October 2021

To Stats NZ

Please find attached DPA’s feedback on the Disability Survey

## Disabled Persons Assembly NZ

Contact:

## **Prudence Walker**

## **Chief Executive**

## **021 546 006**

## **policy@dpa.org.nz** Introducing Disabled Persons Assembly NZ

The Disabled Persons Assembly NZ (DPA) is a pan-disability disabled person’s organisation that works to realise an equitable society, where all disabled people (of all impairment types and including women, Māori, Pasifika, young people) are able to direct their own lives. DPA works to improve social indicators for disabled people and for disabled people to be recognised as valued members of society. DPA and its members work with the wider disability community, other DPOs, government agencies, service providers, international disability organisations, and the public by:

* telling our stories and identifying systemic barriers
* developing and advocating for solutions
* celebrating innovation and good practice

# Importance of the Disability Survey

DPA would like to highlight just how essential it is that both government and non-government organisations have access to timely, relevant, and reliable data on disabled people in Aotearoa New Zealand around the issues that impact us. This information influences a wide range of policy development and decision making around services and supports for disabled people, their families and whānau. Currently we know that disabled people do not have equitable outcomes in a wide range of areas from housing and health through to safety and wellbeing.

Good data provides a foundation for policy and ultimately progress on upholding the rights of disabled people and taking steps to ensure that they are fully realised. The recent announcement by government that there is to be a Ministry for Disabled People set up over the next year makes the importance of the Disability Survey asking the right questions and getting the relevant data more critical than ever. For these reasons it is essential that among other things, the Disability Survey is properly resourced and the sample size large enough to have confidence in the findings.

**Sampling Methodology: Younger Disabled People, Residential Facilities**

DPA believes that it is vital that the sampling methodology for the Disability Survey is not skewed towards older people who are more likely to experience age related health impairments. We know from previous surveys that disabled people over 65 have generally better wellbeing outcomes than disabled people under 65.[[1]](#footnote-2) This is likely because people who are disabled from birth or acquire a disability earlier in life are impacted for a much larger proportion of their life.

Being disabled from birth or an early age can have major impacts on acquiring a language, social development, learning and education, employment and income, health and wellbeing. The impacts of age-related disability acquired after 65 while clearly significant do not have the same lifelong impact. Hence it is important to ensure that younger disabled people are adequately sampled and that the overall findings are not skewed to those over 65.

In addition to ensuring that younger disabled people are interviewed, it is also essential that younger disabled people (under 65) in residential facilities and small group homes are adequately sampled and that they are asked the wellbeing questions in particular .

The sampling methodology for the Disability Survey must ensure robust sampling of those under 65 in residential facilities and not be skewed by the numerous aged care residential providers that exist across the country. One way to address this would be to sample residential facilities for those under 65 separately to those for over 65.

DPA also feels the current cut off for the residential survey risks excluding many disabled people under 65 in small group residential settings but otherwise living in the community. We recommend identifying residential providers for disabled people, such as IDEA services, Spectrum Care and NZCare to ensure that disabled people in these facilities are sampled for the residential survey.

We know from the Royal Commission inquiry into abuse in care and also the recent Ombudsman’s review[[2]](#footnote-3) in 2020 that disabled people are particularly vulnerable to abuse in residential care and that record keeping by the MoH has been abysmal [[3]](#footnote-4)

These findings highlight that it is critical that we get good data on how disabled people in residential facilities including in small group homes are doing.

**The key point we want to make here is that no groups of disabled people should be excluded from any part of the Disability Survey due to their living arrangements.**

**Disabled people in all residential settings or other living arrangements such as those living in small group homes should be included in the sampling of residential facilities and also asked any health , education, employment, leisure or wellbeing questions that may be in the Disability Survey.**

# Ensuring Accessible Interviews for the Disability Survey

When interviewing disabled people for the Disability Survey, DPA would like to stress the importance of providing an accessible and flexible approach from the start to ensure that disabled people are interviewed in a way that best works for them.

This means that the survey must be able to be taken in a variety of modes including (but not limited to);

* by phone,
* in person, (especially important that this is available for people without easy access to a phone, or to digital technology such as video calling)
* with NZSL interpreter support,
* by video call with a professional transcriber or NZSL support,
* with a support person to explain questions in plain language.

In addition, disabled people should be able to provide their responses in the way that works best for them including (but not limited to);

* orally in person, by phone or by video,
* in NZSL,
* via an assistive communication device,
* in writing.

Furthermore, the process must be flexible enough to ensure that each person being interviewed can use any combination of modes that works for them.

For example, a deaf or hard of hearing person may wish to be interviewed online with an NZSL interpreter or with a transcriber or to be able to see the questions in writing but then to respond orally or via an assistive communication device. A Deafblind person may need to receive the questions in braille or by tactile sign.

DPA strongly supports the point that has been made by People First in their submission that the Disability Survey must include the voices of disabled people who cannot answer for themselves. This can be done through a supported decision-making (SDM) process that ensures that the voice of the disabled person (their will and preferences) is heard.

DPA also strongly supports disabled children – particularly those over 12 years being able to answer the questions themselves where they are willing and able.

# Right to be Counted

Article 31 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)[[4]](#footnote-5) highlights the key role of the state in collecting data on disabled people that enables formulation and implementation of policies that give effect to the Convention.

In NZ, the Census and the post-census Disability Survey are a key source of data on disabled people for policy development and strategic planning and prioritisation. For this reason, it is vitally important that both the Census and the Disability Survey ask the right questions to avoid groups of disabled people being underrepresented in these data sets.

DPA understands there will now be some form of disability identity question in the Census to sit alongside the Washington Short Set questions, which is what we advocated for in an earlier submission.

**To have similar confidence in the data from the Disability Survey, DPA strongly recommends that the same identity question used in the Census be included in the screening questions for the Disability Survey.**

# Screening Questions: Limitations of Functional Questions .

**DPA response to Question 1.**

Currently the proposal is to use functional questions for the screening questions for the Disability Survey so that disabled people answering the Disability Survey are limited to those who answer that they are significantly affected in one of the functional areas listed.

DPA’s concern is that this narrow approach risks excluding key groups of disabled people including those living with chronic pain, sensory sensitivity or neurodiversity or a long-term disabling health condition that may have a significant impact on daily activities but are not captured by the proposed functional categories and as well as those with social and communication impairments including ASD and FADs .

As DPA has stated in our previous submission on the Census, there are well recognised shortcomings with the Washington Set Questions (WSQ) which focus on functionality. We are concerned that relying solely on similar (even if expanded) functional questions to screen disabled people for the Disability Survey will result in significant shortcomings of data.

We know that that the WSQ under-samples a number of different groups of disabled people, including neurodiverse people, people with disabling mental health conditions and people living with chronic pain.

Limiting the pool to the listed functional areas means that these people are only included in disability data if or when their impairment or condition effects one of the functional areas listed.

This means that, for example, if an impairment or long-term condition isn't captured in the listed functional area then it risks not being captured in the Disability Survey despite the fact that such conditions do often require ongoing service provision or accommodation as a result of impairment-related needs.

Given that the Disability Survey is a major source of data on disabled people for policy development and service prioritisation over the next decade, DPA believes it is vitally important that people with long-term conditions or impairments, and those with social and communication impairments who may not be captured by the listed functional questions, are still able to be included in the pool for the Disability Survey .

**DPA recommends the inclusion of the same disability identity question proposed for the Census to be used as part of the screening for the Disability Survey to ensure that people with other impairments or long-term disabling conditions are included in the Disability Survey.**

DPA also notes that many people may identify with multiple impairments, for example a person may have a learning disability, and also have a physical disability. Someone may be both blind and Deaf. Someone may have a cochlear implant and use a wheelchair. In these cases, it can be inappropriate to be asked to identify which impairment causes the most difficulty/is the main impairment. Any particular impairment can intersect with other impairments in ways that greatly increase the disabling impact of the impairments. Furthermore, the disabling impact of any particular impairment may vary with the age or life stage of the person.

**For this reason, it must be possible to state that more than one impairment has a major impact and/or not to have to select one impairment as the main one.**

We also note that many people will not know the cause of their impairment, nor be able to state the age of onset since a disabling impairment may develop progressively over time. There should be the ability to state this.

**DPA suggests that the stage of life that the impairment became known or acquired will provide more relevant data than the exact age of onset.**

DPA recommends rather than trying to pinpoint a particular age, the question could be if they acquired/identified the impairment at birth, early childhood ( pre-school), school age , post school, under 65, over 65,

***Question 2: Are there any age groups that are particularly important to your use of the data? What are they and why do you need them?***

*In 2013, the age groups for which data was output were:*

*under 15 years (children)*

*15 to 44 years*

*45 to 64 years*

*65 years or over.*

***Question 3: Should people aged 15 to 17 years be considered as children or as adults? Why?***

**DPA response to Questions 2 and 3.**

DPA considers that the age bracket 15-44 years is much too broad as it covers people in potentially very different stages of life. Most young people 15-17 years are in some form of education and are likely to still be predominantly supported by their family or the state. Merging this age group with adults who may be more likely to be looking for work, in tertiary education or training or living independently potentially muddles the data.

DPA recommends expanding the first age bracket to under 18 years to align with the education system to year 13 and renaming as (Children and Youth) . Young people aged 15 to 17 years should be considered as children and not as adults as that also aligns better with other legislation and international obligations under the UNCRC and UNCRPD.

***Question 4: Do you need information about disabled people who identify with an ethnic group other than Māori or European?***

**DPA response to Question 4.**

DPA believes that it is essential to identify disabled people who identify as Pasifika, those who have refugee status and other ethnicities. This is both because different cultural groups may have different attitudes and world views of disability, and because they may be multiply marginalised. The effect of this is that disabled people from different ethnic groups may be impacted differently or may not access services equitably. To recognise and address these intersectional issues it is critical that we can identify equity issues for disabled people from different ethnicities

***Question 5: Do you need specific information about assistive equipment? What do you need to know and why?***

**DPA response to Question 5.**

DPA supports including specific questions about assistive equipment, including assistive communication devices. Assistive equipment is often fundamental to achieving equity and independence for disabled people and enabling them to access support and services or for social interaction. Barriers to accessing essential assistive equipment can have major impact for disabled people and lead to poorer outcomes in many areas including mental health and wellbeing.

It could also be worth asking questions around if they have a **disability assist dog** to assist them with their daily life. ( Note that a disability assist dog refers to  a dog certified by one of the organisations listed in [Schedule 5](https://www.legislation.govt.nz/act/public/1996/0013/latest/LMS175895.html?search=qs_act%40bill%40regulation%40deemedreg_Dog+Control+Act+1996_resel_25_h&p=1#LMS175895) as being a dog that has been trained (or is being trained) to assist a person with a disability.  These include assistance dogs, hearing dogs , mobility assistance dogs, epilepsy assist dogs as well as guide dogs.) Many disabled people rely on one and they provide an invaluable service. However, cost and lack of housing that will accept a disability assist dog are major barriers for disabled people seeking one.

***Question 6: Do you need specific information about household or general help? What do you need to know and why?***

**DPA response to Question 6.**

DPA supports the response from People First in their submission on this point. In particular there should be a question about support with healthcare. Some disabled people need regular support with procedures such as intermittent catheterisation or manual bowel evacuation e.g., as a result of a spinal injury or spina bifida.

***Question 7: Do you need specific information about health services? What do you need to know and why?***

**DPA response to Question 7.**

DPA strongly recommends asking questions around access to transport to health services, affordability of health services and digital access to health services ( telehealth) and whether people understand the health information they are given by health services .

In our experience these are all areas that are significant barriers to disabled people accessing health services in a timely manner and it would be hugely helpful to have up to date data on this. We would like to see data around disabled people access to specialist services such as physiotherapists, occupational therapists, speech language therapists, and mental health services. These are services which can make a significant difference for many disabled people but which many disabled people are excluded from accessing for a variety of reasons.

DPA also strongly urges that all disabled people, including those in residential services are asked the questions about access to health services. It is unacceptable to exclude disabled people on the basis of their living situation. It cannot be assumed that disabled people in residential facilities have good access to health services. In fact, the known poor health indicators for people with a learning disability [[5]](#footnote-6) make it particularly critical for health questions to be asked of disabled people in residential facilities and group homes.

***Question 8: Do you need specific information about employment? What do you need to know and why?***

**DPA response to Question 8.**

Questions in this section should include questions around the type or nature of employment; including if they are in permanent, contract, relieving jobs or are self-employed, and how long they have been in their current job or position.

Consideration should be given to whether the questions being asked will actually capture the nature of the barriers faced by disabled people seeking employment. DPA is aware from direct feedback from participants in our employment programme Mahi Tika [[6]](#footnote-7) that lack of digital access and accessible transport represent major barriers to employment for many disabled people.

DPA recommends that questions in this section should not be limited to the workplace or building but go more broadly for example questions could be asked around barriers disabled people face in applying for work (for example they may not have digital access to be able to apply for jobs online) or around getting to work (for example no accessible public transport, lack of disability parking).

For disabled people in work or seeking work, questions could be asked whether they use or have used an employment agency to assist with applying and obtaining work or accessing start – up funding for self-employment

For disabled people, in addition to the proposed questions we recommend questions be asked around whether they are able to work flexible hours since this is a significant barrier to employment for many. A question could be asked if they have access to parking spaces or parking provided. Both of these are important factors for many disabled people being able to take up or remain in employment.

***Question 9: Do you need specific information about transport? What do you need to know and why?***

**DPA response to Question 9.**

As mentioned above access to transport and parking has a major impact on some disabled people's ability to seek or obtain employment and access health services.

In addition to the proposed questions, questions could be asked (either here or in the earlier sections) around whether they need to drive to work, whether they need access to parking at their workplace because of their impairment, and if they experience difficulty in accessing transport to any health services. DPA is for example very aware of many disabled people facing major challenges in accessing transport to get to COVID testing venues and vaccination venues.

***Question 10: Do you need specific information about housing? What do you need to know and why?***

**DPA response to Question 10.**

Housing is a core issue for many disabled people. As mentioned previously all disabled people should be asked questions around their housing situation. In particular questions should be asked around what type of living situation they are in; home ownership, renting or residential care, or other, whether they are in accessible housing that meets their needs (note that the proposed detailed questions around modifications will not necessarily answer this since a house or room may be modified but still not meet their needs since the modification may not necessarily provide adequate access), if they are able to keep their homes warm and dry. It would also be worth asking questions around how affordable their housing is when considering things like rent or mortgage, rates, and maintenance.

Many disabled people are in temporary accommodation and have to move homes frequently. It would be worth asking people in rental accommodation how many times they have had to move homes in the last five years. If they are on the waitlist for social housing and if they have been able to access support to ensure their home is accessible. For people with a disability assist dog it would be good to know if they have experienced difficulty in getting housing because of their disability assist dog.

***Question 11: Do you need specific information about education? What do you need to know and why?***

**DPA response to Question 11.**

As stated previously, DPA believes that adults in residential facilities should be included in these questions. We support the points made by People First in their feedback on the Disability Survey. In particular the following:

*The UNCRPD recognises that disabled people have the right to an education, without discrimination and with equal opportunities. We need to identify barriers so that we can work together to eliminate them, so as to enable disabled people to reach their full potential and participate as equal citizens in society. This work aligns with the outcomes of the New Zealand Disability Strategy and action plans.*

***Question 12: Do you need specific information about leisure? What do you need to know and why?***

**DPA response to Question 12.**

DPA strongly recommends additional questions be asked about access to digital leisure activities including online games and movies streamed online; many of which are pivotal for many disabled people for both recreation/leisure and social connection. Yet all too often disabled people are not able to access many of these platforms due to lack of accessibility. For example, many on demand streaming platforms in NZ are not captioned, denying deaf and hard of hearing people access to these.

Many disabled people access public facilities such as libraries and community groups for leisure and companionship. It is worth asking questions around access to these.

As stated previously, DPA believes that people in residential facilities and homes should be asked all questions.

***Question 13: Do you need specific information about wellbeing? What do you need to know and why?***

**DPA response to Question 13.**

It is fundamentally vital that all disabled people in the Disability Survey are asked any questions around wellbeing especially around safety.

Questions should include whether they have sufficient income to meet their needs /buy everyday items (food, housing, medicines, heating),

Wellbeing questions could include; how easy it is to be themselves, if they have been discriminated against in the last 12 months, how well their life is going, how well their family is doing, whether they feel safe when out and about or at home.

**Additional Priority area**

**Digital Access for Disabled People.**

It is becoming very clear that digital access and/or a digital identity is increasingly critical for people to be able to carry out a wide range of activities from accessing health information (both personal and public health), vaccination passport, public services, banking, online shopping through to social interaction.

Hence it is vitally important to have good data around disabled people’s access to the internet and digital devices. DPA has previously collated some information around digital access for disabled people[[7]](#footnote-8) for the Digital Council We know that there are barriers around internet access that are specific for disabled people but more detailed data would be extremely timely and relevant.

Questions should not be limited to whether they have internet access at home but also ask around access to the internet at public places such as libraries, if they own a device that they can use for accessing the internet or if they rely on access to public computers, whether they have their own email address, whether they are able to do online banking unassisted, whether generally websites are accessible, if they need/use accessible digital devices, if they are able to access support that they need to learn how to use digital devices.

1. <https://ccsdisabilityaction.org.nz/assets/resource-files/The-State-of-wellbeing-and-equality-FINAL-ONLINE.pdf> [↑](#footnote-ref-2)
2. [Off the Record: An investigation into the Ministry of Health’s collection, use, and reporting of information about the deaths of people with intellectual disabilities | Ombudsman New Zealand](https://www.ombudsman.parliament.nz/resources/off-the-record) [↑](#footnote-ref-3)
3. [Ministry of Health unaware intellectually disabled people had died in its care, Chief Ombudsman report reveals | Newshub](https://www.newshub.co.nz/home/new-zealand/2020/07/ministry-of-health-unaware-intellectually-disabled-people-had-died-in-its-care-chief-ombudsman-report-reveals.html) [↑](#footnote-ref-4)
4. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html> [↑](#footnote-ref-5)
5. <https://www.health.govt.nz/system/files/documents/publications/health-indicators-nzders-intellectual-disability.pdf> [↑](#footnote-ref-6)
6. [Mahi Tika - Equity in Employment - Disabled Persons Assembly NZ - DPA](https://www.dpa.org.nz/mahitika) [↑](#footnote-ref-7)
7. <https://www.dpa.org.nz/store/doc/DPA-Digital-Council-Response-May-2020.docx> [↑](#footnote-ref-8)