

The Principles in Action

What does a new approach to supports and services mean for Carers



Enabling Good Lives - The Principles

On the 11th September 2012, the Ministerial Committee on Disability Issues agreed to “ a vision and principles to guide future changes in the disability support system”. These principles are below:

Self-determination	<ul style="list-style-type: none"> disabled people are in control of their lives
Beginning early	<ul style="list-style-type: none"> invest early in families and whānau to support them to be ambitious for their disabled child to build community and natural supports to support disabled children to become independent.
Person-centred	<ul style="list-style-type: none"> disabled people have supports that are custom-made to their individual needs and goals a whole life approach rather than being split across programmes.
Ordinary life outcomes	<ul style="list-style-type: none"> disabled people are supported to live an everyday life in everyday places disabled people are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
Mainstream first	<ul style="list-style-type: none"> disabled people are supported to access mainstream services before specialist disability services.
Mana enhancing	<ul style="list-style-type: none"> the abilities and contribution of disabled people and their families are recognised and respected.
Easy to use	<ul style="list-style-type: none"> disabled people have supports that are simple to use and flexible
Relationship building	<ul style="list-style-type: none"> supports build and strengthen relationships between disabled people, their whānau and community.

Main Changes and their Impact

Supports and Services used to be	The new way will see	What this means for Disabled Persons, Families and Carers Knowledge and skills to have
Separate from mainstream services in the community	Increased use of mainstream community supports	Know the possibilities in the community. Able to create personal safeguards
Focussed on building good disability organisations	Focus on making it easier for individuals, families and other community services	Know what you want in your life. Have thoughts about how you can achieve what you want Ideas about how supports can best assist you.
Focussed on providing set 'programmes', services and activities	Supports based on individual preferences and aspiration	Be clear about what you like, what you need and what you want
Standardised	Flexibility	Have good communication and negotiation skills
Access through assessment	Things built around an aspirational personal plan	Have a clear "plan"
Limited number of organisations to choose from	Increased choice regarding how funding is used and who/what you want as supports	Know the options
Families sometimes	Families seen as important	Have 'partnership' skills

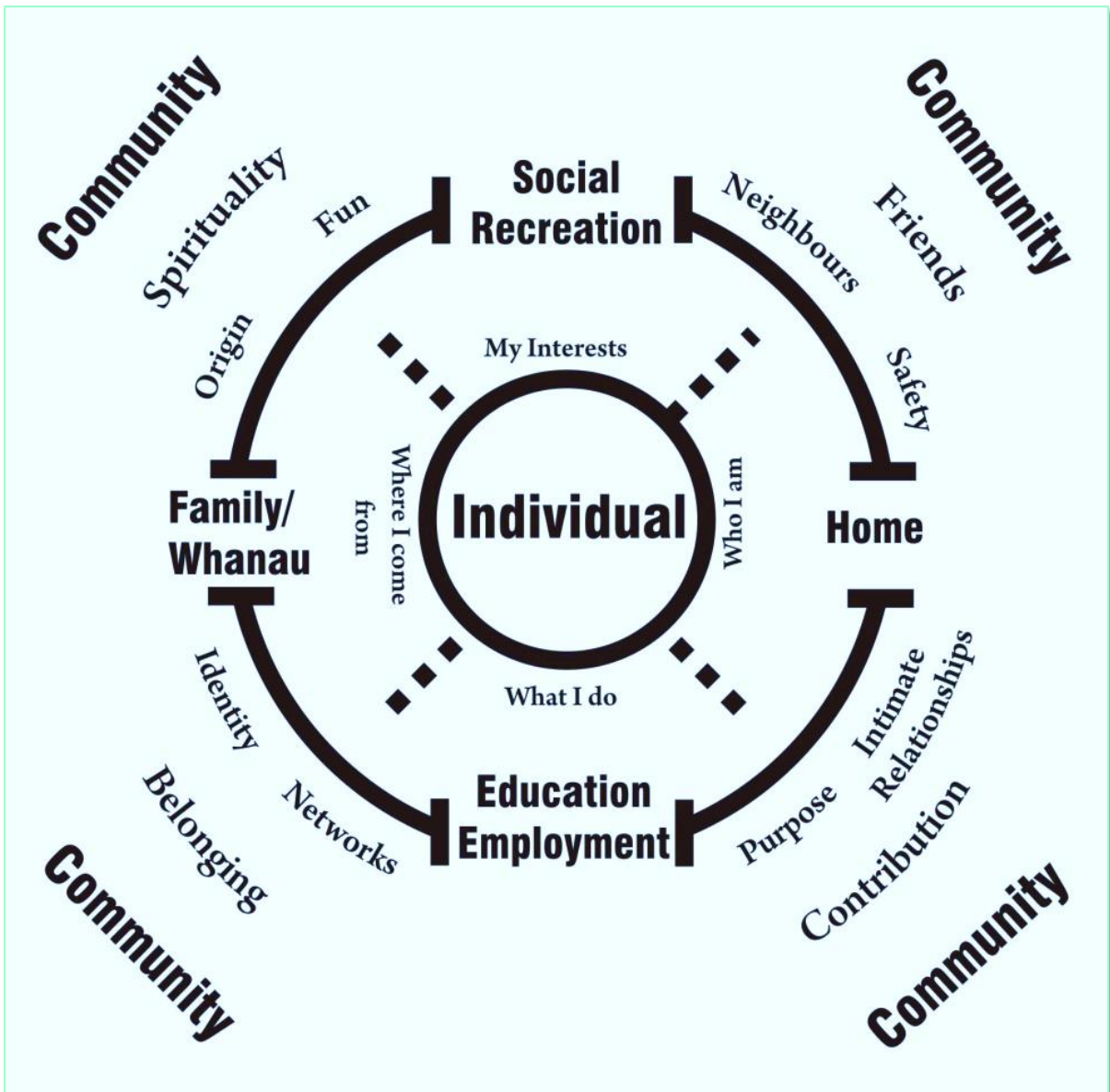
seen as barriers	allies	
------------------	--------	--

What is a “Good Life”?

Many of the new approaches ask disabled people, families and Carers to answer the question: ‘what does a good life look like for you?’ This is usually when you are asked to complete a “plan”. Many supports now attempt to tailor what they do to your “plan”

Disabled people, families and Carers have identified and agreed experiencing a “good life” was often related to the following Figure 1.

Figure 1 – What is a Good Life



A good life is associated with a variety of opportunities that may have different meaning to different people. Creating a vision may include thinking about some of the areas included below.

<p>Being connected with family/whanau</p> <ul style="list-style-type: none">• Loving and caring relationships and belonging	<p>Having friendships</p>	<p>Employment</p> <ul style="list-style-type: none">• Enough money so I can have some choices
<p>Living where I want with whom I want</p> <ul style="list-style-type: none">• A home / a place where I can be myself	<p>Education</p>	<p>Contributing to the community</p> <ul style="list-style-type: none">• Opportunities to make a meaningful contribution and respect within my community
<p>Having fun</p>	<p>Being valued</p>	<p>Being able to get around</p>

The Enabling Good Lives (EGL) Principles are intended to be the basis for how things are done.

The Principles in Action....

Self-determination:

- disabled people are in control of their lives.

Self Determination

Clues that this is happening:

People make informed choices, e.g. where they live, who they live with, involvement with employment and/or education

Supports and/or services are tailored to the expressed preferences and aspirations of the individual/families

Resources and supports are allocated and designed on the basis of individual circumstance and aspiration

Disabled persons and their families have a leadership role in service and or sector development

What I can expect to experience

I am the person who has the “say so”. Nothing happens without me giving my opinion first

I am asked what I like doing, what I have achieved in the past and what I want in my life

What funding I might have access to and what supports do are directly linked to what I want to achieve

I have places where I can express how well I think supports are doing and what changes could happen to the systems to make things easier

What might this look like for you?



Beginning Early:

- invest early in families and whānau to support them to be ambitious for their disabled child
- to build community and natural supports
- to support disabled children to become independent.

Beginning Early

Clues that this is happening

Families/whanau/disabled persons have the right information at the right time and support structures in place to plan for the future

Families/whanau/disabled persons have the knowledge and skills to make informed decisions

Families/whanau/disabled persons have access to natural and universally available supports

There is a planned approach to services and supports which assists the individual to achieve the life they want and is regularly reviewed/ updated

What I can expect to experience

I am given information in a way I understand so I can plan for my future. I have access to support when I choose.

I have opportunities to get information and develop skills to make decisions.

I can easily access the supports I need at different times.

I am able to review and change the services and supports I use.

What might this look like for you?

Information is in plain language (example)



Person-Centred:

- disabled people have supports that are custom-made to their individual needs and goals
- a whole life approach rather than being split across programmes.

Person-Centred

Clues that this is happening:

Supports and services are tailored to individuals needs and goals

Peoples' lives are not split into day, night, home, community, etc

Individuals personal preferences and aspirations drive services and supports

Supports are co-ordinated and assist the individual with achieving their aspirations

Supports are customised to the individual

What I can expect to experience

My needs and goals are the starting point, then I can choose supports and services.

My life is not divided into sections; the focus is on me as a person.

My "likes", dreams and goals are known and respected by the services and supports I choose.

A co-ordinated approach is in place to meet my goals.

I am able to change what is offered so it is in line with my choices and needs.

What might this look like for you?

*I can do things spontaneously.
(example)*



Ordinary Life Outcomes:

- disabled people are supported to live an everyday life in everyday places
- disabled people are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

Ordinary Life Outcomes

Clues that this is happening:

Individuals contribute to the community through a range of activities (ie, educational, social, recreational, employment and/or personal activities)

Individuals have a range of roles that are socially valued

As citizens, disabled persons have the same rights and responsibility as other members of the community

Supports assist people to be 'part of' their community through social participation and relationship building

What I can expect to experience

I am able to participate and am accepted by my community.

I have opportunities to be a part of my community.

I have the same rights and responsibilities as other New Zealanders.

As part of my community I can meet new people and make friends.

What might this look like for you?

I belong to the local
ukulele group.
(example)



Mainstream First:

- disabled people are supported to live an everyday life in everyday places
- disabled people are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

Mainstream First

Clues that this is happening:

Disabled persons have access to mainstream services

Disabled persons have information to make informed decisions about supports

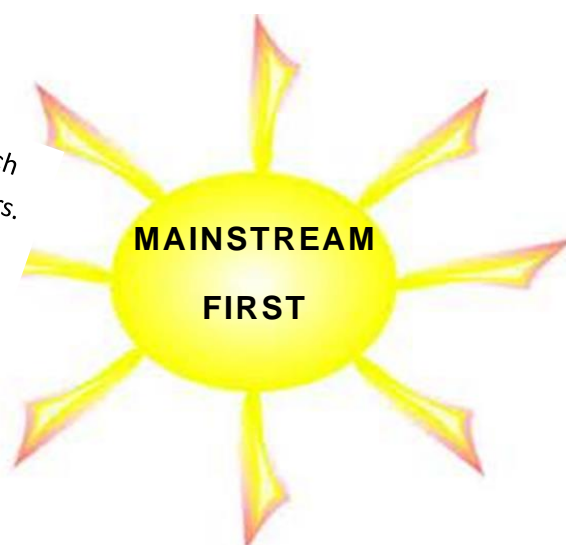
What I can expect to experience

I am given everyday opportunities alongside other New Zealanders.

I have information about opportunities so I can make informed decisions.

What might this look like for you?

*I attend Polytech alongside my peers.
(example)*



Mana Enhancing:

- the abilities and contribution of disabled people and their families are recognised and respected.

Mana Enhancing

Clues that this is happening:

Individuals abilities and contributions are valued

Disabled persons and their families are given opportunities to contribute

Individuals and families have a range of opportunities to influence policies and practice

A partnership approach is central to how services are provided

Individuals experience of supports is valuing

What I can expect to experience

I am valued and what I have to say is listened to.

I have a clear pathway to feed into making change in my community.

I am asked to contribute and am respected as an equal partner in organisations.

I am listened to before and during being supported.

I am respected and treated with dignity.

What might this look like for you?



Easy to Use:

- disabled people have supports that are simple to use and flexible.

Easy to Use

Clues that this is happening:

Disabled persons and their families have a clear understanding of what supports are available and how to use them

Accessing multiple supports is easy to co-ordinate and the process is transparent

Supports can meet the changing needs of the disabled person and their families

What I can expect to experience

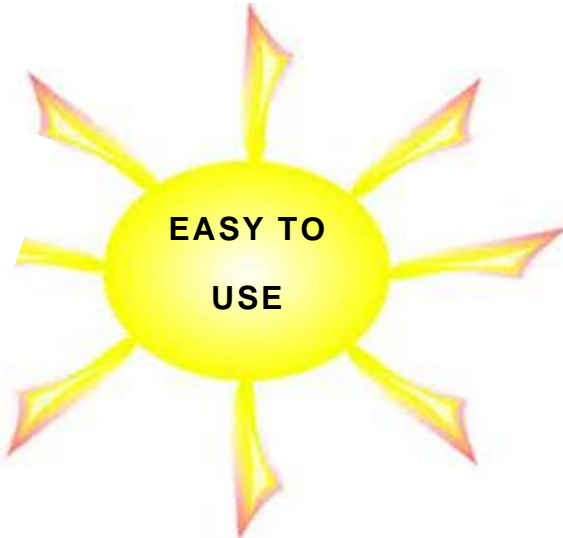
I am given information that is clear and have opportunities to say if I do not understand. This happens in a safe environment.

With the clear and precise knowledge I am able to have a good life using supports that I choose.

I am able to change my supports when I need.

What might this look like for you?

*I understand the paperwork.
(example)*



Relationship Building:

- supports build and strengthen relationships between disabled people, their whānau and community.

Relationship Building

Clues that this is happening:

Services are involved in developing relationships and actioning practices that result in increased opportunities for people with a disability in the community

Services operate in a manner that develops, strengthens and maintains relationships

The individual is encouraged to explore their culture and identity

What I can expect to experience

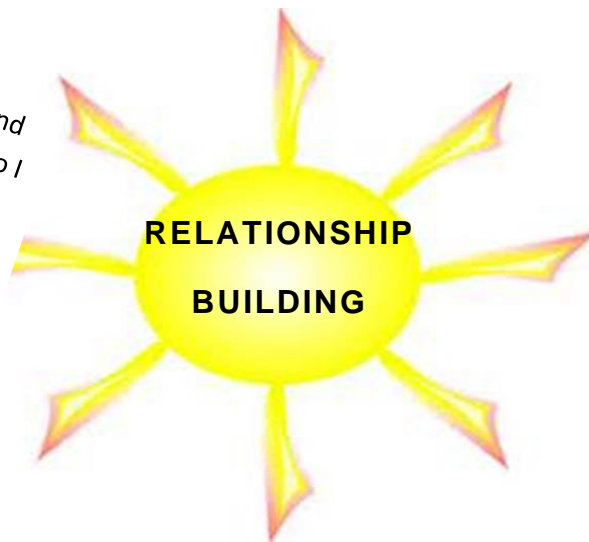
I am having a better life and have services that I have a positive relationship with.

I can expect to be respected and to be seen as an essential partner.

If I choose, I can explore more about who I am and my culture.

What might this look like for you?

*I am seeking information and knowledge about who I am so I can truly build a good life.
(example)*





Principle	The service provider viewpoint might include:	I should experience
<p>Self-determination</p> <p>Disabled people are in control of their lives.</p>	<p>Able to listen to what people want, and then figure out how to make that happen.</p> <p>There are staff who are:</p> <ul style="list-style-type: none"> - skilled in different ways to communicate - aware of personal development strategies - able to assist people to experience new options that reflect the person's interests - knowledgeable about the impact of 'power imbalance' and how to shift authority - welcoming the lead of disabled persons and families - skilled in partnership methods 	<ul style="list-style-type: none"> • being asked about what I want in a way I understand • I am a part of designing my supports • I am regularly asked to participate in reviews in a meaningful way • a shared understanding of what my good life is
<p>Beginning early</p> <p>Invest early in families and whānau</p>	<p>Services create strong trusting relationships with families.</p>	<ul style="list-style-type: none"> • together we plan for the future

<p>to support them to be aspirational for their disabled child, to build community and natural supports and to support disabled children to become independent, rather than waiting for a crisis before support is available.</p>	<p>Planning and trusting relationships support a 'proactive' approach.</p> <p>Staff have a strong sense of optimistic hopes and potential.</p>	<ul style="list-style-type: none"> • thinking about what is possible, rather than focussing on available options only
<p>Person-centred</p> <p>Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.</p>	<p>Services create support around the individual, rather than expecting the person to fit into the programmes they have on offer.</p> <p>Approaches are timely, responsive, creative and holistic.</p>	<ul style="list-style-type: none"> • it's is not a "one size fits all" • I do not need to change to meet what someone else expects • I can expect flexibility and have opportunities to feedback when things are not going well
<p>Ordinary life outcomes</p> <p>Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.</p>	<p>Services and supports are not limited to keeping people fed, housed and occupied.</p> <p>People are supported to develop friendships, careers, live more independently – whatever a good life looks like for the individual.</p> <p>Staff have:</p> <ul style="list-style-type: none"> • a 'whatever it takes' approach • flexibility to support people in a range of environments and situations. 	<ul style="list-style-type: none"> • I have opportunities to live alongside others in my community with an open approach to meeting my idea of a good life • I am able to connect with people outside my family

<p>Mainstream first</p> <p>Disabled people are supported to access mainstream services before specialist disability services.</p>	<p>Services support the individual to get to know and connect to the community in which they live.</p> <p>Connections are made with local people on an individual basis, rather than in a group.</p> <p>The service has diverse, strong and mutual connections with community resources and networks.</p> <p>The service encourages their staff to do the same for themselves and the people they support.</p>	<ul style="list-style-type: none"> • I am part of my local community • I am able to enjoy spending time with other people in my community in an open environment
<p>Mana enhancing</p> <p>The abilities and contribution of disabled people and their families are recognised and respected.</p>	<p>Support provided will increase the respect others in the community have for the person.</p> <p>There are multiple ways for people to express their views.</p> <p>There is a direct link between service practice and ways for people to contribute.</p> <p>People report that they feel valued and respected – and they have mana or authority over what they do and who they are.</p>	<ul style="list-style-type: none"> • I have rights and am a contributor to my community • I design the things in my life, not someone else • I am empowered to sort things out myself
<p>Easy to use</p> <p>Disabled people have</p>	<p>Supports and services are simple to access and easy to change. It is expected</p>	<ul style="list-style-type: none"> • Things make sense to me

<p>supports that are simple to use and flexible</p>	<p>that individuals will change their plans and services will respond accordingly.</p> <p>Communication is accessible and easy to understand.</p>	<ul style="list-style-type: none"> • I measure the success of what is happening
<p>Relationship building</p> <p>Supports build and strengthen relationships between disabled people, their whānau and community.</p>	<p>Supports and services focus on connecting the individual to other people rather than to an activity.</p> <p>The importance of natural supports is recognised and actively developed.</p> <p>There are multiple forums/ways for relationships to be recognised and respected.</p>	<ul style="list-style-type: none"> • I am not alone in holding onto the vision of a good life • The input of my family and friends is valued

