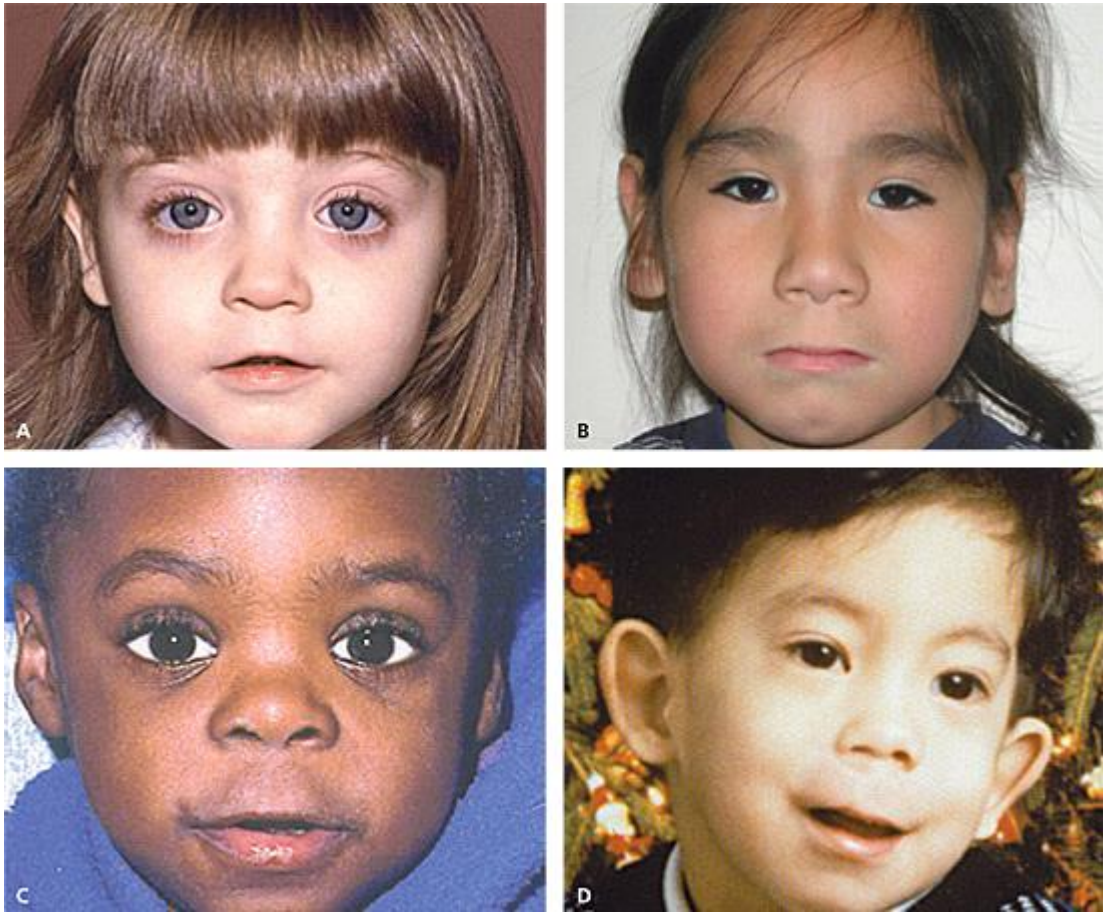
Identifying and Meeting the Complex Needs of Children with FASD

Dr Valerie McGinn, Paediatric Neuropsychologist
The FASD Centre, Aotearoa
vmcginn@fasd.org.nz

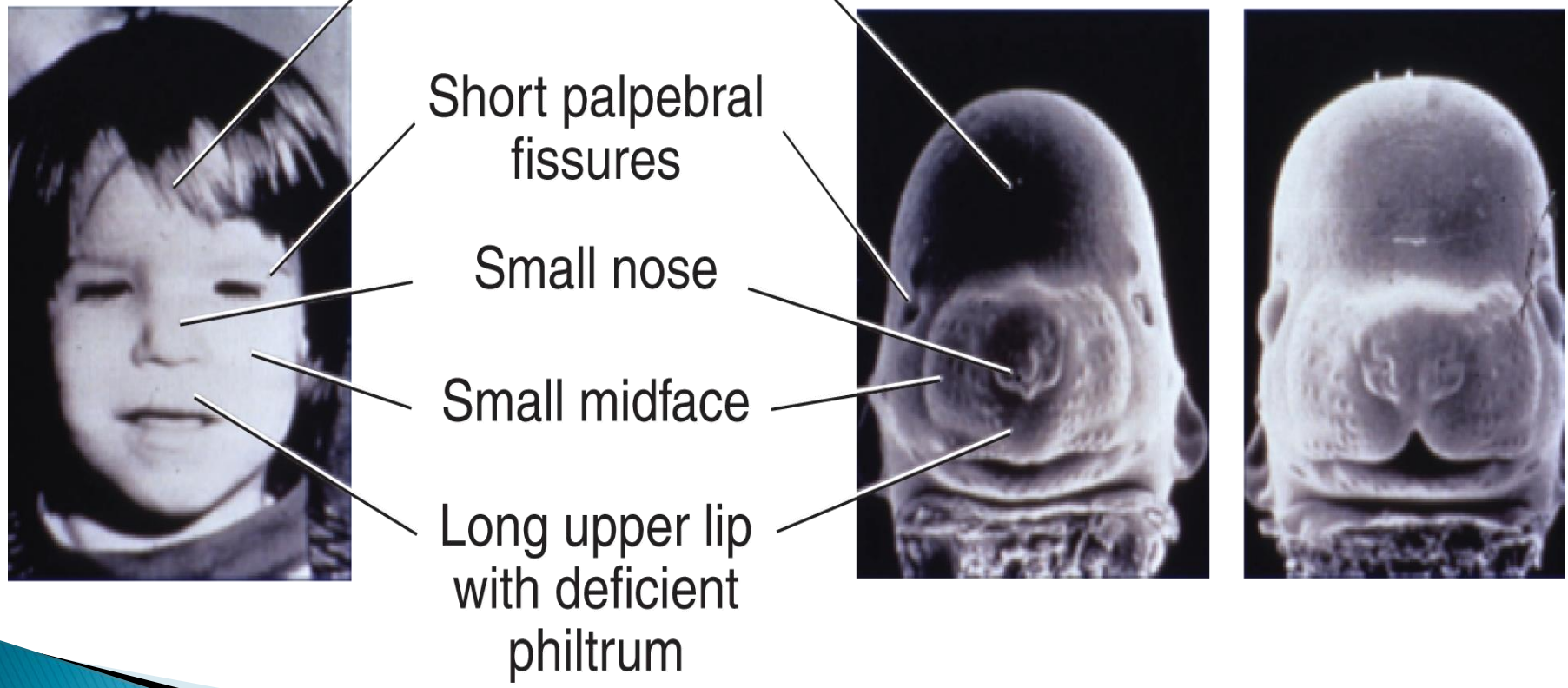
Alcohol is a neurotoxin and teratogen

- FASD is a diffuse acquired brain injury (i.e. brain damage) of the developing fetus
- How the brain is damaged depends on what stage of development it is exposed to alcohol
- How much of the brain is damaged depends on exposure (dose) and vulnerability
- Each person is affected in a unique way
- FASD is a brain based disability expressed through behaviour

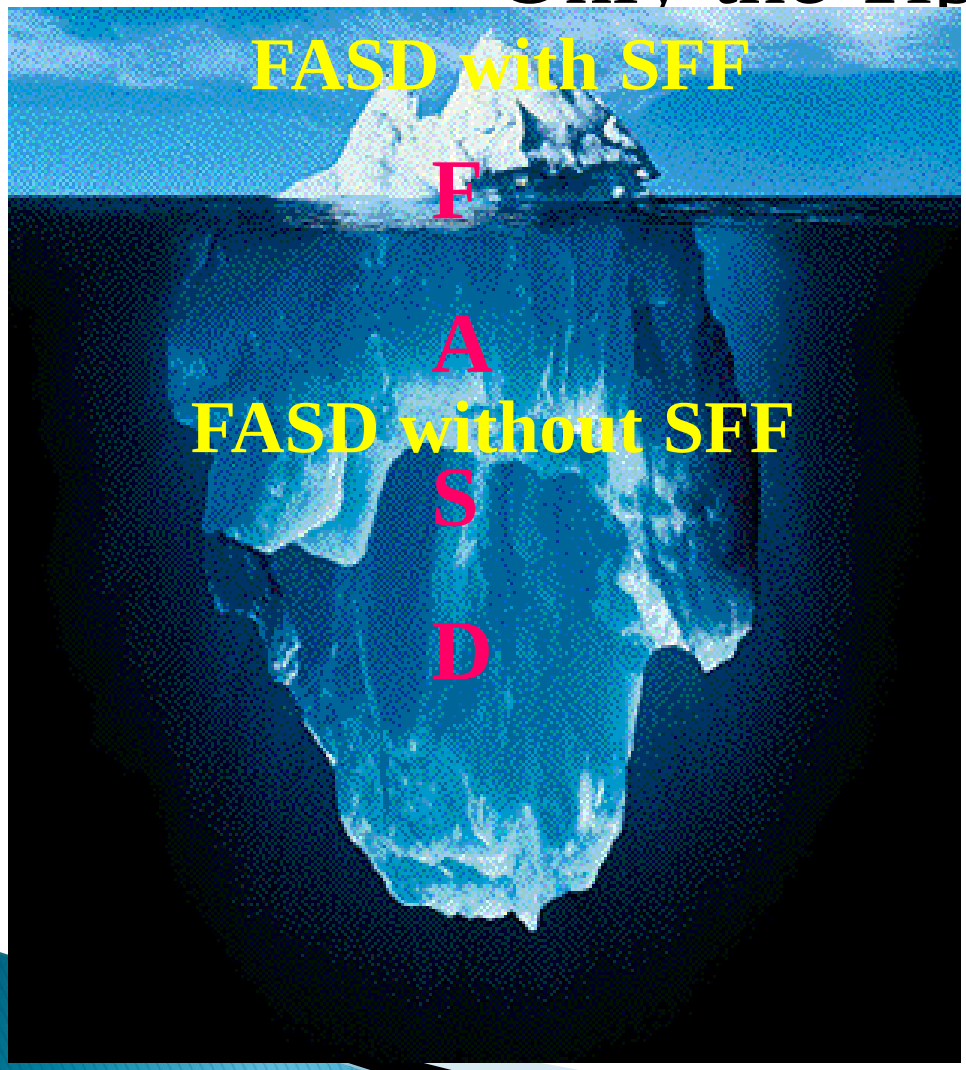
Diagnostic Criteria – FAS



Animal Models – mouse



FASD with Sentinel Facial Features – Only the Tip of the Iceberg

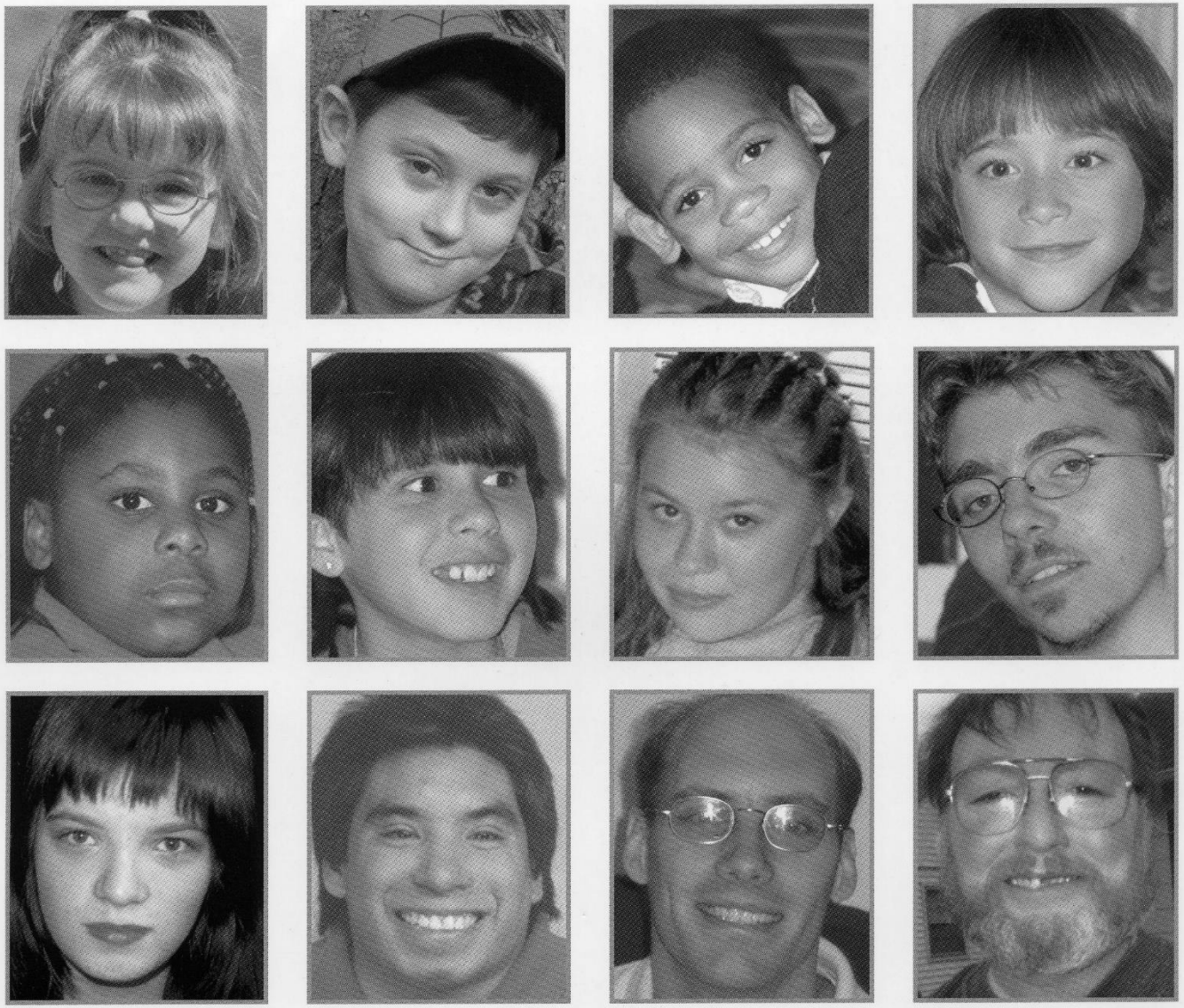


FASD without SFF:

- Clinically look normal, often behavioural issues main symptom
- Neuropsychology testing reveals disability
- Cannot reach their potential

Adapted from Streissguth and Cook

Which Person Has Brain Damage From Prenatal Alcohol Exposure?



Prevalence of FASD

- Internationally 1-4% of births
- Prevalence of FASD in AU and NZ is unknown, may be significantly higher than US or Canada (2-3% WHO study, 2018)
- Otago study 12% heavily exposed creating high risk, 24% reported some drinking post pregnancy recognition, 34% drank at some time (Mallard, 2013)

On a spectrum not a continuum

FASD disproportionately affects children in care

- US data indicates rates of FASD increased 10 to 15 times in foster care systems and 70% of kids diagnosed with FASD are or have been in care (Burd et al, 2011)
- In Canada 30.5% to 52% of children in foster care have FASD (Institute of Health Economics, 2013)
- They go largely unrecognised and undiagnosed in NZ although this is rapidly changing
- Complex difficulties often mistaken for Attachment Disorder, ADHD, ODD, Conduct Disorder
- Children seen in Gateway are at very high risk of FASD
- 10 to 23% in correctional facilities in US and Canada have FASD (IHE, 2013)
- 36% in Banksia Hill Youth Detention Centre

Why diagnose FASD?

- It is a medical disorder with neuro-behavioural symptoms
- Enter into a dialogue with families, caregivers, professionals and others involved to describe and understand FASD
- Qualify child for services: ID, social, education
- Define interventions to address disability and maximise potential
- To stop wasting time and resources with misdiagnosis and mismanagement

Previously…..

- Up until 2016 NZ used Canadian 2005 Guidelines after an investigation into the most appropriate diagnostic schema in 2008
- These guidelines have now been updated, January 2016, NZ teams have been using them (Cook et al, 2015)
- Australia have developed similar guidelines (Bower & Elliot, 2016)
- Now FASD is the diagnosis
- No longer use 4-Digit Code (no growth)

FASD becomes the diagnostic term

FASD with Sentinel Facial Features replaces:

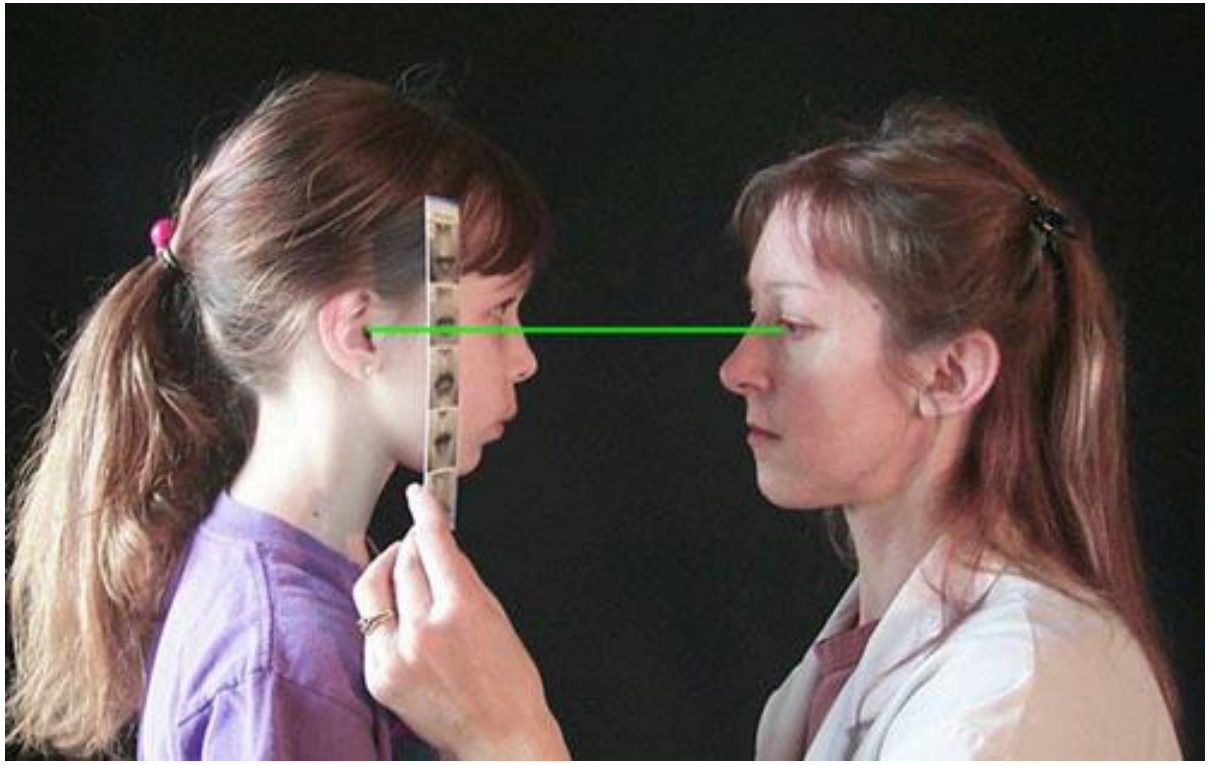
- Fetal Alcohol Syndrome

FASD without Sentinel Facial Features Replaces:

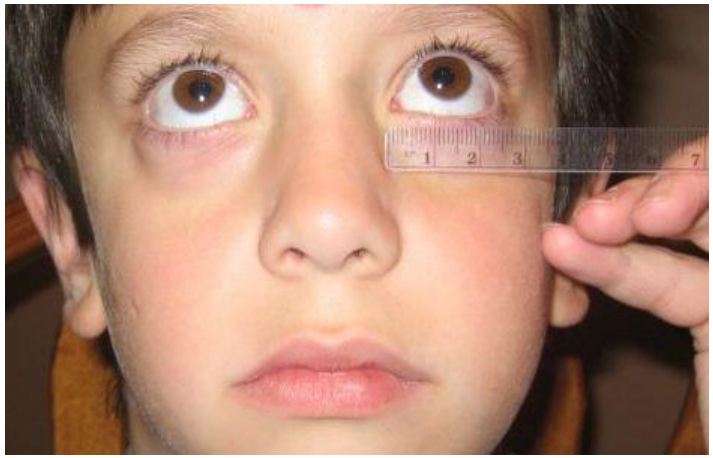
- Partial Fetal Alcohol Syndrome
- Alcohol Related Neurodevelopmental Disorder

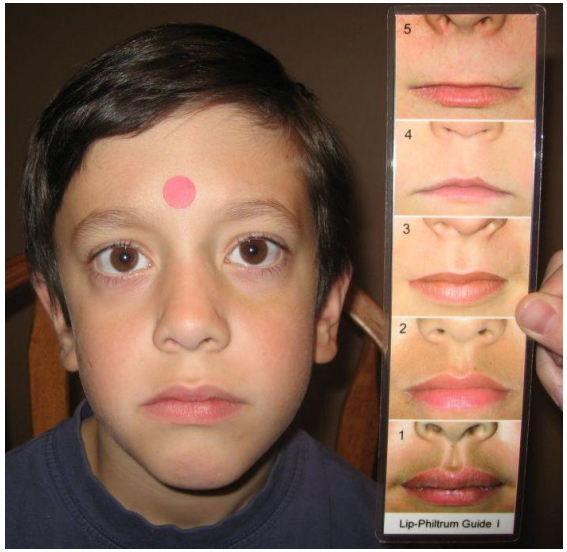
At risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol exposure (designation similar to Neurobehavioural disorder)

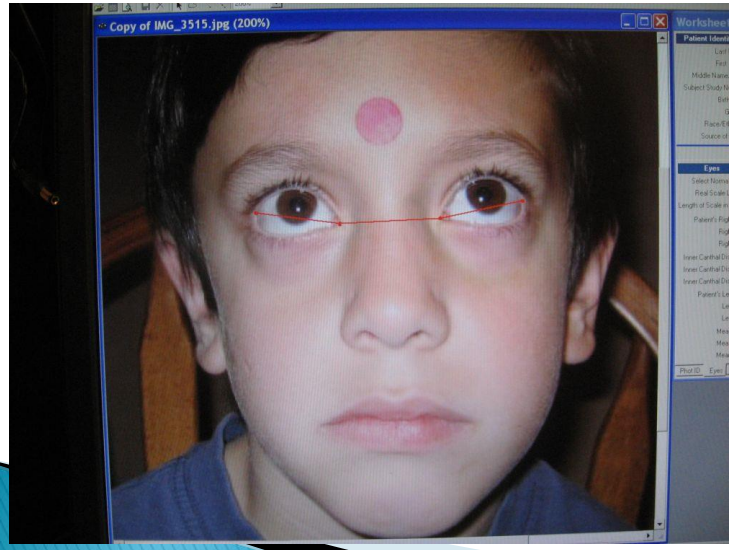
Lip/Philtrum Pictorial Guide

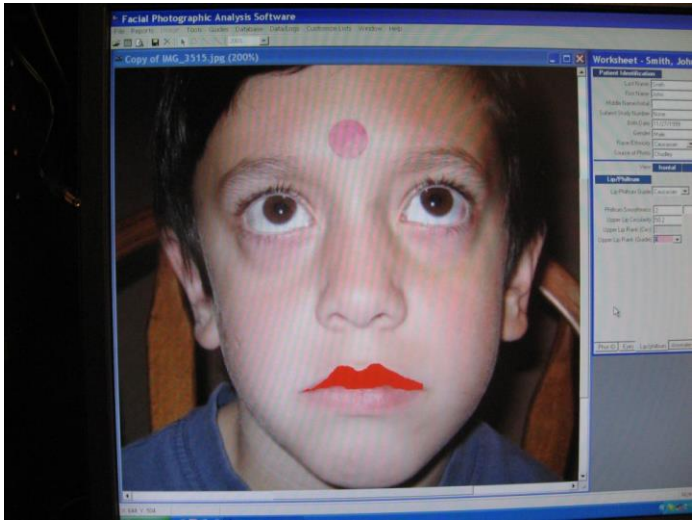


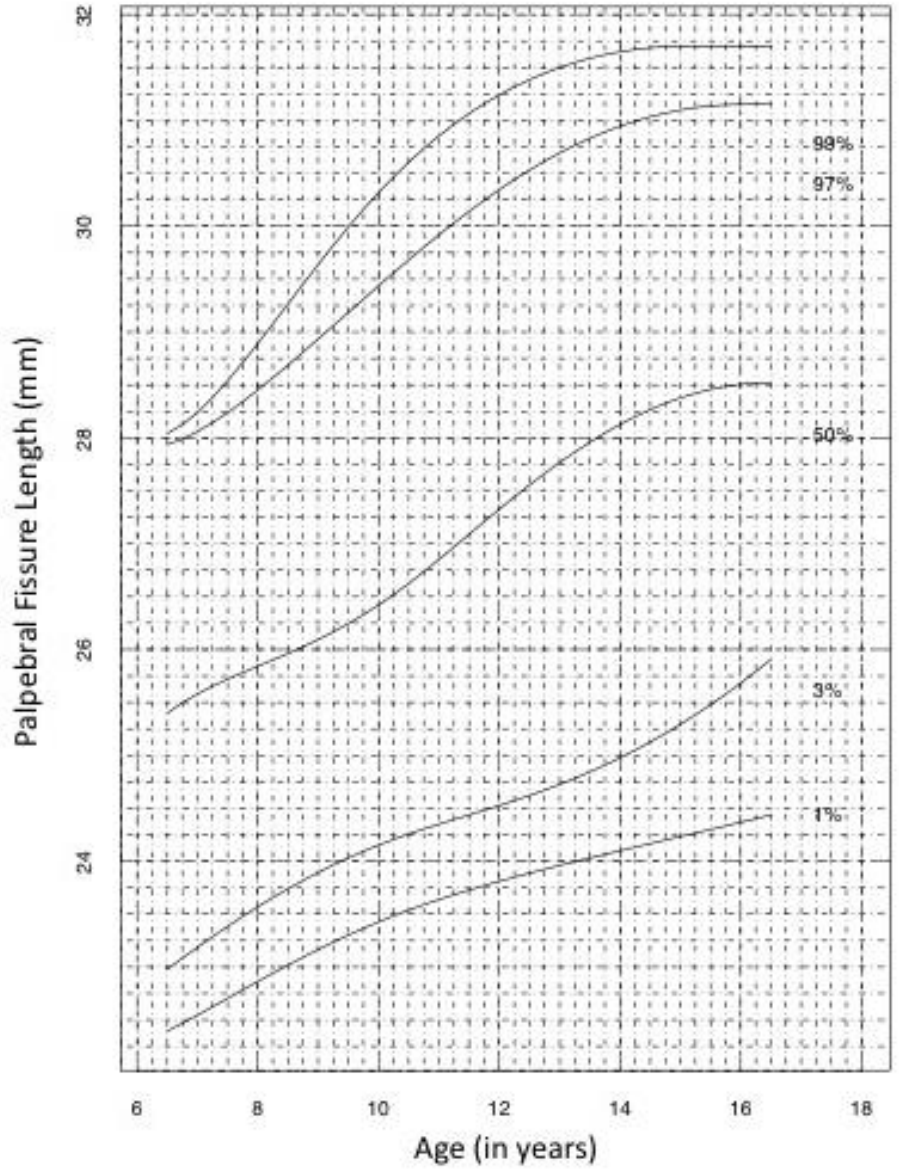
The 4-Digit Code, Astley, 2004



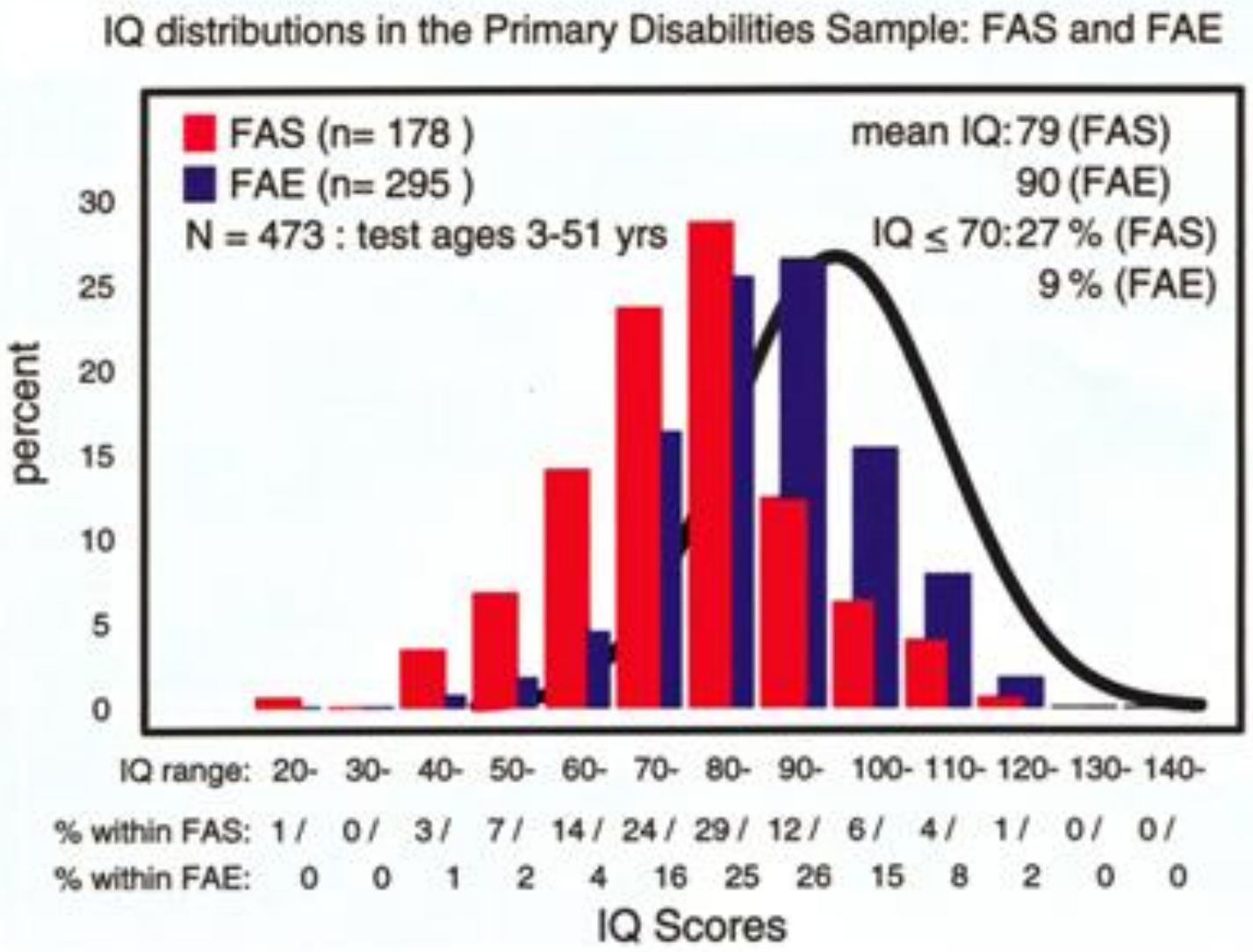

5
4
3
2
1
Lip-Philtrum Guide I


Copy of IMG_3515.jpg (200%)


Facial Photographic Analysis Software
Copy of IMG_3515.jpg (200%)



From Clarren, Chudley, Wong et al.,(Can J Clin Pharmacol FAS Res, 2010)



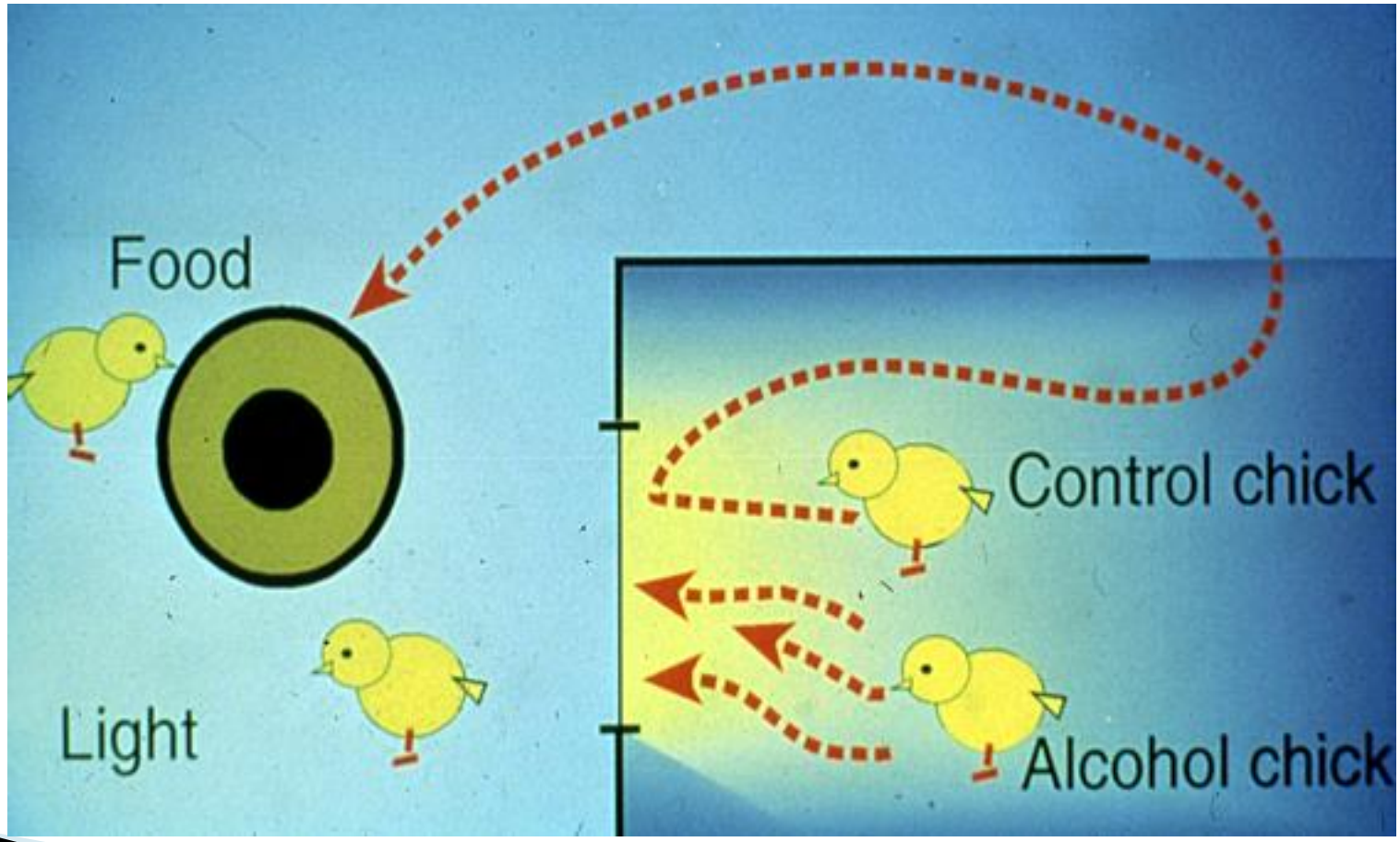
Streissguth et al (1996). *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE).* Final Report. University of Washington.

Multidisciplinary Assessment Process

- At end of assessment the TEAM should be convinced that the overall presentation is one of severe and pervasive disability across multiple convergent sources of evidence
- Diagnosis of FASD implies that alcohol is the causative factor and not just associated with
- Therefore stringent cut off remains
- However, clinical training and judgment are required to interpret test results and experienced clinicians will evaluate scores within the context of a complete assessment picture

ALCOHOL EXPOSED CHICK

Alcohol Chicks Fail Detour Learning Test



Neuropsychological Assessment

- Identify how organic changes to the brain have resulted in a spectrum of difficulties and define them
- Provide empirical data for diagnosis
- Define strengths that can be harnessed for the future
- Provide roadmap for future management

A diagnosis of FASD is only made when there is evidence of pervasive brain dysfunction, which is defined by severe impairment (below 3rd percentile) in 3 or more of the following neurodevelopmental domains:

1. Motor Skills
2. Neuroanatomy/Neurophysiology
3. Cognition
4. Language
5. Academic Achievement
6. Memory
7. Attention
8. Executive Function, including Impulse Control and Hyperactivity
9. Affect Regulation
10. Adaptive Behaviour, Social Skills or Social Communication

Executive Skill Deficits Typically Seen in FASD

- Poor organization, planning, strategy use
- Concrete thinking
- Lack of inhibition
- Difficulty grasping cause & effect
- Inability to delay gratification
- Difficulty following multistep instructions
- Difficulty changing strategies mid-stream (perseveration)
- Poor judgment / illogical decisions
- Inability to learn from experience
- “Fight or flight” panic under pressure
- Poor processing of social information
- Confabulation
- Lack insight into disability

Social Skill Deficits Typically Seen in FASD

- Lack of stranger fear
- Often scapegoated
- Naïve and gullible, easily manipulated
- Immaturity
- Lack of self-awareness
- Lack of other-awareness (boundary problems, empathy deficit)
- Excessive demand for attention
- Poor understanding of social cues
- Clinically significant inappropriate interactions

Chronological vs Developmental Age

Timelines

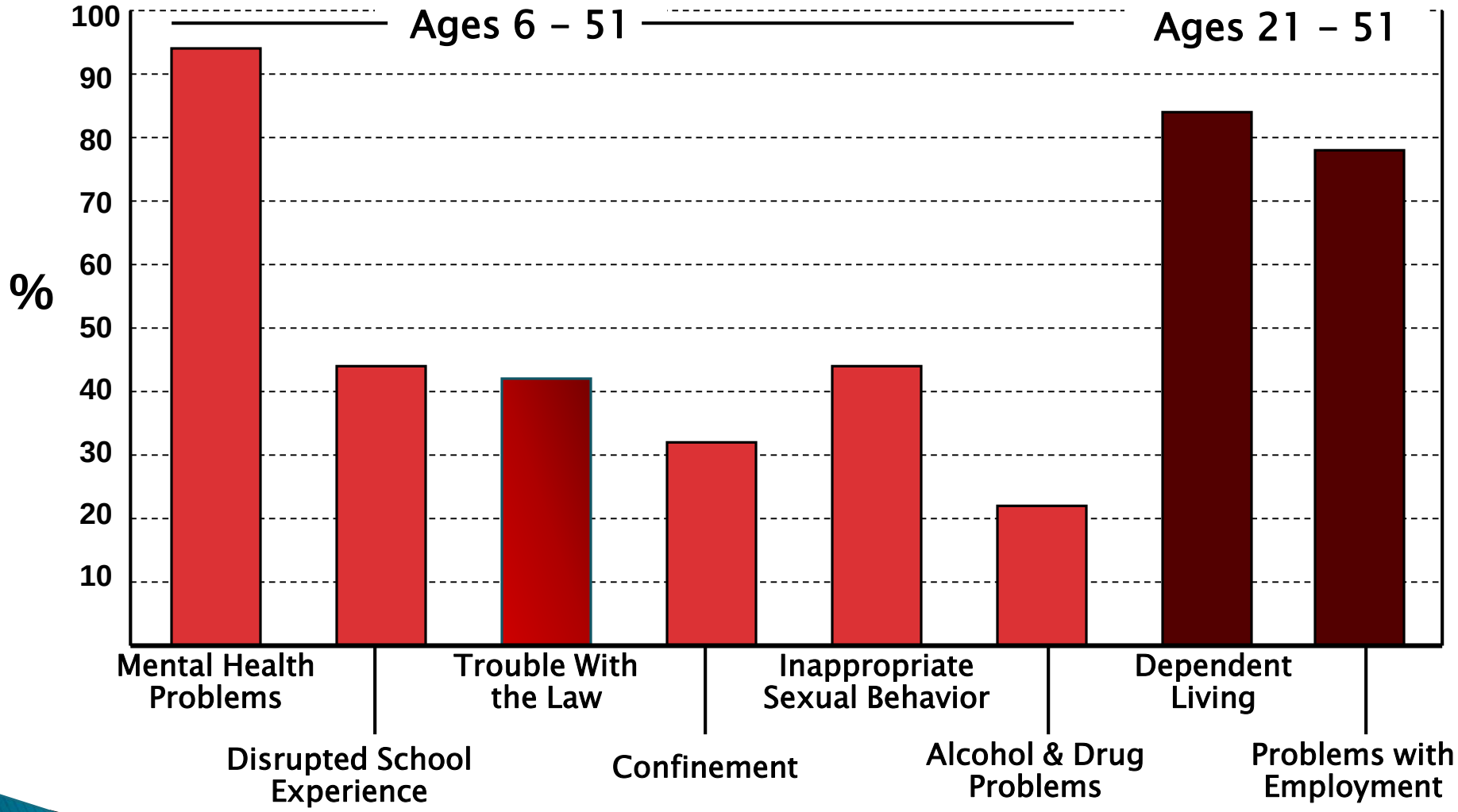
- **Chronological Age -- -- -- -- -- -- -- -- -- -- 18**
- **Expressive Language -- -- -- -- -- -- -- -- -- 18**
- **Social Maturity -- -- -- -- -- -- - -- 10**
- **Math Skills -- -- -- -- -- 8**
- **Reading Decoding -- -- -- -- -- - -- -- -- 14**
- **Reading Comprehension -- -- -- 9**

Typical developmental variability seen in adolescents with an FASD.

Source: Malbin, 2002. Used with permission from Diane Malbin, MSW.

FASD

Secondary Disabilities



Protective Factors

- Diagnosis about age 8 years
- A stable home for 3 years
- An education adapted to FASD
- No abuse or exposure to violence

Taking a Brain Based Approach to thinking about and responding to FASD

A brain based approach

Understanding neurobehavioural challenges and providing appropriate adaptations to reach full developmental potential for their disability

Focus on changing the environment to prevent frustration and provide support

Not target and change a behaviour as in learning theory/normally good parenting

Treat Children with FASD Differently

Consideration 1: Dysmaturity

- Establish developmental age
- Treat like a much younger child
- Realistic expectations so can succeed
- Play, social and learning activities at developmental not chronological age
- Talk to like a younger child
- Supervise like a younger child

Treat Children with FASD Differently

Consideration 2: Communication

- Socially interactive and love to talk
- Use simple words and sentences
- Clear directions & one step instructions
- Might agree or mimic but not understand
- Takes things literally
- Misses social cues
- Talks about what they want
- May have façade of better speech
- Will be definite and insistent

Treat Children with FASD Differently

Consideration 3: Structure Dependent

- Reliant on external direction
- Routines and repetition
- Do alongside
- Simple rules
- No wriggle room
- Will become oppositional if overwhelmed or confused

Treat Children with FASD Differently

Consideration 4: Egocentricity

- me me me children
- Can't see other points of view
- Definite and always right
- Blames others and thinks it's unfair
- It's in the brain so don't take it personally
- Empathy and sympathy lacking
- Give simple clear messages
- Don't reason because they can't

Treat Children with FASD Differently

Consideration 5: Cognitive Rigidity

- Gets fixated and preoccupied
- Repetitive
- Can only see one way
- Black and white thinking
- Can't see errors or correct
- Distract and divert before going wrong
- Error free learning
- Anticipate problems and reduce demands
- Give in because they can't

Treat Children with FASD Differently

Consideration 6: Lacks judgement

- Lack common sense
- Will mimic antisocial or prosocial
- Poor choice of friends
- Not think through to consequences
- Vulnerable to exploitation
- Easily led
- Scapegoated
- Unrealistic expectations for future

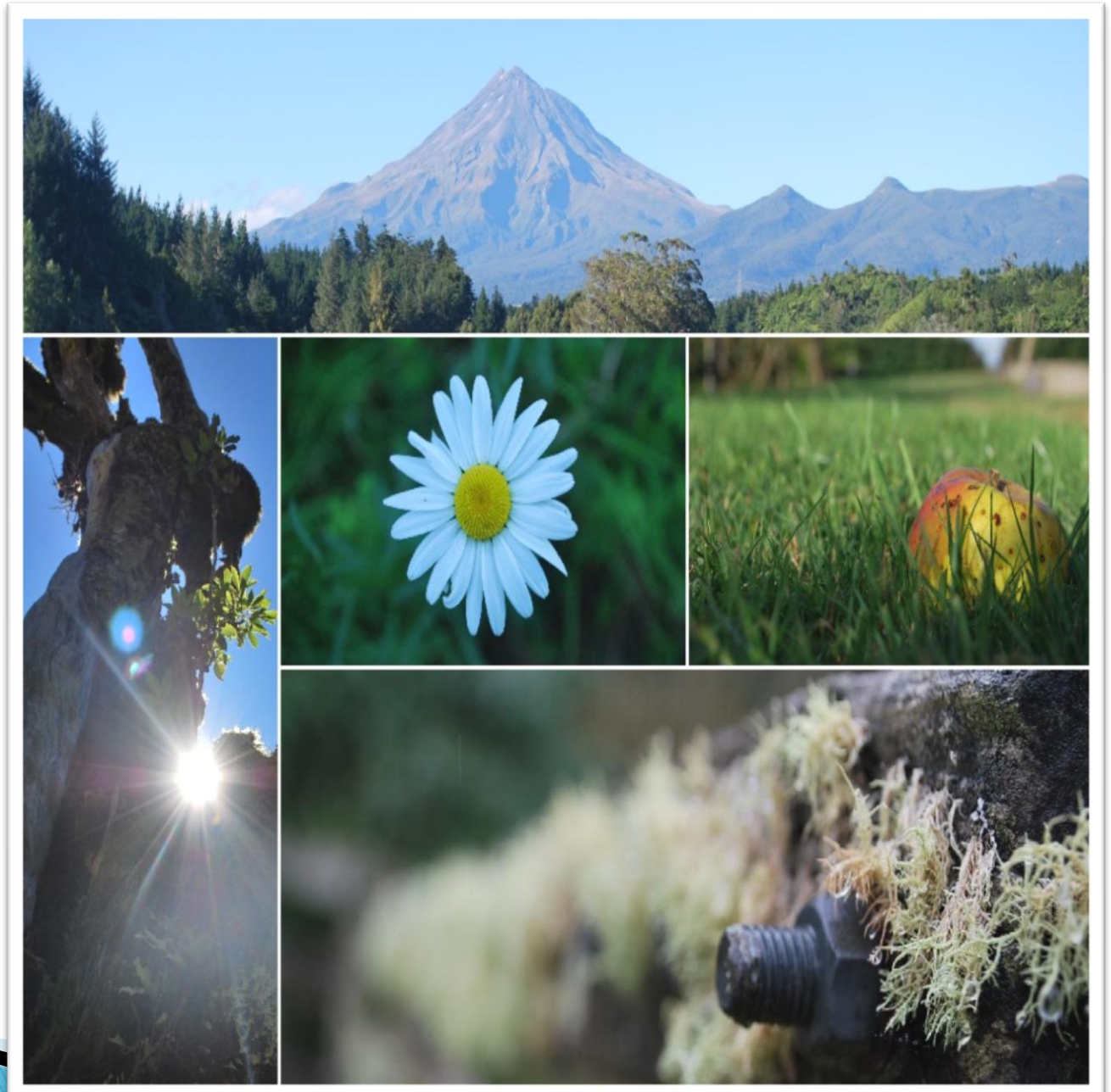
Treat Children with FASD Differently

Consideration 7: Behavioural dysregulation

- Can't moderate movements
- Sensory sensitivities
- Breaks things
- Can't take care
- Impulsive can't inhibit inappropriate actions
- Rule breaking at home school
- Community-offending
- Need for supervision

Consideration 8: Emotional Dysregulation

- Neurologically on emotional rollercoaster
- Extremes of emotions that others can't feel
- At mercy of environment
- Will escalate with stress
- Calm, keep simple and reassure
- Remove demands to de-escalate
- Don't talk and reason
- Consequences don't connect or work long-term
- Offer support not punishment



Paradigm Shifts

- Brain based disability not wilful misbehaviour
- Can't rather than won't
- Adapt environment rather than consequence
- From oppositional to can't adapt
- From attention seeking to needs lots of help
- Attachment disorder to differently attached
- Do alongside rather than independence
- Decide for rather than choices

Parenting Strategies Patrenko et al (2016)

- Parents with greater FASD knowledge were more likely to view child's behaviour as related to the FASD and use antecedent strategies. This was more effective than parents who applied consequences after behaviour and than the use of harsh consequences.
- Caregiver support and stress management for caregivers also required

5 S model

- Structure
- Support
- Supervision
- Keep it Simple
- Build on Strengths

Structure

- Regular routines and systems-visuals
- Ensure good sleep patterns
- Keep things in same place, no clutter
- Fair but flexible rules and boundaries
- Clear language and repetition
- Good role models will mimic the good and the bad
- Realistic expectations
- A stable and nurturing home
- Leisure, social and cultural activities
- Be organised before hand, don't change
- Minimise free time and choices
- Safe and consistent people to manage
- Crisis plan

Support

- Do activities alongside rather than telling
- At developmental level not chronological age
- Offer help every step of the way
- External brain someone to assist in a friendly way
- Repeat over and over and over again
- Respite care and carer support for families self care
- Encouragement and praise
- Warn ahead for change, remind, then act
- Reduce stressors and act on early warning signs of agitation
- Back off and keep quiet when angry
- Be aware of own anger, voice tone, body language that may escalate
- Avoid emotional outbursts and sooth, distract, divert
- Build collaborative circle of support

Supervision

- Monitor at developmental age not chronological age
- Reduce opportunities for child to be intrusive and inappropriate
- Ward off from potentially trouble situations
- Teach what to do if gets lost or in danger
- Reduce dangers eg. fire, knives, substances, solvents
- Screen peers and know where they are and what they are doing
- Direct supervision with younger children animals
- At risk of sexual exploitation
- At risk of offending
- Don’t give these opportunities
- Whoever supervising child needs to know about FASD and risks
- Never let talk to police alone, alert them to FASD disability

Keep it Simple

- Use concrete words
- One or at most two instructions/tasks at a time
- Provide visual cues
- Don't use conditional words (maybe probably might depends)
- Listen and adapt
- Manipulate for own good, sideways
- Nonstimulating environments
- Schedule quiet and non demanding times
- Realistic expectations and opportunities for success
- Make small steps, assign small tasks,

Build on Strengths

- Identify talents and build on them
- Use positive language about what they can do
- Praise efforts and small accomplishments
- Use community resources to build a circle of care
- Support families so that they can manage their family members with FASD in the long term
- Do alongside so that they can achieve success
- Future resilience comes from experiencing success and feeling good about themselves

Parenting Strategies Patrenko et al (2016)

- Parents with greater FASD knowledge were more likely to view child's behaviour as related to the FASD and use antecedent strategies. This was more effective than parents who applied consequences after behaviour and than the use of harsh consequences.
- Caregiver support and stress management for caregivers also required

What's needed "a stable home"

- Caregivers using FASD informed care
- Respite carers on a regular basis
- A circle of care and support wrapped around each and every child with FASD so that they can do well

FASD-CAN

"With shared strength, guidance and wisdom, those with FASD CAN grow and achieve"

- FASD-CAN (Care Action Network) supporting families and caregivers
- Charitable non-profit incorporated society made up of parents, caregivers, extended whanau and professionals united in their passion to improve the lives of those living with Fetal Alcohol Spectrum Disorders.
- Please support our families living with FASD by becoming a member

Resources

- Caregiver Curriculum on FASD 2014

http://www.fasdchildwelfare.ca/learning/caregivers

- Book on strategies for managing FASD:

http://www.faslink.org/strategies_not_solutions.pdf

- Resource for teachers – very practical:

http://www.fasdcenter.samhsa.gov/documents/Reach_To_Teach_Final_011107.pdf

Resources

- Understanding and addressing the needs of children and young people living with FASD: a resource for teachers

http://www.kimberleyfasdresource.com.au/pdf/FASD_ResourceForTeachers.pdf

- New Zealand Ministry of Education

  FASD and Learning

  Inclusive.tki.org.nz

- ORANGA TAMARIKI FASD PRACTICE CENTRE