

# Stories that Build Leadership in the Disability Sector

*Facilitating the Transition to Individualised Funding*

## SUMMARY of a research paper by

Annick Janson

Centre for Applied Cross-cultural Research, Victoria University of Wellington.

In collaboration with:

Michael Kendrick

Kendrick Consulting International, MA, USA.

### INTRODUCTION

Transitioning to Individualised Funding (IF) has had a transformative impact on the lives of disabled people who are eligible for this type of funding. By giving these people a voice through telling their stories, a wealth of information has been shared that was previously unavailable.

Manawanui asked for this research project to be done to capture these stories to show the benefits of being on IF. It has created an avenue for new people starting with IF to get information and connect with others, and to hear the benefits of IF from others who are using it.

People's experiences have also helped Manawanui to improve how it supports people through its Coaching service. IF users and Manawanui have been inspired into action and innovation.

*"Until then I was used to people always saying 'no, no, no' to me; so when we realized that we were in control, we were a little confused. At first, we did not realize how life-changing this was going to be."  
(Interview participant)*

### THE RESEARCH

Story-telling is as old as Humanity. Knowledge has been passed on through story-telling for thousands of years. When people have an opportunity to tell their story and know that they are being heard, they feel a sense of empowerment, being valued and being of help to others. Most importantly, the stories collected revealed four key themes relating to areas of participant's lives that IF had the greatest impact and benefit, and that they felt were important to talk about with others to facilitate the transition to IF. These four themes were identified as barriers which

were overcome through the transition to IF, and which created transformational effects on their lives.

The power of story-telling also came through from the research: sharing experiences, learning and resources; building connections and networks. Because people had the freedom to speak in their own unique, authentic way, others were able to relate and identify with them and their stories.

*"Some organisations show video clips on their websites that sound like advertising clips – I don't watch those – they were clearly scripted and carefully staged – I feel their learning material is washed out and weak. I like the interviews on your YouTube channel – they feel authentic – it's people like me who talk". (Andy)*

Forty-five people were interviewed and had their stories recorded on video. Some people were family members of the disabled person on IF, or it was the disabled person themselves who told their story. They shared their experiences, highs and lows, struggles and triumphs, hopes and dreams. Family members talked about the emotions that arose on their journey with IF. Young disabled people talked about how their world had opened up for them because of the innovative ways they used their IF.

*"The importance of actually sharing your story with other parents is really, really empowering, and it's so easy to speak to people where they understand where you are coming from." (Andrea)*

For new people just starting out on IF, watching their peers' stories and hearing about the transformational effect IF had on their life provided them with ideas they could put into action. It inspired them to improve their own life or the life of the person with disabilities, whom they were supporting. Also, the connections that are created overcome feelings of isolation and despair.

The research project also highlighted the value of using modern technology and social media. The sharing of stories was multiplied: after a person viewed one, they would then pass the link on to someone else, and so on. Through social media, the stories were shared throughout a far wider audience. For example, one participant's video clip posted in the morning on Facebook generated 11 views in an hour, 75 by the night and 2 weeks later, the reach had ballooned to 2578, as reported by the Facebook aggregated metrics. People with no connections with disability or the disability sector at all were also viewing the stories.

These stories can also provide the building blocks for leadership development for people who want to more consciously grow their self-determination and personal autonomy on both personal and professional levels.

Professionals within the disability sector have gained value from the stories, inspiring them into action to achieve better life outcomes for the disabled people they support.

*I found it very informative and I believe that working with people we support – there is a clear path for them trying to be*

entrepreneurs due to the many barriers facing them in a normal job market. I am with the Employment Options team and your feedback came at just the right time... with the resources available to clients.

## THE FOUR THEMES

Four distinct themes emerged out of the stories. These themes identified highlighted areas in which people interviewed found the most benefit from IF, and were important to highlight as areas to focus on when assisting people to transition to IF.

### 1. Building Natural Supports and Networks

**Case Study: Sue wants to be the voice for the unheard.**

Parents of children with high and complex needs face significantly different challenges than others in the disability sector. The financial implications of care 24/7 are astronomical. Families need to make difficult choices as to where to spend their budgets.

Go to: <http://www.youtube.com/watch?v=XpSlfXMtofM&feature=youtu.be>

### 2. Mobility and Technology

**Case Study: Kahu used her interview clip to back up her application for a mobility grant.**

Kahu is a natural community leader. Since she became disabled through an accident, she needs a mobility van so she can carry on her community building work. Amongst other activities, she is adding to the Maori sign language by designing new words based on Maori tikanga.

Go to: <http://youtu.be/Rw4YmO5U0Hs> [this live link needs to be fixed]

### 3. Home of One's Own

**Case Study: The house purpose-built for Jack**

Joanne: Her family built a fit for purpose house for their young adult son to use for respite. He gets time away for himself in a place that is colourful, safe and attractive.

Go to: <http://www.youtube.com/watch?v=wZcE64BxVjo>

### 4. Productivity

**Case Study: Andrea and Tyler planning a transition from school.**

Since becoming an Enabling Good Lives client, Tyler's life has changed dramatically and exciting possibilities are opening to him. He is thinking about how to spread his wings.

Go to: <http://www.youtube.com/watch?v=DaphEptN5rY>

These themes have helped Manawanui to identify what it needs to do to support people transitioning to IF. Manawanui Coaches use the stories to help new people understand how IF works, how to overcome obstacles, how and where to find support from others and to illustrate to people the benefits of using IF so they feel less anxious about making the transition.

The Four Themes have been developed into an Interactive Coaching Tool. This tool can be used by professionals in the disability sector when they're working with

disabled people, or by disabled people themselves as a guide to setting goals and planning their life path.

## THE INTERACTIVE COACHING TOOL

**Transitioning to Self-directed Disability Support**  
**A Thematic Analysis**



**Community contribution**  
The social impact resulting from the roles that people with disability want to fill.  
[Click here to listen to all participants' interviews](#)

**3. A home of One's Own**



**Choosing where you live and who with**  
[Click here for stories about living situation choices](#)

**4. Productivity**



Work and supported employment, Self-employment, Entrepreneurship and social change, Socially valorised role, volunteering....  
[Click here to hear about the impact of productivity on people's lives](#)

**2. Mobility & Technology**



Assistive technologies, Universal design...  
[Click for stories about the impact of technology and mobility on people's lives](#)

**1. Natural Supports & Networks**



Circles of support, PATHS & MAPS, intentional invitations...  
[Click here to listen to people talking about how they get support from the people around them](#)

**Build confidence to overcome transition crisis**  
Enabling role of funding structures, such as Individualised Funding and EIF; EGL and its implications



Transitioning to a personalised model can potentially enhance different aspects of your life. But how can people understand all their options?



[Click to hear how Individualised Funding has inspired people to take new actions](#)



[Click here to listen to interviewees who advocate for those who feel unheard: Very High Needs families.](#)

