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A note about Dr Hilary Stace 🌿

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Recently I attended a memorial service for a wonderful woman, who had been an incredible supporter of my efforts as an advocate, writer and a mum for many years. [Dr Hilary Stace tragically died](#) in July, the ripples of shock reverberated far and wide across many grassroots and ministerial level organisations alike. She was a historian, an activist, and an ally to many. She was also a daughter, sister, wife, partner and mother, and the room was full of people from many different communities she meant something to.



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Back when we first crossed paths, I was very new to the world of EGL, UNCRPD, DPO's, EOI's and OIA's. I was a mum of a small autistic girl who, like my daughter, hadn't yet found her voice. I was tentatively using my writing skills to lobby MP's and make submissions. I had joined some online communities advocating for equity in education and was a sponge, absorbing all the experience of older, more experienced voices than mine.

I was angry. The fire inside me was stoked by the experiences of families around me whose children were just like mine - happy, fascinated, wild, creative, totally unique young minds, being forced to conform to a standard issue version of themselves, just to attend their local school. Their fires were being extinguished, as the last spark was left too long unattended, and was snuffed out.

We had a privileged experience in the early years of school, due to my daughter's 'profound' disability. She did not talk, so nobody bothered to ask of her opinion. She failed the tests, so nobody bothered to challenge her. She turned away from smiling faces, so nobody bothered to include her. She was safe, almost smothered by bubble wrap protecting her from the world. Funding was never an issue, we walked straight into a specialist school with no one protesting her enrolment there rather than her local mainstream school.

Everything was A-O-K in my world. My privilege, my respite, my wellbeing was due to my daughter's exclusion from the mainstream.

I acknowledge that now. At the time I couldn't understand people's wonder at how I managed to find time to blog and go to meetings. My daughter was safe in a place that funding, not worries, were pooled.

Maybe it was guilt, maybe it was a matchbox of social justice that stirred me in to action. I wanted to speak out, for the parents around me who had no energy to do so themselves.

I first met Hilary in the halls outside the select committee hearings at parliament. It was such a foreign place for me, I could have just as easily been bouncing around on the craters of the moon. She recognised me from my online profile picture and introduced herself, and told me how important it was to do things like this in person, rather than advocating vicariously through social media posts.

I was taken aback by Hilary's soft, calm voice. Up until then I had been surrounded by loud, shouty voices screaming, demanding change. Those voices were like bone dry kindling to my inner fire. The heat and intensity increased with every word they spat. Hilary on the other hand, was measured and balanced in her presentation. She read from thoughtful notes, pausing when she needed to. Everyone listened. Not a word was missed.

Hilary advocated for equity, inclusion and accessibility in education. These became the pou that supported the papers, presentations, posts and regular ruminations around education at a grassroots and systemic level I surrounded myself with.

'[Education is for everyone unless you are special](#),' a paper Hilary co-wrote with Giovanni Tiso became my cornerstone for everything - from my daughter's IEP meetings at school, to discussion points with important people at the Ministry of Education. It breathed life and relevance to all the barriers I was facing.

I think back, and reflect that my earlier attempts of advocacy omitted my daughter's voice or her right to advocate for herself. At any point Hilary could have chastised me, reminding me of NZ's shameful history of institutionalisation, but she didn't. Not until I became curious about the source of long held attitudes towards disability and some people's inability to move forward from the medical/charity models of disability towards a human rights model. Then, she was gracious and generous with her knowledge of disability in our country. I am so lucky to have this grounding in disability to call on whenever I write, speak, act or support.

COVID 19 and lockdowns moved our advocacy online, but Hilary was always present online to make a comment following a government announcement on education. She was always the first to send me a message following a webinar presentation or select committee appearance. She was the first person to subscribe to my substack, and the first to contribute to my givealittle page for a customised trike for my daughter. She was always encouraging, and had a way of presenting any critiques on the content with measured kindness.

If I didn't see her online or in person, I would always see her every April in the banquet room at Parliament for World Autism Day. Her son Oscar loved a selfie with the many MP's who would attend, and year after year I would see them there.

I didn't see her there this year. We were both there, but it was a large turn out. I saw Oscar from afar, but never bumped into Hilary this time. I hadn't seen her at any rallies or online hui; life has been busy since I returned to work. Time slips by

- as do the brief opportunities in life to tell people things that are important, but not pressing.

The next time I would see Hilary was on a big screen in a slideshow of photos at her memorial service. Her childhood friend, and former Greens MP Catherine Delahunty talked about their teenage years, where they were resplendent in leather mini skirts making plans to change the world chasing equity and fairness.

Hilary's service was attended by lots of familiar faces from the disability community. Look, there's Erin who was at the first advocacy meeting I ever attended. There's Matt who was there when I made my first keynote speech on disability rights. There's Giovanni who I sat on a board with for years, there's the MP whose public meeting for seniors I crashed to talk about inclusive education. So many connections. There is kinship in our sense of shock and allyship in our mourning.

The room was packed with people, and there are hugs aplenty, and so much laughter.

I think about what I might say if I had the opportunity to stand behind the lectern.

"My name is Rebekah, to many of you I am no one important. To Hilary, I was someone. I am a parent, with a voice and the energy to speak. If you hear the terrified quiver in my voice when I say "I am vulnerable," know that this is my strength. I may nervously stutter my words, but don't be concerned, I will have my say. Hilary taught me that. I can be quiet and small, but powerful. My words may not have as many syllables and references as others, but they will fill the room and reverberate along the corridors of this building.

I am a parent that has faced many peaks and troughs. I have been knocked about, but I still stand tall and strong. No matter what you throw at me, I will endure. Because I have the support of my peers to keep me upright and on course.

I am exhausted, and sometimes weak, but my words can move mountains. I believe in my ability because mothers like Hilary who have begun their journey long before me, have endured and survived, as will mothers long after I have gone.

I am someone. I am someone important. I am someone's mother, and I am valuable.

Thank you Hilary, for believing in me, believing in us, and for being so persistent in your pursuit of kindness."

Moe mai ra, e hoa ❤️ 🌱

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