**People First Cognitive Testing Kōrero**

**What is this?**

On 23 March, Ministry of Health and Stats NZ ran a cognitive testing session with 9 People First members. We tested 5 questions designed to identify people with learning disabilities in either the Disability Survey or PPNHI projects. Below are the preferred questions we arrived at, followed by some notes from the session.

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| **Learning/Intellectual Disability Preferred Questions** |
| **1.** | **Learning/Intellectual****(Identity)** | Do you have a learning/intellectual disability? **Note: This does not include learning differences, such as dyslexia or ADHD.**  | 1. Yes
2. No
3. Prefer not to answer
 | * Identifying people with learning disabilities
 |
| **2.** | **Learning/Intellectual****(Independence)** | Do you sometimes need support to go to the doctor, go shopping or help when things go wrong? | As above | * Screening in people with learning disabilities who don’t identify
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**High-Level Learnings**

**Learning/Intellectual Disability:** People First members were strong against the use of the term intellectual disability and preferred ‘learning disability’. When both need to be used to identify non-People First members with similar impairments, learning/intellectual was preferred with an emphasis on learning first.

**Frontload Questions:** Asking lots of complex questions can be overwhelming for people with learning disabilities. To maximize accessibility, frontload any questions for this cohort to avoid fatigue.

**Questions for People, Not Analysts:** Questions only function if they work for the target audience. For people with learning disabilities only very specific questions work and even then, not consistently. Resist the urge to tweak questions and if you have to, develop them in partnership with People First. For an illustrative example, see below.

**‘Sometimes’:** Many people with learning disabilities also have Autism. If you say ‘do you need’, they will read that as ‘do you always need’. Add ‘sometimes’ to help mitigate this.

**Schooling Examples are Traumatic:** Many disabled people and especially those with learning disabilities had traumatic experiences in school. These examples are both distressing and distracting, avoid them.

**On Complexity: A Human Example**

Below is a transcript of a short conversation between a member of a People First leadership group and a support person. This conversation illustrates well the challenges analysts face when attempting to secure functional, consistent questions for people with learning disabilities:

**PF staff:** “May I ask you a question?”

**PF leader:** “Sure”

**PF staff:** “Do you have a learning/intellectual disability?”

**PF leader:** “Well, I don’t know.”

**PF staff:** “Are you a member of People First?”

**PF leader:** “Yes”

**PF staff:** “Who can be a People First member?”

**PF leader:** “You need to be over 18”

**PF staff:** “Do you also need to have a learning disability?”

**PF leader:** “Yes”

**PF staff:** “So do you have a learning/intellectual disability?”

**PF leader:** “Yes”

**Learnings:** Even when we ask what we deem to be the most direct and simple questions, it’s not a guarantee that individual people with learning disabilities will understand and respond predictably to that question. Answering questions can often be a disabling experience for many people with learning disabilities. The more complex the questions, the more likely they are to be disabling.

During this process we also asked People First representatives about the Washington Group style questions and it was reported to us that these questions are extremely confusing for people with learning disabilities. As such, we shouldn’t expect these sets to capture well people with learning disabilities. Great yardstick, but more evidence that they miss key equity sub-groups.