



Figure 1. A photograph of Janet holding her artwork: The art is an abstract collage. A painted grey CD evoking the gendered Venus symbol is foregrounded on a sea of forest green, royal blue and grey and brown crayon tracing

Janet Bailey is a mixed media artist, currently working out of the Studio2 Gallery, Ōtepoti / Dunedin.

No one knows for certain, but it is believed Janet was placed at Templeton Hospital (Christchurch) as a very young girl before being moved to Cherry Farm Hospital (on the outskirts of Dunedin). Without any traceable family, Janet would become one of the first women to be resettled from Cherry Farm as it began to close in the 1990s.

Janet loves music and dance and singing and cups of tea and stories.

Appropriately, therefore, Janet created the cover art from a deconstructed accordion case and compact disc, washed in her favourite green. The work travelled Dunedin as part of the Fringe Festival event "the road less travelled."

During the event a set of suitcases began by riding the carousel at Dunedin airport before members of public picked them up and put them down about the city.

# **Suggested Citation:**

Luskie, W., Murphy, V., White, D. & Wallace, C. Milner, P., Mirfin-Veitch, B. Tikao, K., & Frawley, P. (2019). "Mean As!" People with a learning disability telling and reading stories of relationships and sexuality. Dunedin. Donald Beasley Institute.

# **Hosted by:**



Donald Beasley Institute www.donaldbeasley.org.nz

# **Funded by:**



IHC Foundation www.ihcfoundation.org.nz

Just because you don't want to be creative,
Doesn't mean you don't have something to say,
And just because you don't want to be a leader,
Doesn't mean you don't know the way.

**Lucy Dacus** The Shell (Historian)

**Research Group:** Advisory Group:

William Luskie Mike Hammond (SDHB)

Vanessa Murphy Anna (Rape Crisis)

Darryl White Gary Williams (Hei Whakapiki Mauri)

Cheryl Wallace Kelly Tikao (Kairangahau Māori Researcher)

Brigit Mirfin-Veitch Katie Wishler (PACT Group)

Paul Milner Louise Pearman (University of Otago)

Hahna Briggs William Luskie (Self Advocate)

Niha Jalota Vanessa Murphy (Self Advocate)

Kelly Tikao Darryl White (Self Advocate)

Patsie Frawley Cheryl Wallace (Self Advocate)

# **Ethical Approval:**

Southern Health and Disability Ethics Committee

(NZ/1/7B02113)

# **Acknowledgement**

# Mā whero, mā pango ka oti ai te mahi

When the mahi (work) of unpacking each of the seven stories that now populate the "Mean As! Library was complete and the researchers with a learning disability sat down to reflect on and write their report, they imagined the project as a jigsaw. A jigsaw, they said, that couldn't be completed without the work of many and the skills, creativity and care of each, differently shaped piece.

In this sense, therefore, "Mean As! has begun a much wider project. Namely to draw people into a community of listeners and actors, connected by the narratives of eight men and women, simply asking for the same right to live and love the way other New Zealanders do.

Placing people with a learning disability at the heart of the project transformed its kaupapa in a way that was consistent with their aim. "Everyone brought value to the project," they wrote, "because we all saw people as equal – nobody is higher or lower." To all those who embraced their kaupapa and brought life, vitality and resolve to the "Mean As!" Project, we are extremely grateful. Those who gifted their time, creativity and resources include;

- The IHC Foundation who first recognised the Project's importance and funded the research as a way of giving voice to the formally voiceless.
- Mike Hammond (SDHB), Anna (Rape Crises), Katie Wishler (PACT Group) and Louise Pearman (University of Otago) who set the waka of this project off on a safe and well considered trajectory and especially to Gary Williams (Ngati Pouru) and Kelly Tikao

(Waitaha/Kāti Māmoe/Kai Tahu) who helped to ensure the project included whaikaha Māori voices in ways that would resonate within their communities and align with tikanga Māori.

- Mike Brummitt, Stacey McCullough, Katie Wishler and Gary Williams, who introduced people with a story to tell to the project and continued to offer support to navigate the risks and possibilities of narration.
- Aiden Geraghty, Tairoa Flanagan, Lucia Veitch and Sam Orchard, who read, listened and answered the stories and instructions of Storytellers with their art.
- Megan Brady and Kay Murray for opening the door to Studio2 and the creativity of all of the artists who work there, but most especially to Janet Bailey and Kama Warburton whose work adorns the project's cover and the narrative "Love yourself pretty much."
- Actors Kelly Tikao, Rihari Taratoa-Bannister, Craig Story, Bella Veitch, Sof Scott and Brittany Sillifant for giving Storytellers a voice in the "Mean As!" Library and Britany and Ellie Swann (Otago Actors) for connecting and corralling their talents.
- **Dr Michael Holland** (appropriately Mike) who recorded, edited and formatted all of the stories in the "Mean As!" Library. Mike invited us into the Otago University Music Department studio and his own home when that became difficult, calmed nervous actors with his quiet professionalism and offered invaluable insight about the place of voice in research.
- **Lisa Hutchison** (Crush Creative) who brought our report formatting into the 21st Century.

- Brigit, Paul, Kelly and Niha (Donald Beasley Institute) and Hahna Briggs, who stepped into people's lives to gather stories without knowing where they might take them.
- Assoc. Prof. Patsie Frawley (Deakin University), whose drive and commitment, both to inclusive research and sexual citizenship galvanised and guided the project.

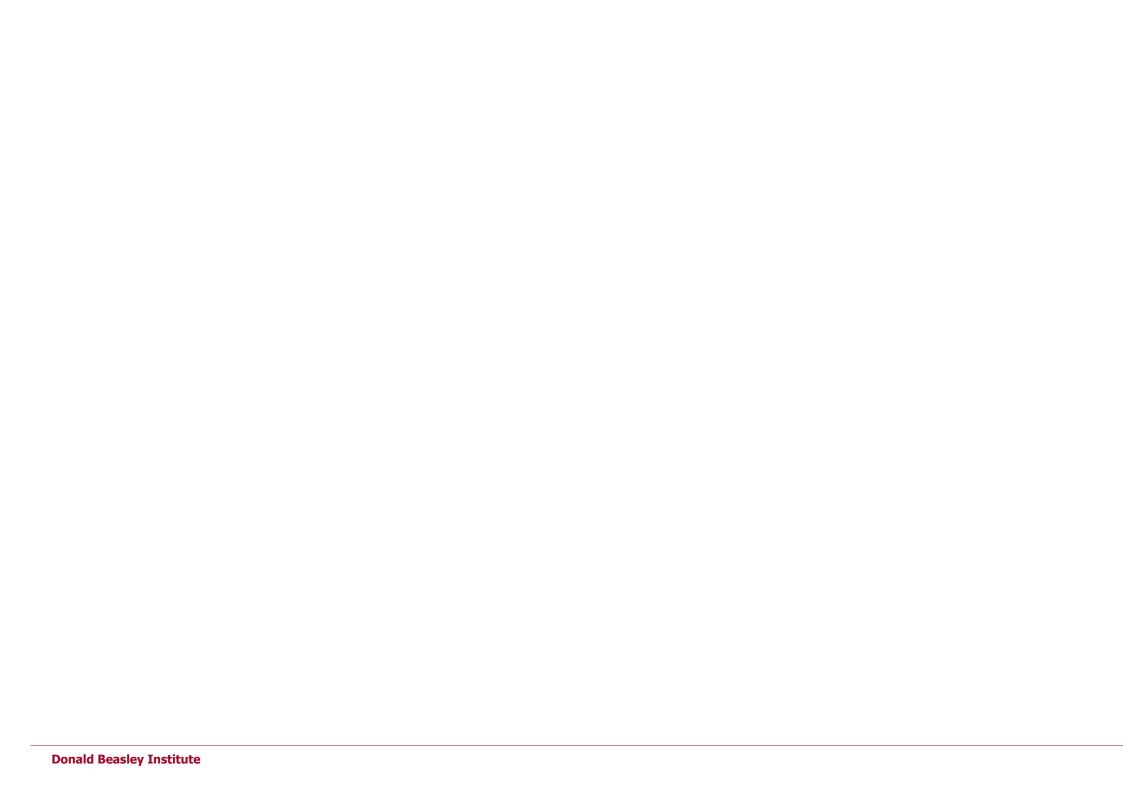
But most importantly;

- William Luskie, Vanessa Jane Murphy, Darryl White and Cheryl Wallace, who listened with the empathy of an insider's ear to stories that were sometimes difficult to hear. Together they have brought fresh ideas to a research space dominated by the voices and theorising of academics and other professionals, greatly expanded the horizons of Inclusive Research Methods and brought (biscuits and birthday cards) and the very best attributes of humanness to the task of reading and responding to the life stories of those at the very margins of ordinary citizenship.
- 8 Storytellers, brave enough to gift themselves to the "Mean As! Library, knowing that the stories they created would need to do the talking for them. They are the first unfiltered stories of relationship and sexuality told by whaikaha Māori and New Zealand men and women with a learning disability and therefore simultaneously represent a bequest to people with a learning disability and the wider communities of self-advocacy and a call to action to all those who find the difficulty Storytellers have living and loving the way we do, dehumanising.

William, Vanessa, Darryl and Cheryl believe the jigsaw they helped create needs to be seen as a beginning rather than a completed project. In their imagining, there are many more pieces that need to be added if people with a learning disability are to experience the same kinds of intimate citizenship other New Zealanders do. In this report, you will hear them speak of the sense of responsibility they feel to take the stories into the community and to change organisations and habits in ways that might also transform the story telling of future generations of whaikaha Māori and people with a learning disability. In a sense, theirs is a challenge to us all. To meet within the kaupapa of equity – nobody higher or lower, and to create a more human future by telling, listening and responding to each other's stories.

# **Table of Contents**

Introducing the "Mean As!" Project		Stories told and read by people	
Who we are: The research group	1	with a learning disability	
Why we were interested in the project	3	About the stories	1.
The Donald Beasley Institute	3	Telling Māori stories	1.
Doing the research	4	Ko te Pūrākau o Tipa	1.
What the "Mean As!" Project set out to do	4	Ko te Pūrākau o Tipa	1
Storytelling and story gathering	4	Key Messages: Ko te Pūrākau o Tipa	20
Working with the stories	5	I am a good man	2
Reading and listening to the stories yourself	7	I am a good man	2
Taking care of yourself as you read	7	Key Messages: I am a good man	20
Using the "Mean As! Report and Library	8	I've got this chance now and I don't want to blow it	29
What's in the "Mean As!" Report and Online Library	9	Key Messages: I've got this chance now and I don't want to blow it	34
Why we think the research is so important  What needs to happen with the stories and the research	10 10	Sometimes I write letters	3
		Key Messages: Sometimes I write letters	4
		We don't jump fences anymore.	4
		Key Messages: We don't jump fences anymore.	50
		I wish we were current	5
		Key Messages: I wish we were current	6
		Love yourself pretty much, before you love anyone else	6
		Key Messages: Love yourself pretty much, before you love anyone else	7
		Te reo Māori glossary	7



# **Introducing the "Mean As!" Project**

# Who we are: The research group

In the "Mean As!" research project, people with a learning disability<sup>1</sup> worked together as Storytellers and researchers to create an online library of life stories about sexuality and relationships. This reseach report has been put together by the "Mean As!" Project research group.

In the research group, four researchers with a learning disability were supported by four academic researchers to; listen to, talk about and to develop what we thought were the key messages Storytellers left in their stories. We all came to the project from different places and we all had different reasons for wanting to help.

### <sup>1</sup> Like National Self-Advocacy DPO People First New Zealand Ngā Tāngata Tuatahi, we prefer to use the term "people with a learning disability" instead of "intellectual disability" when we are talking about people from our community.

# **William Luskie**

I am known as an ideas person. A connector and a collector of people and their ideas. I am often connecting with theories by reading as much as I can. I am especially interested in reading about employment for people with a learning disabilty, citizenship, relationships and sexuality...and anything else that catches my eye.

I am a member of People First, have been a member of DPA and am currently on Advisory Boards at CCS Disability Action and the



Figure 2. A photograph of William standing beside the Donald Beasley Institute entrance plate

Ministry of Health. In my weekly life I am a member of the GASP dance collective. I attend political and disability related meetings across Dunedin and I am an artist. This year I received the Attitude Leadership Award.

I first came to the Donald Beasley, as a participant in a research project and then on a work experience placement. I liked that they listened to my ideas and have worked on a number of projects with researchers at the DBI since. I have also presented papers at national and international conferences and have made an online video for students completing their Graduate Diploma, Disability & Inclusion at Deakin University (Melbourne).

# **Vanessa Jane Murphy**

I work at Cargill Enterprises as a manufacturing assistant doing a variety of jobs like cups and headsets. I have a pet dog called Asha. She is a labrador. Llike horses and love cats and dogs. All kinds of animals really.

I come from Fairlie. It's a small farming community in the McKenzie Country.



Figure 3. A photograph of Vanessa standing outside the Donald Beasley Institute

I think that explains my love of animals. I have also driven a tractor. And a quadbike.

This is the first time I have worked with the Donald Beasley Institute. have really enjoyed listening to the stories. Some will stay with me for a long time. I especially liked the "Good man" poem.



I have lived in Mosgiel all my life. I like to think of myself as a supportive and helpful person. I keep up with current affairs and I love travelling. I also enjoy public speaking and have even MC.ed a local fashion show.

I was a bit nervous about becoming a researcher, but really enjoyed the chance it gave me to be the helpful and



Figure 4. A photograph of Darryl standing beside the Donald Beasley Institute entrance plate

supportive person I want to be. Slowly I came to trust my own voice and in the end found the chance this work gave me to express my views very rewarding.

I think one of the most important things about this library is that it people with a learning disability have had the chance to talk about themselves using their own words. Sometimes beautifully spoken words. This has been a new experience for me and, like Tipa, I hope the stories help other people with a learning disability living in the community.

# **Cheryl Wallace**

Like Darryl, I was born in Mosgiel too, but I have also lived in Balclutha and Gore, I am on the National People First Committee and my real passion is helping to start new groups in smaller rural areas. I am interested in other people with a learning disability getting their voices heard and so became involved in starting the first People First groups in Balclutha and Gore.



Figure 5. A photograph of Chervl standing outside the Donald Beasley Institute

I am continuing to help groups start by mentoring a new group in Oamaru.

I have had a long relationship with the Donald Beasley Institute. Almost twenty years ago I met the research team when I visited in my role as the first national woman president of Ngā Tānga Tuatahi - People First. I knew Brigit before then and I have helped out on a number of research project over the years.

This year I started to learn Te Reo Māori. In this project I really engaged with the two Māori pūrākau (stories) and believe anyone who wants to have their story told should be able to tell it in the way that lets others know who they are. Watching other people with a learning disablity grow and come out of their shell and do things they never thought they could is so rewarding. It has been my journey too.

# Why we were interested in the project

What we all liked about the project was that it gave people with a learning disability the chance to speak for themselves. Because the "Mean As!" Project, allowed Storytellers to tell their own stories their own way, we had the chance to learn how things were for them directly. As researchers, we wanted people to learn from our stories too, because our stories are something like theirs, even though we came to the research for different reasons.

**William** had read a lot about sexuality, relationships and disability and wondered why nothing much was being done in New Zealand. William had read things that Tom Shakespeare wrote about work being done by groups in Ireland and in other places and wanted to become involved in getting something done in New Zealand.

**Vanessa** heard about the project at work and was interested in listening to other people's stories. She said people with a learning disability don't often get to hear each other's stories.

**Darryl** met Paul from the Donald Beasley Institute at Rosemary Scully's book launch. Rosemary is an advocate and life-member of People First (and now author). Darryl was interested in finding out more about the Donald Beasley Institute and disability research. As an advocate, Darryl was interested in how research can help people with a learning disability.

Through her work at People First, Cheryl thought that lived experiences are really important and helps you think about how things are for your peers. Cheryl believes we all need to be able to get access to what you like in life and that people with a learning disability can help each other to do that.

# The Donald Beasley Institute

The Donald Beasley Institute (DBI) was the place that had the motivation to get the "Mean As!" Project done. They created the space for the research to happen and employed researchers to do the story gathering. They also did all of the administration and kept the project going.

The DBI started to talk to people with a learning disability about relationship and sexual rights a long time ago. Five years ago, they invited Patsie Frawley to come over and run workshops about sexuality and relationships.



Figure 6. A photograph of Associate Professor Patsie Frawley and the Cover of the Sexual Lives and Respectful Relationships Peer Education and Program Partner Manual

Patsie told everyone at the workshops about the work people with a learning disability were doing in Australia as peer educators in the Sexual Lives and Respectful Relationships program to educate other people with a learning disability about sex and their rights. This program also uses people's own stories. You can see their work by going to their website www.slrr.com.au

Some of us were at those workshops. For most of the people there, the workshops were first time we had been able to talk about sex without feeling judged. It was the first time we had talked to other people with a learning disability about sex too.

We think it is so important to get people's messages about sex and relationships across. It is important to listen and think about what people are saying carefully and respectfully.

# Doing the research

We think the research was like a jigsaw puzzle. We all brought different things to the research. We were all of value to one another – we fitted together like a puzzle. Everyone's contribution was valued.

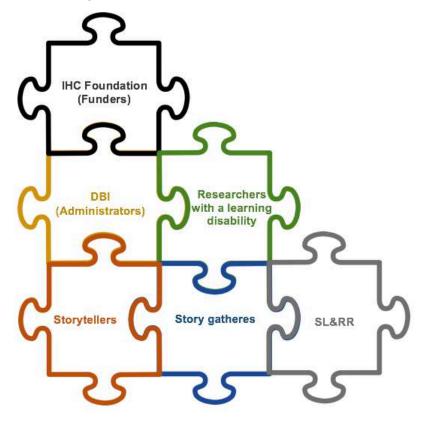


Figure 7: An image of interconnected jigsaw pieces with the titles of organisations and groups who partnered to create the "Mean As!" Online Library. Included as pieces are: IHC Foundation (funders), DBI (Administrators), Researchers with a learning disability, Sexual Lives and Respectful Relationships Program

Everyone involved brought value to the project by reading and listening to the stories because we all saw people as equal to us – nobody is higher or lower.

# What the "Mean As!" Project set out to do

The "Mean As!" Project had three main goals:

- To develop a library of 12 stories told by people with a learning disability that self-advocates and community and disability services can use to think about our human rights.
- To build connections with and educate community health and disability support providers about how best to meet our relational and sexual support needs.
- To do our own research and to add our voices to research trying to better understand how people with a learning disability experience their own relationships and sexuality. We wanted to do research that was "by" people with a learning disability "for" people with a learning disability.

To do this, we needed a library of stories to listen to.

# Storytelling and story gathering

The stories were gathered by the researchers (story gatherers) who met with Storytellers and recorded what they had talked about so that people's stories could be brought out into the open.

The Storytellers chose who they wanted to work with them on their story. They chose their own story gatherer by watching Youtube clips of each story gatherer introducing themselves.



Figure 8. A sequence of screenshots taken from the Youtube clips the five story gatheres made to introduce themselves to people thinking about becoming a storyteller. The story gatherers are (in order) Brigit Mirfin-Veitch, Hahna Briggs, Paul Milner, Niha Jalota, Kelly Tikao

The Storytellers were also able to choose how they wanted their story to be. They could tell their own story their own way and the story gathers and Storytellers worked together until each Storyteller was happy with their story.

Each person's story is different. The Storytellers present their stories to us the way they wanted to. Thumbs up to that! This way they come off the page. One is like a letter and one is like a song.



Figure 9. An image that lines of the covers of all seven stories in the "Mean As!" library

We are not allowed to tell you who the Storytellers are. You are not allowed to identify people in a research project, even if they want you to. Because Storytellers have to change their names and parts of their story, we think it is important that they got to choose their pictures and the way they wanted their story to be. This way they have told their own story. They have left themselves in it. Using art and telling stories in different ways also reminds people reading them that these are real people with real stories to tell.

A recording was also made of each story, so we could listen to the story. We think we got to know the Storyteller better this way. We listened to them as if they were there with us. We felt we knew what was important to Tipa, because he chose to tell his story as a Māori myth (pūrākau) and because he chose to use te reo Māori (Māori language). He couldn't tell his story properly without these words. And we felt like we knew the man who wrote "I am a good man" a little better, because he chose to use the picture of the pool balls as part of his story. Stories presented this way tell a lot.



Figure 10. Photographs of the cover art used for the pūrākau (story) Ko te Pūrākau o Tipa and of the carved tapatoru (triangle) pool rack used in the story I am a good man

We think the Storytellers chose to give their stories to the library as a gift. We think they were really generous to tell their stories. We think they did it to help others because they had something to offer. It was their gift to give.

The way to respect their gift would be to use their story to change things for people with a learning disability.

# **Working with the stories**

The research group would come together at the DBI every two weeks. We'd warm up to listen to the story by going over what we had said and did last time. That way we could see if we still thought the same way or bring ideas that had been on our minds during the week. The stories would stay with you! We would always begin with a cup of tea and a catch-up though! And we would always end by talking about something other than the stories. This was important because sometimes we felt sad or upset after listening to them.

Each story had been recorded, so we could listen. This was really good. When we were listening, we could take the story in. Really listen to what the Storyteller was saying. And it gave us time to think about what we wanted to say too.

Most times there was a silence at the end of a story while we gathered our thoughts. It was like the person was really talking to you.



Figure 11. A photograph of the research group working together. In the picture Vanessa is sharing her reflections about the story the research group have just listened to. Other members of the research group sit listening and Paul is recording Vanessa's idea by wring them into a WORD document on a laptop. Pictured sitting about the table (clockwise) are; William, Vanessa, Darryl, Brigit, Cheryl and Paul

It was our job to find out what the story really said to us. We reacted to the stories – tuned into them. We were hyper-tuned!

We thought hard about the stories. Our heads and our ears were listening. We had our thinking caps on. We were all trying to figure them out and most of the time we didn't want to hear the last word. We wanted them to roll over and over .....

Story by story we would talk about each one, including how listening to the story felt for each person in the research group. We would go around the room, hear how it felt for each of us and talk about what it was like for the Storyteller too. We would think about why things happened the way they did and why the Storyteller might have made the decisions they did.

The kinds of questions we would ask ourselves after listening to the stories were:

- How the story made us feel.
- What we thought the Storyteller was trying to tell us.
- Why their story was important to them and why it was important for others to hear.
- Why they might have told their story that way and why they might have made the decisions they did.
- And what needed to change if people with a learning disability were going to tell better stories in the future.

Paul or Brigit would write down what we said and some of the big ideas were written out on the board. We learned big ideas are called "themes" in research. What we had to say was then grouped together. They are our Key Messages and in this report, we have presented them after each story.

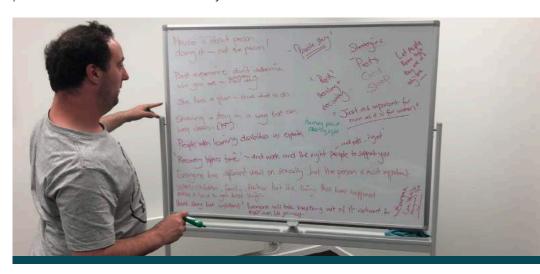


Figure 12. a photograph of William writing and checking some of the research groups big ideas on a whiteboard

Figure 13. A photograph of the cover of the research group's Key messages for the story Love yourself pretty much

When we listened across the stories some themes and concepts kept coming up. We think these give everyone a clue about some of the more important things people with a learning disability are telling us they want addressed.



Everyone will hear different things in the stories. When you listen, or read a story, we would like you to think about what the key messages are for you. You could start by asking the same set of questions we did.

Each Key Messages section ends with the same question.

# What do you think?

# Reading and listening to the stories yourself

The eight Storytellers have all shared very personal things about their lives because they wanted the library to be a place where people could come to learn more about relationships and sexuality in the lives of people with a learning disability in Aotearoa / New Zealand.

Some of the things people talk about in the stories are not easy to hear. Almost all of the Storytellers thought that it was imprtant to talk about some of the bad things that had happened in their lives, as well some of the good things. As we listened and shared our ideas, we realised that similar things had happened in our lives and we worried that they may have happened to you too.

# Taking care of yourself as you read

If the stories are upsetting or bring up issues for you, there are people you can talk to. Some of the people or organisations that you might want to contact in Aotearoa / New Zealand are:



If you would like to talk to someone about a problem you are having or to know more about support services in your community, you can contact

Citizens Advice Bereau



If you would like to talk about sex, contraception, family planning or sexually transmitted infection testing you can contact:

- NZ Family Planning
- Sexual Health Clinics funded by your **District Health Board**





If you would like talk to or get advice if you are or think you may be lesbian, gay, bijsexual, transgender, intersex, queer, takatāpu, you can contact;

- OUTLine
- · Tawhanawhana Trust
- Rainbow Youth





If you want to talk to someone because you are a woman living in fear or in a violent relationship or because you worry about someone else's safety, you can contact

- · Women's refuge
- Shakti
- Rape Crisis







If you want to talk to someone because you are are violent towards your partner or others in your family and want to stop you can contact





If you want to talk to someone because you are are thinking about harming yourself or worried that someone may be suicidal you should contact

Lifeline Aotearoa

# Using the "Mean As!" Report and Library

In writing this report, we wanted to share some of our experiences and ideas too. The people we thought about first were other people with a learning disability. We want to say to you that you are not alone. Others have felt and lived through the same things you have.

We also think that telling stories like those that have been collected in this research project can help people with a learning disability to know they have the same rights other New Zealanders do, to meet someone special, fall in love and to have intimate relationships. Those of us who are involved in self-advocacy groups know that telling stories and talking to each other is a way that people with a leaning disability have used to challenge discrimination and abuse. We hope the library will help to get people with a learning disability thinking and talking about relationships and sexuality.

This research project is called the "Mean As!" Project because it was what Storyteller Tipa said about his pūrākau (story) after listening to it for the very first time. He wanted his story to be different and to make a difference. In Aotearoa New Zealand, when someone says "Mean As!" they are saying something is really awesome. Tipa thought his story was "Mean As!"

Our hope is that the "Mean As!" Library and our Key Messages will become a resource for the community of sexual health educators, schools, disability and all other community support services that can help us to live and love in all of the ways that other New Zealanders do.

Now that the project has finished, we would like to find ways to work with the community to develope the tools and resources we need to carry on the conversation and to educate people about our relationship rights and needs. We have lots of ideas!

This was the first chance whaikaha (disabled) Māori and New Zealanders with a learning disability have had to tell stories about their own sexuality. While lots has been written about people with a learning disability, it hasn't been written by us. We think the library is important for this reason. It is our history! We also think the Storytellers have shown everyone new and more interesting ways to tell our stories.

This project was also the first time many of us in the research group had the chance to become a researcher. Although it took a little time for some of us to find our voices, we think what we have to say about the stories is important, because we have a learning disability. We think the "Mean As!" Project shows why it is important to do "nothing about us, without us." We think including people with a learning disability is really important if research is going to speak for us.

# What's in the "Mean As!" Report and Online Library

In the second part of this report, we have included all seven stories, followed by what we thought the story's key messages were.

The other way you can see (and hear) the stories is by visiting the "Mean As!" Online Library.



Figure 14. Photographs of the process of recording the stories. In one photograph, actor Brittany Sillifant is pictured speaking the story into a microphone. In the other photograph, music producer and University of Otago lecturer, Dr. Mike Holland is recording the story at the Albany Street recording studio

Actors read and recorded each story<sup>2</sup>. You will find these recordings in the "Mean As!" Library too. If you "click on," to them, you can listen to each story. You might want to listen by yourself or you might want to listen to the stories in a group – just like we did.

You will also find two reports in the library – this report and another one written by the academic members of the research team. The

second report tells the story of creating the "Mean As!" Library and in it, academic members of the project team describe why they thought the research was so important, how we went about doing the research and why it was so important for people with a learning disability to lead the project.

The web address for the Mean As! Library is donaldbeasley.org.nz/projects/mean-as

# The "Mean As!" Library contains these resources

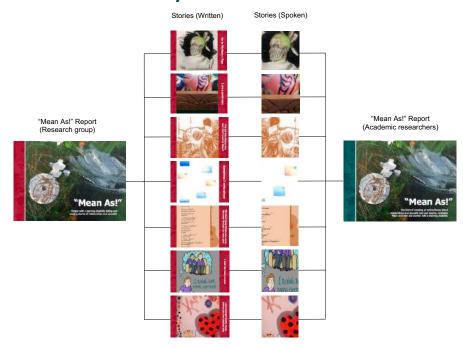


Figure 15. A flowchart that describes how the "Mean As!" Library is organised online. Included in the picture (as vertically organised images) are; the front covers of four (written) stories, radio buttons of spoken versions of the same four stories, the front covers of the research group's (written) Key Messages for the same four stories, the front cover of the "Mean As!" Research Group's Project Report, the front cover of a project report written by academic members of the research group.

<sup>&</sup>lt;sup>2</sup> The actors who volunteered to give voice to the stories came from the University of Otago School of Performing Arts, Arcade Theatre Company, personal connections and the Otago Actors Agency

# Why we think the research is so important

A lot has been written about the lives and sexuality of people with a learning disability – but not by us. The seven stories in the "Mean As!" Library are the first in New Zealand to be written by whaikaha (disabled) Māori and men and women with a learning disability living in New Zealand communities. There is a little bit of every person with a learning disability's life in every story.

The stories are about people's lives and experiences, told by them. They are familiar to people with a learning disability. This research is leaving something behind too. A "legacy," or "a tattoo." Something that is personal and near to us, not far from the lives of people with a learning disability. The "Mean As!" project and its stories are ours. They belong to us and our community and together tell our history. You can put yourself in the picture too. They give you ideas.

People with a learning disability find it hard to talk about relationships or to get answers to the questions we have about sex. It's especially hard for people living in a disability support service. They worry that everything they ask or do gets written down in a D.I.A.R.Y. (whispered by a research group member). People don't talk to us about it. And people with a learning disability don't talk to each other about it either. We don't know why that is!

After listening to one of the stories, we decided that for lots of people with a learning disability, finding sex was as hard as finding a needle in a haystack. When we talked more about why this might be, we thought that other people not talking to us about sex or expecting us to sexual was part of "hay" that made it so hard to reach the "needle" of a loving and intimate relationship.

Because no-one talks about sex and relationships, it's not always easy to know what life can be like. When we hear stories about people with a learning disability doing things like living together and getting married – well that was something we thought could change everything. Some of us were so shocked (in a good way) when we heard people with a learning disability were married!

The stories in the "Mean As! Library are real. They are on the page and we need to lift them off the page. We hope the stories get other New Zealanders talking about and understanding more about the real lives of people who live in their community.

We hope this project helps them to change what they do so that the next stories in the library will be no different from the stories other people in the community might write about themselves.

# What needs to happen with the stories and the research.

We say that; "these stories have heart-value - not dust-value". They must not sit in a report – they must come to life and be used.

We want the stories in the "Mean As!" Library to become known and familiar to all people with a learning disability. We would like people with a learning disability to know where the stories are and how to access them.

We would also like to take the stories to people with a learning disability, by using the People First self-advocacy networks or by presenting at conferences or in other places that people with a learning disability are talking about how their stories can change each other's lives.

We like that each story has been recorded separately. You can listen to each one by itself in the library. We think the stories come to life this way and they are much more accessible to people with a learning disability. You just need to "click on" and listen. We would also like to record our key messages, so they are more accessible to people with a learning disability too.

We think that pamphlets could be developed from our key messages too, or we could make some short film clips that could be used in discussion groups that pick up on some of the main ideas that kept coming up in the stories. We think this would help people with a learning disability to talk more about their lives and what

they wanted to change. We have seen it work when people with a learning disability role play real life events to each other and it would help people with a learning disability know what to do if they found themselves in the same situation as the Storytellers.

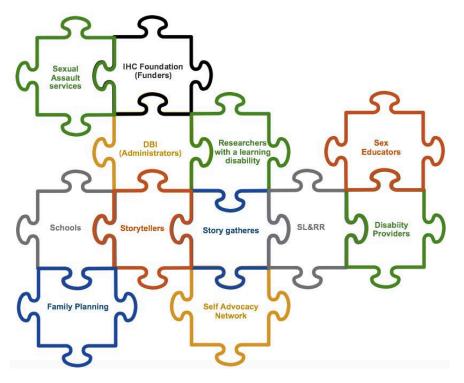
We have also seen non-disabled people woken-up by disability theatre. There are lots of possibilities. We think that working with other community organisations to create some of these resources would find useful is a good idea.

When we thought about what we wanted the words in the project to turn into, we thought we had created an opportunity for people to talk to each other about the stories and whether what happened to the Storytellers was fair. That is why we have libraries after all!

But we didn't just think the stories would be used by people with a learning disability talking to each other. We think the project gives us the chance to start talking to community organisations about how we can help each other. People talking to people as equals – nobody is higher or lower.

Just like the jigsaw puzzle we put at the start of this report, we think we can all be of value to one another if we work on projects that needed us to fit together to change the picture for people with a learning disability. The jigsaw puzzle can grow to include communities of people and organisations who come together to get this work done.

Figure 16. An image of same interconnected jigsaw pieces used in Figure 7, expanded to include the titles of other community organisations and groups (as jigsaw pieces) who could come together to change the lives of people with a learning disability. Additional pieces added to the jigsaw include; Sexual Assault services, Sex educators, Disability Providers, Self-Advocacy networks, Family Planning, Schools



The "Mean As! Library can become a tool for us all to think about what needs to be known and understood to support the relationship rights and sexuality of people with a learning disability.

- Schools could work with disabled students by using the stories and key messages to design projects to address bullying.
- The LGBTIQ+ community could work with gay, lesbian, bi and trans-sexual men and women with a learning disability by using the stories and key messages to design projects that help them find their way to their community.
- Disability service providers could work with people with a learning disability by using the stories and key messages to design projects that help people live and love the way they want to.

• Sexual violence services could work with men and women with a learning disability by using the stories and key messages to design projects that help them educate and provide support to those most likely to experience sexual assault.

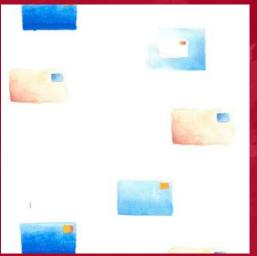
By working together, the project's words will come to life. We think doing this will show the people who shared their stories just how important they are.

# Stories about relationships and sexuality told and read by people with a learning disability















# Stories about relationships and sexuality told and read by people with a learning disability

## **About the stories**

Telling people about your life isn't always easy, especially if it's about things that have happened to you, or that you have done. You need to trust the person you are telling your story to. We think all of the Storytellers were brave.

In this chapter, you will find seven stories, told about relationship and sexuality told by people with a learning disability. Every story is different because every Storyteller decided how they wanted their story to look. Every story is also written in the Storytellers own words. It is their story after all!

We want to remind you that some of the stories are hard to hear. Almost all of the Storytellers talk about times when they felt bullied or picked on by other people and some Storytellers want us to know that they had been the victims of abuse and violence. If you get upset or if a story brings up issues for you, we think that you should talk to someone you trust. You can also contact one of the support services we listed on pages 12 - 13.

All of the Storytellers are kind and all of the Storytellers have good advice for people who might be going through the same thing. We think it is important that everyone listens to what they have to say.

We also have things to say about the stories and how we think things could be different for people with a learning disability. After each story, we have included what we think are the key messages.

We also want to start conversations about people with a learning disability's right to live and love the way other people do. We end each story with the same question. "What do you think?"

# **Telling Māori stories**

We think that the two Māori stories in the "Mean As!" Library are the first stories of relationship and sexuality told be whaikaha (disabled) Māori.

We wanted to start the library by presenting the stories of Tangata Whenua (people of this land) first.

Because the way Māori share their stories are not the same as Pakeha, we wanted to learn more about the place of storytelling in Māori communities. We also wanted to share what we learnt with readers before presenting the stories, so we asked Kelly Tikao (Whaitaha / Kāti Māmoe / Kai Tahu) to write about Māori storytelling (pūrākāu) and how the two stories she helped collect (Ko te Pūrākau o Tipa and I am a good man) were created.

This is what Kelly wrote about Tipa's story.

# Ko te Pūrākau o Tipa

Most New Zealanders know at least one Māori myth or legend.

You may have heard the story of Hinemoa and Tūtanekai's forbidden love, perhaps on the radio, and remember how in the story, Hinemoa swam across the freezing waters of Lake Rotorua, guided by Tūtanekai's flute playing, so that they could be together. Or you may have been read the story of how trickster Māui pulled up the North Island (Te Ika a Māui) with a hook made from his grandmother's jaw-bone. Or perhaps how Māui and his brothers slowed the sun by tangling it in flax ropes and beating it with the same magic jaw bone.

We know myths and legends like these today because they have been passed down to us by generations of Māori story tellers, telling and re-telling them to their children and their community.

Māori call these stories pūrākau. In a culture where nothing was written down, telling and remembering pūrākau was one of the ways that tāua (grandmother's) and paua (grandfather's) could teach tamariki (young people) about the values they thought were important for them to know.

Like most myths and legends, the meanings behind pūrākau are not always clear. You often need to think about the story. And when you think about what a story means, you begin to step into the story itself. In all these ways, a Storyteller can quietly steer an audience in the directions they think are good for them.

One of our Storytellers, Tipa, had listened to pūrākau when he was growing up and the character he thought spoke to him the loudest was Māui. Tipa felt that he and Māui had a lot in common. Like Maui, Tipa was taken from his mum when when he was little and was eventually brought up by foster parents. He called them his taua and paua, and they loved him. It was his tāua and paua that taught Tipa, te reo Māori (to speak Māori) and to be proud of himself.

Like Māui, Tipa also didn't listen. And just like Māui, Tipa thought not listening had led him into a life of mischief and adventure too. It was a life that sometimes was bad for him. Tipa called the places he ended up in, the "darker side of his world." When Tipa looked back, he said he saw that it was his taua and paua had always stood by him through his years of drug use, drinking and mental health issues. When they died, they left a huge hole in his life that he found hard to fill.

In thinking about how he would like to tell his story, Tipa went back to those he had heard before. He choose to tell his story as pūrākau which he thought might become his "gift to his community."

In his story, Tipa drew on the way pūrākau often uses allegory to hide messages. The messages Tipa said he wanted other people with a learning disability to discover by listening were that;

- "Everyone can find love."
- "Everyone can have a future different to the path they are on."
- · "I know it is sad for some people but it's not hard. Just find the woman or man you are interested in. If it doesn't work out, try another one."
- "Communicate with each other."
- "Take it slowly, step by step."
- · "People look at disability and think they can't have a relationship but they can do what they want."
- · "Disabled people can have sex and if people say you can't, that is wrong. Go hard! (Laugh)."

In Tipa's pūrākau, he begins by putting himself at the back of a waka – As "Kaihautu, in charge of all of the paddlers on the boat." In placing himself there, he reminds those who read his story that we all have some control over the places we eventually end up in our lives.

Getting to places is a strong theme in Pūrākau. Māui himself was a master navigator who, like other navigators, would watch for the flight path of birds heading home, track stars across the heavens and feel for the currents that pass benath the waka to reach his destination. He would also change course when the signs tell them they should no longer follow the path they are on.

Sometimes story telling can help us do this too. Tipa, hoped the making and gifting his pūrakau might change the direction of his life towards a destination that his taua and paua had tried to steer him towards through story, years before.

# STATE PROPERTY

# Ko te Pūrākau o Tipa

# **Cover Art:**

Ko Maukatere toku maunga,

Ko Waimakarere toku awa,

Ko Tuiahiwi toku marae,

Ko Ngāi Tūāhuriri toku hapu,

Ko Ngai Tahu toku iwi,

Ko Aidan Geraghty toku ingoa,

Aiden is a young aspiring artist studying graphic design at Otago Polytech who wanted to contribute to the project because of his drive and appreciation for Maoritanga and his belief that the starting place for human rights should be undeniable equity

Figure 17. The cover to Ko te Pūrākau o Tipa is a pastel sketch of a young Māori man with feathered top-knot and facial moko beneath which, the silhouette of a solitary figure stands at the back of a carved waka (canoe). A kaihautu, in charge of all of the paddlers.

# Ko te Pūrākau o Tipa

Toia te waka (he ha), toia te waka (he ha), ka tahi, ka rua, ka toru, toia ra.

At the back of the waka next to the taurapa stood Tipa, a young excitable tane, with more than a glint of mischief in his eye and energy abound.

It was his turn to navigate the waka to the next island to fish for the whānau and it was his turn to be the kaihautu which meant he was in charge of all the paddlers on the boat. They listened to his calls that would guide the waka to its destination.

Tipa knew like the other young men that being chosen to lead the waka was a wero given to each of them when the time was right and the kaumatua felt they were ready to be tested.

Tipa had been waiting to prove himself to those old wise ones. He wanted them to know he could do this as he had been dreaming about leading his people and being the best navigator he could be. No one in his whānau had done this and he wanted to prove that he could.

Tipa's mum had struggled to look after Tipa when he was a small baby due to Tipa being unwell. She tried but Tipa's illnesses were just too much for her to manage and he was fostered out to an elderly couple they became his Tāua and Poua and they lived in another part of the whenua. Tipa didn't know his father very well so his Poua became his Papa also and taught him respect and whakapapa.

As Tipa grew his troubles became hard to control. He struggled to learn at the kura. He couldn't keep up with the other tamariki, they made fun of him and this made Tipa very angry and very sad. He wanted to play outside and be adventurous he wanted to explore his world not sitting down all day and made to be still. Tipa loved being

with his Poua and going with him to the Marae, attending powhiri and tangi. He learnt te reo Māori, tikanga and kawa from his Poua. This made Tipa feel calm and proud.

Tipa's could not contain himself any longer and it was his adventurous side that led Tipa into more mischief, more than he could handle. Tipa entered a darker side of his world

and explored rongoa kino. Tipa thought he could escape some of his challenges by taking rongoa kino and he found out he was wrong when he was captured by another iwi and became their prisoner.

He felt so sad whilst incarcerated, he thought about his life, his whānau and his choices he had made that led to him being captured. He met others like himself who he befriended and they too were trying to improve their lives. Some got into fitness and were an inspiration to Tipa and others he knew he needed to stay away from because they led him into more danger.

When Tipa's Poua passed away his world came tumbling down. Tipa found it hard to live when the person he considered his toka (rock) had left through the tatau pōhutakawa. But in the depths of his pouritanga (sadness) he remembered what his Poua told him and that was to honour his whakapapa. Keep learning his Māori and tautoko his whānau. Kia kaha, kia maia, kia toa!

Tipa has started his mission to join his mother and spend time with her. He is ready to reunite and cherish her as a mother and improve his relationships with his siblings. They are a little wary of Tipa and his past, but he wants to let them know he is ready for new adventures but this time these adventures involve looking after his tinana, his hinengaro, his whānau and ultimately his wairua.

Tipa has struggled with relationships: with his parents, his brothers and sisters and with partners. He is open to new relationships with other people like himself that have some challenges in life and those who have less challenges. He loves meeting people and getting close and intimate with them if they do too. The thought of having little Tipa's running around excites him and scares him at the same time. Oh the things he can teach them about life, whakapapa and being Māori. Tū ihi, tū wehi, tū mana!

Tipa is now in charge of the waka, guiding his crew to the next destination. Calling the commands and feeling in control as the upcoming kaihautu!

Toia te waka, he ha, toia te waka, he ha! Ka tahi, ka rua, ka toru, toia ra!

# **Key Messages**

# Like Tipa, we are all on a journey, away from something and towards somewhere else.

- Tipa's pūrākau made us think about our own life as like a journey away from something and towards somewhere else. We also think;
- Standing next to the taurapa (stern-post), calling out to the paddlers was important to Tipa because he felt he had to prove himself. People with a learning disability often feel as if they have to prove things before they can make same choices other people do.
- One of the key messages we thought Tipa had for people with a learning disability was to be brave. Getting the same things other people have sometimes feels like being on a mission.

# The journey towards somewhere else: Setting off in a new direction.

- We all felt that Tipa's pūrāka was describing a new kind of "mission".
- Tipa was telling us that, it is never too late to change your life.
- Tipa was also telling us to never give up on loving and being loved. You can turn your identitity into a positive one through good relationshps.

# Moving towards your destination: He tangata, he tangata, he tāngata.

 Our advice to Tipa would be to look for another toka (a relational rock or someone to "ground him"). We were reminded of the whakatauki, He aha te mea nui o te ao. He tangata, he tangata, he tangata (What is the most important thing in the world? It is people, it is people it is people). We also thought;

- For people with a learning disability a small number of people can make a big difference in your life.
- Disability Support Services often don't understand just how important these relationships are.
- People with a learning disability almost never get the chance to talk about how to fill the gap when someone who is important to you dies or leaves (like Tipa's Poua who died).

# Paddling away from places.

- We thought that Tipa might be using his waka to get away from places too. We wondered if that included pain in his life.
- We all felt that abuse was common in the lives of people with a learning disability and shared our own stories in the group.
- We also thought people with a learning disability might experience violence or abuse earlier in their lives.
- We wondered how much impact not knowing his parent(s), might have had on Tipa's life. Not being brought up by his mum might be a kind of abuse.
- Abuse is never a woman's fault, but it can make you not think right. You can't help thinking that what happened when you are young makes it more difficult for men to love you.

# Little Tipa's running around: Oh the things he could teach them!!

- We liked the way Tipa imagined little Tipas running around as part of his future. In many of the stories, Storytellers imagined themselves as parents one day.
- We liked that Tipa understood that he had things to teach his children as a parent with a learning disability too.

- More and more people with a learning disability are having children now – but even though it is normal to think about being a parent, other people might be surprised to hear Tipa say he wanted to have kids.
- Having the chance to talk about having children acknowledges that we have the same hopes and dreams as everyone else.
- Not everyone will want to have children but always being told "It would be too much work and too expensive" is the way other people close down conversations about becoming a parent.
- Not being able to make small choices or being let down in other areas of your life make it harder to make big decisions like having children.
- Women with a learning disability sometimes do have unplanned pregnancies, and so do other women, but no one thinks they can't have sex or that they will be bad mothers.

# He couldn't tell his story without the right words: The importance of te reo Māori.

- Hearing the chant at the start let us know we had to listen differently. We think;
- Tipa couldn't tell his story without having the right words. To him those words were Te reo Māori.
- Tipa said that he felt calm and proud when his Poua was teaching him). We think Tipa may have felt the same things, when he heard his story spoken back to him
- Māori members of the research team said they felt calm and proud too.

# What do you think?

# I am a good man

The second story told by a Māori Storyteller is "I am a good man." This is what Kelly told us about that story.

Within the tradition of Māori storytelling, imagery and symbolism (pictures and words) are used to add other layers of meaning. Māori carving and the patterns on tukutuku (woven panels) tell a story too. They also leave something solid and real to go back to, long after a story is told.

"Life's Rack or Tapatoru Ora" is an image or a symbol that grew out of working together to write the story, "I am a good man"

The Storyteller loved to play pool. It is his passion and his dream is to become a competitive pool player, perhaps even playing overseas one day.



While the Storyteller was sharing with me his love of pool, I thought of an interesting way to (re)present his story. So, I pitched the idea to him and he said yes straight away. Together we kept working on the idea of using a pool rack and pool balls as the framework for a story.

The triangle rack is a tapatoru – this is the Māori term for triangle but is also used to describe three elements that make one symbol. The tapa is the sides and toru is the number three - so therefore three sides.

In this framework - the tapatoro might represent three vitally important people in the story: The Storyteller, his mum and his dad.

Figure 18. A photograph of the carved tapatory (triangle) pool rack, drawn on as a symbol and included as an image in the story I am a good man

Or the tapatoru could also represent: The Storyteller and his to tribal afiliations; Ngāti Whatua and Te Arawa.

Or it might be used to represent: The Storyteller, his whanau and his waiapo (girlfriend).

The pool balls might also be thought of as representing the themes that kept coming up in the conversations he had about the story he wanted to tell.

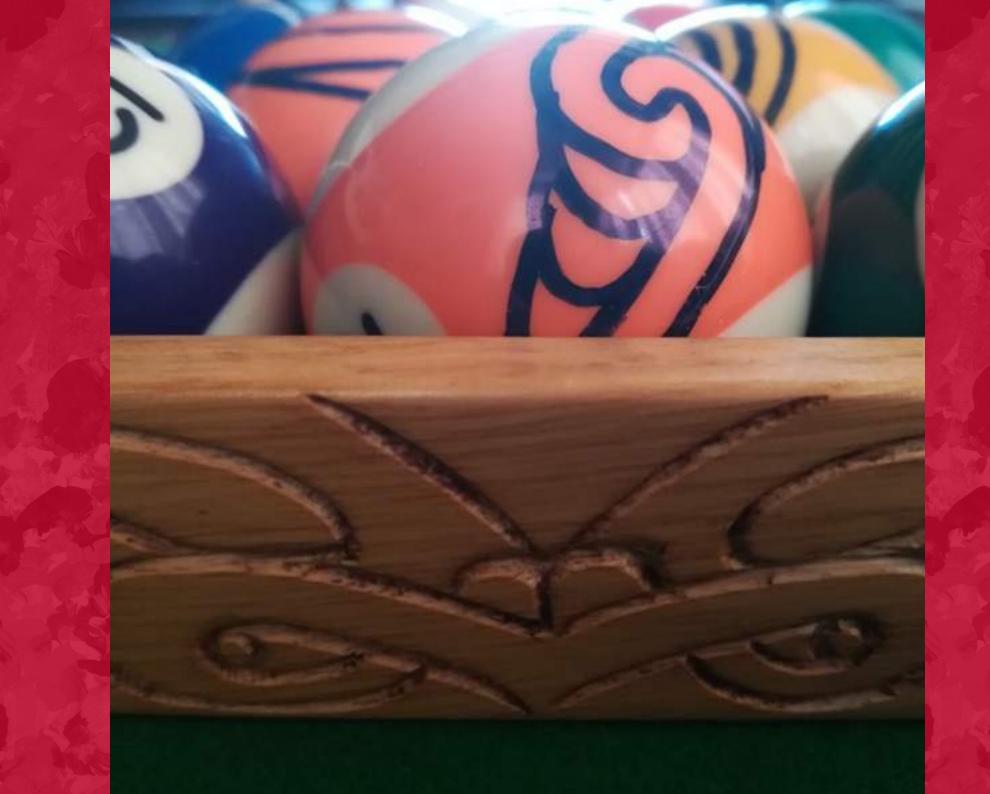
When the pool balls are racked up they can be rolled around within the tapatoru (triangle rack), and each time the tapatoru moves, new themes are revealed on the face of the pool balls whilst others slip from view.

Yet all themes written onto the pool balls make up who the Storyteller is. Some themes are more prominent at times and others less so. Depending on how the balls move around within the tapatoru, when you rack them what face upwards provides a sense of "this is how my life rolls, this is who I am."



Figure 19. An image of the tapatoru (triangle) pool rack, rolled three different ways with lines (themes) from the poem, I am a good man, facing upwards to provide different senses of the way life sometimes rolls

The placement of tohu Māori (Māori symbols) carved into the tapatoru and sketched onto the pool balls emphasied the Storyteller's strong connection with his Māori heritage. The Storyteller's mum, dad and himself are stylized in the carving.



# I am a good man

# **Cover Art:**

Ko Ngai Tai te hapū, Ko Ngai Tai te iwi, Ko Tairoa Flanagan toku ingoa.

Figure 20. A close-up photograph of one side of the carved tapatoru (triangle) and some of the pool balls enclosed by the rack. In the foreground, one of the pool balls also has a stylized Māori motif, pointing upwards and outward, towards the camera.

# I am a good man

Ae, I'm really proud to be Māori.

I respect, I ask and I love.

I like knowing someone and them knowing me.

I love being in a relationship. My two previous relationships have been with women who have a disability, but that does not define who we are as people, as family members or as a couple.

# I like cuddles, closeness and being sexually intimate.

Intimacy and sex is part of being in a relationship – a healthy, normal relationship. I am normal, sex is normal, intimacy is normal and having intimacy in my relationships means good communication.

### I know lust and I know boundaries.

Respecting personal boundaries and not pushing those boundaries. Yeah sure, I want to go further at times but I want it to be right for both of us. For us, both to be ready.

# I am a good man.

I cry when a relationship does not work out.

It hurts when I break up. I'm heart broken, frustrated, angry, confused and unsure.

# I ask, who else would be a good man like me, to her, and will he know how to be her good man?

I really cared and loved my previous girlfriend and it hurts me to think about her with another man. I just keep wondering if he knows her well and is a good man to her as I was?

# I will always love my ex-girlfriends because they were part of me. I get support from my whānau, friends and especially my mum.

I have a really supportive whanau and friends and I know that it will get a little easier over time to accept the relationship has finished

and that I need to keep going with the things in my life. Whanau is key to my wellbeing.

# I work hard, I swim, I do my marital arts and I play pool. I am a good man.

Being busy and being active is important. I do something most days of the week. I want to be a competitive pool player. I'm working my way up the pool ladder. I practice every day on my pool table and go to club champs.

# Who is independent and who has a license to drive.

Being independent is key to feeling good about myself.

Mum has taught me to do things for myself so that I can be independent. She taught me to drive. Took me for driving lessons, and went with me to the defensive driving programme. I learnt that road code so well.

# Around the community I have come to know, And who knows me.

I lived in Rotorua before I came to Ōtautahi, and Rotorua will always be where I am from, but Ōtautahi is a good place, because I know my way around and the people here, and they know me. I like knowing my place.

I attended a mainstream school, and had great relationships with my peers, teachers and the principals of the school. They knew me and I knew them. I still know their names and when they were principals at those schools.

# I am a good man, who will love another,

My whānau tell me I will get through my relationship breakup and meet someone else. I am actually taking someone out this Saturday to the movies but I want to take it really slowly because I want to get to know her.

# And, one day I will be a good... dad.

One day, not yet, not soon, but one day, yeah I would like to have a family and be a good dad (laugh).

# I am a good man

I am a good man

A proud Māori man

Of Ngāti Whātua me Te Arawa descent

I respect, I ask and I love.

I like knowing someone and them knowing me.

I like cuddles, closeness and being sexually intimate.

I know lust and I know boundaries.

I am a good man.

I cry when a relationship does not work out.

I ask, who else would be a good man like me, to her, and will he know how to be her good man?

I will always love my ex-girlfriends because they were part of me.

I get support from my whānau, friends and especially my mum.

I work hard, I swim, I do my marital arts and I play pool.

I am a good man.

Who is independent and who has a license to drive

Around the community I have come to know,

And who knows me.

I am a good man, who will love another,

And, one day

I will be a good... dad.

# **Key Messages**

# He is speaking my language

• The Storyteller spoke for us. It was because he had the same values. He spoke our language. His poem is true for us.

# Words can go a long way

- The words that you say about people are very important. Words can go a long way. These words were beautifully spoken.
- We think the most important words the Storyteller wanted us to hear were that he was a good man because of the way he treated other people. He said he respected, he asked and he loved when he was in a relationship.
- Negative words go a long way too. In other libraries we know we are not written about as good men or women who respect and ask and love.
- People with a learning disability are also talked about as if they are never good enough, or never ready enough.
- Non-disabled men don't have to keep telling people they are good men.
- The problem is other people don't take the time to really get to know men and women with a learning disability.

# I love (too)

- We like that the poem spoke about the love people with a learning disability have for each other. It is important to understand that people with a learning disability love just as much as anyone else. We love just the same.
- We also heard it in the way he didn't move on from his ex-girlfriends because they were important. He said they were part of me. Being loyal in as-well-as out of relationship is important. We also think;

- When you have a real connection with someone it can take years to recover. We all felt that our most important relationships often go unrecognized by others.
- The Storyteller is right in telling everyone that learning disability doesn't define who you are. Inside of relationship, how you treat your partner is who you are.
- Intimacy and sex should be part of a normal healthy relationship. He was normal because sex and intimacy is normal.
- It is important to listen to the Storyteller when he tells us that one day he will love again. He is telling us he doesn't need protecting. He is also telling us that loving someone else is the way he will get his wish to become a good dad one day. We don't want to be over-protected.

# **Talking without words**

- We liked that the Storyteller said that sex was just another part of conversation. A good way of communicating. We also thought;
- He was respectful by not touching too. He went at their pace. To us, he was saying even though he wanted it, he only wanted it if his partner felt safe and felt comfortable. Sex shouldn't be about pleasing one person. It should be about pleasing both people. That is how you show you want them for who they are.
- Knowing when to touch and when not to touch was how the Storyteller showed his partners he truly loved them. We thought the Storyteller might be looking for someone who had the same values.

# The Storyteller's whānau put him on the right path

 We think the Storytellers whānau helped him to know who he was, including his belief that it was normal to have girlfriends, to have sex and to think about marrying and having children. To his

- whānau, learning disability didn't define who he was. They put him on the right path. We also thought;
- Whānau / family can also help "reset" the way people with a learning disability feel about themselves if they are bullied or get negative messages about their future.

# I know my community and they know me

- One of the gifts the Storyteller's whānau / family had given him was the skills and habits he needed to live a life of his own making.
- Driving meant he could be in the places he wanted, when he wanted with who he wanted He could start and be in relationships on his own terms. He wasn't a passenger in a van – he was in the driving seat!
- We think that having ordinary relationships in ordinary places help to set the expectations the Storyteller had for himself. The ordinary wouldn't seem so extraordinary to this Storyteller.
- We wish all people with a learning disability had the same chance to begin relationships doing what they like doing, when they liked doing it, with who they liked doing it with.

# Differences in the amount of baggage people carry with them

- When we thought about the other stories in the library, we thought this Storyteller had less baggage to carry into his future. He hadn't made some of the mistakes other Storytellers said hung over their lives
- We also thought that in all of the stories men told, they wanted people understand they were good men too.
- We worry about how much opportunity men with a learning disability have to re-write their stories if the community never lets go of thinking badly of them.

# What do you think?

### I've got this chance now and I don't want to blow it



### **Cover Art:**

**Figure 21.** A cross-hatched drawing of a man holding a child by the hips - lifting them up, over his head and above the ring of a basketball hoop. In the image that child looks as if they have "dunked" the ball through the hoop before tightly clasping the ring

### I've got this chance now and I don't want to blow it

### I got kicked out of home when I was five

I grew up in [a small town]. And, I got into trouble ages ago. [When I was young] I moved away from my home town for [quite a few] years. When my Nana died, we moved back home. We moved away because mum and dad split - when I was 5. I got kicked out of home when I was 5 with my mum! Me and mum got kicked out of home cause my dad [chose] my brother and another lady over me and mum. My real father, I don't get along with him now cause, you know, he kicked me out of home and it took me a while to get over it.

[When my dad chose my brother and not me] it took, away from me and my brother - we've only just starting bonding now, to get close. So, when that happened, we left [our town], and mum met a new fella [who] became my stepfather and I call him Dad. [When my mum met him] he said I've got a place in [another town], would you like to come? And we got on the bus and I got sick [all the way]. I was a little boy spewing all the way. And I didn't like buses [but it] doesn't worry me now, I can get on a bus and I don't spew!

It was a lovely life [with my stepdad]. Oh, just going to the park and, you know, kicking a ball with your mates. That was one of the things I loved. [School in the new town] was good, yeah. No one picked on me. Got on with everyone.

Till we had to come back when nana got sick and my grandfather got sick.

### Mum was a rock for me

Mum, me and mum got on like normal. Like normal. Mum was a rock for me, you know? I never asked for money, she never asked for money. If she wanted something she would always ask for help you know? [I think what happened] made us closer. [We didn't talk about my father leaving us much] I didn't ask that guestion. I didn't put her through that. I thought well it was not worth it, you know?

Yeah. And I've asked my father, [he goes] "oh yeah whatever". I've asked him why he did that, he doesn't want to tell me, you know? [When I came back to my home town] it took a while you know? It took me a while to think should I [reconnect with my family] ...? Now it's good for me, cause now I've learnt not to build it up you know. Like go see my brother. And it's good for me to go see him cause he's got kids and, I always hang out with him. And one night, well sometimes we go out together and it's good to bond. My sister inlaw, who's married to my brother, she says oh you guys need to have a bit more time together. You know, it's guite good. My [sister-in-law] is important to us. And her family are important.

### Oh, it was kind of hard cause you're in a special class

People would pick on you [at school]. You know, it's not good. People pick on you and go "oh you're a retard, why are you in a special class", and the teachers really didn't stick up for people like that. And I think that's bad. And I thought "oh well no - I'm gonna stick to my guns and [not] go to school. I didn't go to school, and the next day [the Principal] rung up mum. And she said "oh why aren't you going to school?" I told her, and she said "they can't treat you like that". I said "well they are", and she said "well hang on I'll get on the phone" and she made a phone call, got into the principal. And he said "well no we understand what you're going through. We will make sure the teachers understand". And it went smooth after that but [the other kids would go] "oh you're the teacher's favourite!" And you just block it out. The goodest thing I learnt at school was woodwork. I loved woodwork and sports.

### And I don't see her now

[Relationships were easy for me when I was younger] I had about three of them all at once [when I first starting having girlfriends]!

I like girls. I thought [a relationship] was like for two people to go and enjoy stuff you know? Not sit inside and watch TV all the time. Go out, if it was a nice day go for a walk or something you know? Go to the park and hang out. Or go out for meals you know?

My first [serious] girlfriend, cause she was working, she was getting more money than me. And she thought every week we could be going out for tea, we would be not cooking meals. And I just put my foot down one night and said "no, I think it's time, I think we need to have a sit down". And she said "I know what's coming", and I said "no we need to sit down. And talk about it". I said, "I'm not being mean [but] you're too full on, and, I think we need to break up".

[She said] "No, no, no, no I'm not having it" and she grabbed me and she wouldn't let me go. And um, next thing I, next thing she's puling a knife at me. I just said "oh nah it's over", and then the next thing she must have been in the kitchen. I didn't see her, I thought she was just going to get something. And she comes out with this knife, you know. I was thinking what! "What am I gonna do now? Push her out of the road or jump through the window?" [And then] my phone just rung, thank god it rung. And I said to my brother, "you need to come and get me quick". And he said "where are you?" Him and his mates come, and they bought the police with them. Luckily. Cause I would have had to jump out the window. I would've went out the window and damaged my something you know? It was the first time [she had been violent].

[When it happened] I didn't want to push her. And the cops said "you should of". And I said "well yeah and the next thing I get charged. If I had of got the knife off her, I would of probably got stabbed or cut or something you know. Lucky the door was open cause... the police would've kicked the door down. Police said "we're gonna give you

one more chance", to the lady, the girl. She said "I don't care, you can come and I'll stab you." [The police] got through the back door cause the back door was open and the front door was open. One [stood] at the front door and she turned around at the front door and she didn't see the cop at the back, and he handcuffed her. And the cops said "are you alright", and I said "yeah", he said "you're lucky. You're brave, a lot of people don't do that". I said "well what else was I supposed to do? Come through the window or ring somebody to help?" He said "well I would of jumped through the window". And I said "yeah, and I would have had to go to hospital!"

She tried to tell the police it was my idea. And they said "well when I got there he wasn't holding the knife was he?" Yeah, was I holding the knife? [We had to go to court] 'cause she pled not guilty. [She] got charged with something. And, oh what are they, they give you money. She had to pay me money...[reparation]. The judge was alright. And I had a good lawyer and the lawyer said you're gonna win. He said, just sit there and let me talk. He did all the talking. And the judge said oh do you have anything to say? I just said, I said to her I didn't want her charged, I tried to get the charges dropped to make it easy for her. And the police said no [you] can't do that. [I though dropping the charges would mean] she would get help properly. You know? And I don't see her now... nope. Don't see her at all...oh she tries to message me on Facebook, and I block her. I just don't want to go down that road.

### She was kind

[When I met my next girlfriend] we just talked, and I think when I got to 20 I think I just went around there and asked her out. And then we moved in together. We lived with my brother for a while. Till she got pregnant. And we moved in together until I went to jail - before I went to jail, had the baby, you know got convicted, and I had 3 years in jail. And after that it took our life away.

[The pregnancy] wasn't planned because I don't think we had um, condoms and that, that she didn't want to use it, and she said "oh nah I'm on the pill" and I said "sweet as", and then she gets home from work, I get home from work and she's smiling. I said "what are you smiling about?" She said "it's your lucky day". And I'm thinking "oh yeah what have I done now?" She said "oh look over there". And she had this wee box. And I said oh what's this? I said oh what's that? I thought it just was, she must of bought something from the shop. I said "what's in the box?" And I opened it and I said "this is a pregnancy test, what are you doing with this?" She said "do you not see the thing?" I said "nah, nah you're winding me up!" She said "I'm pregnant, I took the test." I said "nah I don't believe the test". She said "we'll go to the doctor tomorrow". And I'm thinking "oh yeah we'll go to the doctor tomorrow!"

[So we go to the doctor] and, and the doctor comes in, he's smiling. I'm thinking "oh god she is right". I thought she was just joking, for a joke. He said "you're gonna be a father!" I said "no they're fake, aren't they?" And he said "do you want to listen to the heartbeat?"

[When I found out my girlfriend was pregnant I wasn't angry, I wasn't angry. I was, I dunno, I don't know what I thought yeah. I didn't think I wanted kids that early, not straight away. Oh, it was nervous for both of us. I think, I think she was right about, cause, most males walk away. That's what she was worried about. Because she was pregnant, [and she thought] "now I'm gonna deal with it on my own". And I said "no, we're not gonna deal, we're not gonna do it on our own, we're gonna do it as a couple. We did everything, and we got mostly everything."

Mum was happy. Yep my brother and sister in law were happy. My brother and girlfriend then, it wasn't sister in law then. Me, I thought "oh well it's time for us to find a house together, because the baby's coming and it's better to make sure he's in his own house and settled down and all that." Yeah. I just wanted to be a good dad to make sure he had everything you know?

He, when he was born I think he was a bit early or something he had to go [into an incubator for a short time] and when I went back at night time, they bought him into the room and he was in his room with himself, and I took [my girlfriend] in there before I went home. Cause I could go back any time. Yeah. I went home, had a shower and would go back. And mum stayed with us, all the way through with it. She was down at the hospital all the time.

### I got into trouble

[When our baby was quite young I got charged and convicted for the trouble I had got into when I was a teenager]. It was terrible. It broke us apart. You know? Just the whole thing. [My girlfriend's family] hated me, you know and I, it's not good for me you know? It teared me apart too. I was scared. When I went to jail I was real scared. I was gonna get a hiding, you know, I just, I just did what I needed to do...People come up to you all the time. "Mate, bro what's up, what you in here for? And you know, people standing at your door ... I did two years.

[I broke up with my girlfriend when] I was still in there. I said it's too hard for you to come in, you get upset every time, you know? It was hard for her.

And now we're not together, it still doesn't matter, she rings me on the odd occasion "oh how are you doing" and all this, "are you alright" and all this stuff. You know?

[We'll never get back together] because [her] family would hate me. You know? My boy wants us to get back together and we've said no to him. He always asks me. You know? Dad why aren't you and mum get, it's too hard you know? It's too hard, cause I've got a job I don't want to give up, and she, we were talking about if we got back together she'd [have to move to where I live]. And she works too she's got a good job.

### When I see my son

[I have to have someone with me when I see my son]. It's a new lady now. yeah. She rings up [my son's caregiver], she makes the phone call. I don't make up the phone calls, they make the phone calls and they tell me when and what time.

We usually go shoot hoops, or go to the Warehouse, or whatever he wants to do. And have lunch you know? Shout him lunch and then he goes back. We have him from 11 to 1. Yeah. It goes guick you know? Yeah I just think oh well, I've got this chance now I don't want to blow it. You know. After so many years. And he, he hates, when I go to [to see him], because he hates me leaving. He starts crying and you know. [Our bond is because I've] done all the stuff I needed to do. You know? To get where I am now. Cause when you come out of jail and people go on the, go back and do stupid things you know. [I tried hard to do what] I needed to do. To do, what was planned, you know, not get into trouble. Not to have a fight with anyone, yell at the staff or scream. The most important thing is my family and friends, and my son.

Eventually I'll meet somebody when I'm ready. I'm not ready yet. You know. I don't want to meet a nice girl and she says "oh no I'm married or something". [I would like someone] who is um, sporty and um you know not, you know happy and all that stuff. [Someone who is happy] doing um, stuff together and eventually meeting my son. You know?

[If I hadn't gone to prison I probably] would've got married [to my son's mother] while mum was alive. Now she's not gonna be there when I get married. You know. And I don't know if I want to get married yet. [I talked about that with my brother] ages ago, [and] he said "do you want to get married?" I said "I don't want to yet". And he said at the end of the day he understands, he said "you don't have to get married". I think the end of the day, it's another piece of paper to me.

### **Key Messages**

### It's terrifying! I thought his girlfriend was going to stab him!

- We thought the story was terrifying and most especially the domestic abuse. We were all a bit surprised at first. It's not so common to hear stories of men being abused by their female partner, but then we thought, well, how would we know [how common it was]. People don't talk about partner violence against men. We also thought;
- The Storyteller was brave to include this part of his life in his story. As a man, it must have been hard to talk about.
- We worried the cops would think it was him.

### He was pulled from here to there

- We noticed that this was another story where the Storyteller had grown up in a home broken up by the separation of his mum and dad. He was pulled from here to there.
- We think being pulled from here to there would have been especially hard because of the Storyteller's confusion about what was happening. He was taken advantage of.
- People with a learning disability carry feelings of being rejected when they are not told (what is happening) and never asked (what we think). Especially for important decisions like where and who you live with. We must be included in decision making.
- The Storyteller always seemed to talk about not having a say when he wrote about the relationships that were most important to him (His parents, his brother, his son) He never got asked what he wanted – all the way through his story.

### (In)justice

• Every time the author had had an opportunity to talk, he seemed to have a kinder solution. We think the writer is "a peace-maker. He tried to work things out for the best.

- He didn't want his girlfriend charged. He wanted her to get help. He said his girlfriend hadn't been violent before. We think trying to get the charges dropped was the Storyteller's way of protecting his girlfriend. He wanted something that was good for her - not to have her punished.
- It was wrong, therefore, that his lawyer spoke for him at the trial. He was told to shut up and sit there. Winning the case probably wasn't what the Storyteller wanted.
- We worry that his girlfriend might not get the help she needed. Everyone missed opportunity to do something good by not listening to him.
- We wonder if people with a learning disability are treated the same as other people when they do something wrong. The Storyteller seemed to get treated more harshly when he made a mistake than other people.
- Prison would have been a "scary place" for a person with a learning disability.
- We think that prison might have broken the Storyteller. It stopped him from becoming the husband and father he wanted to be. Prison just made it harder for him to repair his life – not easier.

### The many drifting away(s)

- We think that the Storyteller's experiences of school marked him out as different - to himself. It was the beginning of his many drifting always.
- Being in a "special class," begins it all. Being picked on and looked at differently is just what happens if you are in a special class.
- School can be a very unpleasant place for people with a learning disability. Bullying and abuse happens all the time. It begins

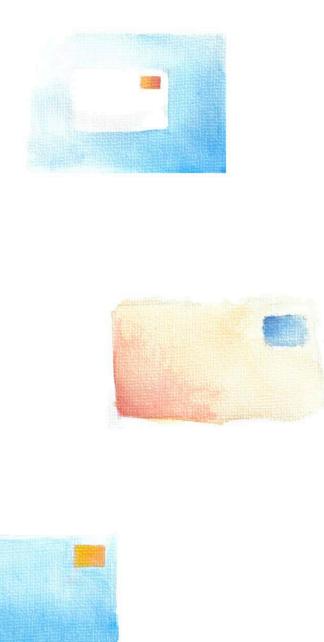
- the separation from friends that people with a learning disability experience as they grow up.
- Our experience is that bullying and being looked at as different - not like a normal person - make it harder for us to learn too. Getting behind at school is another kind of drifting away.
- We wonder, why teachers don't do anything to stop it. Bullying has a life-long effect on people with a learning disability. "It [takes] your confidence away. Not having a positive identity, means you feel worth less and stop expecting to have loving relationships.

### Becoming a dad

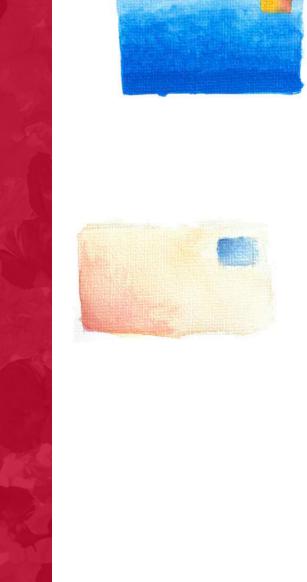
- We think the Storyteller was trying to be a loving dad. He wasn't afraid of being a father - even though he thought [his partner] was joking, and that he wasn't ready. We loved that the Storyteller kept coming back to the hospital at night to be with his baby who was by himself.
- Like other parents with a learning disability, the Storyteller wanted to get (his parenting) right. Even when this meant making hard decisions - like telling his son he and his mother wouldn't be getting back together.
- It doesn't seem fair or right that he couldn't call his son. Or that the time he saw his son was organised by someone else. Or that he only got two hours and the time seemed to go so fast.
- We also didn't like that his son always cried when he had to leave. We think that that the way the Storyteller and his son were forced to meet wasn't good for their relationship and wondered if anyone had asked the Storyteller how he thought things could be worked out for the best. He always had good, kind ideas.

### What do you think?

## Sometimes I write letters







### **Cover Art:**

Lucia Veitch

Lucia is a Year 12 student from Ōtepoti / Dunedin who has a strong interest in design, photography and painting. Inspired by an idea floated by the story teller, Lucia responded to "Sometimes I write letters" by drawing on the more ethereal quality of watercolour to similarly float the cover image.

Figure 22. Watercolour envelopes appear to float behind a white page with the title of the narrative Sometimes I write letters, written in Zaphino font, as if carefully hand written.

### **Sometimes I write letters**

Dear Reader,

First of all, I want to let you know that my story talks about hard things, but they are things that are important to sav.

I am not impressed with what happened with me, nor am I happy with the actions of my rapists. It has made me very upset and angry. My abusers took advantage of me when I was a child and I lost my innocence because of it. It is unfair how my abusers did this. I was raped several times. I remember, on one occasion, I had gone over to the netball courts and was playing with one of my sisters and a friend. I felt thirsty so I went to get a drink of water. That's when he came up to me and told me we were going for a walk. We went for a long walk through the school, past the park, over the bridge, through the rugby grounds and over a few steps. He then attacked me, making my friend (who he had also taken with us) watch while he raped me. I would have hated to be the person who had to watch.

He was 16 years old and I was only seven. I have had more experiences like this as a child and I am not impressed. In fact, I am quite saddened by how people could choose to hurt other people as a path for life.

There is a part of me that still feels hurt because my Mum and Dad were not able to protect me from my abusers as they didn't see it coming. But I know that it's not their fault. I guess my abusers were good at playing the deception card.

Because of my abuse, I have found it very hard to live and do things that your average person should be able to do like working, going outside of the house alone for a longer time, socialising, and having a stable mood. It's so annoying and frustrating because one day I can be fine and the next I can feel way down. I have had a very unhappy childhood because of my abusers and they have affected my relationships with others and my relationship with my physical

and mental health. I am trying to do my best but I have had many challenges to face over the years because of what happened. I hope that no one who reads this story has the same thing happen to them.

My relationship with the opposite gender has been a struggle. I find it hard to trust men because I worry they might hurt me like my abusers did. That is so annoying too because I want a relationship. I am not really in the space to be with someone right now, but one day I would like to find the right person for me. I would like to have a family and be with someone who makes me feel safe. I would love to be able to be married at one of the Temples of our Church somewhere. I would also love to have children. It would be nice if we were able to live on a farm with animals.

My relationship with God has helped me to keep moving, even though my abusers hurt me. Involving God in my life has made things a lot easier for me. He has been that extra person I am able to turn to when things get tough.

My pets are also God's beautiful creations which have been helpful to me in many, many ways. They have all made me feel better when I felt sad about what my abusers did to me. They have also given me an excuse to go for a walk, distract myself and have given me company when I need it. They have looked after me, helped me feel alright and have given me a reason to not kill myself when I have felt really down. I have always been able to turn to them to feel happier.

It is also good to find things you are good at and that you enjoy. This gives us something to turn to when we are having a hard time – it gives us enjoyment and bridges a gap in our lives. Sometimes those of us who have intellectual disabilities can find relationships get strained very easily. This is because we do not always understand what someone is saying or intending to do with their actions, and if we don't understand, how are we actually supposed to figure it out?

Past hurts have made things difficult for me, but I want you to know that it doesn't have to determine who you are and what happens in your life. I know my story won't be the same as yours. We all have our own battles, feelings and experiences. But here are a few things I have learnt that might help you.

I want you to know that abuse is not your fault and you don't deserve all the pain and hurt. But I know it makes you wonder why me? This can make you feel sick, angry, hurt, lonely, trapped, stuck, unloved and unappreciated. I want you to carry on, keep loving yourself and get good sleep!

Not everyone is happy with the opposite gender and can find it hard to embrace a relationship with the opposite sex. For me, because of my religion I would hope not to ever turn to the same sex or bisexuality. It would shame my parents and my God. I would never want to feel like I had done the wrong thing and turn the opposite to what I have been taught while I was growing up. It's just not for me. But if you want to be in a relationship with someone of the same sex, that's up to you. Just try to be with someone who is from a good background, is trustworthy and safe.

I want you to know that bad mental and physical health isn't your doing, it's just part of life sometimes. But there is a lot you can do to help yourself and get support. Mental and physical health is a part of you and helps to make you who you are. So just try your best to live a life that you are happy with. Being close to your family, pets, and God can help you overcome these things.

When I feel sad, or get reminded about my abusers, I also try and write letters. It helps me to let everything out. It might help you too.

### **Key Messages**

### It's a hard story to hear, but it's a positive story

- We appreciate the way the letter writer warned us before beginning her story. It was just one of the many ways we thought she was cared for people who are going to read the story.
- This is important story for everyone. Not just for people with a learning disability. When you are listening to anyone's story, you take on what they are saying. How it might be like for you. It is important for everyone to put themselves inside of this story.
- Even though the Storyteller was writing about rape and the impact that it had had on her life, we felt the story was a letter of hope, especially to people who had been sexually assaulted.

### Sharing stories is what we do at People First

- Battling with feeling angry, hurt, lonely, trapped, struggling with relationships and not being able to do things most people are able to do, are feelings people with a learning disability recognise.
- The story gives practical advice from someone who feels familiar to us. When other people with a learning disability hear it, they will get something out of it - and think through on their life journey and know how this will support them.
- Listening to other people's stories and offering advice is the way people with a learning disability support each other. It is what we do in People First - Share things that I have been through as a way of being supportive of other people who might have had similar experiences. It encourages people on their own life journey.
- The Storyteller trusted us with her private story. We don't get many invitations to talk and think about private things like this. "People and journalists talk about us, but we don't get to talk about our own stories in of our own community.

- We wonder whether not wanting to share personal stories is because of the shyness of people with a learning disability or that the culture around us telling us our stories aren't important. Maybe it's a bit of both.
- This story is important to hear because it is the story of a woman with a learning disability – and not someone else. We are the experts in our own lives.

### Taking control of your recovery makes it easier

- This letter has important messages for people with a learning disability who have been abused. Most especially that abuse is not your fault. Abuse is about the person doing it – not the person who has been abused.
- We liked that the letter started with the writer's anger. I am not impressed she says. We also thought;
- It was important the letter writer had a plan. She knows what to do. We thought that taking control of her recovery meant that she was not a victim.
- It is important for people with a learning disability who have been abused to hear that recovery takes time - and work - and the right people to support you. It is ongoing. It is always. Professionals can't just fix it quickly.
- It is just as important for people with a learning disability to hear that every day is a new day. The letter writer wants us to know past abuses don't define you.
- We noticed the letter writer followed her own advice by loving herself by continuing to love and care for others. She stayed close to her family, walked and loved her pets, talked to her God ..... and she wrote letters that might help others.

- We thought that the key message in the letter was to know you have the right people in your life. We think the right people (to have) in your life are; strong, trusted, intimate, loving and caring.
- We also noticed that the letter writer thought finding a partner who was good and trustworthy and safe was important. We heard it in other stories too like Tipa looking for his toka (a rock) and the way the Storyteller in I've got this chance now described his mum as being his rock too.

### I would like to have a family and be with someone who makes me feel safe. It is so annoying because I want a relationship.

- We thought it was important the letter writer told us that she still wanted to find a loving partner and to have an intimate relationship, despite her deep mistrust of men. It was just that the things that had happened to her that made it hard to get these things. Abuse doesn't stop you wanting things for yourself. We thought that wanting a relationship was (and yet at the same time was not) a very ordinary hope she held for herself.
- We also noticed that, like many of the Storytellers, the letter writer wanted to have children and to bring up a family. She wanted to be a mum. She would have been a good mum - but we don't think it is going to happen for her.

### Everyone will take something out of it that means something to them

• One of the best things about the letter is that it speaks directly to people who have had a similar experience. It tells them that you are not alone and to know that it can happen to anyone's life.

- Although people with a learning disability are often abused and sexually assaulted, they are almost never supported by other people with a learning disability who have had the same experience.
- We could all think of someone we would like to give the letter to – Some were disabled and some were non-disabled. We also thought;
- It would be a good letter for men to read. It would be especially useful for men who were trying to recover from being an abuser in their past.
- It's a letter to the whole community. Even though the writer knew it was not her mum and dad's fault, she couldn't help feeling hurt no one was able to protect her. No one saw it coming.

### What do you think?

### Post script

- On second listening, the letter was still hard to hear (especially at the start) but it did get easier. We wondered if that was because we had had the chance to talk about it together as a group.
- After listening to the story again, we decided that it was a sad letter, made even sadder by the matter of fact way the story is told. We thought the letter writer was a kind and thoughtful person who did not deserve the story she had to tell.
- We asked ourselves, well how does a person with a learning disability get the support they really need then? We took four lessons from the story that we think are important for services to hear:

- o You need to think about the relationship you have with people who have been abused. Are you a strong, trusted, intimate, loving and caring recovery partner?
- o Surviving abuse is complicated. The letter writer no longer trusted men and yet also hoped for a trustworthy male partner.
- o It isn't your job is to fix a person with a learning disability It is the person's journey and the recovery needs to be their own.
- o Be patient. The letter writer said she was broken and that recovery was forever. We liked that she gave other survivors of abuse permission to take their time.
- One of the most positive things about the story was that writing it may have helped the letter writer. We asked the story gatherer to take our comments back to the writer. We wanted to let her know how important it was for us to hear her story and what we thought after reading it. We hoped this would make her happy.
- After taking our comments back to the letter writer, the story gatherer told us that the writer was proud of her story and that she had shared it with one other family member. After reading her letter, she said her family member revealed to her that they had had a similar experience. Neither knew the other was recovering from abuse.

### What do you think?

```
mtro: 19/4/91 STOP
Pavid's got his hat on. He's going out today
letter put your sunscreen on. Sommer's on its way.
6 9 19 1
ilp Hip hip hip hooray. Pavid's got his hat on
A 9 19 1
Summer's on it's way.
     Jess's got her shorts on. She's going out today
IA P.1
fetter put your landals on. Summer's on it's way.
   Hip hip hip hooray. Jess's got her jandal's on
Summer's on it's way.
     Pavid's got that t-shirt on. He's going out today
P: | A | |
look out Jess. Pavid's on his way:
6: P. ID Hip hip hooray, Look out Jess
   9 19 1
Pavid's on his way.
      Jess's got her speed on. She's rolling on her way
ook out Pavid. Love is on its way
      I'P. 10:
Jess has a crush on. She's on her way:
P: I.A. P'III
Look out Pavid. Klases on the way.
ravid and Jess are going out today
Pavid and Jess are going out today
```

# We don't jump fences any more We walk through our own gate

### **Cover Art:**

Figure 23. Lyrics to a song have been placed overlap an image of an acoustic guitar. Half of the guitar is covered. The song is to be played in the key of D with chord changes written between the lyric lines.

"Davids got his hat on"

Tune: "The sun has got its hat on:" Noel Gay & Ralph Butler (1932)

Lyric: Jess Kittay

### We don't jump fences anymore. We walk through our front gate

### We do almost everything together

David and I have been married for three years now.

Well it will be four this March Jess

We do almost everything together. It's how we are, so we want to tell our story - together.

That way it will be right.

### The sun has got its hat on (intro)

David and I first met at a day programme. When David first started, he sat on his own. He didn't have anyone to talk to, so I went up and asked him if he was ok.

Jess coming up was a bit of a shock.

Not a lot of people would talk to me because I was different. I stand out in a crowd.

But Jess came over, and that is where it all started.

David was the first man who really talked to me. Literally from the first time we sat down.

Jess sat and had lunch with me and I asked her how things were for her. Jess told me that she was not really liking where she was living. I told her I had the same problem where I live. I know what you are going through.

There was a sadness in David's life, so what I did was write down how I was feeling about him.

It was the first song I ever wrote.

At that point we had been going out for months but I wasn't allowed near David. My caregiver helped me get to get all the words written out. I rang David before I did.

And what did I say Jess? I didn't have a problem with it. So long as there are no dodgy words.

### The troubles

Getting to know David was a slow process.

We took the relationship slow didn't we. For about three years we took it slow.

If Jess wanted time we just gave it a miss, you know. We didn't commit to any long term relationship until we knew it was right, did we? For a long time we had monthly visits and I wasn't allowed to take Jess to the movies or anything like that.

The day after I met David, I asked him out. But staff stopped it. They were telling me I wasn't allowed this.

I knew people would be telling you "Oh David is not who you think he is - because of the trouble I got into when I was younger." I knew people would be telling you it was a mistake.

But what mistake Jess? You haven't made a wrong mistake at all.

And I said, what's to be careful with. If I don't talk to him, I won't learn what life is about.

He can tell me. He has a voice.

We had our first date on the 29th of April, 2011. We went to a cafe. Jess was 23 and I had just turned 19.

The next time I phoned to see if it was ok for me and Jess to go out they said no because you've got charges. What had happened was a staff member at the house I was living in rang and told Jess's staff I had a conviction. Everyone assumed I had been charged. Because I had a disability they thought I wasn't going to be honest.

I've been hurt basically all of my life because of it. I wasn't allowed to marry Jess and at the start I wasn't even allowed to see her.

### **Jumping fences**

They couldn't stop us all the time. Sometimes I'd run away.

I would often storm off. You know, because I was getting bullied at the house.

Lused to sneak off other times too. When staff went down to the wash-house I would sneak outside and book the mobility van so they didn't know where I was.

And then she would ring me and and say is it all right for me to come in? We spoke to my staff and they decided yep ok, we'll give it a chance.

The taxi drivers knew more about what we were doing.

That's why we get respected as a well known couple.

We would meet secretly at the club too. I started going to be with Jess until one of Jess's staff popped in and put in a complaint and I was stopped from going. In the end I was allowed to go, but Jess always had to bring a staff person.

### The sun has got it's hat on (reprise)

When David started coming I was a bit nervous. I used to have this staff person following me everywhere – like a little puppy.

People didn't come up to me to say hello. I'm just sitting there thinking I'm looking like a piece of trash really. Eventually I turned around and said This can't go on.

I think the other members saw Jess as a very lonely person. When I started going things started to change. I was her boyfriend, not her staff.

My staff were really there to make sure I didn't have any contact with David. That's where the song comes in.

I was there that night. When Jess sung it. Jess was crying and I wasn't allowed to go near her.

I couldn't go up to her and say You did a good job. I wasn't allowed to say, Well that sounded beautiful darling.

The song is about discrimination. People don't have the right to say who you can see. If you were in a relationship with someone, what would you do? If you loved the person, what would you do? Sit there and watch them get discriminated against. I wanted to be with David, so I sang it out over the top of the other members. I sang it to David and I sang it to the support person. David and Jess are going out today.

This man who keeps on coming and fighting for us to be together. David and Jess are going out today.

### Maybe this is the way it's gonna be for yous

I was a bit of a mess back then. I would ring David because he would listen.

I remember ringing quite a lot of times crying.

One day I spoke to one of David's staff members about it all. She was the first person to say, We might be able to make this work. You have turned David's life around.

This crap was constantly going on. So in the end I decided to go to the Needs Assessment Service and say, enough is enough.

I had it all on my laptop. When Jess was talking on the phone to to me I would write it down. In the end I printed it off and took it into the needs assessment service.

I said to them, Hi I am David Austin. I am advocating on behalf of Jess Kittay. And that's where it all came out. Jess gave me her mothers number and I rang her. She told me she knew Jess wasn't happy with the way she was being treated and I said no, neither am and that I had gone to the Needs Assessment because I was concerned.

Her rights were not being respected!

In the end Jess's mum said maybe we need to look at having a sleepover at my place and rang my co-ordinator. That's what happened. The next day and my co-ordinator says, Would you feel comfortable going and spending a couple of nights with Jess and her mum?

I remember lying on mums spare bed... and I said to David, I never want to go back to that shithole.

We were only there for one night...... but It was enough. Enough for Jess to decide we wanna keep this up. So we did another trial. My co-ordinator asked me how it worked. I thought it went really well. I told her, I can't see what the concern is and she goes. Oh well, maybe this is the way it's gonna be for yous.

### Please don't get shocked

Don't take this the wrong way Jess. I was pleased I managed to get you out of there.

I thought no one was going to listen to me.

Were you worried?

Well other people were. They didn't want to see me get used as an advantage to look after you all the time. People would tell me it's hard to look after someone with a physical disability.

They said it would be way too hard for me.

People didn't have a lot of faith in either of us did they?

Jess's disability is not really anything to be worried about and it didn't take us long to figure that out.

The only thing that did worry me was when you told me you had been sexually assaulted. I did go to my staff and say, well what do I do? You know what do I do If she ..... well, wants something ..... or whatever. I'm not going to say because I don't want to embarass Jess.

The topic for her will be a bit awkward.

(Laughs) No!

We don't really talk about that kind of stuff.

For a start I was a bit scared.

I never imagined I could live in my own house. When I'm in bed, I stay in bed. I can't get out.

If there is a strange noise I have to rely on someone else figuring out what the noise is.

David changed everything.

Please don't get shocked, but I was sexually assaulted when I was twelve.

I had a caregiver who used to bring her boyfriend around. They were visiting and he touched me around my ribcage and tried to undo my buttons while I was on the couch. I ran to my bedroom. I shut my curtains, that's how fucking scared I was.

Sorry for swearing.

I didn't know what to do. I didn't know what to say to mum. I do remember telling her to get him out of here.

It was six months before I went to the cops.

Lasked mum if she could come because it was her friend.

They just smacked him on the hand.

They didn't do nothing.

They didn't do diddly squat. He had to do it to someone else first.

Because of that I was frightened of men. I never thought I was going to be married or anything like that. I thought that won't work.

Sometimes I have flashbacks.

Then you have to sit up, don't you?

I have to sit on the end of the bed. I have to do what I have to do.

I was twelve.

### Do you reckon I'm the one?

People were shocked when we got engaged weren't they Jess.

My father was guite shocked. My stepmum was guite shocked. My brother was guite shocked. My little brother was guite excited.

People were actually guite nasty. In the end we got engaged to shut everybody up.

At the time we didn't know anyone with a learning disability who was married. I don't really know why people with a learning disability don't marry.

Well I think anybody with a disability can be married to who they want, when they want. Other people shouldn't have that control. We really didn't think it was so unusual.

To us it was just a normal thing to do.

Well you might not have been thinking about it too much, but I had! I asked David three times. I asked him. Do you think I am the one? Do you reckon I'm the one for you?

### I won't ever get this chance again

The first time we had been intimate was when I fell asleep on David.

I was around at Jess's and she was upset. You know, pissed off at what was happening and so I picked her up and put her on my knee and she just relaxed and ended up going off to sleep.

He was talking to me and then I didn't respond.

Basically David has soft skin. He's got very, very, soft skin. I don't know why I fell asleep on him. It was just the touch. The touch of his hand on my stomach and stuff.

So here I was, sitting there talking to her and the next thing I looked and her eyes were closed and I thought Oh fuck! Anyway, Jess's staff knock and I give Jess a wee tickle on her hip. Woke her up. Put her back in her wheelchair. Did her up because I didn't want to get caught with them walking in and seeing Jess on my knee.

(Laughs). Yeah we had to be very secret. Very, very, very secret.

They didn't aknowledge the way we were. We couldn't talk about it.

They would have stopped it alright!

I didn't trust anyone. Especially the service.

We couldn't really have sex. So we just cuddled and stuff like that. We weren't too sure about it at the start were we. But it all turned around and became ok.

We took it slow, then all of a sudden, yep Jess started wanting me to touch her and that was fine. I didn't have a problem with it.

I took control because I wasn't too sure how to....

How to ask me?

Yes to ask you. So I wrote it down in a letter and got David to read it out.

We had no opportunity to talk about sex so writing a letter was the only way I could think of to let David know.

Sex is a little complicated for me too. We have to do things differently, so I had to find a way to let David know what I wanted.

I didn't know what to think of that did I. To be honest I was a bit hurt.

I had to ask my staff if it was normal. Putting it in a letter like that.

No! You didn't know what to think of that. (Laughs). So I explained it again.

It was also a pretty big step for me. Because of me being abused.

So that's when we leave it.

And at other times I do feel like it. Depending what my mood is.

Sex helps. My muscles get tight. Sex helps me to relax.

Touching me like that also replaces a bad feeling with a good one.

I'm fine with whatever Jess wants to do. I don't want to force things on to her that she doesn't want, you know.

It's her decision at the end of the day. I don't make decisions for her.

Well come on what about you?

Well it doesn't really happen for me that way. I don't really have needs that way.

It was really hard for me to touch Jess at the start.

I didn't want to physically touch her because if someone saw me doing something to someone else, I worried about getting reported to the police.

Because I've had that history I was a bit against it.

And I said, it's your choice if you don't want to touch me. At that stage I was really, really, really wanting to be intimate though.

Which is what ended up happening.

If I ever ended up going to prison, Jess ends up back in care and that's the relationship over.

I won't ever get this chance again.

### They had to state their concerns I guess, didn't they?

When we started living together we didn't know too much about sex did we?

At the all boys school I didn't have many friends. You know, being different.

Well I can remember going home one day and showing mum I had four NCEA credits in sex education!

I remember thinking, how can a disability person pass this test when she hadn't had it?

### I had that as well, but I failed!

I absolutely passed with flying colours.

Sorry if this sounds wrong. I had to put a condom on a stick.

I was guite angry. I turned around to my teacher aide at that time and said, "Do you actually have any faith in me passing this?"

And what did she say?

She goes, No.

And I go, well, how can I learn when I don't try these things? How can a person pass with flying colours when you're telling me I couldn't have anyone to do it with?

It's important for everyone to know that people with a learning disability want a partner.

And want to know more about how to be intimate with them.

Pretty much the only place I talked about sex was in the counselling up at the hospital. They only told be what I wasn't allowed to do.

I always felt as if they were watcing what I said.

You know to decide if I was a bad person.

I went up to the hospital too. I was doing walking, cooking and sexual reality.

Sexual reality was about having a relationship and what the kids would turn out like if we were to have kids. They had to state their concerns I guess, didn't they?

### It wouldn't matter if the child had a disability or not

We did talk about having kids

I looked into it properly because I didn't know if I was allowed to. So I went to Family Planning. They said with my disability possibly not.

They weren't that helpful really. They gave me condoms and god knows what else but I thought to myself, Why aren't you listening?

I went to a male doctor after that and he said you can try but it would have to be delivered early. So we just kind of gave up.

It's a shame we can't have kids because your foster parents said.... I'd make a good father.

We thought may be we'd adopt a child. That way I don't pass my genes and there's is a chance with Jess's disability too.

So we thought maybe adopting would be the safest. Or fostering.

It wouldn't matter if the child had a disability or not. It wouldn't make it harder for us.

If the child had a physical disability, it wouldn't really matter.

I know what to do and Jess would be its mum.

Because we can't have kids ourselves we put a lot of energy into our family.

### The sun has got it's hat on (coda)

Do you know, even after I married David, people would still come up to me and say. You won't last. And I would tell them Just watch this space! You just watch me jump this fence.

### In the end we proved them all wrong.

And we still prove them wrong.

We are still proving people wrong aren't we.

I knew I was able to have a flat on my own. And have a proper relationship.

There was so much negative stuff about us.

If I hadn't met you David, I wouldn't be here today.

How do you mean sweetheart?

Well because you were my advocacy person.

If David was gone, I would have taken my life. That's how I feel.

And if someone was to take David away from me, well what am I supposed to do?

But Jess that's never gonna happen.

Jess helped turn my life around. When you first got with me I was very unsure.

Because of what history I had. I just wasn't sure if a relationship was going to be my thing. But then I thought Jess is worth the risk.

And that's the way it's been. We do things together.

We knew who we were.

In a way that's the point of our song.

When we are allowed to be together and to decide things for ourselves, the future looks brighter.

The sun has got it's hat on. Summer's on its way!"

I do think there is still a lot to be proved, right, but I don't think there's anything major for us to prove anymore.

We have done what we can now.

I don't think there are fences we need to jump now.

In the future we will just walk through our own front gate.

### **Key Messages**

### People with a learning disability always feel like they have to prove something to get something. I don't think that's having the same rights as everyone else

- We noticed how David and Jess always felt they had to prove something just to have or do something. They had to prove a lot!
- Having an intimate relationship feels like the end of a very long ladder. You have to prove that you can do all the lower rungs before you can get there. Disability support services (and others) never assume it's your right to start at the top of the ladder.
- Whether you have a disability or not you have the right to an intimate relationship. You shouldn't have to have a relationship just to prove to other people you can do it. We are no different to anybody else - except that we have to work so much harder to be together.
- We did think that other people always saying "no" might have motivated David and Jess to give it a go though

### **Disability Services control our relationships**

• It is not right that people who work in a service can tell you who you can see and who you can't. It's our choice. Unless the person has asked you to be an advocate staff have no right to step in.

### Disability support services limit the possibilities of relationship by what they do say and do

- Community Group Homes are not spaces to be in a relationship with someone. Friendships are always scrutinised and there is no privacy. You always have to sneak away. You have to escape your service to be in a relationship.
- People with a learning disability are often told they are not allowed to have sex in their service. It's a policy. Couples who are caught

- doing it can get in big trouble.
- When you are not allowed to have sex in your service there is no proper place. You have to do it in places like the park.
- It is like Big Brother is always watching you.

### Just as importantly, disability support services limit the possibilities of relationship by what they do not say or do

- Partner relationships are open and they are equal and you care about each other equally. We think that relationships with a partner are what makes the biggest difference in people's lives. They are really important and should be respected and valued by those whose role it is to support us.
- Relationships take time. You have to build loving relationships by learning how you connect and what you enjoy doing together. We think it is critical that services talk about and provide people with a learning disability the chance to build intimate, trusting and loving relationships by supporting (not surprising) life sharing.
- Relationships are built one-to-one, not one-to-five.
- People who live in disability support services are not often supported to build relationships by doing things non-disabled adults do to become intimate, like out to a restaurant or planned a date. We also think;
- People with a learning disability have fewer opportunities to meet people and become intimate, which means you get no chance to know people in a way that would help you decide if you want to be in a deeper relationship.
- Sex feels like the needle in the hay stack. A precious and hard thing to find surrounded by the "hay" of everyday living. People with a learning disability who spend a lot of time in disability

- support services are steered towards non-sexual lives by the "hay" of being taken to places and kept busy doing things where meeting someone and becoming intimate are not easily possible.
- People with a learning disability never get any practice or to feel confident taking things beyond friendship.
- Not encouraging people to think of themselves in sexual can lead people with a learning disability to doubt that they have the same rights as others. You ask yourself is it ok to go through the gate (of friendship). And exactly what do you do when you get to the other side of the gate.
- We would like to hear that it is normal and natural to have sex and want to be sexual. You need to have trust and faith in yourself to become a caring and responsive lover. Not being able to talk to people as if sex was a real possibility takes away the trust and faith we think you need in yourself.
- We would like to talk about how to have sex. But only with people who are open, and listen properly and accept that we would like to have sex.
- When people with a learning disability talk to staff it often feels like there is a right (approved of) answer. We feel the lack of opportunities to talk openly and honestly harms people with a learning disability because we are more likely to be met by more issues and opinions (discrimination) than people who do not have the label of intellectual disability.
- People with a learning disability don't talk to other people with a learning disability about sex or sexuality either. We think this is because when you are not used to hearing those kinds of conversations you don't know if it is ok to talk about. "Not talking (or hearing) about it makes sex a more complicated thing to talk about.

• We also feel that believing you didn't have the right words (vocabularies) makes it much harder for us to know what to say too.

### Sex Education

- We think the way David's experienced sex education was more about what he couldn't do in a relationship. People with a learning disability are told "no you can't" all the time.
- The messages people with a learning disability hear about sex are almost always negative.
- o Don't get caught
- o You have to be careful of people who are paedophiles or want to take advantage of you
- o Women with a learning disability often get sexually assaulted by men
- o People can watch or record you on their phones
- o You need to have safe sex
- o You can't get people pregnant
- o You can't have children
- o You can't have sex until you have a good income
- We also think men with a learning disability find even getting into the partner zone frightening because of the all the negative messages about male abuse.
- On the other hand, sex education for people with a learning disability almost never includes conversations about sex being pleasurable or a way of showing your partner you love them. Sex as part of loving someone is never talked about. We are never told positive stories about sex.
- (Thank goodness for story-telling).

### What we know is that many people with a learning disability take it slow

- People with a learning disability are prepared to take the time to build a connection slowly. David and Jess took four years to get engaged and both said they took everything slowly. We think that this is the more usual way that people with a learning disability build relationships.
- We think that people with a learning disability tend to take it slowly because they wait until they know they can trust the other person. To a person with a learning disability, trust is one of the most important things in life.

### One of the other things you can't do is have children

- We think that one of the ways that families and disability support services don't trust women with a learning disability is by putting them on the pill without asking or talking to them.
- Being on the pill just means that women with a learning disability can't have children – It doesn't always mean you can have sex. You still can't do that!
- We do know women with a learning disability who have made the decision not to use contraception because it should be a woman's choice. No one else should make that decision for women. Having control over who and when you are in a relationship means that women can be confident their decision is the right one.
- We noticed that Jess and David had looked into becoming parents. We didn't know anyone with a learning disability who was bringing up their son or daughter in our community. We think that that could also be because of the negative messages that people with a learning disability hear about parenting too like;

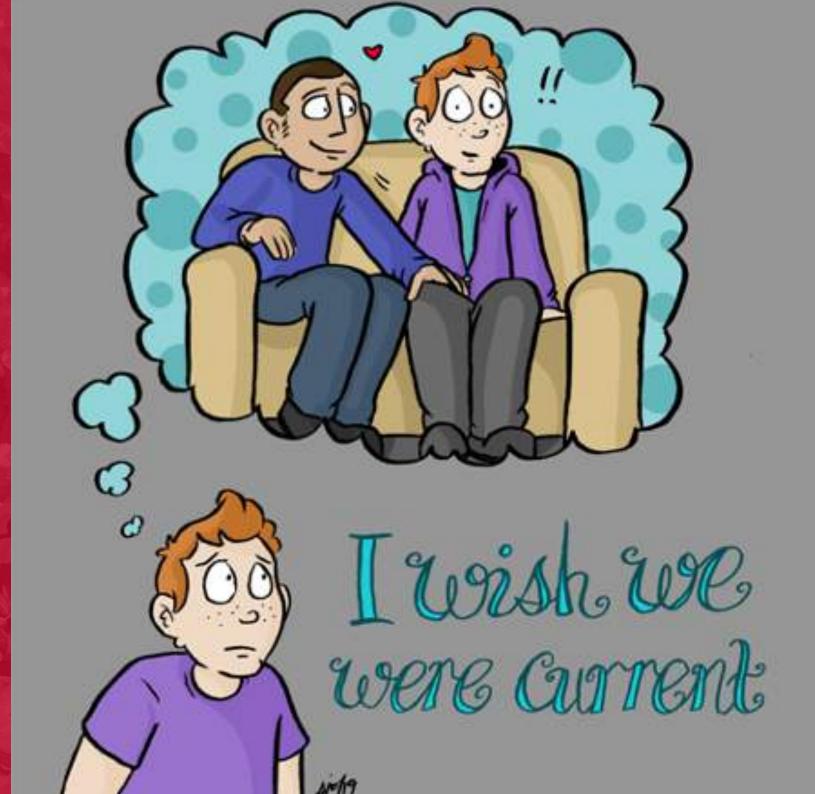
- o There are lots of rules about bringing up children
- o Being a parent will take up all of your time
- o Being a parent will take up all of your money
- o That you don't have enough room in your place to be a parent
- o Being a parent is too much of a responsibility for you
- o Children are a burden
- o You need to be able to drive a car
- o You will have your children taken off you
- We did notice that David's foster parents said to him that he would make a good dad though. We were surprised because we have never heard anyone say people with a learning disability have something special and important to give their children or that being a parent can be the most important thing you do in your life.
- We remembered having dreams about having kids when we were younger and wondered if all of the negative messages about parenting had changed our dreams. We think we just assumed it wasn't possible because we had come to believe that that is the way life is. People with a learning disability aren't allowed to be parents.

### They got engaged to shut everyone up!

- David and Jess said they got engaged to shut everybody up! We wondered whether anyone had said congratulations? That's what most people would say if you told them you were going to get married.
- When no-one expects people with a learning disability to get married we learn not to expect it for ourselves. The first time I heard someone with a learning disability was married it blew my head off. I just didn't think of it as an option.

- Like becoming a parent, we think we dreamed about getting married but then forgot about it.
- Talking more openly and honestly about sex and marriage and may be becoming a parent might help us to reimagine the future -David and Jess's story gave us this chance.

### What do you think?



### **Cover Art:**

Sam Orchard

Sam is a Dunedin artist who uses comic art to tell stories that celebrate difference and works on community projects that use art to create social change.

Figure 24. A comic art image in which a young t-shirted man is depicted imagining or perhaps remembering himself in a "thought bubble." Within the thought bubble the imaginer is drawn sitting next to another young man on a two-seater couch. In this scene, the other man orientates towards the imaginer. Their knees are touching and his hand rests on the imaginers knee. A red love heart hangs in the air in front of the other man and two exclamation marks punctuate the air in front of the imaginer, perhaps explaining his wide-eyed stare.

### I Wish We Were Current

I want people to know that it's ok to be gay and just because you got an ID doesn't mean you can't have a sexuality.

### **Emma**

I remember one day I was playing in the yard with Emma. I was 10 and she was 8 years old. I asked Emma if it was okay for me to rest my head on her butt. I sort of wanted to cuddle her and I felt safe and happy around her. But then a family member saw and they started yelling, I was petrified, I wondered what the hell was going on. I was using Emma's butt like a cushion but this family member saw it as something else. I felt guilty when the family member started to yell. We also got caught a few times, kissing, and they wouldn't let us be alone together, but I kind of liked spending time with her.

Me getting into trouble for that kind of thing probably messed up my sexual growth more. Because it's when I started to get to high school and teen years, sexuality was taboo for me. I felt it was wrong to be straight, it was wrong to be gay, or anything. But I was young and curious!

### Cooper

When adults say, don't hang around someone because they are trouble, it makes you 10 times more want to hang with them. One time Cooper and I were in a corridor at school and he told me he shaves his pubes. And then he showed me, but I don't know why he showed me that he shaved them? I didn't see his penis or anything! I just saw the top part, above the genitals. I kept wondering what he was trying to do. I don't know what that's supposed to mean? I remember at the time, it was confusing, and I remember wanting us to experiment.

After finding out that Cooper wanted to shave his pubes I wanted to do the same. I don't know if it's a gay thing, I'm thinking straight guys probably don't care about it? I tried to shave my legs and probably my chest. Sometimes the skin is smooth but then goes all prickly.

### Coming out

The word gay can pop in and out of people's minds. People can be in denial or it can be completely hidden. When I think back, it's like I don't want people to know I'm gay because it can be a terrifying thing. I do remember wanting to be with other teens when I was a teen but I felt, this was gonna be impossible. I thought things like, no one would want me, how am I gonna meet someone when I'm stuck in a group home and when you're gay, people think you're creepy.

### **Puppy Love**

One day I was going outside to get something, and a girl from next door, grabbed me and started kissing me. I was like, stop! She just grabbed me and started bloody kissing me. I felt a little bit of puppy love. Well, it was strange, I don't know, I kept thinking I will be straight, normal. Actually, what the hell is normal? Does that exist? For quite a while I was interested or curious about girls. At the time, I thought all people had the same body parts, but and then I realized that females don't actually have a penis. I didn't have gay thoughts at this time, I just felt empty when I kissed girls.

### Ethan

When I was 16 I still didn't understand about my sexual orientation. well I didn't have a word for it, I didn't even know about gay. I didn't know the word existed. You don't know about your sexuality or sexual orientation if you can't meet people. But one day, this person Ethan, we were on the trampoline, we weren't talking much, and out of the blue he just said 'I'm gay'. I didn't give a second thought to it, I just said 'I'm gay too'. It's like something inside of me just forced me to say it. I could have done stuff, but I was afraid because of the way that Ethan's carers were watching him like a hawk, all the time.

### **The Diary**

When I was staying with some caregiver, I done this diary of all the confusing mess that was going on in my head. It was like my head was screaming all the time. It wasn't making any sense sort of screaming. It was loud screaming. I was trapped in my head. So, I had to write down in a diary to make sense of it all and figure myself out. It was like a kind of therapy for me in one sense. It started to develop my sexuality. Because of all the screaming, it was like a puzzle I had to put together.

But the problem is one day I had a bit of a tiff with the partner of my caregiver at the time and he read my diary. I found out through a family member later. And that's why I never went back to that caregiver's place again. My family member taught me not to be so trusting. I've learnt after this incident. I don't write anything down, ever.

### **Church and Waffles**

I did go to church for a while, but then I thankfully I moved away from that. They actually didn't know that I might be gay. I didn't feel like I could be open and tell people. There might have been the odd guy I had a crush on. Sometimes we would go to someone's place to have these waffles. That was the good thing about it, free waffles, can't complain. We also went to a bonfire thing, so it was good, but I just felt like if I told them I was gay then I'll probably get rejected and they'll probably kick me out and I won't get to go there anymore.

### Counselling

I remember I went to a counsellor and they tried to make me straight. They showed me pictures of women in bikinis, well it didn't work. I felt like I was being forced to be someone I wasn't. I felt this was very controlling. I realized that I needed to figure myself out on my own and not have someone else meddle in my head. I did go to another counsellor and they talked to me about relationships and showed me pictures of guys. Looking back, I wish my support person wasn't in the room with me, I might have opened up more.

### Learning about consent

I knew about consent when I was young, but it's not actually based on sex, it's based on other types of consent. And it's not completely whether you've been taught it, because sometimes consent comes to you naturally. It's like 'oh, I don't want to do anything that offends or upsets'. The first time it came to me was when I was on the trampoline with Emma. I do remember. I asked if it's ok to rest on her. And that is asking for consent. It's not invading someone's space.

When I was mentally unwell I didn't really think about orientation and relationships because my minds not on that. This means when you're unwell, if someone's interested, you won't be able to consent to sexual activity or anything like that because you're not in the right state of mind.

### Sophia

There is something that did happen that I just keep being puzzled over, and I don't think it's anything you can call abuse, because we were both young. I think Sophia was a few years older than me, I think she might have been 15 and I was 11. But I didn't really feel into it and I don't know if that's because I was too young? She kept coming onto me and I remember thinking back that I just liked that someone was paying attention to me, even though it's probably for the wrong reasons. She was a bit of a predator, when you think it about it. She was a bit creepy.

Sophia and I were in this abandoned house, sort of abandoned, it was falling apart. Months before this person ripped off the wood boards and I was annoyed because we didn't have much privacy. I think I asked if I can kiss her but then I didn't feel a sort of rush type of thing. I didn't know if I was too young and not started the changes yet.

### **Dennis**

I was in a van with Dennis and he started to touch me, he was rubbing my leg. He just touched my knee and I immediately got turned on. I actually only started going through puberty when I was 16. Well my body started earlier but my mind, that took a lot longer for me. That took longer to develop because I remember I didn't even have much sexual thoughts for a while. When I think about it, the way the carers reacted I felt it was deeper than our differences. I felt it was because we were two guys. I didn't think about it at the time, but I think that now because I have more knowledge, you know you gain knowledge over time.

### **Sexual Abuse**

I remember when I was about 8 - 10 years of age this older man tricked me into kissing him. I didn't know what he was gonna do and I knew what he did was wrong. I felt guite disgusted by it to be honest. I wanted to tell people about it, but because of my disability, my lack of communication, I didn't know what words to use. I felt I wanted something done about it, I wanted to tell people about it but I felt I'd get into trouble. The thing is, that person might be dead, but I still want justice and I'll always want justice.

My father abused me and my siblings, that is why we went into foster care. I keep thinking back from when I was 18 and people had this assumption about me, that I would be like my father. I just keep thinking it's because of all of that. I don't understand, because, I mean for crying out loud, I even kept an eye on children. When I went overseas I had to keep an eye on my nephew and because of the past, I didn't really want to. I didn't know how to keep an eye on him, because they wander and move around. When I was 16 I did have to look after a toddler for a while, it was hard work, but at the time my main priority was making sure he was okav.

They gave me that responsibility, they trusted me and so I wasn't gonna break that trust. A close family member and I were hanging out one day and she started assuming that I would do stuff like my father did. It made me uncomfortable her saying all that because it was in a public place and someone could hear her. I told the family member I was never like that. I never am like that. With all that was

going on, it actually was the first time I wanted to kill myself. I wanted to jump into the ocean and swim far, far away from land, and just see how far I could make it. But I didn't want to brave the cold water so I never did that, because I know how freaking cold the water would be.

### **Accusations**

These thoughts of ending my life were also caused by service providers, who were making the same assumptions and accusations about me. They were assuming that I was going to look at illegal pornography. I did look at women online, but it was adult women. It was R18 sites, it wasn't illegal. Some of these false accusations might have been because I was making things up to see how the service provider would react. But then they made a big deal about it and it just made things complicated and made things stressful for people. They wouldn't let me get the internet without signing this contract, and actually I didn't understand what I was signing. I felt like the service provider had control over my life. I felt trapped by the contract, if I didn't sign it they would think I had something to hide.

I got accused of looking at pornography on the computers at my computing course too. It's like they've got nothing better to do! They searched through the computers because, from my understanding, if you've accessed pornography, it doesn't matter if you clear that computer, they have a record of who's been accessing stuff. It would all be backed up. They searched and they found nothing. And because of all that stress, I only managed to pass my level two. I don't think I could do level three because of what the staff at the course put me through.

### Leo

Leo and I where friends through this support organization. They had these rules. They said no one can go into your room and you can't hug anyone. The room part was understandable, but when they said hug, I felt a bit creeped out. When they said that, it's kind of like,

who the hell do they think I am? One day I saw Leo crying at one of the parties they run every year and I wanted to hug him, but I felt I couldn't even do that. I remember feeling a bit sad at that time.

We met years later again, surprisingly at a course I was doing. I met Leo there and I don't know why I had this really painful feeling in me all the time. It was annoying. It wasn't like an actual painful feeling, it was like a psychological painful feeling. It's like you're being ripped apart.

Leo invited me to a party. I got a few drinks and apparently, I was getting a bit tipsy. Leo was saying that I had to leave. Maybe I was drunkenly coming onto him, I don't know! But they say alcohol brings out your true feelings, it can release what you normally control. So, if you're in denial about being gay and if you were drunk, most likely you would find yourself waking up next to a guy.

But Leo was paranoid and I don't know what was happening, but he said I had to leave, but I didn't really do anything. I wanted to stay, but I've kept thinking that maybe the alcohol, because sometimes you can flirt without knowing it. Sometimes alcohol makes you a bit more relaxed about your feelings.

### **Jeremy**

Sometimes I have a type but it's flexible. Like someone might come along that doesn't fit my profile and yet I might find myself falling for him. It's like when I first meet Jeremy, I thought he was ugly. Ugly and old. Jeremy wasn't my type but I did like him, I think I was emotionally attracted to him. He smoked, sort of smelt, that kind of put me off wanting to kiss him when we dated. I don't know if our carers even guessed it was happening. I'm pretty sure they might have known what was going on. But they never said anything.

Well one time Jeremy and I had sex in the open air. His family were homophobic and we couldn't do it in the house so we just done it outside. And it's funny cause there were these people that biked past us and I don't think they knew we were there.

I liked Jeremy mostly because of his personality. But I wasn't 100% attracted to him because like, he didn't have the looks completely. I know when he broke up with me it hurt a bit. And I cried. I don't know why I cried. I don't know if it's cause I wanted someone to move in with me so I could get an affordable place, or if I cried because I actually did like him. I don't know what the actual reason is why I cried. And still don't know to this day!

### Hunter

When I was younger and staying at a group home, I went to a monthly dance and I did meet this guy, Hunter. I approached him and said 'hi', and then I actually asked for his number. We became friends. One day I went over to Hunter's house, and we were watching a movie. I didn't really see it as anything, I just saw him as being friendly. Hunter said to me 'I like you, you're cool'. And he slaps me on the leg. I didn't know what that's supposed to mean. I didn't know if that meant just a friendly thing or what. He did actually come to my house, but there wasn't much to do and I didn't know what we could do. I think he was lost too.

I met up with Hunter again a few years later at the library and then later we caught up on Facebook. Hunter sent me a topless picture of himself. I said to my carer, "friends don't send each other pictures of themselves" and they said "oh they could". But then I replied "they don't send pictures of themselves with their shirt off in bed". What I don't understand is why I don't find Hunter remotely attractive in photos but I seem more interested in him in person? I sent Hunter a photo of myself but I wasn't shirtless. People can share that. We chatted on video once but then Facebook removed my account. I actually had a second Facebook account anyway as back up. It's so addictive that you have to have two! So, I don't think you actually send pictures to each other if you're friends, that's how I see it. But if you're attracted to each other then you probably would.

At first I asked Hunter if he wanted to visit, just as friends, to hang out. I was sitting at the computer desk, Hunter touched my knee and asked me "is it ok to be gay?" I said "yes" and I made it pretty obvious I was into him. Hunter dropped his pants and said "I feel sexy", then one thing then one thing lead to another. It's like sometimes you have an insatiable urge and you can't really stop yourself. It's like a magnet and it goes deeper than looks. I don't know if Hunter was just being friendly, but he liked to come over, and after a while he just ended up turning up out of the blue. No notice. Like one day I was asleep, as you do in the morning. And he messaged me on Facebook and he was sitting waiting outside, and I'm like "oh my god, how long have you been here for?" But then I can't forget that day, how good it was. I was standing in the kitchen and Hunter was kissing me all over my neck. I liked it, I can't deny it either, it felt good.

One day when he came over he gave me a condom. And I didn't really know what to make of it. I was unsure if I was getting mixed messages. I was trying to work out what he wanted, I wasn't sure what I wanted. I was trying to work out if we were on the same level. Because to me, it's all about, if you are on the same level, is this what you both want? An acquaintance was making me feel like Hunter wouldn't be on the same level as me, which is why I probably didn't do anything, because I wasn't sure. I was trying to look out for him because I didn't want to take advantage of him. But it must have been obvious, I mean, you wouldn't give someone a condom if you didn't want to bang.

### If you've got ID (intellectual disability), or whatever you call it, doesn't mean you can't love or be loved

I want people to know that if you're with a service provider, they shouldn't be controlling of your life and they shouldn't tell you that you can't be gay. Families can also stop you being yourself too, if you have ID. Growing up I had to fight to try and enjoy being with

girls. With boys, I had to fight the denial that I liked them. But now I know I'm attracted to guys. I'm gay, but I don't like to stick to labels too much because people's sexuality can change over time. I don't know if there's such a thing as soul mates, if there is I haven't found mine!

### **Key Messages**

### He couldn't come out of his own shell

- We think the worst thing about this story is that the Storyteller never felt free to be who he really was. He was a gay man and couldn't be himself until he had the chance to speak up.
- [The Storyteller] couldn't come out of his own shell. It is important that people with a learning disability feel like they can come out of their own shell.

### You should be respected for who you are

- Whether you are a man or woman or gay or straight you should always be respected for who you are. We noticed that the Storyteller kept avoiding labels. He said 'whatever ID is' and 'whatever normal means'. We wondered if this was because he wasn't made to feel good about either being gay or having a learning disability. Being valued for who you are is very important. The story teller had two labels that he thought made it harder for him to get respected.
- We also thought that it was interesting the psychologist thought the way to correct the Storyteller was to show him pictures of women in bikinis. We didn't think that was respectful - of the Storyteller or women either.

### Can't talk: There is more than one puzzle

- We felt the story tellers didn't feel he could talk about his sexuality. One of the ways you know whether you are respected is that you feel free to talk up and ask questions when you need to.
  - o We noticed he said he didn't trust anyone.
  - o He also said he wished his staff person wasn't in the room. That he might have opened up more to the counsellor if he wasn't there – which made us think he was frightened to talk to his staff.

- We weren't surprised that he said that he said figuring out who he was, was like solving a puzzle because he didn't have anyone to help him. Everyone should feel free to talk up when you need to.
- Disability services never seem to look for diversity. They don't look with rainbow glasses! No one talks about being gay or lesbian or other sexual identities. Staying silent closes doors.
- The Storyteller had to wait for another boy with a learning disability to ask him if it was ok to be gay.
- We also believe that disability services and others need to think about the questions people with a learning disability might have over their whole life time.
- We thought the Storyteller needed help when he was a younger that was different from the support he needed to figure out what was happening when he was older and starting to have sex. There is more than one puzzle to put together.
- He was fighting time. We thought that because he never seemed to get the help he needed when he needed it, he would feel behind other men his own age. We all remembered feeling that other people knew more about relationships and sex - and that not knowing things made us frightened to get into a relationship with someone else.

### He didn't know what was ok

- We realised the Storyteller had very few chances to learn how to get into a relationship with another man. He seemed to be confused about lots of things.
  - o He didn't know why Emma's dad was yelling
  - o He didn't know what Hunter slapping him on the leg meant or what he could do when Hunter came to his flat

- o He didn't know what sending a photo or giving him a condom meant.
- o He didn't know if it was ok to want to have sex with someone who was not on the same level.
- Not being able to talk to anyone would have made it so much harder to know what was ok and how to react.

### The 'no hands on' policy

- If people who self-identify as LGBTIQ are going to love themselves and get to love others in a positive way, staff need to think about what is the right environment for this to happen. You need to get the environment right!
- We believe the Storyteller wasn't allowed to have a positive sense of himself as a gay man. We thought that because he kept saying;
  - o When you're stuck in a group home and gay people think you are creepy
  - o That he and his friends watched like a hawk. He must have felt there was something wrong with him to have to be watched like a hawk.
  - o They checked his computer.
  - o He also said he wasn't allowed to hug anyone he lived with or he met in his service.
- People with a learning disability are often not allowed to touch in their own home. We called them the "No hands on" policy.

### We think he must have been very lonely

• All of the places the Storyteller connected with his community were places where he could not be his true self. His home and his disability service, his church, his family, were places where he felt he could not say he was gay. "We think he must have been very lonely."

- We think the story teller had to have sex in public and other risky places because he had nowhere else. He couldn't go to a motel and he couldn't bring someone home. It had to be in the back of the van, or a house with no boards or outside in the park!
- We wondered what impact that had on the Storyteller's sense of himself.
- Within the culture of disability support it is often impossible for people with a learning disability to bring someone home or to go to another disability support service. Services don't trust each other. It's like two tribes.

### The same rights as everyone

- Not feeling good about yourself, (thinking that you are creepy or are doing something wrong) can make you from think that you have the same set of rights as everyone else. In this story, the Storyteller didn't have the same rights to;
  - o Privacy
  - o To watch what he wanted
  - o To say he was gay
  - o To be in a relationship with someone he chose....

### It's a circle that keeps on going

• The more we talked about it, the more connected everything seemed. To us the Storyteller seemed to be stuck in a circle that kept on going. When we drew it out, it looked like this:

### How do you break the circle?

• What really troubled us was that the circle had led the story teller to thinking about killing himself. Some members of the research group said they had felt the same way in the past. The advice they gave was;

- To un-do feeling bad about yourself it helps to feel valued for a long time.
- We liked the way the Storyteller brought his story back to finding a soul mate. We wondered if what he needed was someone he could be open and loving with too. The kind of things that are about being intimate but not necessarily about having sex. It could be as simple as helping him to find someone he cares about. And someone who loves him so he can love his own self.
- Being able to talk openly and find someone who loves you for who you are should be doable.

### What do you think?

## before you love anyone else

### Love yourself pretty much,

### **Cover Art:**

Kama Warburton

Kama is a young Dunedin artist who loves colour and has previously worked out of Studio2

Figure 25. Vibrantly coloured poster-paints have been used to create a colage of images. A curtain of bright blue and yellow and grey and orange polka dots look as if they have been pulled back to reveal stylized flowers in one corner of the painting and a red heart, be-speckled in ladybird black dots in the other. A small yellow cat sits unobtrusively at the bottom of the page and the artists name is painted diagonally centre-stage.

### Love yourself pretty much, before you love anyone else

### I do remember a lot...

Well I can start from the very beginning. So pretty much I was bought up in foster care because my parents couldn't look after me. My Mum had sort of a similar experience to me but hers was physically worse. She was physically beaten up, she's still lucky to be here and she's still alive but she's not with that person anymore. That was my Dad and because of that. Mum couldn't look after us because Dad kind of brain washed her a lot and she did try to leave apparently but that never worked because he'd track her down.

[It was] domestic family violence and us kids kind of had to, me and my brother and my half-brother kind of saw it, but my half-brothers were of the age where they could leave and live with their Dad. They were worried [about us] but they didn't have to deal with it because they could just pack up and leave because they could decide what they wanted to do. And me and my brother were left but I think from what I was told about it, one of my [half-brothers' rang Oranga Tamariki, which was CYFS back then, and got me and my brother out of that situation and there were a whole lot of family meetings about it but I was never able to live back with my [mum].

[So I went into foster care] and the situation wasn't better, it took Mum about 10 or 11 years to finally get out of her situation and that caused a rift between my relationship with my mum but we're a lot better now - but it's never going to be....

I was five [when I went into foster care]. I was very young ... No-one really wanted to look after me because I was the kid with ADHD and that was kind of full on for anyone.... I was very full on. And also in saying that, Mum's side of the family, they would have tried to look after me but they couldn't because Dad kept threatening them and

stuff like that so that put them in an awkward situation and they had families of their own so it wasn't fair.

There were some good foster places and some not so good. I had lots. I went to about 24 homes, I think. From the age of 5 till the age of 16 or 17.

[One foster home in particular] wasn't good for me though, a lot of stuff happened there, there were other really bad foster children there and it just, wasn't a good situation. Then I went to another home and that was around this way - they didn't have children of their own because they couldn't have children and because of that they didn't really know how to bring up another kid that wasn't their own and just, it wasn't their fault, they just couldn't really understand me. Like I said, I was very hard to raise so they struggled. I didn't have the best behaviour. I understand that and I know that kids with ADHD can be very full on, because I was full on for a fact but I'm not going to compare anyone else.

### I went to two primary schools...

I went to two primary schools. School for me growing up, especially primary school was really hard for me. Because I didn't really fit in with the other kids. I got bullied, I kind of bullied them a bit as well, just like struggling with things

One time because I was getting annoyed because these people in my class were just being real horrible to me, I got angry and I was like right, I'm going to teach them a lesson, so what I did was, I kind of threw a chair at them, like a plastic chair and I got suspended for like two or three days because of it. But I felt really awful afterwards. The [teachers] never really realised [that I was being bullied and that was why I threw the chair] and I did try and talk about it but it was always when the teacher wasn't around so like they couldn't do much about it unless they were caught out on it. I think [the teachers] just thought I was struggling with everything in life and that. I found there were some nice teachers though, I felt like my teacher aide was really good with me and did a lot with me. [I didn't have my teacher's aide] at lunch time or morning teas, I kind of had to figure that out.

I didn't really have friends. Eventually in year four or five, I did make a friend. This girl was really lovely. I'm still friends with her, we still kind of keep in touch at times. Yeah, [she's] a long-time friend, although we don't see each other much and she's doing her thing, and she's a bit older than me. But she's always been my friend. Yeah, but then she left a year before me and I was left, because I got held back a year a primary school. I was kind of left to deal with that and it kind of sucked.

I found [having ADHD] really hard, and still struggle now. Whether that be because my home life wasn't settled enough because of going from home school I struggled with my math, still struggle with my math. And they tried to teach me and also, my learning wasn't up to the standard it should have been for my age.

### High school got worse...

High School, got worse. Let's just say that, I wasn't the bully. I was the one who was getting bullied. Year 10 camp, let's start with that. Year 10 camp we went to [the country]. I was in main stream, I wanted to be in main stream because I wanted to make friends and just be a normal.... Like I know that I'm normal but like fit in, try and at least fit in for that thing but that never happened. Until year 13.

[On school camp], what happened was, we were told to go to bed at a certain time. Everyone had their cell phones and some of the girls, they were just being really horrible and stuff like that and asking inappropriate guestions to me. Just being really inappropriate.

And I'm just like, I don't know what to do about this. Tried to get a teacher, teacher told me to go back to bed so lucky I had my phone on me and I rang a person and this person rung the teachers of the school and really said something to them like..... it's like 11 o'clock at night and these kids are tormenting my child. Well yeah, and she's like and my child is very upset about this and this is not on. This is a school camp, and you guys are meant to have a no tolerance for bullying at this school. And anyway, so the teachers came in and I ended up sleeping the night in the teacher's cabin. But that didn't really change anything.

I don't know [what would stop bullying], but like maybe, there needs to be more put in place for the people with disabilities and like trying to maybe, discussing things with the [other] students in a way that they'll understand and they'll respect these people and remember that their brains don't always exactly be like theirs but in a way that's not going to affect these people and make these people feel like they're stupid of something cos also I think a lot of respect needs to be given to these people and like the [non-disabled] students need to spend time with the people who have disabilities and just make them feel wanted and not horrible about themselves.

For a while, a long time [I always felt horrible about myself]. I did, because of what was going on, I thought yeah I'm usually different from the rest of these people, I'm stupid, I'm all of those and I used to come home crying and just get really angry about it.

### My behaviour got very out of control

Yeah I was going through the teenage years, some really bad teenage years, let's just say that. Ummm, with all the bullying, besides that, there was the relationships, the people I sort of connected with. I look back now and think, why on earth would I go out with those people? Or hang out with those sorts of people? I really don't know [why I did hang out with them] to be honest. I just think maybe I just thought like, I was cool or something - but that wasn't the case. I don't know.

At the time, I just wanted a boyfriend and you know, everyone else my age, in my class had boyfriends and people used to kind of torment me about it. Like, oh have you done this, have you done this? Or have you got a boyfriend, you should get one, and then I'd turn around and they'd try and get me to talk to people I didn't even know. And they asked me if I've ever done that or ever done that? I felt uncomfortable actually, really uncomfortable. I don't know [if they did that to other girls] to be honest, I kind of .... I don't know. I just know that they were trying to make fun of me and stuff because I was a little bit different.

But so anyway, I'm going to get onto the topic about this relationship. He just wasn't a nice person. He had all these charges against him and I was just stupid, young. [He was] a lot older. And I don't know why.....people did try and not allow it but I just wouldn't have a bar of it! I was living at [my foster] home because I was only 16. [The relationship ended], but that was after a big screaming match.

### He asked me for sex all the time

And then the other person I met. So, we went out for a couple [of] vears. He was older than me. He asked me for sex all the time. I felt I couldn't say no, and that he called strangling me, play fighting, used to argue with me, he'd sit on his play station. I got [a pet] at one point and when my [pet] arrived, he was jealous of [it]. I don't know why he'd be jealous of [an animal], to be honest and when [it got a bit older], this person tried to [hurt my pet] and I literally screamed; it was just really horrible.

[I started getting support from a disability service] and my boyfriend was allowed to stay two nights and I used to go round there and stay at his house. That wasn't good either. Any time he got the chance to like maybe physically hurt me, and claim it was play fighting, he'd do it.

He wanted sex all the time. Even if I said no, he'd literally drag me on the bed and really badly pressure me. And I don't know, one

point, I got to the point that I rang my mum in tears. And I was like this is what's going on, and she yelled down her phone. [And when I got invited out he said] you're not going unless I'm going. And I was like, what, so now I'm not allowed to go out by myself and have fun.... And he was like, "[no] - I'm coming". So, I had to ring [the person I was going out with]. I felt like I had to and he made me feel really guilty. And then we did, and we were drinking and that then we got a taxi back home and that night he spewed up all over my toilet floor and I woke up the next morning and I was busting to go to the toilet. I was busting to go to the toilet and what happened was he kept refusing to go to the toilet to clean it up. And he was all "you clean it up, I'm lying in bed, I'm staying in bed", and I was like, you made the mess, you clean it up, it's not my job. So, I ended up scrubbing the floor, cleaning the whole floor up. This was round the time I'd had enough of it all because it got really bad. And [because of him] I would stop contact with my family and all of that and it wasn't good.

[A close friend] actually knew about it, well she actually picked up, I didn't really talk about it. They had a couple of things that I think they were worried about but I never really discussed it. I think I refused to discuss it for some reason. [I know it was an abusive relationship] but my mum was beaten up more that I was beaten up to be honest.

### I snapped...

A couple of weeks after the bathroom incident, we were on the bus and I think we went somewhere, we were doing something and on the bus, he kept winding me up and winding me up, and I don't think the bus driver realised, and anyway, I slapped him across the face because..... I snapped, I had just had enough and then he got off the bus and he was really upset and I kind of was in the mental state where I decided I was going to ring the police on myself which is the most ridiculous stupidest thing to do, see my brain was not right. [But] I wanted to resolve the situation, because I'm a nice person like that.

I felt I was in the wrong when it was actually him that was in the wrong. More or less.... So, what happened was the police went round to his flat and he decided he wouldn't press charges. I don't know why but that just made me feel even more guilty but in saying that, I shouldn't have felt guilty because he was the one who was treating me terribly and then after that with everything, on day, I don't remember the time frame but I do remember this, I'd had enough, and I was like right, this isn't on, this isn't fair to me. This is not a healthy relationship. So, I ended things and I told him to pack up. come down and grab all his crap and all of that. He wouldn't so I ended up chucking a whole lot of things out and he was all "Oh, I can't carry all of that" and I was like "well, if you're not going to get it, then I'm going to chuck it all out", so I chucked most of it out, then he tried to contact me again and I blocked him on everything.

I think I realised this - I didn't want to end up like my mother and live with that for like 10 years or more, and I don't think it was fair to my family to see me go through all of that, and plus I was struggling with my schooling as it was. I was trying to get NCEA level one and I couldn't even focus on that, and I was like well my education is more important than someone putting me through that. That person doesn't deserve to have someone like me.

It felt good that [the relationship] was gone actually to be honest. I was still processing in my mind what had happened. It was kind of hard to process because I kind of knew all about that stuff but vet it happened to me, and I should have been more aware of the warning signs, the warning bells.

### I've learned this...

Well first of all, how do I explain it... I've learned this... maybe if a guy just sits around and does nothing, expects you to do his washing, expects you to do everything, not even taking turns at cooking, you know like normal relationship things that you'd do. Another warning sign would be the really bad arguments all the time. The constant arguing and as soon as he started physically hurting me, claiming strangling was play fighting, that should have been another warning sign I should have taken into consideration.

And, I should have told someone else sooner. I shouldn't have kept it all to myself. But I did because I didn't want anyone to worry about me. After I broke up with [my former boyfriend] I do know that from the experience, it took me a long time to recover from that. He never come back but he told everyone a whole lot of lies about me and claimed that I was pregnant to him. I wasn't.

### He's lovely

Yeah, so I kind of met him online, but I did it the safe kind of way. He decided one weekend he was going to come to [where I live] drive all the way here and meet me. We met at [a park]. And yeah, things just progressed from there and we kind of had a connection and we just talked and talked and that and he ended up staying the night and yeah, it just kind of progressed from there. And in saying that, I wanted someone who was going to treat me right and I think I've finally got that because he is really lovely. Like he comes to see me and I to see him. We go out for lunch, do things normal couples do and you know. He has respect for me. We have our disagreements but at the end of the day we still care about each other. And like even after a hard day at work, he always will talk to me.

[I have found someone] who respects me and has loyalty and love for me, who is not going to abuse me in any form or way. And in saying that, my [close family and friends] absolutely love him and that's the way it should be. Your family should be able to know your boyfriend is a nice person and respect him. And I know his Mum and his Dad. They respect me. Like first time I was really nervous because I haven't really had the best experience meeting [the family of] a person I went out with.

[A good relationship is when the person] respects you and has loyalty and love. It doesn't always have to be about the intimate stuff, it can just be maybe going out to a movie. Maybe going for a walk or something? For a while I was really scared [of intimacy]. It just kind of happened with me and [current boyfriend] aye. Yeah it just kind of happened. No pressure, he never pressured me, it just kind of happened, like I said, yeah... In my opinion, don't rush into things. Wait till you meet the right person. Love yourself pretty much before you love anyone else.

### **Key Messages**

### The big question

- The whole story seemed to change when the Storyteller said she should 'love herself.' It was like flicking a switch [to a new life]. She realised she was worth loving.
- We think the big question is, why is it so hard for people with a learning disability to feel good about themselves? Why don't they feel they are worth being loved and respected?

### She was not safe in any of the places she should have

- We noticed the story teller did not feel safe in any of the places you need to be able to feel safe. She was not safe in her home (family or foster parents), at school (teachers) or in her relationships (partners).
- Our advice to parents, teachers and partners is to:
  - o Stand up to violence
  - o Pay attention by listening Ask for people's stories.
  - o Understand the impact bullying and abuse has on people's lives.

### She only found one true friend

- The story teller only found one true friend but it was her friend for life. We think a true friend is all you need to begin with. True friends are open to truth about what you are finding hard. They are where you can find security and begin to trust.
- You can say you are unsure about what you are doing to a true friend. Without them you mightn't get to say it [when you are unsafe].

### Home wasn't safe

• The Storyteller's mum had had the same things happen to her. All the Storyteller had seen was violent relationships at home. She may not have known anything else.

- We think everybody should have a place where they belong and can talk.
- And we asked ourselves, how does a person with a learning disability find their way out if they are not in a safe place? Where do you go?"
- We also thought all of the moving [between foster homes] would have been hard. She did not have a stable home. It was never her place.

### Relationships with men weren't safe

- We noticed that her violent partners were older men and were very concerned the Storyteller was forced to have sex. Especially that her boyfriend strangled her and said it was play-fighting.
- Sex and strangling seemed to be one of the ways her boyfriend used to have power over her. He also said she couldn't see her family or go out with friends.
- People with a learning disability can feel controlled but put up with when they feel like they might not be worthy of a loving relationship.
- We were interested that the Storyteller chose not to listen to other people who were trying to stop her seeing her violent boyfriend. We think it was because she wanted her own choice.
- People with a learning disability don't get to make many important decisions in their lives. We think that choosing who you see is a decision that is hard for other people to take away. Choosing who you have sex with might be a way of feeling you have some control in your life. You are setting your own goals. Sometimes it can feel better not to listen.
- We also thought she might have felt trapped because, she didn't want people to worry about her and didn't know what to do about it.

• "Worrying about someone can be different. There is caring worrying and there is controlling worrying." They are not the same thing.

### School wasn't safe: We had all been bullied at school

- Being called names like "retard," happens all the time for people with a learning disability. It is especially hard if you live with anxiety or don't know why it is happening.
- The Storyteller said she didn't feel like she really fitted in with other kids. We think feeling like you don't fit in would make it harder to love yourself.
- She said the teachers never seemed to notice that she was getting bullied but did notice when she reacted to it [like throwing the chair or getting someone to phone her teachers]. It was always her that got pulled away [she got suspended, she got put with the teachers] rather than confronting the bullies. The Storyteller is telling us that pulling her away never helped. It was punishment.
- We think schools need to pay more attention to why people with a learning disability react the way they do. What is making them behave the way they do.
- We are especially worried that bullying is often about sex. Other kids would tease the Storyteller by asking if she had a boyfriend, if had she done things, introducing her to people she didn't know and asking inappropriate questions.
- She said it was a way of tormenting her because she was different.

### We thought the Storyteller was brave

- We thought the Storyteller was a risk taker.
- We also thought she was very brave. She threw a chair, stood up to her boyfriend and other bullies, survived abuse and violence

- and offered common sense advice about how other women might avoid violent relationships [as ways of getting some power back].
- She was also brave because, even though she knew family and relationships and school were not always places of safety, she kept going back because she thought it was right.
- The Storyteller said she wanted to be in a main stream school because she wanted to make friends and be normal, but that she was always made to feel she didn't fit in.
- To us she was showing other kids she was normal, just like them, and that the best way to do this was for them to spend time with people who have disabilities.
- We liked that the Storyteller imagined that schools could stop bullying by discussing things with other students in ways that would help them understand and respect people with a learning disability. That their brains worked differently but they were just as normal and bravely trying to change places by showing up.

### It was like flicking a switch

- The other way the Storyteller was brave was she decided to break it by saying she had had enough of this.
- We noticed the switch flicked on sex. Before, sex was about abuse. After she decided to love herself, intimacy wasn't only about sex. Having normal safe and close relationships is more important. Holding hands and going to movies as well as other kinds of intimacy.
- It's about respect mostly.

### What do you think?

### **Cover Art: Figure 26.** A photographic image capturing carved details of prow of Te Paranihi – a 17 metre waka taua (war canoe), thought to have come from the Kapati Coast and now exhibited at the Otago Museum.

# Te re Māori glassay

### Te re Māori glossary

Bargeboard support on a meeting house. A traditional chant or sung poetry often Amo Moteatea

expressing sadness or grief. Tribe or subgroup that share a common Hapu

> Ngāti Whātua Tribal group of the area from Kaipara to ancestor.

> > Pōuritanga

Tāmaki-makau-rau. Hinengaro Mind or thinking.

Foreigner, European or New Zealander of Pākehā Large kinship group that share a common lwi

> foreign decent. ancestor and territory.

Elderly man or grandfather. Poua Person who calls out the time to paddlers in Kaihautū

a canoe.

Traditional customs and rituals.

Karakia Ritual chant, incantation or prayer. Pōwhiri Ceremonial welcome often onto a marae.

Elderly man or woman usually of status Rongoā kino Kaumātua Drugs - Bad medicine.

within a family group. Takātapui Close, intimate friend of the same gender

and preferred referent of gay and lesbian

Depression or great sadness.

men and women. Kia kaha, kia maia,

kia toa Be strong, keep going, be brave, be Tama-nui-ki-te-Rangi Adoptive father of Māui.

> victorious. Tamariki Children or young people.

Kairangahau Researcher. Man - Male. Tane

Korowai Ornamental cloak. Indigenous people. People of the land Tāngata whenua

School or place of learning. (whenua). Kura

Mana Spiritual power, prestige, status or authority. Funeral ritual - lament. Tangi

Mana motuhake Separate identity, autonomy, self-Taonga Property, possession or treasure.

> determination. Taringa Ears. To be deaf.

Village or cluster of buildings about a tribal Marae Tapatoru Triangle.

meeting house.

Elderly woman or grandmother. Tāua Mātauranga Māori Māori knowledge, cultural practices or

The stern-post of a canoe. Taurapa world view.

To support, agree or advocate. Tautoko

Kawa

Te Arawa People descended from the crew of this

canoe from Hawaiki who form a group of

tribes in the Rotorua-Maketū area.

Te Ika a Maui The North Island (Fish of Māui).

Te reo Māori Māori language.

Tihei mauri ora. The sneeze of life – call to claim the right to

speak.

Tikanga The correct procedure – customary values

and practices of place.

Body – self. Tinana Ancestors. Tīpuna

Tiro ā-Māori ki tōna ake Māori world view.

Toka Rock - Something firm and solid.

Tukutuku Decorative lattice work.

Waiata Song or chant. Wairua Spirit or soul. Whaikaha Māori Disabled Māori.

Whaikorero Formal speech making - Oration.

Whenua Land – Territory or place.

Waka Canoe. Wero Challenge.

Whakapapa Genealogy or decent line placed or recited

in the correct order.

Whakataukī A proverb or saying. Extended family group. Whānau

### "Mean As!" People with a learning disability telling and reading stories of relationships and sexuality