



Jenny Truran and her son Jex

FROM A LINK READER

PRIORITY HOUSING

'DON'T KNOW, DON'T CARE'

BY JENNY TRURAN

"We regret to inform you that your application for priority housing has been declined..." begins the letter from Housing NSW and I see red. The ball of useless fury that is always the domain of a mother who has a child with disabilities inflates suddenly, and my breakfast is ruined.

I knew it. I knew the bureaucrat at the interview last week, whom I'd had the audacity to question, even challenge her uninformed assumptions, had hated me on sight. I saw the way she glanced at me disdainfully as she made the suggestion to my profoundly deaf, legally blind, illiterate nineteen-year-old son that he should go out and find his own rental accommodation independently.

"Inappropriate!" My hands shot up as I spoke and signed loudly. My boy looked from where he'd been focusing on the Auslan interpreter and tried to locate me with his pinprick vision. By the time he had ascertained that it was me who had interjected he'd lost the thread of the conversation and it all had to be repeated. The bureaucrat looked at her watch and was irritated. I'm used to repeating things. Once, twice, even three times, and if the light's wrong I use hand-over-hand communication; placing his hands around mine and hoping he gets it, or spelling with my fingers onto his hand.

My boy looks incredulous at her suggestion. I sit back and love him to bits while he gives her his eloquent argument

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made up mostly of questions. “Oh,” he signs fluently “you can see I can't speak so how will I communicate with Real Estate agents? And I'm vision impaired so I can't drive, though I'd love to, so how will I get there to look at a house? And I don't have a job because all the bosses worry too much about OH&S laws, so I don't think I'll be able to afford private rents anyway.” She scribbles onto the page of his future and purses her lips.

I lean forward on the uncomfortable chair to appeal to her sense of reason. Even though it took three months to answer reams of repetitive paperwork, driving endless kilometres attending appointments to include written reports from the family GP, retina specialist and his Vision Australia caseworkers, she somehow needs more information.

Keeping calm I gaze steadily at her, and switch to the patient, explanation voice that I use with my four-year-old granddaughter. “Look, I'm trying to get stable accommodation set up for him while he's still sighted. This means he'll have time to get used to his space, and learn to live independently, before he loses the rest of his vision.”

“Try Youth Housing,” she suggests, and hands him a brochure.

“Inappropriate,” I erupt again. “I am trying to avoid a crisis situation here. He will not be going to a refuge, or short term accommodation. He needs long term stability and home modifications. Strip lighting in cupboards. Flashing door bells, smoke alarms and a yard for his guide dog.” Why can't she get it?

“Things are ok at home for a little bit, but he wants to move out as nineteen-year-olds do, and he's so independent he should have the chance. I'm exhausted and he wants to go, needs to go. I've been doing this for nineteen years now. I am not filling out any more forms, I'm sick of it,” I spit out.

“I can't understand forms,” chimes in the interpreter's voice. “I am not good at reading. Big words and formal things are too hard and Mum has to explain them all to me, then write down the answers.”

My despair trails out as I see contempt in her eyes. I've been labelled again but which one is it today at this particular

service? Have I been judged as the 'control freak', the 'interfering mother' who won't let him grow up? Or am I the 'bitch-mother' who is aware of entitlements and considers them human rights, instead of gratefully accepting any crumbs that are offered? But it's a new label today, I've not heard this one before.

“Do you claim any Carer's Payment or Allowance?” she asks me. I think, “What business is it of yours?” Instead I respond politely: “Yes, I work full-time, but I get the small payment, I'm not sure what it's called.”

“Well ask Mum to help you with the forms,” she smugly says to my son. “That's her job; the government pays her to do that.” The interpreter flinches, but remains professional, and my boy looks confused. I know now why this woman sits behind strips of glass. It's to keep clients like me from grabbing her throat and choking her with the 98 bucks a fortnight that is somehow a substitute for my life.

“Jesus Christ! How many disabilities do you need to get a house?” I explode. But I'm done here. I won't speak anymore – there's nothing to say.

She doesn't get it at all. She doesn't know that every time Centrelink stuff up his payments it's a large chunk out of my day to correct it. She doesn't know that this morning I'd phoned India trying to decipher his phone bill, and typed up a letter to 'Infringements' asking would they waive his most recent \$200 fine for not showing his vision impaired rail pass. He had it with him, but couldn't find it at the time. Blindness is doubly dangerous when you also have Tourettes Syndrome and struggle to organise yourself well.

She doesn't know that each time he applies to renew a service for a companion card, mobility parking, taxi vouchers or perhaps needs a magnifier, he has to prove that he's deaf or blind once again. Why, I'm not sure. Just in case his senses have been miraculously returned by a faith healer or some happy-clappy I suppose.

This means appointments with doctors and referral letters to specialists, the booking of interpreters and trips to the city, more peering and prodding just to get forms filled out to attach to the forms I've already filled out. It's constant, dehumanising and exhausting.

She doesn't know I have other children too, one doing her HSC. I'm the mother of a young adult with disabilities now, and it's still my job to do everything.

This is the landscape of disability service provision in Australia in 2009. Reactive. There's no long term planning or individual care. Services are fragmented and bound by their own narrow paradigms. It's about 'tick and flick' paperwork; if you don't fit they'll write a referral so you can try somewhere else, where you'll probably be told: “Oh, that's DADHC, we're State funded, sorry, we can't help you.”

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■ from page 7

But I have a whole person in front of me here. He lives and breathes, and right now he needs the shape of a house in his difficult, uncertain future. A complicated scenario I’m the first to agree, but I don’t give a shit which government pays for it. With the taxes I’ve paid over 25 years I could’ve paid for it, twice.

I call my local MP’s office. Surely they’ll spot this outrageous mistake and correct it. They call back ten minutes later and tell me they’re satisfied “procedures have been followed”. What? “Do you really think they’d say ‘Oh sorry, we stuffed up!’”

I rant and sob. “Do I need to put on his backpack and deliver him to your office with a little note pinned to him like Paddington Bear saying ‘Please look after this blind deaf-mute?’ I’m sure you’ll soon prioritise him then!” “Don’t threaten us,” comes the stern reply and I’ve made yet another pal in the disability marathon. And I’ve been labelled a psycho.

So I’ll calm down in a few days and begin the appeals process no doubt. I’ll swallow the disgust and sense of unfairness I feel. I’ll question endlessly where I went wrong and what ‘social inclusion’ really means. I’ll ponder the costs, both personal and financial, of fully supported housing for a young man who could’ve learned to live independently if given the chance. I’ll wonder whether its me that’s getting smaller and more bitter, or could it be the rest of the world? And I’ll think about Ghandi’s quote: “A nation’s greatness is measured by how it treats its weakest members.” 🌀