 

# Tell me about youSummary of Research Report

### October 2022

**Note**: this report talks about abuse which may be upsetting for some people to read about.

## 1. Acknowledgments

Thank you to everyone who chose to tell their personal stories about your lives, before, during and after being in care. Your resilience and continuing resistance is remarkable.

We also acknowledge the disabled people across Aotearoa who have never had the opportunity to tell their own stories about their experiences of care.

Thank you to the members of Te Kāhui Arataki, our Māori advisory group.

Thank you to the Royal Commission of Inquiry into Abuse in Care for asking the DBI to do this important project.

Thank you to artist Dale Scoles from Studio2, Crush Creative for the awesome report design and the Make It Easy - Easy Read team for the amazing translation.

Thank you Lana Kennedy and Neeve Wooltorton from the DBI who helped the research team with the project.

## 2. Who did this research?

The people who worked on this project were Brigit Mirfin-Veitch, Kelly Tikao, Umi Asaka, Eden Tuisaula, Hilary Stace, Robbie Francis Watene and Patsie Frawley.

## 3. Content Warning

This report talks about disabled people’s experiences of abuse and violence. If you don’t feel good when reading the report, take a break, do something you like and/or talk to your family, friends and support people.

## 4. Whakarāpopototanga Mātua | Executive Summary

### 4.1 Whakatakinga/Introduction

Many people, including disabled people, lived in State and faith-based care.

People had good, and bad experiences while they were in care. Some people were abused.

The Royal Commission (RC) of Inquiry into Abuse in Care was established in February 2018. The RC was set up to listen to people about their experiences of historical abuse and neglect in State and faith-based care in the period between 1950 - 1999.

The RC wanted to learn about the kinds of abuse that happened, to acknowledge survivors of abuse, and to make sure that abuse in care does not happen again.

Some disabled people did not know about the RC. It was also hard for some people with learning disabilities and neurodiversity to access the RC and to tell their stories.

The RC wanted as many disabled people as possible to tell their stories, so they asked the Donald Beasley Institute to set up the Tell Me About You project.

The project included people with learning disabilities and neurodiversity. We called them storytellers.

## 5. The Donald Beasley Institute

The Donald Beasley Institute (DBI) has a long history of working with people with learning disabilities and neurodiversity to tell their own stories, in their own way. The DBI also has experience reporting on the process of the closure of large institutions and how community-based disability services developed.

### 5.1 Aramahi | Methodology

There were four things that the Royal Commission of Inquiry into Abuse in Care wanted to understand from this project.

1. Whether storytellers knew why they were taken to the care, and if they thought it was a good idea for them to have lived in care.
2. What type of abuse and violence storytellers experienced in care.
3. Why they thought the abuse and violence happened to them.
4. How did the abuse and violence impact them, their family, friends, close supporters and community.

The researchers knew that some people who lived in State care might have not seen their experiences as abusive.

We also knew that people might want to talk about both good experiences and bad experiences.

In the Tell Me About You project, storytellers were asked about their whole lives, and not just experiences in State care. Storytellers were also able to choose how they shared their story.

For example, storytellers told their stories by:

1. chatting with tea and biscuits;
2. walking and talking through the places where storytellers have lived before;
3. sharing photos, films, music or other things that helped them to remember or tell their stories about care;
4. using art or poetry;
5. telling stories with trusted whānau, family, friends or advocates who knew them well;
6. communicating online through email, Zoom or online chats.

#### 5.1.1 Te Kāhui Arataki and Culturally Responsive Research approach

To make sure that Māori storytellers felt safe in the project, this project was guided by Te Kāhui Arataki.

Te Kāhui Arataki was a group of Māori advisors and researchers with lived experience and expertise of disability and State care from iwi and hapū from across the country.

Te Kāhui Arataki helped us to be respectful of Māori tikanga throughout the project.

#### 5.1.2 The storytellers

16 storytellers took part in “Tell Me About You”.

12 were male and four were female.

14 storytellers identified as European New Zealander, one as Sāmoan New Zealander, and one as Māori and European New Zealander.

All storytellers were aged between 45 and 75.

Ten storytellers had learning disabilities, three had autism, and one storyteller had a neurological disability.

At least three storytellers had more than one disability.

One storyteller participated as a family member alongside the storyteller who experienced care.

One storyteller used institutional records to tell the story of their disabled siblings.

Storytellers could choose to use their real name in the project or they could choose a different name so no one else would know who they were.

### 5.2 Kōrero/Stories

In the section below, you can read what the storytellers said about being in care. You can read the full stories on our website [www.abuseincare.org.nz](http://www.abuseincare.org.nz)

1. Why were storytellers taken into care and did they think it was right for them to have lived in care?

Storytellers’ understanding of the reason why they went into care was mixed. Some people had no idea why they ended up in care, while others knew exactly why they went there:

* “I was in Cherry Farm, sort of at the side. I think I was about 28 years old [when I went there]. I don’t know how I got there. I feel like I was born in Cherry Farm. Did you find out how I got there?” [Rawiri]

Some storytellers shared that they did not like being in care, which shows that they didn’t think it was right for them.

* “My mum found it difficult to manage me so I went to stay at Templeton for short stays and then eventually these stays got longer. [...] I didn’t want to stay at Templeton. I wanted to get out. Happy to leave yes.” [Jabert]
1. What type of abuse and violence did storytellers experience in care?

People experienced good and bad things in State care. Storytellers shared their experiences of physical and emotional abuse. Sometimes abuse happened to them many times.

For most people, if they did try to report bullying by other children they lived with or abuse by staff who were supposed to be caring for them nothing happened.

* “The staff were no good to me at Cherry Farm. They used to give me a needle in the arse. They would stab it into me. And give me lots of pills. I hadn’t done anything. I was scared of them. [They would] just knock me around because I used to play up and that. They used to ah, hit me. I got locked up in Cherry Farm. The room was empty. Only floor boards and a big door. I was in that room for a long time. Sometimes I used to hurt people too - I don’t know why I done that.” [Graeme]
* “I got put in a laundry bag once by staff and hung up high.

I told the big boss of Templeton on him – he got a warning.

I got strangled by another and that staff member got a warning also.” [David]

1. Why did the abuse and violence happen to storytellers who lived in State care?

One storyteller shared how there were not many people supporting her at the institutions. While there can be many different reasons for the abuse and violence, what she points out is an important opinion:

* “The institute felt “dark and cold” […] I think that the concept of institutions are not set up to care and look after the disabled people because it is built on a system that dehumanise disabled people. And I think that hasn’t changed much for how the current State care works. Care was about medication, changing, showering and other very clinical procedure that does not taken into account of the very individual needs such as human connection and affection.” [Lusi]
* “Because when staff didn’t understand me and expect me to do things that I wasn’t sure about, then yell at me for getting it wrong, then I would explode, they would just see me as a person who was trying to be naughty or out to be dangerous. And that wasn’t the case at all. I think there was a misunderstanding and I wasn’t being listened to is what the problem was.” [Allan]
1. How did the abuse and violence impact storytellers, their family, friends, close supporters and community?

Storytellers were often separated from their family by being in care.

* “Mum and dad came up and visited me, but it was hard leaving, saying goodbye to them.” [Michael]

Storytellers’ stories about their lives after leaving care were important to listen to. They made it clear what people wanted most about their lives in the community.

* “A good life is going and looking around shops, getting coffee. I’ll tell you a good thing right, if I’m on a radio show, you might hear my voice everywhere. I was on a radio show and I can still be on it. There’s a song I like. “I’ll be home for Christmas, you can count on me”. It makes me a bit happy. One thing that I know, stand up for your rights. You get together with someone and stand up. That means rights. That means rights.” [Graham]
* “I always say this, that everyone should be treated equally. I didn’t feel like I was treated equally before I started living in the community. I think when you are out in the community you have your own freedom and you’re not, you’re not told when to shower or when to eat and you have choices of what you want to do. Rather than what you were told to do. I have control on my own choices and more freedom too. I have a good landlord, a new couch and a new chair. I’ve been very settled here … I’m going to be living in the community until I’m an old man.” [Allan and Nathan]

### 5.3 Kitenga/Analysis of the Findings and discussion

After stories were gathered, story gatherers used the “ecological model of disability violence and abuse” to understand the stories and why storytellers experienced the abuse and violence that they did.

In the ecological model, there are four circles.

The storytellers are placed at the centre of the inner circle.

Around them is the relational circle which is about their family, friends and close supporters.

The next circle is the community circle which is about school, work and where they live. The last circle is the societal circle which is about society and the attitude from their wider world.

This model can tell you how people, places, and the society impact on the experiences you have as a disabled person.

#### 5.3.1 Personal level

Storytellers shared that when they were in care people did not listen to them or trust them.

They also did not have the freedom to make their own decisions, and people did not respect their identity or human rights.

#### 5.3.2 Relational level

Storytellers shared that they experienced physical and emotional abuse and violence by people who were supposed to care for them.

They also told us that other people made decisions for them, and that they were not given opportunities to spend time with their families and friends.

#### 5.3.3 Community level

Storytellers shared that sometimes they were not allowed to have visitors – even their family members.

They had limited access and opportunities to be part of the community.

They also did not get education and training that could help them to get meaningful employment.

#### 5.3.4 The Societal level

Overall, what we learned from the storytellers was that New Zealand law and policy did not respect disabled people’s rights.

It meant that they were able to be separated from their family and community.

It meant that disabled people were excluded from society and not treated fairly.

#### 5.3.5 How the four circles work together

The four circles are all connected with each other and together they create experiences for storytellers. For example, disablism is a type of discrimination against disabled people.

It led to things like separating disabled people from society by placing them into State care. This is called systemic abuse, which means it was not disabled people’s fault that they received this treatment.

It was society’s fault for not respecting disabled people’s rights to be supported to live the life they want in their community.

This discrimination was not always here in Aotearoa New Zealand. The separation of disabled people from their whānau, family and community was part of the impacts of colonisation.

## 5.4 Titiro whakamuri, kōkiri whakamua – Recommendations for redress

In order for the abuse and violence to not happen again, it is important that people who experienced these things are listened to and supported in the community to live well.

Their stories need to be told and kept in visible places in public, such as keeping the institutions as places where people can visit and learn about what happened before. People who provide services and make policy and law need to know about the disabled people’s rights set out in the United Nations Convention on the Rights of Persons with Disabilities [Disability Convention]

It is important that Article 12 of the Disability Convention is used.

Article 12 says that everyone is a capable person before the law, and that decisions about your life should be based on your rights, will and preferences. This means that you have choice and control over your own life.

All recommendations that come out of the RC must be put in place quickly. Most importantly, there must be a justice process put in place that is accessible to all disabled people who were abused in care.

### 5.5 Kupu Whakamutunga/Conclusion

The Tell Me About You project is a collection of stories from only a small number of disabled people.

We know there are many more disabled people in Aotearoa who also have stories to tell about being in care who were not able to be part of the project.

The DBI research team want to say thank you to every single storyteller for sharing their story. They were brave to tell their stories so that other people can learn from them. We are deeply grateful for their contributions.

**End of Summary of Research Report**