From: Shama Kukkady Out of scope

Sent: Wednesday, 26 January 2022 11:58 AM

To: Out of scope @msd.govt.nz>

Cc: ODI (MSD) <Office\_for\_Disability\_Issues@msd.govt.nz>; Brian Coffey

Out of scope

Subject: RE: NCTS Checklist

Kia ora <sup>Out of</sup>

Thank you for getting in touch with the Office for Disability Issues.

From having looked over the document, there seems to be very limited information that aims to capture whether or not the patient has a disability, and reasonable accommodations that they may require.

The Disability, Data and Evidence Working Group, are currently in the process of formulating guidelines for capturing disability through administrative data. I've attached draft guidelines that we have developed which may be of use to incorporate within these guidelines.

Other considerations, based on previous conversations we have had with disabled people would include:

- The surrounding environment/circumstance/context
  - Impairment may be dependent on current circumstance/ environment e.g. who is around, and power dynamics
  - Information may change depending on whether the format of communication is face-toface, form or who is taking information
  - No need for service in every circumstance.
- Avoiding repetition
  - Avoid having to needlessly repeat information when dealing with different people
- Trust, Confidentiality, and data privacy
  - Information sought is useful, with only information that is relevant being disclosed.
  - Will this information be used? Who will use it?
  - Question is not discriminatory or used against person with disability

- Trust with institutions (already low levels for some)
- Choice
  - "Prefer not to say" is included.
- Timing and purpose of question
  - Clarity of purpose i.e. "This question is for statistical..etc" purposes.
    - Question on accommodations / supports should be asked prior to the disability identity question
- Word preferences
  - words that are affirming/allowing
  - align with social model of disability

In addition to this, I would consider contacting Out of scope from the Ministry of Health, at Out of scope <u>@health.govt.nz</u>. Adam is currently working on creating a 'Patient Profile' within health systems which would allow disabled people to record their reasonable accommodations and 'alert' staff to those needs prior to attending appointments. He may have additional insights and suggestions to add to the operational guidelines.

If you have any further questions, I am happy to discuss this with you. Alternatively, I could help arrange for a mini-workshop with some of the Working Group members to provide further recommendations.

Best wishes,

Shama Kukkady