

As this committee is assessing the implications of an ageing population, my submission relates to what an age-friendly, disability-friendly community looks like. It is written from my perspective as a single carer and consultant in the disability and mental health sectors who has the full-time care of an adult son with Autism Spectrum Disorder (ASD) and anxiety disorder.

Many West Australians who are ageing are also single, fulltime carers. My son Patrick and I have no extended family, because like many others in the disability community, and particularly the autism community, our family imploded under the onslaught of autism, and never recovered. I have two older children I never see. Patrick's father has no contact with him or me, and we have no contact with our few remaining family members.

Our "family" now consists of Patrick's godparents, both of whom are 15 years older than me, my godfather, who is 78, our neighbours, support workers, work colleagues and the brave, resourceful and creative families we meet in the disability community.

I know many other single carers who are approaching their sixties, and thinking about the next ten years, both for themselves and their family member. I have recently been thinking about an over 55 village or a lifestyle village, as a possible future living arrangement for Patrick and me. My son, like many people with ASD, has always been happy with older people who tolerate his eccentricities and find him good company.

I have thought about a lifestyle community, as it is the only option available to us which will give us a high degree of security, and many desirable amenities onsite. I recently contributed to an inquiry into accommodation and IFS for people with disabilities, the results of which were compiled in Report no. 3 of the Community Development and Justice Standing Committee, May 2014. This report makes very clear that there is an enormous, unmet need in accommodation choices for people with disabilities who have moderate, high or profound needs.

NDIS, if and when it is working properly, is many years away, and CAP funding is very difficult to get. In a recent CAP round (Oct 2013 to January 2014), there were 679 applications for accommodation and IFS and only 68 were granted. We were one of the unlucky ones who missed out. CAP is an extremely traumatic process to go through; we have been knocked back twice. As we don't wish to put ourselves through any more trauma, we have both realised that we will be living together for the foreseeable future.

However, we cannot move into a lifestyle village because under the current rules, Patrick would not be able to stay when I die, as he would be under 55. Both he and I would like the safety, security and amenities many of the newer over 55 communities offer. Patrick would get on well with, and would be very helpful to many other residents. I have three auto-immune conditions and am not physically strong. He helps with the shopping, pushing the trolley, loading it into the car, and putting it away at home. He also does all the washing up and helps with the laundry.

He would be in high demand on a shopping roster in an over 55 community! To me it is self-evident that people with disabilities and people who are ageing often require the same things. They require security, stable housing which is purpose built for people who may be in the future using wheelchairs, motorised scooters, walking frames etc., and access to recreational and other onsite

amenities. To mix these groups, and have extended families, friends and support workers as part of the wider community for this rapidly growing demographic would be advantageous to all.

I would like to see government policy that would make it economically viable to create such communities, and have flexible, workable rules about tenure and inheritance after the death of the carer. The arrangement would give peace of mind to many older, single carers, and to adults with disabilities, if both knew that after the death of the carer, the adult with a disability could stay in their home, surrounded by a wider network of neighbours and staff with whom they had long-standing relationships.

Social isolation is common to both people with disabilities and older people. Patrick has FLI funding from DSC. It means he can employ people for community inclusion, recreation, respite and other things that maintain us as a family unit. This means that there are always young people, usually university students we employ on a part-time basis, who are coming and going from our home, going out with Patrick, doing things with him at home, and taking him on weekend respite breaks which he loves. These students become part of our 'family.'

If we were living in an over 55 community, they would become what DSC calls 'natural supports' within the wider community. Again, this is a no-brainer. Support workers who are university students are gaining invaluable experience in the fields in which many of them will eventually work or practise. I advertise for support workers on the UWA jobs website. I pick the cream of the crop, and these students are always keen to work more hours with other families and learn from their situations, as well as contributing to the welfare of those families and the person with the disability. If we were able to live in an over 55 community, these students would also become part of that wider community, and perhaps get further experience working for older individuals, or in the administration and working of the aged care and disability sectors.

When these students become practitioners in the health industry or find careers in the disability or aged sector, or indeed, the public service, they have experience of what academic concepts mean in practice, not just on paper. They understand what discrimination, social isolation, and lack of choice looks like or people with disabilities and their families. They understand the crises that occur through lack of funding or waiting for early intervention which comes too late. They have gained the kind of valuable experience that cannot be taught, but needs to be learned, in order to make them good at their jobs when they graduate.

My first view is that to cater for our future needs, the government needs to form partnerships with the private sector, to offer over 55 communities the flexibility and security of tenure that both older carers and adults with disabilities are looking for. Through my consulting work, I have become aware of organisations which used to offer services solely in the aged care sector, but now offer mental health services as well. These organisations are well placed, with the knowledge, training and vision, to partner with government to plan for the sorts of communities I have described. Partnerships with organisations in the building and real estate sectors would be useful.

My second view is that the government needs to provide flexible and creative funding to older carers and the person they care for to stay in their own homes, if that is their choice. As found in the

previously mentioned report into accommodation for people with disabilities, there is a huge current unmet need which will get worse before it gets better. One way of overcoming this shortage is by achieving what my colleague Dr. Jasmine McDonald calls 'architectural separation' in a current home. I have achieved this by a small, inexpensive renovation that has given Patrick an 'apartment' in our two-storey townhouse. By incorporating an unused landing adjacent to his bedroom, he now has a media/TV room, double bedroom, bathroom and large walk in wardrobe/storage, which already existed.

As my home office is on the other part of the landing, and I require confidentiality when talking to clients, the wall of the room has acoustic insulation and the door is solid, not hollow. When his 'apartment' door is closed, it is his *defacto* front door. He feels a greater sense of independence and ownership of his space. We socialise and eat downstairs, but when he needs his downtime, he retreats to his space, or man cave. It is a winning solution for both of us, and one which many other families could use, if they had the funds to do so.

Another solution for architectural separation for ageing carers is a granny flat. A granny flat can have diverse uses. It can be used to house the person with a disability and a support worker. It can be used for other adult siblings still living at home who need architectural separation from their sibling with a disability. If the family can live harmoniously together it can be used to generate some income which would help with the costs of services and therapy.

It could be used to rent out to students who would get a cheaper rent in return for a negotiated numbers of hours per week of support to help the family remain intact and further the independence of the person with a disability. It could be eventually used for the older carer to live in whilst the person with a disability lives in the house with a support worker and/or a sibling. I know of one instance where a granny flat is used to keep a grandparent with dementia at home, with visiting home support and extended family support.

The divorce rate in the disability community is higher than in the general population; in the autism community has been estimated to be as high as 80%. It does not require much creativity to have government policies which will keep families intact, so that the burden of care for families in crisis, older carers and adults with a disability does not fall on the wider community. The cost saving includes Centrelink payments, mental health costs and accommodation costs. Older carers need access to funds which, if used now, will prevent future crises which will invariably be more costly.

Most local councils have now embraced the granny flat option and have changed the rules for family occupancy only, allowing them to be used for rental accommodation. Even a modest amount of funds can prevent a crisis in which the whole situation implodes. Older carers should not have to access what meagre superannuation savings they have, in order to pay for some sort of accommodation solution for themselves and the adult they care for. It defeats the purpose of having superannuation, if because of the lack of accommodation for older carers and the person they care for, older carers have to use their super to solve some sort of crisis in their situation. I know of cases where this has happened.

Families in the disability community like to self-determine with regard to their funding. They know what will work for their situation and what won't. They need funding to be used flexibly and to have access to it quickly. If I have learned anything in 25 years as a parent, single carer and consultant in

the disability community, it's that the future doesn't just happen. It's something we create by what we do now. All futures begin with a dream. A mutually supportive community such as I have described, is what Patrick and I dream about for our future.

Please accept this submission as a contribution into the policy implications of ageing in Western Australia. I give permission for any part of this submission to be used or quoted, and am happy to give evidence before a parliamentary committee in the legislative assembly.

Melissa Kelly

*Melissa Kelly Consulting*

ABN 24 831 412 639