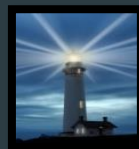
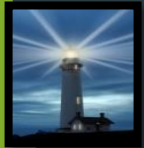


Reach for the Stars



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Not without
some Meteorites
steering us off
course.



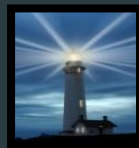
Quotes from Kerry Howell

- ▶ *“This is a road Aaron and many others with FASD never chose to travel along. It’s long and winding with a lot of bumps on the way. Keeping on the straight and narrow is, and never will be, easy. This is why we all do what we do, otherwise what other choice is there? . THERE ISN’T !”*
- ▶ *“If all the roads to success were straight forward the world would be a very boring place”*



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?



BEACON'S GENESIS

- ▶ **Two Professional, Passionate parents**
- ▶ **Backgrounds in Paediatrics, Nurse Education, Policy Development, Government Management and Administration, Dispute Adjudication and Mediation, Foster care, and Social Work.**
- ▶ **Trained in evidence-based programmes that work for FASD.**



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OUR GOAL

- ▶ To improve 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
- ▶ To get the best out of existing services
- ▶ Advocacy for better services – particularly for Adolescents and Adults
- ▶ “Fighting” for individuals like our children
- ▶ Effective and realistic services



SOME NZ ISSUES

- ▶ No accurate NZ Data
- ▶ Based on international research:
 - 1% = 22 children in Hawke's Bay province each year
 - 5% = 110 children in HB each year (5 classrooms every year)
- ▶ Schools in crisis
- ▶ Quote by Russell Wills , previous Children's Commissioner -
“ It is a Hidden Tsunami”
- ▶ Some funding for 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
- ▶ Fundamental to our practice are Te Tiriti o Waitangi principles of Partnership, Participation and Protection
- ▶ Services that cross the lifespan



VALUES & HOLISTIC SERVICE MODELS

Te Whare Tapa Whā



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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, flexibility
- ▶ 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”



Key Programmes and Services

- ▶ Guardian Angel In-Home Parenting Programme
- ▶ Kia Kaha (Stay Strong) Resilience Programmes
- ▶ Relax Kids Programmes
- ▶ Paediatric Continence Services



FASD Whole Body Approach

relax Kids
creating calm confident kids



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FASD Awareness Day 2018



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FASD Awareness Day 2018



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The Hurdles encountered



The Beginning



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Aaron's Journey - let downs and exclusions

- ▶ Challenges at school - lasted 3 weeks in High School
- ▶ Farming courses at local college - passionate and motivated. Short term, and due to disability not accepted into the full-time farming course. Nothing else available.
- ▶ Enrolled in a Disability Employment Service - both had minimal knowledge of FASD - said he was not work ready. Gave up
- ▶ Neighbour offered Aaron casual work in his painting business. Gave information on FASD. Called the next day to say he felt 'the fumes' from the paints might affect his brain. Not prepared to give him a chance.



Dilemma with Employment

To tell or
not to
tell?



If you do
tell, how
much do
you tell?



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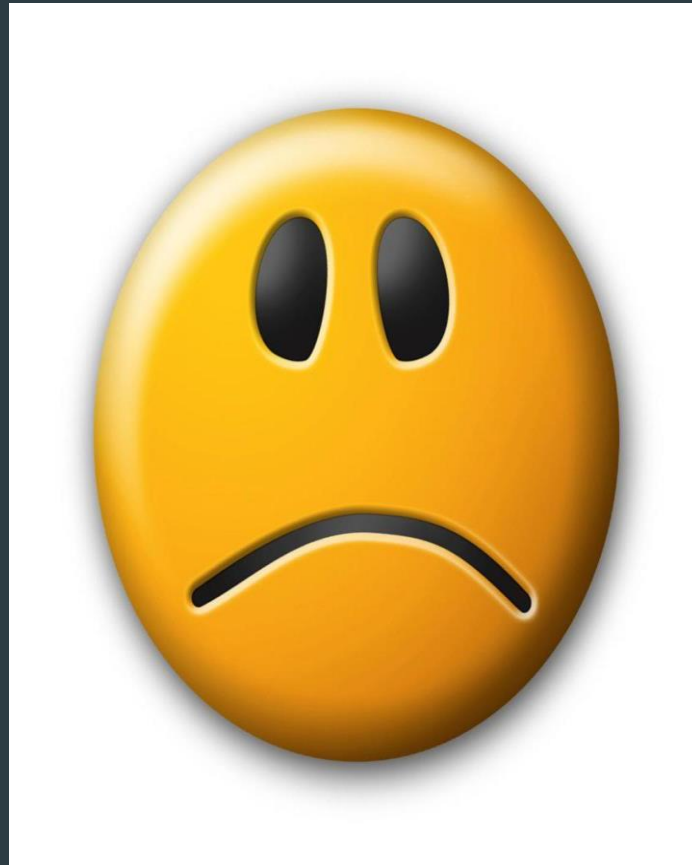
Before Work

Boredom leads to trouble



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Mental health issues



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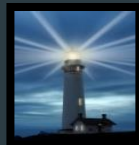
FASD and Employment - A NZ Study (Salmon and Buetow, 2011)

- ▶ 6 Emerging themes - daily challenges in the classroom, daily challenges in the workplace, coping with mental health issues, socialization difficulties, and involvement with the law and authority
- ▶ Many of them disavowed having FASD which made it more difficult to accept support offered or be successful in the workplace.
- ▶ However, with maturity and getting to know about their S & S of FASD they learned to accept their disability
- ▶ Study concluded that there needs to be greater awareness across health and social agencies, educational, employment, criminal justice systems, and policy-makers re: the complex problems that FASD individuals and their families face



*Your angels guide,
protect,
and love you
through every
dark moment,
and help you
to find the
Light again.*

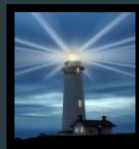
Then A Miracle



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“The Workshop, Ahuriri” : Auto and Marine Services



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A Few Words From Aaron

- ▶ I AM GOING TO DO SOWELL IN AUS I AM GOING TO HAVE A GOOD TME WITH EVERYONE AND NOT BE MEAN TO THE OR ANYTHING LIKE THAT
- ▶ We are going to have lots of fun whiles where are are on holiday me and kerry are going to get along no. More silly behaviour on the rest off the holiday. We are going to do so well at this talk. I am going to do so good at this first time doing this talk I know i am going to do so well at this and i can do anything I putt my mind to it i know i can. No matter what people say about me or to me I can do it. Putting my mind to it i can do it and stay focused at what is at task. I am going to actually speak up for those that have a disability I am going to make them other people so proud

What did working with Kerry do for me?

- ▶ I felt needed and useful
- ▶ A purpose to get up every morning
- ▶ Happier and healthier - no longer depressed
- ▶ Felt important - loved my uniform
- ▶ More positive - “ I can do this” attitude



My Achievements



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Hurdles

- ▶ Knowing when I needed to ask for help
- ▶ Scared to say when I couldn't do something
- ▶ Scared when I had made a mistake - would he growl at me?



Hurdles

- ▶ Honesty - not to cover up or tell a lie about something
- ▶ Frustration when I got stuck, especially when I had been able to do it the day before
- ▶ Being able to focus on work when other problems were in my head
- ▶ Leaving my cellphone alone during work hours



How My Boss Helped

- ▶ Got to know Me
- ▶ Clear consistent communication
- ▶ Structure and routine each day
- ▶ Working alongside me
- ▶ Would show by drawing diagrams
- ▶ 7 P's - Plan, Prepare, Positive Patience, Practice, Praise, Perserverence



"Don't walk behind me;
I may not lead.
Don't walk in front of me;
I may not follow.
Just walk beside me
and be my friend."



How My Boss Helped Me

HE BELIEVES IN ME

FLEXIBILITY WITH WORK
The Workshop Bus



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Kerry's Journey - The First 3 weeks



- ▶ fantastic talented young man and willing to learn
- ▶ doing what he is passionate about
- ▶ he is a pleasure to be around



What/who helped in the first few weeks

- ▶ Leaflet “FASD in the Workplace” by Claire Gyde
- ▶ Daily communication with *BEACON* - helpful practical advice from both Lisa and Kim
- ▶ *Beacon Bites* around communication
- ▶ “Broken Beaks and Wobbly Wings” story by Theresa Kellerman
- ▶ Aaron’s Safety Plan - explained in detail by Lisa
- ▶ “Trying Differently, Rather than Harder” by Diane Malbin



After 3 weeks - Honeymoon well and truly over

- ▶ Dealing with fixation over Aaron wanting to buy a bike
- ▶ Lead to a 'meltdown'
- ▶ True reality of this invisible and complex disability



BEACON Notearoad Shining a light on Fetal Alcohol Spectrum Disorder and Neuro-disability

...a person with FASD is
...alk in the park".

ark!!!!



STEPPING UP TO SUPPORT AARON



Lots of discussion and information sharing with Beacon Aotearoa



Knowing and caring about the individual person and how FASD affects them uniquely



Advocating for Aaron - at work, the courts, support agencies, friends and family



Shift in my thinking from “Won’t to Can’t”.



Observe the Early Warning Signs that Aaron is not coping with something, and being that “external brain” to support and guide.



Realization that it takes a circle of informed people to support an individual with FASD.



Supporting a Person with FASD in the Workplace

- ▶ Applying the Treaty of Waitangi Principals to FASD
- ▶ Participation
- ▶ Partnership
- ▶ Protection



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FASD and Employment

- ▶ Employment can be a protective factor against secondary disabilities, and can reduce poverty and dependency
- ▶ Focus on the individual strengths of the FASD Individual
- ▶ Cognitive , emotional and behavioural difficulties can make it difficult to obtain, sustain, and maintain employment

Green C, R 2016



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Some NZ Facts on Employment for Disabled People.

- ▶ 1 in 5 NZ have some form of disability
- ▶ Huge gaps between disabled and non-disabled employment rates - approx. 23% of disabled adults employed compared to 69% of non-disabled (similar rates as Canada and Australia)
- ▶ Unemployment rate for disabled people (11.4%) was more than double the rate for non-disabled people (4.5%)

Labour Market Statistic (Disability): June 2017 Quarter - Media Release



Busting the Myths About Disabled Employees

- ▶ **Myth 1** - Providing accommodations for disabled people are expensive. Only 10% of disabled workers required modification. **The most common reasonable accommodation is flexible working arrangements.**
- ▶ **Myth 2** - Disabled employees are a greater health and safety risk - False
- ▶ **Myth 3** - Disabled employees have a higher absentee rate - False



Supporting FASD in the Workplace - Recipe For Success

1 cup of education

1 cup of structure and routine

1 cup of practical, hands -on training and coaching

Add plenty of repetition and praise

1 good handful of supervision

*Mix well with the spoon of understanding and
tolerance*

Claire Gyde 2016

FASD-CAN



What have I learned on this FASD Journey



Once you know better you do better - knowledge is everything



Make the most of the best times and least of the worst - humour helps.



Move on quickly - tomorrow is a new day



Never give up even though at times the going really gets tough



Never blame a person with FASD



Never blame myself when things go wrong



A Final Note



Everyone is Part of the Solution!



The Four A's - Awareness, Acceptance, Accomodation, Action



Proactive - Alcohol causes a lot of harm in our community. Lobby at every level for change in our laws



FASD informed community - service providers. Every single person will know someone affected by FASD if we do not take action now.



You have to believe in them for them to believe in themselves



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- ▶ Toolkit for Parents, Caregivers and Families : www.nofasd.org.au
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- ▶ Egerton , J (2013): Fetal Alcohol Spectrum Disorder - Interdisciplinary Perspectives. Barry Carpenter
- ▶ Trying Differently, rather than Harder (2014) . Diane Malbin
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