Educational system, parental and family support

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Many questions

- FASD has been well described and the aetiology clear cut - why then does it remain a clinical challenge and a public health issue?
    - Lack of information?
    - Failure of public policy?
    - Insufficient resources?
    - Programs of uneven or poor quality?
    - Lack of expertise of clinicians?
    - Cultural barriers to tackling issue of alcohol abuse?

    - What does the road map look like?

Making a difference - the road map

- Prevention
- Early detection
- High quality (early) intervention programs

Seems pretty straightforward!

'Nothing hard is ever easy'

- Don Berwick

Core concepts of development

- Human development shaped by a dynamic and continuous interaction between biology and experience (the 'transactional model' of development)
- Developmental outcome is the result of complex, dynamic transactions between biological factors and the environment
- FASD the result of clear cut biological insult to developing brain
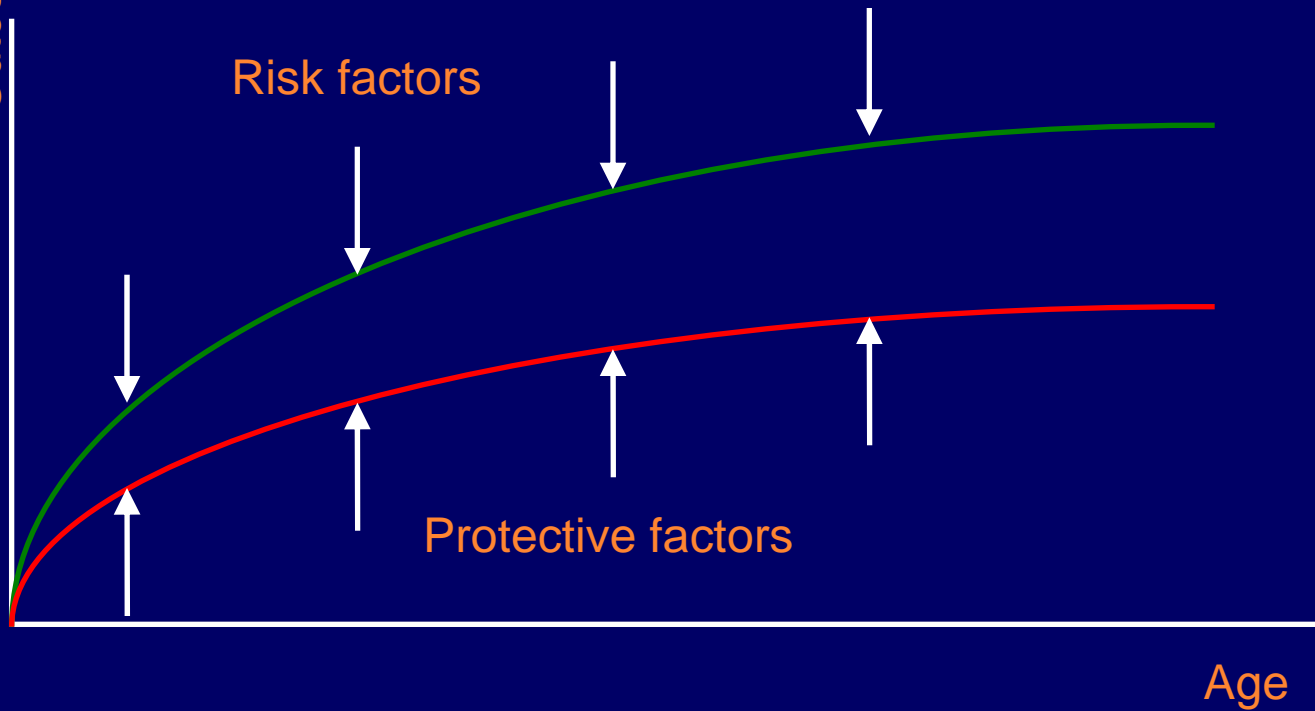- Subsequent outcomes determined largely by environmental factors

Influencing outcomes

- Biology - focus on prenatal prevention (how strong is the evidence base?)
- Environment - strong evidence base for factors that promote or hinder good developmental outcomes
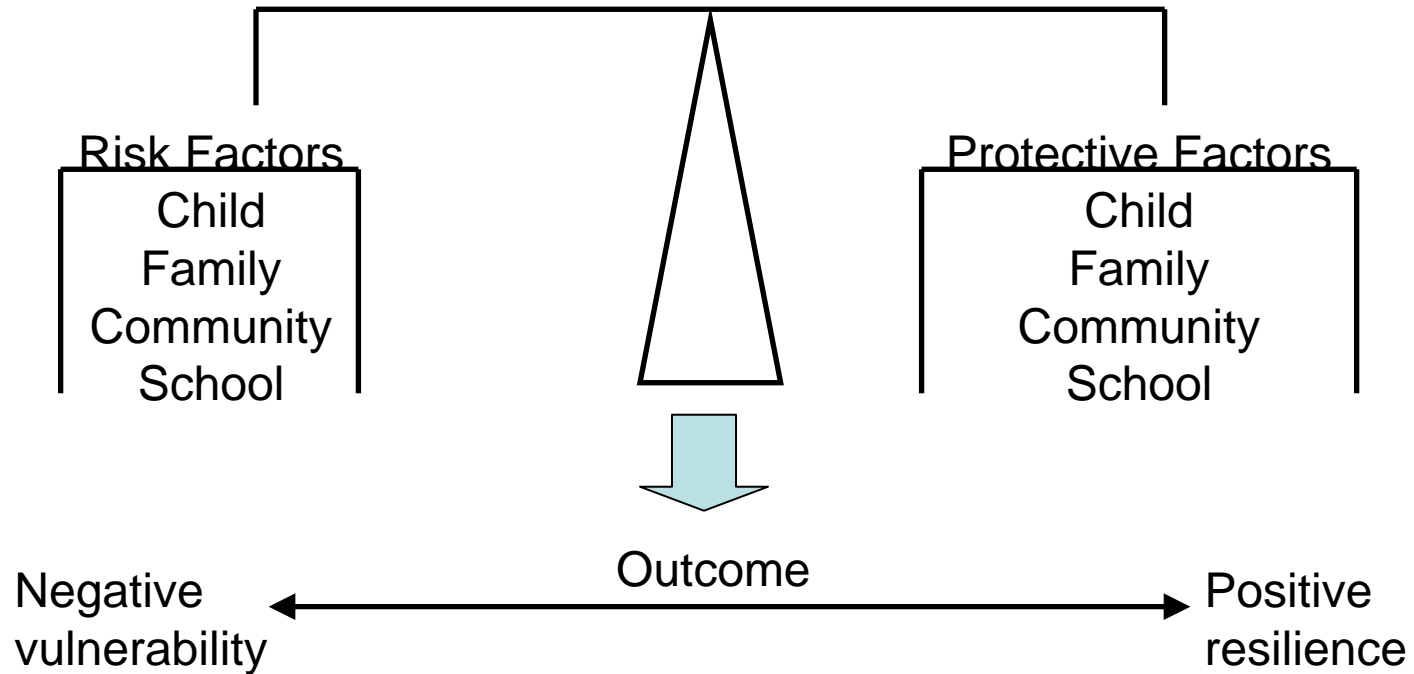
The developmental trajectory and life course

Outcome

Risk factors

Protective factors

Age

Risk and protective factors

Risk Factors

Child
Family
Community
School

Protective Factors

Child
Family
Community
School

Outcome

Negative
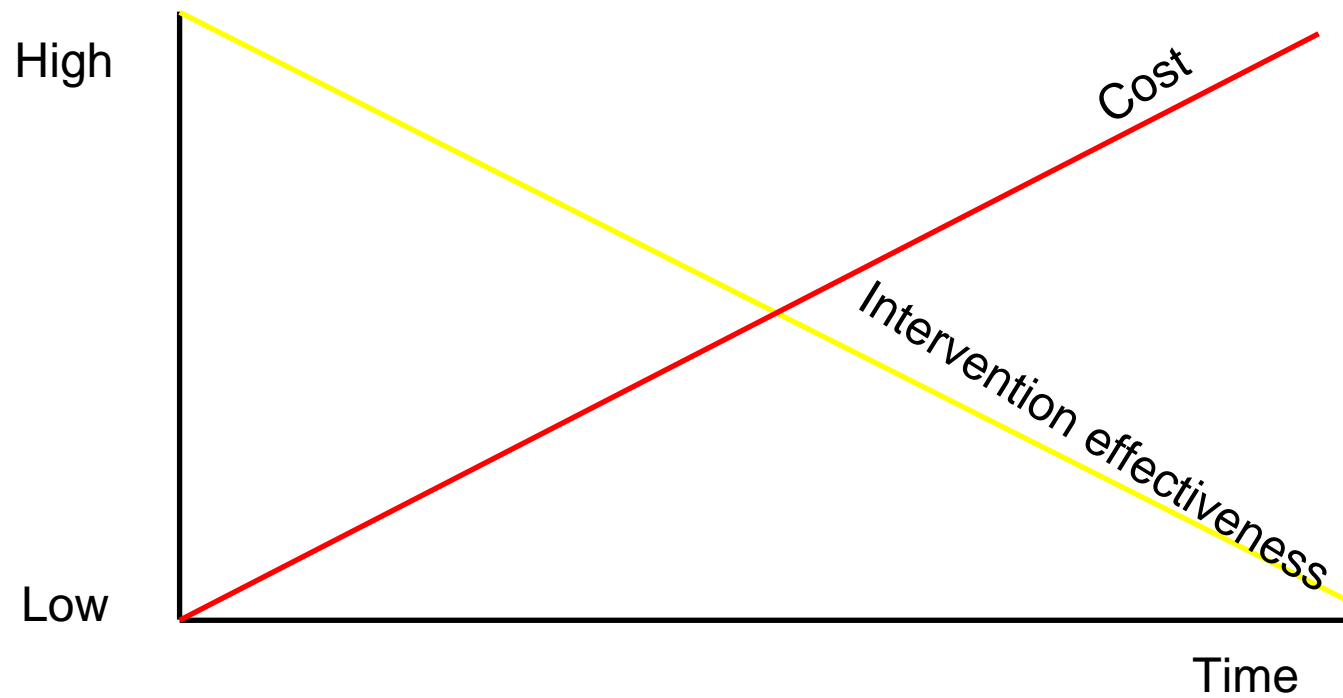vulnerability

Positive
resilience

Making a difference

- Address risk factors and emerging difficulties before they become entrenched problems

- Goal is to diminish or remove risk factors and strengthen protective factors, so improving chances of good outcome

- The earlier the better - more leverage in younger years
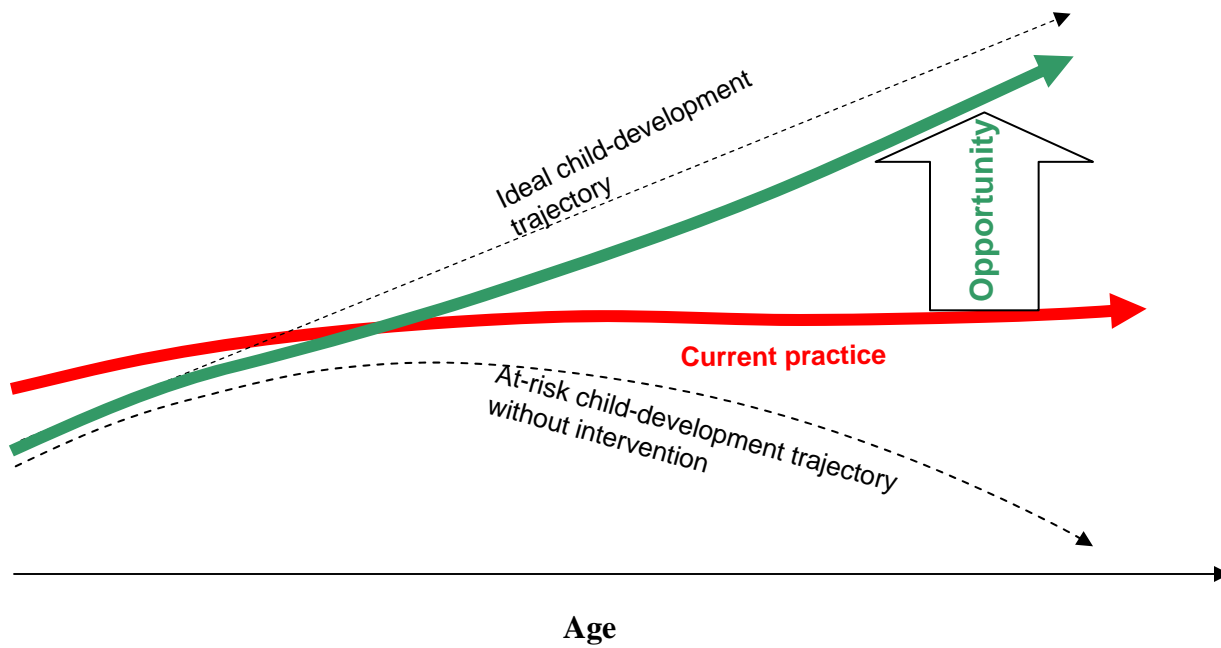
Intervention effects and costs of social-emotional mental health problems over time *- after Bricker*

Developmental health - Aims

'For every complex problem there is an answer that is clear, simple and wrong.'

H.L.Mencken (1880-1956)

More - if only there were more...

- Speech pathologists
- Social workers
- Mental health professionals
- Family support workers
- Counsellors
- Occupational therapists
- Preschool teachers
- Etc…

Better - if only we could…

- Improve professional practice
- Provide better training for professionals
- Have better trained staff
- Devise better (bigger, newer) interventions
- Have better schools, curriculum, teaching methods
- Have a better coordinated service system
- Provide better resources
- Etc…

Many examples of good programs promoting ECD

- *Problems -*
  - small numbers
  - difficulty of going to scale (cost, efficacy vs. effectiveness)
  - program fidelity
  - competing models
  - one size fits all
  - no local ownership
  - lack of efficacy data ('the biblical method of evaluation')
  - sustainability
  - individual rather than population approach

The road map

- Not about 'more' or 'better'
- It is about 'different'

Features of 'different'

- Changing the approach
- Population strategies - shifting the curve
- Changing the service system
- Embedding treatment and support services into the mainstream service system
- Use of data
- Using evidence

Old approach

- The needs of the individual are addressed in isolation
- Policies are focused on fixing individual deficits - offer specific interventions or treatments
- Strict eligibility requirements - categorical
- Resources allocated only when problems become severe enough to warrant attention
- Policy criteria - dollar amounts allocated
- Services delivered in narrow departmental and disciplinary silos

New approach

- Prevention and early intervention focus
- Holistic intervention and support
- Respond flexibly to family and community needs in coordinated approach
- Address barriers to access - reach out to families
- Increased community and consumer participation
- Focus on outcomes

New approaches based on key elements

- Community collaboration and shared accountability
- Outcomes based accountability, rather than present focus on process and delivery targets
- Systematic training of professionals to work differently and in partnership
- Build capacity in communities
- Good data collection - at local, regional and national level - to benchmark progress

Twelve principles of effective programs

Centre for Community Child Health

- Are built on existing structures
- Are sustainable
- Encourage partnerships
- Are multidisciplinary
- Are flexible
- Are evidence based

- Have a quality framework
- Can be evaluated
- Are replicable
- Practice linked to policy
- Are family centred
- Delivered from universal base

Developmental risk

POPULATION

Low   High
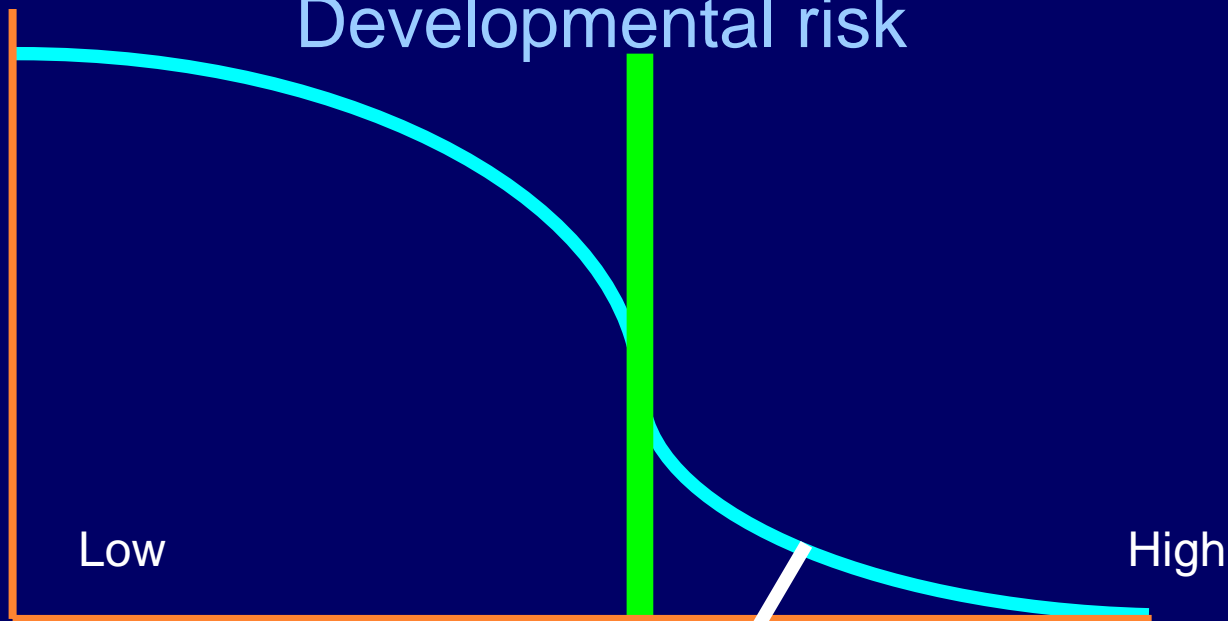
Effort is devoted to identifying and managing the high risk group

Developmental risk

P O P U L A T I O N

Low

High

Effort is devoted to reducing the risk amongst the entire population

Community services

Child health information

Family support

Childcare

School

Early intervention programs

Child protection agency

Parenting programs

FASD PROGRAMS

Pediatrician

Preschool

Disability services
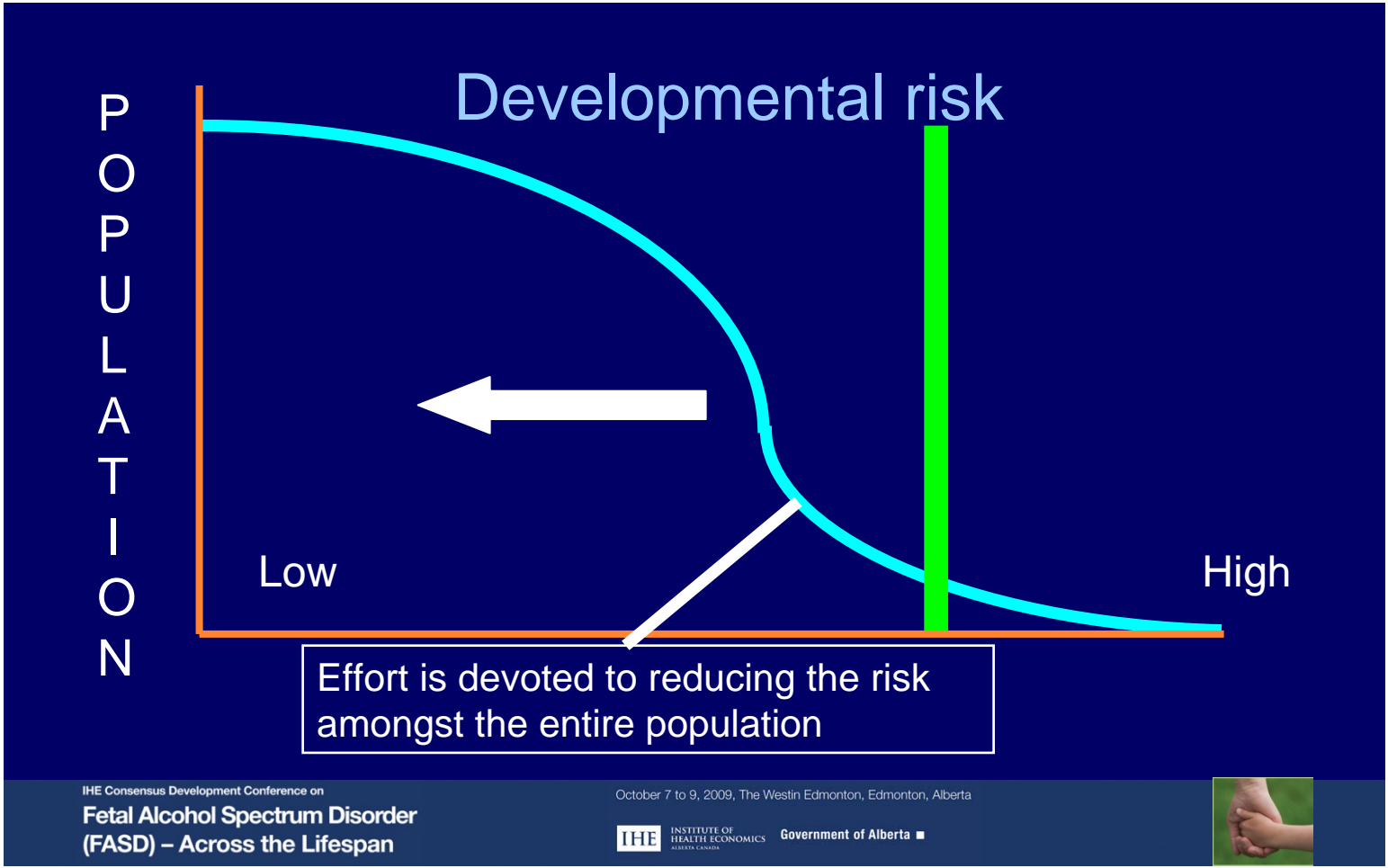
Children's library services
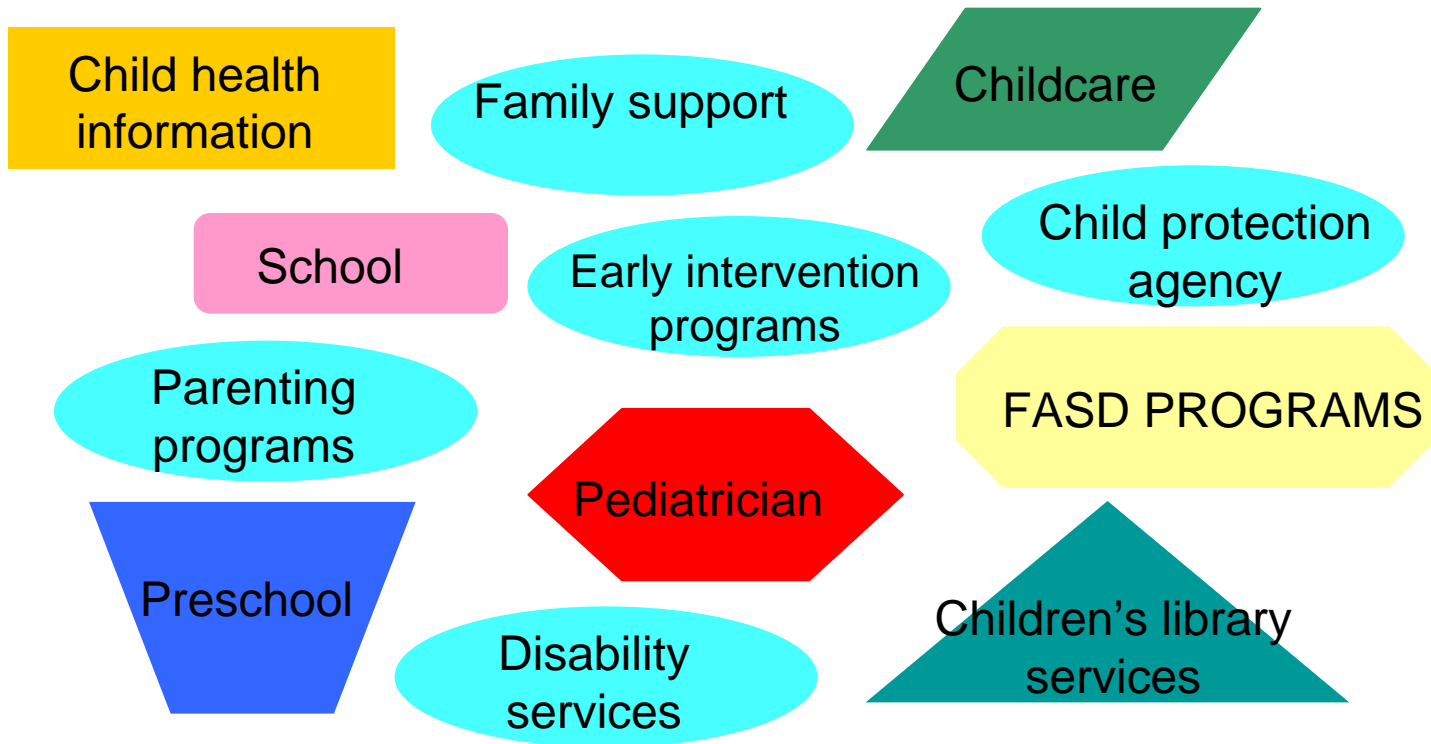
The existing service system

- Fragmented service delivery
  - different sectors (health, education, welfare), funding streams, cultures
  - lack of co-ordination - operate in silos
- Difficulty accessing services
  - demand greater than services available
  - narrow programmatic criteria for eligibility
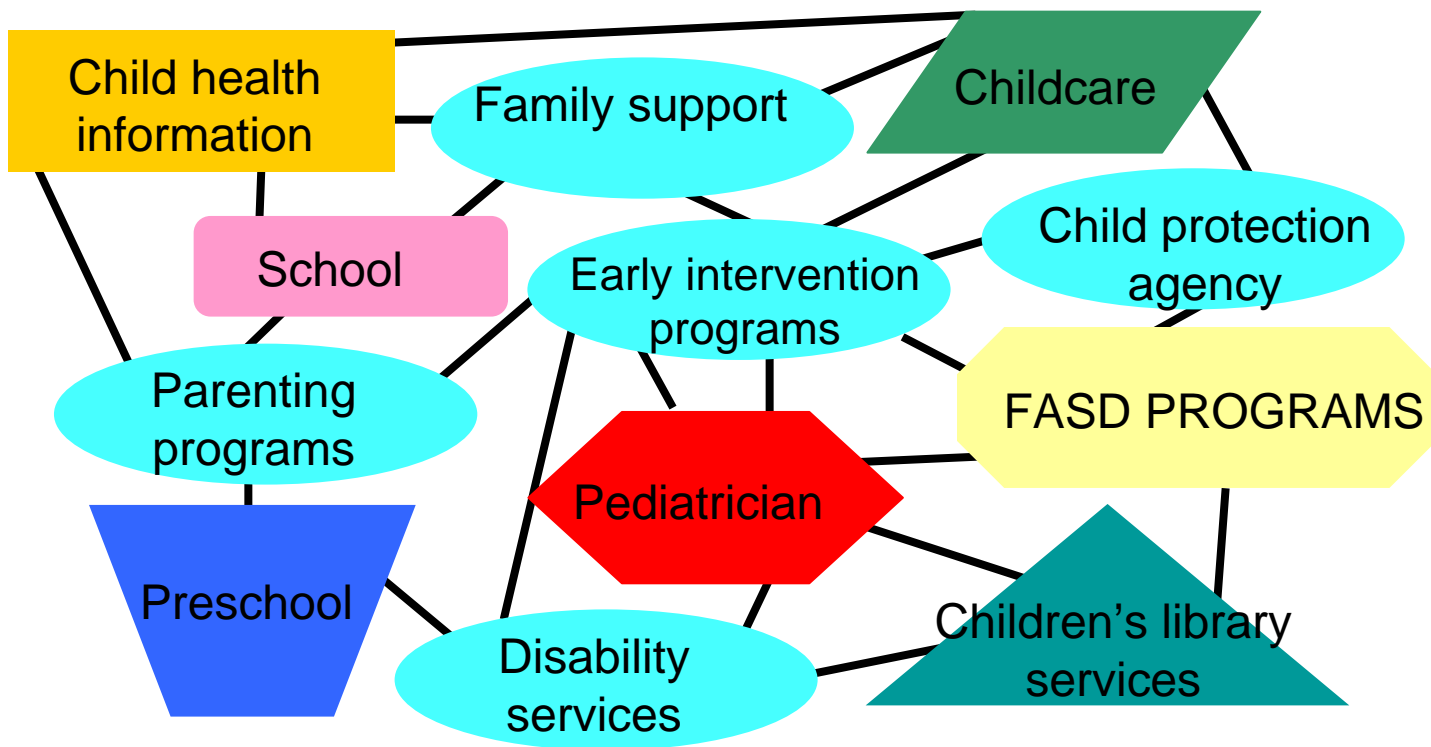 - social gradient in treatment and outcomes

The existing service system

- Uneven quality
  - families have complex needs, often beyond capability of any single service
  - variable understanding of FASD issues
- Model of care is limited
  - focus on treatment rather than prevention/early intervention
- Local community limited accountability or responsibility

Linked services

Child health information

Family support

Childcare

School

Early intervention programs

Child protection agency

Parenting programs

FASD PROGRAMS

Pediatrician

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INTERFACE

Community **Family** **Child**

Universal **Secondary** **Tertiary**
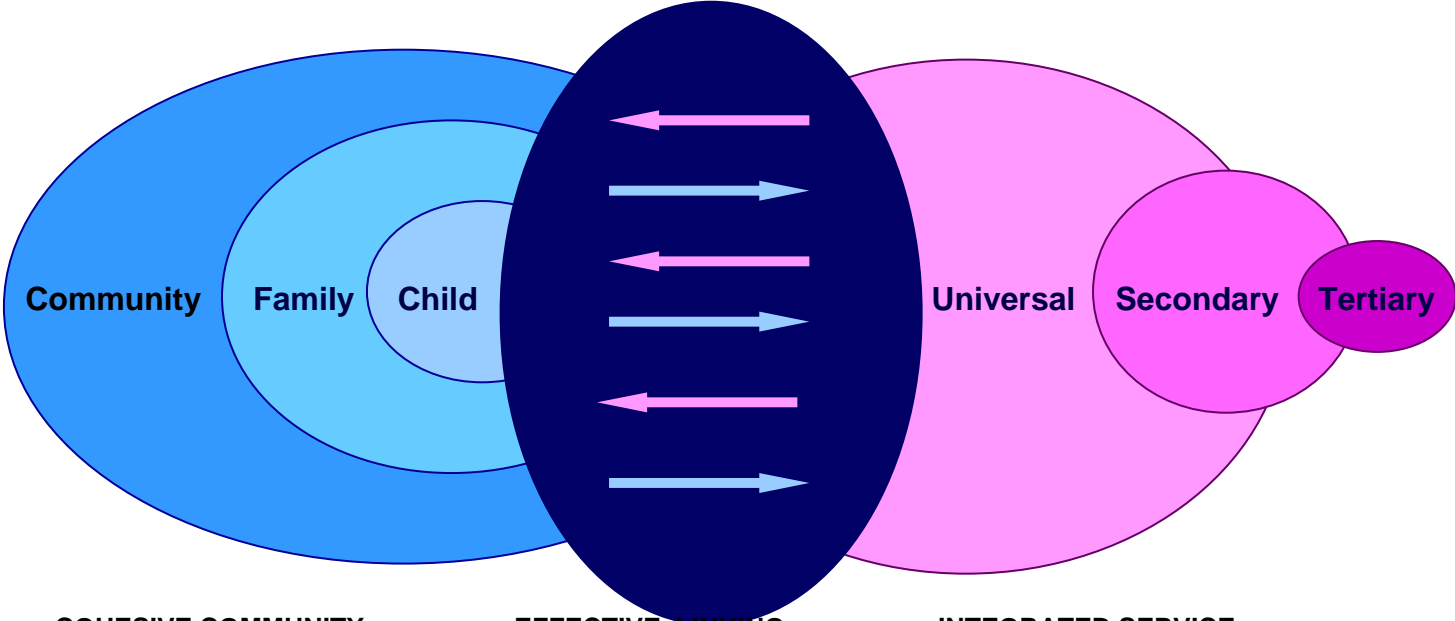
COHESIVE COMMUNITY SUPPORT PROCESSES that provide rich and supportive social environments for young children and their families

EFFECTIVE LINKING PROCESSES that ensure that the service system responds promptly to the emerging needs of young children and their families

INTEGRATED SERVICE SYSTEM that provides a well-coordinated and easily accessible tiered system of services for young children and their families

What do we need to do?

Three forms of change

- ***Change the system***: change the way that services connect with one another to make the system more accessible and cohesive

- ***Change what we provide***: change the services we provide to make them more responsive to child and family needs and circumstances

- ***Change how we deliver services***: change the manner in which services relate to families and communities so as to engage them more effectively

Standard school model

Curriculum & teaching

Governance
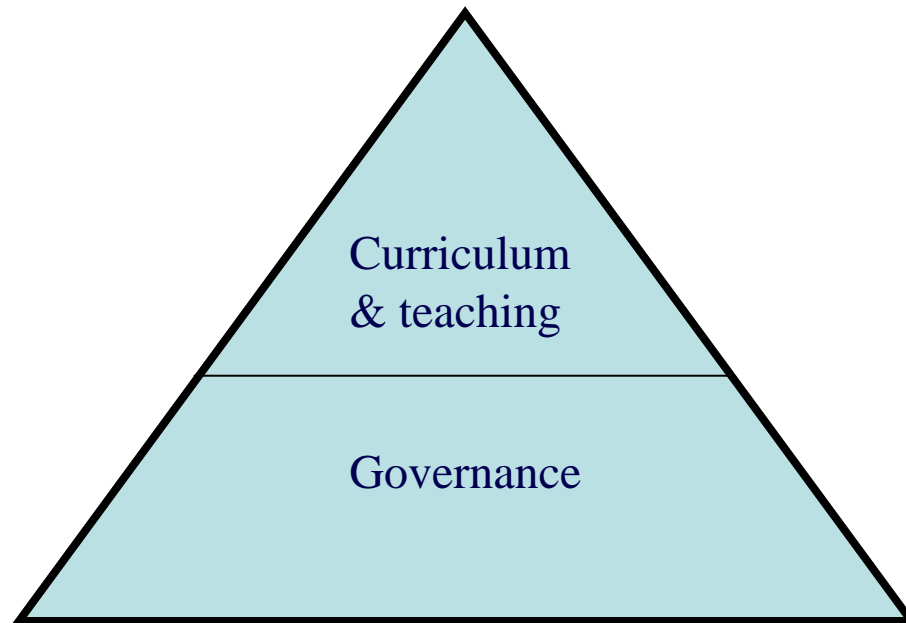
New school model
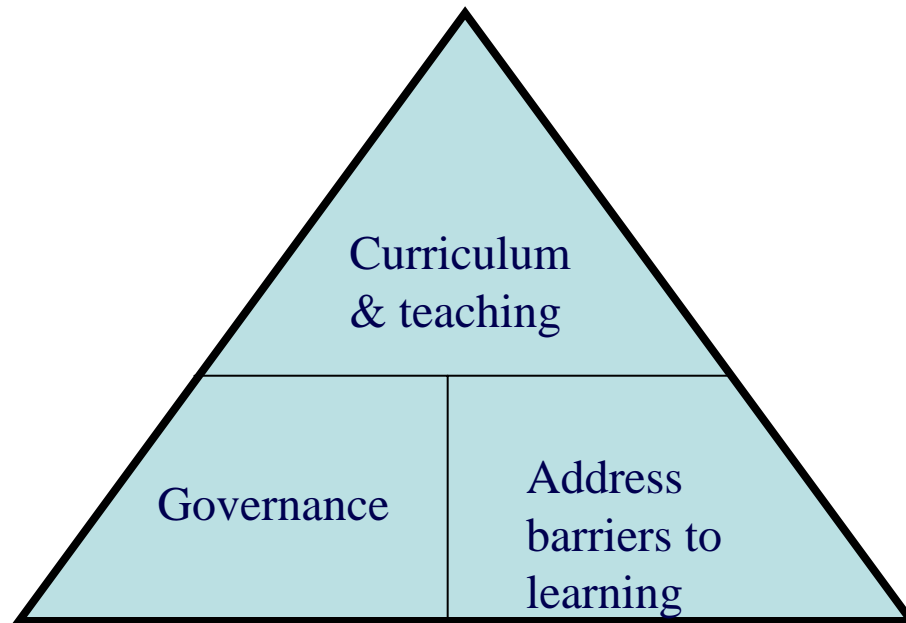
Barriers to learning - 3 groups

1. No barriers to learning - will do well regardless

2. Severe barriers - generally have access to special services which begin prior to formal schooling

3. Subtle to moderate barriers to learning and school success - may elude early detection, and intervention often delayed until problems entrenched and difficult to treat - eg FASD

IHE Consensus Development Conference on
**Fetal Alcohol Spectrum Disorder
(FASD) – Across the Lifespan**

October 7 to 9, 2009, The Westin Edmonton, Edmonton, Alberta

IHE INSTITUTE OF
HEALTH ECONOMICS
ALBERTA CANADA **Government of Alberta** ■

What are the barriers to learning?

Biological (sometimes the consequences of FASD) and/or environmental

- Developmental weaknesses - language, memory, visual-motor integration, etc

- Attentional and behavioural problems

- Poor environmental circumstances in the early years

Breaking down the barriers

Comprehensive ongoing process by which school and community resources are restructured and woven together to address barriers to learning and development

The Platforms concept

- Builds on the notion that in the early years young children and their families make contact on numerous occasions with a range of community providers - child care, MCH nurses, GPs, preschools, schools

- Reframe these visits into a 'platform' where parents are supported, and concerns elicited and responded to

- This provides the best opportunity both to support parents and detect emerging problems and risk factors at an early stage

Aims of Platforms

- Strengthen capacity of the existing service system
- Improve coordination and access to services
- Re-orient services to prevention and early intervention.
- Develop earlier identification and responses to child and family issues
- Improve professional practice through systematic training of professionals and community organizations.
- Encourage greater flexibility of services, evidence-based and outcomes focus

PHASE 1	Raising awareness of ECD (FASD)
PHASE 2	Community engagement and documentation
PHASE 3	Planning
PHASE 4	Implementation

Challenges

- FASD does not exist in isolation - associated with other risk factors - individual, family, community - cumulative risk
- Interventions need to be broad enough in scope to address risk factors beyond FASD
- Biological (prenatal) and environmental (postnatal) risk
- Embedding FASD programs in mainstream service delivery
- Sustainability
- Reliable data to inform planning, evaluate interventions

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