

IT'S NOT A GLITCH, IT'S MY LIFE!

Mikayla Goodwin-Reid

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Indigenous Youth in Care

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IT'S NOT A GLITCH, IT'S MY LIFE!

Mikayla Goodwin-Reid

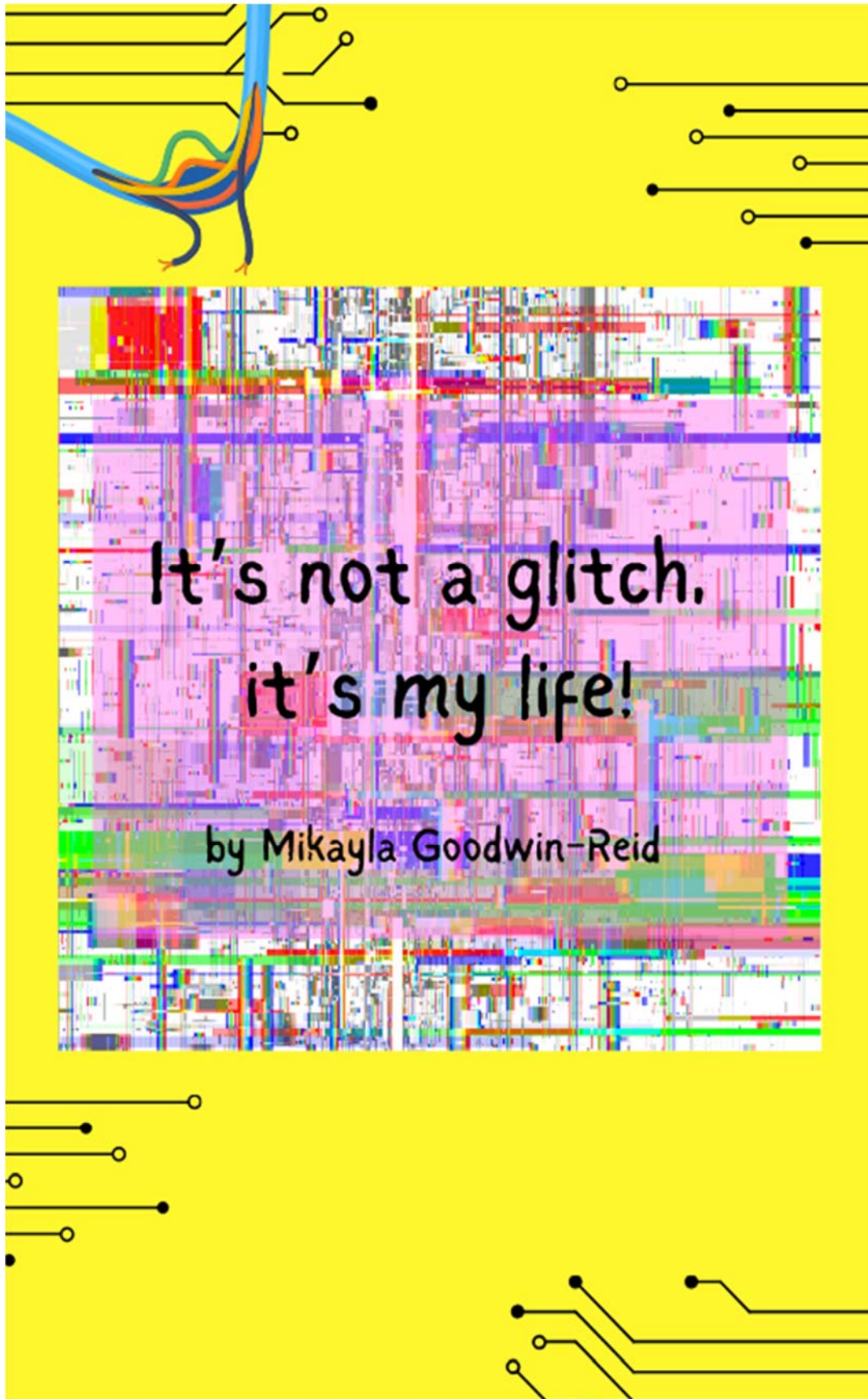


Keywords: Indigenous children/youth in care, adult FASD, FASD supports, Indigenous youth and FASD, invisible disabilities, destigmatization of FASD

Acknowledgement: We raise our hands in deepest respect and gratitude to the ancestors and families of the *lək^wəŋən* and *WSÁNEĆ* nations and to our own ancestors and Nations. We raise our hands to all Indigenous children and youth who have grown up in colonial systems, to those we have lost, and to those who survive, resist, and imagine justice and resurgence. INVINCIBLE is grateful for funding provided by the Social Sciences and Humanities Research Council of Canada (Insight grant 435-2020-1191) and the Canet Foundation.

Mikayla Goodwin-Reid is an Indigenous youth in care and an INVINCIBLE youth storyteller/researcher who has been working with the Kinship Rising research project at the University of Victoria since 2023.

Please contact the Kinship Rising project: kinshiprising@uvic.ca

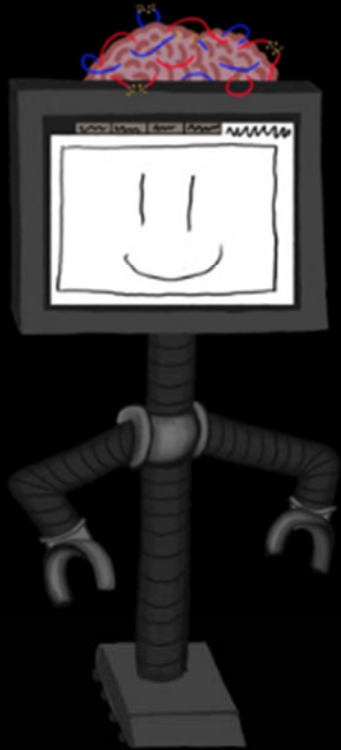


What is FASD?

FASD stands for Fetal Alcohol Spectrum Disorder.

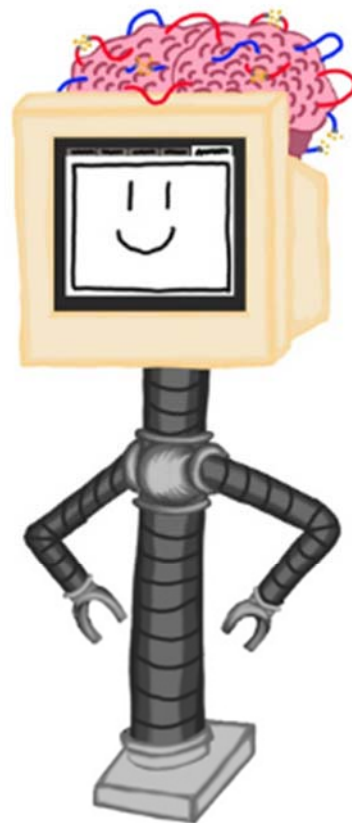
What this means is while a mother was pregnant, she drank alcohol. This causes lifelong harm to the developing fetus.

FASD is a spectrum disorder, meaning there's a range of symptoms to diagnose. It is also a developmental disorder, which means it impacts your social, cognitive, and physical development. FASD is also a form of brain damage, unfortunately, and can cause physical defects.



Something to
keep in mind is:
Age is not a
factor here.
this is brain
damage.

There's not much
difference if I am 5 or
55 - my brain is still
damaged. I will get
better at managing,
but it may always be
a struggle. I may
always need some
assistance, but I will
figure it out.





Why does this story matter?

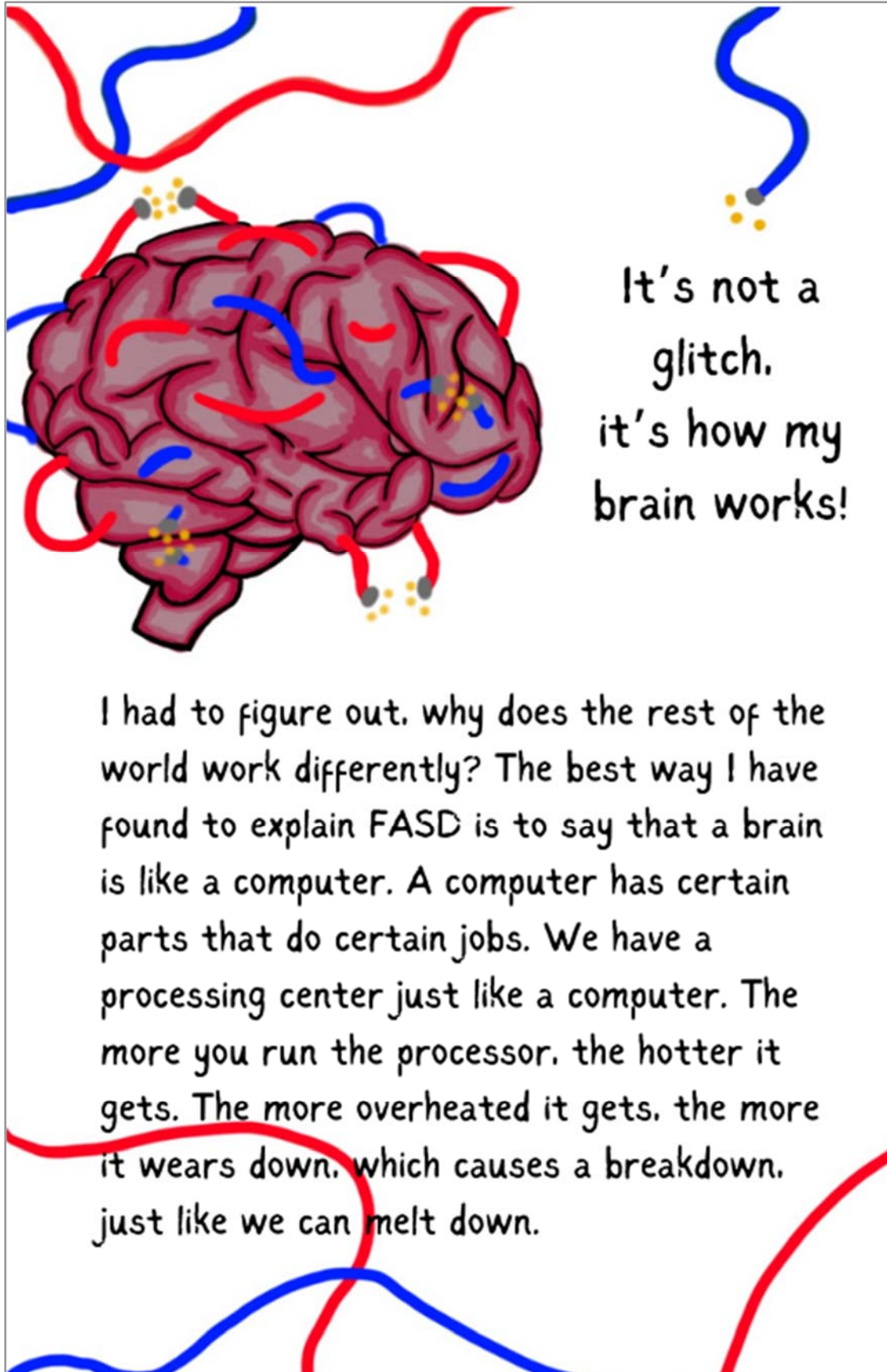
There's next to no resources for adults with Fetal Alcohol Spectrum Disorder, or for teens. We are misunderstood. There's no consistency in information, and there's nothing out there for us.

I had to teach myself about FASD because I knew I wasn't understanding everything around me.

Why am I so different?
How do other people work?
What am I doing wrong?

I had so many questions. I wanted to help people too. I got a lot of counselling growing up, and this really helped. I learned about the brain and eventually FASD through an interest in psychology. I've taken many classes. I learned the brain is misformed and not 100%, and that helped me understand. My 100% is like everyone else's 80%, so we have to understand the differences.

So my main thing is, I really want information out there that people can use and relate to. There is a lot of information about autism, ADHD, and anxiety, but not much at all about FASD, especially adult FASD. It's so invisible in the grand scheme. It's also extremely stigmatized. We need to remember that with FASD, someone made a mistake, and we can't go back in time to change it, so let's work with it.



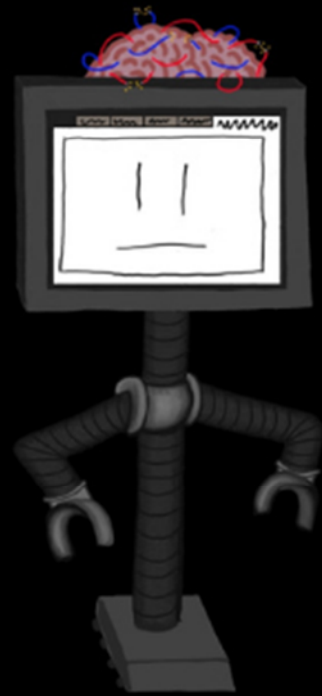
It's not a
glitch.
it's how my
brain works!

I had to figure out, why does the rest of the world work differently? The best way I have found to explain FASD is to say that a brain is like a computer. A computer has certain parts that do certain jobs. We have a processing center just like a computer. The more you run the processor, the hotter it gets. The more overheated it gets, the more it wears down, which causes a breakdown, just like we can melt down.

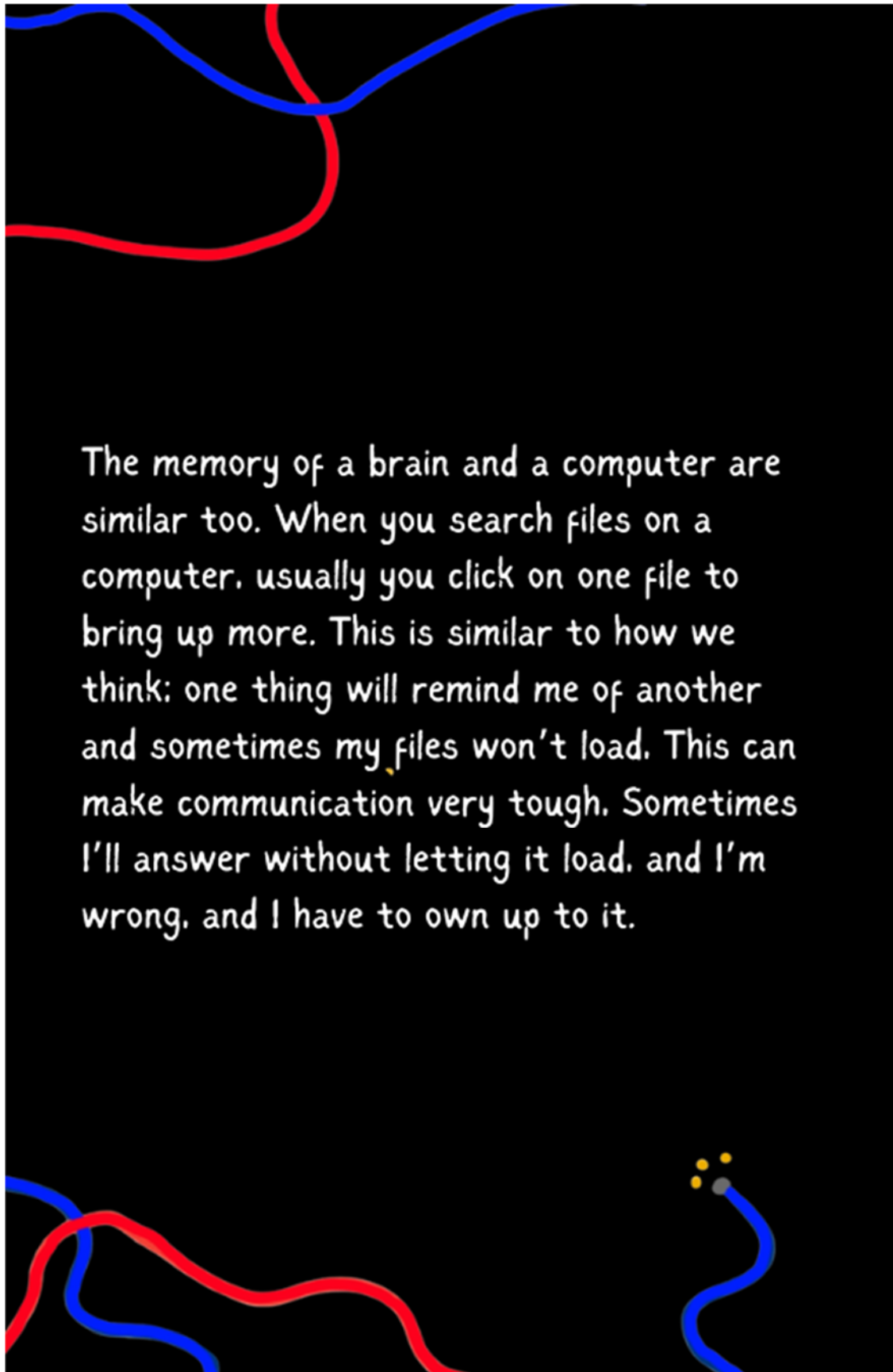
At the end of the day, your brain has limited processing capacity. A computer processes everything too. Even if you don't visually see it, it's processing all the code all the time.

My FASD brain is like a disconnected computer. Some of my wires don't connect fully, causing disruptions. Sometimes I just need a reboot.

This is a problem with many different kinds of disabilities. They have problems with things like executive functioning. Trying to cook dinner plus do other things like homework, watching kids, or general problem solving is similar to having too many tabs open. You may start slowing down or not be able to process new information. Your hard drive will essentially get overloaded. This can cause you to burn out or crash.



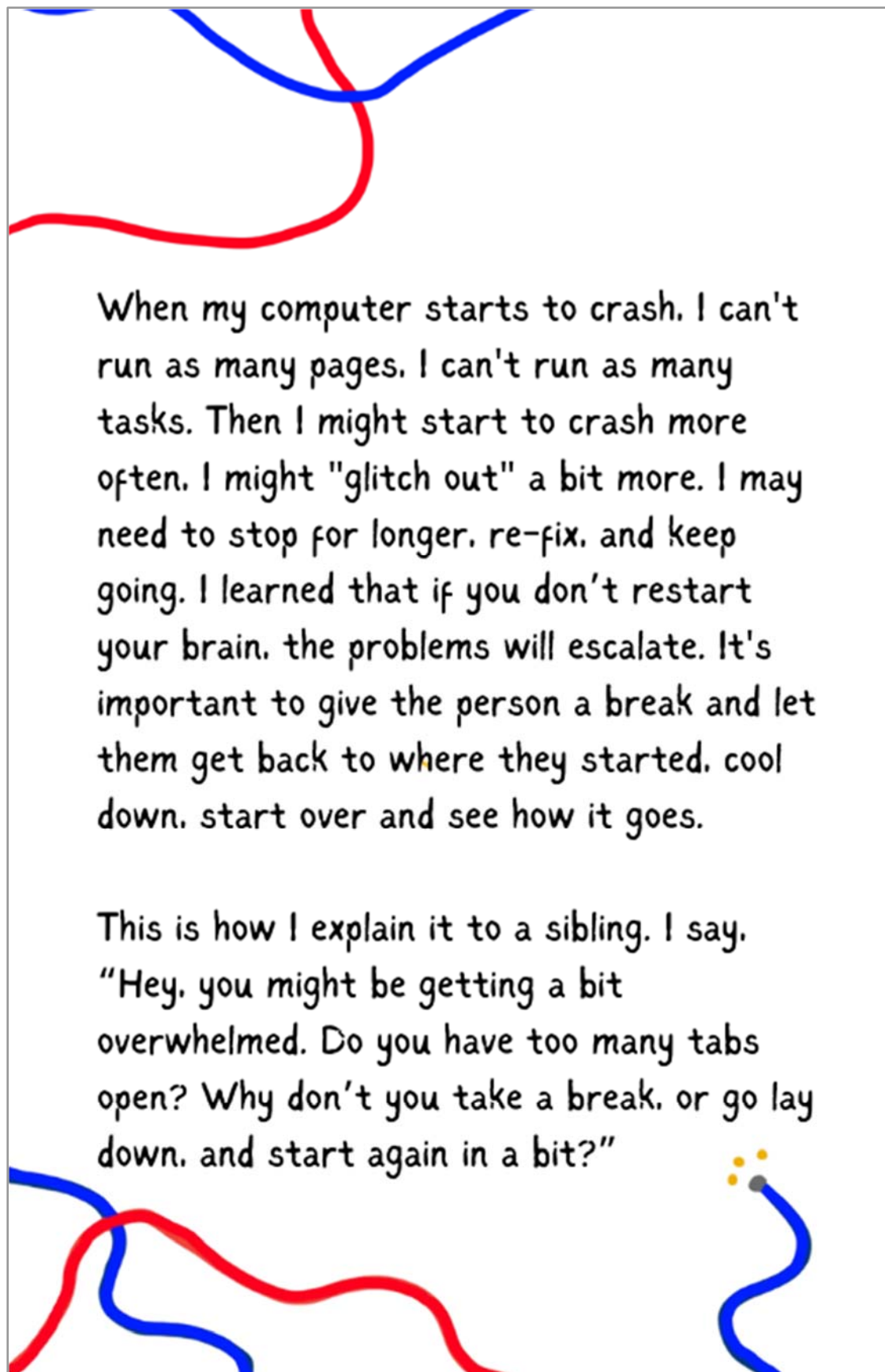
Similar to how a computer browser sometimes doesn't load when you search something, and it gets stuck there - that happens to our brain sometimes. It will just get stuck there and has to reboot all over again. It can take a while. So if you're doing a task like taking notes in class, that can be really rough.



Brain development is like having
a software update.

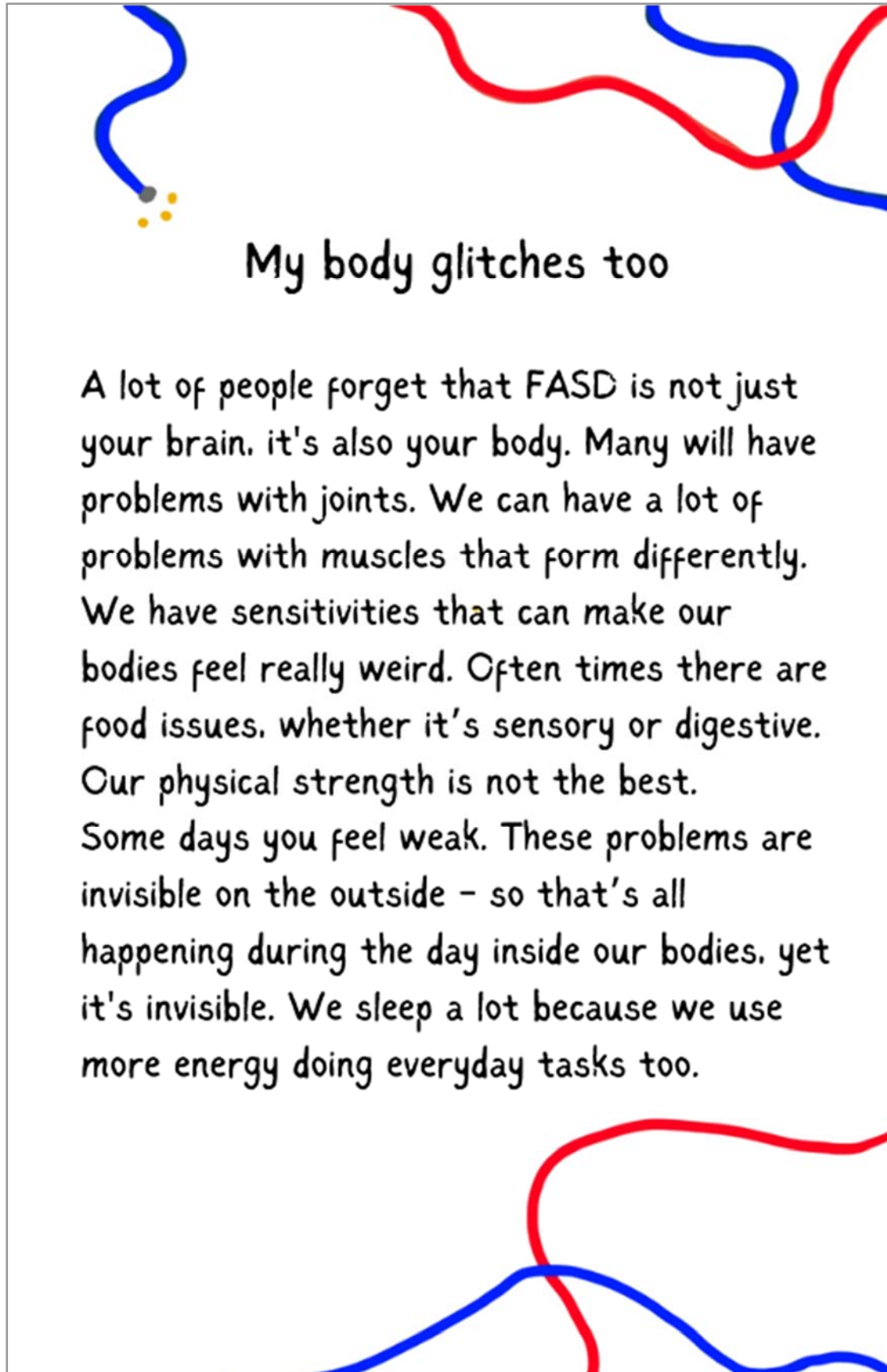


If you think of the exterior — your body — like another processor, you can hook it up to things such as, a support person to bounce ideas off of, or an extra terabyte stick could be like using a fidget toy that allows you to focus longer, and take in more data.



When my computer starts to crash, I can't run as many pages, I can't run as many tasks. Then I might start to crash more often. I might "glitch out" a bit more. I may need to stop for longer, re-fix, and keep going. I learned that if you don't restart your brain, the problems will escalate. It's important to give the person a break and let them get back to where they started, cool down, start over and see how it goes.

This is how I explain it to a sibling. I say, "Hey, you might be getting a bit overwhelmed. Do you have too many tabs open? Why don't you take a break, or go lay down, and start again in a bit?"



My body glitches too

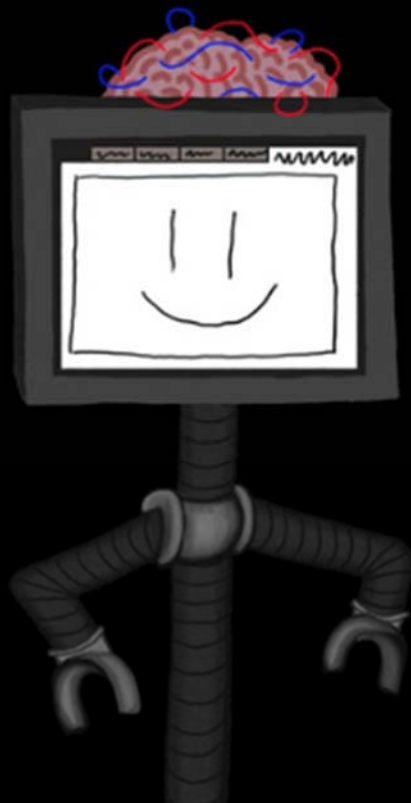
A lot of people forget that FASD is not just your brain, it's also your body. Many will have problems with joints. We can have a lot of problems with muscles that form differently. We have sensitivities that can make our bodies feel really weird. Often times there are food issues, whether it's sensory or digestive. Our physical strength is not the best. Some days you feel weak. These problems are invisible on the outside - so that's all happening during the day inside our bodies, yet it's invisible. We sleep a lot because we use more energy doing everyday tasks too.

Emotions are hard too, hard to figure out. I'm not going to lie. I can be very dull to emotions, or very sensitive to them... in short, I am either full of emotions or numb to them.

It can be very hard to find balance, especially out of the house. It can be hard when you're trying to figure out stuff and you're getting frustrated, and the rest of your body doesn't cooperate. I'll be overheating or shaking when I'm flustered, and my emotions really affect my body. It's really weird – it feels like my bones are on fire. I'm vibrating. I can't walk, my legs don't cooperate. I vibrate in a very weird way. Wear and tear on my body creates mental drain, which impacts me.

Sometimes when I go to take a step, there's a disconnect between my brain and my body. My leg won't really move and it looks like I'm playing chicken with a ghost!! I look awkward.

I need to have humour with these topics sometimes, as they're very frustrating issues to deal with daily.



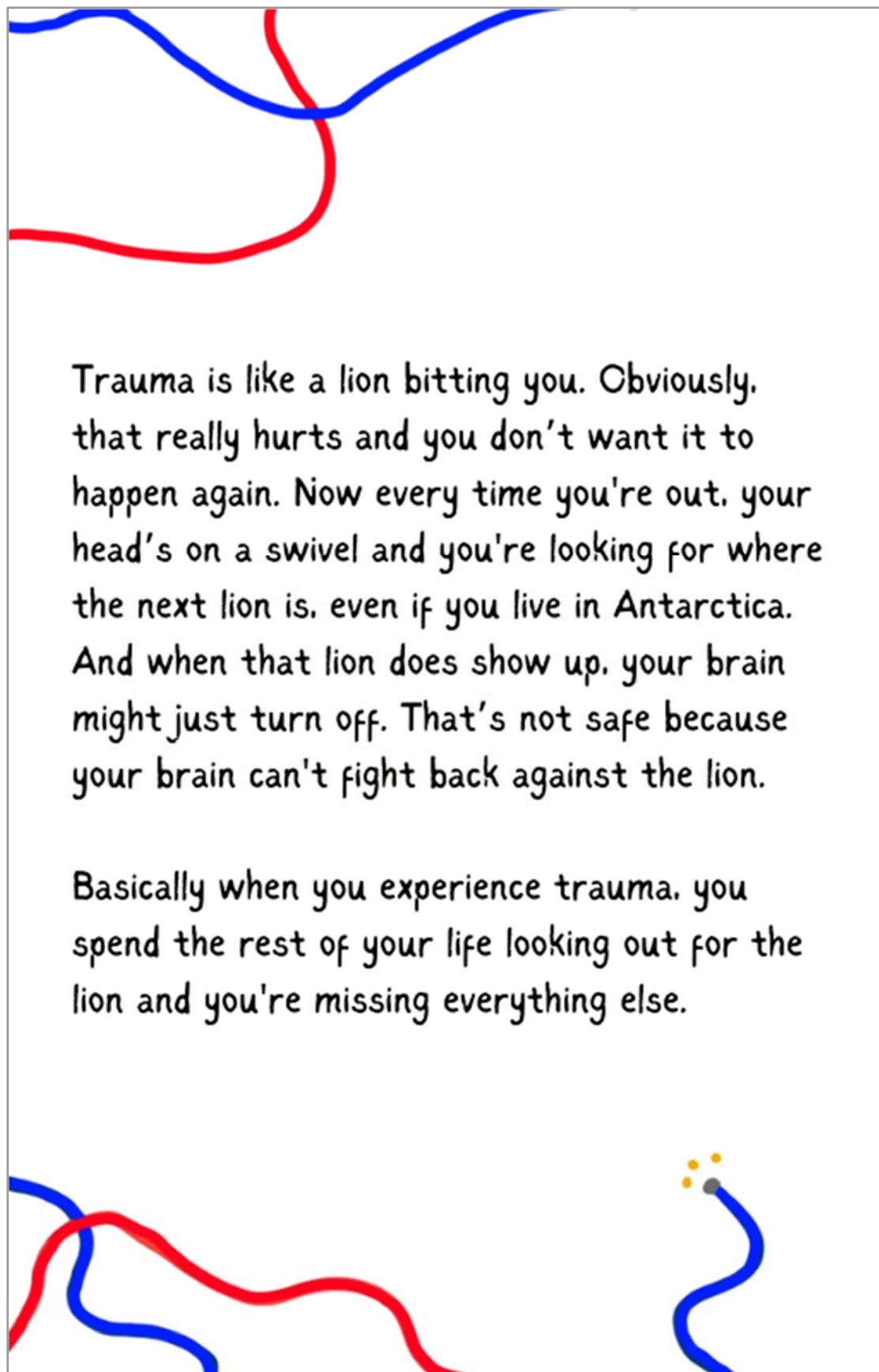
Childhood Trauma

I have FASD - my parents weren't in the soundest of minds. My childhood wasn't good for the first 4 years of my life. As an adult it's hard to understand why someone would do that. The more you think about it, the more you picture yourself hurting a kid, you realize you couldn't do that at all. Why did they do that so easily?

It's so hard to understand, it stays with you your whole life. The amount of damage that you do to a kid when they're young by abusing them can be impossible to undo. So many patterns have been created. You have to find all those patterns, and dismantle them. It's such a painful process. It's never fun.

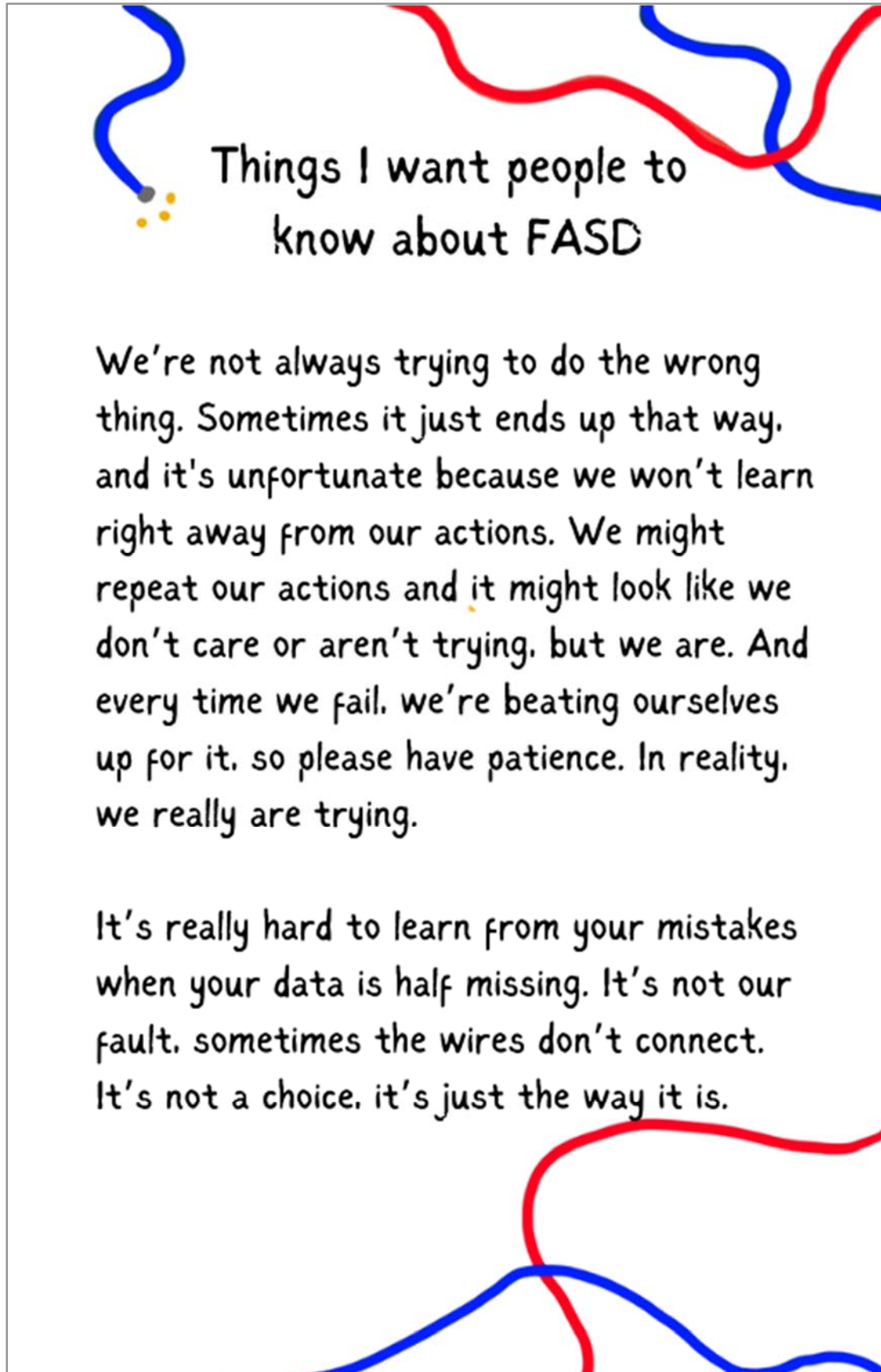
It holds a lot of people back, trauma. People won't try things because they're scared of something bad happening or that they're going to react to something. That can be very limiting. They're scared of being judged or something going wrong.

With past trauma, there is still an influence on you. You think it's gone, but it's always there. The biggest impact I find is that it slips into your unconscious. There's never a break. It comes when you sleep and it never ends. It's always there in the back of your head. This is why video games are so effective with PTSD treatment, they let your brain disconnect.



Trauma is like a lion biting you. Obviously, that really hurts and you don't want it to happen again. Now every time you're out, your head's on a swivel and you're looking for where the next lion is, even if you live in Antarctica. And when that lion does show up, your brain might just turn off. That's not safe because your brain can't fight back against the lion.

Basically when you experience trauma, you spend the rest of your life looking out for the lion and you're missing everything else.



Things I want people to know about FASD

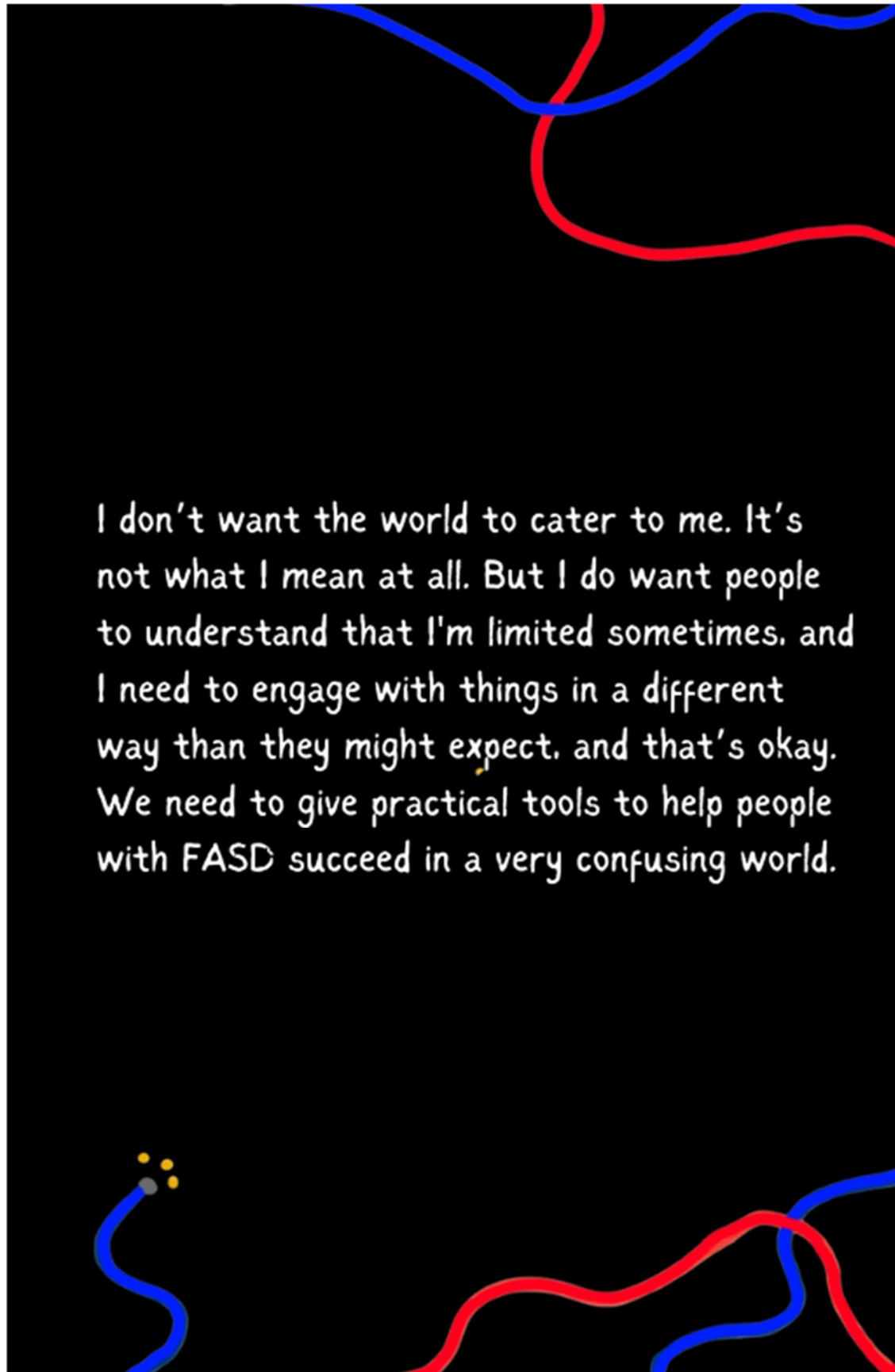
We're not always trying to do the wrong thing. Sometimes it just ends up that way, and it's unfortunate because we won't learn right away from our actions. We might repeat our actions and it might look like we don't care or aren't trying, but we are. And every time we fail, we're beating ourselves up for it, so please have patience. In reality, we really are trying.

It's really hard to learn from your mistakes when your data is half missing. It's not our fault, sometimes the wires don't connect. It's not a choice, it's just the way it is.

A lot of time with FASD people, employers will notice what they're not doing well.

I would suggest coaching them, and giving them concrete suggestions as they work. You could verbally correct them, without shaming them for what they're doing wrong.






Unconditional love. a safe place. and more supports

I was in some programs for kids with FASD when I was younger. My grandparents did a lot of info sessions about it, and it really helped. My grandma even helped create additional FASD programs. My house was well informed. Having the people in your home understand FASD is the most important thing. That's where emotions come out. That should be our safe place for things to come out.

It's a lot easier when people in the house have a plan and understand. What my grandparents will do, if I'm freaking out, is they get eye contact from me and ask me what the issue is. Then we solve it together, which helps calm me down. Without that simple interaction, I would probably take over an hour to recenter myself.





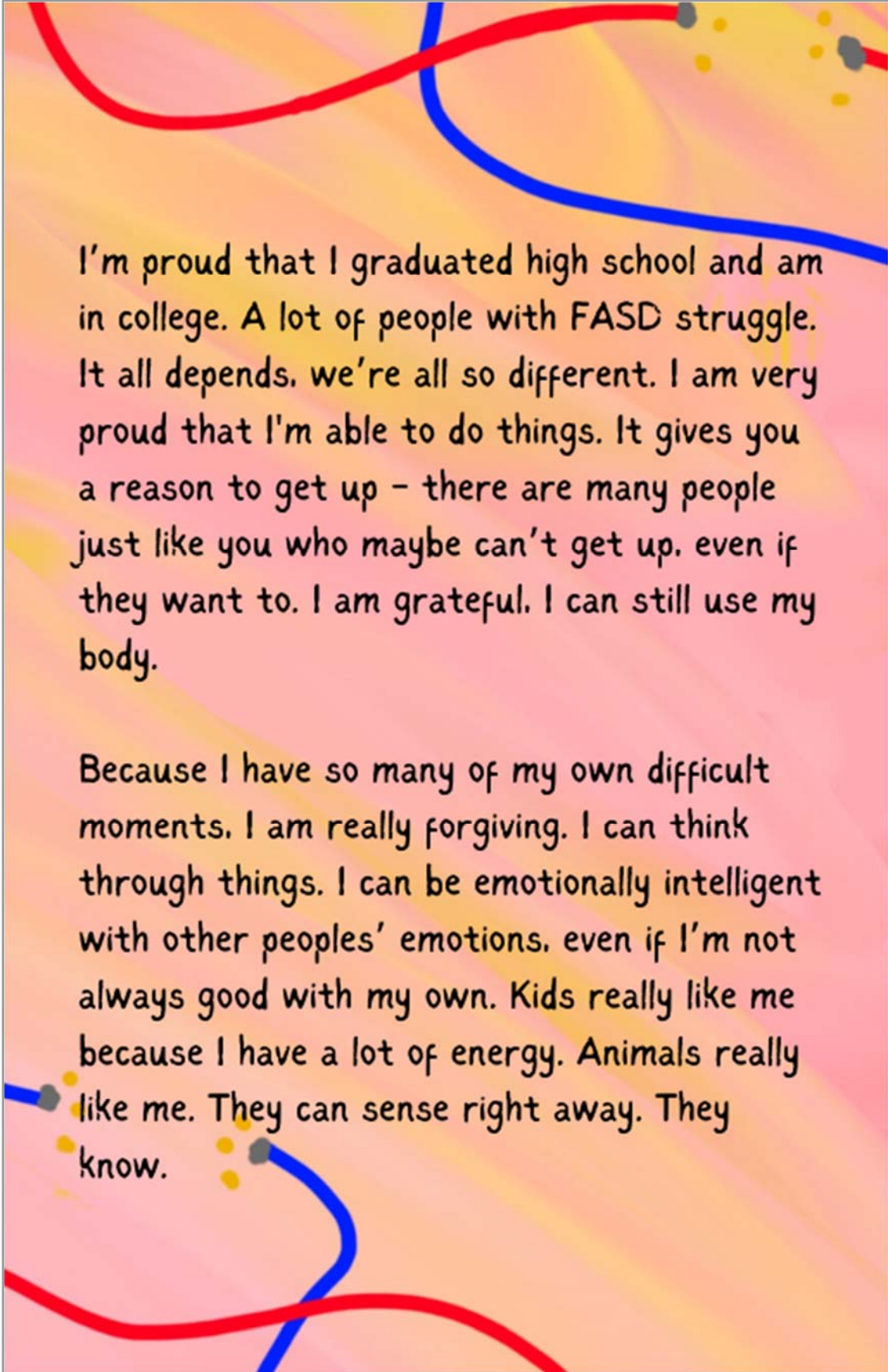
I get really embarrassed when I freak out around someone I don't know very well. I feel ashamed and I don't want to see them again. I get a lot of anxiety. So at home with people I love, we have found ways to solve problems, and move on, and still love each other. My grandma and grandpa will still give me a hug and help me even if I had a meltdown.

My grandparents created a kind space in our home. Not a lot of harsh actions, a lot of forgiveness and unconditional love. It's a whole family effort. It goes without saying, it takes a village to raise a child. We were raised with respect. No matter how often we melt down, we still need a hug. If we said something mean, we do know it's wrong. We can apologize and start over. We need grace, but we can also be accountable for our actions.

My superpower!



My superpower is that I'm very creative. I have a lot of energy and usually I can help others when they want to do something. I really like how I can easily recognize patterns. I can recognize math patterns without thinking. I find I'm really good with certain numbers, and adding numbers in my head - seven's and three's. I can do that math very quickly.



I'm proud that I graduated high school and am in college. A lot of people with FASD struggle. It all depends, we're all so different. I am very proud that I'm able to do things. It gives you a reason to get up - there are many people just like you who maybe can't get up, even if they want to. I am grateful. I can still use my body.

Because I have so many of my own difficult moments, I am really forgiving. I can think through things. I can be emotionally intelligent with other peoples' emotions, even if I'm not always good with my own. Kids really like me because I have a lot of energy. Animals really like me. They can sense right away. They know.

I am pretty good at organizing too. Piles look messy, but it's all organized. I'm good at having a system of organization, such as using a tablet for school. Creativity really helps me. I can draw parallels and metaphors and analogies. I can draw connections between random things and it really helps. Analogy is a powerful teaching tool for my family, friends, and peers.

I know what I went through. I finished school and I'm doing college. All of us are alive, which is amazing given the statistics for kids with disabilities in care.

There are a lot of pros with FASD that we need to focus on more.





Mikayla
Goodwin-Reid
Métis

Life plan:
To have fun, be happy, and help others.

Likes:
Art, nature, animals, water, and
making connections with others.

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