EASY LANGUAGE ✓

Saying who you are

A project about how to support people with intellectual disability in the LGBTQ community

WE ARE LGBTQ PEOPLE WITH INTELLECTUAL DISABILITY.

THIS IS WHAT IS IMPORTANT.

To respect our gender and sexuality as LGBTQ people
To use our pronouns
That the relationships that matter to us are seen and respected
To have good people around who understand us
That we spend time with people who make us feel proud to be LGBTQ
That we can be who we are on Country*
That all of our relationships are loving, safe and respectful
That we are part of the LGBTQ community and events
That our access needs are met by the LGBTQ community and events
That other LGBTQ people and actual allies respect and include us
That we can advocate for other LGBTQ people with intellectual disability
That support workers respect who we are
That support workers have more LGBTQ training
That we are safe everywhere
To have access to information about being LGBTQ and our rights
The rainbow flags show us the places where we can be ourselves
It is important that we are happy

A Report By:

Cameron Bloomfield

Amie O'Shea

Diana Piantedosi

Jenni Northcott

Acknowledgement of country

From our hearts, we acknowledge the First People of Australia, Aboriginal and Torres Strait Islander people.

We show our respects to Elders past, present and future and to Mums and Dads, Aunties, Uncles, cousins, nieces and nephews and family. Brotherboys and Sistergirls are part of the rainbow flag.

For all the self-advocates who are people with intellectual disability: Nothing about us without us.

Self-Advocacy acknowledgement

We recognise and thank all rainbow Self Advocates who have worked very hard over many years for equality and human rights for all.

We acknowledge that there are rainbow people with disability who are part of the community.

inclusiondesignlab

Contents

What is this report?

This is a report about a project that happened in 2022.

The **National Disability Research Partnership (NDRP)** paid for the project.

The full name of the project was:

Saying who you are:

Identifying best practice to support positive identities for LGBTQ people with intellectual disability.

The project was a **research** project. **Research** means finding out more about something important. This research project was about **lesbian, gay, bisexual, trans** and **queer** people with intellectual disability. Another way to say this is **LGBTQ people with intellectual disability**. The project was about supporting them to be proud of who they are.

The team that ran the project felt it was important to write a report about the work they did.

The first part of the report is about each person who worked on the project and the report.

The second part of the report is about the project. You can read about how the project worked and what we learnt from the project.

Here are some names you will see in the report often. Three are organisations and one is a website.

Rainbow Rights and Advocacy

We talk about the group called *Rainbow Rights and Advocacy* a lot in this report. It is a long name. Sometimes we just say *Rainbow Rights* in the report because this is easier to read.

Deakin University

Deakin University led the project that this report is about. Amie, Jenni and Diana were from Deakin. The team at Deakin has worked on many projects with LGBTQ people with disability.

Inclusion Melbourne

This easy language report was made with help from the Inclusion Designlab team at Inclusion Melbourne. Inclusion Melbourne supports people with intellectual disability.

Rainbow Inclusion

The people who worked on this project also worked on Rainbow Inclusion. Rainbow Inclusion is a website that has lots of information for LGBTIQA+ people with intellectual disability.

Go to **www.rainbowinclusion.org.au** to see more.

LGBTIQA+ LGBTIQA+ means lesbian, gay, bisexual, trans, intersex, queer, asexual, and plus. Plus means other people in the LGBTIQA+ community who use other words to talk about themselves. It is a big community!

LGBTQ Our project was about people with intellectual disability and their sexuality and gender identity. We worked with lesbian, gay, bisexual, trans and queer people with intellectual disability.

Cameron Bloomfield

I was a **Peer Researcher** on this project.

A Peer Researcher is someone with a disability who helps researchers work well with people with intellectual disability. My job had three main parts:

1. **To help make sure things were accessible:**
   - I helped the researchers to put things in easy English.
   - I was the Chair of the Advisory Group meetings. An Advisory Group is a group of people who make sure the project works properly.
   - I made sure everyone had equal access.
   - I worked on the questions we were going to ask people to make sure everything made sense.
   - I made sure all the information we learnt was put together in a way that everyone could understand.

2. **To collect information for the research.**
   - I led the focus groups in Stage 1. I led the one on one interviews in Stage 2. I asked questions and helped anyone if they did not understand what was said.

3. **To share the work we were doing at conferences and with other groups.**

   It is important to have a Peer Researcher because you should include people with intellectual disability in research. Talking **to** us and **with** us, not **about** us. We can teach other researchers about using easy language and not to use jargon words.

Jenni Northcott

I work at Deakin University. I helped Cameron to write this report. We met once a week for about an hour.

Cameron spoke to me about the project and I typed up what he said. I asked him questions about each part of the project. I also asked him questions to get more information when he got stuck.

The hard part was to type exactly what Cameron wanted – not what I wanted! This was really important. I reminded Cameron that it was really important that the report was his words and his voice. Saying this each time helped me remember it too.

I also helped Cameron with other things. I helped him prepare for the Advisory Group meetings. I helped him get set up on the Deakin University staff system. I helped him record the hours he worked.

Dr Amie O'Shea

I am a researcher at Deakin University. I led many parts of the project:

- I wrote letters to organisations who could give us money for the project. We got money from the National Disability Research Partnership (NDRP).
- I helped bring all the partners and researchers together.
- I recommended that we use the **Delphi method**. It would work well for our project. It would help people with disability get involved too.
- I wrote the Human Research Ethics approval. We needed to do this so that we could do research with people.
- I made contracts with Inclusion Melbourne and Rainbow Rights.
- I made sure everyone in the project was paid and supported well.
- I went to meetings with other people who got money from the NDRP. I shared what I learnt with our team.

I supported Peer Researchers to collect information from people in the project. This is called **data collection**.

We learnt lots of things in this project. I talked about these things at conferences. I wrote about them in articles that other researchers will read.

I made sure the project money was used in the right way. I made sure everyone was included and respected for who they are and what they could do in the project.

Diana Piantedosi

I worked with the team to look for research reports called **articles**. I wanted to learn about other projects where people used the **Delphi method** to learn about intellectual disability. I found many articles and I studied them all.

I wanted to find out:

1. **What did people with intellectual disability do in the research?**

   We found out that a lot of people do research **about** people with intellectual disability. Not many people with intellectual disability get a chance **to be researchers**.

2. **Some projects include researchers with intellectual disability. How much of a say do they get?**

   Sometimes people with intellectual disability **do** get included as researchers, but there are still problems. Sometimes there are lots of other people working on the research project. This includes families, carers, medical people, and researchers who **don't** have a disability. Other people in the group may not listen to the researchers with intellectual disability.

3. **What have other researchers done to make sure people with intellectual disabilities can participate as experts when they use the Delphi method?**

   We looked at ways the **Delphi method** could be changed to help us find the best way to include people with intellectual disability in our project.

I helped Amie and Cameron with **data collection**. I helped to make presentations about our project for conferences.

I worked with Cameron, Amie, and the Advisory Group to get ready for the **Delphi study**. This included working with an Aboriginal person in the Advisory group. This person describes themselves as having three important identities at the same time. Disability, Gender Diversity, and Aboriginality. They wanted to make sure people understood what we meant when we talked about the special relationship to land First Nations people have. In our statement about Aboriginal and Torres Strait Islander people, they asked us to use a (*) asterisk after the word Country*. We use an (*) asterisk to show people there is extra information to look for. I worked with them to develop this extra information:

*Country is the word often used by Aboriginal and Torres Strait Islander people to describe the spiritual connection, identification, and relationship to their own lands by birth, ownership, and family ties that they have had for a very long time and continue to have.

The project had lots of meetings with people with disability. Each person had a chance to say things that they felt about being an LGBTQ person with intellectual disability. Each thing a person said was called a statement.

After each meeting, I worked with another researcher in our project called Dr. James Lucas. We looked at all the statements and we gave them a score.

We wanted to make a poster at the end of the project. The statements with the highest scores went on the poster.

Other people in the team

Cameron, Jenni, Amie, and Diana did most of the work on this project. Some other people helped them. There were people from:

- 🏛 Deakin University
- 🏛 Inclusion Designlab team at Inclusion Melbourne
- 🏛 Rainbow Rights and Advocacy

These people helped us to ask other organisations for money for the project:

- 👤 Professor Sharon Brennan-Olsen, Deakin University
- 👤 Nathan Despott, Inclusion Melbourne

These people helped us do the project work:

- 👤 Sarina Avramovic was a Peer Researcher
- 👤 Dr James Lucas was an Academic Researcher
- 👤 Dr Cadeyrn Gaskin was an Academic Researcher

Our advisory group

This was a group of people who made sure the project worked well. There were people from lots of different backgrounds. There were people who understand disability and the LGBTIQA+ community. LGBTIQA+ means lesbian, gay, bisexual, trans, intersex, queer and asexual people. We did not include intersex and asexual people in the Focus Groups, but we invited some to the Advisory Group. Cameron led the meetings. We met on video using Zoom.

- 👤 Dr Amie O'Shea, Deakin University
- 👤 Billie Stimpson, WWILD
- 👤 Cameron Bloomfield, Deakin University
- 👤 Diana Piantedosi, Deakin University
- 👤 Matthew Parsons, Rainbow Health Australia
- 👤 Nathan Despott, Inclusion Melbourne
- 👤 Remus/Laura Short, SECCA
- 👤 Rhys Nagas, First Peoples Disability Network
- 👤 Professor Sharon Brennan-Olsen, Deakin University

Guests from Rainbow Rights

- 👤 Jack Richardson
- 👤 John O'Donnell
- 👤 Sarah Waardenburg

We are proud because most people in the project were people with disability. Most people were also LGBTQ. We are proud that we made something *about us, with us.*

What happened before this project?

Cameron met Amie at a conference at the Melbourne Town Hall in 2018. Cameron was a member of Rainbow Rights. Amie worked at Deakin University.

Amie asked Rainbow Rights to be involved in a project at Deakin University called Sexual Lives and Respectful Relationships (SL&RR). Inclusion Melbourne worked on the project too.

Amie, Cameron and Nathan had a good relationship. They trusted each other.

They started to work together on another project in 2020. The project was called Rainbow Inclusion. There were many LGBTQ people with intellectual disability in the project. Cameron became a peer researcher in the project.

Amie found out that Deakin University could ask for money from the NDRP in 2021. Amie asked Rainbow Rights if the group wanted to work on another project together with Deakin University and Inclusion Melbourne. Everyone said yes!

Why did we do this project?

Rainbow Rights wanted more people to know about self-advocacy. They wanted people to know it is OK to be LGBTQ and have an intellectual disability.

A Rainbow Rights member called Ian said: 'It is OK to say who you are'.

Rainbow Rights members felt good about themselves and who they are. Other people that Amie and Nathan knew did not have the same opportunity to 'say who they are'.

We wanted to learn more about helping LGBTQ people with intellectual disability feel good about themselves. We decided to do a project that ONLY included LGBTQ people with intellectual disability. We wanted to include all the members of Rainbow Rights. We also wanted to include some LGBTQ people who are not part of a self-advocacy group. We wanted to learn about what helps people **to say who they are**.

This research project was really important to Rainbow Rights. All the members of Rainbow Rights are different, but they come together with one voice. They all have intellectual disability and want their voices to be heard in the larger LGBTQ community.

Cameron and Amie talked to the members of Rainbow Rights about the project. They met on Zoom. Each person liked the idea and wanted to be involved.

The government has money that people can use for research about disability. This is called the National Disability Research Program or the NDRP. Amie did some work to ask the NDRP for money. We got the money we asked for!

The research project

In this section we describe the research. We talk about what we did and how we worked together.

Data collection

Data means what we found out during the research. This includes the words people said and the ideas people talked about. **Data collection** means the things we did to find the data. We had two stages of data collection. These were Stage 1 and Stage 2.

Stage 1 – Focus Groups

We ran small meetings with groups of people from Rainbow Rights. We wanted to find out what helped them to feel good about being LGBTQ. We wanted to know how they felt **before they came out** and how they felt **now**.

Amie, Diana and Cameron worked together at Deakin University in Geelong to get ready for the meetings. Amie and Diana talked about the questions and words they wanted to use. Cameron made sure they were in easy language. They came up with other questions for Cameron to ask.

We made slides to help us. We used photos of Rainbow Rights members from the Rainbow Rights website. We wanted the Rainbow Rights members to feel included.

We talked to 12 Rainbow Rights members in Stage 1. Some people did not want to talk in a big group. Cameron and Diana met with them on their own at another time. One member didn't have a meeting because we could not get in touch with them. All the focus groups were online because of COVID.
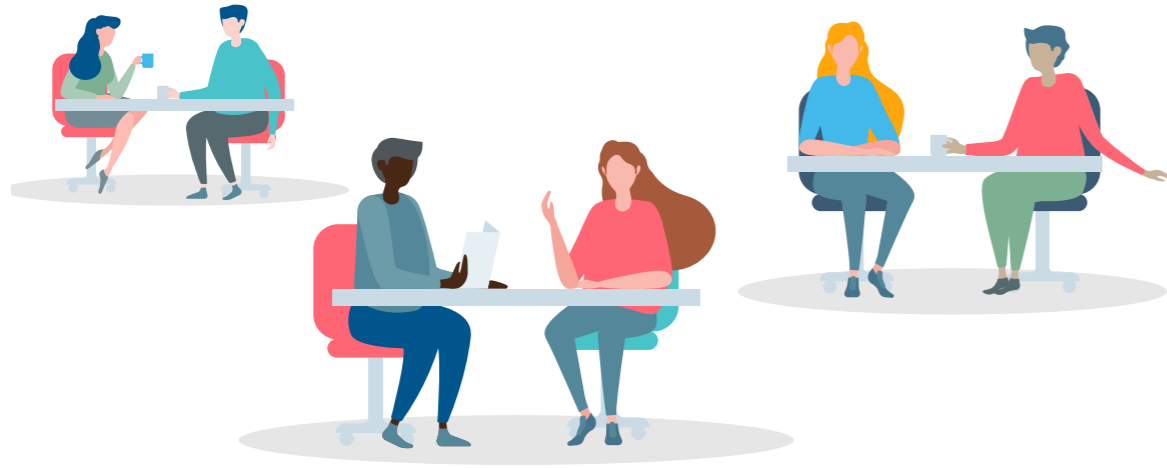
What happened in the Focus Groups?

Cameron led the research Focus Groups with an Academic Researcher (Amie or Diana).

Amie or Diana showed the slides on the big screen. Cameron used notes on his computer to help him talk.

▸ He read the Acknowledgement of Country and Self Advocates Acknowledgement

▸ He told the people in the meeting about the rules for the meeting.

▸ He talked about how everyone can get involved in the meeting. He talked about how to answer questions.

▸ He made sure everyone had a chance to talk. He asked extra questions if people needed some help when they were talking.

The researchers made some questions before the Focus Group meetings. Cameron, Amie and Diana asked these questions to the people in the Focus Groups:

1. How did you feel about being LGBTQ when you first realised you were LGBTQ?

2. How do you feel about being LGBTQ now? Also, what helps people feel good about being LGBTQ?

   Here are some examples:

   ▸ Family
   ▸ Support workers
   ▸ Rainbow Rights
   ▸ Housemates
   ▸ Friends

3. What do you think other people with intellectual disability need to feel good about being LGBTQ?

   Here are some other ways of asking this question:

   ▸ If there was a group starting up in another city like Rainbow Rights, what would they need to do to help people?

   ▸ What about pronouns? Do you think people need to have their pronouns respected?

   ▸ Is there anything people need to know about their rights to feel good?

   ▸ Is there anything people need to know about the law to feel good?
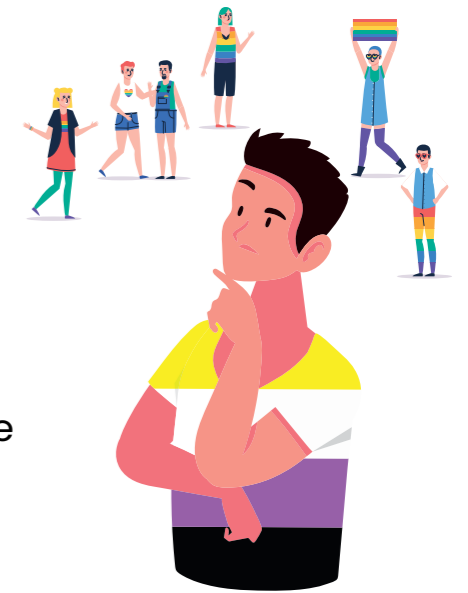
4. **Is there anything else you want to say about being LGBTQ?**

Cameron works with an organisation called *Voice At The Table*. This organisation trains people with intellectual disability, organisations, businesses, and the government. *Voice At The Table* makes sure people with intellectual disability are included well in meetings.

This work gave Cameron a lot of experience in running meetings and how important it is that everyone gets a turn to speak. This experience helped Cameron a lot in running the Focus Group meetings.

Cameron made sure everyone had a chance to have their say. Sometimes he asked a question to each person, one at a time.

The focus groups were **transcribed**. This means that someone wrote down everything people said in the focus groups. It gets turned into a document – like a booklet – called a **transcript**.

Diana read the transcripts. They decided we needed to understand more about what Aboriginal and Torres Strait Islander people thought. Cameron planned another meeting with some of them. This was important. They got more information in this meeting.

We wanted to make a list of things that are important to LGBTQ people with intellectual disability. Here is how we did it:

1. **Diana looked at all the ideas in the transcripts. They worked out which ideas were the same or almost the same. They put these ideas into groups.**

2. **Amie checked the groups. Amie checked that the ideas were in the right groups.**

3. **Diana, Amie and Cameron wrote a sentence for each group. These sentences started with "It is important..."**

   For example: "It is important that support workers have more LGBTQ training".

   They called these sentences **statements**. There were 22 statements!

4. **We sent an email to the people in the Advisory Group. We put the statements in the email. The people thought about the statements. The Advisory Group met together to talk about the statements. They made some changes to the statements to make sure they were as clear as possible. Cameron checked the new statements to make sure the words were easy.**

5. **We used the statements to make something called the 4 pillars of best practice. This means 4 important ideas to think about when we work with LGBTQ people with intellectual disability. The 4 ideas are:**

   Recognition: Having people who **understand** you. This means you feel that people **hear** you or **see** you.

   Relationships: Connections to other people who are safe and important for you. The are people like family, partners, friends, or support groups.

   Place: Places you can access and where you can be yourself. Place is really important for Aboriginal and Torres Strait Islander People because they have a very close connection to the land they are from.

   Community: When you feel you are a part of a group of people. This could people who live near you. It can also be people who have the same culture of faith as you. It could be people who are like you in other ways, like people with a disability or queer people.

Stage 2 – Delphi method

We used the **Delphi** method. In the Delphi method, you follow some steps. The steps are:

▸ A group of people comes together. The people are experts about a topic. It could be a problem, an idea, or something else.

▸ Researchers ask the people about the topic to get their thoughts and ideas. The researchers listen and take notes. They work out the main things people are saying. They work out what everyone agrees on.

▸ The meetings can be an interview between a researcher and each person. The meetings can also be in a group.

▸ The people and researchers meet a few times. The people talk more about the ideas. The researchers work out what they all agree on.

Delphi is all about bringing people together to work out what we agree on.

The people in our group for Stage 2 were LGBTQ people with intellectual disability. These were different people to the people in Stage 1.

Delphi is all about agreeing.

We wanted to come up with a list of final statements. We wanted to **keep** the statements everyone agreed on. We wanted to **leave out** the statements people did not agree on.

First, we had to work out **how much** agreement is enough agreement! Did we need everyone to agree with a statement to keep it? Or most people?

We decided to keep a statement if **almost everyone** agreed on it.

We decided to use a **scale**.

There were lots of ideas about scales in our team. Some ideas were:

▸ People could read a statement then choose a number. 1 means I really disagree. 5 means I really agree.

▸ People could choose these words: strongly agree, agree, not sure, disagree, strongly disagree.

We talked about this a lot. Cameron's idea was to use faces. We liked this idea.

Cameron looked online. He found faces that fit with words like 'very bad' or 'very good'.

We decided to use pictures, words, and numbers in the scale. For example:

> A face that looks happy, next to...
>
> The words 'Very Good' next to...
>
> The number '5'

Very Good

5

We came up with two rules:

1. **We needed almost everyone to agree that a statement was good. We said 8 out of 10 people needed to agree. This is the same as 80%.**

2. **The answer from these people had to be 'very good'. We needed almost everyone (80%) to say a statement was 'very good' to keep a statement.**

We made PowerPoint slides. We worked together to design them. There was one statement on each slide. Cameron made sure the writing was the right size so people could read it easily.

Statement:

To respect our gender and sexuality as LGBTQ people

We talked about what order to put the statements in. There was one statement about being Aboriginal and Torres Strait Islander. We agreed that only people who are Aboriginal and Torres Strait Islander could tell us what they thought about it. People who were not Aboriginal or Torres Strait Islander did not have enough experience to answer this question.

Some of the statements were still a bit hard to understand. We changed the words a little. Here is what Cameron said about these changes:

At first, statement 1 said 'It is important you have good people around who understand you'. When I read that out it was coming across that I was not their peer. But I am the same as them, so we changed it to 'it is important we have good people around who understand us'.

In statement 2 to start with we had 'It is important that I can choose who I tell that I am LGBTQ'. When I read it out it sounded like I was talking about me, not the participant. So we changed it to 'It is important we can choose who knows that we are LGBTQ'.
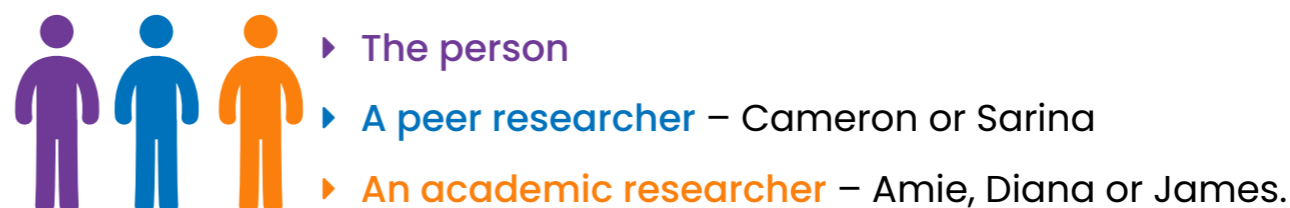
Statement 12 said 'It is important to be part of the LGBTQ community events'. We added 'and' to say 'community and events' because it made more sense.

The interviews

We met with the LGBTQ people with intellectual disability. We had an interview with each person. We used Zoom because of COViD.

We had two rounds of interviews. This means people had two interviews each.

Each interview had three people in it:

- ▸ **The person**
- ▸ **A peer researcher** – Cameron or Sarina
- ▸ **An academic researcher** – Amie, Diana or James.

Cameron came up with the rules for the interviews. **We ran all the interviews in the same way.**

We asked the people about each statement. We asked if they agreed with the statement.

- ▸ We asked if the statement was right for them.
- ▸ We asked if the statement was right for ALL LGBTQ people with intellectual disability.

Here is what each person did in the interviews:

Peer Researcher:

- The Peer Researcher went on Zoom with the Academic Researcher before the meeting.

- They welcomed people to the meeting. They talked about what each person had to do.

- Cameron used notes and a script to help him remember what to do.

- Cameron:

  › shared his screen.

  › read the Acknowledgement of Country and the Self Advocates Acknowledgement.

  › made sure the people wanted to be there.

  › introduced everyone.

  › asked the Academic Researcher to talk about what they would do. The Academic Research helped Cameron and made sure the people could do the survey.

Academic Researcher:

- The Academic Researcher made sure we followed the **Human Ethics** rules. These are the rules about doing research with people. The rules are about privacy, safety, and dealing with emergencies.

- They supported the other people in the meeting if they needed help.

- They asked if the person being interviewed was able to do another interview. They asked this at the end of each person's first interview.

Getting ready for the interviews

The Peer Researcher met with the Academic Researcher before each interview. They talked about the person they were going to interview. They talked about how to make sure the person was supported well.

One person did not want to use Zoom. The Researchers talked with them on the phone instead. Diana was the Academic Researcher for this interview. Diana and Cameron talked about how to talk about the scale. This was because they could not use pictures in the phone call.

Doing the interviews

This is what happened in each interview:

- The Peer Researcher read out the first statement.

- The Peer Researcher read out the scale. The scale had numbers from 1 to 5, with some words and a face.

- The Peer Researcher asked the person if they wanted to hear the scale after every statement or just the first statement.

- Sometimes the person didn't understand the question. The Peer Researcher explained more about the question. Cameron could work out if the person was confused or needed to learn more about the question. Cameron talks more about how he worked this out on page 28.

- For example, one person didn't understand what pronouns were. They thought it was the same as an identity – like being gay or trans. Cameron talked about pronouns and how to use them.

- The Peer Researcher asked the person about all the statements.

- The Peer Researcher thanked the person for coming. They reminded the person that they would get a gift card.

- The person left the Zoom meeting.

- The Peer Researcher and Academic Researcher stayed on Zoom a bit longer. They talked about the interview to talk about what they learnt. They talked about how to make the next interview even better.

First round of interviews

We planned for each interview to go for one hour. Each interview only went for 20 minutes. That was quicker than we expected!

Here is what Cameron said after the interviews in Round 1:

"I was relieved at the end of Round 1. One day we did three interviews in a day, and I felt like a broken record, constantly repeating myself over and over again. One thing I learnt was that everyone takes in information in different ways. I had to be patient with people to explain things in a calm, gentle way. I had to not get frustrated if I had to repeat myself."

We did other things to make the interviews easier for people:

- James and Sarina joined the team a bit later in the project. This meant people could choose the researcher for their interview. They could choose a researcher who was lesbian, gay, bisexual, trans or queer.

- The Peer Researchers had a script. They could use this if they needed some extra help.

- Jenni spoke with people to find out the best time for an interview. Jenni also sent an email to each person. The email had the date and time of the interview. It also had the names of the researchers in the interview. She sent another email in the morning on the day of the interview. She sent the Zoom link in this email.

- People could call Jenni if they needed extra help.

- People could answer questions about the statements and the scale in different ways. They could use the words, the number or the colour of the face in the scale.

How did we choose the final statements in Round 1?

James and Diana looked at all the answers after Round 1. They looked for statements that everyone had agreed about. There were 9 statements! They were:

- ✔ It is important we have good people around who understand us

- ✔ It is important to respect our gender and sexuality as LGBTQ people

- ✔ It is important that all of our relationships are loving, safe and respectful

- ✔ It is important that we are part of the LGBTQ community and events

- ✔ It is important other LGBTQ people and actual allies respect and include us

- ✔ It is important that support workers respect who we are

- ✔ It is important that support workers have more LGBTQ training

- ✔ It is important that we are safe everywhere

- ✔ It is important Aboriginal and Torres Strait Islander People can be who they are when they are on Country*

*Country is the term often used by Aboriginal peoples to describe the enduring spiritual connection, identification and relationship to their own lands by birth, ownership and family ties

–Quote provided by a proud Aboriginal LGBTQ person with intellectual disability from the Project Advisory Group

Second round of interviews

We wanted to make sure the final statements were right. We also wanted to check the answers people gave us. This is why we had two **rounds** of interviews. This means we did the interviews twice with each person.

We had two groups of statements after Round 1:

▸ 9 statements that people agreed about

▸ 13 statements that people were not sure about

We wanted to learn more about the 13 statements that people were not sure about. We used them in Round 2. We told the people more information about the statements. This helped the people understand them better.

This is what happened in Round 2:

▸ Jenni set up the interviews. Amie, Diana and James helped her.

▸ There was one person from Round 1 who could not take part in Round 2.

▸ We ran the meetings in Rounds 1 and 2 in the same way.

▸ We showed people the results from Round 1. We showed this in a PowerPoint. We showed the 13 statements that people were not sure about in Round 1.

▸ The picture below is an example of a statement with the face that each person chose. The Peer Researcher said: "The last time we asked this question, this is what the people said".

Bad 🙁

In the middle 😐

Good 🙂🙂🙂🙂🙂

Very good 😁😁😁😁😁😁

James and Diana looked at the answers after Round 2. The people in the group agreed with 8 more statements! These were:

✔ It is important to use our pronouns

✔ It is important we have access to information about being LGBTQ and our rights

✔ It is important that the relationships that matter to us are seen and respected

✔ It is important that we spend time with people who make us feel proud to be LGBTQ

✔ The rainbow flags show us the places where we can be ourselves

✔ It is important that we can advocate for other LGBTQ people with intellectual disability

✔ It is important that our access needs are met by the LGBTQ community and events

✔ It is important that we are happy

Not enough people agreed with the last 5 statements. We did not use these statements in the poster. These were:

✖ It is important we can choose who knows that we are LGBTQ

✖ It is important we can show our gender and bodies in a way that feels right for us

✖ It is important that we are able to feel sexy with people who we are attracted to

✖ It is important that we know other LGBTQ people like us

✖ It is important for people outside of big cities to have LGBTQ communities

Finishing the project

We finished our meetings. We had 17 statements that people agreed on.

They were the most important statements for the people in our project. We were really proud of these statements.

We wanted to make a poster with the statements.

We worked with a **designer** to make the poster. A designer is a person who makes art, drawings, and images. Designers also make books, websites and posters look good.

The designer made the poster in two different ways. The research team chose the parts we liked the most.

The designer made the final poster for us.

We wanted to find other ways to tell people about the project. We asked the Advisory Group for ideas. We talked about:

- Making a tea towel
- Presenting at conferences
- Putting the poster on lots of websites
- Writing an article about the project

> **The poster is now on the Rainbow Inclusion website**
> **www.rainbowinclusion.org.au**

More people will know about the project if we talk about it in more places.

How we felt about this project

We want to tell you what we thought and felt about the project.

Cameron

This is my first ever time being a leader in a research project. I liked teaching people along the way. I liked teaching the researchers about easy language. Not many people with an intellectual disability get to do this!

Academics often write **about** people with disability. Academics don't often work **with** people with disability.

There should be more projects that are run like this. I was equal. I was respected.

I have trouble with typing words in emails. That was not a problem in this project. I could pick up the phone and call someone or send a message and ask them to call me. They were all happy to do that. I want to do this again.

Diana

This project made me think a lot about many things. It made me think about my identity. It made me think about my power and my life. I have a disability and I am queer. I know a lot about what it means to have a disability. This gave me lots of passion for the project.

BUT I don't have an intellectual disability. I am not Aboriginal or a Torres Strait Islander. I needed to learn new things. I had to make sure I was very careful to listen to people with intellectual disability. I learnt a lot from Cameron and Amie. I learnt how to ask questions in new ways. I learnt more about co-design and how to include people with intellectual disability.

It is important to tell people about the work I do. Sometimes there is a lot of information to tell people. I learnt new ways to talk to people about research. I can tell people about one part of the project, then another part, then another part. Learning more about this will really help me work better in the future.

Amie was a great leader. She taught us all about building relationships with people in the community. I understand why it is so important to include people who have different backgrounds – like age, culture, sexuality, gender, and disability.

Amie

Our project started small. It began with conversations with Rainbow Rights and Advocacy and grew into something really big. The project made sure lots of people in the community understand more about life for LGBTQ people with intellectual disability.

We often talk about 'pride'. I am truly proud of my work about LGBTQ pride. All of the people in our project team really wanted to make sure we heard what LGBTQ people with intellectual disability wanted to say. We tried new things to make sure this happened! We found a new way to use the **Delphi method**. We made sure researchers with intellectual disability were included as well. I hope other researchers will learn from our project. I hope they will include more researchers with intellectual disability in their work. This is what 'nothing about us without us' means.

How we wrote this report

We want to tell you more about how we wrote the report.

Cameron

We started writing the report in May 2022. We finished it in December 2022.

Jenni and I worked on the report. We tried some new things to make sure it was in my words. It was important that this report was written in my own words. This is how we did it:

- Amie wrote some questions for me to answer. Jenni broke the questions into smaller questions. She sent me one or two easy questions by email before our meetings. The questions were to help jog my memory and to help me focus on each part of the project. I had to answer the questions.

- I met with Jenni each week to write up the answers. We met online. We used Zoom. Sometimes Jenni shared her screen with me so I could see what she was writing.

- I told Jenni what I wanted to say. Sometimes it did not make sense or the sentence was not clear. Jenni helped me fix this. She started with the first words then I finished the sentence. Sometimes Jenni asked me more questions to help me think.

Here is an example. I said this to Jenni:

"If they looked like they were having trouble understanding the question I would explain more into the question. For example, one person didn't really understand what the pronouns were, so I explained it. They thought it was your gender identity like being gay or trans."

Jenni asked me a question. "Cameron, how did you know they were having trouble?"

I added one more sentence:

"I could tell if they were having trouble if they looked confused and made comments that didn't match the statement."

- We did this until we had all the answers!

Jenni

Working with Cameron on this report was really great. I learnt how to use easy language. I learnt how to listen better.

Typing this report was different to how I wrote reports in the past! Cameron and I talked together while I typed the report. I asked questions and he answered them. We talked about how to turn his answers into writing. The report needed to be in easy language – but it also needed to be a research report.

I learnt to be patient and to make sure I wrote what Cameron really said. Sometimes he would repeat something or say it in a way that was a bit hard to understand. I asked Cameron to read out what I typed so he could work out what to change. Then we talked about other things we could write instead.

Amie read the report. She met with Cameron and me to tell us her ideas about it. Cameron and I talked about how to make the report better. He learnt to use 'Tracked Changes' in Word. This helped us finish the report.

Inclusion Designlab

The team at Deakin University made a draft of the report using clear words and ideas. They sent this draft to Inclusion Designlab in 2022. This is a team at a disability organisation called Inclusion Melbourne.

Nathan and Jenna at Inclusion Melbourne worked on the report in 2023. They turned it into an **easy language** report. This is what you are reading now.

The poster we made

WE ARE LGBTQ PEOPLE WITH INTELLECTUAL DISABILITY.

THIS IS WHAT IS IMPORTANT.

To respect our gender and sexuality as LGBTQ people

To use our pronouns

That the relationships that matter to us are seen and respected

To have good people around who understand us

That we spend time with people who make us feel proud to be LGBTQ

That we can be who we are on Country*

That all of our relationships are loving, safe and respectful

That we are part of the LGBTQ community and events

That our access needs are met by the LGBTQ community and events

That other LGBTQ people and actual allies respect and include us

That we can advocate for other LGBTQ people with intellectual disability

That support workers respect who we are

That support workers have more LGBTQ training

That we are safe everywhere

To have access to information about being LGBTQ and our rights

The rainbow flags show us the places where we can be ourselves

It is important that we are happy

* Country is the term often used by Aboriginal peoples to describe the enduring spiritual connection, identification and relationship to their own lands by birth, ownership and family ties.
Definition provided by a proud First Nations LGBTQ person with intellectual disability from the Project Advisory Group

From our hearts, we acknowledge the First People of Australia, Aboriginal and Torres Strait Islander people. We show our respects to Elders past, present and future and to Mums and Dads, Aunties, Uncles, cousins, nieces and nephews and family. Brotherboys and Sistergirls are part of the rainbow flag. For all the self advocates who are people with intellectual disability: Nothing about us without us.

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Saying who you are

www.rainbowinclusion.org.au

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