
ICAV Perspective Paper

Navigating Disability and Rare Medical Conditions as Intercountry Adoptees



14 December 2022

Introduction

During the month of November as Adoption Awareness month, I wanted to bring attention to those in our adoptee community who are rarely visible. Despite declining numbers of children being sent via intercountry adoption to all countries globally¹, it is this segment of the adoptee community who continues to be sent abroad - they are adoptees with disability and those with medical conditions, often referred to in the adoption industry as “special needs” children. Their disability and medical conditions is regarded as a justification for their intercountry adoption where it is perceived their medical and social needs will be better catered for.

Have you ever wondered how adoptees with special needs traverse the journey of being an intercountry adoptee? Do they have a “better” life? Is it a roses and unicorns journey as the common narrative of adoption likes to imply? Does being adopted internationally really “save or rescue”? I aim to challenge this narrative by helping to raise awareness of the extra complications and vulnerabilities experienced. So with input from 6 brave intercountry adoptees in the USA and Australia, we ran a webinar on 23 November to highlight a few of the many complexities within this experience.

Not all issues could be talked about within the 1.5hr webinar hence I gathered more input from another dozen so you can get a sense of the depth and complexities of the issues lived. After talking deeply with the 6 panellists, I provided some basic questions to get adoptees thinking deeply about their experience in which they were free to write about any, all or other aspects. The questions were merely a starting point to initiate reflection.

The questions were:

A little about yourself, your adoptive family structure, how old you were at adoption, and knowledge or not about your disability or rare medical condition.

Was your condition discussed in your adoptive family?

How did others in your adoptive family respond to your additional requirements for support?

¹ <https://assets.hcch.net/docs/a8fe9f19-23e6-40c2-855e-388e112bf1f5.pdf?fbclid=IwAR1LzLqP9J-481I2aos81T5pCIXbFNZvCZWU1hOZZyUkXbsiZeVN9jQr5co>

How did your adoptive family cope with finding supports in your childhood?

How do you prefer people talk to you about your disability/condition?

How did you navigate schooling life?

How has it been transitioning from a child under parental care to being a young adult and becoming / seeking independence?

How has it been navigating further education?

How has it been navigating seeking and retaining employment? What barriers if any? How did you navigate those?

What would you share about the feelings of shame for your condition? How have you learnt to deal with feelings of shame?

What would you share about dealing with people's reactions eg pity or expectations?

What would you say about the intersections of adoption and disabilities with developing one's identity?

What has it been like navigating medical professionals and how you are treated?

What has it been like trying to find the right medical treatments you need? What barriers have you faced?

Would you like to comment about the complexities you face as an adoptee with disability in intimate relationships and sex?

What are your thoughts on genetics and passing these to your next generation?

How do you navigate this with your partner? What thoughts does this generate for you about your biological family?

If your adoptive family have divorced, how has that impacted you?

Have you experienced suicidal thoughts or acted upon those? What would you like to share about suicide for adoptees with disability/medical conditions?

Please share your strategies you've developed to cope / flourish in life and how to create your best supports.

Suggestions for adoptive / prospective parents, for adoption professionals who assess prospective parents, for mental health professionals supporting you or your adoptive family, and for medical professionals supporting you or your adoptive family?

I was deeply touched to receive the feedback to these questions and I feel so honoured to be trusted to uphold their experiences and intention to help educate the wider community.

A deep, heartfelt thank you to our 18 adoptees who contributed to both the webinar and this perspective paper. Special thanks to Wes Liu who was brave enough to reach out and ask me for whether support resources existed as an intercountry adoptee with rare medical condition. Sadly, I answered there was nothing I knew of, globally. So with such little research and support resources available, we aimed to fill this gap and become a starting point for further work to be done in educating the public, given the children being intercountry adopted today, are those with special needs who have disabilities and/or medical conditions.

Regards

Lynelle Long

Founder & Executive Director
InterCountry Adoptee Voices (ICAV)

December 2022

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Born in China and adopted to the USA

I lived in an institution in my home country for several years before being adopted out internationally to the USA by a white single woman with a disability who I'd come to know as my mother. My community was primarily white as I grew up and I assimilated with my new surrounding as best as I could without acknowledging my roots. This became more detrimental in my later years. My challenges in learning during my school years never surpassed investigation beyond some extra accommodation for time. I wanted to fulfil the stereotype of being smart because I was Asian, so I worked extra hard to achieve my grades.

What I had was invisible and my family never had a name for why I struggled in learning. I was told I was smart but I constantly felt inadequate because I was in some "special classes" and turning in my work or asking for help to read over assignments embarrassed me. I tried to get out of my "special classes" but was encouraged to use the classes while I had them.

My extra accommodation was only seen by my immediate caregivers and it was never discussed beyond that point of school meetings because I was doing well in school from an outside perspective. Emotionally, I was hindered as well but that was not the concern of the school system as it didn't cause them trouble.

Besides the extra time accommodations I got at school and the occasional meetings required to discuss my continuation of the utilisation of "extra services," no real exploration of my needs was investigated or explored.

It wasn't until my university days and getting accused of plagiarism by a staff member that looked at the inconsistencies in the flow of thought in my work due to my coping skills to compensate for the thought challenges that prompted me to start seeking answers to why I struggled in learning.

I prefer to disclose my lifelong challenges and do not always discuss the topic with others. Only those who I trust and whom I work with that see my work are made aware of it. I prefer to be known for my abilities and don't want what I have to be a distraction

from my work abilities. “You did a good job for _____.” I’m more than just that piece of me. I want to be known for my accomplishments and not associated with just one circle I intersect.

Being Asian and having that stereotype of “being smart” pushed me and made me try harder and hide my struggles. I over-compensated during my schooling years to make up for my struggles — so others didn’t see me struggling. At the same token, being “smart” was attributed to my being Asian and my hard work was diminished in its efforts by some. It’s an interesting duality I lived, contradictory but also what I wanted to some level. I just wanted to fit in and get along with my peers. I didn’t want to acknowledge my differences and neglected myself in exploring that piece of me until my university days.

Unbeknownst to me, to adapt to the time, I developed a higher comprehension ability to compensate for my short fallings. Once I obtained information in a different format, I was able to provide above-grade level replies, but I’d have to dumb them down from time to time due to not being able to communicate my thoughts cohesively and consistently without proper tools which I wouldn’t discover until much later in life. The tools I had in primary school often revealed to others my struggles that I’d prefer not to use as a result. I adapted where I could and formed a coping tool to meet my needs but held myself back as a result.

Transitioning from being a child under parental care to becoming a young adult and seeking independence was freeing. My family just didn’t, and to some capacity, couldn’t understand. I didn’t have the emotional and mental knowledge of how to address it either.

I came to a cross point where I could accept where I was and not investigate my challenges and just get by or I could step out of my comfort zone and challenge myself to live beyond what I knew. By that point, I had developed a sense of self that was more familiar with being uncomfortable due to circumstances to accelerate my independence. I chose the latter and explored my options.

Having an invisible disability allowed me to camouflage in society. I wasn’t aware of the difference between a disability and a disabled meaning. I didn’t identify with the disability community, so I never disclosed that information to my earlier coworkers and employers. I continued to use the coping skill of dumbing things down and remembering key information where I could to get tasks completed. I avoided projects that required

extensive writing tasks or reading as much as possible. I limited myself during my earlier years.

But after college, after gaining new insight into my challenges, I was able to develop new tools that were more effective. It wasn't 100% but it dramatically improved my abilities better than my prior tool of dumbing down my words or avoidance. Even then, I still didn't start disclosing my needs until I discovered my local Center for Independent Living (CIL) organisation that focused on the inclusion of those with a disability in my area of the USA, and I was shown and modelled what challenges others lived with. Once I had those models, I was able to start disclosing my needs and it made a world of difference in my performance. I went from just good enough to pass to accelerating and having a voice. I didn't have to hide my struggles and I could use my tools to succeed in the company of others who used their tools to elevate their quality of life. I equate it to someone that uses a wheelchair. A wheelchair is not the person but it's a tool that helps improve an individual's quality of life and abilities.

My feelings of shame could be hidden and that's what I did for a long time. I held myself back and blended where I could. In the beginning, I didn't know what the cause of it was. I didn't even have a name for why I had that shame. But after exploring, I had a name for it and adjusted to accommodate which improved my abilities and participation in life.

In elementary and high school, pity from those who knew I struggled, my teachers and intimate family member, made me feel guilty, sad and insecure. Add that to my ingrained stereotyped ideal of "you're Asian, you're naturally smart" compacted on itself which resulted in my poor self-esteem and emotional outbursts during my special accommodation meetings. I avoided attending those meetings if I could. Looking back, having the ability to self-reflect on my younger self, I avoided those meetings because of how they made me feel and I didn't have the skills nor was I learning the skills, to navigate those complex feelings as a 10-year-old. The system in that regard failed me at that time. It didn't try to help me understand, it just wanted me to get through. And that's what I did, but others are not as fortunate and instead were victim blamed and labeled as bad kids.

In my view, the intersection of adoption and disability in developing one's identity just compounded itself and made it harder to succeed in terms of their criteria. It resulted

in lost opportunities in social and learning facets. I lost time that I'm trying to make up or compensate for. Some of it, I'll never be able to regain.

I've been very fortunate to have stable physical health so I've been able to avoid additional encounters with medical professionals outside of what was required for school. I will say that the medical forms I need to fill out for family history are annoying due to not having any history available for the family. It's just a reminder of how genetically alone I am.

My country's health system is not where it needs to be. It's one of the worst things about my country that I dislike. It's a nightmare to navigate, even with my good health physically. I understand why people avoid getting the help they may need if they can. I worked with individuals who had higher health needs and the amount of work needed to get the proper help can be traumatic.

I don't have any kids at this time, but I do have reservations about if I can pass what I have to them in the event that I do have children as well as not knowing my genetic disposition for health that could be running dormant in my bloodline that I don't have prior knowledge too. Also, there is navigating my cultural identity. How would they fit into that? What is it like to have someone that looks like you? I'd like them to be more connected to their Asian side and to have opportunities to grow in that area that I may not have had but can I facilitate that?

It's scary to think about genetics and passing them onto my next generation. I don't want my kids to struggle unnecessarily. There are always going to be challenges in life, but what can I do to give the best outcome? Would it be better to abstain? The idea of getting a genetic test is stressful as well and the fear of having something more problematic with my genes is also a barrier. The cost doesn't help either. So due to these complexities, it has resulted in no children at this time.

I am fortunate and in a privileged position where suicidal ideation hasn't been an active need to address. I sought help when things got dark and I have a very good support system I've built for myself. Coming from my educational background, I understand this is not the case for all and it's a real challenge that plagues the adoption community and takes lives unnecessarily.

My strategies to cope and flourish in life and how to create best supports has been to ask for help when I needed it. Swallow pride and know it's human to need help. Put in the work where you can to improve life situations where control can be had by oneself. There are just going to be some things that are outside of your control and it's not worth beating yourself up about it. Knowing one's value helps too.

My suggestion for adoptive / prospective parents is do your homework and ask questions even if it's painful to know and dredge up feelings. It's okay to have sad, complex, feelings — acknowledge them and work through them. Love is important but it doesn't solve all the needs that will come up with the adoption.

My suggestion for adoption professionals who assess prospective parents is to ask can the prospective parent(s) admit to failure and how do they adjust for that occurrence? Parent(s) aren't perfect, they are human too but it's what they do in that kind of situation that tells you a lot about their character and how they will handle being a parent(s).

My suggestion for mental health professionals supporting adoptees and adoptive families is don't assume everything that adoptees deal with, stems from their adoption. We are people too and have other challenges in our community and growing up that also affect our mental health.

My suggestion for medical professionals supporting adoptees and adoptive families is be aware and apply a box for "unknowing family history" instead of making adoptees verbally confront that barrier every time an update or new patient information is needed.

Angela

Born in South Korea and adopted to the USA

I was adopted before my third birthday in 1984. The adoption listing in Holt International catalogue listed me as special needs placement, showed a photograph of me, mentioned I ate more than my portion, liked cracker “biscuits” and said I began saying ‘omma’, then the description ended with, “adoptable as is.”

The form where I was evaluated to immigrate from South Korea to the USA reports my “condition” as Cerebral Palsy and my appearance as ‘cute.’ I am unsure if this document was provided to my mom before I joined her in the USA. I assumed it was provided afterwards because of a comment my mom made about taking me to a doctor to obtain a diagnosis and to try to find out if the age reported on documents was an error. I learned to take what my mom says with a grain of salt.

My parents were not provided with any background information about my biological parents, prenatal care, or any other incidents which could have caused my disability at birth.

It was clearly communicated that I was considered “special needs,” but as to an in-depth conversation on my disability within my adoptive family, I do not believe we had any. My mom was already familiar with cerebral palsy since she grew up with a younger sibling close to her own age who was diagnosed at birth with cerebral palsy.

The presence of my closed fontanelle cleft palate was not found until I was 5 years old. I ate mainly soft foods. Food often came out my nose and I had a high risk of choking. I was operated on at age 8 years old to graft skin and sew the gap for my soft palate. My medical chart had a dosage error and I was given an overdose of anti-epilepsy medication which caused me to be in a medicated coma during recovery.

I had tubes inserted into my ears at age 6 years old, since I had so many ear infections in succession. When I was 10 years old, the doctors had to pry the tubes out of my right ear because it had become embedded into my ear canal. I do not like things on or in my ears as a result.

I've had years of medically traumatic experiences, such as teams of residency students and interdisciplinary doctors observing my exams. I'd have to wear shorts for them to see my knees hyperextended, and to observe my ankles rolling, touch me to see my hip abnormalities which is probably hip dysplasia that got blamed on my Cerebral Palsy. I vaguely remember hearing that I would not be able to get orthodontics on my teeth because the doctor felt my choking and gagging would be problematic along with the fact I am unable to hold still, and my poor head/neck control. I had 3 teeth removed when I was 9 years old because my mouth was overcrowded. I did not like to brush my teeth because it was physically difficult, the mint from the toothpaste burned (as an adult, I believe I have a mild allergic reaction to mint). I did not obtain braces for my teeth until I was 36 years old.

Others in my adoptive family were supportive for my accommodations in school. My dad built a ramp and re-modelled a back porch so it could be used as a bedroom for me. He built a ramp with railing on both sides so I could get outside independently for the school bus.

I attended a preschool for three years because I was behind with my developmental milestones such as sitting up, standing, walking and talking.

My suggestions for adoptive / prospective parents are:

Question your motives for becoming parents. Then question your reasons for adoption.

There's a myth that babies don't have issues or problems. My dad taught me every child and person has needs, and a loving parent does not cherry pick what to help their child with. For example, a baby might not have lived long enough to show signs of a learning disability or a rare genetic disease. It still has needs. Maybe it struggles with language or developmental delays. Guess what, a biological baby/child is not better or worse. All it means is they need parents and family to help meet their needs.

Anonymous

Born in Colombia adopted to the USA

My earliest memories of my body being different from “normal” are based on stories about me that were told to me. “You were born with dislocated hips.” There were photos of me, both my legs in a cast from foot to hip, with a metal bar in between keeping my legs in a wide V position. Following surgery, the casts were fitted and refitted as I grew from around 6 months to 18 months of age. The whole contraption looked quite uncomfortable. The scars it left on both my knees and the heel of my right foot confirm it was not just uncomfortable but downright painful.

I was only a few months old when I was displaced from Colombia to the USA via intercountry adoption. It is unclear whether or not the orphanage I was in noticed that my hips weren’t sitting correctly. If they did notice, they certainly didn’t do anything about it. It was only when I arrived in the US that I got the medical attention I needed.

“If I hadn’t adopted you, you wouldn’t be able to walk today.”

I cannot count the number of times my (adoptive) mother said that to me. It was a phrase she repeated so many times it turned into an actual belief on her side of the family. In my younger years, part of me believed what she said and part of me didn’t fully believe it. And an even bigger part of me didn’t like the way her words made me feel. Like I owed her my life. Like I wouldn’t have as much worth if I couldn’t walk.

As with many experiences in my life as a person who was permanently displaced out of my family of origin and into a genetically foreign family, I was the only person I knew who had been born with congenital bilateral hip dysplasia. I was also the only kid I knew who had orthotics for flat feet and nightly pain running up and down her legs. My mother would massage analgesic cream into my legs at night to try to alleviate my pain. Although the cream helped temporarily, the pain was explained away as “growing pains.” But, again, none of my friends had such pain. And no one in my adoptive family had legs or feet like mine. The same could be said of my fingers. Both of my adoptive parents had small hands with short, stubby fingers.

My fingers have always been disproportionately long and thin and extremely flexible. Strangers would comment on them (and still do) and ask if I play the piano. Um, no, I don’t.

From my mid 20s through my mid 40s, I experienced numerous ear infections (one that led to a ruptured eardrum – more painful than natural childbirth in my personal experience!) All medical personnel that have ever looked in my ears have mentioned how narrow and twisty my ear canals are. What other adults get that many ear infections? None that I knew. Then there were the trips to the emergency room for severely sprained ankles, and rounds of physical therapy for hip pain of unknown origin. One orthopedist I was referred to for hip pain told me, with a slight chuckle, that my musculoskeletal system was, “incredibly poorly constructed.” That was almost 20 years ago, and I can still see his face and hear his words like it was yesterday. It was an insult to me and my ancestors.

All of this is to say that at the intersection of adoption and a collection of signs and symptoms of *something* there was me. Just me. Alone in my embodied experiences. I had no genetic mirrors to look to or ask about how their bodies experience the world. My adoptive family’s medical history was useless to me. I was my entire family medical history.

It wasn’t until December 2019 that the pieces started coming together. We were visiting friends, one of whom is a doctor, when my elbow or my fingers moved in a way that’s normal for me but that caught the attention of my doctor friend. She asked a few questions, said that she had a few patients with similar hypermobility, and suggested I get evaluated by my doctor. The following week I had an appointment with my doctor who referred me to the Ehlers Danlos Syndrome clinic. After 2 years of being on the waiting list(!), I was finally seen and heard. I underwent testing and was diagnosed with a connective tissue disorder called hypermobility spectrum disorder. Every single one of the physical symptoms I had experienced was connected. (Don’t ya just love medical puns?!)

Over time, I have come to question my adoptive mother’s statement, “If I hadn’t adopted you, you wouldn’t be able to walk today.” Why make such an assumption? Why say such a thing to the child you are raising? It is clear that the orphanage I was in did not give me any medical treatment. Even if they did notice something was wrong, I was a commodity to them. Soon to be sold. Soon to be shipped out. Not to be given medical treatment.

But, what if my first mother had been given the support she had needed in order to keep and care for me? If family preservation – instead of adoption – had been the option

offered to this pregnant woman who found herself in need of help, she would have kept me. I know this because I found her in 2012. If I had been in my mother's care, I know she would have noticed something was wrong with my legs long before surgery was the only option to fix them. And I know she would have gotten me the care I needed, as she has done for all of her other children. Thanks to reunion, I also know that my mother's fingers look and move like mine, and just like my daughter's. I was once all alone, but now there are at least three of us, in a straight line, in our family. Seeing this bodily connection is medicine that no clinic can provide.

August

Born in China and adopted to the USA

My name is August and I was adopted from China at the age of 6 months and flown to the United States, and raised in rural Wisconsin. That is to say, I was supposedly found in a basket in an alley in ZhuZhu, given to an orphanage then a foster home and eventually be given to a half White American, half Mexican-American household; who lived in a log cabin in small town (predominantly White) Wisconsin.

I am a Disabled and Transgender advocate, content creator (TikTok 100K+), speaker and writer.

We didn't know I have a rare illness until I was 21 years old. I had symptoms, but they were never seen as valid, either blaming my hormones or psychological state. My adoptive family, while curious, did not give me the empathy or understanding I needed. Much less my extended family. I remember the first time I was sent to the hospital. I was living in NYC at the time. My mother told me she and my father were hosting Thanksgiving and couldn't change plans, until my roommates at the time begged them to fly my mother to see me.

I have what is called Behçet's Disease. The best way I can describe it is like herpes + mono + Chrons + arthritis + fibromyalgia. You could be asymptomatic, or you could be like me. Or you could be worse.

If you're like me, your immune system is shot. It's the bane of my existence. It blisters, burns, stings, stabs, throbs, and it's seemingly unending. It's also unpredictable. Every day my symptoms are a surprise.

And if you have Neuro-Behçet's (which I keep getting tested for), you may have a whole other set of symptoms, often beginning with memory loss.

I had to drop out of school, change my dreams, it was a mess. Further education may never be an accessible option for me. Same goes for any job that does not (actually) meet ADA (The Americans With Disabilities Act) requirements, which seriously cuts down job prospects.

The feelings of shame are real, I won't lie to you. There was always an unsaid agreement in my family and childhood household, that you do your best to earn your keep. And being diagnosed with a life-altering, rare illness was seen as a personal failure. I have lost a lot of friends and family because I was suddenly a "burden." Do not listen to these people and their ableist expectations of you.

Of course this is easier said than done. I have battled with my mental health all my life and when it comes to being sick, the chronic pain alone is enough to make anyone suicidal. I have attempted countless times. I may always have that ideation, but now I have the proper support I need. This for me comes from community.

The Adoptee, Transgender, Queer and Disabled communities have been instrumental in my survival. Find your people. Get on the internet and start by looking around (with justified caution). Pick a social platform. Look for local support groups. Create one! But know that you are never alone. And there are always folks rooting for you.

Sending you love,

August 

(he/him)

Carmen

Born in Hong Kong and adopted to Australia

I was born in March 1996 in Hong Kong (HK). I was raised in HK and moved to Australia in 2014 at age 17 and live in Brisbane, Australia. I have no genetic confirmation but it is likely that I am at least half ethnically Filipino. Filipinos made up a significant proportion of domestic helpers in Hong Kong.

I am adopted and the eldest child in my Caucasian white family. My parents moved from Brisbane Australia to Hong Kong around 1993, and wanted to start a family. After being unable to have a child of their own, they turned to adoption. I was adopted at around 9 months on Christmas Eve. My parents were able to have children a few years later with a brother and sister being born 6 and 7 years after me respectively. At this time there were no indications that I had any health conditions. I was adopted from an orphanage, having been abandoned at a church and have no information about biological family.

My conditions of Achalsia, Migraines, and Osgood-Schallters didn't really manifest until I was 11 years old and I was only accurately diagnosed in 2019. So I lived 12 years of not knowing what my condition was. My condition wasn't discussed. My mother made efforts to take me to doctors but there were few answers. As my condition was 'invisible' or didn't exhibit any obvious physical symptoms, the rest of my family did not take note of my condition.

This also meant there were little concessions made for me. My conditions prevented me from swallowing food and caused significant pain in my oesophagus. I did my best to hide this. Still, it was difficult to mask a problem that had me going to the bathroom every few minutes. No food adjustments were made, and there was even annoyance by parents that I could never finish my food.

I was taken to health professionals - GPs, dieticians, etc., and underwent investigative procedures - a few endoscopies and barium swallows. Day-to-day supports didn't occur.

I am very open with my condition. It has improved in some ways after a medical procedure but has recently manifested in a different part of my body. The formal

diagnosis called Achalasia affects the whole digestive system. All of my friends are very understanding of any limitations and happy to make considerations if I need it.

School was both a haven and a hell. I had my friends and I had things to focus on. I enjoyed learning and being with my friends as it helped to take my mind off the health deficits. I engaged with sport up until my other condition 'Osgood-Schlatters disease' which caused significant pain in my knees. I rarely missed a day in school as my mother had me go to school unless I was 'sick' in bed. Some of the conditions I went to school in had teachers shocked that I was even attending. They encouraged me to go home but I remember saying that I wouldn't be allowed to.

The biggest benefit of becoming independent as I got older was being able to control what I ate. I was not a fussy eater and ate widely and enjoyed many cuisines but anything and everything had the potential to get stuck. Even water. Being able to control what I ate when I went outside (beyond Uni commitments) and my day-to-day activities gave me a long relief from the anxiety of being caught in an environment where my condition might manifest and had nowhere to hide.

I completed a 4 year double degree with the condition still present. I was able to do work, even in cases under duress due to the condition, with success and rarely had issues that inhibited my attendance. A few years later and returning to uni, my condition has returned and has worsening symptoms in my stomach. The pain and the inability to eat without pain and the lack of energy has become a major hinderance to my ability to succeed at uni. At this time I have considered changing my major from Engineering to IT as the latter allows me to complete online education. The commute from home to uni was significant enough that I could not travel.

I have had few barriers to employment. My condition wasn't a major hindrance as it was 'invisible' and I could manage it to a degree that I either soldiered through or it wasn't causing major issues to my work life. Most of the jobs I got was through friends and/or environments where other staff knew me. They weren't all aware of my health issues but having friends in my work place created a much more secure work environment. I am currently working as an independent tutor for a uni student which allows me to dictate my work hours. It is ideal for a uni student with a health condition.

When I was younger I had the fear that because I was 'defective', my parents would think I was a poor investment. As the eldest and only adopted child in my family I always

felt like both the test-run child that the eldest child can feel, as well as the ‘better than nothing’ substitute, as my mother mentioned she had tried to have biological children but wasn’t able to until a few years after my adoption. I felt like I was a burden on my family and already experiencing emotions of not belonging and ‘otherness’, the health condition enhanced those emotions significantly.

Reflecting on that experience, I try to focus on the achievement of getting through high school and university despite all my barriers. My parents were financially supportive but lacked a lot of the emotional intelligence to help me. I never felt comfortable approaching them with my emotional needs, both as a teenager let alone as an adoptee. I was raised to be ‘just part of the family’. Adoption was never discussed. It was just a ‘fact of life’. I now have a partner who supports me and while the shame of them having to endure the emotions and strain that my body goes through continues, I’ve had to accept they’re not going anywhere. They don’t see me as a burden, while I can’t say the same for my parents.

I’ve been fortunate that most people I have engaged with either don’t know me well enough that my condition does not affect them, or are well aware of my condition and make a great effort understanding how I am affected and if they can do anything to support me. Pity definitely comes from people who don’t know me as well and I always laugh it off and say something like, “It keeps me skinny” as a way to lighten the mood. I don’t like positioning my condition as my ‘personality’, just a nuisance that affects my life.

I think the intersections of adoption and disability in developing one’s identity is a very complex concept, with the context of each other determining how they impact the development of identity. Speaking from my own experience, adoption was the greater factor of the two that created identity crisis. With no connection to my heritage, being adopted outside my ethnic country and raised by parents who weren’t local to the country I was being raised in, it created a lot of disconnect with all places that should have been relevant to me. I am Australian, born and raised in Hong Kong. Australian by citizenship, I have an Australian passport, and I sound Australian. No one has ever doubted my Australian-ness, despite being Asian. But I am also an international citizen. I travelled a lot when I was younger, I was raised in an Asian city but couldn’t speak the language. I am also South East Asian. I get looks from people who look like me trying to figure out why I sound ‘white’. I get people who look at me and say, “Oh you look kind of ...” and list a bunch of countries that I had visited but never had a strong emotional connection to. My condition and several other health issues did not define me but they aggravated some

of the negative associations with being an 'outsider' in my adopted family. I was the different and sick one. But despite my deficits, I felt like I had to work even harder to prove my worth, that I deserved to be 'saved' by my white family. I didn't want to give them a reason to think I was a bad investment and I had to continually perform well at school and be perfect. I think every adoptee has a moment that they thought, "If I am not what they want, they're going to send me back". No matter how irrational this thought is, it crossed my mind that if they weren't happy with me, they were going to reject me.

I've had excellent medical professionals. The Australian general practitioners (GPs) and health staff who have helped me finally get a diagnosis and move forward have been excellent. I am currently working with my GP with the resurrection of my health condition and they have been very invested and diligent in covering all the bases. I am fortunate enough that every aspect of my health thus far has been covered by Medicare. I believe this is because my condition is 'life threatening' enough to be completely bulk billed. This includes all investigative and medical procedures to 'fix' the problem.

The biggest barrier has easily been finding out what the problem was. It took over a decade to identify the problem and this was mainly due to the limited technologies. I have been told by health specialists that between the time of my initial diagnosis and now, there has been significant advancements to help diagnose conditions like mine. I was supported by the hospitals and while there were waiting lists, everything got moving very quickly when my health deteriorated.

Being adopted has never impacted my sex life when I was in my early twenties. Funnily enough, being SE-Asian and Australian was an 'exotic premium'. Being physically ethnic but otherwise Western had great appeal. With my condition having worsened more recently, my sex life has paused mostly. I am still intimate with my partner who is very understanding and supportive. They prioritise my health over anything else.

Whenever I was meeting a new health professional, family heritage was something I always had to prepare myself for — for their reaction mostly. When they asked if I had any family history, I would answer 'adopted' and 'no idea'. Sometimes they would hesitate for a moment but they were always very professional. They would just acknowledge and move on. Looking into all my conditions, I haven't noted anything that would suggest hereditary. It was a concern when it was still a mystery what was causing my oesophagus issues but now I realise I'm just a 'lucky' person whose body doubles as a pharmacy.

My partner is extremely supportive. They're supportive of anything I can do and any limitations my health creates. A part of me has always wondered if my biological parent knew that there were potential health risks and that's why I was abandoned, with the hope that someone else could afford to help me. Or if it was just a fluke.

As my condition began to manifest during my pre-teen stage, it was almost unavoidable to develop some pretty traumatic thoughts. I am still navigating these emotions now. I am almost surprised that my younger self didn't make significant suicide attempts because in hindsight, I was in physical and emotional hell. I personally think that suicide and adoptee mental health is something still stigmatised by the notion that adoptees are being 'saved', usually by Caucasians and we should be 'grateful' of the opportunities that we have. Maybe the assumption is that mental health is a small price to pay for being someone from a less fortunate ethnic background having the same opportunities in a Western society. I think it is important to both dissect the traumas of adoption and health separately first, then discuss how these two factors interact. I believe a lot of adoptees have the excellent ability to compartmentalise their emotions and experiences as a coping mechanism. Therefore I'd imagine many people have done the same for their adoptee experience and their health experience. For me, it can be quite overwhelming to recognise the connections that may aggravate one or both factors. Most importantly, take one step at a time and it's about getting through the day, not finding a perfect solution.

Being mostly bed-ridden these days, finding the day when I can actually get out of bed means I need to be put it to good use. For me, that's getting on the computer and playing some games. I play competitively for my university and casually with my parents and friends. I also try to meet up with friends for food, or my sister and go somewhere. I listen to a lot of music, and it can help me separate myself from my reality for a little while. I have trouble watching TV and movies as they don't hold my focus for long and with pain being a main factor, I prefer things that distract me in small bursts. Shorter YouTube videos of topics I enjoy are the best. My best supports are definitely my family and friends. A good handful of my friends have undergone health issues and some experience chronic conditions like me. Having people who understand the health aspect of it has been very helpful in accepting my condition.

My suggestion for adoptive / prospective parents is to accept that if your child has a health condition or develops one down the track, the best thing you can do is listen. Don't

tunnel vision on making them better because they are already most likely afraid that their imperfections are worsening their value to you. Emotional health is just as important and in the long-run will create an even stronger bond. In general, find the supports that your child is willing to respond to. This could be counselling or psychology, or joining a sport, or hanging out with friends. These days gaming and socialising online is a common medium where young people find support.

For adoption professionals who assess prospective parents, it's important to understand that adoption isn't the magical insta-family experience. In most cases, adoption comes with trauma. Children are being taken from biological families that were either incapable of taking care of them for whatever reason, or have passed. The reality of not being able to remain in the family that birthed you can be hard for a young child to process and can become a confrontational fact as the child gets older. This is something that needs to be recognised with supports put in place. The young person may never reach out but knowing support is there, is the most reassuring thing that can be done.

Educating prospective parents on the challenges of adoption should be a priority. It isn't just about changing diapers and getting them to school on time, it's about creating a safe space for a potentially traumatised child to thrive. It's about not just giving them opportunities to be academically and financially successful, but also giving them a family they can be a part of. They're not there to give your existing child a sibling, they are there so a child in need knows the joy of being in a secure family unit. They're not there to fulfil your empty nest syndrome or inability to have biological children where adoption is the next best thing, they're there because you're passionate about helping raise young people.

For mental health professionals supporting adoptees and adoptive families, I think it's important to work with as many adoptees as you can. There are so many unique experiences, with so many critical factors that can change how you engage with adoptees. One thing might trigger one person yet be something that another laughs about. Understanding the complexities beyond face-value in adoption is essential in being able to have an adoptee engage with you. Many adoptees excel in hiding their insecurities and pain, as they may have had to do so with their adoptive families. Many of us may look like hopeless cases but being heard and knowing we are heard is the best thing you can do.

For medical professionals, in cases where genetics are highly suspected of being the root cause, do not focus on this. This will create a lot of self-blame and potentially hatred

towards the biological family. Acknowledge but reassure patients that health is a lottery and when it comes to illnesses, there is nothing the individual could have done. Focus on the future and set realistic goals. Help families understand the condition and help eliminate some of the fears of “otherness” that diagnoses may create. Make it known that the adoptee is more than their health condition.

I'm sure most adoptees have had fantasies of who they could have been. Maybe when you were younger you were the child of a celebrity, or a royal from a far away land. Or maybe you were just in a home where you looked like your parents. What I have come to understand is that in some way, we are superheroes. We can't fly but we have this strength that is uniquely ours. Sure we have our good days and our bad days and with health problems, those bad days seem like the many and those good days the few. But funnily enough, being adopted with all the trauma and emotional pain it involves, it is one of the reasons that I have gotten this far and have the mental fortitude to go on. For adoptees, we spend our lives looking for belonging and I have learnt that belonging isn't a place. It isn't our home country or the homes we were raised in. Belonging is the realisation and acceptance that while being adopted is isolating, we aren't so alone.

Eftychia

Born in Greece and adopted to the USA

I was adopted from Greece via a proxy adoption in the scandal-ridden Cold War decades of the 1950's and 1960's. My adoptive parents had been childless for 12 years and were told about the possibility of adopting a child from Greece by a friend who had done so through the auspices of a Greek priest in San Antonio, Texas. I was 8 months old when I arrived in America from the Vrefokomeio Athinon (Athens Municipal Nursery). My parents were wonderful, kind, loving people and gave me a wonderful life. I am an only child.

I have ADHD and was diagnosed as an adult in my 50's. Looking back, I know I've always had ADHD. I was always highly energetic, talked too much, couldn't sit still for long, and either fidgeted with my hands or rocked back and forth when I was talking to someone. I later learned that this was common for people with ADHD and that it helps to keep them focused on the conversation. I struggled with both anxiety and mild depression at various times in my life and was treated with anti-anxiety medications that never really helped, because the root cause of these was the ADHD.

At the time when I was growing up, ADHD was not really a recognised diagnosis, or even something that very many people knew about. My parents just always thought I was "full of energy". My dad once joked that if we could bottle my energy and sell it, we'd make a fortune.

Looking back, I think my parents did what they could to temper my enthusiasm, so to speak. My dad recognised my impulsivity and I remember him gently discussing it with me and redirecting me when it occurred.

ADHD "wasn't a thing" when I was growing up and there was little or no support available. Even if there were supports available, it wasn't well-known to the general public at the time.

Most people wouldn't know I have ADHD unless I told them. So, it's often one of those hidden disabilities. But I don't mind talking about it or people knowing that I have it.

I actually thrived in school. It's well-known that even today, girls with ADHD are often overlooked or misdiagnosed as opposed to boys. Girls often compensate by being over-achievers and people pleasers and that's what I did. It became an obsession to make straight A's and be an academic over-achiever. I am also a procrastinator, another trait common to ADHDers, especially when tasks are unpleasant or uninteresting. I can't recall how many times I had weeks to prepare a paper, only to wait until the last few days and pull some all-nighters to finish – but I still got an "A".

As a mature adult, I can look back now and see that I had some difficulty "cutting the apron strings". I was an only child and extremely close to my parents, so I had more difficulty than most trying to be independent and set boundaries in my adult life.

Navigating further education was much like my early education – people-pleaser and academic overachiever.

I've had a few different careers in my lifetime and I think that's in large part due to ADHD and the inability to focus on a single thing for an extended period of time. At first, new things are exciting and stimulating and I would have an almost laser focus. But over time, the newness and excitement wear off and the ADHD brain craves stimulation. I have a biology degree and I've worked in a lab, went to medical school and gave it up for a career in country music, worked in accounting in an oil and gas firm, went to nursing school and became an RN. My nursing career lasted the longest. I'm still an RN but I no longer work in the hospital. I am the administrator of my husband's business.

It's not so much feelings of shame but feelings of regret for my condition, primarily regret for the misunderstandings that ADHD can cause between me and those with whom I interact. For example, I know that I interrupt people without thinking about it. It's not because I'm rude or disrespectful, it's because my mind races and I want to express something that I've thought of before my mind moves on to something else and I forget about it.

I think that frustration is the reaction I deal with the most from people. I do not use ADHD as an excuse but as a reason why I sometimes do the things I do. Sometimes, when I explain to others what they are dealing with and educate them, they then have an understanding of the disability and are better equipped to become a partner in helping to cope with and navigate personal interactions and relationships.

I would say that developing a healthy identity as an adopted person with a disability would depend first and foremost on what sort of adoptive parents one has and how they respond to and support the disability. This would entail recognising there is a disability, obtaining an accurate diagnosis, seeking the proper help and supporting the adoptee's self-esteem.

Before I was diagnosed with ADHD, I had bouts with anxiety and mild depression at various times. I've also suffered from panic attacks. I saw various doctors, who prescribed anti-anxiety medications which never helped for very long. One doctor even misdiagnosed me with agoraphobia after a panic attack! I finally quit taking any sort of anti-anxiety medications. And things went well for a time, until all of my coping mechanisms failed – I had two sick elderly parents I was taking care of, one child getting ready for college, the other a senior in high school struggling with ADHD, working full-time as a nurse and helping my husband start a new business. It was too much. After three tries, I found a wonderful therapist who encouraged me to see a psychiatrist. The first psychiatrist was a bust but the second was a Godsend. He sent me an 18-page questionnaire and when I was answering the questions, I had an epiphany. I had ADHD and when I saw him in the office, he confirmed it. I was started on Adderall and I haven't had to take medication for anxiety or depression since then, as ADHD was the root cause of the anxiety and depression.

I firmly believe there is a genetic component to ADHD, as many studies have shown. My son was diagnosed with ADHD at age 10, although I firmly suspected he had it when he was much younger. At the time, I thought that it must have come from my husband because I couldn't possibly have ADHD, right? Also, after finding my biological family, I am convinced that my biological mother has ADHD and several other serious comorbidities, including narcissistic personality disorder, oppositional-defiant disorder and anti-social personality disorder. While she hasn't been diagnosed with any of these, I can't help but draw these conclusions from the family history and from my own interactions with her over the past five years.

My husband and I have been married for thirty years. At times, there have been difficulties caused by my ADHD. But once I was diagnosed, I found that educating him on ADHD and how it affects women has helped immensely in strengthening our relationship. For example, we've set up subtle cues in social situations if he sees that I am talking too much or rocking back and forth or fidgeting. As for my biological family, I am

thankful that I wasn't raised in an environment where I would have had an undiagnosed parent and no support at all.

Education about ADHD has been key. Even though I educated myself about ADHD before my son was diagnosed, I still failed to recognise it in myself. Educate your family and friends so they can be a part of your support system and help you to flourish. I was misdiagnosed several times and I cannot stress strongly enough to always get a second or even third opinion. I went through multiple doctors and multiple therapists before finding the right one. Trust your instincts – if after the first visit you aren't comfortable, you just don't "click" or something doesn't seem quite right, see someone else. Therapy isn't helpful if you don't feel a connection with your therapist. Get a life coach if you can afford it. It's helpful to have someone help you learn strategies and life hacks to cope with everyday tasks, to minimise disorganisation and procrastination.

For adoptive and prospective parents, children with any type of disability will always need support. Don't adopt a child if you cannot love and support them unconditionally. Many non-physical disabilities aren't recognised right away. Be sure that you are prepared to go the distance if you adopt a child and later discover a disability that will require all the love and support that you can give. Be sure you are willing to seek the best medical and mental help and support for your child.

For adoption professionals who assess prospective parents, perhaps one of the first questions you should ask is if you adopt a child and later discover a disability, how would you handle the situation? Would you love and care for the child the same as you would a child without a disability? What would you do to educate yourself, family members, friends and others about the child's disability? What would you do to ensure the child has a healthy self-esteem regarding his disability? This is merely a start – there are many for questions that could be asked to ensure that prospective parents are fit parents for any child, and in particular, a child with a disability.

For mental health professionals supporting adoptees and adoptive families, I recommend involving and educating the adoptive family. There should be family therapy sessions as well as individual therapy sessions because ADHD does affect the entire family, including the siblings. Siblings, in particular, have difficulty dealing with a sibling with ADHD – especially adolescents who become frustrated with the behaviour of the sibling with ADHD and don't have the tools to cope with it.

For medical professionals supporting adoptees and adoptive families, I suggest don't take the easy way out by making the easy diagnosis. It's easy to make a diagnosis of anxiety or depression. But don't take that at face value. Dig a little deeper to find the root cause. If you treat the cause, you often treat the sequelae. It doesn't mean that you don't need medication for lingering symptoms of anxiety and depression but finding the cause will help to formulate better strategies to deal with the disability or disease. It certainly helped me to deal with my ADHD.

Emma

Born in Vietnam and adopted to Australia

I was fostered at the age of 4.5 years old for 2 years. I arrived in Australia on a medical visa in order for my eyesight to be restored but this was unsuccessful.

As far as I know, my eye condition was never discussed in my adoptive family. Some strangers would invariably ask how I became blind. It was easier to say that I was born that way. Back in those days, people with a disability were not catered for and the services were quite limited.

Apart from attending a school for the blind, there were teachers that specialised in helping people with a visual disability to learn reading and writing.

Strangers would ask about my blindness. Somedays I did not mind speaking about it, while others I did not feel like explaining to them.

The primary school I attended taught reading writing and social skills. Back then, people did not understand the capabilities in people who had blindness or visual disabilities. So the education received was way below that of mainstream peers. It was not until many years later that integration was discussed and obtained. If integration had been established at a much earlier age, it would have been somewhat easier in terms of education. But of course, there are complications to this scheme. Often the person with the visual disability was the only one in that mainstream school and teachers were not always available to give the support needed to help us integrate.

From an early age, I knew I wanted to live on my own. But with services increasing and support of good friends, independence was possible. It was important that an instructor be available to help learn about the area in which one lived and someone else to come if necessary to teach daily skills like cooking. In this day and age, there are support services to help with shopping and medical appointments.

Australia is still sadly antiquated when it comes to tertiary education. It was very difficult to obtain the necessary materials in the format requested. At TAFE, I found it was much easier in terms of getting support.

In the years when I was seeking employment, The Royal Blind Society were very active in helping people. This meant providing training and if modifications were needed to be made, the employment officer would speak to the employer of the company about what they could do to make life easier in the work place. When downsizing occurred, obtaining other employment was quite difficult. I sometimes felt ashamed that I would be accused of being lazy.

Thankfully my friends did not take pity on me nor try to speak down to me. With strangers, it was just a matter of explaining to them that pity is not needed in dealing with people of a visual disability or any other disability.

In terms of identity, it is important not to stress the disability too much, understanding is the key to that. For example, if possible, never address a person as that blind person or that other disability first. Meaning, I am a person with a disability but I am a human being first.

For the most part, I've not had too many problems with medical professionals. If genetics are discussed, I explain to these professionals that it is impossible to trace genetics because I don't have a biological family. Genetics do play an important role especially for those with a disability and rare diseases. That is an important discussion to have within the adoptive family.

Thankfully, there is technology available for genetic testing. That does not mean it is always accurate but at least there is the option, as it was not available in the early years.

Dealing with suicide was quite difficult to seek help for. For it was almost impossible to find anyone who could understand the pain nor that I am adopted as well. There was a time when there were thoughts of suicide but I did not act upon them but I did think of many ways to commit suicide without upsetting anyone. Fortunately I found a good doctor with whom I could discuss these feelings and how to deal with them.

Coping with life is an ongoing journey. Sorting out how to deal with that without demanding too much of my friends is the way I try to cope with life. Only when all avenues are run out do I ask for help.

If any prospective parent wishes to adopt a child with disability, it is very important to ask questions such as: why do you wish to adopt, what support will you give to that adoptee either to find their biological parents or to maintain connections with their culture and language in order to keep as much of their identity as possible. Be supportive to your adopted child while they are on the journey of discovery and help find any services that will help the adoptee, as well as yourself, to becoming more understanding. If the child has special needs, do as much research as possible so the adoptee can have ongoing lifelong support where necessary. Always have options.

When a prospective parent wishes to adopt, I suggest the counselling requires them to do research, provide the prospective parents as much material as possible. Help list the services that they can access - not just for the adoptee but as a whole family.

Seek therapy , discuss all options in getting help for the adoptee. Try to communicate clearly and if possible, have one on one therapy and/or group therapy. Talk about any ongoing issues and make the place safe for the adoptee to speak their truth.

Erin

Born in South Korea and adopted to the USA

I have Cerebral Palsy and use a specialised wheelchair with my head. I was sent to the USA before I turned 6 years old. I am one of seven children. Five of us are Korean adoptees. I was the last to be adopted into my family in 1991. I knew I had a disability but didn't fully understand what my disability entailed until I started going to Shriners Hospital for my care.

My disability was discussed in my adoptive family when I would require a different medication or equipment or when we would return from a doctor's appointment. But educationally, it was not discussed too often.

My parents would bring up my posture whenever it became problematic in the hopes to correct it, as well as for me to be aware of what my body was doing.

I'd say for the most part, my family members were supportive, since my youngest sibling also has Cerebral Palsy and a few of my other siblings have their own conditions to contend with.

My parents coped by befriending other adoptive parents who were in similar situations of raising disabled, adopted children. But I think it was difficult for my parents because this was new to them. Occasionally, they had friends take care of me so they could have respite. As for my siblings, I think they coped the best they could. With the amount of doctor appointments and physical therapy, I imagine it was difficult for some of my older siblings to have the attention and support they needed from my parents.

I prefer people to ask if they don't know what my condition is, instead of assuming.

I navigated school with school aides every year. They helped me with everything from bathroom transfers, to getting my homework out of my backpack, to taking notes for me.

Transitioning from a child under parental care to being a young adult and becoming / seeking independence was difficult at first. It felt like a rude awakening. I basically went from having all the help I needed to not having nearly enough.

Navigating further education was challenging at age 18 when I was going as a half time student. I no longer had someone who could help me all the time, so I had to rely on the kindness of my classmates and professors with simple tasks. Years later, after I moved to be with my husband, I attended college classes and it became easier to attend with my husband's help.

Currently, I don't have a paid job as my medical benefits would be jeopardised. However, many of the places I volunteered at were fairly accommodating. I think the biggest challenge for me was having people who could assist me with the bathroom.

I would say the feelings of shame stems from having spasms and people staring at me for something I can't control. I also felt shame asking for help because I know my disability can be seen as burdensome. It is difficult to be vulnerable and rely on others.

I've learned to accept myself as I am. People are going to stare regardless of what I do. There are a few methods to help me contain my spasms when I am excited or nervous, like taking some deep breaths and holding my arms together until I'm ready. I think the biggest help to overcoming my feelings of shame has been to accept and embrace my differences.

I have found that people will do one of two things: pity me or ignore my existence. I detest pity from strangers. They assume because of my disability I can't do anything and must have a horrible existence. I also despise people who ignore me and ask whoever is next to me about my condition or expect others to answer for me when I can speak for myself.

With regards to the intersection of adoption and disabilities in developing one's identity, for me, my identity of being an adoptee came from being disabled. They are two sides of the same coin. Had Korean society been kinder towards people with disabilities, I probably wouldn't be here.

With that said, most of the time my first identity by other people's standards would be my disability. My adoptee identity isn't brought up until I'm asked where I am from.

Navigating medical professionals and how they treat me has been challenging at times. Mostly because I have had so many doctors over the years and some of them don't

know much about my condition. As for how I'm treated, thankfully I've been treated well and listened to. But I feel that I have to be assertive just to show them I'm perfectly capable of speaking and understanding what they are saying.

It has been challenging to find the right medical treatments. I have to go through doctor's visits to get a referral to see a specialist for everything. And as great as my healthcare has been, insurance has been a barrier for some of the specialised care I need to maintain my health and keep my disability from deteriorating.

I think there are some challenges as a disabled person when it comes to intimacy and relationships in general. There is a desire to get close but there is also a high degree of vulnerability for the disabled person. I think in hindsight I have wondered if the individual was attracted to my looks or if they were under the impression it's easier to get with a physically disabled woman. Thankfully I don't have to worry about it anymore as I am with my husband. But there have been times people have asked him how we are intimate, to which the answer is, "It's none of your business".

I'm not worried about genetics and passing onto my next generation. Cerebral Palsy is not a hereditary condition. My husband and I have discussed the different scenarios but it's highly unlikely the condition will pass to our children.

As for thoughts about my biological family, I think they tried to take care of me but they weren't able to continue my care. But part of me wishes they tried harder.

I acted on suicidal thoughts when I was 16 years old. And truthfully, those thoughts never truly go away. I think the best way to combat the thoughts is to have a good support system. Go to a counsellor or therapist, talk to people you trust about what's going on, take a moment to see objectively what's causing you to feel the pain and let yourself feel but withhold acting rashly. Have something or someone to ground you to reality. It can be a pet, your friend, family member or partner.

I have found radical acceptance helps me to cope with life. Instead of thinking solely about the problem, thinking of solutions in order to move forward. I've also learned it's okay to feel depressed but not to stay depressed. I find listening to music, drawing or going out are good ways to cope and flourish. Even having a relaxing moment to drink coffee and read something I enjoy helps me to cope with whatever I'm going through.

Being able to have multiple outlets through hobbies and relationships have helped me navigate this life.

As for suggestions for adoptive / prospective parents, I would say learn the culture and traditions of your child's homeland. Let them decide how involved they want to be in learning about their heritage. Listen to them when they are struggling with their identity and be there for them if they decide to find their biological families.

For adoption professionals who assess prospective parents, my suggestion is make sure they are mentally and emotionally capable of loving a child that isn't biologically theirs. Follow up with the families after the adoption. Reassess every year if necessary.

Lastly, my suggestion for medical professionals supporting adoptees and adoptive families is give disabled people an easier way to receive specialised help without jumping through so many hoops.

Linzi

Born in Sri Lanka and adopted to Australia

I was adopted as a 6 month old baby to Australia in 1986. I was very, very sick and had bronchiolitis and struggled with breathing. After my adoptive parents met me, they had trouble finding a doctor to sign off on my medical paperwork because I was so sick — to the point it was assumed it would be unsafe for me to travel to Australia. My parents ended up finding a doctor to sign off my paperwork but only after my mum said she was an asthmatic and that her brother is a doctor in Australia and she guarantees I will get the best treatment.

Asthma was always openly discussed within my family. I'm not sure when they discussed it but I always remember it being an open topic. I was on a preventative and a reliever from a very young age because my asthma would get very bad when I had a cold, flu or some type of virus. Those sicknesses would usually go straight to my chest and I'd end up in hospital. It was interesting though that I never wheezed much, so my mum had to be very firm with the doctors and nurses so they'd understand how bad my asthma was. I'd be admitted and end up in hospital for 3 days to a week, quite regularly.

My mum always made sure to stay on top of my asthma needs. She got me in to see a wonderful asthma specialist in the city. She made sure all my teachers and everyone around knew about my asthma. Asthma for me was also induced by exercise and mum made sure my teachers were aware too.

For some reason asthma is a condition that a lot of people prefer to hide. I was one of those. I never wanted to use my reliever in public especially during the pandemic because people would look at me strange. Having asthma during the pandemic was not fun because every time I saw a doctor, I'd need a covid test done.

My schooling life was affected by asthma. I always had to have a reliever with me and I have a memory problem so I'd need my friends to remind me as to where my reliever was or to use it. My mum made sure I was always playing a sport to help my lungs and my breathing so I did swimming, water polo, netball, etc.

As an adult I'm quite good at managing my asthma. I can usually manage with steroids or a nebuliser at home rather than going to hospital. I've also become an Asthma

Champion for Asthma Australia - helping them in speaking up about my experiences to help other sufferers. Being part of that community has helped to remove the stigma from asthma, by sharing my story.

I found employment difficult with asthma. People would assume I'm faking being unwell when I was struggling to breath. It was really stressful because not many understand how dangerous asthma is. We should all be able to breath properly and understand how bad and how quickly, asthma can get.

I would say to people who have asthma, don't be ashamed it's a common thing. It's often a part of who you are for life and learning to accept and not be embarrassed will help you take back control of asthma and your life.

Regarding people's expectations, I found the common issue was people don't take asthmatics very serious unless we end up in hospital. For fellow sufferers, know how serious it is, know what you have to do and ignore what other people think. Your health is the most important!

Being adopted and having asthma was interesting because the second I say I am adopted, people say, "Well you're so lucky, lucky to get the treatment you need, you might not have been alive if you'd stayed in Sri Lanka". They'd say this even though there are heaps of asthmatics in Sri Lanka still living. I started to feel pity towards myself after a while because of that narrative, thinking, "Oh poor me, the fragile child who needed to be adopted to survive". I know now that's not the case.

As a young adult during my reunion with my Sri Lankan mother, I found out she was also an asthmatic and she was surviving quite well in Sri Lanka. The interesting thing for me is when I went to live in Sri Lanka, my asthma improved drastically. Asthma is actually linked to stress. I think being adopted put my body through stress and I held it within me. Once I got back over there and lived there, that stress was gone and I could breath pretty much perfectly. I don't remember using my reliever at all during the 6 months that I lived there.

Navigating medical professionals has been tricky because going to hospitals I'd often have the professional look at me saying, "But the colour of your skin is fine". When I was younger, I'd have my mum with me and she'd validate and emphasise the impact asthma was having on me by saying, "No, this is not her normal skin colour, it's grey

compared to her usual colour". But the medical professionals couldn't see that without a white adoptive parent validating me. Even now when I go to the doctor, they dismiss my asthma because I'm not wheezing as they expect. So the doctors end up putting me on a machine that measures my lung capacity and only then do they realise how impacted my breathing is.

One of the struggles I had of living with severe asthma and being in a relationship was that my husband didn't understand the daily impacts. For example, when he lived with house mates and I'd put on my nebuliser machine, he'd question did I have to do that now because it's really noisy. I felt it was really rude and dismissive but now he understands.

As an adoptee, knowing about one's genetic history is really important, especially to know what we pass to our children. My son has had breathing problems. He's not diagnosed with asthma and is quite little, but there is a high chance he might develop asthma. I also recently found out from family in Sri Lanka that the sugar sickness (diabetes) is also genetically in my family so I have a high chance of ending up with that as well.

I have been suicidal and attempted a few times. One time I actually overdosed on antidepressants. I remember ending up in hospital and I was lying there, they'd pumped me full of medication, then the monitor went off and I was having an asthma attack. The doctor came over and abruptly asked, "What's wrong?" I said I couldn't breathe. He didn't fully believe me and treated me pretty poorly for someone who had just tried to take their life. I was also told on a separate occasion by a doctor that I should be grateful for all my parents do for me because I had sensory issues and was chewing through my clothes. He regarded me as being a bit of a spoilt brat and didn't understand that this was a way for me to cope with stress and anxiety. I didn't have any good experiences with being in hospital and being suicidal.

Over the years I have seen medical professionals, mental health professionals and I have learnt that I am my best support. No-one understood how my adoption affected my mental health nor my asthma. So I've had to learn all of that for myself. I think growing up my adoptive mum was on top of everything to the point where I didn't need to think for myself. I know she did it out of a good desire to help and support me, but I wished she'd given me the space at an old enough age to learn from myself. Or she could have

explained how it all worked with seeing doctors and staying on top of my action plans for asthma and other health issues.

The home I grew up in with my adoptive parents was very old and had a lot of mould in it which would have contributed to my asthma. Adoption professionals need to thoroughly check the adoptive home to ensure it is safe for the child and their medical conditions.

I think mental health professionals need to understand a lot more about adoption and adoption trauma and how it affects our physical and mental health. When I was seeing a psychologist in high school I was diagnosed with severe depression. I couldn't explain then how I felt but it was only after meeting my Sri Lankan mother that I realised I was never depressed. I was grieving my mother for my whole life and didn't know why. I know now that this stress affected my asthma along with other things.

Marie-Stephanie

Born in Madagascar adopted to Belgium

My name is Marie-Stephanie, I'm 24 years old and from Madagascar. I was adopted by a family in Belgium when I was 1 year old. I've been living my whole life in Belgium.

I've been officially diagnosed with dyslexia and ADHD at the age of 22. I received this diagnosis after I decided myself I needed to get a diagnosis so accommodations could be provided for in my academic studies. At the same time, I was also diagnosed with multiple allergies and polycystic ovarian syndrome (PCOS) that wasn't treated before even though I showed multiple signs of these medical conditions. PCOS is considered like being intersex for some people because most health professionals don't know how to treat it. The professionals are more focused on people not having a period regularly and gaining weight rather than the actual wellbeing and needs of the patient. And it also intertwined with emotional sensitivity and my general fatigue caused by untreated ADHD and dyslexia.

As a child, my medical condition didn't have proper care most of the time. I had to start doing it myself as I became an adult. For me, it felt violent because I realise I had to take care of myself and learn all these new health conditions. My situation is particular because my adoption was also an experience of neglect.

Concerning my ADHD and dyslexia

My mother was a teacher and knew what dyslexia is and what it implies as a student at school. My parents acted like being dyslexic did really have an impact on my daily life. I have no actual support regarding my dyslexia, no test was actually done to diagnose me in my childhood and the teachers were not informed of it during my schooling. School was and is difficult and frustrating. I never had a proper diagnosis for my dyslexia nor proper help. In my adoptive family we didn't talk a lot about me being adopted and dyslexia wasn't talked about at all. They even pretended it didn't exist in some cases when I struggled at school or with my homework.

School was not an especially good experience for me. I just endure it because I didn't have any other choice other than to go to school until 18 years old, as is mandatory in Belgium. I used to struggle a lot with writing and teachers gave me a lot of negative comments about it. School was a lot of pressure and lowered my self-esteem. Having

ADHD and dyslexia meant I get easily tired because every load of work seems bigger for me.

Now that I'm older, I am aware I might have had depression during my teenage years, linked to being dyslexic and ADHD and feeling different and late in development compared to a neurotypical student. While undertaking academic studies, I developed anxiety problems. Having depression and anxiety is common for people with ADHD and dyslexia means I tire more easily. It's always been difficult to explain my conditions to people because in my case, they don't understand why I can't read or write as fast as most neurotypical people or be as efficient as them.

As a black, neurodivergent woman, it's difficult to go on job interviews because I have to face the bias as a black woman and socialise as a neurodivergent person. It is difficult and an especially stressful situation. I keep feeling stressed even though I know I can manage it because ADHD is not recognised as an official disability in Belgium.

I don't know yet if I want children but I have some doubt about it sometimes because having my genes won't be a gift for anyone. Especially knowing how ableist society is.

My recommendations for adoptive parents and adoption services

- Be prepared to do medical exams all the way through the childhood and teenager years of your child. Be prepared also to face the racism in the medical field.
- Stop saying to adoptive parents that we are fully healthy and non-disabled. You can't prove it if you don't know our complete medical history of our birth family.
- Be aware we might have genetically inherited disease even though we have no proof of it.

Michelle

Born in South Korea and adopted to the USA

I am the only child adopted in my family. I am the oldest of 3, so my brother and sister are my parents' biological children. I was 6 months old when my parents received me. I was very ill. I was born with congenital syphilis. At 6 months old, I weighed 11 pounds.

My condition was not discussed in my adoptive family, nor did they seek out any resources or support as adoptive parents.

As I am not officially diagnosed with a chronic illness, I just like to be recognised as a person with undiagnosed chronic illness.

I was sick so many times during my schooling life. In middle school I suffered from emotional and psychological problems. I was suicidal and hospitalised. In high school, I still suffered with that, but also had physical illness and although I went to see many doctors, a diagnosis was never reached. I lost a lot of weight. I missed a lot of school. I went to college but because of mental and physical illness, I dropped out. I returned later in life, a decade later but due to family life circumstances and another bout of mental illness, I dropped out again.

I became pregnant with my first child at 19 years old. I was 20 when she was born. Her biological father was not involved. I did end up getting married at 21. I thought I was doing everything I was supposed to be doing as a responsible, healthy adult with 3 young children but as I have learned, unresolved traumas kept coming back with mental and physical illness. It has taken me MANY years to get to a healthy spot in my life where I am staying stable.

With being 47 years old this November, I have decided that a college education is something I no longer desire or need. The nonprofit work and networking I have done has gotten me where I can navigate spaces without a degree.

I have not worked “outside” of the home for over 11 years. I have lived a very privileged life but not because I didn’t want to work. I think at some point, my adoptive parents realised that I struggled with balancing many things. After I kicked out my ex-husband with substance use disorder, I had 3 teenagers and 2 small babies. There was no way I could “work”. I also get sick a lot. Keeping a full-time job was sometimes impossible, especially when all of my ailments could not be diagnosed.

Once when the big kids were at school and the boys were just toddlers, I legitimately had the flu. I called and asked my adoptive mom for help for a couple of hours. She told me, “I would but honestly, I just never know when you are actually sick”. She did not come to help. I was very hurt and angry. My adoptive dad came the next day and offered to give me more money (stipend) per week. I did not speak to her for a year.

I am smart and attractive. I do so much community and political work. I am in a much better place about all of this now but throughout my life, being sick and with no explanation, insinuations that I was making it up, lying, lazy, manipulative, or wanting people to feel sorry for me - it takes a toll on how I view and feel about myself.

Fortunately, my beliefs align with an anti-capitalist belief system, so I know that my worth is not dependent upon how much money I make or how “productive” others see me.

People have high expectations of me because I am a doer, a go-getter, I believe in fighting for equity and access for all people. Again, as I’ve gotten older, a lot of those false narratives that we are socially conditioned to believe, have been shed and living fully as myself is much easier.

It has been in the intersections of adoption and disability that there has been much loss, confusion, anger, frustration, misunderstanding, self loathing, self harm and trauma. For me, there is a whole segment of who I am, how I entered into this world, into this 93% white town I still live in, that is just UNKNOWN.

While navigating the medical professionals, I am very articulate. Many assume that I am a doctor or at least in a medical profession. They believe I understand more sometimes than I actually do. But then, I’ve been treated like a hypochondriac because I am “always” sick, for apparently no reason.

Trying to find the right medical treatments, the barriers I have you faced remain being undiagnosed. That is the theme of my life. Often I hear, “All of your lab results are normal” when I KNOW I am not feeling well.

I have finally gotten into the healthiest version of myself emotionally and psychologically. I therefore have a really supportive and good partner who loves me and my illnesses. I think in the past, being sick and seriously tired all of the time (I am still tired too often I think) really takes a toll on a relationship. I was always hypersexual, so like with many relationships where the sex is “good”, the rest of the relationship may not be so healthy.

I have 3 adult children and two little boys aged 10 and 11 years old. I know that my 24 year old daughter and I share many genetic similarities as far as medications that are most likely to help us with our mental health. I am diagnosed with depression and anxiety. However around 24 years old, I was diagnosed (incorrectly, but at the time may have saved my life) with Bipolar Disorder. This same daughter has been diagnosed with Bipolar Disorder and although we do not know “why” she has this diagnosis, it carries a certain weight for me as her mother that I need to help her.

For my 24 year old daughter and much like with me and my differing ailments, my partner knows, we discuss and he understands that we will always have to take care of my daughter in some way shape or fashion, for the rest of her life.

I have been suicidal a couple of times in my life. I think suicide for adoptees with disability is very prevalent. I think it is trauma based, maybe not always circumstances or just “regular” depression.

With regards to strategies for how I’ve coped and learnt to flourish in life, I had monetary support from my adoptive parents. They did not spend much time with me but supported me with money (housing, vehicle, etc.). I know it was because of this monetary support that I was not only able to survive, but thrive. This is not normal circumstances and clearly I could not consciously say this is a healthy solution but it did end up working out well for me.

My top suggestions for adoptive / prospective parents is TRAUMA EDUCATION AND THERAPY for themselves and for the adoptee. My best suggestions for adoption

professionals who assess prospective parents is to make sure they do not expect the adopted child to be anymore grateful than a child that came from their body. For mental health professionals, I highly recommend EMDR therapy and adoptee centred counselling. Trauma causes so many things — we cannot assume there is just something characteristically wrong with us. My suggestions for medical professionals is to understand that trauma based therapy is necessary.

Reijha

Born in Bangladesh and adopted to the Netherlands

My official date of birth in my Netherlands passport is different to my true date of birth. My adoptive family already adopted one girl from Bangladesh. I was supposed to be at least 9 months old upon arrival. Medically, I was healthy. Upon arrival at the airport I was transported to hospital to die. I was in the hospital for long time to "recover" from starvation. Until I was 30 years old, I was told my skeleton problems were from malnutrition. When I was 30 years old, I was diagnosed with a genetic disorder called Thalassemia or Cooley anemia. At 9 years old I complained again about my pain in my hip joints. At that time they had no clue and diagnosed me with Perthes' disease. My adoptive parents didn't want a disabled child, so I was forced to act as if I was "normal", even though I already faced several small and huge surgeries.

Within my adoptive family, my condition was not discussed at all. My adoptive brother from India was diagnosed at age 6 with a similar disorder and he wasn't able to walk or ride a bike. He was already costing too much of my adoptive mom's time. Our adoptive family did not respond well to our additional requirements for support. I was bullied and forced to act as if I was cured. My crutches were taken away and I was forced to walk long distances as proof I was healthy. My adoptive family did not find supports for me in childhood, they just expected me and all of us to keep silent. The weird thing is that my teachers, neighbours and others in my life were very sweet.

Navigating school, I managed well. In Middle school, my teachers were also very nice and allowed me without question to help with many, many adjustments even if I didn't ask for it. Even our class schedule was adapted for me and my low energy problems, that occurred severely in teenage years. Every kind of education and studies I did in my life, was adjusted without effort.

Transitioning from being a child under parental care to being a young adult and becoming / seeking independence meant I was in heaven. I had an awesome connection to all of my medical doctors. I got a wheelchair since I was 19 years old.

As I got older, I got a disability income, which was enough. Even if I was dismissed from work, I always worked a minimum of 10 hours volunteering. I am a city guide on a tour boat for the last 10 years. The only barrier is the reaction of our tourists by saying, "You speak very good Dutch". The captain is more surprised about the reactions of my origins than my wheelchair or scoot-mobile. I am blessed by all who have supported me at whatever volunteering job I do.

After I turned 18 years old, I started to trying to no longer hide my disabilities but I wasn't very successful. I am thankful others are mindful of my disabilities but I always feel like I should hide them. That part is difficult to reprogram. However, my assertiveness helps me to ask for whatever I need. I am homeless and I live in a shelter and the people are amazing. I get the biggest room for my wheelchair but I still feel I'm not worth it, but I accept it. I feel awful though for others living here even though they reassure me that I "deserve" it. While child protecting services find disabilities a huge problem for being a mother (I have not seen my daughters more than twice a year) this organisation is helping me to see my daughters on a regular basis. So yes, I feel embarrassed for not being there for my daughters because of my background. Being single, disabled and adopted is apparently a big red flag for becoming psychotic and other stupid assumptions. This "home" is reinforcing my power and supporting me with so much than just practical stuff.

When dealing with people's reactions eg pity or expectations - it is just harsh. At the end of the day I do mind all their opinions and need reassurance that it wasn't caused by me. Even if I reacted perfectly on whatever remark they made, it still hurts so much. I am also very tiny at 1.40m. According to Belgium doctors it is trauma related because of separation. Everything is just stacked up against me. I stopped blaming myself. However, I wish I didn't have so many features to be judged on. I keep telling myself their judgements are on their heads and not mine. I don't get angry. I will always be friendly but explaining myself to everyone all the time, is not fun. Dealing with pity is even worse because in this pity, people have the best intentions and it took away my children. It is bizarre I have to prove I am severely disabled.

My thoughts about the intersections of adoption, disabilities and developing one's identity is very difficult because I had to hide it for a long, long time. I know unfortunately from a fellow adoptee friend who had a big cyst on his forehead, his adoptive parents used it for pity and to show others what amazing well doers they are,

while he was dressed in suits and yet they refused to remove his cyst. He was also bullied in his home for his cyst and his skin colour.

I think both adoption AND disability are a huge impact in forming our identity. Many children with disabilities have trouble feeling excluded and like they are a handicap. At the rehabilitation centre I had difficult conversations among many of my peers. They didn't feel good enough of deserving a healthy or pretty/handsome partner, willing to share their companionship and character. They didn't dare to flirt with 'healthy' people. My heart broke when a pretty awesome girl in a wheelchair said she would never find a man. So it enhances the feelings of insecurity and self worth.

Being our fan and most amazing supporter would be better. We are not our circumstances. We are personalities with virtues. Those virtues should be more valued and recognised. Yes, we are doubly different, however, it makes us doubly aware of the intentions of those who are using our 'specialness' for their own honour. We should not feel thankful for all the medical help for our disabilities. It is a difficult discussion and even more difficult to say something about developing our identity.

In terms of navigating medical professionals and how I am treated, my paediatrician always looked for malnutrition. I had severe cysts in my shoulder joints and they failed me when I was about 27 years old. It was not just a neck hernia. X-rays showed heavy damage and Dutch doctors refused to pay any attention to it. I had to go to Belgium for a second opinion. There they diagnosed me as a Thalassemia Beta Carrier. Belgium had a Congolese community with the same cysts. In Belgium, it was acknowledged I had Thalassemia PLUS being separated from my country and family as trauma related and therefore also detachment disorder from home and family.

Trying to find the right medical treatments I needed and the barriers I've faced have been many. I am still fighting for a little recognition about both. I have to show my x-rays as proof that I am physically disabled and not just mentally because I speak such good Dutch. I would like to see it acknowledged that separation of family and roots worsens our disabilities. It feels like Ronald McDonald missed out on this one. Being in the hospital for longer than 2 weeks without emotional support from the biological parents WILL be damaging for anyone. So these insecurities will raise our cortisol levels and survival mode even more. These extras should be kept in mind when a child is handicapped AND adopted. I am also advocating for more Thalassemia tests among adoptees. I was told we were sent off, knowing we had this anemia at birth, hoping for a

medical treatment for the anemia and bringing knowledge with us back to our country of origin. I was told I was sent off on purpose but I think it is underestimated and the damage later can be severe.

The complexities as an adoptee with disability in intimate relationships and sex are also difficult to navigate. Stupid remarks like, “What is so special about you that your partner stays with you without having sex”. Or stupid remarks like, “You must give amazing blowjobs for not being able to have sex”. Well... just stupid remarks. I think that people with disabilities have a better sex life than healthy people. Simply because it has to be discussed openly between partners. I even helped many find solutions with their disabilities to enjoy intimacy and understanding how to please the partner or what to say to allow the partner to please them. This kind of discussion has a big taboo on it however, I also received amazing tips at a Kama Sutra exhibition for even more fun in the bedroom. Tools and toys in this circuit are more available than many could ever think of, so no, there are no complexities in my life about having an intimate and healthy sex life.

I did pass my Thalassaemia to both my daughters. Their caretakers are refusing to acknowledge they have mild anemia and need Vitamin D, folic acid and follow up by a paediatrician. It breaks my heart. The fathers of my daughters are the ones to blame me and feel that they themselves are better parents because they have no disability. Blaming me for not taking proper care for them, while they refuse to acknowledge their anemia, but they complain my daughters are lazy, while they suffer low haemoglobin.

At 17 years old, I had my suicide attempt. At 20 years old, I was in a rehabilitation centre with a wheelchair. In talking to others at the rehabilitation centre I realised I was just an excuse for society around me to be assholes. Those of us who struggle are the cornerstones of society and it is their darkness to attack us because they feel uncomfortable. Those of us in rehabilitation reflect everything about them. It was never about us and people should say sorry. Often our being in rehabilitation is not our fault to begin with.

Strategies I've developed to cope / flourish in life has been having an amazing lawyer. Letting her do my requests which frees my energy to socialise and be the amazing me. I also love my crying time as well, allowing myself a maximum of 15 minutes a day to feel sorry for myself. My 15 minutes of self pity works like a charm, so no energy can leak away because it will be addressed when I close my eyes. I also have an amazing network of many who help me regularly or just when I need. I have chosen not to have any further

contact with my adoptive family. If I want to be humiliated, standing along the road at football games will do the same. Of course football supporters have no right to do so, however it is the best place to go to get insulted.

My suggestions for adoptive / prospective parents is to involve whatever biological family member you can and make sure all are supporting the adoptee. Never ever dare to say you have 'saved' a life. We are just amazing!

My best suggestions for adoption professionals who assess prospective parents is do not adopt. Unless you lived with the child for at least 6 weeks and accept the biological parents as your own brother and sister, make sure these parents can keep in contact with their child. Or provide annual visits for parents or the child allowing cuddle time once a year in their country of origin.

My suggestions for mental health professionals supporting adoptees or adoptive families is refer them to mediation, mediators and psychics. Find a good network. Don't allow yourself to get isolated. The next meeting will be in the next life. My adoptive mother has her karma pretty well. Now she is more disabled than I ever was and she is not my problem in this life anymore. Although I will suffer guilt when she dies, I can manage that.

My best suggestions for medical professionals is we need more awareness by paediatricians. Some home help would be ideal so adoptive families can be more available instead of being busy with household chores. In former Catholic churches we had godfather and godmother for extra support in case you dare not ask your parents.

My height is a clear sign of being adopted and traumatised, my growth was literally blocked. My little daughter also stopped growing for 9 months when I was stuck in Bangladesh. At 4 years old she was only size 86! One year later she wore the same size clothes. Lacking growth and height is a serious and visible sign of damage from being separated from our mother, deported, or abducted. Having a disability as a child is also very difficult to cope with. Being adopted makes it even more complex. Being in the hospital makes it even more difficult. So I think we should be aware of damaging a child. Not being able to pay for disability surgeries for your child in poor countries is already horrible. All of the pros and cons is just one of the ethical dilemmas of life — what should be better and what is not. In every pity case of adoption, I will reply with, "Why didn't you just go there and help the parents remain together with their child?"

Wes

Born in China and adopted to the USA

I'm Wes and I'm adopted to the USA at the age of 7. I have Imperforate Anus (IA) which is a rare birth defect in which malformation of anal and rectal areas of the foetus are formed. IA is known to be caused by genetic and other random mutations. My adoptive parents were aware of my condition during the process of adopting me.

My adoptive parents know of my condition but I never felt comfortable or aware of how my disability/condition affected my childhood, and how it still affects me. My extended adoptive family don't know the specifics of what I have and I'm more than glad to keep it that way. My adoptive mother sought out resources (facebook groups, a specialist for what I have, events, etc) but I wish she had pushed more to find other people with what I have, as it would've been less isolating for me.

I never mention I have disability/condition as it is invisible and I'm more comfortable keeping it that way. I never told anyone I had a disability and with that, when it would interfere with my life, I would just suffer in silence. In high school however, the nurse saw I had a condition in my records and I had the ability to access the nursing assistance whenever I needed, but I rarely ever felt comfortable using it (only when I wanted to get out of class because it was boring lol).

The transition is still happening with me but I'm confident in myself in being able to advocate for my medical needs in the healthcare system (this comes with being privileged as well).

Fortunately employment hasn't been an issue with my disability. I didn't realise I held a huge sense of shame with me or how that coincides with my sense of worthlessness being an adoptee. I've come to begin the process of acceptance for what my body can and can't do, while also validating my own experience and how there is loss connected with my disability.

Given that I've been very low key with my disability, I've avoided the pity from people. But at times when those words come out of people's mouth, it annoys me and I tend to avoid it. That's why I continue to be discreet to whom I share about my disability

with. I don't ever need or want pity from anyone about anything. My disabilities, along with other things I live with, are things that I, nor anyone else can control.

Worthlessness is a word I connect to. For me, I notice that I have had two "coming out of the fog" phases. One where I truly realise how impactful my disability and adoption has been on my life and secondly, how those can intersect and affect each other. Fortunately I've been privileged enough to see a specialist who's been professional at answering my questions about my disability with the little medical history I have. But outside of the specialist, I don't mention my disability as it rarely has anything to do with their area of expertise.

Growing up, I struggled to manage my condition (part of that I think was because I was still growing). But given that I've grown older and am physically maturing more, it's been easier to find a medical routine that works for me. I still have moments where my disability and its effects fluctuate, but given that I have no control over it, I just have to accept it for what it is and go with the flow.

I find myself seeking sex as a means to be more intimate with another person. However, given that I can't physically provide that sexual need to a partner, it is another loss. I feel like if I'm able to give a person sex, they'll want me and will stay, instead of leaving (haha adoptee abandonment trauma). I've missed out on certain relationships because I am not capable of sexual activities that most people participate in — and my sexual needs are rarely met as well. It's a double edged sword, but maybe I hope someday to meet a person who meets my needs and I meet theirs, both in intimate and sexual ways. It still sucks cause sometimes I'm just severely horny and want to experiment with certain sexual activities but I just can't.

I refuse to ever contribute to having a biological child. I don't know my medical history and I'm risking passing on what I have. I've never had conversations about such topics as these with a partner before, as I've never gotten to that point.

My adoptive parents divorce happened at a time where I was quite aware how the divorce needed to happen. My relationship with my adoptive father was shit at the time, but the divorce between my two adoptive parents has somehow improved my relationship with my adoptive father. I learned to be more empathetic to both sides.

I have attempted suicide, multiple times for multiple reasons. One thing I would share is that my disability simply added to the heavy and raw emotions I was feeling that led me to attempt, not to slay.

I've learned to navigate my condition on my own and I'll keep doing that. But being able to find other people who struggle in the same way would be monumental! Finding my people has been life changing — words can't describe how grateful I am for them.

My suggestions for adoptive families are to find supports and seek other people and adopted children who have similar struggles. They might not realise it while they're young, but when they are older they'll look back and think how helpful and impactful it was to just be able to relate to someone else in regards to disability.

Adoption professionals should always assess the racial, social and overall mental health competence of the adoptive parents, as well as their financial ability to provide for the adopted child. It needs to be rigorous. Too many adoptees are thrown into families filled with bigoted people.

Medical professionals should be more competent in understanding that a lot of adoptees just don't have medical history whatsoever, so stop asking for it.