

A GOOD START IN LIFE

PRACTICE GUIDANCE

This guidance is about whānau, community and services working together to ensure children with disabilities get a good start in life.

*HE WAKA EKE NOA
WE ARE ALL IN THIS TOGETHER*

Whānau

Services



Table of Contents

Section 1: Introduction and overview	1
1.1 A Good Start in Life	1
1.2 GSIL practice guidance	1
1.3 Terminology	2
1.4 Context	2
1.5 Taking the journey together	3
1.6 How can this guidance be used?	3
Section 2: Signposts for whānau	4
2.1 Looking back on my start in life – Martine Abel-Williamson	4
2.2 GSIL parents' voices	5
2.3 Key messages	5
2.4 Services work when ...	6
2.5 Questions for whānau and services to ask early on	6
2.6 Parents supporting parents: parent led peer to peer networks	7
2.7 What works	8
2.8 Key messages from parents for parents	9
2.9 Some stories from the community ...	11
Section 3: Signposts for services	13
3.1 Why do we need common practice guidance?	13
3.2 What are the services and shifts that are needed?	13
3.3 What are the key practice change themes?	14
3.4 Creating the platform for practice changes	14
3.5 What do the practice themes mean?	15
3.6 Describing the practice change themes	16
Section 4: Stories of change	20
4.1 Story 1: Find me	20
4.2 Story 2: Becoming family centred	22
Section 5: Appendices	23
Appendix 1: A Good Start in Life (GSIL) project information	23
Appendix 2: Enabling Good Lives (EGL) principles	24
Appendix 3: References	25

SECTION 1:

Introduction and overview

1.1 A Good Start in Life

New Zealand is working towards being the best place in the world for children, a place where all children are loved, nurtured and safe; have what they need; belong, contribute and are valued; are happy and healthy; and are learning and developing¹. This guide focuses on children from birth to eight years.

How we see disabled children is important. Making New Zealand the best place in the world for disabled children requires consideration of children's rights both as children and as people with disability (See Appendix 2).

This guidance from the Good Start in Life Project (GSIL) is about whānau, community and services working together to realise children's rights and to make sure they get a good start in life.

The GSIL project used co-design approaches to capture the voices and experiences of families and whānau of disabled children and the services that support them (see Appendix 1). Research and latest thinking have also been used to gain an understanding of a good start in life for young disabled children and their whānau.

For all children, including those with disabilities "...meaningful participation is the engine of development and the key to attaining a true sense of belonging and a satisfactory quality of life."²

1.2 GSIL practice guidance

This guidance provides a common foundation to be used across services and whānau. It is intentionally broad so it can be applied in many settings and reflect the wide range of children and whānau³. This guidance lets families know what they can expect from services and informs practice across a broad range of services. It can be used to strengthen and inform existing and future models, standards/guidelines and policy. **A key focus of this guidance is about enabling children and young people and their families and whānau to be in the 'driving seat' to be able to achieve their goals and aspirations.**

Use this guidance to ensure disabled babies and young children:

- » participate fully in family and community life
- » have services and supports that are culturally responsive
- » have their needs identified and responded to in a functional, holistic, strength based and timely way
- » have access to support and systems that are flexible, comprehensive, coordinated, efficient and equitable.

1 Child and Youth Wellbeing Strategy, <http://childyouthwellbeing.govt.nz/>

2 Moore, T., 2012.

3 The guidance is not intended to be specific to service, need (type or level), services type (government, non-government, paid or voluntary).

1.3 Terminology

In this guidance

- » **Whānau:** refers to parents, families, caregivers and whānau and acknowledges that each whānau is unique and different.
- » **Children:** refers to babies and young children from birth to eight years. Young children are indivisible from their whānau. They live their lives, learn, play, and grow within the context of their families and whānau. They also engage beyond their families and whānau for example:
 - › attending their local early childhood service and school with friends
 - › being involved in community activities and
 - › using health and disability services.
- » **Services:** refers to all those who provide support or services for children and their whānau⁴. This guidance is for every service working with children, not just disability services, because every service should be effective in working with disabled children.
- » **Disabled children and young people:** refers to children from birth to eight years and beyond with a disability. There are many words and terms that are used to identify disability. The way these are understood differs. For some, the term 'disabled people' is a source of pride, identity and recognition that disabling barriers exist within society and not with us as individuals. For others, the term 'people with disability' has the same meaning and is important to those who want to be recognised as a person before their disability. The term disabled children and young people is used based upon advice provided by the NZ Office of Disability Issues (ODI) and in line with the NZ Disability Strategy (2016-2026)⁵.

1.4 Context

GSIL and this guidance are informed by national and international obligations including:

- » the Treaty of Waitangi including the principles of self-determination, protection of rights, and partnership
- » the United Nations Convention of the Rights of Person's with a Disability (UNCRPD) and the United Nations Convention on the Rights of the Child⁶
- » the New Zealand Disability Strategy and Disability Action Plan
- » the Enabling Good Lives principles to inform the long term direction of change. The principles and how these apply to disabled children and their whānau are listed in Appendix 2.

1.5 Rights and Obligations

How we see disabled children is important. Disabled children are part of the community of all children; they have rights as children and as people with disabilities. Realising these rights means working together to make sure disabled children:

- » enjoy their rights and freedoms on an equal basis with other children
- » have the accommodations and supports they need for a good childhood, as people with disabilities.

4 Including early intervention services, child development services, paediatric services, disability support services, Tamariki ora well-child services, Whānau ora, non government organisations, ACC, and Oranga Tamariki.

5 New Zealand Disability Strategy, 2016-2026

6 United Nations Convention on the Rights of Persons with Disabilities (CRPD)

Some of the rights disabled children have are the rights to:

- » enjoy a good life without discrimination
- » have their best interests guide decision-making
- » grow and develop into the person they are meant to be
- » have their views taken into account
- » receive the support they need to participate equally in society
- » grow up in a family environment, as far as possible, knowing and being cared for by their parents
- » be part of their community
- » be safe
- » be healthy
- » learn and play
- » have their privacy, culture and identity respected.

1.6 Taking the journey together

This practice guidance aims to help families and whānau journey together with services, so that disabled children have a good start in life. The metaphor of a two-lane highway is used in this guidance because, just as on a highway where vehicles are travelling the same route and direction, whānau and services each take children forward. While each has a different role, or lane, each makes an essential contribution to ensure travel in an agreed direction, for a good start.

Changes and improvements across services are needed, so that disabled children, and their families and whānau, have what they need to be the drivers and navigators of their own journey.

Extending this metaphor, a third lane can be considered. Along with whānau and providers, community is also an important contributor to supporting disabled children and their whānau to have a good life.

The following sections provide GSIL key themes or signposts to drive changes and service improvements.

1.7 How can this guidance be used?**Whānau**

For whānau it sets the expectation of a good start and provides information about how this can be supported.

Services

The intent is that a wide range of services will use the guidance to:

- » support continuous improvement through self-review and planning at an individual and service level
- » develop stronger partnerships with families and whānau
- » provide pathways to enable stronger integration across services and providers
- » guide professional learning and development, and to initiate and support professional practice conversations
- » inform the development of other practice standards and guidelines and examples of practice change.

SECTION 2:

Signposts for whānau

FOR WHĀNAU

Whānau

2.1 Looking back on my start in life – Martine Abel-Williamson

“Life is what happens when we’ve planned something else” – I’m sure, Estelle, my mum, realised that soon enough, especially when I got diagnosed as blind with a very negative prognosis at the age of 6 months. Because most in the medical profession focused on a cure rather than a holistic approach around a future quality of life, the prognosis was given in a very solemn tone as if it’s going to be the end of the world for her and me both.

Estelle soon decided though that she’s not going to let the opinions of others influence how she raises me. I grew up with scrapes and bumps and a lot of blood flowing in the process. She believed that I should learn by mistakes just like other kids (otherwise, how else would I adjust in this world), so, as a totally blind child, I climbed trees, swam in creeks and basically did what our neighbourhood kids did, alongside them.

And, when I started to learn braille at the age of five, she decided to teach herself braille so that she could read my writing and correspond with me. Her little notes made my life as a young child. In that way I wasn’t made to feel different to other kids and I know it couldn’t have been easy for her.

Then, she never talked down my aspirations and dreams. I remember vividly, telling her, at the age of five, that I’m going to become a vet when I grow up, as I wanted to treat sick animals. She just said, that’s fine. Maybe, internally she thought to herself, “how do I keep things realistic”, but her not limiting my expressed goals at that early stage, allowed me to think the world’s my oyster and that I can become what I want to. In the end I did study psychology and rehabilitation, so, working with people as a end goal, might not have been that far off from working with animals in the end!

She then made it a point to find out what might be in store for me as an adult, so, she looked into what other blind adults became, as in employment-wise. Finding role models that she could remind herself of, was vital. She knew that having peer to peer support with parents with similarly aged children is fine but, to really enable her to think ahead, even when I was still not even 8 years old, she’d need to become inspired with and reminded by adult role models, so that her expectations of me, whether high or low or somewhere in the middle, wouldn’t stifle my development.

2.2 GSIL parents voices

Whānau interviewed in the GSIL project described different stages in their journey such as: finding out, the toddler stage, starting preschool, and starting school. They said:

- » they are proud of their children and that their children bring them joy
- » they want to feel listened to and not judged.

2.3 Key messages

- » Whānau know their child best and are the expert on their child. They are powerful agents for change.
- » Every child and family is unique and services need to be based on individual needs and circumstances. There is no one way to support whānau.
- » Early experience, including at the time of diagnosis, stays with whānau and can impact on the future.
- » Having and maintaining a range support is important, such as for example, family and friends, community, whānau, online forums and support groups.
- » Relationships and mutually respectful partnerships and accountability lead to the best outcomes.
- » Whānau and services need to build trust, understanding and capacity together to achieve agreed outcomes.

2.4 Services work when:

- » they engage and work in ways that fit the whānau. This means working in ways that respect and reflect the whānau's identity, language, values and culture.
- » processes work for whānau. Actions and appointments are timely, necessary, coordinated, and responsive, including place, time, day of the week, so the right people can be present. Services go to the child and whānau wherever possible. Transport and parking needs to be accessible, including the cost.
- » a key person who is trusted by whānau is identified. Their role will vary according to need but building informal support and connecting to community is a vital part of the role.
- » service providers think about the lives and pressures of the whānau. They negotiate an approach that will work for each family, (not 'one size fits all' rules and processes).
- » whānau have control over their information and they develop or contribute to the information to be shared so they don't continually have to repeat their story.
- » services are coordinated within and across sectors, gathering around the whānau and working together to support the goals and aspirations of the family.
- » services go across boundaries and transitions such as from home to early childhood, between health and education, from early childhood to school. Things that impact on families like wellbeing and health, housing, finances and transport are considered.
- » changes in key people are kept to a minimum.
- » everyone understands a good start is not just about services. Informal supports and small practical things can make a big difference, like moving closer to whānau, finding a support group, getting some help at home, finding the right information.

Each child, each whānau is different. They all have different goals and aspirations, identity, languages and cultures, resources, strengths, attitudes, experience, skills, environments and social connections

(Co-designing with parents).⁷

2.5 Questions for whānau and services to ask early on

1. What does a good life look like for my/your child and family?
2. What is important for my/your child and family?
3. Who are my/your family supports and networks and how do/can they help?
4. What else would be helpful?
5. How can providers help my/your child and family?
6. What will make the biggest difference for my/your child and family?

2.6 Parents supporting parents: parent led peer to peer networks

In the GSIL project whānau told us how important and effective peer to peer support could be. Through everyday experiences, parents develop knowledge and expertise in many different areas. By sharing this knowledge and expertise, families and whānau can support others.

It is good to use informal supports instead of formal supports wherever possible, if this works for the family and whānau.⁸

Parents said that parents supporting parents:

- » provides opportunities for emotional support
- » provides opportunities for development of knowledge and skills for parenting a disabled child
- » provides a sense of belonging
- » reduces isolation.

Common types of parent-to-parent support include:

- » informal relationship between two or more parents
- » specific programs that match parents, based on specific criteria
- » parent registries that include the names of parents who have volunteered to be resource parents or contacts
- » parent groups that are either parent led or service provider led.⁹

“We can’t begin to tell you about all the questions we had after the diagnosis. So much of it we had to find out ourselves. We were both afraid of the future and didn’t know how we would cope. Then we met another family who shared their experiences with us and we realized we could do it and we weren’t alone”

(Parent to Parent support sheet Can Child).¹⁰

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

(Co-designing with parents).¹¹

8 McWilliams, R.A., 2010, Routines-based early intervention.

9 Law, M., Rosenbaum, P., King, G., King, S., Burke-Gaffney, J., Moning-Szkut, T., Kertoy, M., Pollock, N., Viscardis, L., & Teplicky, R., 2003.

10 Law, M., Rosenbaum, P., King, G., King, S., Burke-Gaffney, J., Moning-Szkut, T., Kertoy, M., Pollock, N., Viscardis, L., & Teplicky, R., 2003.

11 GSIL, Co-designing with Parents. Connect & Co, 2017.

Peer to peer networks often provide the platform for families and whānau to create their own community to get the help they need and build their own networks. Below is an example of how a peer network has evolved to create their own community.

Families Empowering Families is a peer network that has been incubated by the McKenzie Centre in Hamilton. We welcome families of children with disabilities to join our FaceBook group.

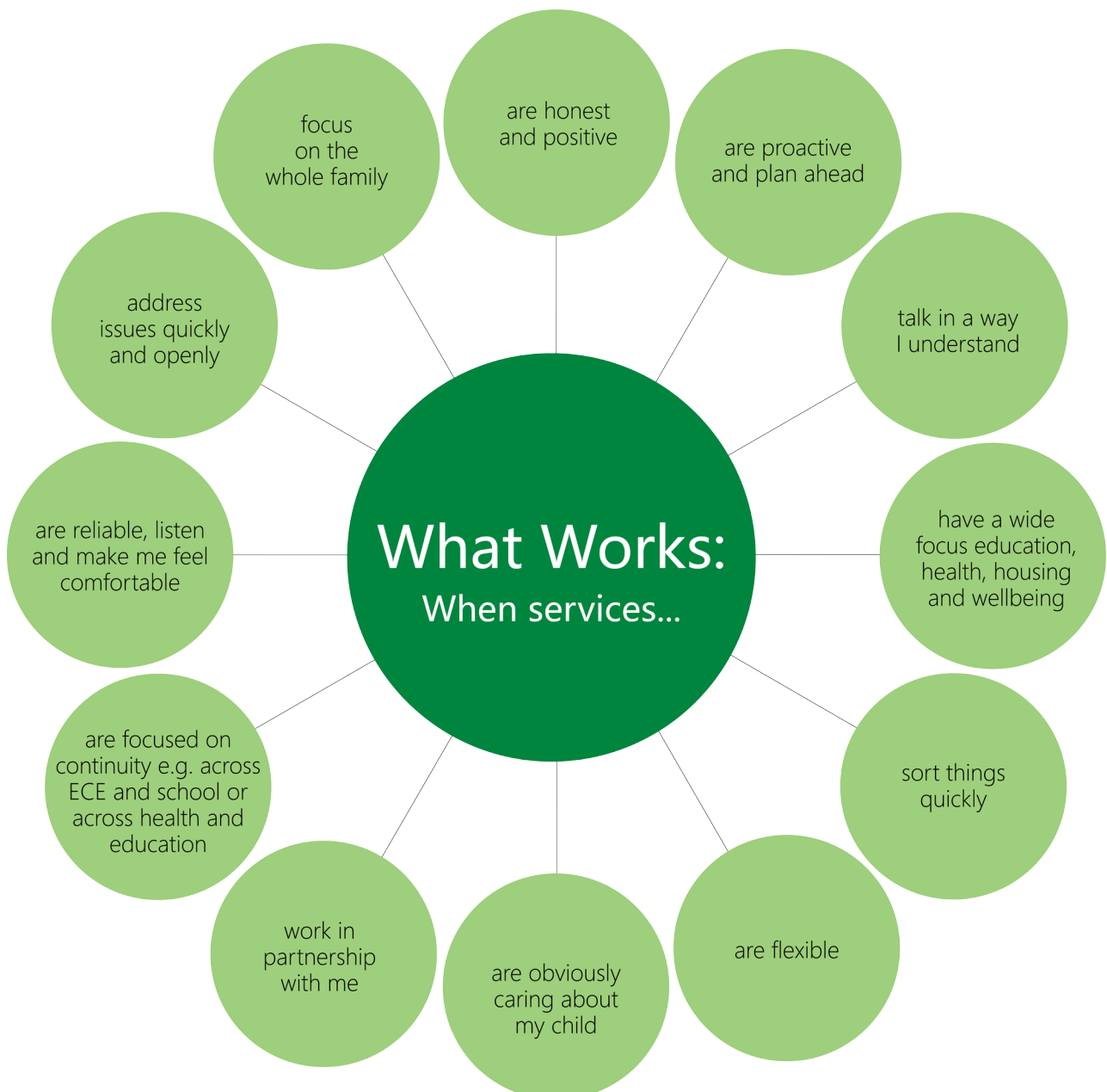
Our group uses the wide range of means available to us to support each other - including face to face opportunities, workshops, information sharing, and social media.

As parents we have learnt that having a network where we are able to share lived experiences and support each other can:

- › build strength between families, which is important for developing an ongoing support structure
- › create a sense of belonging, when so often having a child with a disability can feel quite isolating
- › build a network to provide education and share ideas to help our children
- › create a group with a shared goal to change the way people see disability and to make the world a more inclusive place
- › provide a parent voice to the sector and decision makers.

2.7 What works

While the journey for each whānau is different, there was consistency about what worked for whānau who were interviewed as part of the GSIL project.



2.8 Key messages from parents for parents

These messages below were written by and for parents who graduated from the Now and Next programme at Plumtree Children's Services¹²

The best partnerships...	<ul style="list-style-type: none"> » have the best interests of our children at their heart » are firmly child and family centred, reflecting the strengths and needs of our children and their families » respect the unique expertise that we, as parents, have as our children's frontline educators » equally respect the knowledge and guidance that professionals offer to us and to our children » are based on open, honest, and respectful communication between parents, professionals, and children so that relationships are safe, collaborative and supportive for all parties, and recognise the expectations required of parents, professionals, and children, to achieve the most positive outcomes for our children.
The best relationships develop when...	<ul style="list-style-type: none"> » parents and services together agree upon the most meaningful goals for our children » goals are measurable, achievable, and relevant to us as unique individuals » we plan together the strategies and processes we will use to implement and achieve our child and family goals » we agree on how we will together evaluate our progress » professionals support the capacity of our families to implement strategies in the natural settings of our homes and communities » the whole family is empowered to support the achievement of our children's and families' goals.
Our children need professionals who...	<ul style="list-style-type: none"> » see our children as children, and not as their disability or diagnosis » are empathetic, understanding and passionate » are flexible, supportive, child centred in their interactions » develop a personal relationship with our children directly » develop sessions that are as enjoyable, fun, engaging, relevant and meaningful to our children to our children as is possible » relate to our children within the frame of their individual interests and strengths.
We have responsibility to...	<ul style="list-style-type: none"> » be the most powerful agents for change for our children » believe in our own agency as the experts in our children, and embrace our experiences and wisdom as valued and valuable » share our expertise with our service partners to achieve the best outcomes for our children » be confident leaders in relationships with services providers because of the unique insight we offer » engage in self education and self knowledge so that we can continue to be active and informed leaders in our partnerships » share our knowledge and expertise with other parents, so that we can build a strong network of educated and empowered parent leaders who have confidence in their own self-worth and competency.

¹² The above Parent-Professional Relationship Statement was formulated during the Now and Next conference, April 2017 and collated by Dr Melanie Heyworth, a mother and researcher who graduated from the Now and Next programme. <https://plumtree.org.au/the-parent-professional-relationship-statement> Plumtree is an Australian not-for-profit organisation that provides support for young children aged birth to 8 years old with a developmental delay or disability and their families

2.9 Some stories from the community ...

Having 'ordinary life outcomes' and 'mainstream first' are two of the Enabling Good Lives Principles (EGL) that encourage whānau to live and participate alongside other whānau in their community. Using and creating a range of natural supports within the community can enhance the opportunities for families and whānau to authentically attain these outcomes.

The stories of change below are some examples of families, whānau and people in the community working together.

Story One: Swimming Lessons for Ayla

I asked about swimming lessons for my daughter at the swim school my other children attend. They seemed very unsure and reluctant. They were hesitant because they didn't know how it would work and what the assigned instructor would think, my child was older and bigger than the other children, she would need an adult in the pool with her and the price of individual lessons for a child who cannot yet blow bubbles or kick was a barrier for me. It sounded too difficult and I ended up feeling silly for asking.

A while later I tried again, approaching a different swimming instructor. The response was completely different. They had no hesitations, in fact they felt lucky to have the opportunity to help my daughter learn water safety skills and they welcomed the challenge as something new, exciting and meaningful.

Story Two: Parents utilising the local gym

We're just three mums trying to achieve more than what is available by the system for our children and others by filling a gap. Our children all have severe physical challenges and upon talking found that our main issue was that the services offered didn't go far enough and that we individually had to go, even as far as Australia in one instance for a 3 week intensive physio course, to get what was needed for our children to maintain their current function or improve it with the right assistance. So we identified a gap and are now working to encourage the system to work with us to meet the needs of our children and others in the community.

We are at the planning stage but have already managed to secure a local gym who are happy to provide space and training for a nominal fee, spoken with Hospital Physios who will provide the knowledge and training for the gym instructors, made plans and identified what is needed to support the goals identified and fund what equipment is needed with parents already discussing ways to utilise home equipment or improving purchasing power for 1st or 2nd hand specialist equipment.

There's much going on behind the scenes that I haven't told you about here in this short story but for us, the message is clear; There's a gap that needs to be filled and we parents can do it. We feel much more empowered and hopeful for our children's futures and feel that the ball is more in our hands rather than having to put up with what is available.

Story Three: Parents working with the local council

Wow, who knew that so much was already available in our public parks in Palmy North! A group of parents got together to think about what was lacking in their lives and communities for their children with disabilities and safe play areas was identified as a big one. So I arranged to speak to council staff to discuss this. He was amazingly receptive, offered to take some of the families available around to show what already existed and get feedback on the design and building of the latest park to be upgraded. It was so positive to know that we weren't going to have to be pushing hard for this to happen and that we would be encouraged to give input.

We did the tour and were shocked by how little was known about what was available already in our community but really wanted to have so much more in one place for all to see and appreciate. Memorial Park is now being upgraded with the input of families and their children. Level, graded playing areas for all so that children in wheelchairs can join in with the group instead of being separated, appropriate fencing so that all children can play in relative safety and family/caregivers can relax about their children not being able to run away or into danger, changing facilities that can be used by those with needs beyond their physical years being considered are just some of the things we look forward to experiencing in the new year. Thanks so much Palmerston North City Council for enabling us to contribute positively for the good of all those families in our community.

SECTION 3:

Signposts for services

FOR SERVICES

Services

“Some stories enhance life, others degrade it so we must be careful about the stories we tell and about the ways we define ourselves and other people”

Burton Blatt (1987)¹³.

3.1 Why do we need common practice guidance?

There is a need to drive changes and service improvements across all services to:

- » create a shared language and understanding of our work across services and agencies
- » communicate and work in new ways to bring about change
- » create a shared understanding about what working in true partnership with each other and with whānau means and looks like
- » develop communities of practice within and between services that draws on the ‘best of evidence of evidence based practice, which when it is connected to locally grown expertise, enables sustainable and effective services’¹⁴
- » improve the integration of services and support within and between agencies to reduce the fragmentation and complexity for whānau.

3.2 What are the service shifts that are needed?

Research indicates the types of shifts that are needed in services for disabled children and their families.

- » **Value family centred services:** Go beyond supporting families to family centred services and family wellbeing as the primary goal of all services and programmes. Evidence shows family centred services result in positive impacts on parental wellbeing, reduce family stress and increase satisfaction with services.
- » **Move beyond diagnosis:** Go beyond the traditional notions of disability to think of responding to the full diversity of human ability.
- » **Shift our philosophy from fixing to support for function and participation:** Go beyond remediation and treatment to build on child and family strengths, abilities and goals to increase opportunities for meaningful engagement in everyday life.
- » **Create environments that enable and nurture:** Go beyond traditional notions of discrete programmes to creating everyday environments that are able to cater for the individual and collective needs of all children and families. For disabled children this means focusing on fitness, function, friends, fun, family and future.¹⁵

¹³ Blatt, B (1987) cited in O'Brien, J, & Mount, B, (1991), Telling new stories: The search for capacity among people with severe handicaps. In L.H. Meyer, C.A. Peck & L. Brown (Eds.) Critical Issues in the Lives of People with Severe Disabilities. p.89.

¹⁴ A Good Start in Life: Summary Report, 2018, What it Takes, p.4

¹⁵ Rosenbaun, P, (2018). Changing policy thinking around childhood disability. <http://policyoptions.irpp.org/magazines/august-2018/changing-policy-thinking-around-childhood-disability/>

3.3 What are the key practice change themes?

This guidance is organised around four key interconnected practice change themes. These themes are underpinned by current evidence from families and whānau, evidence from professionals and services, and evidence from the literature.

The key practice changes are:

1. Family and whānau centred and culturally responsive practices
2. Inclusive and participatory practices
3. Integrated supports and partnership practices
4. Continuous improvement and evidence informed practices.

Each theme is described below. Examples of 'good practice' are provided as practice shifts describing what we are wanting to move **from** and what we are wanting to move **towards**.

3.4 Creating the platform for practice changes

Shifting practices will require deliberate and planned approaches to ensure that staff are able to see themselves in this change process, to build upon their specialist practices, skills and knowledge and also create the deliberate opportunities for new learning.

Practice is a shared history of learning. Practice is conversational. Coming together as people who share a concern or passion for something they do and to learn to it better will lead to growth for ourselves, for others and for our organisation.¹⁶

Professionals and programmes seeking to be family centred must not only establish a trusting relationship with families, they must also continuously use specific strategies that equalise the balance of power such that families become the ultimate decision makers and agents of change.¹⁷

¹⁶ Wenger, E., McDermott, R., & Snyder, W., 2002

¹⁷ Espe-Sherwindt, 2008, p.139

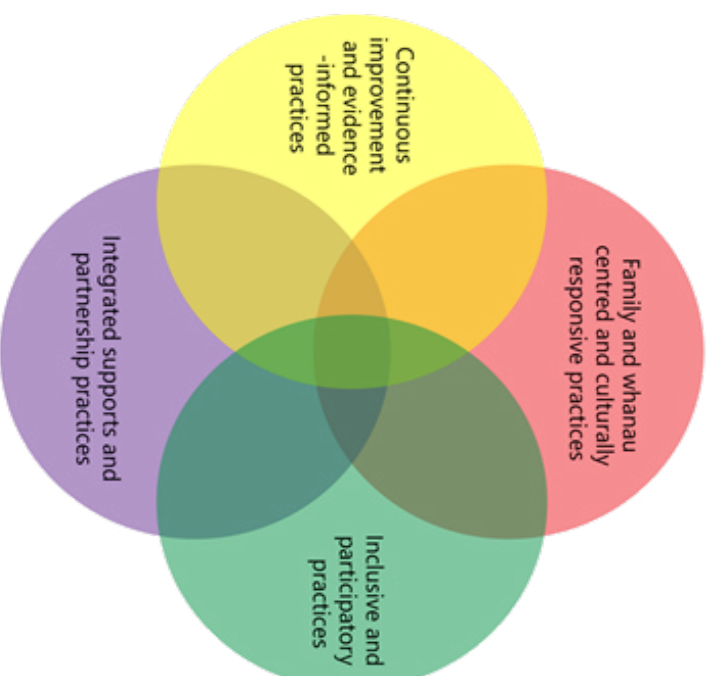
3.5 What do the practice themes mean?

Family and whānau centred and culturally responsive practices means...

- » A way of thinking and acting that ensures families, whānau and professionals work in partnership - with family life priorities and aspirations driving what happens^{23,24}
- » Families feel welcome when professionals respect and acknowledge their unique identity, culture and language.
- » Recognises that each family is unique, and the constant in their child's life and that they are the experts on their child's abilities and needs²⁸
- » Understanding that working in partnership is an integral part of the work we do and involves a set of skills and personal characteristics that we need to work at deliberately.
- » Building upon and enabling family and whānau strengths and networks, with acknowledgement that families are the primary influence on children's learning and development.

Continuous improvement and evidence informed practices means ...

- » Evidence is drawn from multiple sources i.e. experience, skills, knowledge of families/ whānau and professionals and current literature and research.
- » Māori frameworks are used to guide working with whānau e.g. whānau rangatiratanga
- » Human Rights and Disability legislation and conventions are reflected in practice, processes and policies.
- » Continuous improvement systems and practices are in place to ensure ongoing quality of serves and support.
- » There is a focus on outcomes that measure participation in meaningful activities and routines at home and in the community, with mechanisms in place to measure these outcomes.
- » Services have an emphasis on providing timely, accessible and equitable services and support.



Inclusive and participatory practices means....

- » The child participates fully and meaningfully in all aspects of their life (family and community).
- » The child has the choices, opportunities and experiences available to all children.
- » The child's views, preferences and aspirations are central to all decision-making.
- » The child's role and contribution must be valued by all involved in a child's life, so participation is meaningful.
- » Participation in everyday environments and routines is vital to the health, development and quality of life of all children.
- » Learning occurs through meaningful participation in a variety of enjoyable activities and through everyday routines.

Integrated supports and partnership practices means

- » The team around the child focuses on shared goals driven by families; where families, whānau and professionals work together as a collective, with families the final decision makers.
- » Services value collaboration and working in partnership with families and whānau as a way of working to provide seamless services, with one team member identified as a 'key worker' to be main person working with the family and whānau and to co-ordinate other supports.
- » A flexible teamwork model that is easily understandable and identifiable for families and whānau, and all the key people in a young child's life.
- » The focus of services is on a building family and whānau capacity and capability - supporting and enabling the team around the child.
- » Services work together to provide integrated support for young children their families and whānau.
- » There is a balance of power, with families and whānau involved in decisions, with the quality of the relationship being directly linked to good outcomes for whānau as it enables the right expertise to be applied at the right time.

3.6 Describing the practice change themes

The following section identifies the shifts in practice that will be needed and the practices that we need to move from and towards.

Family and whānau centred and culturally responsive practices

Uehara taku toa I te toa takitahi engari he toa takitini – I come not with my own strengths but bring with me the gifts, talents and strengths of my family, tribe and ancestors.¹⁸

'It was like being the CEO of a big company, not really knowing what everyone does but hoping it's alright. It was a full time job co-ordinating all the appointments and making sure we were home or in the right place... Sometimes I would pretend I knew who they were, it was awful, they were really nice... but I never really knew if it was all any good for Jack'. (GSIL Parent interview)¹⁹

In practice this looks like moving...

from family allied

- » Professionals view families as being able to implement interventions, but needs and goals are identified by the professionals
- » Families rely on professionals to be the main decision makers
- » Families' unique culture, language and identify are not considered or valued.



to family centred/led

- » Shift in focus to family capacity building - where families are confident in leading their own planning and decision-making
- » Environments are welcoming and culturally inclusive, with staff respectful of and knowledgeable about diversity.
- » Equal and respectful partnerships and relationships, that are open, non-judgemental and are responsive to the uniqueness of each family
- » Participatory and relational practice that honours family and whānau choice, control and involvement
- » Facilitated opportunities for parents to support families and whānau through formal and informal parent to parent networks
- » All families and whānau receive support that honours and reflects their culture
- » Strength based practice, where there is a focus on what the child can do and has emerging ability to do, and on the opportunities to develop these abilities in a range of contexts.

¹⁸ Te Whariki, NZ Early Childhood Curriculum, 2017, p.12.

¹⁹ A Good Start In Life, 2018.

Inclusive and participatory practices

'Participation is one of the three defining features of inclusion in early childhood settings.... and this means 'using a range of instructional approaches to promote engagement in play and learning activities, and a sense of belonging for every child'.²⁰

...all children will be empowered to learn with and alongside others by engaging in experience that have meaning for them. This requires kaiako to actively respond to the strengths, interests, abilities and needs of each child, and at times to provide them with additional support in relation to learning, behaviour, development or communication.²¹

In practice this looks like moving...

from a focus on fixing and fitting in

- » Focus is on the child fitting in with existing structures activities
- » The focus is on fixing the disability
- » Activities are focused on skill deficits, with limited emphasis on functional participation and using natural routines and environments
- » Sessions or activities focus more on individual skill development in isolation from other children, families or naturally occurring activities.
- » The child's abilities are assessed using normal developmental scales to identify deficits.



to belonging, active participation and accommodating need

- » All activities and experiences focus on enabling belonging and active participation
- » There is an understanding of what makes the biggest difference for children: function, family, friends, fun, future, fitness
- » Emphasis is on adapting the environment to meet a young child's needs rather than expecting the child to 'fit in'
- » The focus is on functional and participatory activities within the child's environments
- » The child and family's everyday routines drive the context for goal settings
- » Learning activities are based upon what the child and family like to do in natural setting, which builds on their strengths and interests.

²⁰ Moore, T, 2010, p.7-8

²¹ Te Whariki, p.12

Integrated supports and partnership practices

If practitioners have a shared framework for building partnerships with whānau, and across their teams and networks, more effective and sustainable parent – directed help will result. Positive outcomes result where the notion of partnership and the importance of the whānau contribution to the work is understood, explicitly acknowledged and facilitated through the support network.²²

The fragmentation of services is particularly problematic for families of preschool age children as there is no one universal service that all families access.²³

Working towards a more integrated approach to services for children and young people requires a strong commitment across agencies to working collaboratively, and having shared culture, vision, values, resources and importantly, shared principles that underpin this approach.²⁴

In practice this looks like moving...

from multiple assessments and multiple professionals

- » Multiple assessments with goals from a range of disciplines
- » Goals driven by professional expertise
- » Agencies and professionals working more in their own area of expertise i.e. more siloed
- » Focus is on 'fixing' or treating individual needs
- » Approach is more expert focussed.



to having one shared plan and coordinated support

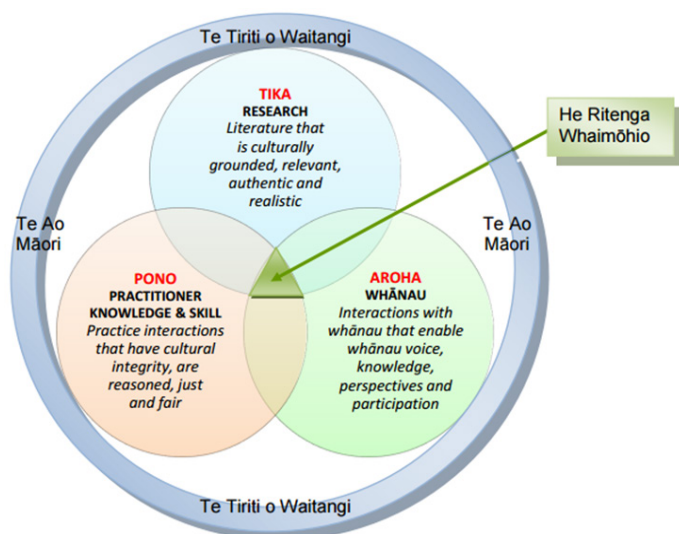
- » Sharing of knowledge across disciplines is valued and supported
- » One plan of support
- » A key worker or lead worker model is used to co-ordinate information, services and supports
- » Agencies working in a joined up way to provide a seamless approach for families – sharing their knowledge and expertise with each other and with families
- » Common approaches to assessment – moving away from multiple assessments
- » Coaching / adult learning approaches and strategies are used to deliberately build and enhance family capabilities
- » Recognises and further enhances capabilities of families
- » Staff are skilled in building and enabling leadership capabilities of families and whānau, and of other professionals.

22 A Good Start in Life; Summary Report, 2018

23 Moore, T, 2010

24 Keast, 2008

Continuous improvement and evidence informed practice



He Ritenga Whaimōhio (Macfarlane, 2011) is an evidence based framework that reflects three concepts highly regarded by Māori: Tika (right, true, correct), Pono (fair, just, honest) and aroha (care, compassion, love). Te ao Māori and Te Tiriti o Waitangi surround the 'kete' reminding us of the importance of Māori worldview perspectives and the three Treaty principles of partnership, protection and participation.²⁵

In practice this looks like moving...

from a focus on outputs

- » Output focused
- » Rigid thinking which limits innovation
- » Thinking that the same strategies and approaches that have always been used will always be effective.
- » Thinking that increased interventions will result in improved outcomes



to a focus on outcomes and continuous improvement

- » Outcomes focused
- » A continuous improvement approach underpins practice
- » Evidence is used to guide decision making
- » Staff are knowledgeable of current evidence in their practice
- » Evidence from three perspectives (family/ whānau, professionals and literature) is used to guide decision making
- » Opportunities to create and share own evidence through a range of forums
- » Practice decisions are based on continuous assessment and progress data
- » Reflective practice is evident through a range of informal and formal review processes
- » Innovations are encouraged and tested
- » Knowledge of key legislation and conventions guides practice.

SECTION 4: Stories of change

4.1 Story 1: Find me

About two years ago we picked up the first signs that our second child Omar who was then 2+ years old had difficulties in social interaction and speech. We decided to enrol him into a kindergarten, keeping him at home was not adding any benefit and also the fact that we usually interact in 2-3 languages at home was probably not helping him much either. Oh! First let me first introduce myself, my name is Mohammed and my whānau consist of my wife and 3 amazing children. We have chosen the beautiful Aotearoa as our home for the past decade.

Starting Omar at the kindergarten was a challenge as everything was new and change is something he resisted very much. He did take some time before he settled down but we knew we were against some more challenges. Making friends was one of his weakest strengths, so he was alone and would play by himself and find it hard to follow instructions.



His involvement in any activity was marginal or non-existent at times. But during the same period a series of changes happened for our family that made a difference for Omar. I believe the best part was that we associated with McKenzie Centre an early intervention centre based in Hamilton where we received individual care support. We were one of the first pilot families to be enrolled in the Now & Next programme, which helps to develop positive outcomes for the child, family and most important self. In the same course we picked up concepts such as 'Goal to Action', 'Signature strengths' and 'well-being'. We also did a Hanen programme which gave us more insights into real life of an Autistic child.

Together in collaboration with professional resources from early intervention centre, Kindergarten and using the concepts and learnings from the Now & Next programme we would implement / test / fail / try a new strategy / succeed and acknowledge the accomplishments together as a team on our journey.



We were amazed from the results and how much progress we have made together as a strong team and our champion Omar now gets involved in activities and follows instructions and most importantly tries to communicate with little choice of words. Looking back to where we have come from 2 years ago we see this as a strong success, which is measurable.

4.2 Story 2: Becoming family centred

As an early childhood intervention centre in Hamilton, NZ we support children aged from birth to school age, and their families/whānau.

In 2017 we began our internal investigation into our family centred practise. We asked ourselves as a team: "Are we actually doing well with this?" and we used an article by Espe-Sherwindt²⁶ as a basis for our team discussion.

When we looked at the definitions of the levels of practice, we scored ourselves as a "family allied model!" As professionals we were tending to lead the intervention but we had fabulous relationships with our whānau. Our relational practice was far stronger than our participatory practice.

So what did we do? Following guidance from the Good Start in Life project, we intentionally began to invest in building the capacity of our staff and our families. For our staff, we undertook training in coaching. For our investment in parents, to increase their control, choice and involvement, we invested in the Now and Next programme, in partnership with Plumtree Children's Service, Sydney Australia.

What we have achieved has been tremendous. We have exceeded the scale we used from Espe-Sherwindt, which had our initial end goal to be truly 'family centred' with professionals and families as equal partners. We now feel we are working at a level of 'family capacity building' (Dunst)²⁷. We now have parents who are employed at McKenzie Centre as Peer Workers (supporting parents by parents), facilitating courses and initiating a huge impact on the way we support children and their families. Many families are leading their own Individual Planning meetings and are empowered to build and strengthen their parenting abilities with greater confidence and leadership.

26 Espe-Sherwindt, M. (2008) Family-centred practice: collaboration, competency and evidence. Supporting for learning. Volume 23. Number 3.

27 Swanson, J., Raab, M., Dunst, C., (2011) Strengthening family capacity to provide young children everyday natural learning opportunities. Journal of Early Childhood Research.

SECTION 5:

Appendices

Appendix 1: A Good Start in Life (GSIL) project information

Initiated through the Disability Action Plan (DAP) 2014-2018, GSIL is a cross-government project to develop policy options to improve government supports for disabled children aged 0-8 years and their whānau. The Ministry of Education has been the lead agency since its inception in 2014.

The project focus is on improving the way the system as a whole works for parents, family and whānau with young disabled children.

Working closely together has been a feature of the project. The Ministries of Education, Health, Social Development and ACC have been the main government departments partnering in the work. Disabled Person's Organisations and allied organisations such as CCS Disability Action, IHC, Parent to Parent, Autism New Zealand, SAMs have been closely involved. Project work has been supported by a Reference Group, a Working Group and a Steering Group. The views of a group of parents who have been involved in the reference group, along with the voices of parents and providers in the co-design and provider workshops have been essential to keep the focus on system wide change for families.

From 2015 to 2018, the project has completed multiple work streams including a literature review, co-design parent interviews and provider workshops and action research to build the capability of practitioners to work in partnership with parents.

Based on the findings of these work streams three high-level priorities for change were identified in 2018. These include:

- » developing common GSIL practice guidance
- » capability building for providers and whānau as a catalyst for change
- » working to develop integrated models of service delivery.

In the final phases of the project work has focused on sharing the project findings from the co-design and capability building projects, sharing stories of change, developing the GSIL practice guidance and progressing the GSIL priorities for change in existing change programmes:

- » disability system transformation
- » the review of Child Development Services
- » the Learning Support Action Plan and the Learning Support Delivery Model.

The GSIL project work concluded in December 2019, with participants continuing to share GSIL findings and to contribute to system wide change.

Appendix 2: Enabling Good Lives (EGL) Principles

The Enabling Good Lives (EGL) long term direction for change and principles apply to disabled children as follows:

EGL Principle	Example of application to young children and whānau
Self-determination:	Disabled children have a voice in their lives; families and whānau have choices, are able to be aspirational for their disabled child and decide what is best.
Beginning early:	Supporting disabled children, their families and whānau from the beginning; building community and natural supports. Taking proactive approaches, rather than being reactive when a crisis arises.
Person-centred:	Disabled children: have supports that are tailored to their individual needs; are able to use universal services on an equal basis with non-disabled children; and a whole life approach is taken across programmes and services.
Ordinary life outcomes:	Disabled children are supported to live an everyday life in everyday places, as citizens with opportunities for learning, having a home and family, and social participation - like other children.
Mainstream first:	Disabled children are supported to access the services available to all children before and as well as specialist disability services. All services including mainstream services are expected to make reasonable accommodations for disabled children.
Mana enhancing:	The abilities and contributions of disabled children and their families and whānau are recognised and respected.
Easy to use:	Disabled children have supports that are simple to use, flexible and integrated across their lives.
Relationship building:	Relationships between disabled children, their whānau and community are strengthened by supports and early intervention.

Used together, these principles and rights provide a roadmap for child-focussed, family and whānau-centred practice that is inclusive and participatory, based on partnerships and integrated supports.

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