

**From:** Maree Maxfield [REDACTED]  
**Sent:** Monday, 4 April 2016 11:38 PM  
**To:** FCDC  
**Subject:** submission on autism

To whom it may concern

Old people are generally only old on the outside.

I am an ageing adult who is diagnosed as being on the autism spectrum. I care for my adult daughter who is also on the spectrum.

I fear my old age as I watched my ageing mother receiving inadequate and resultant cruel treatment in aged care until she died. Much of this was because people didn't understand her needs. She did not have dementia and was very frail, but people didn't understand her needs such as her love of solitude, her prolific reading, her dislike of loud amplified noise, her fire independence and self sufficiency, a distinct dislike of contact and her particular ways of doing things. She became institutionalised. She was no trouble and everyone said they loved her but after two years in one institution I asked at a meeting, if anyone could tell me anything about my mother's life. Nobody could. There was no dignity for her. I moved her from there but it was too late.

I know there are countries which have villages and places with communities set up for people ageing with autism. Unfortunately I don't live in one of them. I hope by the time I need care that I do!

I would like to be part of something that helps to design such integrated communities. I have lived a very unusual but vibrant, self sufficient life, tasting all sorts of things. I do not want to be institutionalised in a stark place with no originality and people who do not understand me. I want to be part of a community that I have some say in designing in preparation for my old age so that I can age gracefully in the community with comfortable surroundings that cater for what other people like to call my quirks. I would like to go somewhere where I can fill in a comprehensive profile of the things that actually scare the hell out of me that other people just take for granted and don't worry about. For example how I like to be showered and how the touch of water on my skin the wrong way almost sends me into a meltdown. Or how I may like to stay up at all hours of the night and early morning and then sleep later in the morning and get up when I feel like it. If I am old that should not worry anyone. And if I want to wear the same comfortable clothes every day that are not necessarily in fashion that should be okay as well. I believe that wherever I am there should be dogs.

There are some things I have seen in institutions for aged care that I never ever want to see in my aged care. The main ones are country and western music shows, patronising attitudes from people who call old people 'Love' and 'Dear' and don't bother to learn their names or introduce themselves, Stark uncomfortable rooms with uncomfortable beds, coded, disgusting food that I would not feed to a dog, locked doors that stop people accessing outside, chicken nuggets and orange cordial. Why is there so much orange cordial?

I would like a community that is supported, caring carers with good communication skills and a sense of humour, a common garden that grows food and flowers, a really good Internet and computer hub, decent fresh food, access to great coffee, decent music, natural beauty and a picture theatre that shows up to the minute movies, not some crap from the 1930s.

I don't think the NDIS will help me. There are many things I would like to add but that is my starting point.

Yours sincerely,

Maree Maxfield

