

 Feedback from public consultation

on the Enduring Questions

19 September 2016

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**Introduction**

Over 80 people participated in the August 2016 workshop sessions focused on the enduring questions consultation. Representatives from government agencies, independent organisations, Disabled People’s Organisations, service providers and universities/research institutes attended the sessions.

Eighteen submissions were received during the online consultation on the enduring questions. The breakdown of responses was as follows:

* Disabled person – 2
* Family/whānau member of a disabled person – 1
* An interested individual – 1
* Disability sector worker – 2
* Responding on behalf of an organisation – 10
* Other – 2.

The overall thoroughness of the draft enduring questions document was commended by respondents.

Respondents stated that the introduction to the enduring questions document needs to include a timeframe. It should be made explicit that the document has a finite life to collect information over time.

Respondents’ comments relating to issues which were not with within the scope of the consultation on the draft enduring questions - have not been incorporated into this *Feedback from public consultation on the enduring questions* document. This includes operational issues about the delivery of services and the making of moral judgements by respondents.

It is also worth noting that very little feedback was received on some topics. These include:

* Topic 5 – Travel
* Topic 6 – Standard of living
* Topic 8 – Community and social life
* Topic 12 – Products and technology.

**General themes from the submissions**

Several general themes cut across many of the participants’ comments in the workshops and the online consultation.

*Topic descriptors*

Respondents commented that the introduction to each topic requires further detail and issues need to be made more explicit. What each question covers also needs to be further specified. In this regard, supplementary enduring questions may be required.

*Cross-cutting topics*

Many respondents mentioned wanting data by personal characteristics or impairment characteristics. Respondents also noted that it was not clear in the document that cross-cutting topics apply to all topic areas. These topics should be made quite explicit and separated out from other topics. The cross-cutting topics include the following:

* Disability, impairment and limitations
* Personal characteristics
* Attitudes and awareness
* Accessibility
* Personal autonomy (if it becomes a separate topic).

It was noted in the feedback that the order of topics should be re-arranged. Topic 17: Disability, impairments and limitations and Topic 16: Personal characteristics should become Topic 1 and Topic 2 respectively.

It was suggested that the cross-cutting topics follow the new Topics 1 and 2. The order of questions under each topic in the document also needs to be scrutinised.

*Disabled population is not a homogeneous group*

Many respondents emphasised that the complexity of the disabled population needs to be recognised. Disabled people should not simply be compared with non-disabled people. Disabled people themselves can be compared in terms of personal characteristics, impairments, health conditions, gender, ethnicity, regional location etc.

Of relevance also is that some responders did not like “disabled and others”.

*Defining disability, impairment and functioning*

A prominent theme in the responses was that the formulation of the enduring questions needs to be grounded in explicit definitions of “disability”, “impairment” and “functioning”. It was emphasised that New Zealand urgently needs a national approach to identifying disabled people in surveys and administrative data.

*New topics*

Two new topics were mentioned for inclusion in the enduring questions document:

* Families and social relationships of disabled people
* Legislation and funding.

Several respondents mentioned the importance of families and social relationships (including, for example, intimate relationships) to the wellbeing of disabled people.

The importance of legislating on disability issues and the provision of sufficient and appropriate funding were also highlighted as areas needing attention to make a positive difference in the lives of disabled people:

* What legislation supports, for example, education, work, community/social life, civic engagement?
* To what extent is legislation adhered to (compliance)?

*More questions required from an institutional/organisational/state perspective*

It was observed by respondents that there is too much of a focus on individuals in the enduring questions. Rather, the questions need to be posed more in a way for organisations, government etc (rather than simply disabled individuals) to answer. What can health facilities, for example, do to accommodate the needs of disabled people?

In this regard, it was also pointed out that the enduring questions document talks about doing things “on” disabled people rather than “with” disabled people. The tone of the document must embrace inclusivity.

*Support Services*

Respondents pointed to the importance of distinguishing between:

* disabled people’s access to mainstream and specialised services
* disabled people’s access to formal and informal supports.

*Barriers and facilitators*

Focusing on both barriers and facilitators for disabled people in all questions was a key theme in the commentary. It was stressed that “facilitating” rather than “enabling” terminology should be used.

*Accessibility of the enduring questions document*

The inaccessibility of the enduring questions documents for various groups of disabled people was mentioned. It was stressed that the document should be available in various communication formats: Plain English, Easy Read etc.

**Key respondents’ comments on topics**

As shown in respondents’ comments below, a wide range of views were expressed on the topics. Key issues raised in relation to each topic have been highlighted.

1: Labour market

More detail on Question One – what does it mean? Make explicit that **labour market systems** include:

* Employment status (self-employed) and if manager etc
* Labour force status
* Profession
* Under-utilisation and under-employment.

Paragraph Four in labour market refers to Article 17 – check if this is meant to be Article 27

Mention that **volunteer work** should be included in community and social life.

**Barrier** – address the fact that the **structure of the labour market and benefit system** is a barrier?
*“Talk about the barriers but needs broadening regarding disincentives. For example, there are parts of the benefit system which discourage people to take up work. A lot of people working for NGOs ask not to be paid because they end up getting less (economic disincentive).”*

Discuss **values of work** in the introduction - including skill advancement and social networking, and include details regarding the nature of education and training services, systems and policies

Question required on: How are **tertiary qualified** disabled people fairing in the labour market?

List education/training/qualifications as facilitator for labour market participation?

Add length of employment into Question One details.

2. Education and training

Discuss **benefits of education** in introduction – not just advancing skill/knowledge, but preparation for workforce, satisfaction, social networking etc

Discuss or specify **transitions** during the various stages of education/training and into employment either in a question or introduction.

How much time is allocated to **teaching teachers the skills required to teach disabled people**?

Add question about **achieving your own goals**. Feedback informing: *What does achievement mean? Getting a qualification or going on to get a job from your education gained?*

Break down education by **types of education** which is mandatory up to 16. Primary/intermediate/college and universities/polytechnics, but also include other **training** establishments and apprenticeships etc.

Specify split in legal/compulsory education and tertiary education (i.e. non-compulsory/choosing to go to university) in gap analysis. May need notation in document.

Add definitions for educational achievement/participation.

3. Health

Include **health conditions** in both in Health and Disability/Impairment topics?

Add **mortality and morbidity** to life-expectancy. Also, specify **suicide** (link with psychosocial impairments).

Do disabled people feel **informed** about their health conditions, does this differ from others? – Most likely, it should be moved to accessibility, given that it is part of understanding and receiving information.
*“Disabled people’s level of* ***health literacy*** *needs to be included (e.g. understanding of and access to health services.)”*

Add **prevention programmes** – look at this in more detail.

Better define **health products** and give more examples

**Bioethical** topic: Prenatal early screening regarding disability - there are ethical issues around that.

Detail is required on how well **health services** care for disabled people, include how well people are diagnosed. The health system often produces dual diagnosis – an indication that the health service is not meeting needs.

Note **ACC/non-ACC differences**. Disabled people who have access to ACC support have a different experience to those who do not – disparity.

**Rehabilitation** and retraining to return to work. There should be a question on health rehabilitation.

Specify **training of health** (and education) **professionals** in relation to how well do the services meet needs.

4. Domestic accommodation

Getting past discrimination by landlords’ attitudes/awareness
Add universal design as accessibility point

Domestic accommodation should look at/cover:

* Home ownership
* Private housing and social housing
* Community housing
* Tenure
* Affordability.

Questions Two and Three could be moved to Demographics/Personal Characteristics topic.

Mention cost/affordability as a barrier

5. Travel
Include details of **different types of transport**:

* Public transport – buses and trains
* Private transport – walking/driving/taxis
* Differences between these modes of transport
* Information needs: Does the person, for example, have a driver’s licence?

6. Standard of living

Investigate **time-use** and **conversion costs** implications in standard of living. Investigation should inform any need for question changes.

7: Support services

Clearer definition of support services

Differentiate between **mainstream vs specialised services.**

New question: To what extent do disabled people use **informal support** networks compared with **formal networks** and why?

Discuss informal supports in participation in community/social activities

Include point regarding service delivery consistency. Quality service is timely etc.

Add the word “consistently” to Question Four

Discuss **unmet need**

**Attitudes and awareness** **by support services** brought up throughout feedback – specify types of support services. For example, landlords of rental properties, WINZ employees etc

Types of services feedback requested specified:

* Community services card
* After-school care
* Information (health service)
* Support in leisure activities as well as day-to-day care.

**Support services need definition /detail around types of support** (include psychological, mental health, addiction services)

Question Four - differentiate between services, and should cover amount and source of funding (ACC vs non-ACC)– make explicit in introduction to this topic.

Specify income/cost as barrier to services.

8. Community and social life

Discuss impact of disability on sport and recreation, connectedness. Mention the importance of **being/feeling** of being in a community

Clarify participation as voluntary

Specify that **volunteer work** is a part of community and social life (not labour market) in the introduction.

9. Civic engagement and institutional trust

Explain civic engagement as a basic right of citizenship.

Rephrase statement: “the disabled community has distinct characteristics and goals” to "disabled *people* have distinct characteristics and goals..."

10. Crime and justice

Question One – add: “if patterns of victimisation differ, then why?”

More detail:

* Specify types of crime – e.g. cyber-based crime. Either as footnote for Question One or in introduction.
* Question Four footnote or detail in introduction about prisoner health and support

Discuss **rehabilitation** (including mental health and addiction services) of offenders as part of justice system (this is also part of support services?)

11. Personal safety and civil protection

Are levels of **emergency preparedness** different between disabled peoples and others? Question Four for households, individuals and informal networks.

Specify types of **victimisation**

**Access to violence and abuse services** – support services barrier.

More explanation on Question Four in Paragraph Four. Explain what agencies do.

12. Products and technology

Specify housing modifications as a type of product.

13. Attitudes and awareness

Make clear that this topic is cross cutting other topics.

Remove Question Four.
Change Question Three to: How are people’s attitudes towards disability and disabled people being influenced – now Question Three.

**Institutional context** – government programmes to affect/influence attitudes

Feedback showed Question Eight’s bracket text (good/bad/as a culture) was not understood as examples of answers. Move this bracket text to the introduction text and make explicit that these are examples. One comment said *“unsure if culture was the correct term but there is something about adapting to understand yourself and making yourself independent”*

Pre-natal diagnosis and outcomes are a bioethical issue. Feedback was received on bio-ethical issues. We need to have a better understanding of what bioethical issues are and if/how they should be in the document.

14. Accessibility

Put accessibility as a cross cutting topic, explain accessibility in labour market, education etc.

Flesh out types of barriers and facilitators for accessibility.

15. Self-assessed wellbeing and personal autonomy
Separate the two topics. Personal autonomy to become a cross cutting topic.

Change well-being and wellbeing to be consistent across document.

Question Five: Add “if so, why?” Read up further on **personal resilience** – this is next well-being trend.

Remove Question Six.

Self-assessed wellbeing should include:

* Feelings of belonging (and social exclusion)
* Social isolation
* Loneliness.

16. Personal characteristics

Personal characteristics should include:

* Geographic locations/regions
* Urban/rural
* Relationship status/marital status
* Household composition (relating to relationship)
* Income is in standard of living, however income may need to be crossed with other things (i.e. services)
* Socio economic differences - NZ DEP/median income
* Hapu /iwi
* Gender
* Citizenship
* Number of dependent children
* Type of communication (language, NZSL and Braille)

17. Disability, impairment and limitations

Make explicit that this is a cross cutting topic. Needs to be at the beginning of the document

Include:

* Types of limitations
* Health conditions – in health, however, may need to be cross-cutting
* Number of impairments.
* Cause of impairments
* Onset and duration of impairments
* Severity
* Disability self-identification

“Limitation” and “impairment” need to be defined.

Include a question on the **cost of disability**:
*“There should be a question on the “real” costs of living (and unmet need) for different groups of disabled people, including:*

* + *Appropriate technology/assistive technology*
	+ *Understanding of the cost of labour as a disability support, e.g., having a cleaner, household management, child care support*
	+ *Appropriate standard of living, meaning that people are able to have time and energy for some free time or leisure.”*