



## Re-imagining parenting for mothers and fathers with a learning disability



## PARTICIPANT INFORMATION SHEET



You are invited to take part in research about what it is like to be a parent with a learning disability.

This Information Sheet is to help you decide if you would like to take part in the study.

This information sheet is 13 pages. Read all the pages.

## Who is doing the study?



Researchers from the Donald Beasley Institute are doing this study.



The Donald Beasley Institute is a disability research institute that is based in Dunedin.

You can learn more about the Donald Beasley Institute and the work it does by visiting their website:

[www.donaldbeasley.org.nz](http://www.donaldbeasley.org.nz)

## What is this study about?

This study is about the experience of being a parent with a learning disability.



In this study twelve parents with a learning disability will talk about their experience of being a parent. We would also like to speak to people that the parents tell us have helped them with their parenting. The parents will be asked who they want us to speak with.

We will write a parenting story for each parent. We will then compare the stories from the 12 parents to find out how parents with a learning disability can best be supported.



## Why is this study important?

Parents with a learning disability do not always get the support they need. Some have their children removed from them.

This study is important because it will help

us to understand what parents with a learning disability need help with. While taking part in this study might not help you, it might help other parents with a learning disability.

## What will I have to do if I choose to take part?



When we meet we will make sure that you want to take part.



**12 months**

If you choose to take part in the study you will be interviewed about 3 times over 12 months.



You will be able to have someone with you if you would like their support. We will make sure that person knows the information that you tell us is confidential.

We will talk to you about how often we will meet during that time.



At the first interview we will ask you about the months before your child was born. We will also ask you what it was like for you when you became a parent.



In other interviews we will ask you about being a parent as your child grows up.



We will also ask you who has helped you with being a parent. We will ask you if we can talk to those people.



If you agree we will talk to those people about how they have helped you. We will not tell them what you have told us. We will not tell you what they tell us either.

## **What will happen with the information I tell you?**



We will keep the information private. The information you tell us will only be seen by the researchers and the person who writes up your interview.

These people have agreed to keep your information confidential.



Password?

We will keep your information on a computer. Only the researchers will know the password for the computer.



The information will be kept on the computer for 10 years. After 10 years it will be destroyed.

No information that could identify you will be used in the reports of this study.



If we are worried about the safety of you or your children we will talk to you about that.

If we need to tell someone else about our concern we will let you know first.

Unless we legally have to we will not talk to anyone about you or your family without your permission.

## What else will happen?



Your interview will take place where you are comfortable.

This could be your place. It could also be another place where we can talk in private.



The interviews will be audio-recorded. You can ask to have the recorder turned off whenever you want to.



The researcher might write down some notes during or after the interview.

We will check that you are happy for us to use your information in the study.

You can ask us if you want to read a copy of the information that was written after the interviews.



You will be able to let us know if you don't want us to include your information in the study.

## Who can be in this study?



You can be in this study if you are:

- ✓ a parent,
- ✓ have a learning disability and
- ✓ can consent for yourself,

## What do I do if I want to be part of the study?



If you want to take part in the research complete the Participant Interest Form. Return it to the Donald Beasley Institute in the stamped envelope provided.



If you prefer you can phone or email us.



## Will I be paid?

You will receive a \$40.00 gift voucher for each round of interviews in which you take part.

## What happens if I don't want to take part?



Nothing will happen.

If you don't want to take part that is OK.



No one can tell you that you have to take part in this study.

## Is it safe for me to take part in this study?



This study has been approved by the Northern A Health and Disability Ethics Committee.

This means that a special group of people have made sure that the study is safe.

They expect that we will work with people in a kind and respectful way.

## What do I do if I want more information?



You can call or email Lana Kennedy.

Her telephone number is 03 479 2162

Her email address is  
[admin@donaldbeasley.org.nz](mailto:admin@donaldbeasley.org.nz)

For Māori health support you can call or email Kelly Tikao.



Her telephone number is 027 4826324

Her email address is:  
[ktikao@donaldbeasley.org.nz](mailto:ktikao@donaldbeasley.org.nz)

## Who can I contact if I need different advice about taking part?



If you would like to know more about your rights as a participant in this study you can call a Health and Disability Consumer Advocate.

The phone number is: 0800 555 050.

Thank you for thinking about taking part in this study.

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## Consent Form



	<p>I have read (or had read to me) the information about the study.</p>	
	<p>I understand the information I have been given.</p>	
	<p>I have had enough time to decide whether or not to take part in the study.</p>	
	<p>I have been able to have a friend, family / whānau member or support person with me when I learned about the study.</p>	
	<p>I am satisfied with the answers I have been given about the study.</p>	
	<p>I have a copy of this information sheet and consent form.</p>	
	<p>I understand that taking part in this study is my choice.</p>	

	<p>I understand that I may withdraw from the study at any time.</p>	
	<p>If I withdraw from the study, I agree that the researcher can still use the information I have told them up until that time.</p>	<p>Yes    No</p> <p><input type="checkbox"/>    <input type="checkbox"/></p>
	<p>I understand that information about me is private.</p> <p>The research team will not talk to any other person unless I am in danger or someone else is in danger.</p>	
	<p>I understand that the research team will talk to me first if they are concerned about the health or safety of me or my children.</p>	
	<p>I know that when the researchers write about me they will change my name so that no one else will know it is me.</p>	
	<p>I know who to contact if I have any questions about the study.</p>	
	<p>I understand what I need to do as a participant in the study.</p>	
	<p>I want a summary of the study when it is finished.</p>	<p>Yes    No</p> <p><input type="checkbox"/>    <input type="checkbox"/></p>

**Declaration by participant:**

I hereby consent to take part in this study.

Participant's name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Declaration by member of research team:**

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_