# The Conversation: Supported Decision Making Hui Film

Hui Film Captioned Notes – April 2016

General Notes about the Hui Film and Captions:

* The Hui film features people who attended the Hui sharing their thoughts, ideas and experiences of supported decision making. There are also presenter and crowd shots from Hui sessions.
* The film’s captions and speakers’ details are contained within these Notes.
* The film is 13.30 minutes in length. It is divided into nine sections. The name of each section is included in the note under ‘Section’.
* Each speaker’s name and identifying information is included in the notes under ‘Speaker’.
* Where Te Reo is spoken, the English translation of each phase is included in the captions.
* Where crowd pictures of the hui are included, they are noted under ‘Picture’.
* Often the speaker is seated against a standard background. Where the speaker and standard background is used it is referred to as the ‘Speaker Background’. It is described here. Each speaker is facing the camera and with a brown wall behind them. There is a green leaf of a large indoor palm partly visible on the very left hand side of the screen behind the speaker.

Section: Introduction

Picture:

The start of the Hui, people gathering in the banquet rooms at Waipuna Hotel, Auckland.

Speaker:

Matua Waitai Petera opens the hui with a karakia.   
Caption Text:

Morena.

Good morning.

Kia ora tatou katoa.

Welcome to us all.

Ki tu mai tatou katoa ki te Waiata.

Let’s all stand together to sing our song.  
Singing of waiata Te Aroha in the background.

Speaker:

Martine Abel, Auckland Disability Law’s (ADL) Steering Group Chair.

Caption Text:  
The Conversation: Supported Decision Making Hui. A Human Right and in Practice. Hosted by Auckland Disability Law.

Speaker:

Robert Martin, MNZM, Life Member of People First NZ. Ngā Tāngata Tuatahi.

Picture:

Hui attendees watch a hui presentation video featuring Robert Martin. In the video, he is seen reading from the *United Nations Convention on the Rights of Persons with Disabilities*.

Caption Text:

Article 12, supported decision making, is important to many of us with a learning disability and other disabled people.

I was part of the writing of the Convention.

Picture:

Robert Martin pictured at the United Nations with Paul Gibson, pictured on a panel in Shanghai.

Caption Text:

We fought for our friends who find communication very hard.

All disabled people have the right to be part of all the decisions in their lives.

Speaker:

Minister Nicky Wagner, Minister for Disability Issues.

Picture:

Nicky Wagner stands at a podium at the front of the room and addresses hui attendees as part of her presentation on ‘Enabling Good Lives’.

Caption Text:

We’re here to have a national conversation about supported decision making.

I know it has many challenges, but there are also opportunities.

Picture:

Minister Wagner taking a photo with Martine Abel, Brigit Mirfin-Veitch, Kate Diesfeld and Jan Moss.

Caption Text:

We need to have a really strong understanding of what it really means in practical terms.

It has to result in disabled people having better lives; more choice and more control over their lives.

Picture:

Photos of people in discussion after the Enabling Good Lives Presentation.

Section: What is Supported Decision Making?

Speaker:

Paul Gibson, Disability Rights Commissioner, Human Rights Commission.

Speaker Background.

Caption Text:

Supported decision making is the means by which people who require the most support can express their own choices, will and preferences.

It contrasts with substitute decision making where somebody else makes their decisions.

Picture:

Paul Gibson is pictured, alongside Professor Kate Diesfeld, during a Panel Discussion on Supported Decision Making and the Law: ‘Working with What We’ve Got’.

Speaker:

Gabby Hogg, Autismo Girl, Autistic self-advocate.

Speaker Background:

Caption Text:

Everyone needs to practice making decisions.

If we don’t have the chance to make decisions, then we are going to grow up to be dependent on others.

Picture:

Gabby Hogg pictured with Sharon Brandford during a Panel Discussion on Supported Decision Making in New Zealand 2016: ‘How does it look and feel?’

Caption Text:

For supported decision making to work we need to start in early childhood.

Just because we can’t speak doesn’t mean we haven’t got anything to say.

Speaker:

Dr Chris Perkins, Old age psychiatrist, Chair NZ Dementia Cooperative.

Speaker Background

Picture:

Speaking and reading from the book ‘The Happy Economist’.

Caption Text:

Even if you have dementia, there are still many areas of your life that you can make decisions on.

“… extensive psychological research has shown that human’s decisions more usually are instinctive, intuitive and emotional.”

You don’t actually lose that sort of stuff in dementia.

Section: Why is Supported Decision Making Important?

Speaker:

Dr Esther Woodbury, Disabled Persons Assembly, New Zealand.

Speaker Background

Caption Text:

When some people talk about supported decision making, they talk about the dignity of risk.

That’s important because everyone has risks when they make decisions.

Everyone weighs up the pros and cons of what they want to do in their life and their decisions.

There’s no reason that disabled people shouldn’t also have that ability to take risks.

Picture:

Esther Woodbury pictured with fellow panel members, Chris Perkins and Gabby Hogg, during a discussion on Supported Decision Making in New Zealand 2016: ‘How does it look and feel?’

Caption Text:

It’s really important to have the patience and take the time to support people with their decisions.

Pictures:

Pictures of Esther Woodbury answering audience questions during the Panel Discussion ‘Supported Decision Making – Who Gets to Hold the Remote?’  
Caption Text:  
Unfortunately disabled people have really high rates of being abused.

That’s one of the reasons that supported decision making is so important.

It builds up people’s confidence and allows them to set their own boundaries.

Section: What does Supported Decision Making mean for individuals?

Speaker:

Trish Grant, Director of Advocacy, IHC.

Speaker Background:

Caption Text:

It’s such an important human right.

Article 12 of the Convention gives people with learning/intellectual impairment the right to get the support for them to make decisions in their own lives.

Speakers:

Jodie Turner, Midland Region President, and Alex Snedden, Northern Region Vice President, from People First New Zealand. Ngā Tāngata Tuatahi.

Speaker Background:

Caption Text:

Jodie:

Did your family or friends ever tell you what to do?

Alex:

Yes. Sometimes it is hard. They make their choice into our choice.   
It’s not good.   
Picture:

Picture of Alex Sneddon and Alexia Black during the People First NZ Presentation “My Life. My Decisions.”

Speaker:

Jodie Turner:

Speaker Background:

Caption Text:

I made a choice to move away from my family home because of the way they were treating me.

It was the best decision I have ever made. It was my own choice.

Speakers:

Pelenatete Lam Sam and Tina Mataiti, DIAS Team, Vaka Tautua.

Speaker Background:

Caption Text:

Pelenatete:

Supported decision making is important because we’re acknowledging that person in the family.

When you give them the right to, or allow them to make decisions, you’re acknowledging that they are people.   
Picture:  
Tina Mataiti and Pelenatete Lam Sam pictured with other members of the Vaka Tautua team.

Tina:

In a Pacific family it’s about a circle of family.

Section: What does Supported Decision Making mean for families?

Speaker:

Tania Thomas, Mana Whakahaere/CEO, Te Roopu Taurima.

Speaker Background:

Caption Text:

For the family, supported decision making can look scary.

It can also be quite a relief because many families know their loved one really well.

I think they get really frustrated by the fact that some support workers don’t give their loved one any credit for being able to make any decisions.

Speaker:

Paul Gibson:

Picture:

Picture of Paul Gibson speaking during the Panel Discussion ‘Supported Decision Making – Who Gets to Hold the Remote?’

Caption Text:

Families need to work alongside their disabled family members.

But also listen to others in a circle of support.

Speakers:

Tina Mataiti and Pelenatete Lam Sam.

Picture Background:

Caption Text:

Tina:

A lot of families say to us, “I don’t want to put my child in a special education school.

He’s going through mainstream even though he has Down Syndrome”.

But that’s just Down Syndrome. First of all he’s a human being.

Section: What does Supported Decision Making mean for organisations?

Speaker:

Paul Gibson.

Speaker Background:

Caption Text:

Organisations need to upskill themselves and understand a human rights model of decision making.

How they can support families, support disabled people to express themselves, so their choices are realised.

Organisations could influence legal and health professionals who can have a big say in the decisions in disabled people’s lives.

Speakers:

Tina Mataiti and Pelenatete Lam Sam.

Speaker Background:

Tina:

Getting everyone on board with supported decision making means working through organisations.

This includes the churches, sports clubs, women’s, young people’s and children’s groups. But for our Pacific people it is definitely the churches.

Section: What tools are there for Supported Decision Making?

Speaker:

Gabby Hogg:

Picture:

Gabby Hogg using her iPad.

Speaker Background:

Caption Text:

There are different types of speech generation device apps such as Proloquo2Go, which I use.

Augmentative and Alternative Communication (AAC) also include NZ Sign Language and picture exchange communication system.

Really anything that supplements our ability to talk.

Speaker:

Lisa Holten, Complex Care Group.

Picture:

Lisa Holten and Sarah Holton, with Sarah’s AAC device.

Caption Text:

It’s not a hierarchy about technology.

It’s about what is the best access mode to unlock this person’s ability to communicate.

That hierarchy, particularly for girls like mine, just locks them out.

For 20 years you try to find a way that’s right for them because you want to unlock a means for them to communicate.

Speaker:

Sharon Brandford, Consultant on Disability Supports, Registered Psychologist.

Speaker Background:

As a psychologist I’m often asked to provide information to help courts make difficult decisions.

I was looking for new tools to help me give voice to a person’s preferences.

I found out about talking mats.  
Pictures:  
Pictures of talking mats with icons that describe common phrases such as ‘drinking’, ‘dad’ and ‘brushing teeth’.

Caption Text:

They seemed a low tech, simple, visual strategy that could be used in a variety of situations.

For some people, I’ve had a similar conversation repeatedly.

It has become a sequence of evidence to say to the court.

She changes some days, but notice that every single talking mat spoke about the importance of her sister Jean.

Speaker:

Judge Philip Recordon.

Caption Text:

We have at the Auckland District Law Society a disability sub-committee.

It looks at decision making processing and other aspects of disability law.

Section: How do we build a movement?

Speaker:

Martine Abel.

Speaker Background:

Caption Text:

I think it’s important that we build a movement.

At the supported decision making hui, it was great to meet with new people from different sectors.   
We had the older persons’ sector, mental health and intellectual impairments, lawyers and researchers.

Part of the problem is that we haven’t worked with each other before.

This National Conversation could be the beginning of a movement. We know that there is much to do.

And that will probably be our mandate, to stick together and to do things more collectively.

Pictures:  
Pictures of attendees from various backgrounds engaged in conversation during the two day Hui.

Speaker:

Paul Gibson:

Caption Text:

The disability community needs to lead a social movement around supported decision making. Around realising the rights of disabled people.

We need to keep having the conversations amongst ourselves.

Spread it to all disabled people, their families, to those who work in the disability sector, including health and legal professionals.

Step it up to a political level so that law makers understand that there is a need for law change to make supported decision making universal.

We need to look at the structures behind it which can help safeguard disabled people and their families.

An office of supported decision making which has a more modern process than an office of public guardians.

Speaker:

Tania Thomas:

Speaker Background:

Caption Text:

In the future I see supported decision making just being a part of ordinary everyday life for everyone.

I see that we’ve stopped trying to control other people’s lives.

We’ve stopped sticking our noses into other people’s business.

We’ve started to realise that people can make their own decisions.

It’s just some of us need a bit more help than others.

Section: End Credits.

Background singing waiata: Whaakaria Mai (How Great Thou Art)

Caption Text:

Auckland Disability Law would like to thank:   
Our lead partner: The Office for Disability Issues.  
Our partners: The Human Rights Commission, Te Roopu Taurima, People First New Zealand. Ngā Tāngata Tuatahi.  
This project’s main funder is the Ministry of Social Development’s Think Differently Fund.  
Director: Julie Watson.  
Cinematography, audio and editing: Rebecca Swan.  
Photography Garrett Keirnan and Vicki Hall.  
Production assistant: Harry Adams.

Speaker:

Matua Waitai Petera closes the hui.

Caption Text:

No reira e tatou ma huri no tena tatou katoa.

Therefore one and all, again greetings to us.