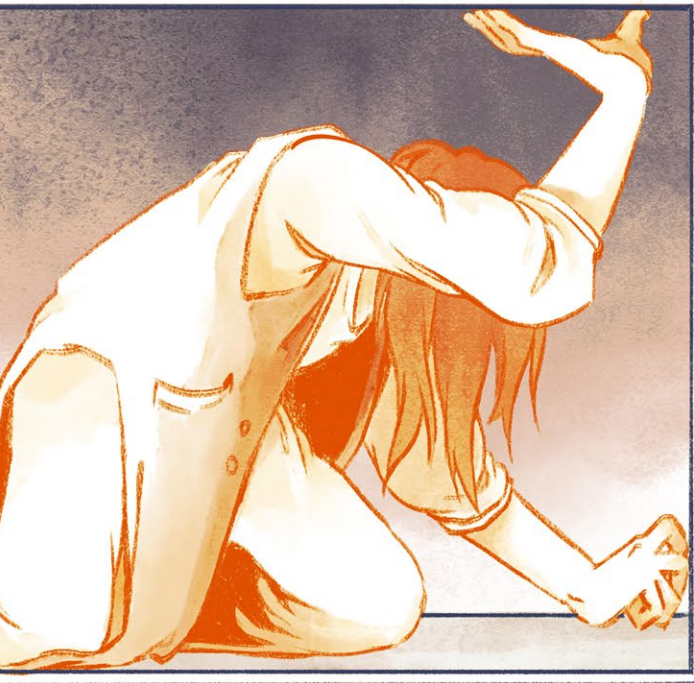


BOX

Scarlet Wings Kaili



PREFACE

The lens which we understand life comes from our own experiences, and the lens which I wear is of a late diagnosed autistic adult who has been failed and traumatized by the medical system multiple times.

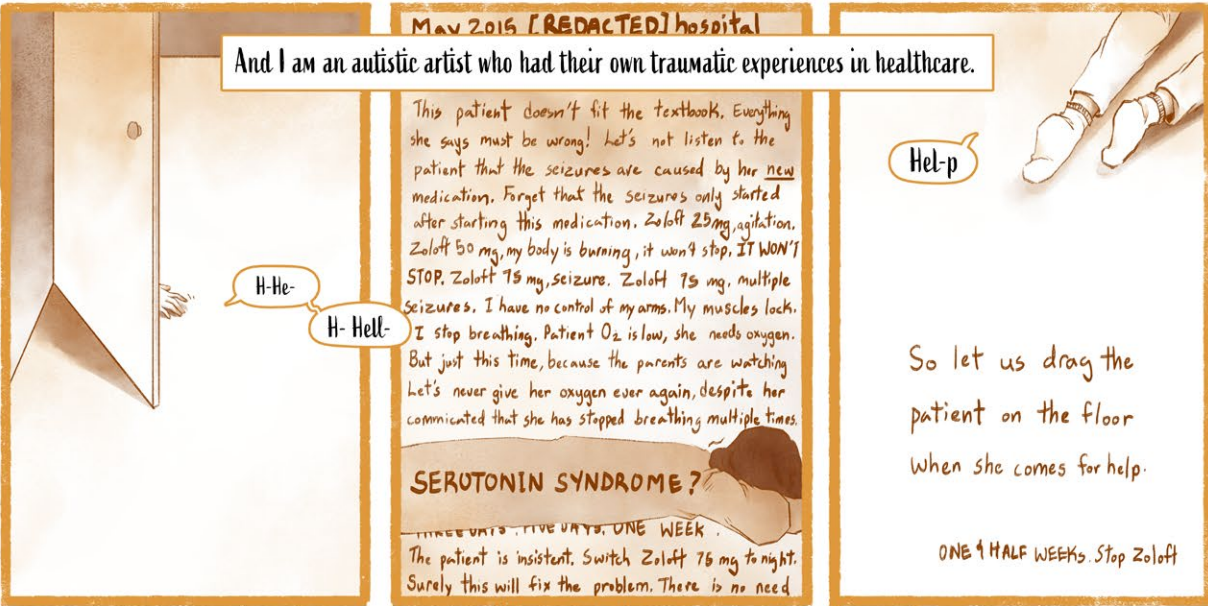
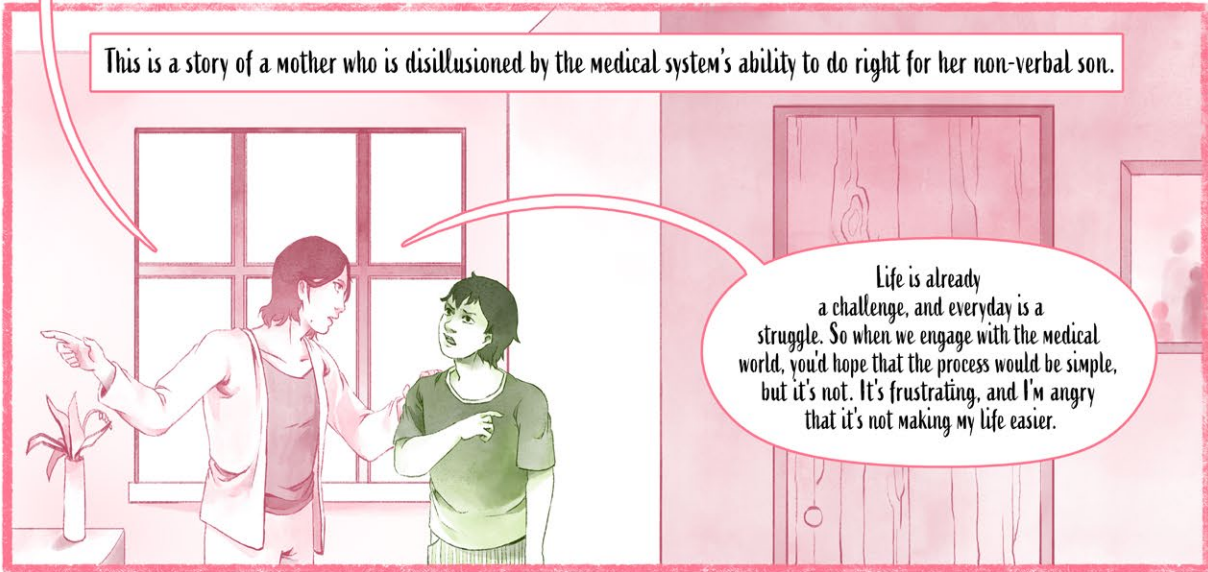
As I read through the interview, I felt depressed. Having fallen through the gaps in the healthcare system my entire life, I understood the despair. I resonated with the lack of agency, the fear, the trauma and the betrayal. How could a system meant to help people be so detrimental?

But I also felt conflicted. Here I was, in this unique position as an autistic with lived experience, but who am I to define another person's experience? After all, I also remember when language was a luxury I did not have.

Before I could communicate for myself, others defined my life for me. When I was first diagnosed with speech and language delay, my dad cried. My parents were told what I was capable of and what to expect. My mom fought for my right to an education as my kindergarten teacher didn't want me in her class. People assumed I didn't know what was going on. When I was 7, I was called stupid in front of the class by my teacher. I couldn't respond back, even though I wanted to say, "Only stupid people call other people stupid".

Today, I have a voice, and I don't take that for granted. I am also cognizant there are others who don't, and depend on others to help them. 3 different situations, 1 comic, "BOX" is the story about being neglected by the healthcare system.

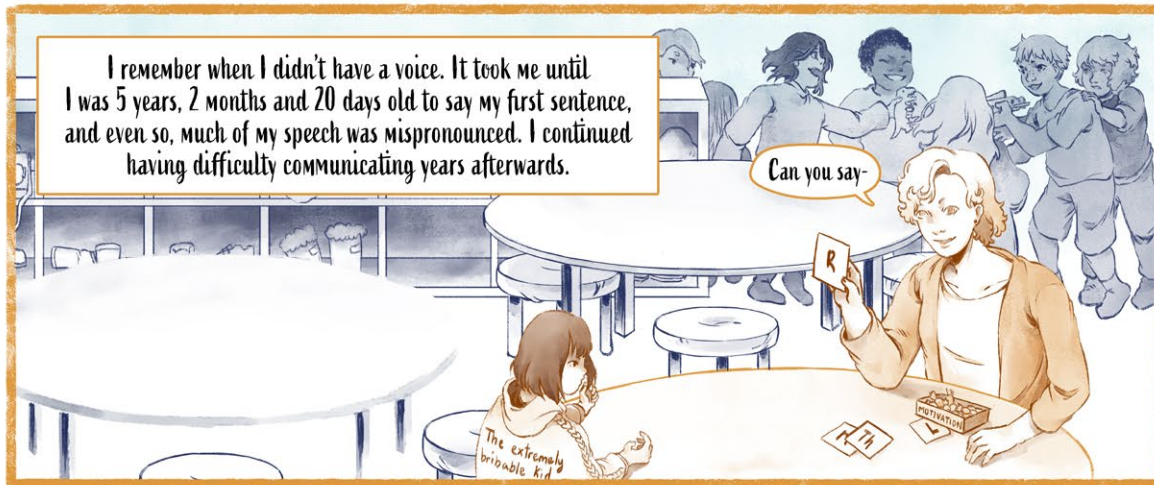
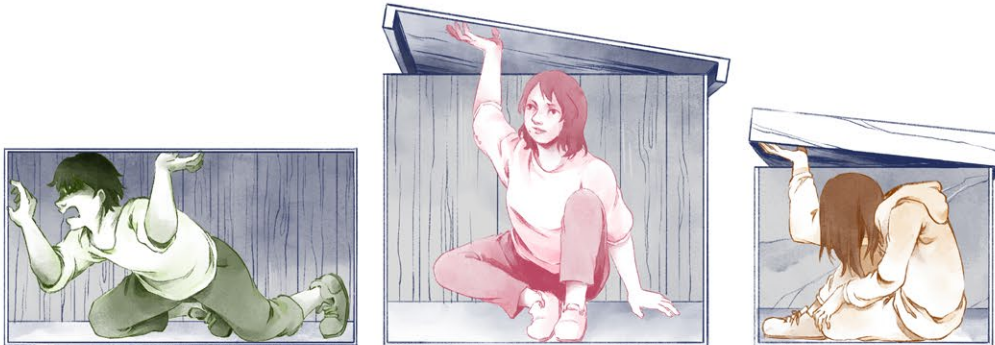
BOX



In this tale of three, who and what is this story about?



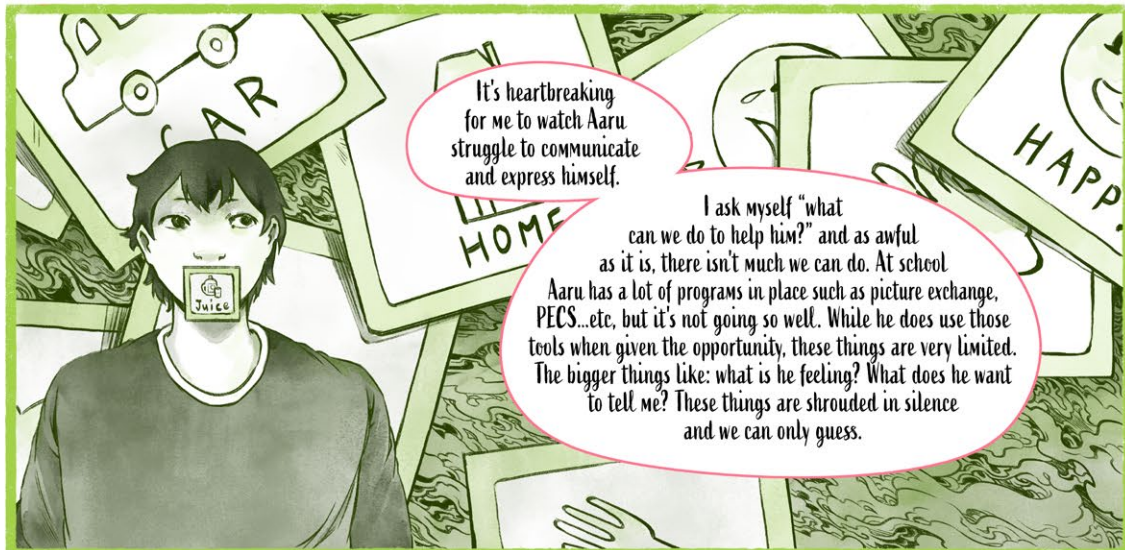
And who can speak about it?



I remember when I didn't have a voice. It took me until I was 5 years, 2 months and 20 days old to say my first sentence, and even so, much of my speech was mispronounced. I continued having difficulty communicating years afterwards.

Can you say-

The extremely bribable kid



It's heartbreaking for me to watch Aaru struggle to communicate and express himself.

I ask myself "what can we do to help him?" and as awful as it is, there isn't much we can do. At school Aaru has a lot of programs in place such as picture exchange, PECS...etc, but it's not going so well. While he does use those tools when given the opportunity, these things are very limited. The bigger things like: what is he feeling? What does he want to tell me? These things are shrouded in silence and we can only guess.

As a result, I remember not having control over my own life, as well as my many different attempts to communicate.



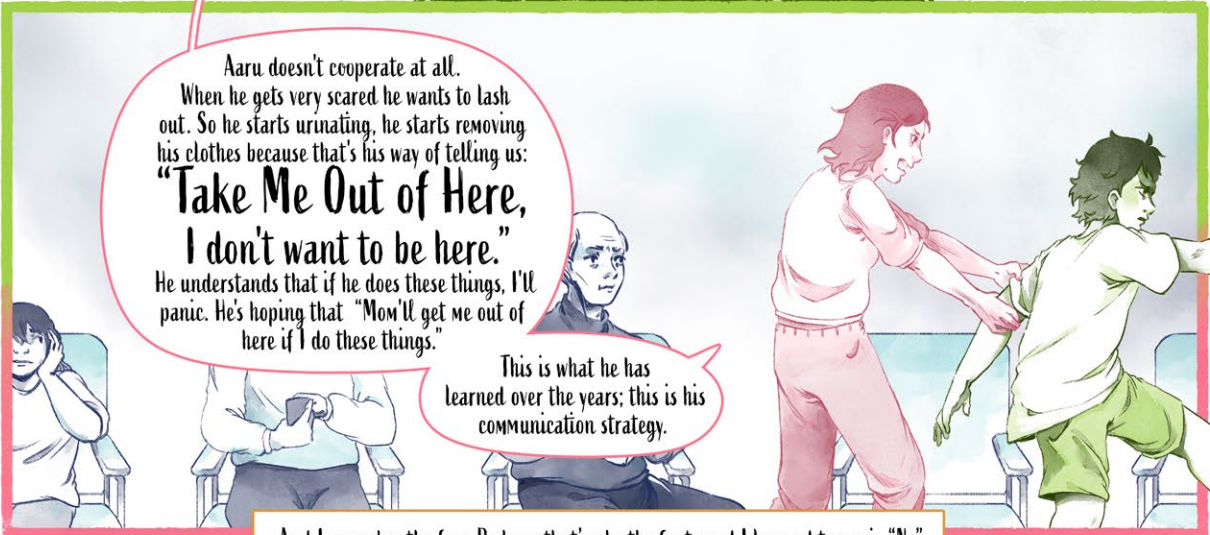
Since Aaru is completely nonverbal, he communicates by leading me to what he wants or bringing us an object. Sometimes he'll bring us an object: a plate for when he's hungry, or a cup when he's thirsty.

Some methods were more effective than others.



I know he is frustrated. It's frustrating when you can't communicate: when you can't express your feelings. Because of that, a lot of the behaviors we see from Aaru is all communication.

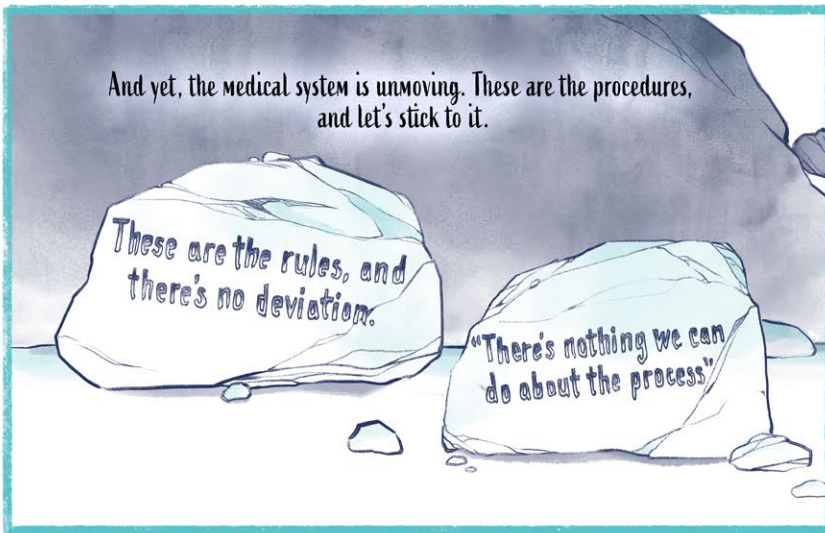
I remember my isolation, my frustration and my alienation.



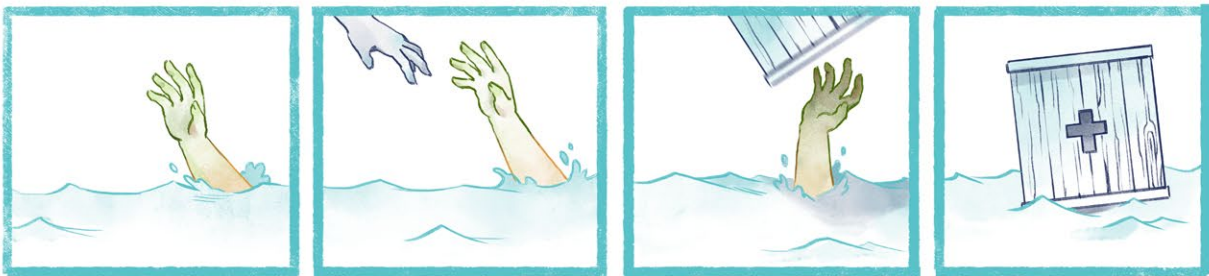
Aaru doesn't cooperate at all. When he gets very scared he wants to lash out. So he starts urinating, he starts removing his clothes because that's his way of telling us: **"Take Me Out of Here, I don't want to be here."** He understands that if he does these things, I'll panic. He's hoping that "Mom'll get me out of here if I do these things."

This is what he has learned over the years; this is his communication strategy.

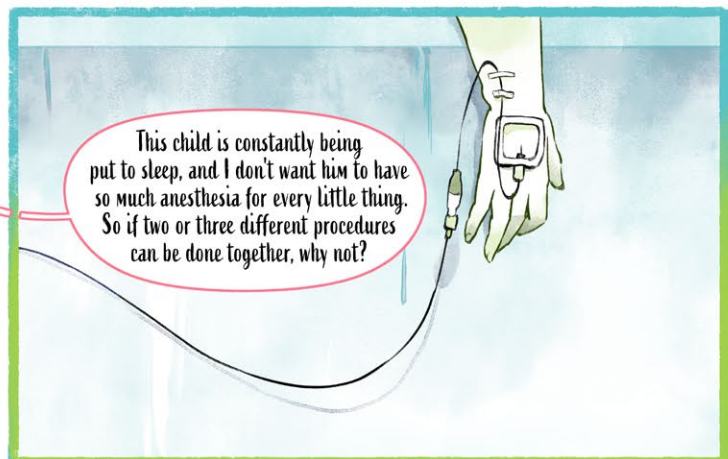
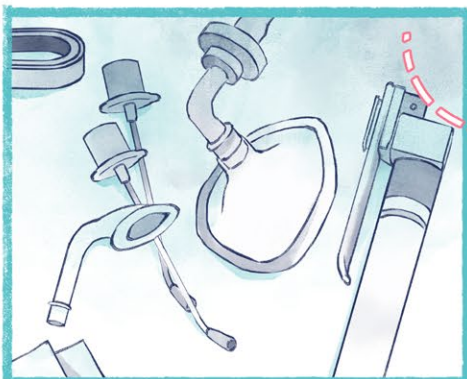
And I remember the fear. Perhaps that's why the first word I learned to say is "No".

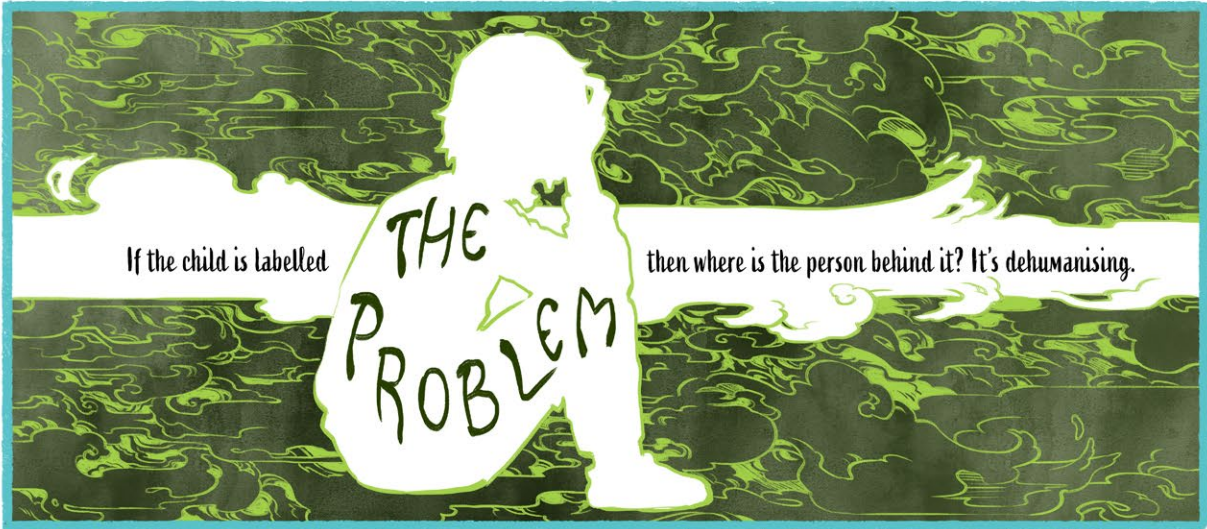


The hippocratic oath dicates, "Do no harm", and yet those who don't fit in the norm suffer.



If the answer is sedation, why not limit the short and long-term risks?



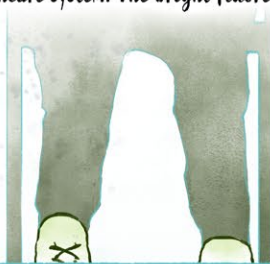


We are more than that.





Lost in between the gaps of a healthcare system. The bright fluorescent lights cast a shadow on accessibility.

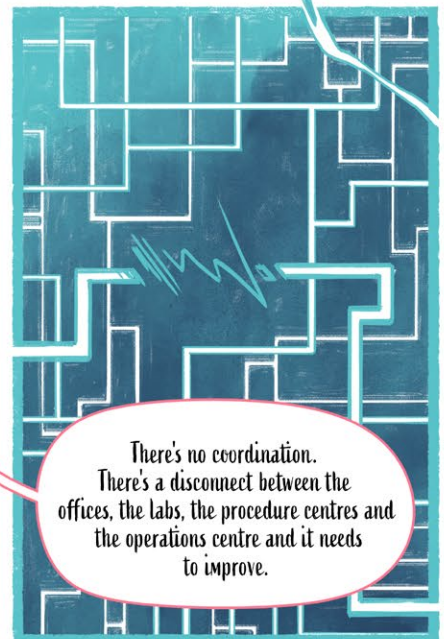
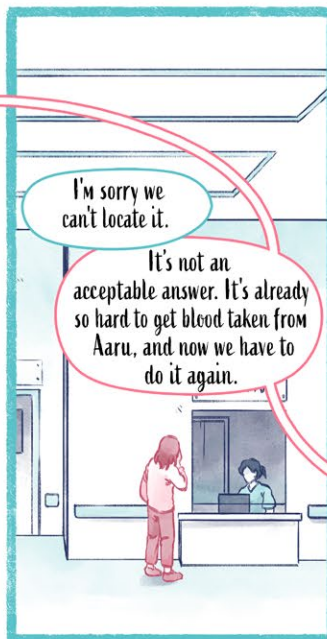
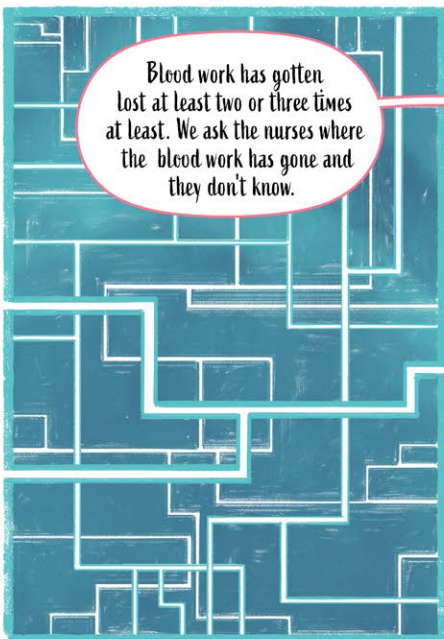


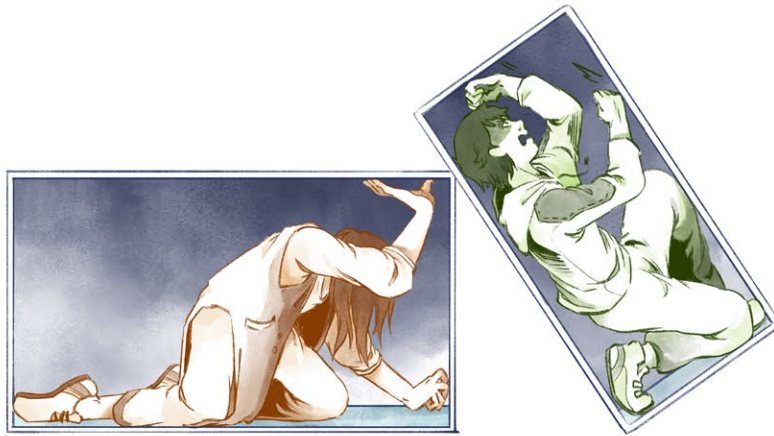
Blood work has gotten lost at least two or three times at least. We ask the nurses where the blood work has gone and they don't know.

I'm sorry we can't locate it.

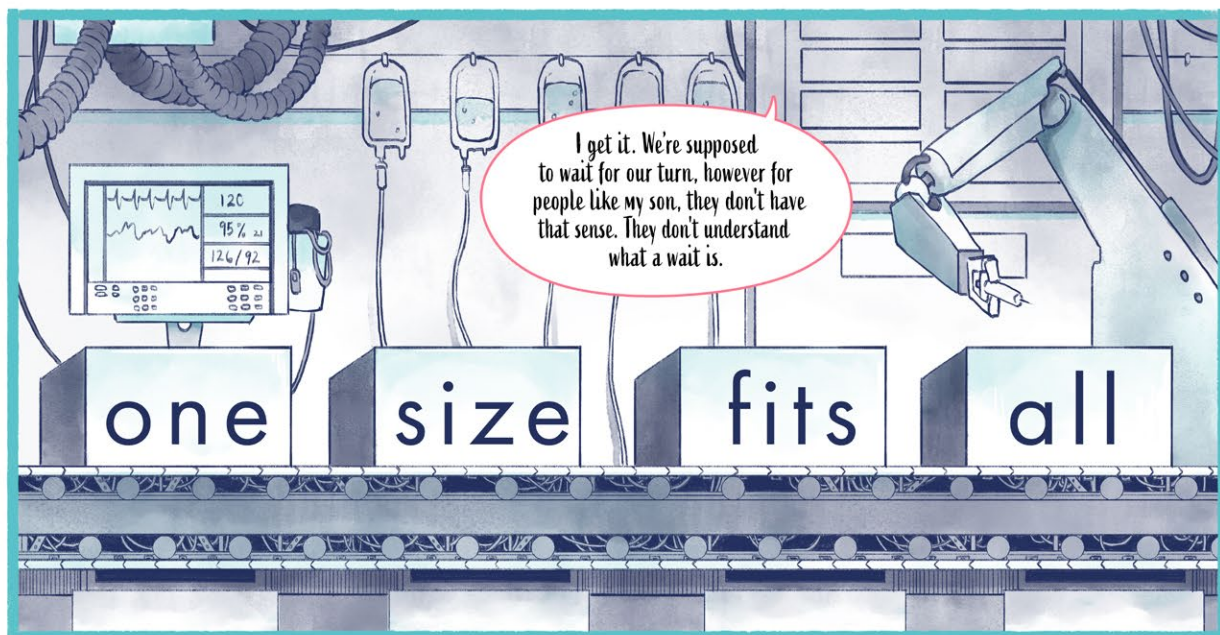
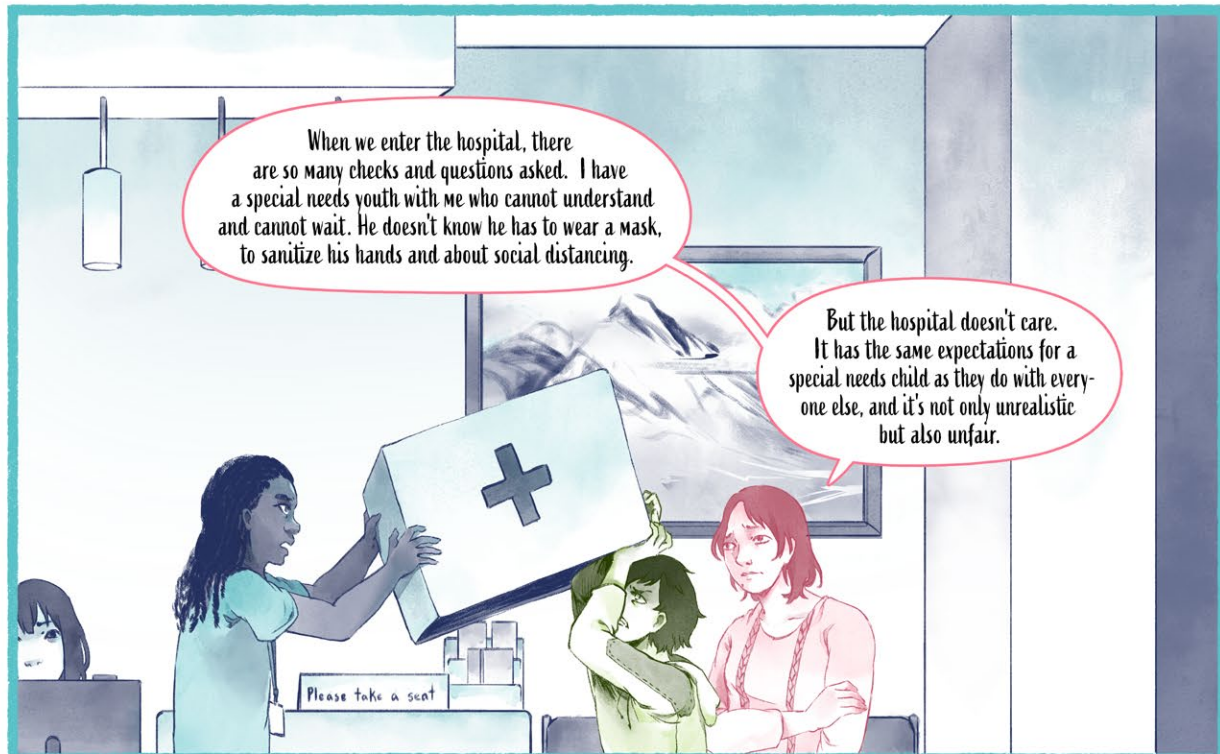
It's not an acceptable answer. It's already so hard to get blood taken from Aaru, and now we have to do it again.

There's no coordination. There's a disconnect between the offices, the labs, the procedure centres and the operations centre and it needs to improve.

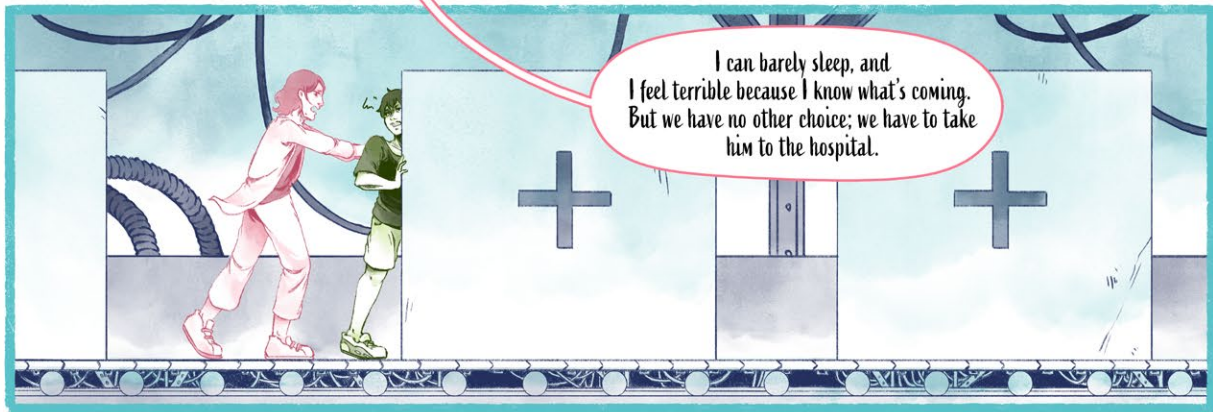
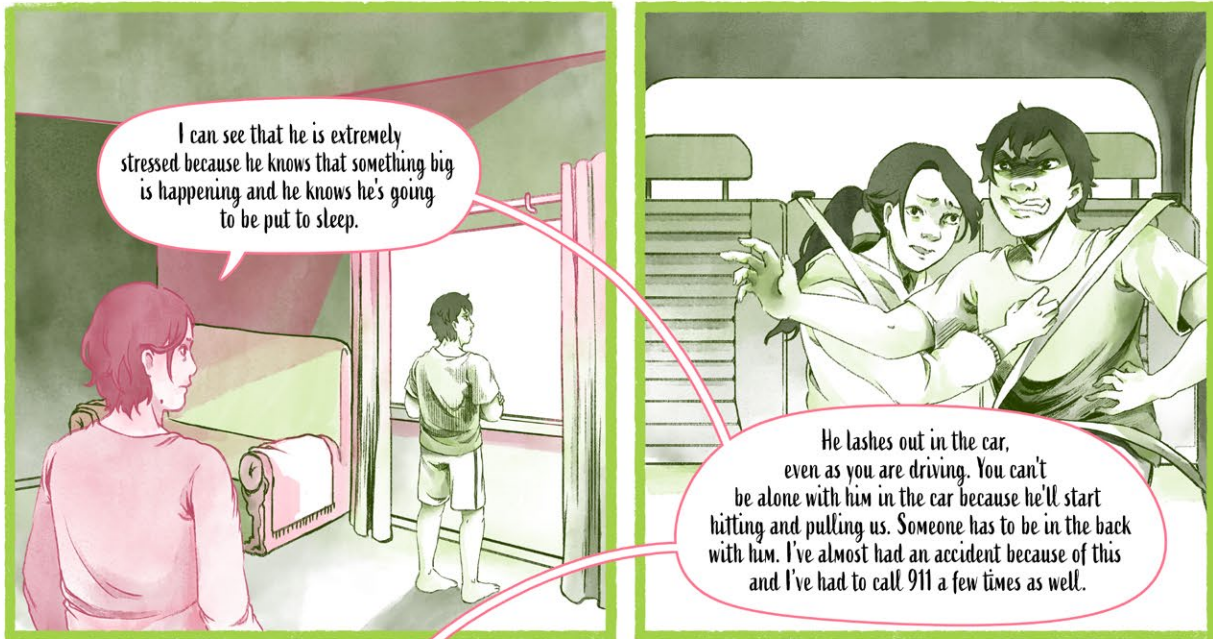




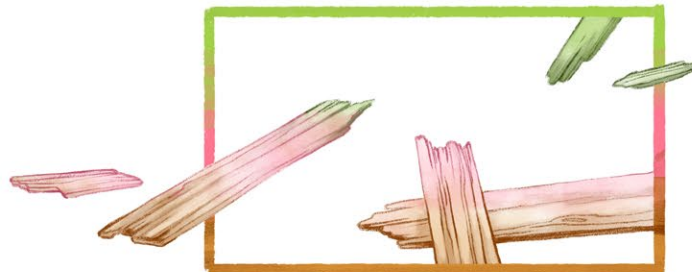
A system that loves “boxes” and concrete procedures even when it’s not beneficial to the patient.



Why not make the system less traumatising for neurodivergent people and their caregivers?



This is a story of someone who cannot speak for themselves. This is a story of a mother who is disillusioned by the medical system's ability to do right for her non-verbal son. And I am an autistic artist who had their own terrible experiences in healthcare.



In the end, this is a story about change.

The odds are still stacked against autistics.

The average lifespan for autistics is (depending on the study) 39-54 years old. In addition, we tend to die from health complications 20 years sooner than the general health population. Why? Is it because our health needs are less likely to be met and that we tend to be more medically complex patients? Is it because there is a lack of access for adult services? Is it because we are at greater risk for trauma, and for comorbid psychiatric conditions, such as PTSD, EDs, OCD etc. Our suicide rates are abysmal and downright horrifying. How can we possibly thrive in a system not made for us - a system that believes that the lives of autistics and other people with disabilities are less worth living?

Personally, I was kept on medication (despite protests) that gave me seizures for a total of two and a half weeks because I didn't fit neatly into a textbook. Later, I was denied care because I was not the typical patient. I became a game of hot potato that doctors played. Eventually, I was diagnosed in 2023 by a neuropsychiatrist after being admitted into hospital, and I feel I was "lucky" to become sick enough to have access to a diagnosis. It was there I was told that the reason I had such adverse effects to medication was because I am autistic. However, the damage has already been done. To this day, I have to constantly engage with the system that gave me medical PTSD.

My story is not unique, nor is the story of the child in the interview. The system must change.

AFTERWORD

