I am a wife and mother to 2 young children, at the time of print my daughter is aged 4 and my son is aged 5 and a half. My son has an undiagnosed profound level of both intellectual and physical disability so as you can imagine the care is around the clock, 24/7, and will become back-breaking over the years. Granted we are very early into our lifelong journey of caregiving, however the cracks are already beginning to surface. We have no extended family support and I believe our family will breakdown in one way or another (be it financially, emotionally , physically - or all 3) before this journey is over, it's more a question of when?

To date the wait-lists have been endless and we are forever joining one list or another that often vanishes before our turn comes around, doctors at the Children's Hospital don't even have wait-lists anymore and are not prepared to see new patients, even though our regular doctors at the hospital make the referral - isn't that a sign that disability and illness is more prominent than ever? After 12 months on the PADP wait-list for a standing frame I telephoned looking for an update or estimated delivery and was told that we would never get a standing frame as it is considered a "luxury item" yet they approved our application and left me on a wait-list which would never eventuate? Needless to say our application vanished and we never received the item. If a standing frame for a disabled child is a luxury item then it appears early intervention is a luxury majority of us are not entitled to, as a result our son has developed bad habits which will cause many more costly problems in the future. We waited 4 years for a 6 month program with a speech therapist....not an early intervention in our case. Many of the other therapies have been similar.

HomeCare and respite is non-existent leaving families to explore moving abroad or bringing their own carers in from another country, even if we could afford this option the red-tape trying to get visas through on this basis is so difficult it's hardly worth it.

Holding down employment whilst caring full-time for a profoundly intellectual and physically disabled child is incredibly taxing on the mind, body and soul. In our case the Government pays us $106 per fortnight to lose our identity, our career and generally run ourselves into an early grave whilst trying to nourish a family, be a wife and a mother, a therapist, a nurse, an advocate and hold down some form of employment to contribute in some small way to the expenses we incur....just one example in an endless list of many is $20,000 quoted to modify a car (on top of the cost of the car).

The only light at the end of this tunnel is the knowledge that one day our child will access a residential care facility so we can become parents and siblings for the very first time BUT there is nowhere near enough housing available, and I'm not entirely sure all the housing that is available is necessarily suitable for the severe-profound sector. I don't believe it is is good practice to mix the mild with the profoundly disabled in a living arrangement - there certainly are some horror stories around. I believe in interacting with different people - of all cultures and abilities - but believe the needs of the severe-profoundly disabled in a day to day living arrangement are very different to a milder level of disability. It would make sense to have a facility filled with appropriate equipment, hoists, ramps etc available for the severely disabled so everyone is kept safe and happy.

The band-aid solutions and the system as it stands today is forcing good families to consider relinquishing care or dumping their adult children in hospitals - can you fathom ever being faced with that decision? I have met families that are seriously considering this option as their only one left after a lifetime of caring has not made for a healthy mind or body. It's impossible and unreasonable to expect parents to continue this care into their twilight years when they deserve to trade in the nappy changing and retire with some dignity to pursue a hobby, to travel, or simply watch a film and enjoy a restaurant for the first time in 20, 30 sometimes 40+ years whilst interacting with their disabled child as a parent rather than a caregiver. It should be our right after saving the Government billions of dollars for working 24/7 with no wages, no super, no sick leave, no support and no rights.

What would help our family and so many others?

Now that we are moving out of the early intervention stage our main focus is the future and in particular the area of accommodation. Years seem to pass with no change whatsoever being made to better the situation. I am still reading news reports year after year about families relinquishing care as no other options are available to them.

There are clearly different levels of need which have to be considered when developing the housing model. The "system" did away with institutions many years ago, however the severe and profoundly disabled and their families need a facility of some sort where it is safe and happy. They are incredibly vulnerable. We already know at 5 and a half years of age that our son will not be able to fit into a group or cluster home setting with a carer helping him to live independently. All his needs have to be met medically and physically with hoists for lifting, suitable bathing facilities, beds, therapy, sensory opportunities etc. In today's society parents don't want to send the children away to be forgotten about. These facilities should be sensory and caring places where families can connect and contribute without the daily load of physical caregiving. It needs to be a safe and happy place - there is no need for a grey walled institution. Often our homes are not purpose built, bathing is difficult, lifting and moving is difficult (and dangerous to both the patient and carer). Nursing homes are necessary for the elderly, the need for the severe and profoundly disabled is no different. Why can't the retirement model be replicated for say the disabled 18-45 age bracket, with bright colours, sensory gardens, music, bubbles etc then move our children/adults to an aged care facility from 45+? The transition from young adult to aged care is valid.

I believe the disability and Government system needs to tap into the hospital and ADHC system and monitor the children and families on the books throughout their schooling years so that once they reach 20 years of age a suitable place will become available for them to live. Particularly with the severe-profound disabilities it is very easy to partially predict what the future needs are going to be. One thing we can't predict is the affect of sitting in a wheelchair day in and day out will have to his physical health, his hips, his spine, We love our son dearly and continue to do therapy and help him to gain as much independence as possible however to be realistic we are talking about perhaps managing to feed himself independently or using a switch or communication device to voice basic needs - he will never walk or talk, go to the toilet on his own, or dress himself therefore the system has a good 10-15 years to plan accordingly and ensure places are available (or establishments are built) within a reasonable timeframe after finishing school. This will give families and the primary caregivers a lifeline and a goal to work toward.

I believe that more community awareness is required. School students should have the opportunity to volunteer for a term at a special school or respite facility so they can get to know a disabled person for who they are and what their needs may be. This in turn may help with a general acceptance and understanding in the community but it also may encourage young people to join the industry as therapists, doctors, psychologists, counsellors or to donate to charities or even to volunteer time in the future. I believe it would nourish the souls of all involved.

I continue to hope, pray, join the other voices and stamp my feet so the disabled, their families and caregivers begin to be acknowledged as important members of society. They deserve to be nurtured and looked after just as every Australian is entitled to.