

Self leadership

Family leadership

Peer leadership

Community leadership

A photograph of two women sitting at a table, smiling and looking at each other. They are both holding papers. The woman on the left is wearing a dark jacket, and the woman on the right is wearing a red and white top. They appear to be in a meeting or a collaborative work environment.

Sharing our stories provides us with the inspiration we need to carry on making a difference for our families and caring for our disabled children...

*Presented to our stakeholders by
The Te Whanau Kotahi Board,
Barry Davies, General Manager and
Annick Janson, Researcher.*

Parents leadership newsletter. Report by Dr. Annick Janson, Ecosynergy Group for Te Whanau Kotahi

Sarah and Layne Coates



"Together we are stronger"

Before their son's diagnosis was ascertained, Sarah and Layne made a conscious decision that they would strengthen their couple as a safety guard, as the one stable factor in their son's life.

They discussed what this strength meant and what each partner had to contribute to the couple.

They are going through this voyage together and will not let the stresses and challenges of supporting their disabled son endanger the stability of their relationship.



Shelley Bishop



"When a job needs to be done – just knuckle down and DO it... to get to the next level"

When her son needed to learn how to interact with other children without frightening or hurting them, this meant an all day long shadowing job for mum... it might have been 'easier' to avoid social contact with peers, but Shelley chose to do the job, even if she dreaded having to play this role.

However with time, and lots of trials and errors, Sam learned to interact with other children. Shelley's work had paid off and Sam achieved a milestone.

Of course, next were other challenges but Shelley reflects that it was important to have knuckled down and done 'what needed to be done' even if she was not inspired by it at the time. It was necessary for Sam to reach his next developmental stage.

Angela Lumsden



"if you cannot get a piece of the cake, you are ready to settle for crumbs... but then when things don't go well, you are afraid to risk losing the crumbs."

What started as a great school turned within weeks into a nightmare. Angela's challenge here was to identify what was not working (the negative attitude of the staff) and how to respond to behavioural issues arising for a child who had never had them! After recognising that this school was not the right one for her son, she then had to take action... The Special Education team from the Ministry of Education supported her as much as it could.

Angela recalls the turning point as when she enrolled a friend as an advocate for school meetings and wrote verbatim what was said - including special ed staff from the College suggesting she supplements ORS funding with personal top up to pay for extra help... (Cont' below)

Angela Cont'

Angela reflects on the impact that having another person at these meetings had on her and how it gave her the courage to look for another school.

Angela's learning is that sometimes the help of someone (who may be very close to you in the first place!) gives you that little bit of courage to overcome the fear (to loose even the crumbs you had) and that if one person cannot help you then carry on looking until you find the right people to achieve the best outcome for your child!! By overcoming her fears, Angela got: ***"the cake, the icing and the cherry!!"***

Parents can share stories to inspire each other. ***"If even one more parent listening to my story can learn from it how to identify a negative school situation and how to get out of it, then this interview would have been worth it!"*** Angela concludes.

Linda Thompson

"My son taught me to be a better person".



Linda reflects about the role of whanau and family in bringing up her son. Parents of children with disabilities need to look for natural support systems... or create their own if needed. Through her experience, Linda discovered strength she did not know she had - she changed into a person that appreciates every instant in life. She grew to be a more caring person, in her own eyes. Linda concludes: *"with the deep love for your children and the right support system you are a conqueror"*.

Kellie Collingwood



"When we share our stories, we instinctively think we are helping others understand what we went through and by extension assist them to learn from our experience... What we may expect less is what we GAIN from sharing..."

Kellie reflects on the insights she reached while telling her story... that she needed to take good care of herself and, in the process strengthen her family.

This, however, is not an obvious one, as parents often put themselves last. When it comes to distributing resources and time, we often put our children first, all the more when they have a disability.

Kellie however explains how she realised the impact that taking care of herself actually would have.

Rebecca Stockdale



"I'm the annoying mother, the one that always checks up the information she is given, the one that always follows up, the one that is always nagging... but I'll wear this as a badge of honour".

As the mother of a son with high needs Rebecca has had to advocate for her son at each step of the way. Finding out about Individualised Funding was liberating as she could go back to full time work - after caring for her son in his first years.

Rebecca's determination drives her to research and find out information that even local paediatricians did not know - that Stanford University was carrying out a study on his condition.

This allowed many New Zealand families to become part of this trial and made a real difference to them and their practitioners.

Sandra and Warren Aitken



"We fought the fight so other families won't have to go through what we went through"

How does a family overcome the denial of their child's application for primary school? Sandra and Warren addressed school processes.

Through mediation with the Human Rights Commission, the school changed their registration process and developed staff to include disabled children.

They share their story to give confidence to other parents to challenge the system and get what their child needs:

"Sometimes you have gather strength for a big fight... but ongoingly, you build resilience to address the almost daily issues that arise - it's about being alert to your child's needs and secure in your role of life advocate for your family."

What action could you take next to make a difference to your family's life?

Suzy Brown



I have but one voice – but this is all that is needed. If you listen, hear and feel what I am saying then hopefully a small change can start to occur. I drop a stone in a pond and pray that the ripples can begin a movement. A change in attitude towards exclusive education. This change needs to start from the top of the school structures where exclusion exists – the principals, deputies and BOT's.

Suzy wants to be a voice that advocates for all schools to review their inclusive practices for decision makers to hear first hand from parents how devastating it is to have your child denied school registration on the basis of a disability.

Suzy found an embracing and inclusive school for Bianca: *"I trust them implicitly with my daughter because I know that they have her needs, her safety and her well-being at heart. Each and every child there is a valued and respected individual regardless of their different abilities... If only every school was as inclusive!!!"*

Trudy Hulena



No matter what the time of day or night is, you can turn on your computer, pick a (TWK parent) story, click through; you might think 'this one I can relate to - this one I can't' but I think it will give us in our hearts that sense of not being so alone. I would love to hear other people's stories and know that there is other people in the same boat that I am in... so write in!!"

Trudy is a grandmother bringing up her daughter's son. She recalls that whilst in the workforce she used to get annual leave, but since she has taken up the care for her grandchild, it took 4 years for her to be "brave enough" to give herself a holiday. She learned from her first week off, what worked and what didn't but found that it was essential to build his strength.

Trudy calls on other parents to join her in the "Self Care" project that she wants to create: parents forming small groups, and taking each other's children when sick or needing a break. Money will not be an issue, we will gather the help we need from those around us.

Ellie Griffin



"If we did not have to face the extra challenges that society throws at us then we could just get on with the job of parenting and enjoying our kids."

Ellie's journey is "challenging yet exciting". Her learning about social model of disability showed her that the challenges that people who live with disability encounter are compounded by society's reaction to their condition - lack of resources, fragmented services or people's attitudes.

Video interviews extend the advantages of face to face planned or ad hoc discussions with other parents - reducing loneliness, recognising commonalities of objectives, strength building and dealing with the fear of the unknown. Stories help build leadership.

Before embarking in her journey, she spent many sleepless nights worrying about Zac's future. Being on the Board of the Bay of Plenty Disability Support Trust is empowering: *"I find a lot of hope in planning Zac's future".*

What have parents told us?

September 2013 workshops and parents interviews

At a glance...

Angela

At what point do you take action to change?
Face the fear of losing even a bad situation
Gather the courage to make the first move
Enrol people who can help you

Ellie

Take up a leadership role - you will gain control and expand into new networks
Learn from other parents - there is a lot of information out there that will be useful to you

Kellie

Take care of yourself - to better take care of your child
Acknowledge the insight you gain from helping others

Linda

Enjoy each moment life gifts you
Enrol support systems around you

Rebecca

Seek out the information you need - and advocate!
Chose work / family balance choices that work for you
Don't only rely on experts - seek out information to remain the expert on your child's needs

Sandra and Warren

Follow your intuition
Confront systems to change them
Re-consider and re-direct choices

Sarah and Layne

Bank on your child's most important advocates – the parents / family
Embark on the adventure together - Take active steps to strengthen your relationship
Sustain your energy

Shelley

Trust that you know when to put your child first
There are times when you just have to be the support and therapist of your child!
Make a difference where you need to - even if it is not what you feel like doing at that time

Suzy

Speak out for inclusion - and get policy and decision makers to understand parents
What can the early childhood education field teach us?

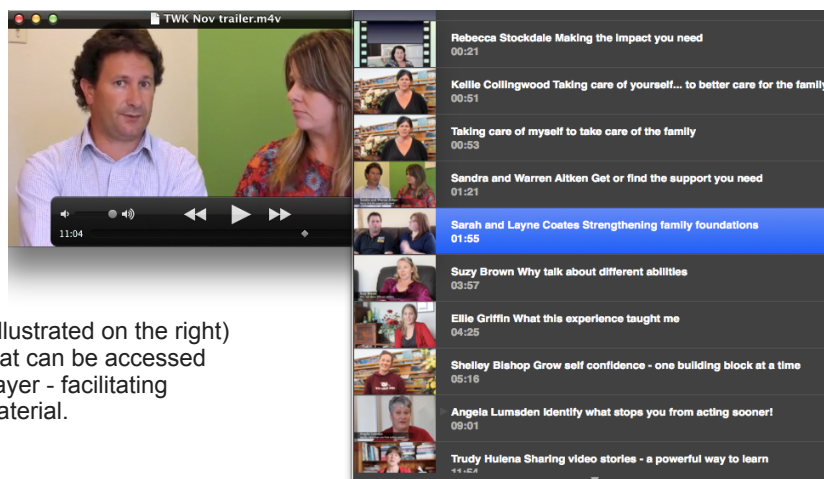
Trudy

Families helping families
Create and enrol the help you need - with no additional resources
Capitalise on the power of stories to strengthen yourself

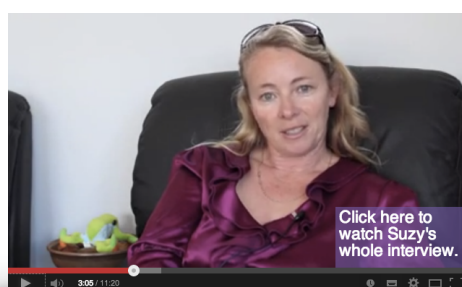


A Peer-Learning System that harnesses the dynamics of story sharing

Access trailer and all interviews at <http://tinyurl.com/TWK-Parents-Guide>

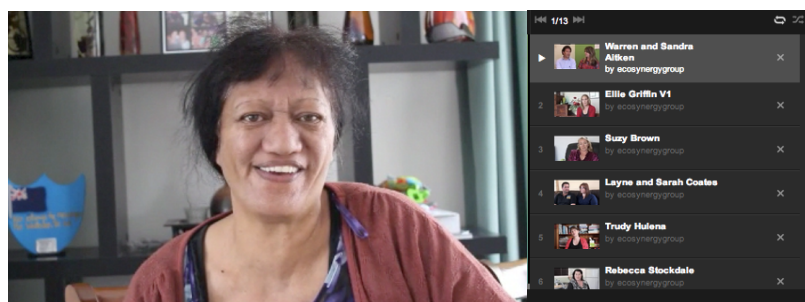


Example 1: The introductory trailer (illustrated on the right) is divided into introductory segments that can be accessed separately using the free QuickTime player - facilitating impactful group presentations of this material.



Example 2: Once online, this trailer becomes more interactive (left). Viewers can click buttons that lead to the full interviews as described on the screen.

Example 3: The playlist includes 10 full interviews of parents for users to access in their own time. The player allows for easy access (below left) to the different themes that families have reflected about when asked about their source of strength or milestone events that have contributed to building resilience.



Example 4: The trailer and playlist offer flexible access online and via mobile devices and tablets (right). The project research data makes it clear that we need to think beyond the concept of face to face workshops. Meeting and real time interactions make a difference in certain cases; but at other times the impact we are seeking to make is different.

"Sometimes it is only at 11pm when kids are asleep that I have the mental energy to put into myself. I want to learn - in my own time"

*"If I had had access to such stories when my child was first diagnosed, our lives would have been different. When you realise your child has a significant issue - whether it is at birth or later on - your whole world is turned upside down and you need a massive amount of **(the right)** support to get through"*

"We had no idea other people felt the same as us. Doctors say nothing because of confidentiality issues and this reinforces the isolation and despair you find yourself in. Some peer groups I attended or individual conversations aggravated the situation as I found myself amongst people who were more into complaining than building strength"

"What I liked about this material is the power building angle they take - I get an idea, a different perspective or a new thought. I can browse the stories via the written material or listen/view a story at the time that best suit me. I want to contribute to developing this resource further so that in the future families can learn about the growing list of issues that we all face as life goes on - and come out stronger for it"

