

for ON-OFF GRID,
A Thought Leadership Series
a reflective dialogue
#2 FRIENDSHIP IN A STORM

Simplicity is beautiful
& profound.



2020: A V-REBOUND REALITY FOR ALL

A PARENT'S HONEST REFLECTION REGARDING TRISOMY 21:

Why do I not use the term 'special needs' anymore?

I don't know how to explain it but somewhere in the evolution of my journey as a mom of a child bestowed with trisomy 21, I came to understand that there is no out of the box of feeling like a victim, feeling like being in a struggle, feeling the weight of the burden and the guilt of having to do something more, and that anything that I do or don't do is ever going to be considered good enough, or enough, ever. And that means I would have been defeated from the gate go, and there is never ever going to be an out, if I remain framed in a legacy narrative. (*Until -*)

There is this constant framing of judgment. (*Until -*)

That somehow becomes so heavy, that you can't even begin to do the basic – which is to simply embrace your child, and enjoy each other. Every moment of it, and life isn't really ups and downs, but an adventure. Just like sometimes it rains and sometimes the sun shines, and sometimes you get things coming your way, and sometimes you just simply don't. And sometimes things are harder than you think and sometimes things are just flowing on no account of your doing, yet you get to be the recipient of that flow of goodness.

I am not against the science, medicine, developmental intervention, education, inclusion efforts – by no means am I not valuing, treasuring and honouring this incredibly brave and worthy work, but I am saying over and over again – we can't begin here.



We can't begin in advocacy either – disability, inequality, inclusion, enable. They don't mean anything to a parent already under water. Not from anything, but just from the sheer weight of cultural legacies regarding trisomy 21. Because culture frames and entraps when it tells you that you are strangely entitled, or not, to something – impaired, not good enough, disadvantaged, challenged, disabled, different. A very strange learnt helplessness creeps in, or some kind of differential definition that suddenly identifies you, and that you think there is something more or less that should be done about that. When really, the conversation isn't about that.

The conversation is simply – do you even know who I am? Do you even know who is your friend? The very child, parent, professional, person in front of you, who has suddenly become a part of your life: isn't it simply splendid, that we have encountered one another in our lives?

And maybe, we should just find delight and enjoyment in each other's company, instead of constantly trying to fix each other, or things. All the time.

Maybe we made things broken, by defining it as such, instead of accepting that – life is simply so. Sometimes it is really a bit wonky and rocky, and we feel a bit overwhelmed, and especially, during these times, we simply need someone to hold our hand, as we figure through it all. And then, we can and must go about life again. And well, at that too.



One of the things that I did for myself to keep afloat, was to keep making floaties for myself. It got so many that now I have a sea of floaties.

If someone were to ask me, so how do I do it – live like me? Meaning that I no longer have any more weight and pain regarding this matter. How did I free myself?

You have to transcend the narratives. Just float upwards and get that breath of fresh air. Swim to the top of the water.

Swim as if your life matters and is significant. Because no one will be able to define it for you if you stay under water, and be awashed by everything that was already pre-defined and pre-determined for you.

I don't think all those politicised terms are helpful. They get you all riled up. Being enraged didn't get me anywhere. It got me very fatigued. So, I no longer desire to constantly be put in a spot where I have to keep swimming for my life either. I no longer desire to make the tank inadvertently bigger nor have all my efforts and life suddenly becoming a swim that made no sense, and be caught in a constant swirl because of being caught in the tensions and narratives that are beyond all of us, or all of me, or my child, anyway. And that keep making no sense, as every splash I make only serves to make the tank bigger, and myself, sinking even further nowhere – undefined, inexistent, fluid, unable to solidify.



I simply desire to float on water, having a tranquil river-like relaxed stance on my floaties, looking at the skies, enjoying the rainbows. Take every drop of rain, every whiff of air like they are the sweetest fragrance of all of eternity put together. Does COVID-19 exist in my universe and reality? Of course, it does. Just like trisomy 21. But it's a scientific matter. Like trisomy 21, I just learnt all about it, and then I don't let the bogeyman scare me anymore. **So, empowerment looks a bit like this.**

You work at it. Learn all about it. And then, you let it go.

I don't think the journey forward for any parent or professional serving this field is the journey of the inner work that I did. It took me 12 years. Don't take 12 years. Just jump and port to the now. To the place where there are no labels, no need for labels.

But instead, names. Personal names, and the rightful dignity of every life.

I think that's really what it all means for me.

For anything really.

Where does this leave me? I simply have a duty of care and commitment to protect & nurture the dignity of each and every one of our lives whom I have the good serendipity to encounter – our humanity of each other.



And for the duration that I am on this earth, I know your name, and you know mine. And we get to spend time together doing phenomenal things. And really, that's all there is to it, for me, and most likely, for those who haven't stopped reading what I have just rattled on for quite a bit about. And then life does just roll on.

Thing is – we cannot possess this story. Or any story.

The reality of our lives is like a breeze that rustles the leaves of the forest ever so gently, and sometimes, a storm blows through. But the trees – they still stand. Somehow.

I was struggling to frame this session regarding the state of inequality in our society for *ON-OFF GRID, A Thought Leadership Series*. Strangely, I stumbled upon - friendship.

Maybe we rebegin here.

Peng-Ean Khoo, a mom

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www.thehappyheartschool.wordpress.com is a blog about Living lifelong human care, development, education, learning and service for all. It is dedicated to all individuals, families and friends, who protect and nurture the dignity of all lives.

