Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability and the organisation’s motto is “nothing about us without us.” QDN operates a state-wide network of members who provide information, feedback and views from a consumer perspective to inform systemic policy feedback to Government and peak bodies. QDN has over 2000 members and supporters across Queensland who provide QDN with the perspectives of people with disability.

QDN provides this submission to the Royal Commission into Aged Care and Quality and Safety in response to the range of issues that QDN members have raised about the impacts on people with disability as service users in the aged care system or those who are trying to enter.

QDN is aware there are many people with disability currently living in aged care facilities as a result of acquiring a disability or because their support needs have increased as a result of a degenerative disability and they are unable to continue being supported by their loved ones or their support packages are not adequate to cover the costs of their care. This results in many people being inappropriately placed in long stay wards in acute care or prematurely entering aged care facilities.

It is widely acknowledged that living in residential aged care can be detrimental for a younger person with disability. It can result in reducing their independence, limiting their ability to reach their full potential and it can be socially isolating – 83% of younger people in residential aged care rarely or never go outside and around 13% never go outside[[1]](#footnote-1). Whilst the National Disability Insurance Scheme (NDIS) has been introduced and is at 80% of implementation in Queensland, there still continues to be high numbers of young people with disability living in residential aged care facilities, compounded by the issue of lack of affordable, accessible and safe housing. There is an urgent need to *move younger people with disability out of residential aged care settings* as these do *not provide suitable supports for younger people*.

QDN members have raised a range of issues, experiences, challenges and discrimination in the aged care system which has impacted upon their health, wellbeing and also their access to essential services.

Feedback from QDN members has included that some people have experienced a lack of respect, and lack of responsive, person-centred care and support within the aged care system. As people who may experience additional vulnerability due to their disability, the risk of abuse and neglect is higher.

QDN members have also reported that the waiting time to get community based aged care support is long and there are lengthy waiting lists to be able to access these supports. These supports are critical in keeping people out of the formalised aged care facilities longer. These long wait periods reflect a system that is underfunded and unable to respond to the growing needs and demands. People with disability report that this places greater pressure on families and informal supports, who may already be exhausted and stress upon the family unit. Critical funding and investment in respite and support for carers needs to be part of the solutions going forward.

When these community based care packages are received, members report that these are greatly inadequate for the level of support needed for individuals related to their disability. People with disability also report that the level of funding under the Aged Care system is NOT commensurate wit the funding for people with the same disability and support needs under the NDIS. For some people with disability, this discriminates against people who have had life long disability with multiple support needs and were over 65 at the time

QDN members also report challenges for people with disability in accessing information in user friendly, accessible ways and it is important that everyone has access to information to be able to participate in their care and support.

Lack of choice and control by the service user and no flexibility of funding was also reported about when, how, and what services are delivered. For many people with disability, this is a contradiction and challenge in seeing the transformational change the disability service system has undergone through the NDIS and the user centred system that has been designed and delivered in disability. Going forward, there will be ongoing need for system integration and collaboration as people may or may not transition from NDIS to aged care.

QDN members have also raised the lack of workforce capability and capacity with a limited pool of suitability trained people to keep up with demand and being able to match suitably skilled staff with individual needs. The aged care workforce needs to be adequately trained and resourced to be able to deliver person-centred individualised support that meets peoples need and rights to quality, safe care, and what this means in day to day support to provide people with support based around choice and control and consumer-driven care and support.

Once in the Aged Care system, people report that the system is difficult to navigate, and they have a significant need for assistance to be able to receive the support they need to navigate their journey. Access to assessments, coordination of access and entry to the aged care system needs to be seamless, and learnings from the NDIS implementation reinforce the importance of a system that is responsive to the service user, that does not further traumatise people and make the process more challenging. A case management/case coordination approach where a service user has one consistent point of contact to assist them on their journey.

Older persons with disability need education and information to help inform their planning and to be able to understand what they need. People report frustration with having to talk to multiple people and report going around in circles, so any system reforms need to address improving the pathways and journey for individuals and their families.

Giving people the support, information and education they need to understand the system and be active and informed users within the system is critical to delivering better outcomes and support for people. Shifting to a system that places older person, including older persons with disability in the drivers seat will be a key part of the service system reform to deliver quality and safe aged care system in Australia.

1. For more information see: <https://www.agedcareguide.com.au/talking-aged-care/younger-people-with-disability-in-aged-care> [↑](#footnote-ref-1)