Family, children and young people information sheet

Experiences and decision making practices of Individual Education Plans for disabled children, young people, their whānau, and professionals, in an education context, Aotearoa, New Zealand.

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Primary Supervisor:	Dr Allyson Calder BHSc (Physiotherapy); PGCertCT (clinical teaching) PhD Senior Lecturer School of Physiotherapy University of Otago

Study Site: University of Otago

Contact phone number: 0211375325

Ethics committee ref.:

The physiotherapist is conducting this research as part of her PhD through the University of Otago. She has been working in specialist education including being part of the Independent Education Plan (IEP) process for over 20 years.

You are invited to take part in a study which explores how families, professionals, disabled children and young people participate in an IEP, including the way decisions happen.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family/whānau, friends, or school staff. Feel free to do this.

If you agree to take part in this study, you are welcome to ask any further questions before signing the Consent Form. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 8 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

VOLUNTARY PARTICIPATION AND WITHDRAWAL FROM THIS STUDY

This study is separate to any IEP meetings run at your own school. It is okay for you and your child to join in the study and okay for you to decline to participate either for yourself or your child. You are free to withdraw from the research at any practicable time, without experiencing any disadvantage and without giving any reason. This is up until the writing up of the common ideas/themes, at which time your data will contribute to the overall thoughts and ideas going forward.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study to seek the voices of families/whānau, their disabled child or young person and professionals about the IEP process. We would like to explore your experience of IEPs, what decision making processes are used, and what factors influence decision making in the IEPs. We recognise that some families may attend IEPs for more than one child or young person, and we would welcome discussion about your experience from either one specific child/young person or from all disabled children or young people in your family.

HOW IS THE STUDY DESIGNED?

All participants will take part in an individual interview, either face to face or virtual. This interview will be recorded and then transcribed word for word. The transcription of interviews will be reviewed by the researcher to generate themes. Families/whānau, including the disabled child or young person, will be interviewed first and the responses will then inform the questions used for interviewing the professionals.

This study will form part of the PhD candidates research about decision making and will be written up as part of their thesis. It will also be written up to submit for publication in an international journal.

WHO CAN TAKE PART IN THE STUDY?

We are looking for families living in the Waikato region who have child/ren or young people with Ongoing Resource Scheme (ORS) funding and have been involved in at least two IEP meetings at school. You will verify that your child or young person will have ORS funding due to extra learning needs either high or very high ORS. Your child/ren or young person can be any age between 6 – 21 years. Your child or young person can participate if you or they choose. They do not need to be verbal to be included, as alternative forms of communication can be used. If you choose not to have your child or young person participate then you are still able to still participate.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

Should you agree to participate then you will be invited to a face-to-face or virtual interview with the PhD candidate at the venue and time of your choice. This can be your home or somewhere in the community (e.g., library, café, room at your school). You can participate without your child or young person being present or with your child or young person present. You are welcome to have a support person present. The interview will be approximately one hour and involve a discussion about IEPs. If you feel uncomfortable or hesitant about answering any questions, you do not have to. It is entirely up to you what you tell the researcher.

Following the interview if you consent for your child or young person to participate, the PhD candidate will ask you some questions about using a toolbox of communication strategies, including language, device use, visual use, a social story and any gestures your child or young person uses. They will be asked questions about IEPs that will be at a level they understand e.g. do they attend IEPs; do they like them; do they want to go to them. Your child or young person will be firstly asked if they would like to talk, if your child or young person does not wish to engage in this process, then we will discontinue. Your child or young person withdrawing from the project will not disadvantage you in any way. Your information is separate from your child/ren or young person.

Following the interview, the transcript will be returned to you to review. You can ask for any information to be removed from the transcription or anything to be added.

WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?

The risks of this research are low. You may feel some anxiety meeting a new person, you may feel upset if you are discussing an upsetting event. The interview can be paused or discontinued at any time.
Your child or young person may not wish to engage with a new person, the interview with them will be discontinued if they show any signs of showing us that the interview is not what they want or any form of distress.

WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

The possible benefit to this study is increased knowledge about IEPs, how decisions are made and what works best for the decision making process. There will be a follow up study based on these results where the researcher will support a group of families to develop a toolkit to use when preparing to attend IEPs. This will be to support families to share their ideas, aspirations and make decisions that are relevant and meaningful to them.

WILL ANY COSTS BE REIMBURSED?

Family groups will receive a $50 supermarket voucher in recognition of costs incurred with a participation certificate for children or young person involved.

WHAT WILL HAPPEN TO MY INFORMATION?

Identifiable Information

Identifiable information is any data that could identify you. Only the research team will have access to your identifiable information. This will include the following: adult relationship to child or young person, adult/child/young person gender, child/young person's age, ethnicity, iwi affiliation; this may include hapū, rohe, or whakapapa, cultural identity, or connections that are important to the individual and schooling: history, type of school now attending, level of ORS.

Interview Address

On the day of the interview the physical address of the meeting place will be given to the PhD candidates next of kin. This measure is for safety purposes, to ensure that someone in the local area knows the PhD candidate's whereabouts and can confirm that they return home safely. This information will only be the address of the interview. No other contact information such as your name, contact email or phone number will be shared. On safe arrival home the physical address information will be deleted.

De-identified (Coded) Information

To make sure your personal information is kept confidential, information that identifies you will not be included in any report generated by the research. Your comments may be used in the reporting, to do this you will be identified by a pseudonym.

The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you.

Security and Storage of Your Information.

Your identifiable information is held on a University of Otago secure hard drive with sole access by the PhD candidate. Following families checking for accuracy the audio file will be deleted. The transcribed file will be stored at least 10 years, then destroyed.

Risks.

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with coded and anonymised information, there is no guarantee that you cannot be identified. The risk of people accessing and misusing your information (e.g. making it harder for you to get or keep a job or health insurance) is currently very small but may increase in the future as people find new ways of tracing information.

Rights to Access Your Information.

You have the right to request access to your information held by the research team. You also have the right to request that any information you disagree with is corrected.

If you have any questions about the collection and use of information about you, you should ask the researcher.

Māori Data Sovereignty

Māori data sovereignty is about protecting information or knowledge that is about (or comes from) Māori people. We recognise the taonga of the data collected for this study. To help protect this taonga:

- We have consulted with the Ōtākou Whakaihu Waka ki Ōtautahi (University of Otago, Canterbury) through their Rangahau Māori consultation Plan and Ōkākou Whakaihu Waka (University of Otago) research partners Ngāi Tahu about the collection, ownership, and use of study data.
- We allow Māori organisations to access de-identified study data, for uses that may benefit Māori.
- There will be a wide range of dissemination of the research findings including: a copy of the final research summary to Ngāi Tahu Nga, Ōkākou Whakaihu Waka (University of Otago), a summary to the local iwis from where participants are situated, Te Poutāhū (curriculum centre) as they oversee IEPs, Te Mahau (education support services) in the areas where participants are situated and to Ka Hikitia (MoE Māori strategy teams)

CAN I FIND OUT THE RESULTS OF THE STUDY?

There is a section on the consent form to indicate if you would like to see the results of the study. A short summary of the anonymised synthesised finding from all participants will be emailed to participants so they can see that initial generated common ideas/themes.

WHO IS FUNDING THE STUDY?

The PhD candidate is completing her PhD in Physiotherapy with the support of a University of Otago post graduate research scholarship. No other funding is available at this stage, but it will be applied for following ethics approval and if successful will be documented here.

WHO HAS APPROVED THE STUDY?

This study has been approved by an independent group of people called a Health and Disability Ethics Committee (HDEC), who check that studies meet established ethical standards.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Leanne Robinson, PhD candidate
0211375325
Roble067@student.otago.ac.nz

Or primary supervisor
Dr Allyson Calder
0274450415
ally.calder@otago.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone:	0800 555 050
Fax:	0800 2 SUPPORT (0800 2787 7678)
Email:	advocacy@advocacy.org.nz
Website:	https://www.advocacy.org.nz/

For Māori cultural support please contact:

Cara Meredith
Kaitohutohu Rangahau Hauora Māori, (Māori Health Research Advisor)
Maorihealthadvancement.uoc@otago.ac.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Email:	hdecs@health.govt.nz
Phone:	0800 400 569 (Ministry of Health general enquiries)

University
of Otago
ŌTĀKOU WHAKAIHU WAKA

Consent form

Experiences and decision making practices of Individual Education Plans for disabled children and young people, their whānau, and professionals, in an education context, Aotearoa, New Zealand.

Please tick to indicate you consent to the following

I have read the Participant Information Sheet or have had it read to me in a language I understand, and I fully comprehend what it says.		
I have been given sufficient time to consider whether or not to participate in this study.		
I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study.		
I am satisfied with the answers I have been given regarding the study, and I have a copy of this consent form and information sheet.		
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my child or young person's care at school.		
I consent to my interview being recorded.		
I consent to the physical address where the interview will take place being known by the researchers next of kin for safety purposes.		
I understand that our family will receive a $50 voucher for taking part in this study and my child will receive a certificate.		
I consent to the research staff collecting and processing my information, including basic identify information.		
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		

I know who to contact if I have any questions about the study in general.		
I understand my responsibilities as a study participant.		
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:
I hereby consent to take part in this study.

Participant’s name:

Signature: Date:

Declaration by participant on behalf of their child:
I hereby consent for my child to take part in this study if they show they are willing to engage with the researcher for the interview.

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: