



*A good Start*

For children with disabilities

# CO-DESIGNING *with Parents*

CONNECT+CO 2018



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A GOOD START FOR CHILDREN  
WITH DISABILITIES

# CONTENTS

Thank you	2
Introduction	3
Approach	4
<b>ANALYSIS</b>	<b>6</b>
Workshops	14
<b>WHAT WE LEARNED</b>	<b>16</b>
Key insights	16
Examples of tipping points	18
The four groups of parents	20
Rocky start	20
Positive	21
Up and Down	21
Struggling	22
Statutory intervention	22
Asian parents	23
Pasifika	23
Children	23
Key learning from the workshops	24
Ideas	24
Practical supports	24
Family, whānau wellbeing	24
Building community	24
Prototypes	25
A key person	25
Coordination across sectors	26
Training and support	26
Appointments	26
Parent-held information	27
Useful information	27
A change from looking for risk to supporting parents	27
<b>CONCLUSION</b>	<b>28</b>

# THANK YOU

*The Good Start in Life* co-design project was established to bring the voices and experiences of parents, family and whānau of children with disabilities into the centre of decision making about the system that supports them. It depended on people giving their time and talking openly about their experiences. Sometimes this were very difficult and painful.

Thank you to the many people who took part in this project and were so generous with their stories. They saw their involvement as being important to developing solutions and many commented that they'd never been asked about their lives or their ideas before.

The involvement of those who receive services and support in design can be powerful – and has the potential to bring simple, practical and sometimes low cost solutions.

Having the flexibility of a key person being a whānau member, rather than a paid expert, developing online support groups, promoting information that is current and evidence-based, organising appointments based on need – these are ideas that are achievable.

Everyone involved got excited about looking for solutions, they found the parents' experiences powerful and were keen to use these tools when developing their own services and projects. The commitment of the sector to this process was encouraging and people had multiple ideas for creating change – some of which they were going to implement themselves.

Thank you to everyone who gave their time and ideas to this project. Your generosity was amazing.

## *Core design team*

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# INTRODUCTION

*A Good Start in Life* is a collaborative, cross-sector project which aims to develop policy options to improve support for parents, family and whānau with disabled children under six years of age. It has been established as part of the New Zealand Disability Strategy which is guiding the work of government agencies from 2016 to 2026.

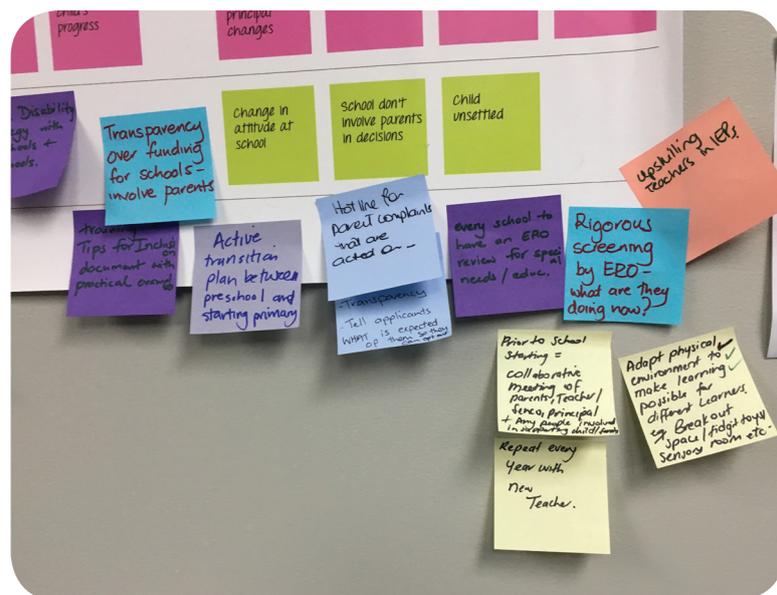
The approach acknowledges the importance of parents, family and whānau being valued and having choice and control in their lives. This co-design project did just that – it started with listening to the stories and experiences of parents and caregivers, exploring common themes and then going back to parents and those who support them and asking them for their ideas.

This is different from a consultation approach which commonly has fixed questions and is distributed through networks to people who are more likely to be connected and vocal. Effort has been made to connect with parents and whānau through community connections and relationships, and this led to a range of voices being heard. Time was also given to explore the experiences of each interviewee in depth and in places that suited them.

The interviews were only part of the process – parents and whānau, and the people who support them were then given an opportunity to discuss the themes and insights and to develop solutions.

This project intersects with the action research initiative undertaken by What It Takes<sup>1</sup> in 2017. This used the My Working World framework which provides a philosophy, principles and tools to support collaborative relationships with whānau and among people working in the service system.

More information and regular updates on progress with the *Good Start in Life* strand are available at <https://www.odi.govt.nz/nz-disability-strategy>.



1. A Good Start in Life, Action Research Project, Megan Ellis, November 2017



# APPROACH

A *Good Start in Life* co-design project used a user-centred design approach to understand the lives of parents and their disabled children and then to involve them, along with government and NGO employees, in developing ideas that could address the issues that most affect them.

The project was guided by a reference group from across the government and NGO sectors, a number of whom are disabled and/or have children with disabilities. This group acted as a touchstone for the project, first setting the intent and scope, then the area of focus and finally guiding the insight and ideation phase.

## The reference group asked that the project include:

- a range of disabilities and ages
- a range of locations, including large city, rural isolated and provincial
- parents whose voices weren't often heard
- Māori, Pasifika, refugees and migrants
- a range of caregivers including fathers, grandparents and single parents.

It was agreed that Northland, the Wairarapa, Central Otago and Auckland be the areas of focus. Parents and whānau were identified through intermediaries in local communities who approached parents, many of whom were rarely involved in consultation or interactions with government. Before each interview began, participants were informed of the purpose of the project, privacy parameters, and were asked to sign consent forms.

The user-centred design framework is recognised as a way to put those most affected by a service or product at the centre of the design process. It is increasingly used across government as agencies work to “drive a deeper understanding of the New Zealanders we serve and how to make a bigger positive impact on their lives.”<sup>2</sup> A recent example of this is the redesign of *Oranga Tamariki*, which involved young people who had experience of living in state care.

At the heart of this design process is empathy interviewing, which uses open-ended questions to understand what interviewees think, feel, say and do. Instead of asking “what do you want?” or “what’s not working?,” interviewers ask questions about what is happening when things are going well, who parents turn to when they are not coping, who is important in their lives, and what good services look like. By asking these questions it is possible to build an understanding of people’s lives that can be turned into common insights and themes. These can then be used in co-design sessions with stakeholders, including service providers and parents, to create ideas that can create the most difference.

A total of 63 parents/whānau have been interviewed. Prospective interviewees were approached by staff working at a range of agencies in the identified communities as well as by parents/whānau themselves.

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2. Prime Minister Bill English, Speech to the Institute of Public Administration New Zealand 19 February, 2015, <https://www.beehive.govt.nz/speech/speech-institute-public-administration-new-zealand-1>

The people interviewed were mothers, fathers, aunts and grandparents of young children. There was considerable depth of experience in caring for children with a wide range of disabilities. A number of children had multiple disabilities and/or disabilities that had no formal diagnosis. Some parents/whānau were simultaneously caring for several children with disabilities and some were living with disabilities themselves.

Those interviewed were of Pakeha, Māori, Pasifika, Asian and Indian ethnicities, and included a number of people from migrant backgrounds. Some parents from refugee backgrounds initially agreed - via an intermediary - to be interviewed, but subsequently withdrew. The intermediary, who was already engaged with these families, was interviewed instead, providing valuable information about the experiences and preferences of refugee families and the barriers to help-seeking. Similar interviews were undertaken with intermediaries for other hard-to-reach groups, specifically Chinese and Pasifika families.

Interviewing began in Wairarapa and continued through Northland and Central Otago, finishing in Auckland six weeks later. The majority of the interviews were undertaken by Connect+Co. Four other interviewers, one from the Ministry of Education, one from the Ministry of Social Development, one from CCS Disability Action and an independent community worker, were involved in a small number of interviews.

The interviews were semi-structured and empathy based, following the lead of the parent or whānau member as they described their experience. Throughout the process the interviewers explored the parents' and caregivers' thoughts, feelings and actions at different stages of their journey.

Consistency of interview approach was ensured by discussion with interviewers about the purpose of the interviews and the empathy approach, ongoing discussion of interviews, and review of notes and transcripts. Each interview took around an hour.

Each interview was recorded (apart from three, where the parent asked for note taking only) and then transcribed with all identifying information removed.



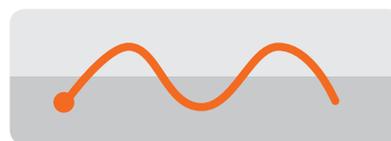
# ANALYSIS

The two lead interviewers then led an analysis process with four members of the reference group. Each transcript was read, discussed and analysed by a minimum of two members of this group. A profile for each parent or caregiver was then created on a large sheet of paper. This included key insights from each interview. These were rated on a series of sliders or continuums to describe the interviewee's experience, in relation to a specific issue, from negative to positive. Quotes illustrating these were extracted and recorded. The parent/whānau member's journey, as described in each interview, was then visually represented by a small tracker - a linear diagram showing the progress of the parent/whānau member over time, relative to their wellbeing.

The design group looked for patterns across the profiles. It wasn't possible to create clear segments according to ethnicity, age of child, disability or where they lived. The group then identified patterns based on the well being trackers drawn for each interview. These were grouped according to the progression of the tracker. Four clear groups emerged based on the wellbeing tracker: Positive, Up and down, Rocky start and Struggling.



POSITIVE



UP AND DOWN



ROCKY START



STRUGGLING

The analysis group then went through each profile in each of the four segments and were able to identify common themes and insights in the groups, these are explained on pages 20–22.

Four experience journey maps were created based on these common themes and insights. These illustrate the stages in a child's life, the activities that happen at each stage, the typical feelings of the parent at each stage and significant pain points. These were used at co-design workshops to illustrate common experiences and prompt the development of ideas and solutions that could address the issues identified.

# POSITIVE

These parents have support and resilience from the beginning. Although things go wrong, they bounce back and remain positive and committed to advocating for their child.



POSITIVE



Actions



Feelings



Pain points

Finding out

GP refers child to pediatrician	Pediatrician diagnoses condition	worry about adequacy of parenting skills	Relief at diagnosis	working out the system skills	Not knowing what's wrong/normal
Mum makes plan with partner	Mum moves home to be near whānau	Grief and fear	Confusion - needing to sort things		
		supported by whānau			

Toddler

Proactive support from provider	Seeking information - online and from professionals	In control - even with the hard stuff	My child makes me happy	Juggling appointments	waiting for services
		Hope		Finding trusted/positive information	

Pre-school

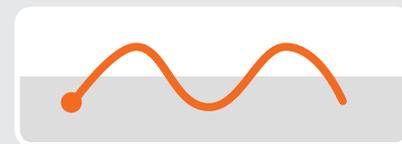
Child starts at kohanga	Finds useful social media pages	I can manage the system	My life has purpose	Key people keep changing
Gets speech language therapist		Pride in child	We're part of the community	

School

starts school		Nervous - school wasn't great for me	valued - other people listen to me	Transition hard for child	Change in support people
Mum gets part time job at school	I trust my instincts	I can help others	I can see the future	Perceived lack of resources	Everything's decided in Wellington

# UP AND DOWN

These parents have their ups and downs but usually recover from difficult times. They bounce back from challenges.



UP AND DOWN



## Actions



## Feelings



## Pain points

### Finding out

Diagnosis at birth	Transferred to different hospital	Shock, fear and uncertainty	Protective of baby	Medical staff obviously uncomfortable at birth	Frequent travel - away from home and family
Given information		Confusion about who does what		Unsure of prognosis	Telling and retelling story to professionals

### Baby

Taught how to manage at home	Re-admissions to hospital	Tired, exhausted	There are other people like us	steep learning curve	Multiple appointments - travelling and juggling
Spending time on social media	Referred to local early intervention team	Trust in the early intervention team	Uncertainty about future		

### Toddler

Join local support group	start leaving child with aunty	There are others like us	We can do this	child often sick	continuing to juggle appointments
		worry about child's health			



### Actions



### Feelings



### Pain points

#### Pre-school

start at day care

Get to know day care staff

Feel teachers don't understand

We're part of this community

Teachers anxious about seizures

Child can't attend full-time

Relief when child's day goes well

Pride in child's progress

#### School

Existing principal leaves

Mum returns to work part-time

Powerlessness when principal changes

I've got time to see my friends

Change in attitude at school

Child unsettled

Child gets home support

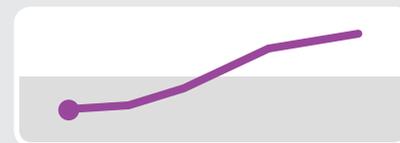
I need to keep speaking up

I feel supported at work

School don't involve parents in decisions

# ROCKY START

These parents find it really hard at the beginning but develop strategies and confidence over time.



ROCKY START



## Actions



## Feelings



## Pain points

### Finding out

Admitted to hospital prior to birth	Baby in NICU	Distressed	Frightened and lonely	Unclear diagnosis	Different info from doctor, internet and handouts
Possible diagnosis after 2 weeks	Mum stays, Dad goes home with sibling	Confused and shocked		Focus on worst case scenario	Major disruption to family life

### Baby

Re-admissions to hospital	Connects with GP	Exhausted and overwhelmed	What did I do wrong?	Tension in couple relationship	Family doesn't know what to do
Referred to early intervention team	Re-connects with antenatal group	Scared baby will die	Feel alienated by peers	Constant appointments and re-admissions	Retelling story over and over to professionals
		Guilt about other child			

### Toddler

Disabilities becoming more noticeable	Move to be nearer family	Frustration at lack of services	Pride when child reaches milestone	New paediatrician has different approach	Waiting for services - speech language, occupational therapists
Find online support group	Start to understand child's needs	Supported by friends	Guilt over other child		



### Actions



### Feelings



### Pain points

#### Pre-school

start at day care with education support worker

Dad working long hours so Mum can stay home

Happy when see positive stories online

Relief when child's teacher is welcoming

Education support worker keeps changing

Multiple appointments that sometimes clash

Planning for school

Get respite care

I know what to do

We're part of this community

Nervous about school

#### School

Complete parenting course

start school

I've got people I can call

I know my child

Still on speech language therapy waiting list

Mum called to school when teacher aide sick

Develop family routines and strategies

Get some home support

It's hard seeing my child with their peers

Worried child won't learn to talk

Mum enjoying time to herself

I feel included in the school community

We're secure with our routines

I can contribute

# STRUGGLING

These parents find life hard. They struggle from the time of diagnosis and feel they have to constantly battle to get what their child needs. They have ongoing feelings of grief and pain and don't feel supported by their family or services.



STRUGGLING



## Actions



## Feelings



## Pain points

### Finding out

Go to GP with concerns	GP says wait and see	Frustration	Stress	GP minimises concern	Six month wait for pediatrician in public system
Go back to GP	GP refers to pediatrician through public system	Anger	Confusion	Having to go private	Husband is not concerned
Go to private pediatrician		No one is helping us	Isolated	Family thinks mother is overreacting	

### Toddler

Referred to early intervention team	Referral gets lost	Frustration	Anger	Calls not returned	Not listened to or believed
Husband leaves		Isolation	Exhaustion and guilt	Waiting for help	
		Feeling judged			



### Actions



### Feelings



### Pain points

#### Pre-school

Child starts day care

Mum and teacher clash

Angry

I have to battle all the time, no one listens to me

Education support worker keeps changing

Long commute to new day care

Mother moves child to new day care

Education support workers supporting child

Feeling judged

My child doesn't fit

No family support

Friends have dropped away

Isolated

Depressed

Continual battling

Services slow to respond and don't communicate

#### School

Child starts school

School gets funding for part time teacher aide

My child isn't getting what they need

Exhaustion

School minimises support needs

Parent feels funding is inadequate

Mum offered parenting course

Offended by parenting course offer

I have to keep battling

Parent feels services not responsive or timely

Child's behaviour escalating

Isolated - there's no one I can trust

The system isn't working

Lack of engagement from services

## Workshops

A series of co-design workshops were held to test the insights and themes that emerged from the interview process.

The workshop format and tools (the parent journey experience maps) were first tested with the Good Start in Life project team and reference group. Feedback was used to iterate the approach. Critical friends from other co-design practitioners were also asked to review the process and their feedback was incorporated.

### **Workshops, walkthroughs and group meetings were then held with:**

- parents, government and NGO staff in Wairarapa (13 people – a mixture of parents, NGO and government staff)
- staff from Auckland, Counties Manukau and Waitemata DHBs (approx. 25 people - a mixture of clinical staff from pediatric and maternal mental health teams)
- early intervention specialists from across New Zealand (approx. 30 EI specialists)
- parents and NGOs across Auckland (approx. 18 people, mostly parents)
- social workers from the health sector across Auckland (8 people, all social workers)
- staff from Northland DHB - (9 people)
- parents, whānau, government and NGO staff in Whangarei – (13 people – a mixture of parents, whānau, NGO and government staff).

### **Where possible, the facilitators of the workshops followed a run sheet that included:**

- an overview of the project and the intent of the co-design process
- a summary of the project so far, including insights and tipping points (see page 18)
- brainstorming ideas and selecting those most impactful to participants
- designing early prototypes of the selected ideas
- presentation of the prototypes and general discussion.

In two cases this process wasn't followed because of time constraints, but the insights and journey experience maps were shared at all sessions and ideas collected. Single ideas were recorded on post-it notes during the sessions and participants were asked to pick those that they felt would be most impactful.

This process generated feedback that was a mixture of comments, ideas and prototypes. Most of the comments were responses by parents and staff to the experience journeys (for example recognition of parent's own experiences or those of their peers), feedback about the value of the process, and statements about their wish for practical outcomes that will make a real difference to the lives of parents, whānau and those who support them.

*The workshop process also led to some immediate change. After reflecting on parent experiences, a group of social workers agreed they would meet with a local medical team to discuss how they could better support parents of children in hospital.*

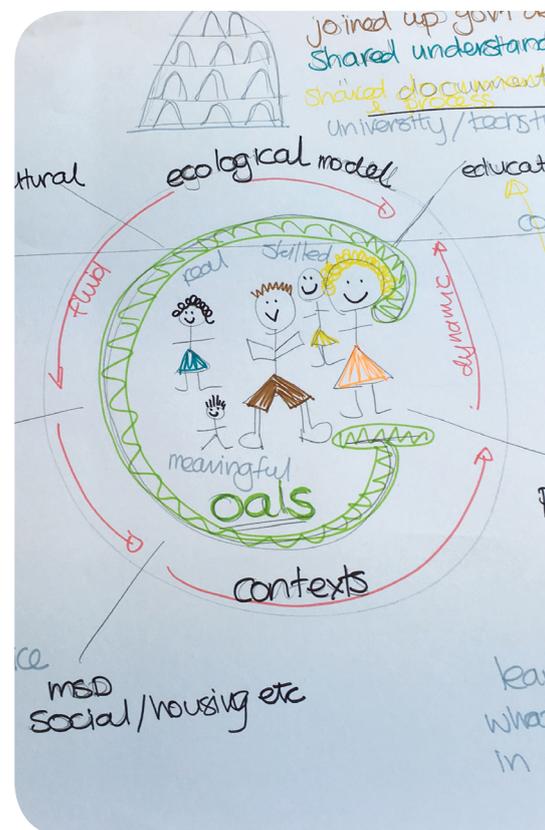
At the conclusion of the workshops the ideas and prototypes developed were sorted and themed. The post-it notes from the brainstorming sessions were reviewed to ensure often repeated workshop ideas were retained.

The strength of the co-design approach is the ability to facilitate diverse groups to engage fully with parents experience and to develop solutions and ideas from these. The conventional consultation approach, while it engages with many more people, tends to rely on a question and answer or meeting format that favours those who are confident about speaking up or writing formal responses.

The co-design workshops were held in different settings, for example in a tea room in a hospital, a Ministry of Education meeting room, a parent hub and at the end of a training day for early intervention staff. The process was able to be adapted according to constraints such as time and the availability of busy stakeholders. The parent experience journey maps have subsequently been used for a design session outside this process.

The ideas and prototypes that were developed were relatively similar across the workshops. They indicate that generating more isn't necessary – rather that those that were developed could be iterated and developed more fully.

A further round of workshops and walkthroughs, which would focus on iterating the ideas and solutions with a wider group of stakeholders, is a recommended next step.





# WHAT WE LEARNED

## Key insights

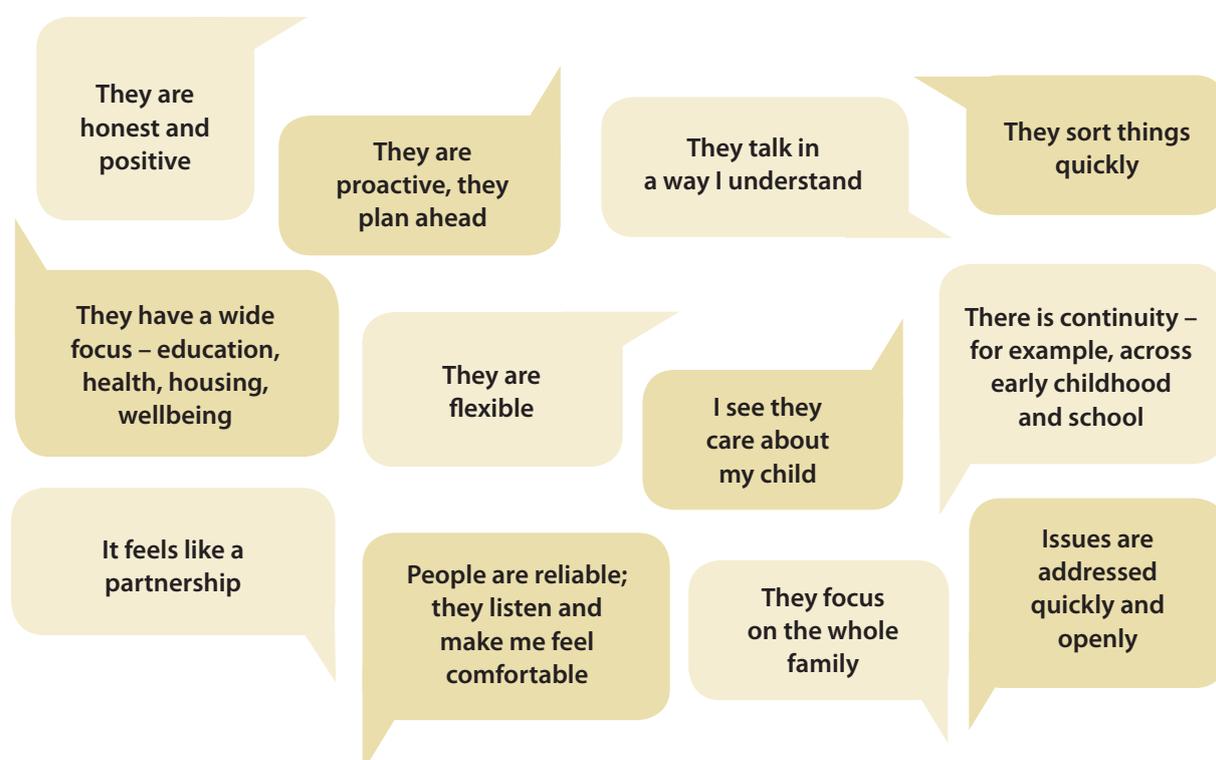
There were a number of insights that were common across the interviews. These emerged as each profile was mined, and then each of the four segments reviewed and common stories developed.

*Each child, each parent, each family is different. They all have different strengths, attitudes, experiences, skills, environments and social connections.*

It wasn't possible to group parents according to ethnicity, age of child, disability or where they lived. Parents commented that the system wasn't flexible and didn't take individual child and family needs into account.

*Most parents expressed frustration with services and support. If parents are doing well, they cope with services not being responsive. They advocate for their child in a positive way. When parents are struggling they talk about continually having to battle.*

Parents were consistent about what made a service or support work well for them and their child.



Some parents chose not to use professionals who they felt weren't listening or noticing what was going on for their child or their family. They were able to research their child's condition themselves, and join online groups centred on a particular condition. This created some tension when parents asked for treatment they had researched online, and medical professionals were cautious about adopting treatment they had not researched. One family was managing their son's epilepsy medication themselves because they felt the doctor wasn't listening or addressing serious side effects.

**"We don't even go to [the pediatrician] anymore. All he's going to do is read a textbook."**

***A range of informal support is key to how well parents cope. This is provided by friends and family, community and cultural connections, social media groups and support groups. Feeling listened to, respected, believed and not judged, are key.***

**"At first it was really hard. But going to the first [xxx syndrome] conference that we went to, after that I was like 'oh my God, we're not the only people with a daughter with xxx syndrome. There were hundreds of them.'"**

Many parents talked about finding a local support group or online groups – one parent who talked about feeling suicidal started a Facebook page that connected her with other parents from her cultural community. Other parents chose not to join groups, they were happy with a supportive partner or family member, and had friends who they could talk to openly.

A grandparent, who lived with her daughter's family, talked about the importance of a welcoming neighbourhood, where her grandchildren were able to play safely with other children. This street was a cul de sac and had minimal traffic – an example of environment influencing connection.

**"We have lots of friends who come and help whenever we need it. Government help is very slow and it doesn't work with the developmental stuff."**

Many parents offered their support to others, becoming teacher aides, running groups, or taking an active part on social media.

***A small practical thing can make a big difference – moving nearer family, finding a support group, getting some home help, finding relevant information.***

The analysis group went through the profiles of parents in the Rocky start segment and found that small practical things created major change (tipping points) for many parents. This group gives some clues as to how parents can move from a difficult time into one where they feel positive and proactive. Parents talked about feeling like an expert, having aspirations for their child, seeing a future or making a decision to change their life to care for their child.

## Examples of tipping points

Three children placed by CYF • no support



**developed parenting approach** • routines and stability

Diagnosis muddled • no support  
• child didn't fit in box



**read book about Asperger's** • learnt how to manage daughter's behavior  
• support from family and friends

Two children diagnosed • first years very tough



**supportive work environment** • self care

Negative info from doctor • didn't know how to parent  
• no family support • felt suicidal



**started online community** • found strategies and support

No time, stressed  
• little family support



**got individualised funding for home help**  
• able to spend time volunteering at school • made friends

Diagnosis



**found support group** • included in conferences and events • people listen to me  
• I've changed for the better

Scary information at diagnosis • support offered without empathy • Notification to CYF  
• issues with privacy re professionals • three months in hospital • home



**positive, practical relationship with provider**

Pediatrician said wait and see, didn't listen



**took charge, started fighting** • child walking and talking

Diagnosis, no support or referral



**worked out how to manage behaviour** • joined support group  
• work together as a couple • vision for future

*Almost without exception parents were proud of their children and said they brought them joy*

For some parents, having a child with a disability is transformational – they made a conscious decision to change their lives so they could care for their child. Some gave up drinking or addressed relationship issues. Many said it made them a better person.

***The experience of parents at diagnosis stays with them and can impact on how long it takes them to move into a positive outlook.***

For many the experience stays with them for a long time and affects their ability to trust professional help.

Parents' lives were often very busy. When children had complex medical needs, which was common, juggling appointments, often including travel, was very difficult. Travel could involve going from Central Otago to Auckland for long periods and/or going between local health services and hospitals in larger centres.

*Helen lives in a small rural town with a small local hospital. Her daughter Bea has a complex condition that involves lots of appointments in different departments. She juggles appointments at the local hospital, as well as those at the hospital in a city an hour away – often on the same day. She doesn't have a car and has to travel by public transport. She says she just can't turn up to them all.*

***There is no one way to support parents – some talked about wanting to “just be told the truth” while others talked about being given the worst case scenario.***

This links to the individual needs of each child, parent, family and whānau. There is no one way to communicate or support a parent, but if a professional is able to develop trust quickly, they will be able to work out the approach of the individual parent.

***Services are dependent on the people who deliver them – if a key person changes – teacher, principal, therapist, education support worker, teacher aide – there can be substantial, upsetting, change for children and their parents.***

Parents talked of many people going in and out of their lives and were able to identify individuals who they felt really cared about them and their child. They often saw success at school as being dependent on particular individuals.

**“I’m not stumbling home. I have a clear picture of my life and his life... I didn’t think I’d be able to give up drinking because I loved it.”**

**“I had to bite the bullet and say I’m committing myself to my son. ... he teaches me every day now... That’s what I feel his purpose is now, cos he’s come along and has taught me patience and to overcome my own barriers.”**

**“I’m just one of those pragmatic people who wants to know everything, even if it’s bad, I want to know. I’ll deal with the emotions later, but I want the information first.”**

**“If you get to know us, you’ll get to know how the interaction could be.”**

**“That first psychologist, I really enjoyed working with her... I could see the passion in her... my opinions were valued.”**

One parent talked about the early success of her son at school, where there was a teacher who worked hard on his behalf. She left and her replacement was not as experienced. The parents felt their son's education was no longer going well at all.

*Services worked when they were proactive, practical and went across boundaries – from early childhood to school, housing and transport etc.*

**"It's all dependent on the individual people that work with them, the individual principal, individual teacher, individual teacher aide..."**

The relationship between the parents and their children, and the people who support them is paramount. Having one person or provider who is able to support the child and their parents consistently over time was seen as key – but not a common experience.

## The four groups of parents

As described on page 6, four groups of parents were identified through the analysis process. This was based on the parents' description of their experience and how they coped with the different challenges that came their way. This was then recorded on a small wellbeing tracker which was used to segment the groups.

### ROCKY START



This was the largest group. It comprised parents who found the time around diagnosis difficult, but then developed a positive outlook over time. Developing confidence in their parenting, having strong informal support, practical help and a focus on making decisions that would help their child were key. The tipping points for these parents are illustrated on page 18.

*Annie was admitted to hospital, three hours away from her home, when she was pregnant. Her baby was delivered early and she ended up staying for four months.*

*Annie has worked out what Leo enjoys and says she has learnt not to compare him with other children. Looking back she says it would have been easier if she had been told about Leo's diagnosis somewhere private, when her husband was there to support her.*

*Annie is confident about her parenting and is clear about her aspirations for her boy.*

**"The next minute there's a doctor giving me this form and that was it... I got to the third paragraph and I had to walk out and burst into tears. She [the pediatrician] left me to that."**

**"He's taught me a lot. To be patient... because I was never a patient person. .. It's just common sense. I grew up with all my sisters and their wee kids."**

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## POSITIVE



This comparatively small group didn't experience significant issues when their child was diagnosed, and maintained a positive outlook. Most had strong informal support from family and friends and formal support tended to be proactive and practical. These parents felt that they understood their child and they had aspirations for the future. Their children had a range of disabilities, some very complex - one family had three disabled children.

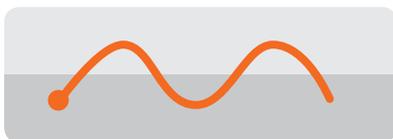
*Priya lives with her husband and two daughters, the youngest of whom has a visual impairment. Priya says she is a person who loves to google, and she came across a support group for her daughter's condition very quickly.*

*Priya's daughter receives ongoing practical support that is based on a series of agreed goals. She knows what is happening and when, and feels supported. She is already planning ahead for school and wants to set everything up before her daughter starts.*

**"I thought, oh my God, I can actually rely on a few people to tell me what I'm in for. I sent a message and that's how we got the ball rolling in terms of information collection and who else was there."**

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## UP AND DOWN



This group experienced a series of issues that influenced their wellbeing, but they were able to recover each time. Some had dealt with traumatic experiences, including the death of a supportive parent or a notification to CYF, but proactive support and aspiration for their children were key to them dealing with these issues. Family and practical support were essential to being able to get through difficult times.

Parents talk about having to advocate for their child, and although they experience frustrations with services and systems, they are able to see beyond these. Some have made a clear decision to look after their own wellbeing and others mentioned support from their workplace. For some parents, a strong connection to place and culture was key to managing some very challenging times.

*When her son was admitted to hospital with a serious illness, the social worker at the hospital put through a notification to CYF. Her Family Start support worker helped her to sort this out.*

**"He's my first child and I'm only young - I'm 18. I didn't know how to cope with it at all. I was just happy my mum was there to help me with it all."**

She then had further issues when “they cut me off the list [Family Start] because we had to go and bury my mum and we stayed down there for three to four months.”

The mother was then referred to a specialist disability provider by the pediatrician and was helped to find a place in a local kindy for her boy. They have also helped Mere and her family to find a house and they continue to provide support as needed.

**“I just want to be proud of who he is. I’m very proud of him. He’s a very bright child, very clever.”**

## STRUGGLING



There was a small group of parents who were exhausted, frustrated and angry. They felt nothing was going right for them and that they had to battle for everything. These parents talked about feelings of shame, fear for the future, not trusting others and lack of support from family or friends.

Vasa has two disabled children. Her husband works full time but “financially it’s like a forest we’re trying to find our way out of.” Both children were born with a rare, life threatening condition, but Vasa said she didn’t get any support until her oldest boy was eight.

Vasa worries about the future, “it’s gonna be hard. I don’t know what their future is, what they’re gonna do.”

When asked what would help, Vasa says she needs more of everything. She says she doesn’t have any good days.

**“I’m gonna fall down soon... I never have good days. I always have bad days... It’s really tiring thinking about the worst day coming and what it might be like.”**

## Statutory intervention

Several parents had experienced notifications to CYF<sup>3</sup>. In most cases this was caused by concerns about the child’s wellbeing (for example, failure to put on weight) and in one case by an argument with a nurse. The parent concerned had been in hospital with her child, away from her home, for several months. Her comment was that the CYF staff member was helpful but “nothing happened to the nurse.” One parent felt her age (16) led to the notification.

3. Now known as the Ministry for Vulnerable Children – Oranga Tamariki

## Asian parents

For some Asian parents (Chinese and Korean) there was an attitude of denial either by the parents themselves, or their extended family.

This can mean these parents receive little informal or formal help and can become very isolated.

**"My mother had the traditional Chinese thinking that if we tell each other about Lydia's situation, when she grows up she won't be able to get a job or a boyfriend."**

## Pasifika

Traditional Pasifika parents also experienced difficulty seeking help because of shame or fear. Parents, and those who support them, talked about the dominant role of the church and the place of men in the family, which led to decisions being made that isolated the mother. It was also noted that some parents felt unable to question doctors, and agreed with everything they were told, but didn't follow through. One father thought he was responsible for his child's disability because the genetic mutation came through the male side of the family. This caused relationship issues and took some months to sort.

These are complex issues that require understanding of culture and generational difference. More exploration of these issues and some co-creation with these communities could lead to the development of appropriate support and engagement.

**"I find my husband and his family – no one is accepting. Even now my husband is like 'he'll be fine.'"**

## Children

Many of the parents' children were not able to be interviewed because they weren't able to talk or were not at home. Given the sensitive nature of the interviews, this was encouraged. They enjoyed being with their families, school and playing. One young boy was having problems at school because of bullying – this had led to conflict and he had been stood down. The mother and grandmother felt they were getting little understanding from the school about this issue.

## *The co-design workshops*

Over 100 people were involved in co-design workshops and feedback sessions. Participants included pediatric and maternal mental health teams, parents and whānau, NGOs, early intervention support workers and professionals, social workers, school and staff from ministries of education and health staff. The approach used to create and develop ideas was first tested with the reference group before being taken out to the community.

The co-design workshops centred around the parent experience maps (see pages seven to 13), which were used to create an understanding of parents' pressure points and prompt ideas. Participants then chose the ideas they felt were most impactful and developed these.

A common thread was placing the child and their parents and whānau at the centre. This is not a new idea, but the ideas and solutions developed provide practical ideas that make this a reality. Some of the ideas appear small, but they address issues that are vitally important to parents and their impact has potential to reshape the system.

## *Ideas*

### **PRACTICAL SUPPORTS**

Respite – a range, choice, include family, in the home, on holiday, available in an emergency

Transition – early planning, good information flows, celebrate success, plan, give adequate support to child, family and support people.

Information all in one place so we don't have to keep telling our story

Trusted information – consistent, reliable, current, understandable

Coordinated appointments, easy to access, well-timed, necessary

Trusted key person – in the family or community or through a provider, not agency or role specific

### **FAMILY, WHĀNAU WELLBEING**

Culture of partnership

Empathy, listening, believing, free parking, user-friendly hours and locations

Among staff and agencies – staff care and retention, improved recruitment, across teams and sectors

Accountability to families, including better use of funding across sectors

Training – soft skills such as listening, “vulnerability lessons”

### **BUILDING COMMUNITY**

Building networks of multiple, trusting relationships – playgroups, online support

Building and valuing natural supports in families and communities

## Prototypes

Co-design workshop participants then chose the most powerful ideas and developed prototypes. They did this using tools such as Lego, drawing diagrams and writing scenarios. If time allowed these were presented to the whole group and discussed. Some weren't practical designs, but concepts, drawing out the child and family centred approach. It was acknowledged that this had been promoted for many years, but there was little commitment to it at a practical level.

The following are the prototypes developed – several at more than one workshop.

### A KEY PERSON

Each co-creation workshop developed a prototype based on this idea. Having someone parents trust, whose role can be developed according to need, rather than a prescriptive service response, was seen as integral to early parent-centred planning. For some parents this was a light-touch approach, with a family member supporting them through decision making. For other families it was a trusted person from an agency who was able to provide practical support across a range of issues including housing, transition, respite etc. A focus on building informal support and connecting to community is a vital part of this role.

This reflects the individual needs of each family which can be supported by a tight-loose-tight support approach. A tight focus on family-driven goals, flexibility in how these are supported and delivered and by whom, and a tight focus on accountability and outcomes based on the goals.

It also creates an opportunity for family and whānau to be included in meetings and appointments to lessen the onus on parents to try to repeat what they have been told, particularly if it's complicated or stressful.



## COORDINATION ACROSS SECTORS

Coordination at a national level, with government agencies working together, and at a local level, with services gathering around a family supporting co-created goals, was a strong theme. One group called for legislation that would require government departments to work together – and others developed ways this could be done at a local level through co-location, facilitators and/or key people, case management meetings and online information portals.

**“Our families are just dying and we fight over which bucket they belong to”**

## Training and support

A workforce development framework that included a building relational skills approach was identified as critical.

Parents supported approaches for schools, where teachers had a range of coping strategies, including professional development in practical skills such as managing behaviour and communication.

There was also a strong call for all staff to be recruited carefully and supported and supervised. This was a response to the flow of people in and out of parents' lives, and the disruption this caused. It was noted that some staff spent a lot of time out of their offices, but didn't have the equipment to respond to emails and calls quickly – one social worker's cellphone was so old she didn't bother taking it with her. To a parent trying to make contact this looks like the worker doesn't care.

**“Services should follow the child rather than being sliced and diced according to age, body parts, criteria/service. Government agencies are joined, with liaison roles, peer case reviews and relationships that focus on outcomes for families.”**

## Appointments

This was a focus of the workshops and there was excitement about the impact of making every appointment timely, necessary and of coordinating support across services.

This represented a shift in thinking about processes, to thinking about parents' lives and the pressures those processes can create – and the subsequent impact on the child. The task of juggling lots of appointments, transporting a potentially fragile child, finding and paying for parking, possibly taking time off work, only one parent being able to attend and catering for other children can be extremely difficult. The workshops came up with some very easy ideas that could be implemented quickly (for example asking if every appointment is necessary rather than automatically rebooking, or replacing a hospital-based appointment with a phone call).

**“We should focus on the right thing for each family and plan to achieve that, rather than appointment stats”**

## Parent-held information

In response to parents talking about continually repeating their story and having little control over their own information, groups came up with practical suggestions.

## Useful information

Parents often talked about using the internet to research their child's condition. Many expressed discomfort with the way information was presented to them at diagnosis. This was particularly concerning when they were given information that was negative, for example parents were not ready to see photographs of older children, particularly if they were extreme examples.

One suggestion to overcome this was a disability clearing house, much like the Family Violence Clearing House<sup>4</sup>. This acts as a hub for research and information and is managed by the University of Auckland. Another idea was to develop a list of links to useful sites that providers could suggest parents go to for more information, along with contacts for support groups.

**"The local medical centre has an online management system where information is fed in and you can make appointments. It could sit across all the different systems and everyone could work together to make it easier for families. It would feel like a virtual team. It could have a messaging service to remind families and we could see everything that was going on which would make professionals accountable. We could even work out carools for travelling to the city."**

## A change from looking for risk to supporting parents

The examples of CYF notifications led to some interesting discussions about the focus on risk. A group of social workers expressed concern that in recent years their work had focused on looking for problems, rather than understanding what was happening for parents, particularly in hospitals where parents often spent long periods of time.

4. <https://nzfvc.org.nz/>

# CONCLUSION

Over the years there has been a lot of consultation about special education and disability issues. This project wanted to go beyond just asking people what they thought, it set out to involve parents so they could make a contribution to the identification of issues and solutions. It wanted to acknowledge parents as experts.

The aim was to spend time with people who weren't always included in consultation rounds because they were isolated or busy, or because they didn't see this process as truly listening to their experiences and stories. It takes time and intent to hear people's stories, to work through them and see the patterns that create a larger picture. Sitting in people's houses, seeing the environment that they lived in, their children's toys and equipment, the photos on the wall, the lists on the fridge, the whānau coming and going, gave an insight into lives that is absent in a survey or a meeting in a local office.

As each transcript was analysed, the team worked hard to understand the essence of the parents' lives. Reading through the transcripts brought the people interviewed into the room. Time was taken to summarise, discuss, check, rewrite, group, critique, regroup, look for patterns, check again and again. It was a highly iterative process where eventually parent wellbeing was identified as the clue to understanding where the pressure points and opportunities lay.

This is not formal research, it is a design process that begins with understanding and ends with a series of insights and ideas that can be brought into the system transformation process currently underway across the social sector. It puts the voices of parents at the centre.

Parents weren't just asked to tell their story, they were invited to be part of the next stage of developing ideas and solutions. The design sessions we had with parents and the people who supported them were rich in ideas, some very practical (free car parking) and some larger (designing systems that talk to each other). There was energy and optimism as people went through the journey maps and saw opportunities.

Some of the design sessions were large, with groups drawing system maps, others were small and informal and over a cup of tea. The parents' stories and journey maps inspired them all to think differently and to play with new ideas.

The next step is to take these stories and ideas into the system redevelopment process, to keep the people who are most affected by change at the centre. Central to this are the key insights: Relationships are key, proactive and practical cross-boundary support is best, everyone is different and has different needs, and services are dependent on the people who deliver them.

*E tu kahikatea, hei wakapae uroroa.  
Awhi mai, awhi atu, tatou, tatou e.*

Kahikatea stand together; their roots intertwine, strengthening each other.



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