



Facing the Challenges Together

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All activities must include the participation of persons with disabilities:

‘Nothing about us without us’

United Nations Convention on the Rights of Persons with Disabilities

www.un.org/disabilities

In this paper we will describe how Tautoko Services works alongside families of children with disabilities who are presenting behaviours that challenge. We will explain the context in which this work occurs, the theories and principles that influence the way the work is carried out and how we believe the work is useful.

What is it we do and why?

Tautoko Services focuses on the following outcomes:

- To contribute to better lives and choices for people with an intellectual impairment and people on the autism spectrum and their families.
- To contribute to better quality of support and service for disabled people.

Tautoko Services is funded by the Ministry of Health to provide Specialist Behaviour Support.

People with disabilities who have a diagnosis of Intellectual Disability or Autism Spectrum Disorder (hereafter throughout we will use the acronyms ID and ASD) are entitled to access our service when they have “challenging behaviour”. The majority of referrals to our service are for children and our service therefore focuses on working alongside families.



Challenging Behaviour

There are differing opinions about what constitutes challenging behaviour. Our service sees challenging behaviour as behaviour which other people find challenging. This can be because they don't understand what the behaviour is about or because they don't know how to respond to the behaviour in any helpful way. The person displaying the behaviour finds that their access to everyday situations and interactions becomes limited and problematic and their quality of life is affected.

People use a variety of phrases to describe what this behaviour looks or sounds like when they come across it. Often the challenging behaviour is seen to be connected to the impairment of the person.

Challenging behaviour is socially constructed and is a product of an interaction between the individual and their environment. Assessment and intervention must therefore address the person, the environment and the interaction between the two”

(Royal College of Psychiatrists: 2007:90)

The range of behaviours we all use can be extreme at times and challenging to others. People around us either understand that something is wrong and respond in a helpful way, OR we ourselves realise we have overstepped the mark, gain control again and apologise or explain why we behaved as we did. It is important that we accept that disabled people are human beings and not differentiate between the human behaviour of “us and them”.

“Seeing people with disabilities as us has hastened and broadened our search for understanding the complex influences that affect problem behaviours”

(Bambara, 2002:60)

Society is not very inclusive; as acknowledged by the United Nations Convention on the Rights of Persons with Disabilities and the Disability Strategy. Neither is it good at meeting what it sees as special needs. Societal attitudes cause frustrations, confusions and anxieties for people with impairments. Challenges are created when the person tries to cope by using behaviours from their repertoire. These behaviours are often misunderstood and so the situation escalates!



This societal attitude is highlighted in the New Zealand Disability Strategy (Page 7, paragraph 4) which refers to the effects that stigma, prejudice and discrimination can have on behaviour.

We believe that in order to meet people's needs, listening to the communication inherent in their behaviour is vital.

“Difficult behaviours are messages which can tell us important things about a person and the quality of his or her life”

(Pitonyak, 2007:2)

Historical Perspectives

In the past our society has not been kind to those with intellectual impairments and challenging behaviours. People with impairments have been viewed as incapable and incompetent in their capacity for decision-making and development. People who were labelled as challenging were supported through medical interventions and often were the subjects of aversive practices. These attempts to change their behaviour resulted in a huge personal cost to the individuals. Very little was done to recognise and accommodate individual needs or rights as contributing members of society.

Like many people our own initial understanding of disability was influenced by the teachings from the medical model. The large Psychopaedic Hospitals around our country reinforced the belief that people with ID needed medical care and support. Most of society who did not have direct contact with a disabled person believed this to be the best option for children, adults and their family / whanau.

This resulted in services that were provided from a perspective of providing care and medical support.

“Western concepts of disability have tended to emphasise physical, sensory, Psychiatric/psychological, learning or intellectual impairments, and reduced functioning.”

(Ratima 2001)

This paradigm of disability is consistent with a western world view of health which looks at cause and effect; disease process first and person second, with the aim of health care being to cure disease and consequently the aim of service interactions being to fix problems.



Although this perspective still persists to some degree; enlightened approaches in New Zealand have moved more towards an indigenous view point as described by Maori.

Maori Understandings of Disability

Maori concepts of health are holistic in nature, locating individuals within the whanau context and, therefore, emphasising interdependence, recognising determinants of health (including cultural and spiritual determinants), incorporating a focus on continuity between the past and the present, and viewing good health as a balance between interacting variables. (Ratima 2001)

A Maori perspective sees all life experiences as affecting the health and wellbeing of an individual, their whanau, hapu and iwi. This perspective focuses on a balance of all components within the Maori world view.

It is these views that we can draw upon when supporting a person and their family / whanau. Tautoko Services Te Kauri model therefore takes into consideration this range of variables throughout our processes of interaction.

Maori believe cultural identity is inherent to Māori concepts of health. (Durie 1998)

The ability to establish identity requires access to cultural resources. Disabled Māori have expressed the value they place on their identity as Māori (National Health Committee 2004). More recent concepts of disability, as expressed in the New Zealand Disability Strategy, are centred on the interaction between the individual with the impairment and the environment. This is a generic concept that applies to all cultures.

Māori concepts of disability and disability support are likewise broad and emphasise the creation of environments conducive to attainment of balance; spiritual and emotional wellbeing; maximum functioning; strengthening positive interdependence; and whānau are central to maintaining and reinforcing a secure cultural identity.

Principles that underpin our work

Tautoko Services' way of working is rooted in Maori concepts of disability which makes the Treaty of Waitangi the primary document underpinning our work.



It is our belief that all human beings have a right to participate within their communities and be treated with dignity and respect. These are the principles inherent in the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities. We will now discuss how these three documents guide our practice.

Treaty of Waitangi

The Treaty is a fundamental document to guide the unique way in which we operate in New Zealand society to honour the partnership between Tangata Whenua and Tauwi.

“We (Maori) must not forget that the treaty is not just a Bill of Rights for Maori. It is a Bill of Rights for Pakeha too. It is the Treaty that gives pakeha the right to be here. Without the Treaty there would be no lawful authority for the pakeha presence in this part of the South Pacific.”

Chief Judge Eddie Jury Waitangi address 1989

The concept of partnership is captured in a Maori whakataurangi – proverbial saying – which states:

“Nau te rourou, naku te rourou ka ora ai te iwi (with your basket and my basket, we will cater for our guests). In the context of our work this saying is interpreted as being able to combine resources, collaborate and cooperate to get ahead.

This is one of the fundamental principles of the Te Kauri model (we discuss this later), which is always carried out in partnership with those we engage with.

New Zealand Disability Strategy

The New Zealand Disability Strategy (hereafter referred to as the Disability Strategy) was published in 2001 and preceded the U.N Convention. It presents a vision of NZ as a “fully inclusive society”. This resonates with Tautoko Services’ mission statement “to support all people with an intellectual disability or ASD whose behaviour challenges to lead valued lives in the community”.

One of the objectives of the Disability Strategy is to value families, whanau and people providing ongoing support. This objective is key to our model of working.



So from a parent's point of view you need to be supported and given the message that your child is your child, a unique and wonderful human being. You as their parents know them best, and are the most important people in their lives. You can parent them well whatever the label or category created for them. This also means that if you struggle with the idea and experience of parenting any child, then you will also struggle with the experience of parenting a child with impairment. You may therefore need additional support to learn how to parent in a positive successful way. This may require for example access to appropriate parenting programmes.

“It is assumed that it is the impairment of the child per se that causes distress and hardship for the family / whanau, rather than the structures, systems, policies and attitudes of society towards the family / whanau”.

(Dowling & Dolan, 2001:21)

Part of Tautoko Services' work may therefore require supporting the family / whanau and the individual to challenge some of the systems and attitudes that are creating problems for them.

Our approach does not minimise the fact that life can be **more** difficult for the child or the family / whanau, where impairment is a factor. This is where Tautoko Service can have something useful to offer in terms of information and strategies around the influence of the impairment on day to day functioning.

Today we work from a model of inclusion which stems from the social model of disability. As we have worked alongside individuals and their family / whanau they have taught us about their own values, traditions and cultural identity. This has made us aware of ensuring there is balance between professional judgement and consideration of family / whanau values in the plans we develop and the strategies we recommend.

United Nations Convention of the Rights of Persons with Disabilities

The United Nations Convention (hereafter referred to as the Convention) formally became part of international law in May 2008, was ratified by the New Zealand Government in September 2008, ensuring official agreement to abide by the Convention in domestic law.



The Convention reinforces the right of disabled people to: education, access and protection by the legal system, make their own decisions, be part of our community, be informed and participate in cultural life. The Convention defines disability as:

“Those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”

The Convention links strongly with all aspects of the Te Kauri model, which we now describe.

Te Kauri Model of Working

The Tautoko Services’ logo is the Kauri tree. We have chosen this symbol to represent our work because of the strength of the tree and the role it plays within the ecological systems of Aotearoa/New Zealand. (Appendix 1)

Based on the principles of the Treaty of Waitangi, NZ Disability Strategy and the UN Convention we have developed our organisation’s practice, Te Kauri.

Te Kauri has four different aspects:

Whakapapa (understanding empathy, to walk alongside); Whanaungatanga (inclusion, to bring people together); Manaakitanga (strength based) Whakaaroaro (to ponder, consider carefully, give thought to, reflect on). Within each aspect there are many layers interwoven which contribute to new perspectives and understanding and to the natural progress of growth just as the Kauri does.

We will now discuss in detail these four aspects.

WHAKAPAPA

Understanding, empathy, to walk alongside

Whakapapa is viewed as being the foundation for the first layer of knowledge. This contains a person’s history and provides an understanding of how they arrived at the place they are now.



When we become involved, we spend time developing a relationship of trust. We enquire about people's dreams and aspirations and gain an understanding of their knowledge and experience of their cultural identity, values and personal beliefs. This is fundamental to our process of assessment and therefore integral to the plans and strategies that follow. In order to understand the behaviours you must know the person.

WHANAUNGATANGA

Inclusion, to bring people together

The second layer of knowledge is to learn about who is important in their life, who do they relate to, who provides for them, who cares about and supports them.

Fundamental to whanaungatanga is whanau which is interpreted not just as blood relatives but as those around the person who share a common bond and values.

Families are often overwhelmed and challenged severely in the face of adversity, and they do stumble, experience disharmony and imbalance, and sometimes even deteriorate in the face of a family / whanau trauma. These family / whanau crises are often successfully negotiated by the family / whanau using its own resources, capabilities, and ability to recover. Families do bounce back and adapt to the situation by changing their patterns of functioning and changing the aversive condition that has placed or maintains the family / whanau system in its current problematic predicament (McCubbin et al. 1997:6)

Whanaungatanga is a family / whanau systems approach. This means that in our work our focus is to view the child within the context of his/her family / whanau.

“without a family centred approach, the carer's quality of life may well be compromised in their caring for a family / whanau member with a disability”.

(Dowling & Dolan 2001)

In order to be successful in our interactions we need to listen to people's stories. We utilise their strengths, and reframe our focus from an individual intervention to interventions in terms of the family / whanau as a whole. An awareness of family / whanau structure, routines, needs, and capacities is crucial for success of any intervention. It is part of our approach to ensure that family / whanau guide the decision-making processes, directing and controlling change.



MANAAKITANGA

Strength Based

The third layer of knowledge is to recognise that all people have strengths.

Strengths include skills and talents as well as personal qualities. We recognise people's strengths and abilities, support enhancement of current abilities and skills and support the development of new abilities, skills and opportunities.

Person/ family / whanau-centred service delivery relies on a willingness to evoke significant change in the ecology of the service delivery system.

Manaakitanga recognises the importance of working with all significant people and services providers.

WHAKAAROARO

To ponder, consider carefully, give thought to reflect on

The fourth layer of knowledge is the reflection and evaluation gathered from the people we work with. This has led us to develop "Te Rakau Whakaaroaro," "the reflective tree" as a means of capturing if in the opinion of the people we support we have made a difference. This evaluation process is woven into the Te Kauri model of practice. Throughout our process of engagement we use a diagrammatic tree (appendix 2) as a tool to guide our work. This enables the individual and the family / whanau to identify the goals they wish to focus on, and how well they are coping now in their current situation. As we proceed we can reflect together on progress. At the end of the process we can evaluate what has changed in the quality of life for all and whether goals have been achieved.

Through the organisational practice of Te Kauri we gain an understanding of who the person is and what is occurring for them. We are able to identify the needs of the individual and their family / whanau and strengths of the relationships and support systems. Only with this information can a holistic approach of support be implemented.

Te Kauri in action

Just as the Kauri feeds and beautifies the ngahere (forest), and nga manu (the birds) and elevates their strengths, so through our processes of interaction, we seek to strengthen whanau and community links, and celebrate the person.



The Te Kauri model provides a process whereby we gather information for an assessment. This enables us to build a plan based on: skills, strengths and abilities; individual learning style; unique characteristics or preoccupations; dreams and interests. It is important that the assessment acknowledges a person's emotional, physical, spiritual, and family / whanau needs, and captures information about the current situation. This is in effect a holistic functional assessment.

Lovett (1996) talked about the importance of really listening to the words and actions of the people we support instead of historical approaches to functional assessment which were developed from a narrower behavioural scientific perspective. In order to do this there is first and foremost a need to form a genuine relationship.

Through taking a collaborative assessment based approach we are able to assist individuals, family / whanau and support networks, to develop intervention strategies that are effective and to see and identify the many variables that can influence and impact on behaviours.

This collaborative approach to assessment reflects an empowerment model of support. We don't come in as experts, we don't impose, we walk alongside parents/ family / whanau who know the person they love and care for best. Our role is to interpret what is happening for the person and come up with some extra useful ideas and tools.

We can't fix people!! Horner (2007:2) quite clearly states that "our job is not to fix people, but to design effective environments". People can change their own behaviours given the knowledge, opportunity and support. All behaviours occur within the context of relationships and it is often the relationships which require change. The plan for interventions is Person-Centred and identifies strategies and supports which are realistic and achievable.

One role of our service is of interpreter and enabler to expand the skills of society as well as the individual and to support the transfer of information across situations.

This approach is endorsed by the western theory of Positive Behaviour Support.

"Positive Behaviour Support is a set of research based strategies used to increase quality of life and decrease problem behaviour by teaching new skills and making changes in a person environment."

(Dunlop et al 2003)



Positive Behaviour Support is an approach taken by Tautoko Services. A child's life can only be viewed in the context of their family / whanau and therefore the wellbeing of the family / whanau is a key consideration. The most important principle of Positive Behaviour Support is that it is conducted in partnership.

The goal of Positive Behaviour Support is to improve the quality of life for the individual.

“Positive behaviour support is a great and worthy idea predicated on the notion that creating a life of quality and purpose, embedded in and made possible by a supportive environment, should be the focus of our efforts as professionals. Our chief concern is not with problem behaviour, and certainly not with problem people, but rather with problem contexts”.

(Carr, 2007:3)

From our perspective our role is to provide support and tools for individuals and their family / whanau and networks to use in a manner which accords them dignity and respect.

Individuals have said they do not want to be told what to do but want to be shown how to do things differently where they can have control and choice over their life.

Families have said they want to be acknowledged as knowing their child best, but also need to feel able to ask for support to learn how to best meet their child's needs. Often parents just want people to be non judgemental when their child for example 'melts down' in the supermarket because a noise or smell overwhelms them.

“parents needed to respond differently to the child concerned, often creating behaviour management challenges especially if there was more than one child in the family / whanau”

(Munford & Sanders, 1999:99)

Te Kauri is a model based on Maori principles. It also translates into and corresponds with best practice from a western perspective based on the theories of Positive Behaviour Support and the social construction of disability.



An Example of Te Kauri Model in Action

In order to demonstrate how Te Kauri works Roz would like to present a case study.

Adam (not his real name) is a 5 year old boy who has been referred because he was hitting his younger brother, screaming whenever someone came near him, head banging and biting his hands, causing calluses. Adam had recently been diagnosed as being on the Autism Spectrum. Prior to receiving this diagnosis Adam was perceived by people as being a naughty child.

Adam's parents are in their early 20s and Adam is their first child. When first meeting with his parents they told us Adam had developed and reached normal milestones up to approximately 18 months of age. He walked at 11 months, by 14 months he could say a few words and was recognising people. Language development was a little delayed but there were no real concerns. His parents said they always had difficulty with getting him to eat; his food range had become narrower over recent years. Adam's sleeping pattern had also been erratic and he would often be awake for three to four hours each night. As Adam became older he began obsessing about specific television programmes and this became extreme when he was about 28 months old. When Adam began kindergarten mum noticed he was not engaging with other children. He was very active and busy but didn't settle at one activity for any length of time. By the time he started morning kindergarten he was still incontinent and his language was still delayed. His teacher found it difficult to get him to comply with the rules and she eventually sort support from the Group Special Education Early Intervention Team, who on observing Adam recommended he be seen by a paediatrician. Consequently the paediatrician assessed Adam and diagnosed him as being on the autism spectrum. The paediatrician also referred Adam to the Child Development Services for physiotherapy, eating programme and social work support. This occurred 10 months prior to a referral being made to our service.

To establish a picture of what was occurring for Adam, we needed to gather contextual information regarding what, when, where and why behaviours were being presented.

Whakapapa

Firstly we addressed the aspect of whakapapa; as in this context whakapapa is viewed as being the foundation for the first layer of knowledge. This contains a person's history and provides an understanding of how they arrived at the place they are now and was gained by



listening to his parents tell their story of what life with Adam was like. More importantly it becomes the first layer for building future supports.

To understand the importance of and the impact whakapapa had for Adam required observing how he perceived and responded to his world and those around him. It was about finding out his likes and dislikes and idiosyncratic behaviour patterns. His history, family / whanau dynamics, past and present influences have shaped who he is today.

This required learning of the parents' beliefs, values and practices and observing these being applied in their every day care and support of Adam. This enabled the challenging behaviours to be viewed in the context of his environment. I was then able to write an assessment for the family / whanau which we could consider together. They were then able to establish goals to work on, which were captured through the process of whakaararo, the reflective tree. This information was also presented in a booklet to Adam and his family / whanau in visual and simple narrative form of who Adam is and who is important and significant in his life. This was important in reducing Adam's levels of anxiety. Placing Adam at the centre ensured all planning focused on improving his quality of life.

Whanaungatanga

This aspect ensures inclusion and collaboration occurs where family / whanau are involved in all areas of planning implementation and evaluation. It is about building and strengthening relationships and draws upon people skills and knowledge.

Gaining an understanding of the family / whanau dynamics, who the family / whanau members were and the roles they fulfilled, gave a picture of where Adam fitted within the wider family / whanau. It also identified who was part of his support system and where the gaps in support were. As part of Adams plan we established respite support for Adam and his family / whanau, which involved a mixture of family / whanau and paid services support. This allowed some breathing space for his parents and also enabled his extended family / whanau to establish their relationships with Adam. The booklet that was created for Adam was also used by paid respite providers to give them a view of who Adam is and how to effectively support him. Background information about what was occurring for Adam in the various environments was also gathered. I observed the interactions and communication methods used in each environment and how these related to his presenting behaviours such as hitting, screaming or being self injurious. I then developed a resource that Adam could carry



across all environments. It contained a simple visual communication system and activities that adults around Adam could do with Adam to reduce sensory overload which resulted in a reduction of the previous behaviours.

Manaakitanga

The capacity to care, manaakitanga, is a critical role for family / whanau especially in respect of children and acknowledges that all people have strengths and the capacity to build and develop new skills and opportunities.

It was important to understand how Adam's quality of life was affected by the impact of his impairment, which is autism; the influences of the sensory environments; the level of anxiety; his communication methods and his physical wellbeing. People with autism often have difficulty taking in information through their senses and putting it altogether in their brain in order to make a meaningful response. To help with this process a sensory diet of activities was created for Adam to be used on a daily basis in all environments which enabled him to regulate his body and increased his ability to participate with others and reduced the extreme behaviours. This together with the communication resource made a significant difference to his quality of life.

Adam's quality of life was also dependent on the ability of the family / whanau to maintain a level of energy to enable them to meet the complexity of his needs and to incorporate their current knowledge of possible strategies with new knowledge. The respite that was introduced had a positive impact on his parents' ability to maintain their energy. Adam's parents then began to learn the different teaching techniques. This enabled them to break down tasks into small steps for Adam so as he was able to expand his range of skills and independence.

Having completed this process of holistic assessment planning and intervention, together we were able to create a better balance of wellbeing for Adam and his family /whanau. A particular event which demonstrated this change was when Adam and his dad attended a local rugby match together which they both enjoyed.

Whakaaroaro

The process of reflection and evaluation was used throughout our work together. When we first became involved the issues and concerns identified by his parents were Adam's



aggressive behaviour towards them and other children, his erratic sleep patterns and his obsession for specific television programmes. At the end of our work we revisited the process of Whakaaroaro, the reflective tree. Adams family / whanau could see that what had been viewed as a challenging behaviour was in fact Adam communicating his distress. Providing him with a communication mode which he was able to carry with him enabled him to engage with people appropriately in each environment and make his needs known. His parents had put into practice a bed time routine which enabled Adam to sleep longer. He is now able to engage in a variety of activities out doors, which better meets his sensory needs and his television watching is reduced to scheduled times which fit with the rest of the family / whanau. All these factors have led to an improvement of Adam's quality of life and that of his family / whanau. Consequently Adam's parents were able to identify an improvement in their family / whanau wellbeing. They were now able to participate more in community activities with Adam, they were more aware of the triggers for Adams challenging behaviours and had a toolbox of strategies to avoid these situations. Their range of support was extended and their confidence level had increased.

How do we know what we do is useful?

Parents of children with disabilities have identified that they need a broad range of support from service providers in order to facilitate positive outcomes for their children. They may also have a different opinion to professionals about what constitutes actions that are helpful. (Prezant and Marshak, 2006:31).

The evidence so far from our use of the process of whakaroaro, the reflective tree with Adam's family / whanau and with a number of families who have completed this process is that positive change can be achieved and goals can be reached. People identify an improvement in their wellbeing; their ability to cope with and manage situations they find challenging; an increase in their community participation and an improvement in their support networks.

These comments reinforce the importance of the key principles of Te Kauri model, whakapapa, whanaungatanga, manaakitanga and whakaaoraro and the effectiveness of this approach.



Conclusion

In this paper we have endeavoured to show how our service works alongside families based on a holistic approach, Te Kauri model, which has four key aspects whakapapa, whanaunatanga, manaakitanga and whakaaroaro.

We have identified the principles and theories from which this model has been developed. We have shown a commitment to work in partnership with Tangata Whenua which demonstrates our application of Te Tiriti o Waitangi.

The objectives of the New Zealand Disability Strategy, to value families/ whanau and to enhance all aspects of community participation for disabled people are demonstrated through our way of working.

Our process of working alongside people and placing the disabled person at the centre of our work, clearly demonstrates our endorsement of the United Nations Convention on the Rights of People with Disabilities.

We have explained how Te Kauri model translates into practice and is in alignment with western concepts of best practice. Using this model we are able to bring about change for people with disabilities who have challenging behaviour.

Mā te rongo, ka mōhio; Mā te mōhio, ka mārama; Mā te mārama, ka mātau; Mā te mātau, ka ora.

Through resonance comes cognisance; through cognisance comes understanding; through understanding comes knowledge; through knowledge comes life and wellbeing.



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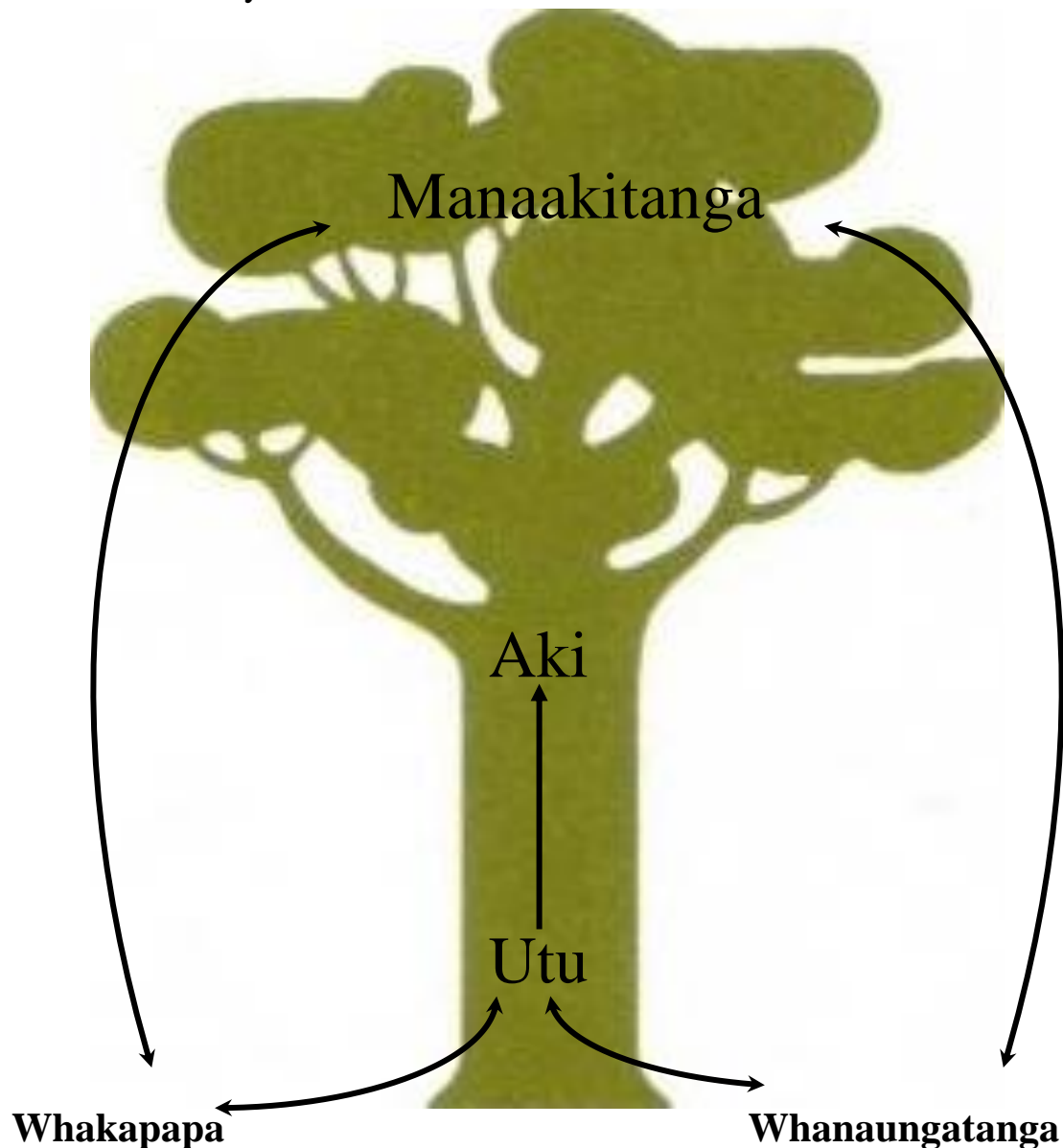
Appendix 1

Te Kauri

This visual representation of Te Kauri illustrates the fundamental principles from which Tautoko Services operates.

Through the metaphor of the Kauri Tree we embody the living nature of our work, our organisation and our place within the community.

The key features of Te Kauri model shows the process of whakaaroaro through Whanaungatanga, Whakapapa and Manaakitanga in a way that is understood and accessible by individuals and whanau.

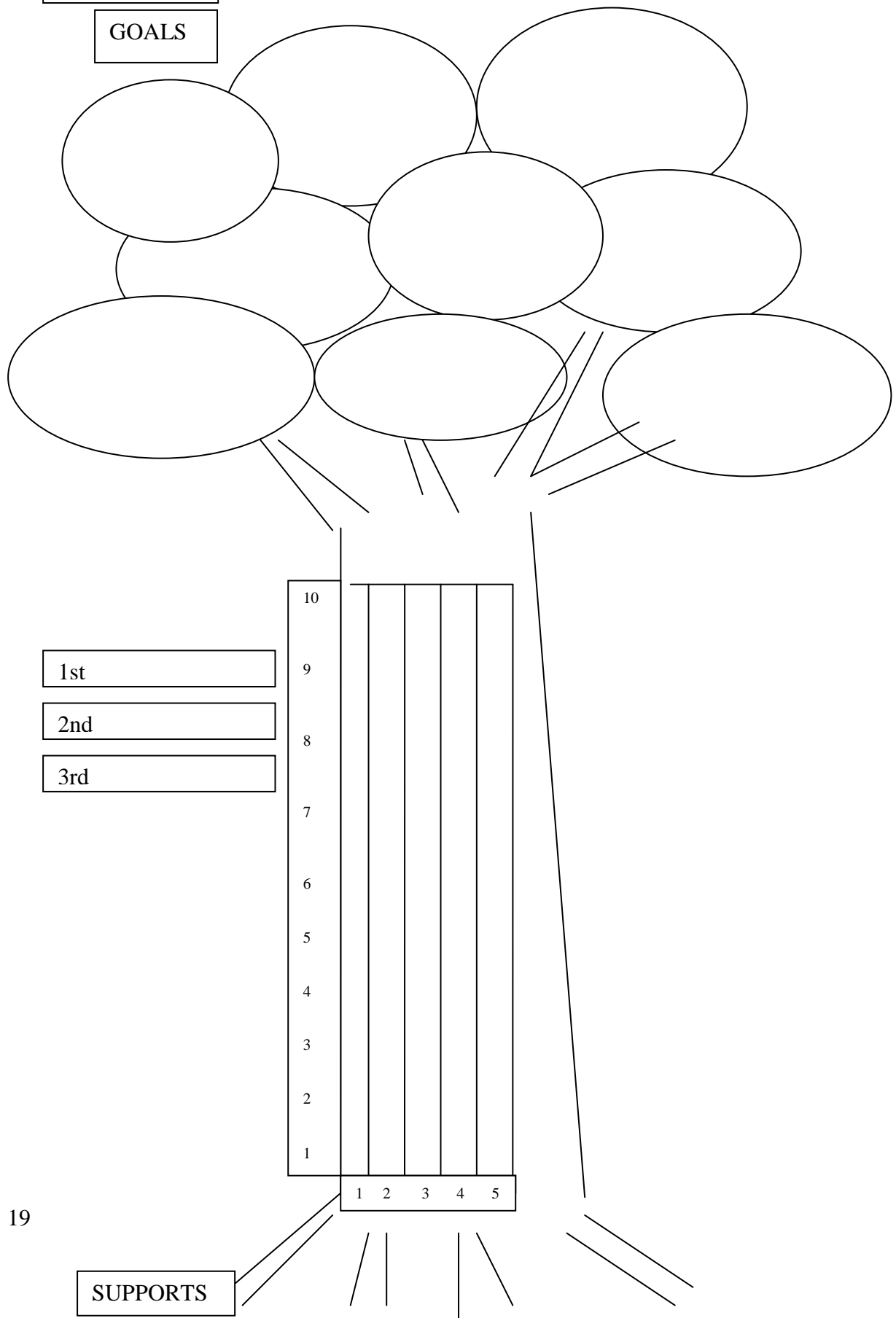


Appendix 2

REFLECTIVE TREE

Name

GOALS



1st

2nd

3rd

10					
9					
8					
7					
6					
5					
4					
3					
2					
1					
	1	2	3	4	5

SUPPORTS

1. Where would you rate your family's well being now?	0 1 2 3 4 5 6 7 8 9 10 Comments
2. How do you rate your family's ability to cope with the challenging behaviour now?	0 1 2 3 4 5 6 7 8 9 10 Comments
3. How do you rate the skills you have In managing the challenging behaviour now?	0 1 2 3 4 5 6 7 8 9 10 Comments
4. How do rate your ability to go out and participate in the community?	0 1 2 3 4 5 6 7 8 9 10 Comments
5. How do you rate the support you receive for challenging behaviour now?	0 1 2 3 4 5 6 7 8 9 10 Comments