

# *BEACON* Aotearoa Shining Light on Fetal Alcohol Spectrum Disorder [FASD] and Neuro-disability

E TIAHO ANA TE MARAMA I RUNGA I FETAL WAIPIRO  
TŪĀWHIORANGI WHAKARARURARU [FASD]  
ME NEURO-HAUĀTANGA



*BEACON* Aotearoa: Shining a light on Fetal Alcohol Spectrum Disorder [FASD]  
and Neuro-disability

# LEARNING OBJECTIVES

- ▶ Why did we set up *BEACON Aotearoa*?
- ▶ What are the aims of our service?
- ▶ How do we deliver our services?
- ▶ How do we meet our client's needs?



# WHO ARE WE?



**BEACON Aotearoa:** Shining a light on Fetal Alcohol Spectrum Disorder [FASD] and Neuro-disability

# BEACON'S GENESIS

- ▶ Two professional, passionate parents who want to make a difference in supporting FASD individuals, and their whānau
- ▶ Backgrounds in Paediatrics, Nurse Education, Policy Development, Government Management and Administration, Dispute Adjudication and Mediation, Foster care, and Social Work.
- ▶ We know where the “gasps” and needs are!



# LEARNING OBJECTIVE ONE:

## Why did we set up *BEACON*?

- ▶ 35yrs combined lived-experience of FASD
- ▶ Knowledge of gaps in supports and service provision
- ▶ “Know better, Do better”
- ▶ Learn from our hard-won knowledge and mistakes
- ▶ Practical based programmes and services based on ‘real life’ experiences



# BEACON AOTEAROA'S OFFICE IN NAPIER, NEW ZEALAND



**BEACON Aotearoa:** Shining a light on Fetal Alcohol Spectrum Disorder [FASD] and Neuro-disability

## BEACON AOTEAROA'S VISION

- ▶ A New Zealand where FASD affected individuals and their families/whānau are given the recognition, support, and help they need.

## NZ GOVERNMENT ACTION PLAN

- ▶ People with FASD and their family/whānau live the best possible lives.

( MOH 2016 - 2019: Taking Action on Fetal Alcohol Spectrum Disorder)



## OUR GOAL

- ▶ Significant improvement in the lives and outcomes of those individuals, families/whānau, and caregivers affected by FASD.





# LEARNING OBJECTIVE TWO: What are the Aims of our Service?

- ▶ Fill support and service gaps for FASD
- ▶ Share our hard-won knowledge
- ▶ Avoid pitfalls with professionals
- ▶ How to get the best out of existing services
- ▶ Advocacy for better services – particularly for Adolescents and Adults
- ▶ “Fighting” for people like our children
- ▶ Effective and realistic services and advice



# SOME NZ ISSUES

- ▶ No accurate NZ Data
- ▶ Based on international research:
  - ▶ 1% = 22 children in Hawkes Bay each year
  - ▶ 5% = 110 children in HB each year (5 classrooms every year)
- ▶ Special Education Services in Crisis
- ▶ Schools in crisis with behavioural issues
- ▶ Quote by Russell Wills , previous Children's Commissioner - " It is a Tsunami"
- ▶ Some funding for school age children - minimal resourcing for Adults



## LEARNNG OBJECTIVE THREE: How do we Deliver our Services?

- ▶ With humour and pragmatism
- ▶ We are a values-based holistic neuro-disability service provider
- ▶ Everything we do, and how we do it, is based on these values.
- ▶ Fundamental to our practice are Te Tiriti o Waitangi principles of Partnership, Participation and Protection



# BEACON'S CORE VALUES

## ▶ Whanaungatanga

We seek to develop relationships and a sense of belonging, and taken time to get to know one another

## ▶ Manaakitanga

We care, we give, we share, we reciprocate

## ▶ Mauri

We acknowledge that everyone is unique, and we treat everyone with dignity and respect

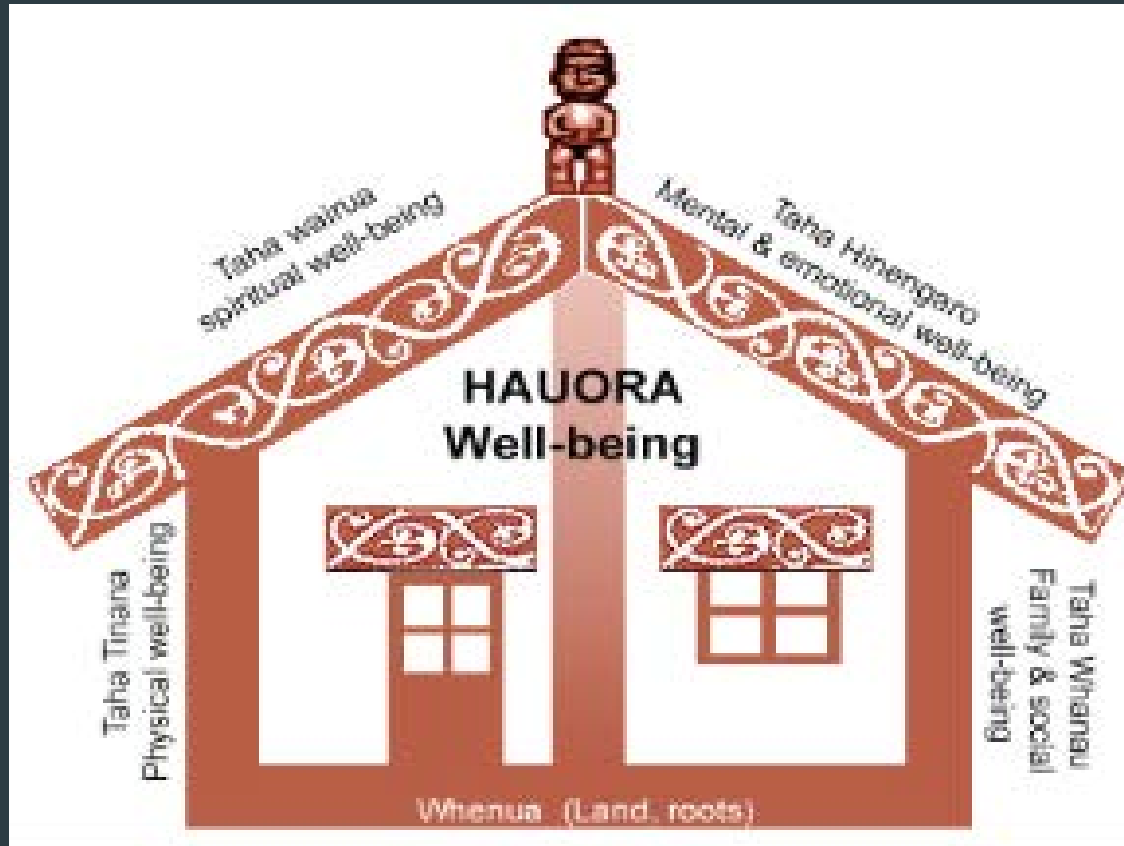
## ▶ Pono

We interact with people with truth, honesty, genuineness, and sincerity. We work with integrity.



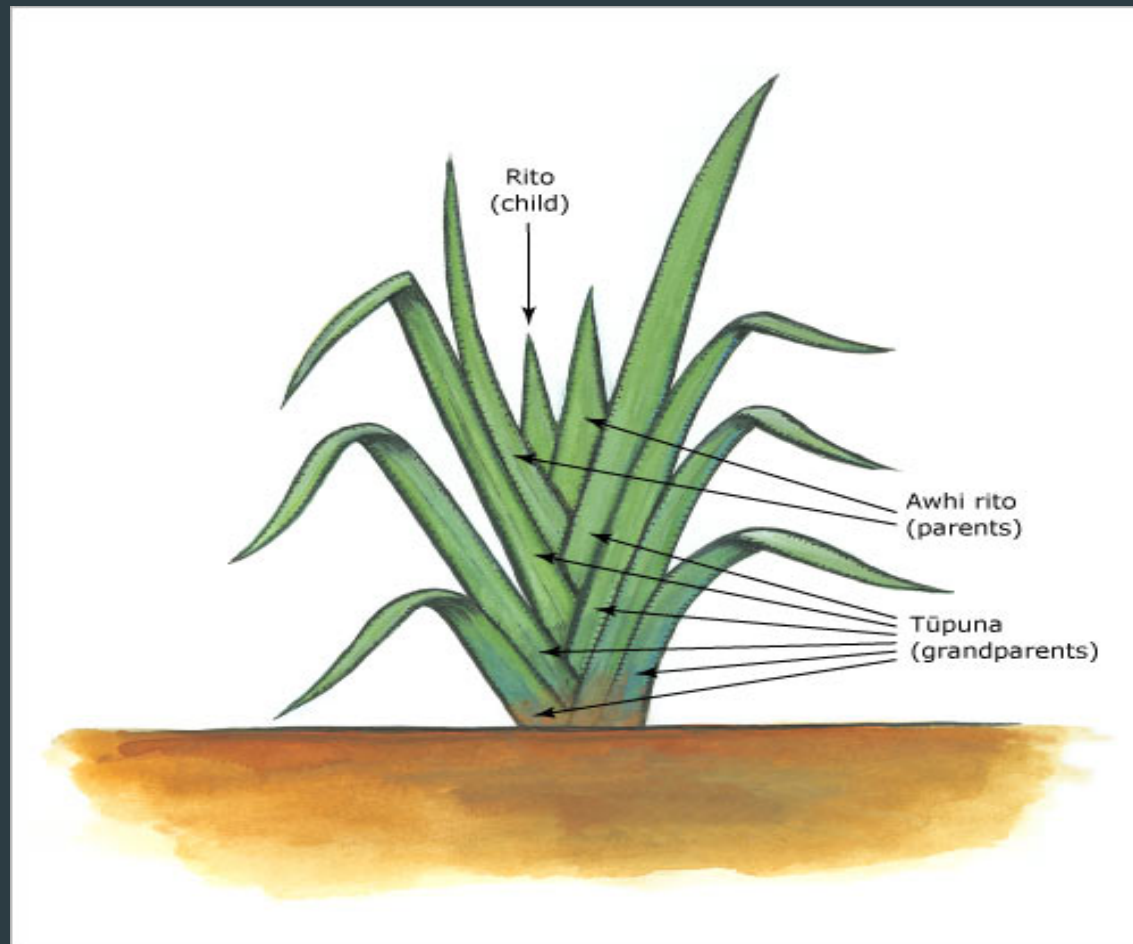
# VALUES & HOLISTIC SERVICE MODELS

## *Te Whare Tapa Whā*



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# Te Pā Harakeke



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# APPLICATION OF FUNDAMENTAL PRACTICE PRINCIPLES

- ▶ We are dealing with an organic brain injury over which the individual has had no say but must live with the rest of their life
- ▶ It is not that “they won’t” but they “can’t” ... without the right supports in place.
- ▶ Active implementation of the Treaty of Waitangi - Te Tiriti o Waitangi principles of Partnership, Participation and Protection in our practice.
- ▶ A focus on strategies that build self-esteem in the FASD individual.



- ▶ A focus on practical and realistic strategies - Doing what works for that person and family/whānau.
- ▶ Building on the FASD individual's interests and strengths by using a strength-based approach and strategies.
- ▶ A focus on strategies that build capacities and resilience within the FASD individual and their family/whānau to support future success.
- ▶ Identification and management of safety concerns and risks associated with the FASD individual and their family/whānau.



# LEARNING OBJECTIVE FOUR: How do we meet our Clients Needs?

- ▶ Listen to understand, not to reply!
- ▶ Gather holistic information
- ▶ Identify & focus on priority areas of concern
- ▶ Develop individualised strategies
- ▶ In-home support
- ▶ 24 hour availability for crises



- ▶ Providing advocacy and support in meetings
- ▶ Spend time with the whānau
- ▶ Lived experience means more acceptance:  
because “they know, we know!”
- ▶ Sharing examples
- ▶ “Laughter is good medicine”
- ▶ “You wouldn’t believe ...”



# SERVICES AND PROGRAMMES BASED ON NEEDS & GAPS

- ▶ Education and Raising Awareness
- ▶ Advocacy
- ▶ Programmes
- ▶ Services



# BEACON AOTEAROA – OUR ANNUAL FASD AWARENESS EVENT 9<sup>TH</sup> SEPT



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# AND FINALLY FASD – “FANTASTIC AARON SUCCEEDS DESPITE.....”



Big Thanks to Kerry Howell, The Workshop, Ahuriri, Napier who has kindly paid conference fees for us to attend.





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# Q&A Posers

- ▶ Do you have experience in getting client engagement from different cultures? What worked, what didn't, & why?
- ▶ What are the gaps you have experienced in service provision for FASD adolescents and adults?
- ▶ Have you been able to overcome these and how?
- ▶ What is your biggest concern or what do you see as the most important gap in service provision in your country?

