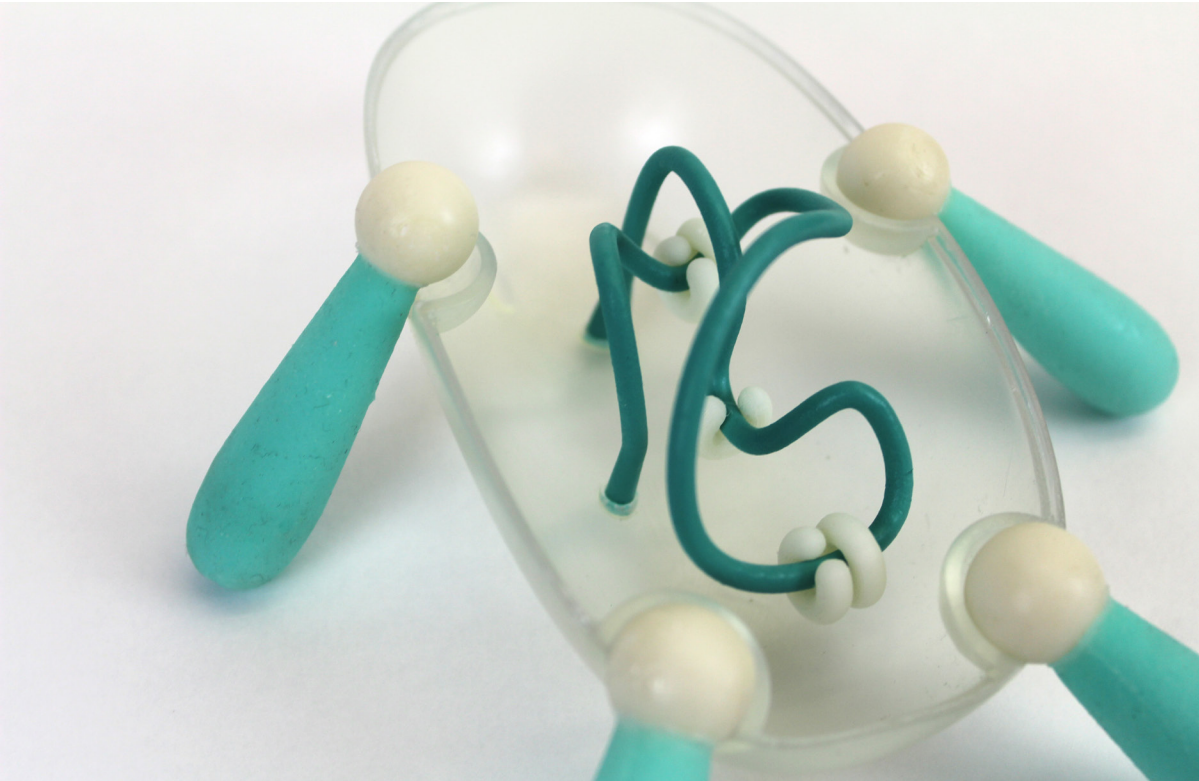
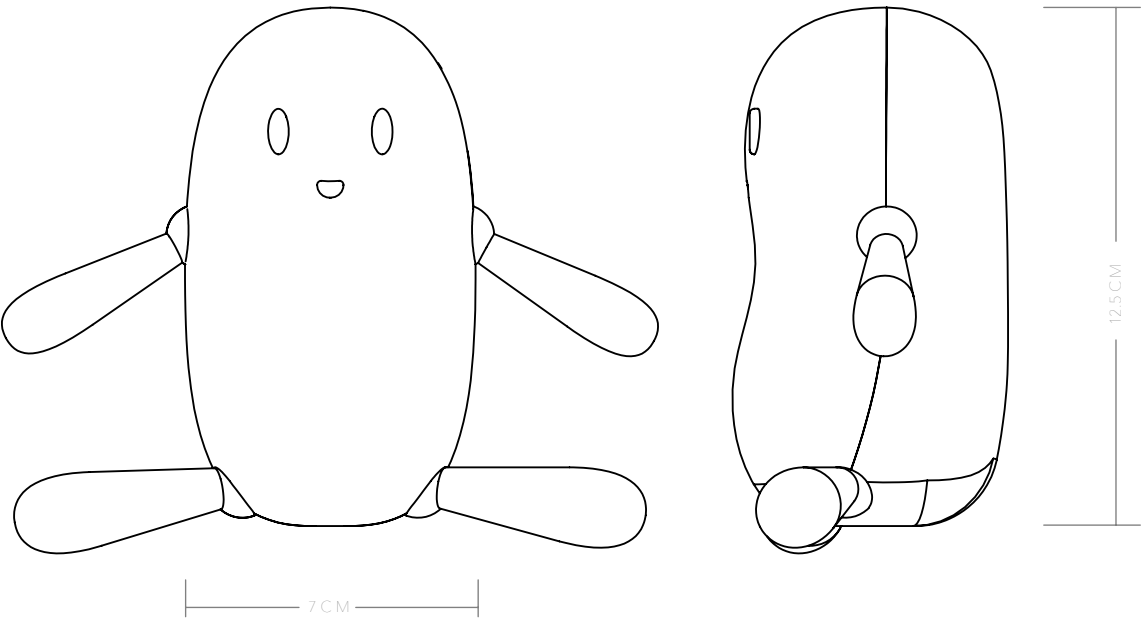
I made several amorphous ellipsoidal shapes, that ranged from jelly beans to potatoes, and varied in proportions to find the right one. The doll's body needs to be large enough so that the child can grab it with their constantly developing gross and fine motor skills. Similar to the Waldorf dolls that “seek to enliven a child's imagination” (Bella Luna Toys), the Tubie doll with its amorphous human-like body shape is ambiguous on purpose: so that the children can identify themselves more in the doll.

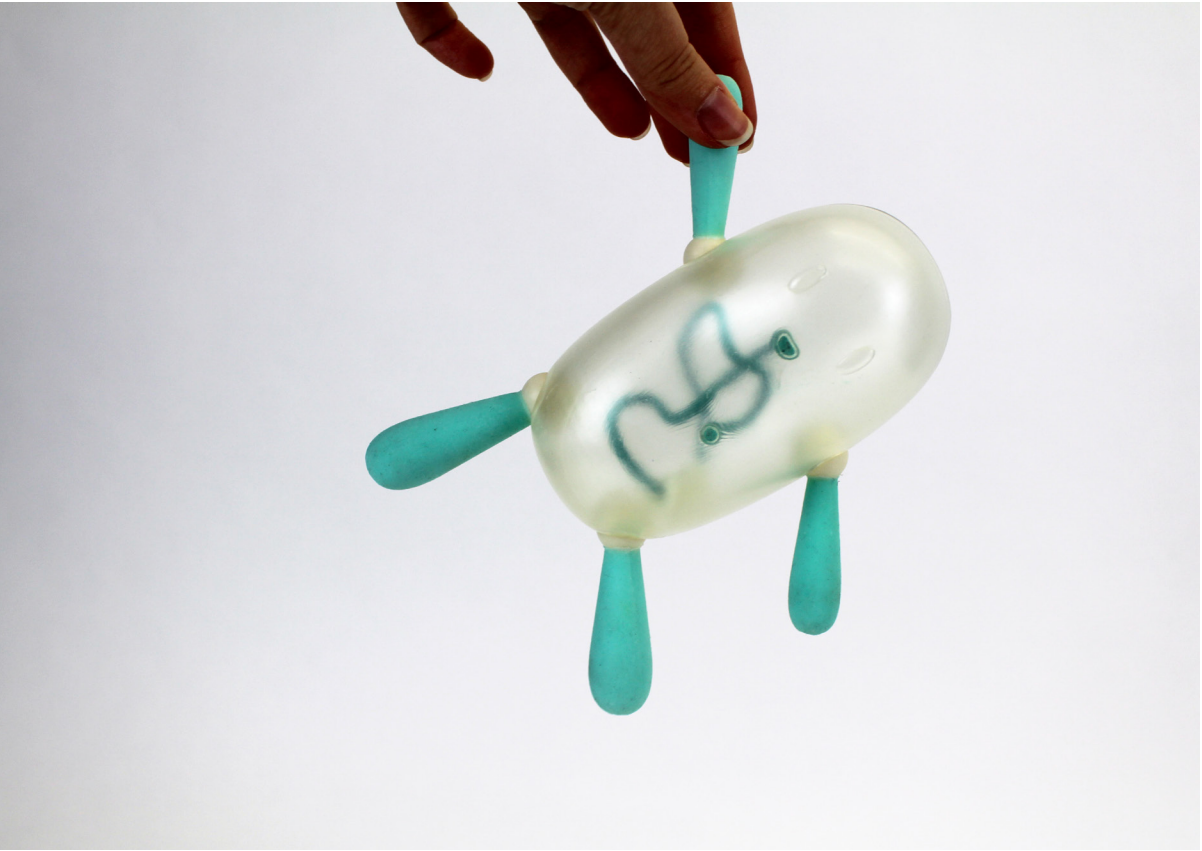


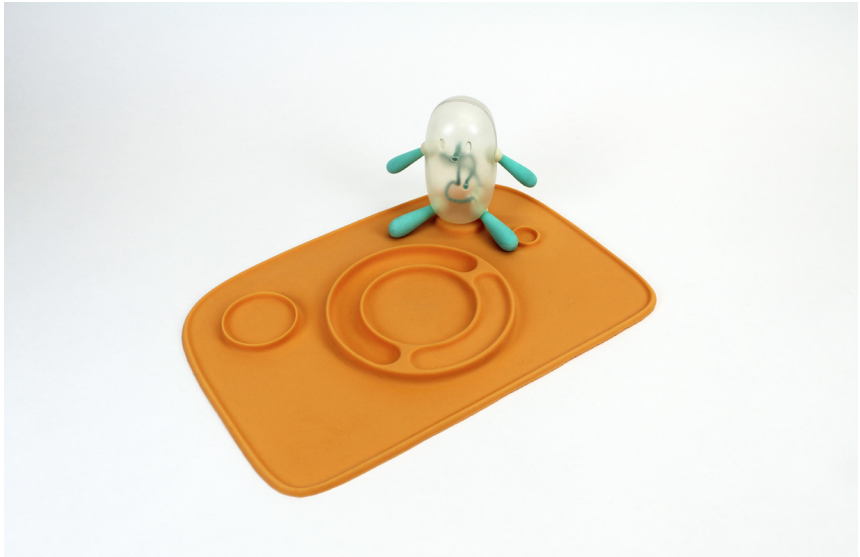














TUBIE BOOK

THE SUPER TUBIE GRADUATE

The story and character were always an afterthought. Instead, I was looking to design an app for the child and a pamphlet for the parents, but it was not the appropriate solution. A story needed to be included to either educate the parents or find tubie representation for the children, so why not both? I developed a quick storyboard that immediately resonated with me and made sense – Sammy the Tubie.

The story shows the good and the bad things in a tube fed child's life, but overall the happiness they already have and the fear of trying new foods. Most importantly, the story ends in a positive note to motivate the children that will read the book.

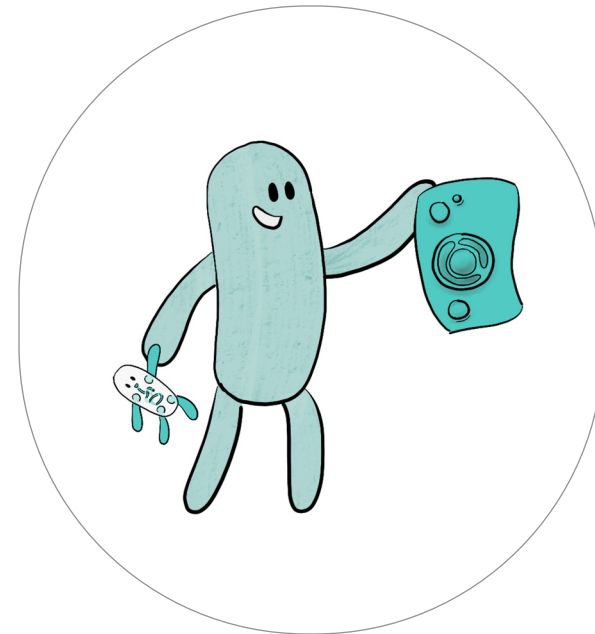
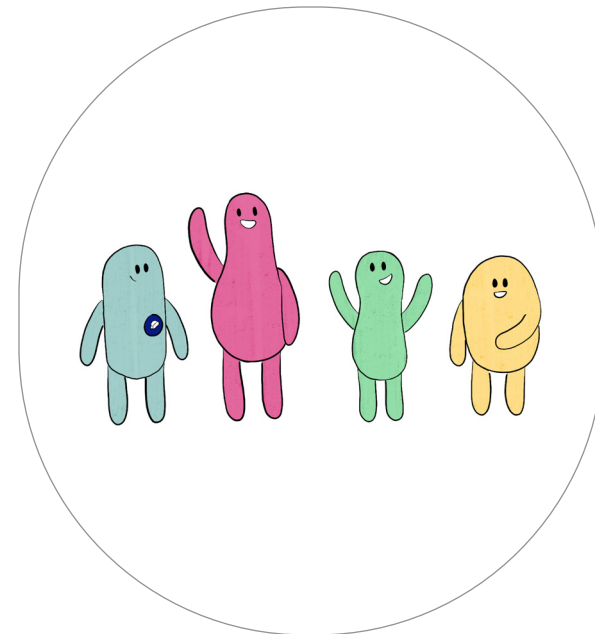
The Tubie book is also to educate the parents: they get a better understanding to what their child is going through and the struggle to overcome the fear caused by the extreme food aversions.

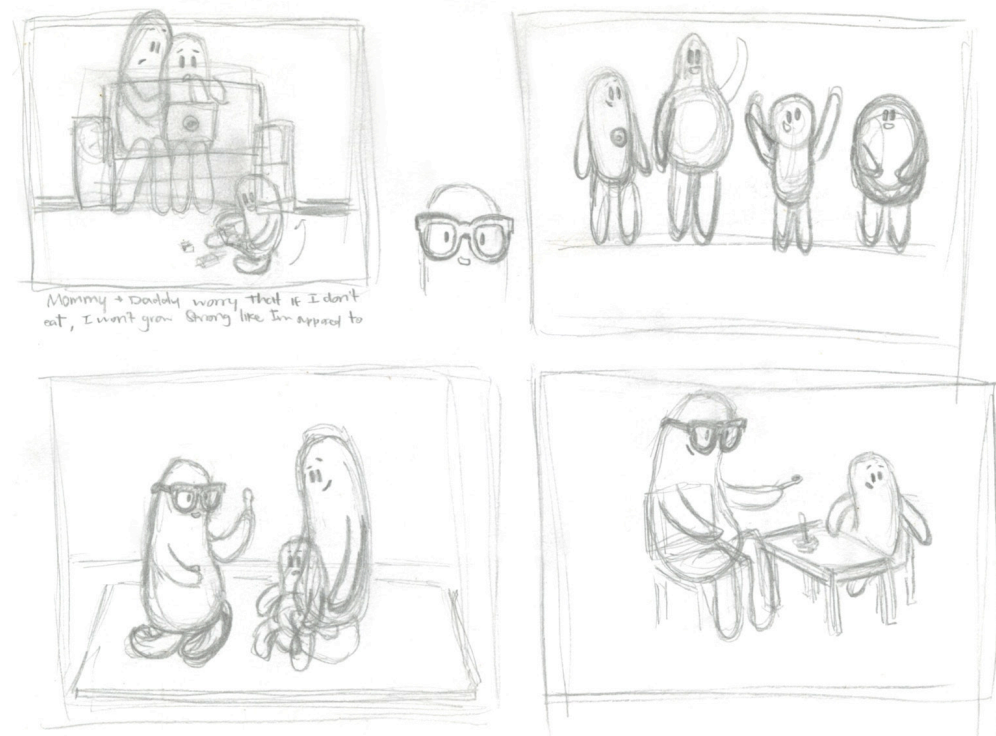
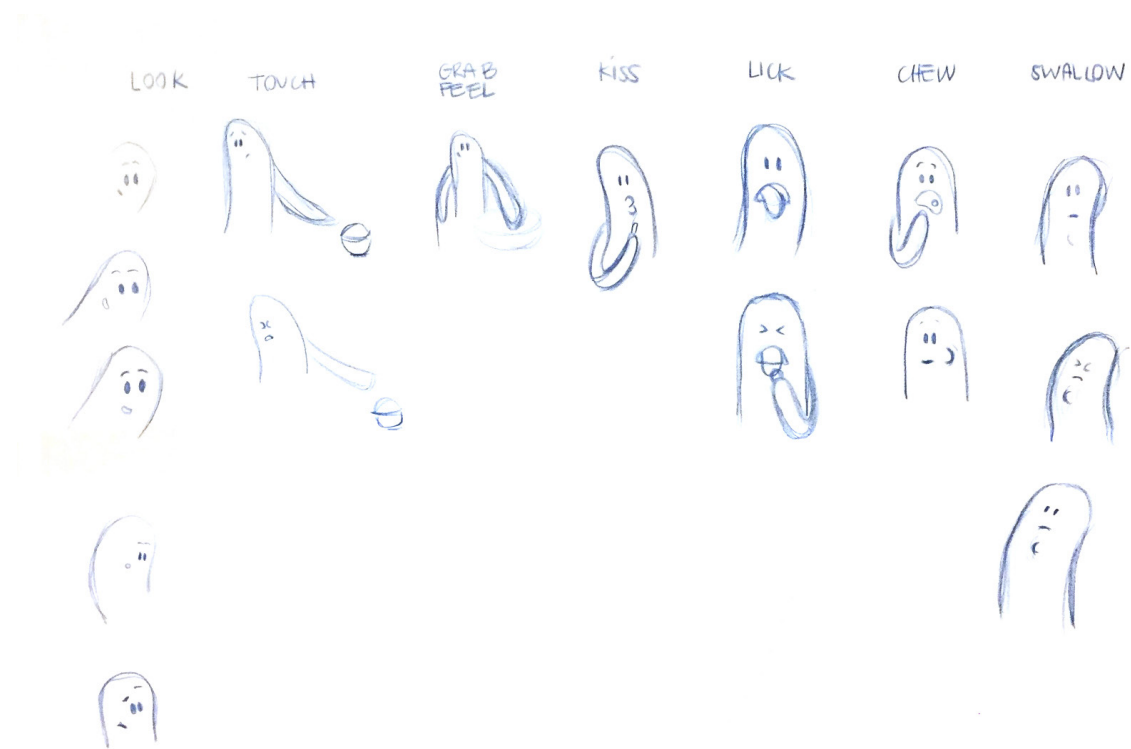
CHARACTER DESIGN

SAMMY

Before I thought of writing the story, I imagined different types of characters in a two-by-two matrix: from realistic to abstract and from human to animal. I chose an abstract humanoid or a bean-like shape so that the children and parents can see themselves in the characters more easily.

The use of a color-neutral and gender-neutral character was a deliberate design decision so that every child can feel represented by Sammy, which is a common nickname for Samuel or Samantha.



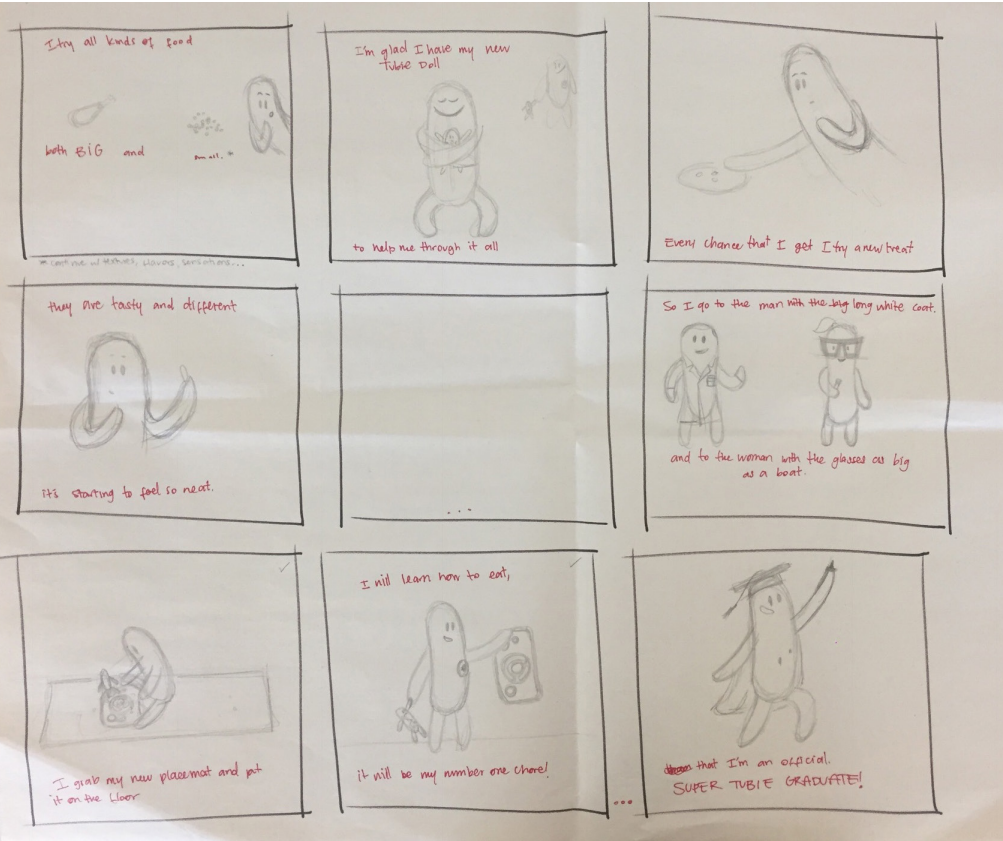
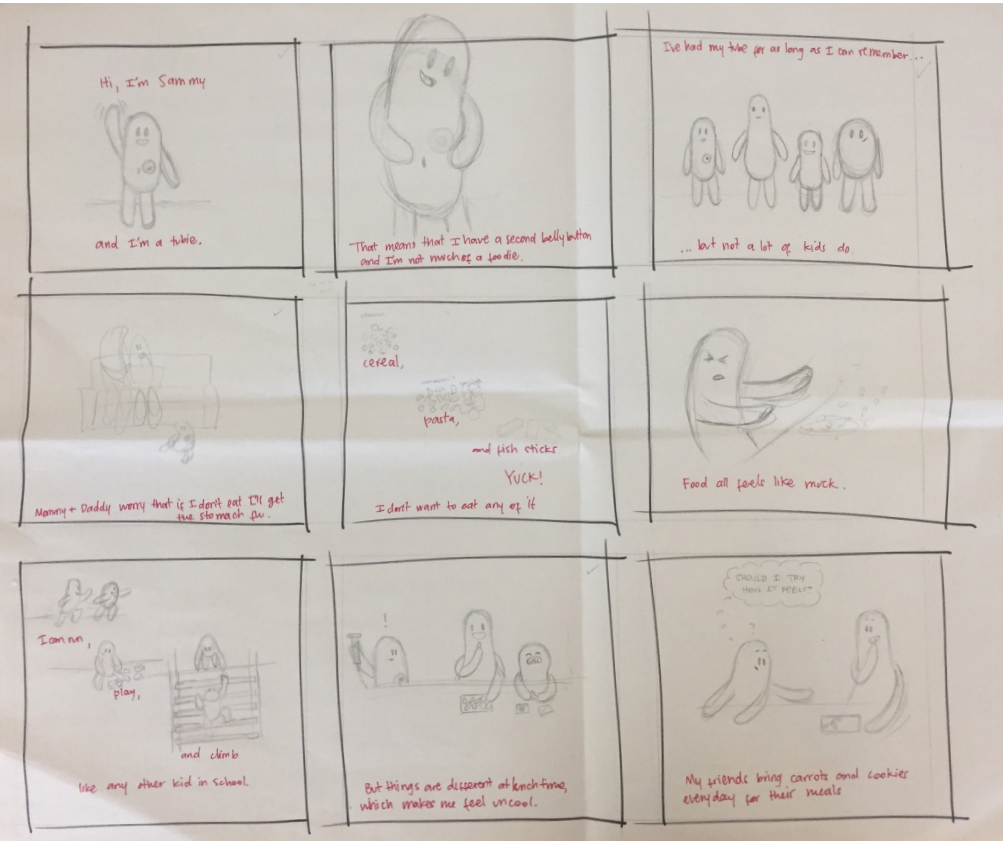


STORY



To make the story more relatable, I used “Tubie” and “Super Tubie Graduate”, which are terms used in the feeding tube community. Tubies are children that are tube fed and Super Tubie Graduates are children that successfully wean from the feeding tube (Feeding Tube Awareness Foundation).

The story focuses on the point of view of Sammy, a tubie, and their struggle in the tube weaning process. The rhymes makes the book more pleasant to read for the child and evokes nurture to those who read it. This way, parents can also empathize with the tubies story and understand better what they are going through.



THE SUPER TUBIE GRADUATE

Hi, I'm Sammy and I'm a tubie.

That means I have a second bellybutton and I'm not much of a foodie.

I've had my tube for as long as I can remember, but not a lot of kids do.

Mommy and Daddy worry that if I don't eat, I won't grow strong like I'm supposed to.

Cereal, pasta, and fish sticks. Yuck!
I don't want to eat any of it! Food all feels like muck.

I can run, play, and climb like any other kid in school.

But things are different at lunch time, which makes me feel uncool.
My friends bring carrots and cookies every day for their meals.

They look like they're having so much fun!
Should I try how it feels?

So I go to the man with the long white coat
And to the woman with the glasses as big as a boat.

They tell me to try foods, both big and small
and gave me a new tubie doll to help me through it all.

She told me to eat a banana and that she would be my guide.
but I'm afraid to swallow it, so I fussed and cried.

I see an orange on the table, it looks pretty rough.
Food seems interesting, I'm gonna check out more stuff.

Applesauce is mushy, I don't like how it feels.
I'd prefer to play outside with any toy on wheels.

I touched a potato chip and it made a *crunch*
I wonder how my friends eat that at lunch.

But I press forward and give a puff a little kiss.
It's light and fluffy, I didn't think it would feel like this.

Yogurt looks different, but I give it a lick.
It's soft and cold with a strawberry kick.

Every chance that I get I still try a different treat.
I was scared at first, but now it feels neat.

I grab my new place mat and put it on the floor
I will learn how to eat, it won't feel like a chore!

It's been a long journey, I don't need my tube anymore
I thought I'd be sad, but it's everything I could ask for!

I'm on my way home, I feel so great
that I'm an official Super Tubie Graduate.

A photograph of children playing with food in a kitchen, overlaid with a teal filter. In the foreground, a young boy with glasses and a white shirt sits cross-legged on a white cloth, holding a small red sippy cup. To his left, a girl in a white shirt and grey pants sits on the floor, also playing with food. In the background, another child is visible, and a woman is partially seen on the right. A shelf with various kitchen items is in the background. The overall scene is playful and messy.

5

CONCLUDE

"PLAY IS THE WORK
OF THE CHILD"

MARIA MONTESSORI

Many children are born with complex diseases that prohibit them from chewing, swallowing, or keeping food down, making it impossible to drink liquid or eat solid foods. Because of this, they receive nourishment through a feeding tube. when pressured to eat and drink orally, these children experience trauma from vomiting and gastro-esophageal reflux disease and often must endure complex surgeries and associated side effects. They develop an oral aversion to foods, and often show animosity towards *any* physical object close to their mouths.

After resolution of the medical condition, children must wean from the feeding tube by physically learning to touch, chew, and swallow through feeding therapy. How can we utilize design to transition feeding therapy practices into the home

environment continuing the tube weaning process with children that have been tube fed since birth? By educating parents, making the mealtime playful, and creating a ‘tubie’ representation, the *Play With Food* set answers this question. The Tubie Book and Tubie Doll help tube-fed children associate themselves with a character that is just like them while showing the parents their child’s perspective. The Playcemat creates a playful eating environment to permit free interaction with food, reminding parents to allow their child to do so - no matter the amount of food eaten or messy consequences.

By applying approaches from different feeding therapies, such as free play to reduce stress and anxiety, and exploration with a variety of foods, the tube-fed child can become desensitized and slowly transition to chewing and swallowing, opening their culinary horizons. *Play With Food* seeks to transform the home feeding environment into a stress-free space where the tube-fed child feels more comfortable to do what for most of us feels incredibly normal - to simply eat and drink.

Moving forward, I want to continue developing these products to make changes in these people’s lives, even if it is just one family. I will continue working with the feeding therapists and speech language pathologists that provided their insights to this project and supply them with a Playcemat so that we can measure the impact it has on tube fed children. Additionally, I would also provide a Playcemat to close friends and family as a sample for their ‘regular’ weaning children.

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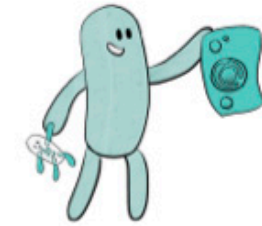
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APPENDIX I

TUBIE BOOK



THE SUPER TUBIE
GRADUATE

Written by David and Nicole Wiener
Illustrated by Nicole Wiener

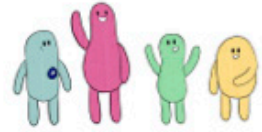
This book is dedicated to all the tube fed children
around the world and their amazing families.

Hi, I'm Sammy and I'm a tubie.



That means I have a second bellybutton
and I'm not much of a foodie.

I've had my tube for as long as I can remember, but not a lot of kids do.



Mommy and Daddy worry that if I don't eat, I won't grow strong like I'm supposed to.



I go to the man with the long white coat...



... and to the woman with the glasses as big as a boat.



Cereal, pasta, and fish sticks.

Yuck!

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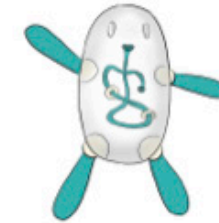


They tell me to try foods, both

BIG

and

small...



... and gave me a new tube doll to help me through it all.

I can run, play, and climb like any other kid in school.

But things are different at lunch time, which makes me feel uncool.

My friends bring carrots and cookies every day for their meals.

They look like they're having so much fun!

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But I'm afraid to swallow it, so I fussed and cried.

I see an orange on the table, it looks pretty rough.

Food seems interesting. I'm gonna check out more stuff.

Applesauce is mushy, I don't like how it feels.

I'd prefer to play outside with any toy on wheels.

I touched a potato chip and it made a

CRUNCH

I wonder how my friends eat that at lunch.

I grab my new place mat and put it on the floor.

I will learn how to eat, it won't feel like a chore!



But I press forward and give a puff a little kiss.

It's light and fluffy, I didn't think it would feel like this.

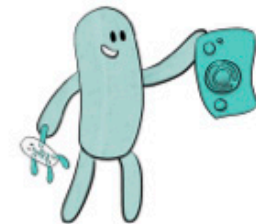
Yogurt looks different, but I give it a lick.

It's soft and cold with a strawberry kick.

It's been a long journey, I don't need my tube anymore.

I thought I'd be sad, but it's everything I could ask for!

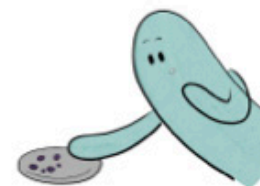
I'm on my way home, I feel so great that I'm an official



SUPER TUBIE GRADUATE!

Every chance that I get I still try a different treat.

I was scared at first, but now it feels neat.




nicole wiesner