World Elder Abuse Awareness Day Forum June 17th, 2021.

Some thoughts from an aging disability advocate

Elder abuse is any deliberate or unintentional action, or lack of action, carried out by a person in a trusted relationship, which causes distress, harm, or serious risk of harm to an older person, or loss or damage to property or assets.

Adult safeguarding Unit SA Health

Systems abuse occurs when people are harmed through the action, but more likely inaction, of decision makers- Ministers, CEOs and managers- because of their indifference; lack of interest, awareness, courage; and/or sense of accountability.

Richard Bruggemann

1 Introduction

Over the past two years, two Royal Commissions have been examining the abuse and neglect occurring in our aged Care and Disability sectors. The publishing of the report of the Royal Commission into Aged Care Quality and Safety has highlighted a system in need of major reform and the interim report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has flagged very similar issues. Both have created community expectations of significant change which the Government is already attempting to hose down. Our experience with Royal Commissions shows us that changes are often minimal, implemented with glacial speed, and often do little to change the power imbalances that sparked the need for the review.

With these two Royal Commissions reporting so closely together, there is a unique opportunity for us to make significant, meaningful, long-lasting structural changes.

Rather than working in separate vacuums, each sector should learn from the other, so that we can have a coherent system for supporting all Australians with disabilities, whether they are aged-related or stemming from long term impairments.

Here are some thoughts of what such a system might look like.

2 Value our older citizens

Australia does not value its older citizens, nor recognise the huge storehouse of experience and wisdom they possess. We jokingly talk about retirement, "putting your feet up", and disengaging from employment. Many who take this path discover, with hindsight, the importance that employment played in their lives, not only for economic wellbeing but also for its connections, affiliations and sense of purpose. Those who continue to be involved might be dismissed as the "Old Brigade." Even if we can't or don't want to continue to work, it is important that we maintain our links with our communities and Governments should lead from the front, clearly demonstrate that they value older citizens and enable them to continue to work and/or contribute. This would include leadership to ensure that work and workplaces could be restructured to include older workers.

We should reflect on the past leadership of Governments, and particularly the then minister, Don Grimes in promoting such values after the passage of the 1986 Disability Services Act. Importantly, training for all staff working with people with disabilities was not just about developing the skills to do the job, but also about such values-base issues as empathy and respect for individuality.

We also need to recognise and have plans to deal with one of the darker realities of our society that family members are often the major source of abuse of our older citizens as indeed they are of children, spouses and vulnerable people.

3 End ageist discrimination

Your 65th birthday is the defining point in your life in many wonderful ways! Unfortunately, it also delineates a striking inequity of access to government services. Under age 65, if you have disabilities that impact on your ability to live independently, you can, subject to eligibility, access the National Disability Insurance Scheme (NDIS). Over 65 you can access, again subject to eligibility, My Aged Care. What two individuals with identical needs, one 64 years, and the other 65 years, can access through these two programs can be mind-blowingly different!

As a 65-year-old using My Aged Care, the current maximum aged-care package is a $52,000 a year. As a 64-year-old accessing the NDIS, the package could be 6-10 times that amount!

Furthermore, NDIS "participants" have three options to manage their funds. They could manage the package themselves; they could have their package administered by a plan manager; or they could opt to have the funding go to a service provider. However, I could find no option how, as a 65 year-old funded through My Aged Care, you can fully self-manage. Your funds are channelled through, and largely managed by, an aged care provider. The packages of My Aged Care recipients are charged a mark-up on the cost of the services they receive as well as paying regular "admin" fees. A recent letter to the Advertiser reported that 40% of a relative's package was consumed by fees. If you want to, why can't you manage your own package?

There are restraints on how and where recipients of My Aged Care can spend their diminished funds. For example, they can't use their package to continue to pay their neighbour's teenage son to mow the lawn in a mutually advantageous arrangement. Another chink from your independence; another community link broken! Neither can they opt to use funds from their package to continue to see their long-time physiotherapist or cleaner who is happy to move furniture and dust unlike her packaged-funded replacement.

A solution would be to replace My Aged Care and the NDIS with the "Community Living, Independence and Connections Programme." It would have many of the characteristics of the programmes that it replaced, but would draw on the best of both existing programmes. As at present, there would be an assessment process to determine eligibility and the package that participants would receive. However, the package should not have arbitrary caps. Rather it would largely be based on the "necessary and reasonable" test that is used within the NDIS.

Furthermore, there should be options for the management of these packages that include the current options available through the NDIS. It is important that people are able to manage this themselves if that is their wish and ability, rather than having their funds managed by a provider organisation. It is a continuation of their independence and empowers them to exercise choice and control over their lives.

It must be stressed that there are some major differences in the funding of the two current programmes which would need significant adjustment to ensure fairness. Being an "insurance" rather than a welfare programme, the NDIS is not means tested. The support an individual receives is determined by his/her functional impairment and is not affected by income or assets. The My Aged Care programme is partially supplemented by a basic daily fee, set by the government at a percentage of the single basic age pension and varies depending on level of the package. There is also an income-tested care fee, an

extra contribution that some people pay, determined through an income assessment.

4 Help people stay in their homes and communities

Most people with disabilities under the age of 65 either live with their families, in their own homes or in small settings. Most states are closing or have closed their institutional services. A relatively small number of people with disabilities under the age of 65 live in residential aged care facilities. The NDIS support packages mentioned above enable people with significant needs to live in their communities. In the My Aged Care programme, the capped packages are often inadequate to provide the level of support required to enable people to live in their homes and communities, driving many into residential aged care facilities and into what many consider "social death!" The Community Living, Independence and Connections Programme would be based on need rather than arbitrary age markers, and could defer the need for residential aged care for years.

Secondly, whilst the Commonwealth government can provide capital grants for building or upgrading residential aged care facilities, there appears to be no such programmes to assist families in upgrading their homes to provide accommodation for an ageing infirm parent. A recent 7.30 special on superannuation and ageing highlighted these intergenerational initiatives and their benefits.

Such arrangements have often worked on the basis of adult children providing the hands-on support that their aged parents required. Being in a family home can provide aging adults with a sense of social and emotional support, a sense of value and place within their family, an opportunity to share and maintain culture and traditions with younger generations, independence, privacy, and connection to the community, all of which is often lacking in residential aged care facilities. However, without the necessary support in place, the caregiver children, usually daughters, can become overwhelmed and overburdened, leading to strain on the family and, in a worst case scenario, neglect and abuse. If these arrangements were supported by care provided through the person's package , we could achieve the best of both worlds. The needs for affiliation and a sense of belonging could be met through the family connections and the provision of care being provided through the package.

5 Make residential aged care a necessity for fewer people

With the Community Living Independence and Connections Programme enabling people to stay at home even longer, we could slow the demand for new residential aged care facilities and the huge investments they require.

6 Do things differently

When you go into residential aged care and discover that breakfast won't be oat bran, yoghurt, blueberries and a banana eaten at 6.15 am like it has been for the past 20 years, but will be porridge or toast served at a time to meet the convenience of the organisation and staff, you might get stroppy or distressed.

When you ring the call bell to be taken to the bathroom, only to learn your aid has gone on break, you might become anxious, feel helpless, and a sense of hurt dignity and pride.

When you realize that most of these activities of daily living that you've taken for granted all your life are no longer in your hands but are in the control of strangers whose faces you don't even recognize, you start to act out to exert some sense of control and agency over your life.

When you refuse medications, refuse to get dressed, withdraw to your bed, become irritable, yell or swear at staff, you are labelled as "problematic," a "bad patient."

The current solution is not to develop an understanding of what is triggering your reactions, but rather to mask your distress with medication. Where are the counselling or psychological services that might assist you to cope with a foreign and frightening environment?

Our wonderful daughter-in-law, Dr Elizabeth Ruff, works as a psychologist in a New York City nursing home. All new admissions are referred for a psychological evaluation to determine the emotional impact of their recent stressors on their mood and behaviours.

Psychologists not only offer support for patients who are grappling with a loss of independence, financial, social, housing, and interpersonal stressors, they are also an important part of an integrated treatment team approach. Psychologists receive referrals to support both staff and patients by providing in-depth behavioural analyses to determine the root cause of common behaviours within the nursing homes and provide practical recommendations that ultimately improve the experience of the patients and the facility.

They provide non-medicinal coping skill training for pain management, sleep, hygiene and mood regulation, which has been shown to reduce the duration and

dosage strength of related medications. Their work also includes staff training, family support, and linking with other departments including physical rehabilitation and recreation. The presence of psychological services in nursing homes result in reduced hospital admissions, reduced use of psychotropic medication, better plan development and compliance and better-educated and skilled frontline staff, all of which lead to a better quality of life for the individual.

7 Remember Maslow!

Those of us who remember Maslow's hierarchy of needs will understand the needs we all have for a sense of purpose, affiliations with other people, and fulfilment, often referred to as "higher order needs." The 2017 "Old People's Home for 4 year Olds" documentary series followed a group of residents of a nursing home, most of them frail, immobile, and depressed, who interacted closely with a group of kindergarten students for several weeks. The results were measurable improvements in both their physical and mental wellbeing. Why was this so exceptional that it rated a TV series and what is being done to ensure that those higher order needs are being met? Social fulfilment is not congregating in a common room, playing a tambourine in an organised sing-song with the music therapist – at least not for me and, I suspect, most people.

8 Raise the bar of regulation

The current regulatory processes set a very low bar. Both the NDIS Quality and Safeguards Commission (NDIS Commission) and the Age Care Quality and Safety Commission (Aged Care Commission) are largely concerned with preventing the bad things, the assaults, thefts, sexual assault and exploitation, from happening. However they do little or nothing to ensure that the good things that make lives happy and meaningful are happening. They should be replaced by one regulatory body which should work to a different set of enforceable standards that would include meeting higher order needs such as a sense of affiliation, inclusion and accomplishment.

Were TripAdvisor to use the Commissions' current approach, it would not report *"This is a great hotel. The rooms were spacious and beautifully furnished and the food and service in the restaurant were exceptional"* but rather *"This is an adequate hotel. You won't get beaten up in the lobby or have your luggage stolen."* Although some organisations do a great job in meeting higher order needs, there is seemingly no systemic approach to ensure that meeting higher order needs is an enforceable standard.

9 Safeguard rights

There are two areas where older Australians could benefit from programmes developed in the disability sector to recognise and safeguard rights.

The first relates to the use of restrictive practices, that is, any practice or intervention that has the effect of restricting the rights or freedom of movement of a person. Within disability services funded by the NDIS these practices are highly regulated by the NDIS Commission, with an emphasis on strategies to reduce their use. Restrictive practices, particularly chemical restraint, are used in aged care services and should be regulated, again with an emphasis on positive programmes that reduce the need for their use. The South Australian Government should enact legislation, mirroring the *Disability Inclusion (Restrictive Practices-NDIS) Amendment Act 2021*, to ensure the appropriate authorisation of restrictive practices in aged care facilities.

Community visitors have, for many years, had a key role in monitoring services and safeguarding rights for people with disabilities. Visitors, who have been selected and trained through a rigorous process, visit a range of services, observe, ask questions and report on their findings to the Principal Community Visitor. Any adverse findings are discussed with the organisation to ensure their accuracy and, where necessary, to develop treatment plans. The reports of their visits, which covered both areas where there could be improvement as well as examples of great practice are valued by disability service providers. As well as safeguarding individual rights, some reports have led to huge practice changes within organisations or systemic improvement initiatives.

10 Conclusion

At the very time that we are seeing the number of people under the age of 65 with disabilities living in large residential facilities decreasing we are seeing the building and filling of more residential aged care facilities. Institutions foster learned helplessness and loss of dignity – people lose agency and become a "resident" and sometimes a "patient" and are subject to rules which, if broken, render you recalcitrant and a "problem". How do aged care facilities preserve individual freedom to pursue own interest and to have projects and goals

For people with disabilities, living in smaller community settings has not only been a worthwhile goal in itself; it has also been a vehicle whereby people with disabilities have been increasingly included in the fabric of our society with opportunities to participate in, and contribute to their communities. Increasingly, many older people are being segregated and their connections to community diminish.

Our society does better when all of its members do better; when diversity is celebrated and supported. We have seen this with people with disability; we need to ensure we have the right policy settings and programmes to enable this to occur for our older citizens.