BEACON Aotearoa
Shining Light on Fetal Alcohol Spectrum Disorder [FASD] and Neuro-disability
E TIAHO ANA TE MARAMA I RUNGA I FETAL WAIPIO TŪĀWHIORANGI WHAKARARURARU [FASD] ME NEURO-HAUĀTANGA
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
- 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.

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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
LEARNING 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.

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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

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BEACON AOTEAROA – OUR ANNUAL FASD AWARENESS EVENT 9TH SEPT

BEACON Aotearoa: Shining a light on Fetal Alcohol Spectrum Disorder and Neurodisability
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?