# Facing disability: For the first time I have been given the tools to survive

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| **Author** | Jessica Birch |
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*In support of International FASD month, throughout September Drink Tank is sharing the stories of individuals and families living with*[*Fetal Alcohol Spectrum Disorder (FASD)*](https://www.nofasd.org.au/alcohol-and-pregnancy/what-is-fasd/)*.*

*Jessica shares her lived experience of FASD in an effort to arm individuals, families, carers and health professionals with information to create successful interventions and support. She feels awareness and action are key to not only slow the rate of children being born affected by prenatal alcohol, but also to be able to accurately assess and diagnose those children, so they have the best chance for happiness and success.*

*To find out more about FASD visit the*[*NOFASD website*](https://www.nofasd.org.au/)*. To find out more about referral, diagnosis or supports, call the NOFASD Helpline on 1800 860 613.*

Last year, at the age of 33, I was diagnosed with FASD – irreversible brain damage caused by exposure to alcohol while I developed in the womb, the consequences of which I have carried my whole life.

Living with FASD is a diagnosis of disability, of being ‘disabled’, and the narrative that follows this label has been usurped, arguably by people who don’t possess the title.

So, in roughly 900 words, I am going to take it back.

When I was a kid I had some quirks, some more concerning than others, but looking back I didn’t quite seem to fit into the world around me. As I grew, so did the alienation I felt, and with it a deep-rooted belief that I was not as good, smart, likeable or as capable as everyone else.

Despite these feelings, I believed in the notion that hard work paid off, that you’re only as good as the effort you put in – that big effort equals good outcomes. This message was reinforced throughout my life with the encouragement that I was wholly capable and could achieve anything I set my mind to. Expectations were set, and I would strive to meet them.

By the time I was a fully-fledged adult (the quirks came with me), all that effort had inexplicably not borne the fruits of its labour. I was exhausted, profoundly confused and deeply unhappy.

My physical health started to deteriorate and I became entrenched in the public healthcare system. I was diagnosed with clinical depression and anxiety. My physical symptoms (too numerous to list) – often leaving me isolated and bed-ridden – were dismissed as medically insignificant. Despair and hopelessness set in and for many years I was trapped in this state.

When Susan Robinson speaks publicly about losing her sight she says she hates using the word ‘disabled’ to describe people, noting:

*“It detonates a mindset of less than, that utterly disregards capacity, ability, potential, instead prioritizing brokenness and lack”.*

Some people reading these words will understand the differences between the medical and social models of disability, but for those who don’t I will briefly summarise.

The social model of disability encourages people to see individuals not as ‘dis’-abled but as having a disability; it encourages acceptance of disability not as a deficit or problem needing remedy, but an intrinsic part of who you are. It demonstrates the ongoing issues faced by people with disability trying to function in an inaccessible society, suggesting that the ‘remedy’ is a change in the interaction between the individual and society.

Conversely, the medical model encourages the view that disability is negative and a problem that needs to be fixed or ‘normalised’, that the issue lies with the individual and it is up to them to integrate themselves into society as best they can.

I know well what it is like to feel broken and less than, I know what it’s like to feel one is lacking. But it wasn’t because I was labelled ‘disabled’. It’s because I wasn’t.

For most, our view of disability (conscious or not) follows the narrative of a medical model –  stigmatising our most vulnerable members of society by perpetuating the idea that acknowledging an individual’s disability is acknowledging their shortcomings, their deficits as a ‘functional member of society’ –  in effect stunting the individual’s desire to seek out the accommodations needed to be part of their community because of the shame it creates.

I lived nearly thirty years before intervention, trying to be ‘functional’ without the knowledge that I was born fundamentally ill-equipped to meet the challenges and responsibilities that society expected of me. Decades spent internalising what I ‘should’ be able to do and couldn’t as my own lack of fortitude and drive – an innate ineptitude that no amount of effort was able to release me from.

I had a mindset of ‘less than’, because the framework that I was using to regard my individual capacity, ability and potential was not in alignment with my unique functioning. The result was the loss of self, trapped under the weight of self-loathing and disappointed hopes. All I could see was my brokenness and lack.

The diagnosis of FASD is that of a brain-based disability that uniquely impacts my cognitive and physical development; it is a rough road to travel and the prognosis is often grim, but I am the happiest and most hopeful today than I have ever been, and this is why: My disability, now clearly defined in me as a unique set of strengths and weaknesses, has lifted the burden of life’s challenges off my very tired shoulders and placed it fairly back on the shoulders of FASD.

It has allowed me to shift the shame and sadness of my perceived shortcomings (which had been so instrumental in damaging my fragile sense of self), and redefined them with a new appreciation of what I have overcome, and what I have managed to achieve despite them.

For the first time in my life I have been given the tools to survive in a world that wasn’t designed for my survival, and that has empowered me**.** I have escaped my darkness to see a brighter future because I know all the parts of myself.

People often say that your disability shouldn’t define you, but it does define me; the alcohol that coursed through my developing body has determined my essential makeup and has coloured all my life experience. I cannot be extricated from it, or it from me. It is a fundamental part of how I see and interact with the world.

Being disabled freed me from the chains of my narrative; I am no longer lost in the quagmire of brokenness and lack in which I saw no way out. The narrative has been re-written, because I know I’m disabled, and knowledge is power.

### Metadata