A Window on Disability

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Health Quality & Safety Commission
Te Tāhū Hauora

Cover artwork by Sasha Wells, Dunedin, 1986.

Sasha Wells is a Studio2 artist. Sasha likes to draw dogs and cats, using different colours to layer paint, pens, and coloured pencils. Sasha enjoys coming to Studio2 because it’s fun – ‘This is a picture of sleeping dogs.’

Studio2 is a creative studio space in Ōtepoti Dunedin, where disabled artists are supported to create artwork, experiment with a range of materials, and develop their own artistic styles and profiles.

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Chapter 5

Life-course stage – Older adults

While 'older age' remains a dynamic concept shaped by social and cultural definitions, this final chapter of the life course examines disability and adulthood from the age of 65. In the New Zealand context, this milestone typically triggers a transition into retirement and eligibility for superannuation, while necessitating a shift in the delivery of health and wellbeing supports.

Improved access to medicines, supports and services has contributed to increased life expectancy among disabled people compared with earlier periods. At the same time, many non-disabled people acquire age-related impairments and disabilities later in life. However, there is limited data distinguishing between these groups and their distinct health needs. In the context of an ageing population, this makes older adulthood a critical life stage for investigation.

Among older adults, the population identified as disabled in the Disability Survey shifts from:

- 26% at age 65–69 (roughly 66,000 people)
- 29% at age 70–74 (roughly 61,000 people)
- 34% at age 75–79 (roughly 56,000 people)
- 42% at age 80–84 (roughly 45,000 people)
- 45% at age 85–89 (roughly 26,000 people)
- 54% at age 90 or older (roughly 18,000 people)

The percentage disabled grows while the numbers fall as people age.

The Health of Disabled People Strategy[91] states:

> Our current disabled population is likely to live longer than previous generations, and existing impairments and conditions are often exacerbated with age. This will result in increased demand for specialised support as disabled people age.

The Health of Disabled People Strategy also calls for initiatives that:

- ‘aim to maintain quality of life for disabled older people to help them do things that are important to them, enhance their participation and social connection, provide appropriate care and assure their dignity in their later years’ [92]
- ‘include supports that enable disabled older people to remain in their homes and with their whānau for longer’.[93]

For this stage of the life course, it is also of note that the experience of those who acquired their disability early in life, and have lived with disability long term, differs markedly from those who have acquired disability late in life. However, we cannot disaggregate the data between these two groups. We show what we can with what useful data we have.

A high-level summary of the findings

In Box 9, Robyn Hunt talks about the experience of ageing with disability into a cohort characterised by newly acquired disability, including the negotiation of a health system that is primarily set up to address late-acquired and age-related disability.

This chapter also addresses the quality of care in home and community support settings for older disabled adults, their experience of this care and what could be improved.

Robyn Hunt – disability and the 'silver tsunami'

Robyn Hunt is a disability consultant, blogger and commentator. Her story is adapted from an article in The Spinoff,[94] slightly abridged.

I find myself, with some surprise, riding the dreaded 'silver tsunami' – a wave that is bringing lifelong and long-term disabled people with it. We are the generation of disabled people who mostly escaped institutions. Some of us are better educated than past generations, benefiting from advances in technology, medicine and other areas. We've had partners, children, jobs and even careers, albeit sometimes patchy. We're living longer than previous generations of disabled people, and as activists, we've worked for change then and still do now.

Yet support systems for older people are unprepared for us. Predictions have been possible since 1996, and the growth of the ageing population has been well-documented. But little data is available about the disability and age status of our cohort, and the lack of data leads to poor policy and service decisions.

Many disabled older people don't feel their needs are being met. For us, disability came first, and ageing followed. This distinction matters. We don't always fit neatly into the categories of younger disabled people or those acquiring impairments due to age. We've spent a lifetime adapting to our impairments, but we face unique challenges as we age.

For example, someone like me – a lifelong wheelchair user, vision impaired, and hearing impaired – has different attitudes, skills and strategies for managing disability than someone who begins losing their sight or mobility in later life.

Continued over

Once we turn 65, we often become invisible, our voices lost in the medicalised view of ageing. We're lumped together with those acquiring impairments with age, and our unique lived experiences are ignored. We lack representation in important areas, such as on advisory committees for disability services. Excluding older people from these spaces, while younger voices are encouraged, silences the knowledge and expertise that we have, especially institutional knowledge that remains vital.

Medical and care professions often see us as just a collection of health conditions to be managed, rather than respecting our autonomy and identity. As activists, we're not prepared to lose our agency and be treated as passive recipients of care. We've fought too hard for our independence.

The systemic problems go deeper. In 2001, the government separated Disability Support Services (DSS) for older people, believing that older people's disabilities were related to worsening health, not lifelong impairments. Before this, there was a seamless service for disabled people as they aged, but the change in structure resulted in more medicalised, less holistic care. Disabled older people were left out of the conversation, and their needs weren't addressed.

For some of us, impairments may accelerate with age. For instance, a wheelchair user's shoulders can wear out, and conditions like Ehlers-Danlos can worsen. When this happens, we may require more or different support than what's available. DSS, however, remains focused on people under 65, leaving us at a disadvantage.

Eligibility for DSS is unclear, and many disabled older people feel neglected by a system that's supposed to serve them. Agencies need to integrate services better to address the widening definition of disability and offer a more cohesive system that works for people of all ages.

Medical advancements and better services mean we're living longer, but the approach to policy and support hasn't kept up. Disabled older people face environmental and social barriers to involvement in our communities, such as a lack of accessible transport, contributing to isolation. The stereotype of older people as 'fit and able' ignores the reality that some disabled people may need supported living at a younger age than others, facing higher costs and limited resources.

Poverty is also a real issue. Disabled people often have broken work histories due to their impairments, and access to stable housing near transport is a constant struggle. This affects older women particularly, who may not have had partners or owned homes. The same is true for people with learning disabilities who once faced institutionalisation.

Another issue is unequal access to information. Many disabled older people still lack access to the internet or the technology needed to navigate increasingly digital government and financial services. Public sector websites are often not accessible, and gaps in available information leave us in the dark.

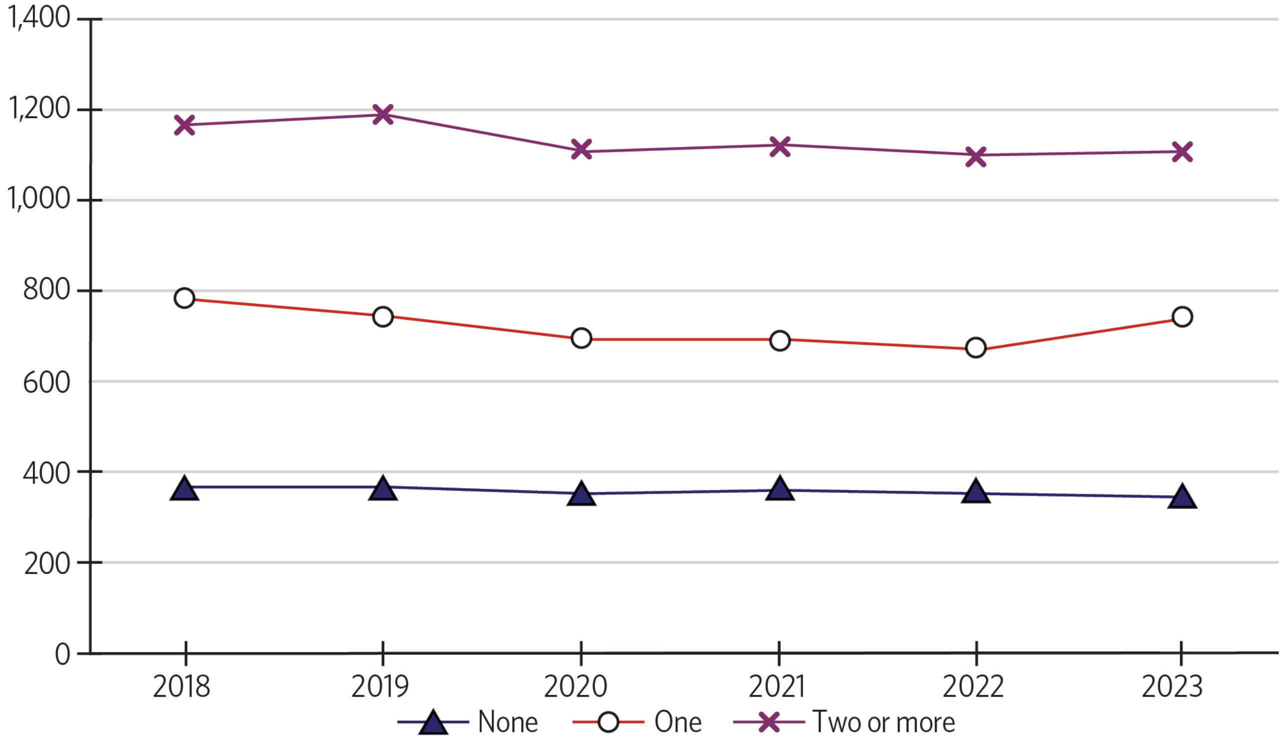
Disability and ageing rarely get meaningful public discussion. Most of the conversation happens within medical or academic circles. Disabled older people must take the lead and bring our voices into the conversation, or we risk being forgotten. ■

Hospitalisations of older disabled people and emergency department use

With older age, the number of impairments directly correlates with increased hospitalisation, higher average number of days spent in hospital, and more use of ED.*

Compared with those aged 40–64 years, who have a hospitalisation rate of 700 per 1,000 population, the hospitalisation rate for people aged 65–79 with two or more impairments grows by a third, to about 1,100 per 1,000 (Figure 70). It is unknown if these impairments are pre-existing, or age-related.

Figure 70: Hospitalisation rate per 1,000 population, ages 65–79 years, by number of impairments, 2018–2023



Source: IDI

Among disabled people, the average length of stay in hospital of about seven days for those aged 40–64 grows to nine days for those aged 65–79. The average length of stay for people with multiple impairments is three times that of non-disabled older adults (Figure 71).

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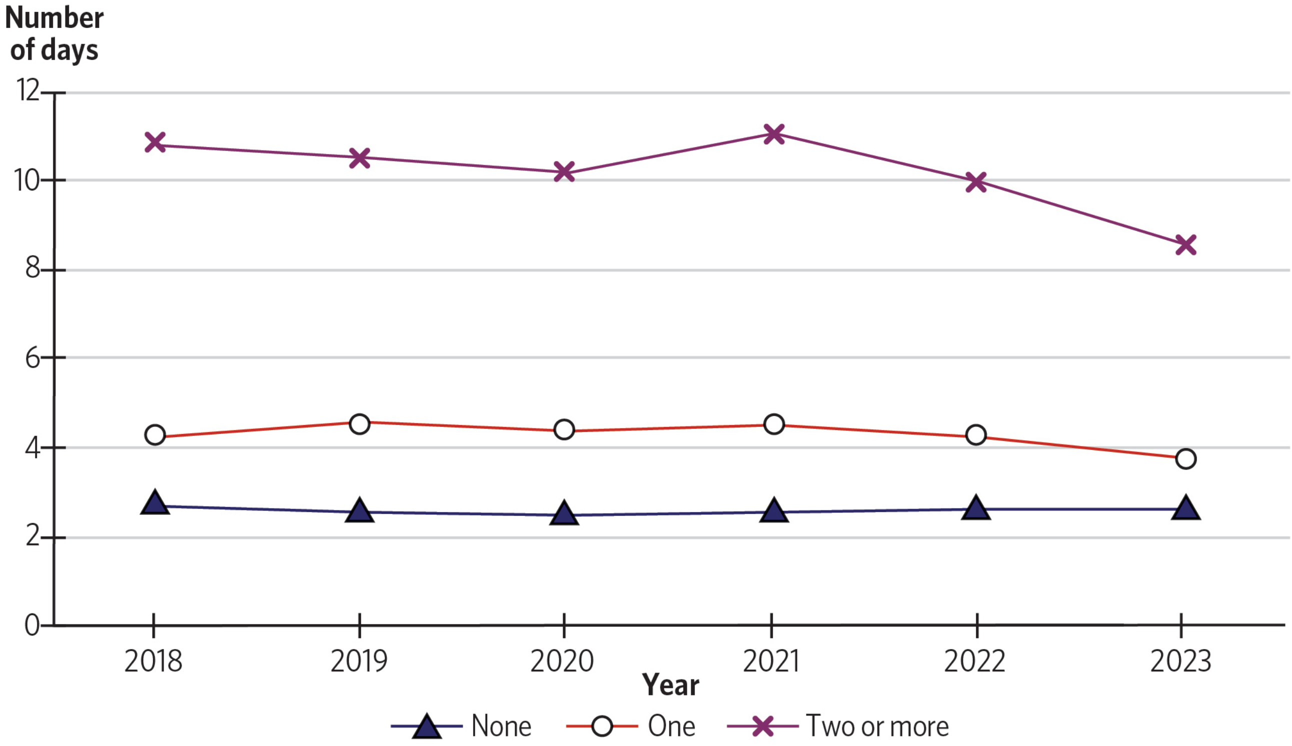
* Noting that Figure 70 does not distinguish between age-related impairments and ageing disabled people.

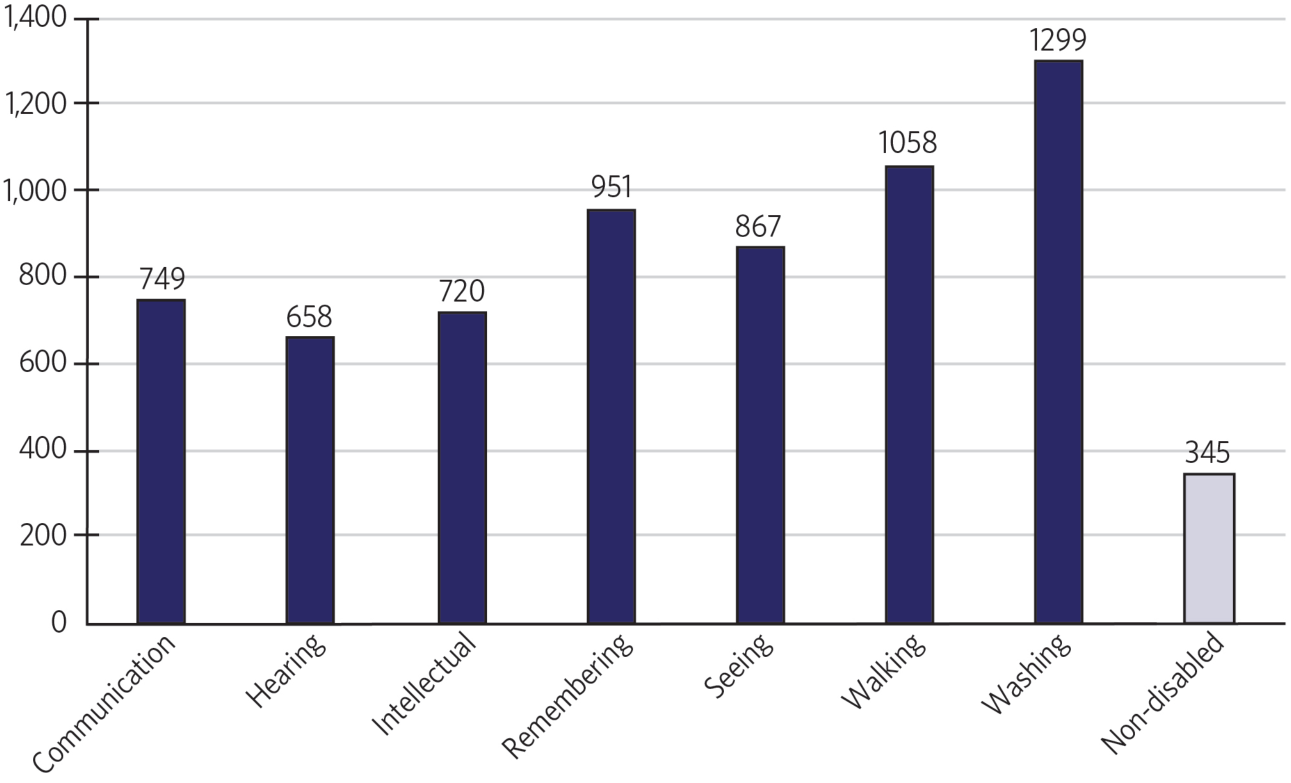
Figure 71: Average length of stay in hospital in days, ages 65–79 years, by number of impairments, 2018–2023



Source: IDI

People in the washing disability domain had a hospitalisation rate of 1,300 per 1,000 population in 2023 (Figure 72). All disability domain hospitalisation rates were higher than non-disabled people, and these findings are unlikely to be due to chance.

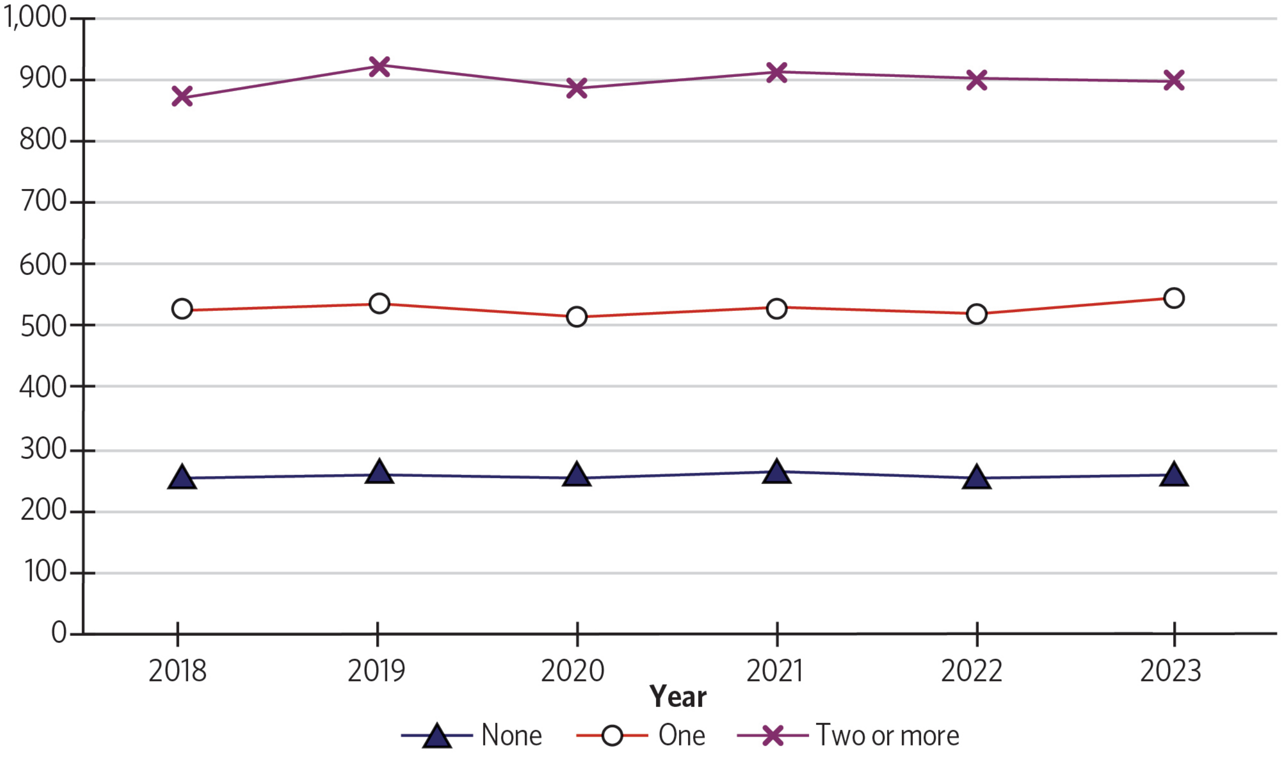
Figure 72: Hospitalisation rate per 1,000 population, ages 65–79 years, by WG-SS disability domain, 2023



Source: IDI

ED presentations for those with two or more impairments in this age group (65–79) are also higher, at 900 presentations per 1,000 population, compared with around 700 presentations per 1,000 population in those aged 40–64. For people with one impairment, the rate of approximately 100 presentations per 1,000 population in those aged 40–64 rises to over 500 per 1,000 population in those aged 65–79 (Figure 73).

Figure 73: ED presentations rate per 1,000 population per year, ages 65–79 years, by number of impairments, 2018–2023

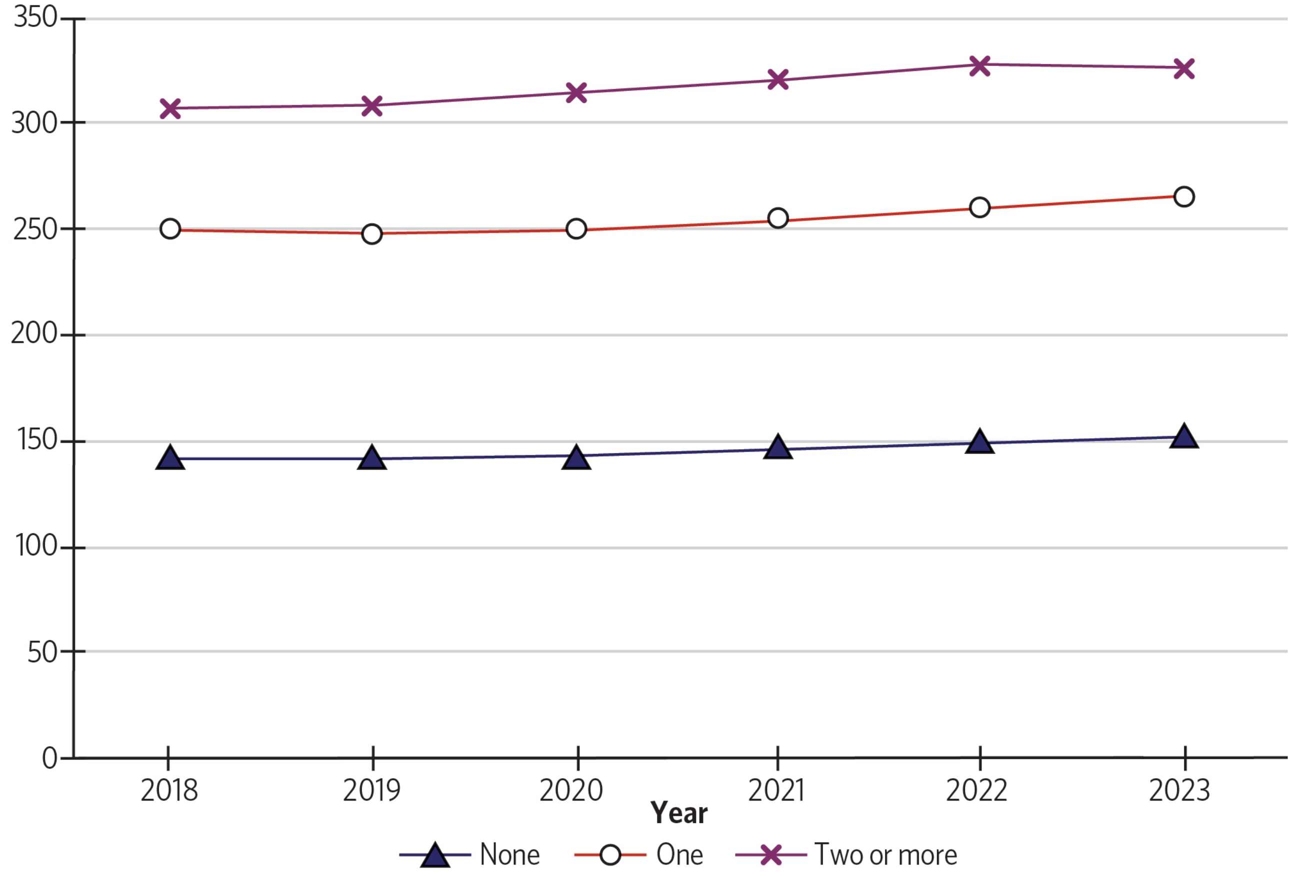


Source: IDI

Diabetes in older adults

Diabetes in older people is both a disabling condition and a comorbidity that older disabled people live with. Regardless of whether an individual falls into the former or latter category, the risk of diabetes increases significantly with age.[95] In 2023, among people with two or more impairments, the prevalence of diabetes for those aged 65–79 is more than 300 per 1,000 population (Figure 74), increasing from 230 people per 1,000 in those aged 40–64.

Figure 74: Prevalence of diabetes per 1,000 population, ages 65–79 years, by number of impairments, 2018–2023



Source: IDI

Experience of home and community support services

Although data on older disabled people's health experiences remains scarce, one data set offers important insight into the support experiences of disabled people over the age of 65.

Home and community support services (HCSS) provide support with household tasks and personal care to help people live independently at home. They also offer support outside the home, such as help getting to appointments, doing essential errands and staying connected with community activities. These services support older disabled people with both short-term needs, such as injury-related support, and long-term sensory, physical or cognitive disabilities.

The Health Quality & Safety Commission has begun a new survey of HCSS experience.[96] [97]

To explore the HCSS experiences of older disabled people, the Commission analysed seven questions from the HCSS survey that broadly concern:

- respectful and kind care
- effective and reliable scheduling
- the ability to attend activities in the community.

The analysis shows that services and support for older disabled people (aged 65 years or over) are being delivered in a respectful and kind way. The effectiveness and reliability of scheduling, including communication about scheduling, need improvement, and there is wide variation in responses by HCSS provider.

There is also a gap in the provision of services at a national level to enable older disabled people to attend community activities, or hapū and iwi activities, if they want to. As highlighted by the Better Later Life – He Oranga Kaumātua 2019 to 2034 strategy, ageing in the community safely and independently can improve physical and mental health, wellbeing and social connectedness, while also reducing the amount of time that people require residential care services.[98] This applies to both people acquiring age-related impairments, and older disabled people.

Respectful and kind care

The great majority (89.7%) of older disabled people reported that their support workers always treated them with respect and kindness. There was no statistically significant difference in response between ethnic groups and variation between providers was comparatively small.

While this appears high overall, it does mean that around one in ten older disabled people are not always feeling that their home and community support workers are treating them with respect and kindness. Further, this result was slightly lower than that for older non-disabled people (92.7%) and was lowest among older disabled people with three or more impairments (80.5%) (Table 1).

Table 1: Percentage of older disabled people reporting that their support workers always treated them with respect and kindness, by ethnicity and number of impairments, HCSS survey 2024

		% (95% CI)
Total older disabled		89.7 (88.6–90.8)
Ethnic group	Māori	91.5 (87.3–94.4)
	Pacific peoples	89.1 (77–95.3)
	Asian	87.6 (80.8–92.2)
	European / Other	89.7 (88.5–90.8)
Number of impairments	Non-disabled	92.7 (91–94.1)
	Self-identified	92.2 (90.4–93.7)
	One	91.5 (89.8–92.9)
	Two	86.8 (83.8–89.3)
	Three or more	80.5 (75.7–84.6)
Provider	Highest performing	100 (88.6–100)
	Lowest performing	84.2 (76.4–89.8)

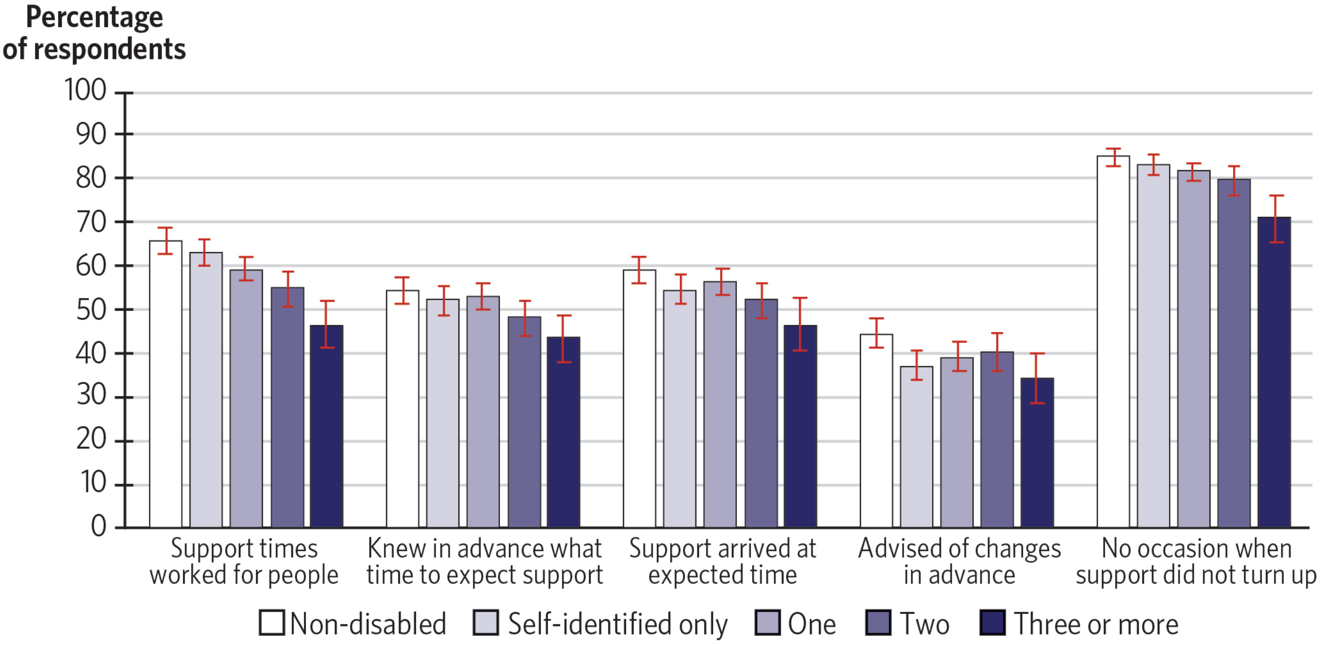
Effective and reliable scheduling

These questions give insight into the degree to which the scheduling of support was person-centred, and the quality of communication around this from providers to clients. Part of providing a high-quality and safe service includes ensuring that support workers arrive as expected and on time. Findings from the HCSS national report revealed that scheduling was the lowest-performing section in the survey.[99]

The following were key findings from the scheduling questions.

- For all but one of the scheduling questions (‘knew in advance what time to expect support’), disabled people were significantly less likely than non-disabled people to report the most positive experience.
- There was a clear pattern by ethnic group, with Māori older disabled people reporting better scheduling-related experiences than older disabled people in the European/Other group. The only exception was the measure ‘no occasion when support did not turn up’, for which there was no difference by ethnic group.
- There was not always a clear trend in experience by number of impairments, although in all cases people with three or more impairments were least likely to report the most positive experience (Figure 75).
- There was wide variation in positive responses to these questions across the different HCSS providers. This variation indicates the potential for process improvement for some providers and highlights the value of benchmarking across the sector.

Figure 75: People reporting the most positive experience for each of the scheduling questions, by number of impairments, HCSS survey 2024



Source: Health Quality & Safety Commission Te Tāhū Hauora patient experience survey

Support times worked for people

Among older disabled people, 58.3% reported that in the last four weeks their support workers always came at times that worked for them. This result was significantly lower than for older non-disabled people (65.9%) and dropped to 46.7% for older disabled people with three or more impairments. There was also a large variation in performance among providers (with at least 30 respondents) for older disabled people, ranging from 86.7% to 42% (Table 2).

Table 2: Percentage of older disabled people reporting that their support workers always came at times that worked for them, by ethnicity and number of impairments, HCSS survey 2024

		% (95% CI)
Total older disabled		58.3 (56.6–60.1)
Ethnic group	Māori	69.6 (63.3–75.2)
	Pacific peoples	60.9 (46.5–73.6)
	Asian	61.5 (52.6–69.6)
	European/Other	57.2 (55.3–59)
Number of impairments	Non-disabled	65.9 (63–68.7)
	Self-identified	62.9 (59.8–65.9)
	One	59.4 (56.6–62.1)
	Two	54.8 (50.7–58.8)
	Three or more	46.7 (41.2–52.2)
Provider	Highest performing	86.7 (70.3–94.7)
	Lowest performing	42.0 (36.3–47.9)

Knew in advance what time to expect support

Among older disabled people, around half (51%) reported that in the last four weeks they always knew in advance what time to expect their support worker(s). This was the one scheduling question where older disabled people reported a similar experience to non-disabled people (54.5%). However, there was a large variation in performance by provider (ranging from 76.7% to 28.7%; among providers with at least 30 respondents).

Support arrived at expected time

Among older disabled people, just over half (54.1%) reported that in the last four weeks their support workers always arrived at around the time expected. This result was lower than for older non-disabled people (59.4%), by an amount that was unlikely to be due to chance. There was large variation in performance among providers for older disabled people, ranging from 85.7% to 34.9% (Table 3).

Note that this question was asked only of those who had previously answered that, in the past four weeks, they always, usually or sometimes knew in advance when to expect their support workers.

Table 3: Percentage of older disabled people reporting that their support workers always arrived at around the time expected, by ethnicity and number of impairments, HCSS survey 2024

		% (95% CI)
Total older disabled		54.1 (52.3–55.9)
Ethnic group	Māori	68.2 (61.8–74)
	Pacific peoples	59.5 (44.5–73)
	Asian	58 (49–66.5)
	European / Other	52.6 (50.7–54.6)
Number of impairments	Non-disabled	59.4 (56.4–62.4)
	Self-identified	54.7 (51.5–57.8)
	One	56.4 (53.6–59.3)
	Two	52.2 (48–56.3)
	Three or more	46.7 (41–52.5)
Provider	Highest performing	85.7 (67.3–96.0)
	Lowest performing	34.9 (26.5–44.4)

Advised of changes in advance

If changes were made to their support arrangements in the last four weeks, around four in ten (38.3%) of older disabled people reported their provider always let them know in advance. Disabled older people were significantly less likely to report this than non-disabled older people (44.6%).

'Provider always let them know in advance' includes, for example, being informed ahead of time if their support time was changed, that the support worker could not make it, or that the support worker would be a different person from who was expected. The denominator excludes people who did not have changes to their support arrangements in the past four weeks.

No occasion when support did not turn up

Among older disabled people, 80.8% reported that in the last four weeks their support workers always turned up when they were supposed to (ie, answered 'no' to the question 'in the last four weeks, has a support worker not turned up at all when one was supposed to?'). This rate dropped to 71.1% for older disabled people with three or more impairments. This means that around one in five of all older disabled people, and nearly one-third of those with three or more impairments, experienced at least one occasion in the previous four weeks when their support worker did not turn up when expected.

Describing the outcomes of ineffective and unreliable scheduling

Some people described the outcomes of ineffective and unreliable scheduling in response to open-ended survey questions. Examples included:

- people trying to complete tasks themselves without necessary support, creating risk to safety such as falls, accidents or taking medication inappropriately
- whānau carers experiencing additional burdens by completing tasks that were assigned to support workers
- medication and meals being provided to older disabled people too early, too late or not at all
- people being unable to make plans for the day or to go out because of the need to wait for support to arrive at an unknown time

- people’s stress arising from being prepared for support to arrive and then experiencing long waits. Other people reported support arriving unexpectedly early, and no-shows
- support being given at times of day (eg, mornings) that are not suitable for people’s health.

Able to attend activities

Only a quarter (24.5%) of older disabled people were definitely able to attend community activities, or hapū and iwi activities, if they wanted to. This compares with half (51.5%) of older non-disabled people and fewer than one in ten (8.6%) of older people with three or more impairments being able to definitely attend community activities, or hapū and iwi activities, if they wanted to. There was no statistically significant difference in response by ethnic group and variation between providers was small.

Older disabled people, particularly people with multiple impairments, require better support to be able to attend activities and participate in their communities. While home and community support service providers may be constrained by the scope of individual care plans, and other barriers such as inaccessible community facilities and transport also play a role, these findings point to a clear national-level gap in service provision. This gap has significant flow-on effects, contributing to social isolation and negatively impacting the physical and mental health and wellbeing of older disabled people in New Zealand. ■

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