Putting the ABLE back into childhood disability

Chair: Susan Gibb
Speakers: Catherine Marraffa
Dinah Reddihough
Katrina Williams

The Children's
Excellence in clinical care, research and education

The Royal Children's Hospital Melbourne

Murdoch Childrens Research Institute

The University of Melbourne

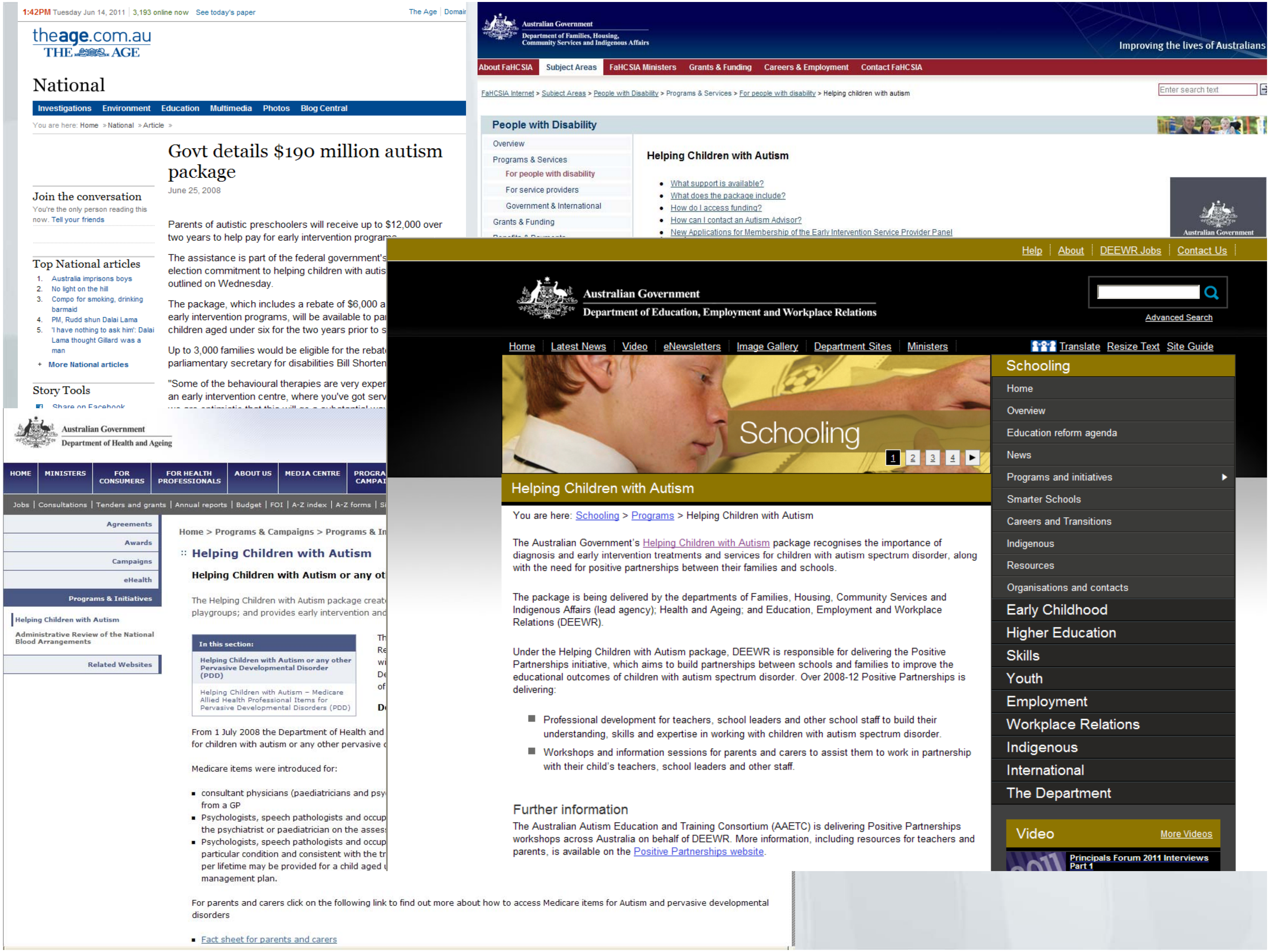
RACP Congress
Melbourne
May 2017

Outline

- Overview of approaches to disability care, the gaps and opportunities for improvement
- Putting the ABLE back in disability for children with cerebral palsy
- When disability meets child abuse and neglect: a case example
- Questions and Comments please

Different locations or funding for care

- Setting
  - Tertiary/Quaternary hospitals
  - Community Health
  - Disability Services
  - Rehabilitation services
- Type of funding
  - Private sector
  - Public care
  - Non-government organisation
  - Federal
  - State / Territory



1:42PM Tuesday Jun 14, 2011 | 3,193 online now See today's paper

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THE AGE

National

You are here: Home » National » Article »

Govt details $190 million autism package

June 25, 2008

Parents of autistic preschoolers will receive up to $12,000 over two years to help pay for early intervention progra

The assistance is part of the federal government's
election commitment to helping children with autis
outlined on Wednesday.

The package, which includes a rebate of $6,000 a
early intervention programs, will be available to pa
children aged under six for the two years prior to s

Up to 3,000 families would be eligible for the rebat
parliamentary secretary for disabilities Bill Shorten

"Some of the behavioural therapies are very exper
an early intervention centre, where you've got serv

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Top National articles

1. Australia imprisons boys
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3. Compo for smoking, drinking barmaid
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5. 'I have nothing to ask him': Dalai Lama thought Gillard was a man

+ More National articles

Story Tools

Australian Government
Department of Families, Housing, Community Services and Indigenous Affairs

Improving the lives of Australians

FaHCSIA Internet > Subject Areas > People with Disability > Programs & Services > For people with disability > Helping children with autism

People with Disability

Helping Children with Autism

- What support is available?
- What does the package include?
- How do I access funding?
- How can I contact an Autism Advisor?
- New Applications for Membership of the Early Intervention Service Provider Panel

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Australian Government
Department of Health and Ageing

Home > Programs & Campaigns > Programs & In

:: Helping Children with Autism

Helping Children with Autism or any ot

The Helping Children with Autism package creat
playgroups; and provides early intervention and

In this section:
Helping Children with Autism or any other Pervasive Developmental Disorder (PDD)
Helping Children with Autism – Medicare Allied Health Professional Items for Pervasive Developmental Disorders (PDD)

From 1 July 2008 the Department of Health and
for children with autism or any other pervasive

Medicare items were introduced for:

- consultant physicians (paediatricians and psy
from a GP
- Psychologists, speech pathologists and occup
the psychiatrist or paediatrician on the asses
- Psychologists, speech pathologists and occup
particular condition and consistent with the tr
per lifetime may be provided for a child aged
management plan.

For parents and carers click on the following link to find out more about how to access Medicare items for Autism and pervasive developmental disorders

- Fact sheet for parents and carers

Australian Government
Department of Education, Employment and Workplace Relations

Schooling

Helping Children with Autism

You are here: Schooling > Programs > Helping Children with Autism

The Australian Government's Helping Children with Autism package recognises the importance of diagnosis and early intervention treatments and services for children with autism spectrum disorder, along with the need for positive partnerships between their families and schools.

The package is being delivered by the departments of Families, Housing, Community Services and Indigenous Affairs (lead agency); Health and Ageing; and Education, Employment and Workplace Relations (DEEWR).

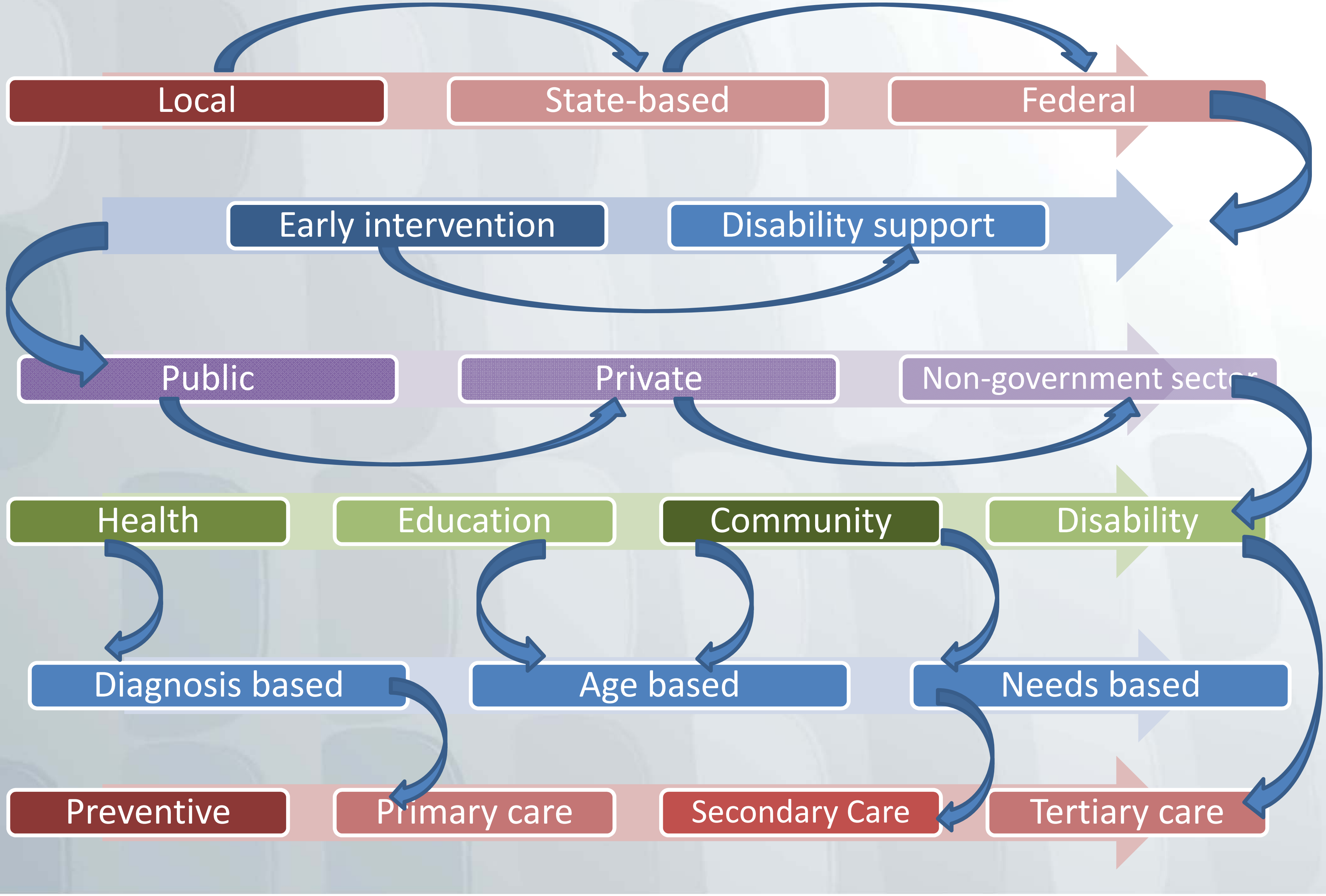
Under the Helping Children with Autism package, DEEWR is responsible for delivering the Positive Partnerships initiative, which aims to build partnerships between schools and families to improve the educational outcomes of children with autism spectrum disorder. Over 2008-12 Positive Partnerships is delivering:

- Professional development for teachers, school leaders and other school staff to build their understanding, skills and expertise in working with children with autism spectrum disorder.
- Workshops and information sessions for parents and carers to assist them to work in partnership with their child's teachers, school leaders and other staff.

Further information

The Australian Autism Education and Training Consortium (AAETC) is delivering Positive Partnerships workshops across Australia on behalf of DEEWR. More information, including resources for teachers and parents, is available on the Positive Partnerships website.

Different types of services



Local
State-based
Federal

Early intervention
Disability support

Public
Private
Non-government sector

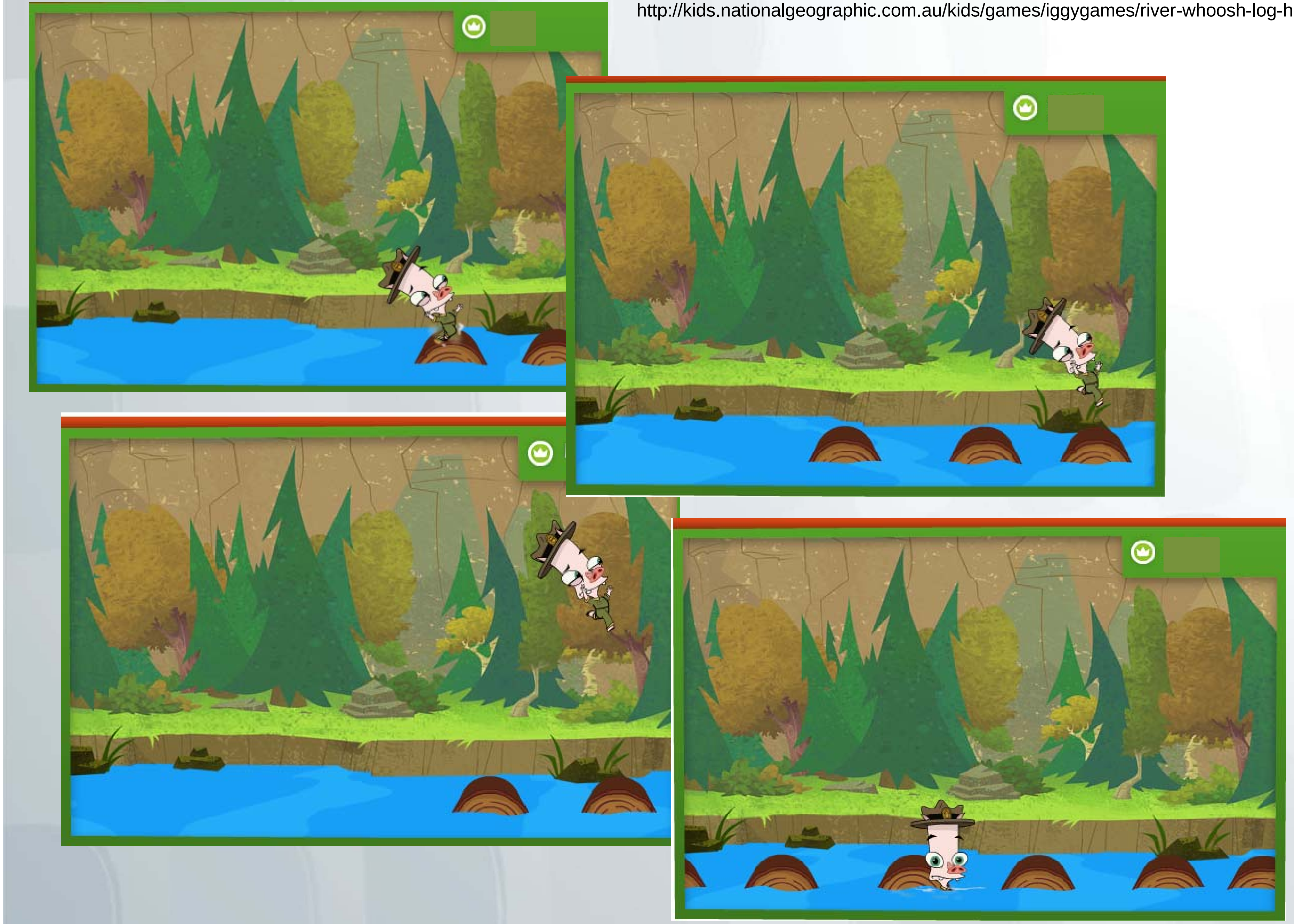
Health
Education
Community
Disability

Diagnosis based
Age based
Needs based

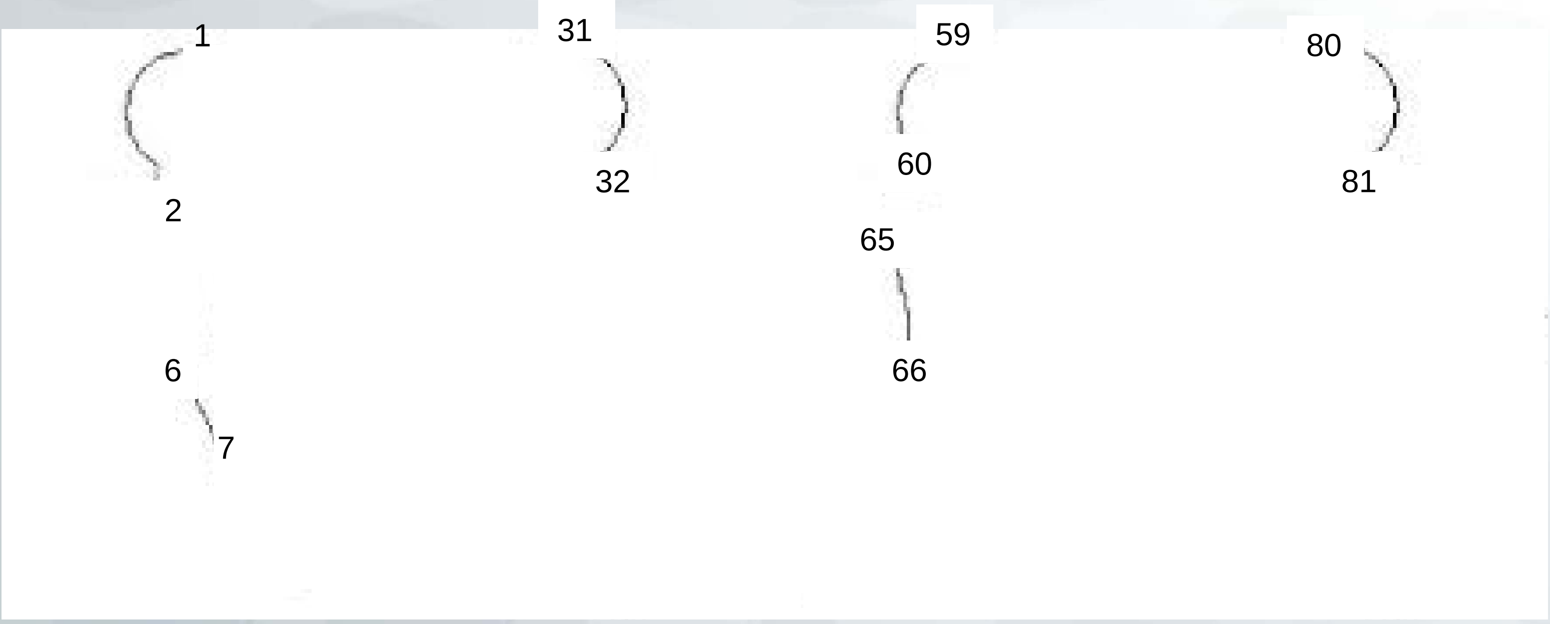
Preventive
Primary care
Secondary Care
Tertiary care

Access varies

http://kids.nationalgeographic.com.au/kids/games/iggygames/river-whoosh-log-hop/



Are we developing shared understandings and ways of working?



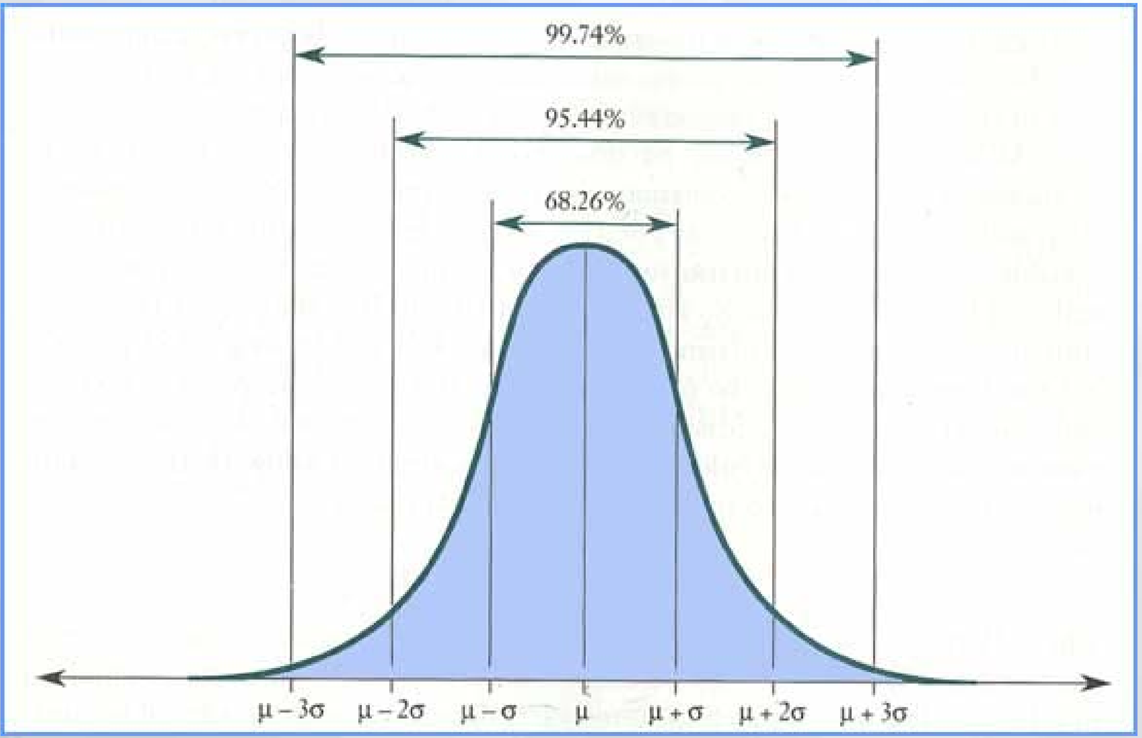
Are we joining the dots?

Different models and frameworks

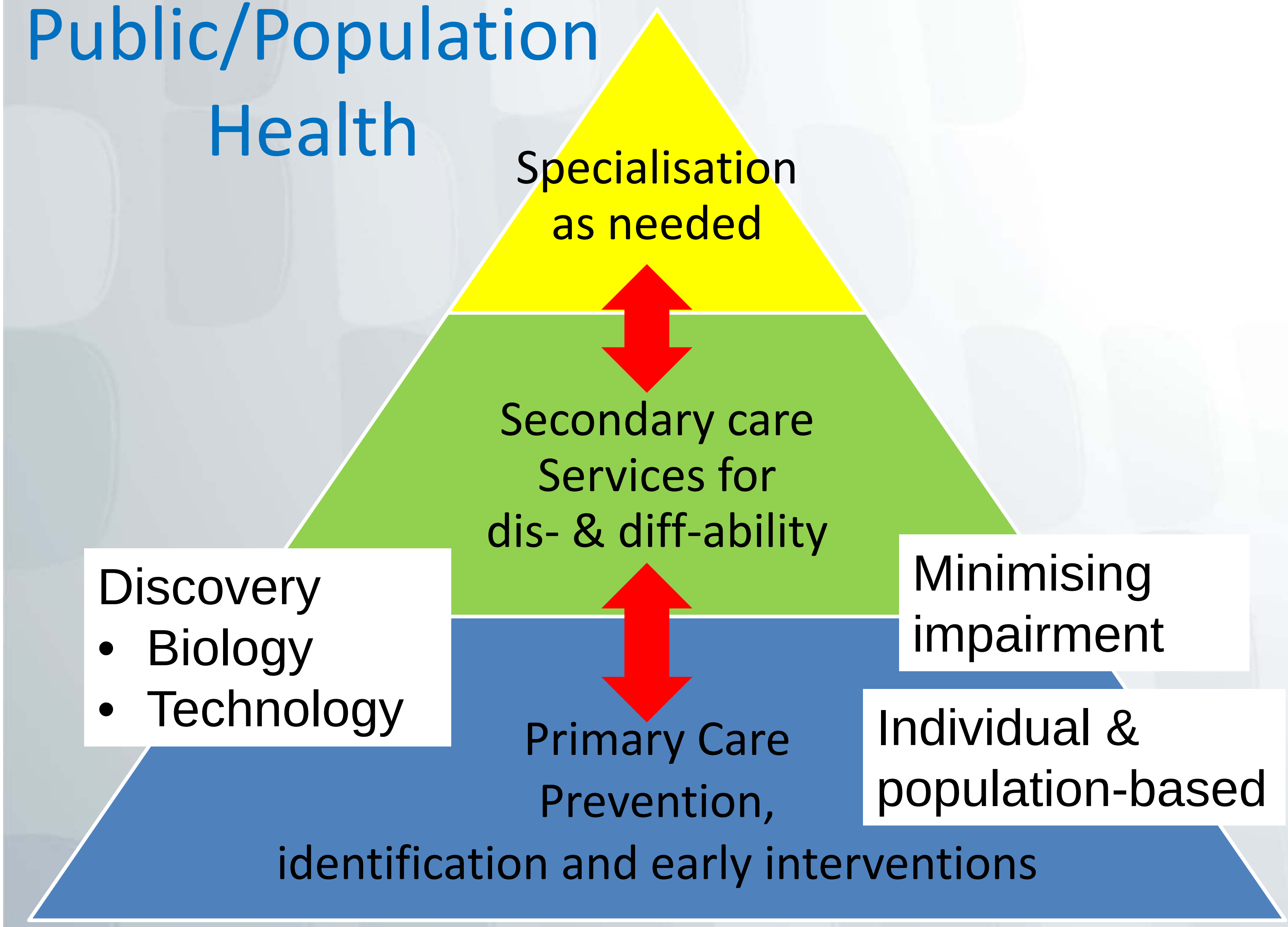
- Medical model & Family Centred Care
- Bronfenbrenner’s ecological model
- Social model of disability
- International Classification of Functioning, Disability and Health and the ‘f’ words adaptation
- Economic models
- Human rights – Disability & Child
- Ethical practice
- Evidence-based care
- Chronic & complex care/ Care coordination
- Public health approaches

Social Model

"…… challenge the physical, attitudinal, communication and social environment to accommodate impairment as an expected incident of human diversity."



Public/Population Health



Specialisation
as needed

Secondary care
Services for
dis- & diff-ability

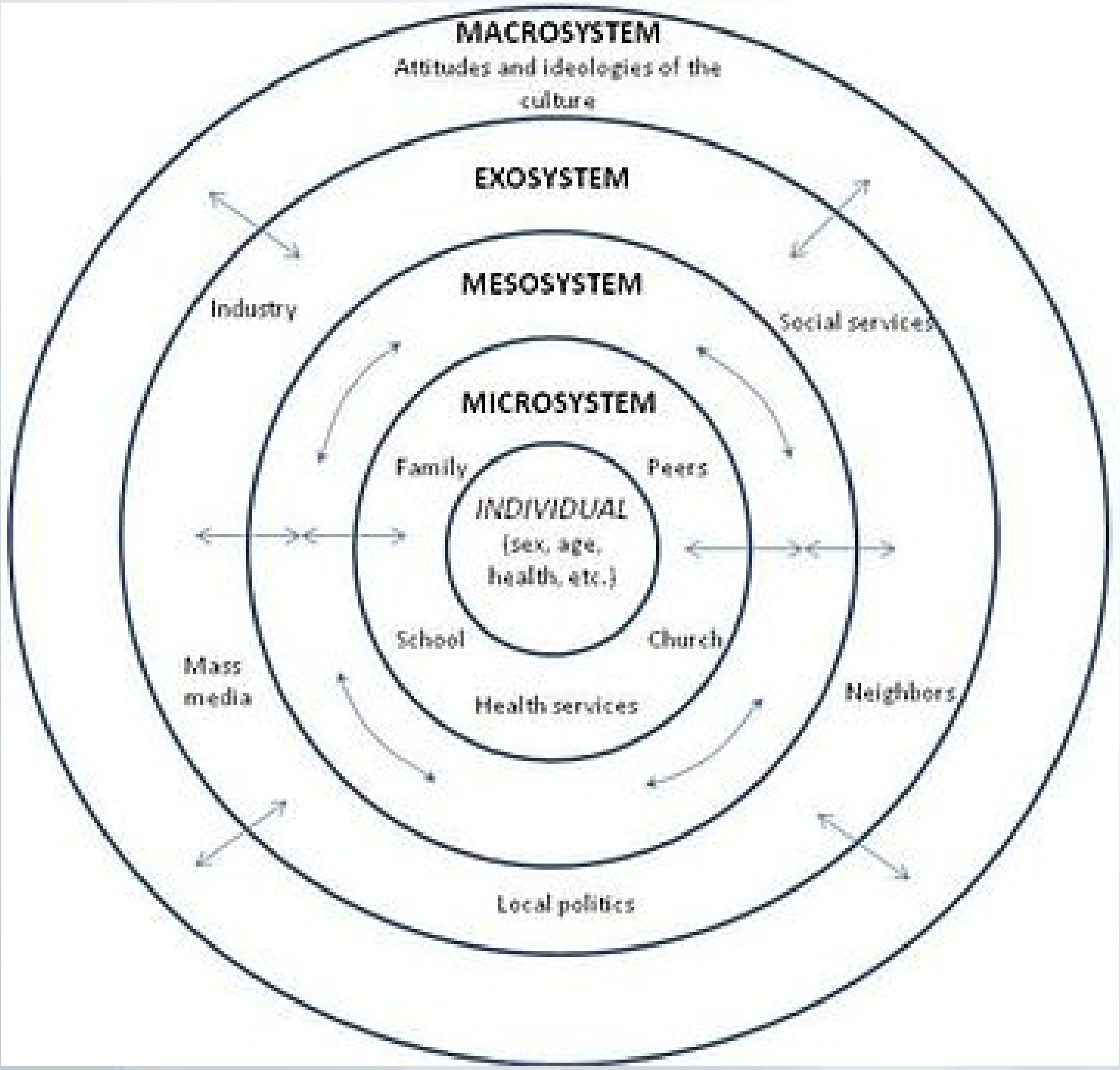
Primary Care
Prevention,
identification and early interventions

Discovery
- Biology
- Technology

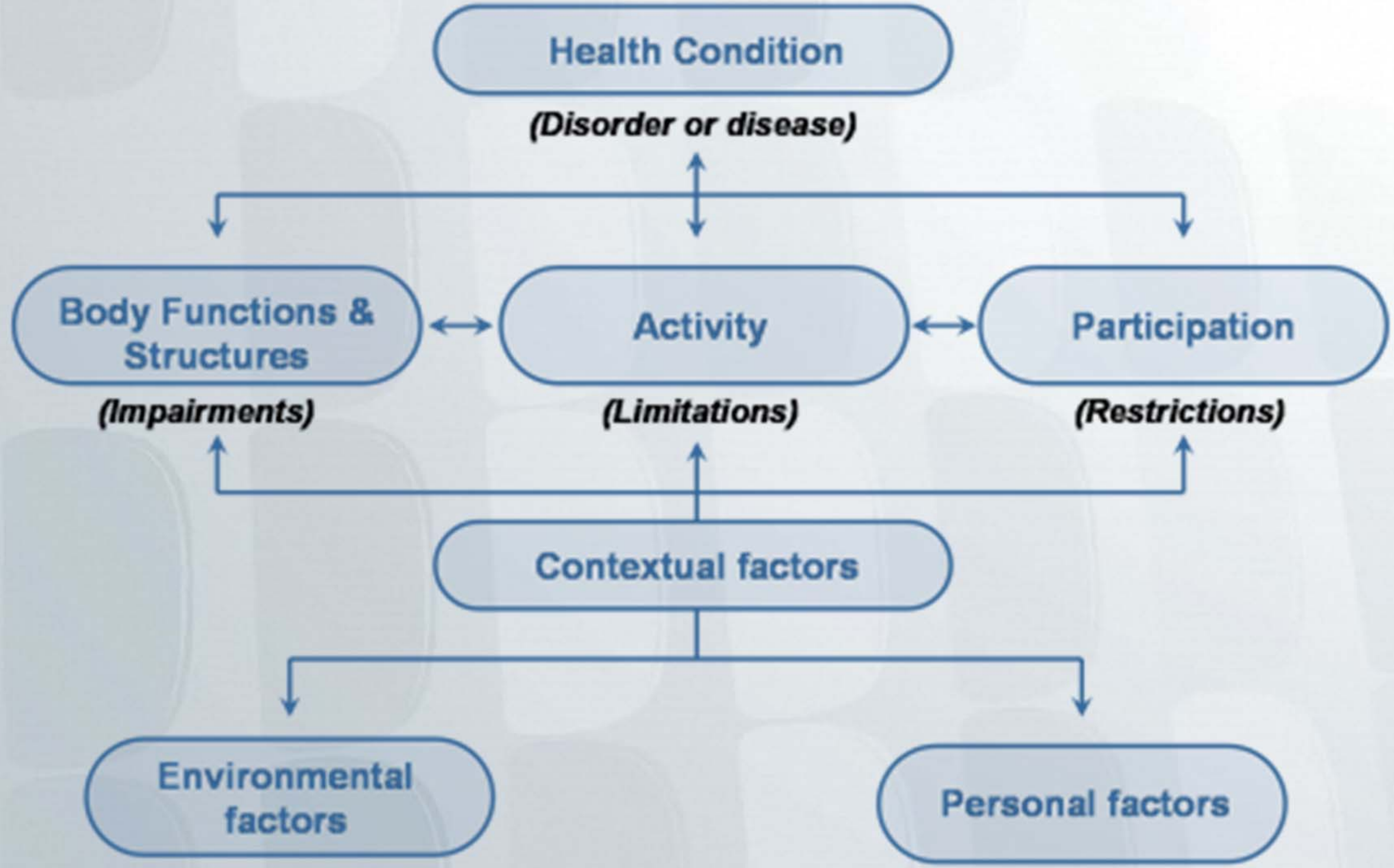
Minimising
impairment

Individual &
population-based

Bronfenbrenner's ecological framework



International Classification of Functioning, Disability and Health



Health Condition

(Disorder or disease)

Body Functions & Structures

(Impairments)

Activity

(Limitations)

Participation

(Restrictions)

Contextual factors

Environmental factors

Personal factors

Many common themes

Service coordination across artificial silos

Minimise the impairment

Effective individual care

Well being and mental health

Support the carers

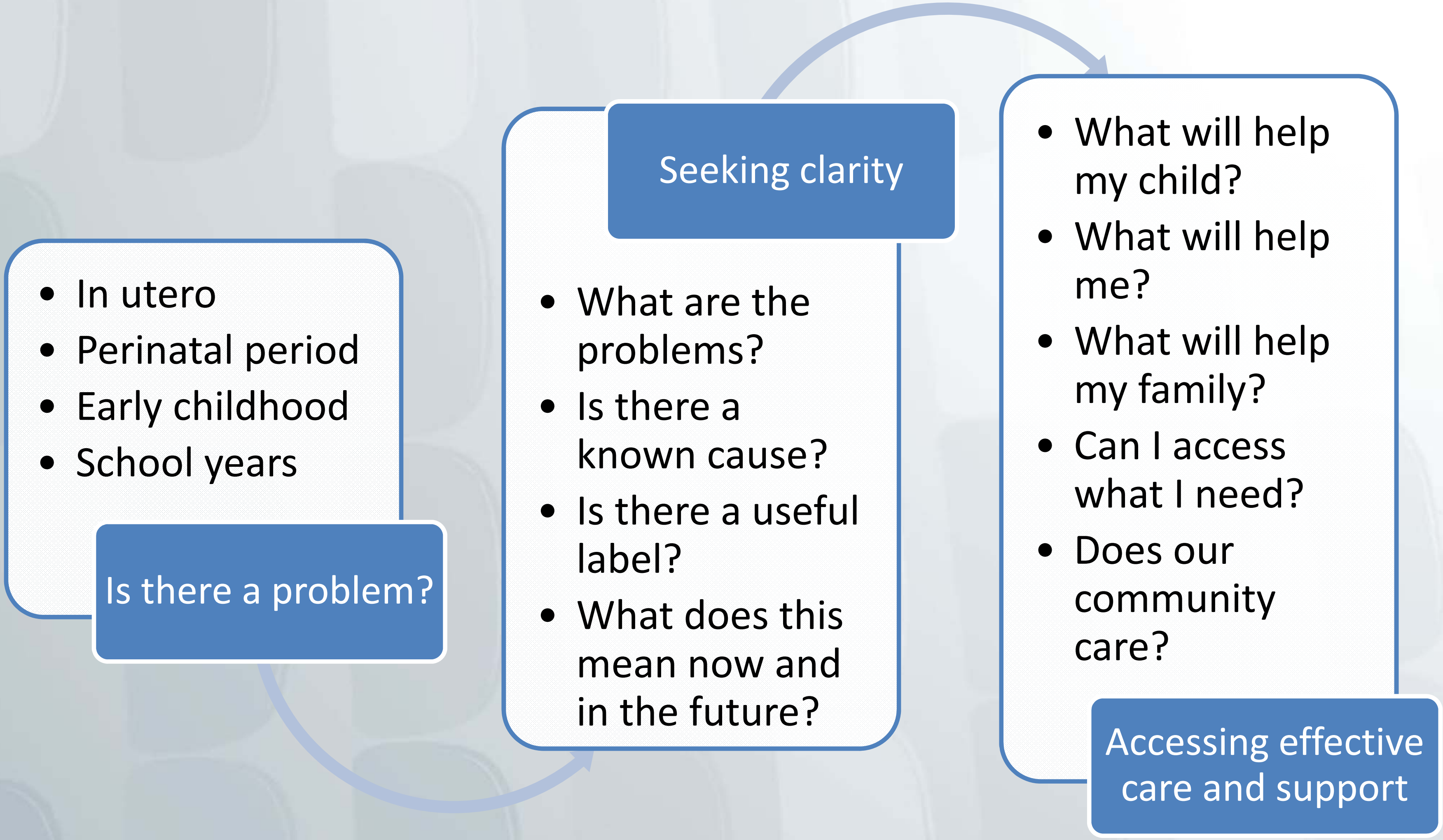
Everyone engaged in the community

The built environment

Modify the environment

The way people think and behave

The child and their family's journey



- In utero
- Perinatal period
- Early childhood
- School years

Is there a problem?

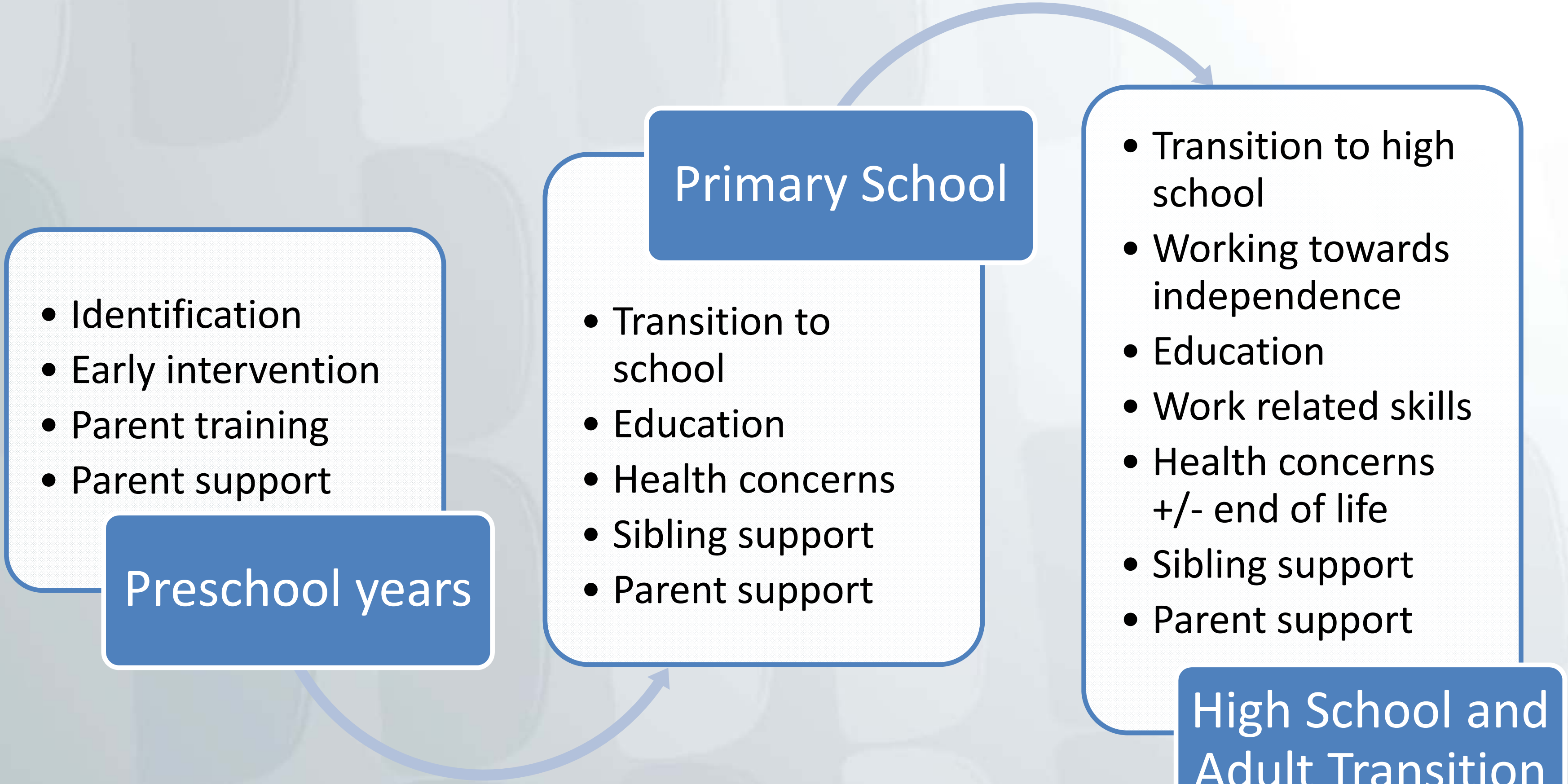
Seeking clarity

- What are the problems?
- Is there a known cause?
- Is there a useful label?
- What does this mean now and in the future?

- What will help my child?
- What will help me?
- What will help my family?
- Can I access what I need?
- Does our community care?

Accessing effective care and support

The chronological journey



Preschool years

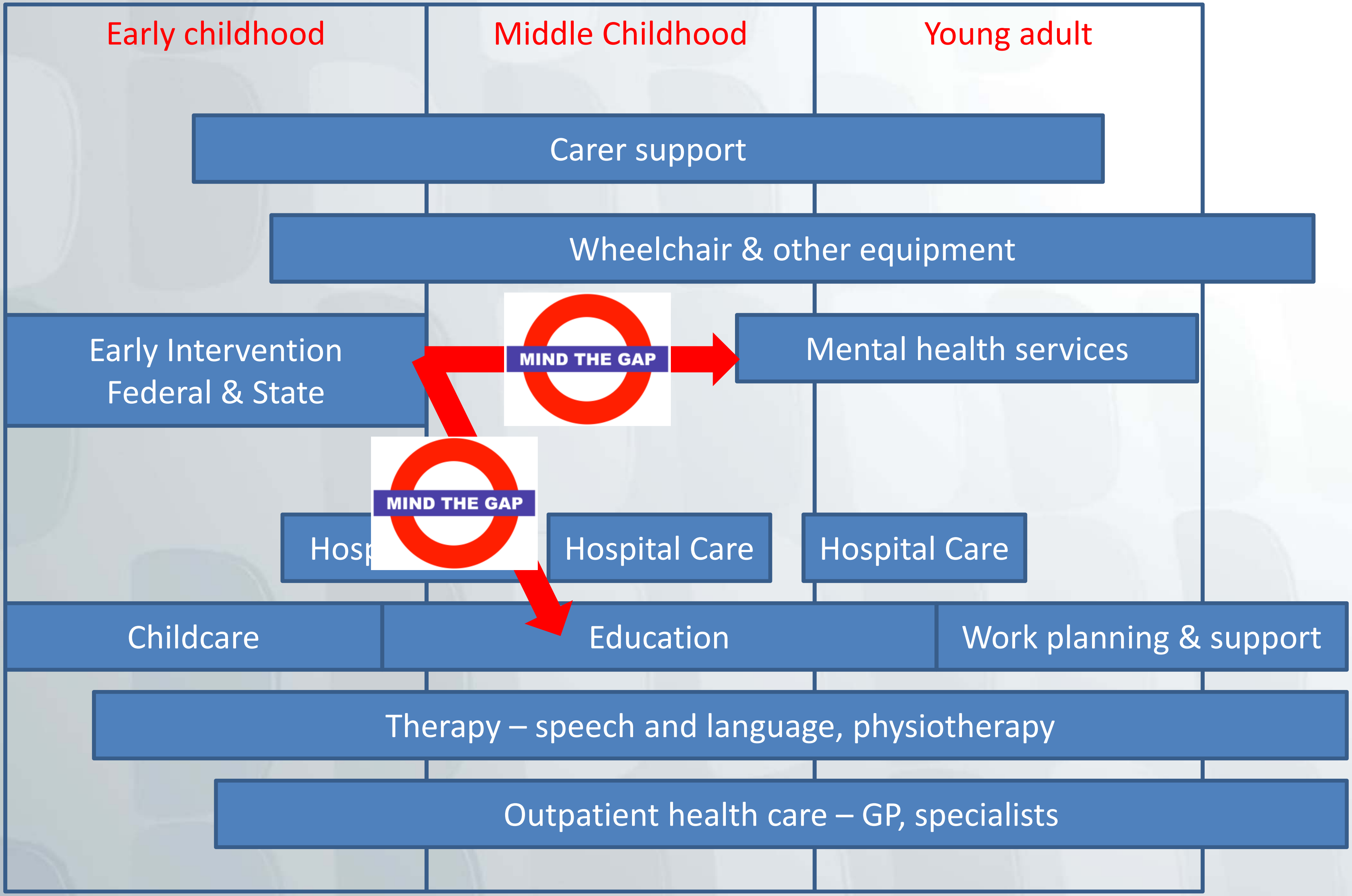
- Identification
- Early intervention
- Parent training
- Parent support

Primary School

- Transition to school
- Education
- Health concerns
- Sibling support
- Parent support

High School and Adult Transition

- Transition to high school
- Working towards independence
- Education
- Work related skills
- Health concerns +/- end of life
- Sibling support
- Parent support



Early childhood

Middle Childhood

Young adult

Carer support

Wheelchair & other equipment

Early Intervention
Federal & State

MIND THE GAP

Mental health services

MIND THE GAP

Hosp

Hospital Care

Hospital Care

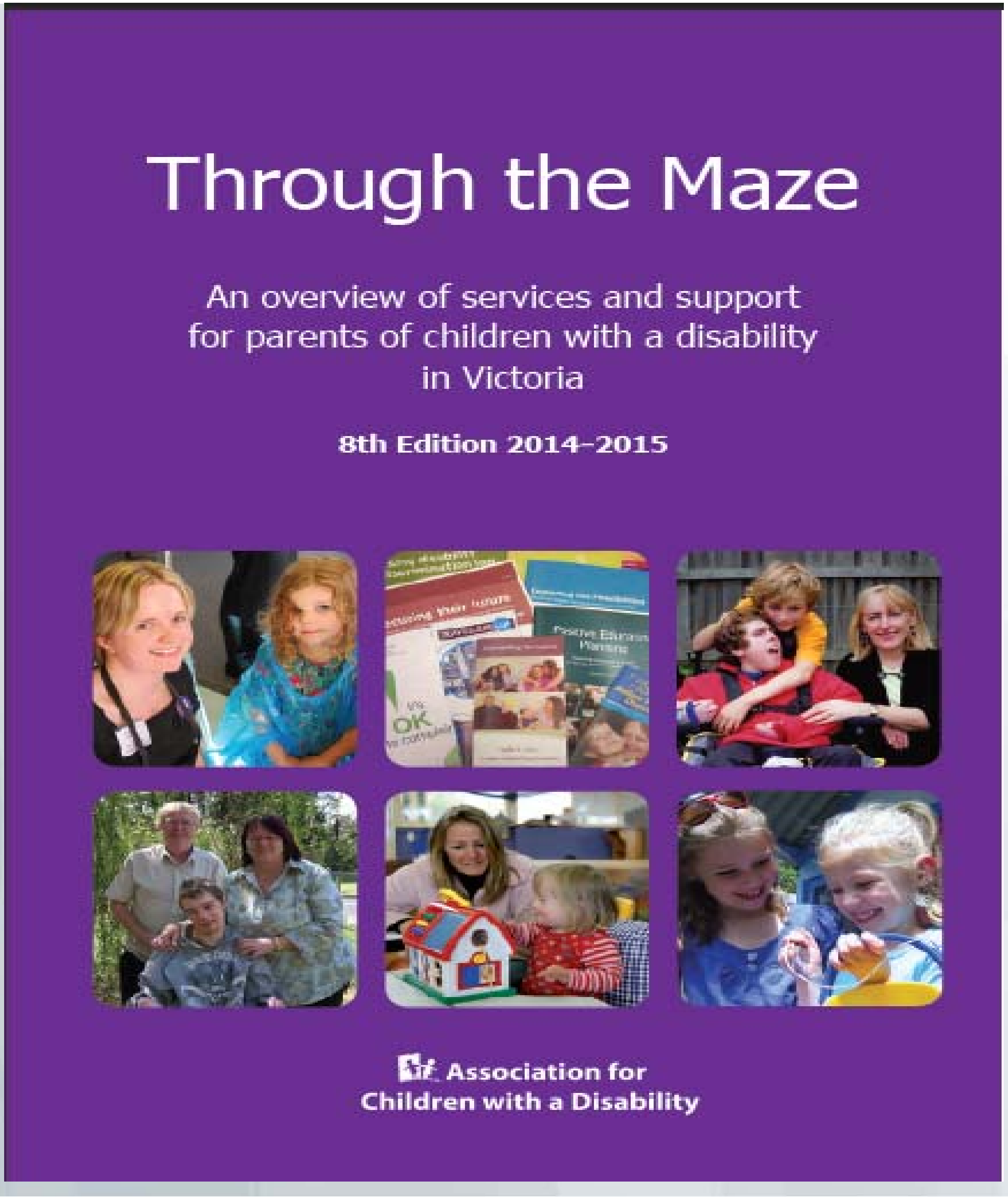
Childcare

Education

Work planning & support

Therapy – speech and language, physiotherapy

Outpatient health care – GP, specialists http://acd.org.au/wp-content/uploads/2014/02/acd_through_the_maze_resource_8th_edition_WEB.pdf

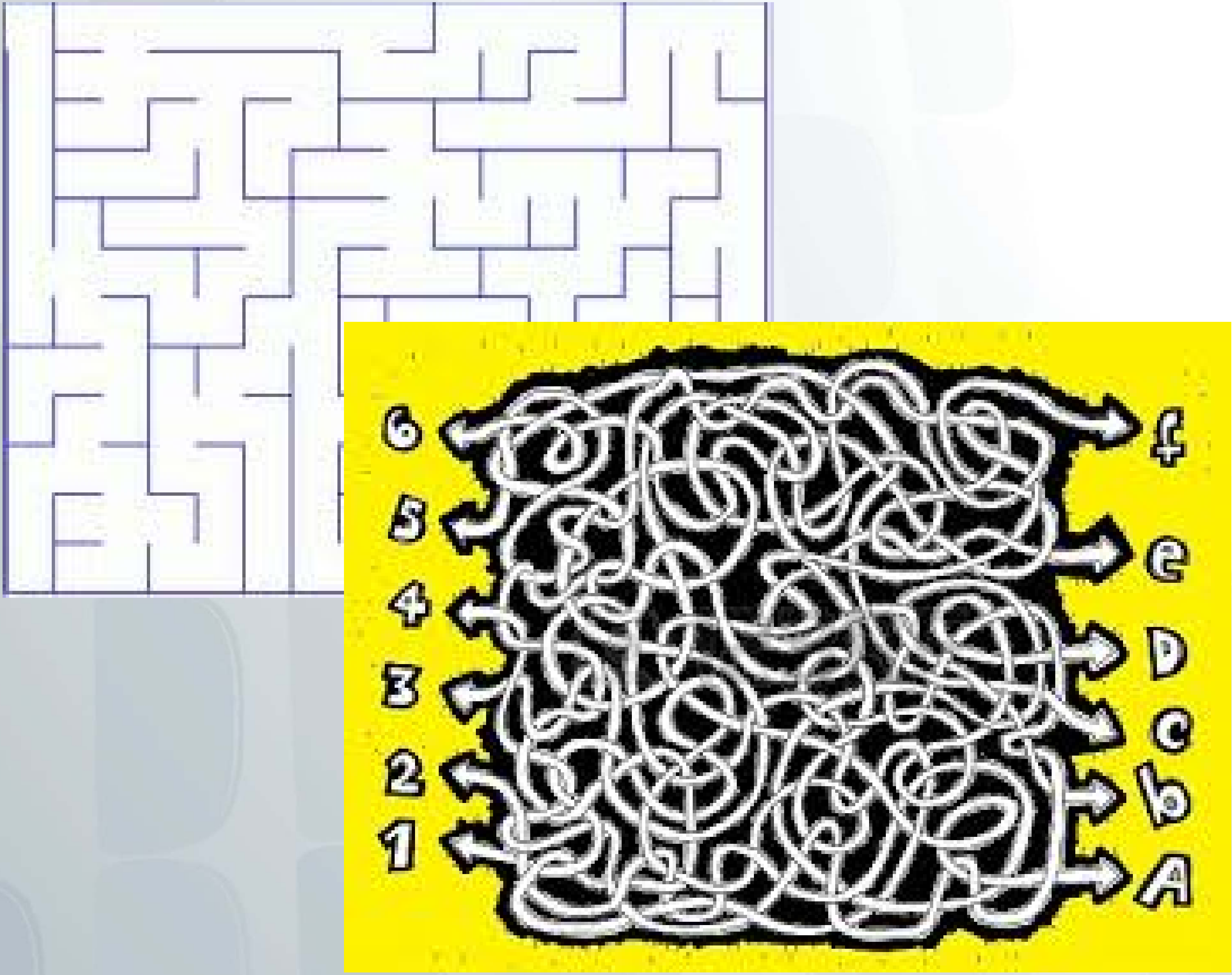


Through the Maze

An overview of services and support
for parents of children with a disability
in Victoria

8th Edition 2014–2015

**Association for
Children with a Disability**


6
5
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A

The “F words”

Thanks to Peter Rosenbaum and Jan Willem Gorter

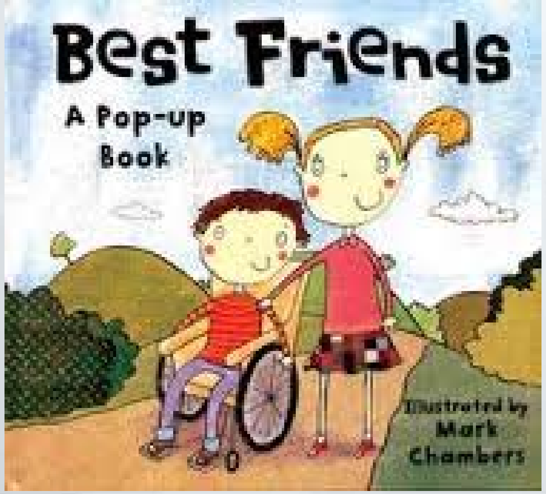
Function – What has your child done well over the past few months?

Friends – How is your child getting on with other children?

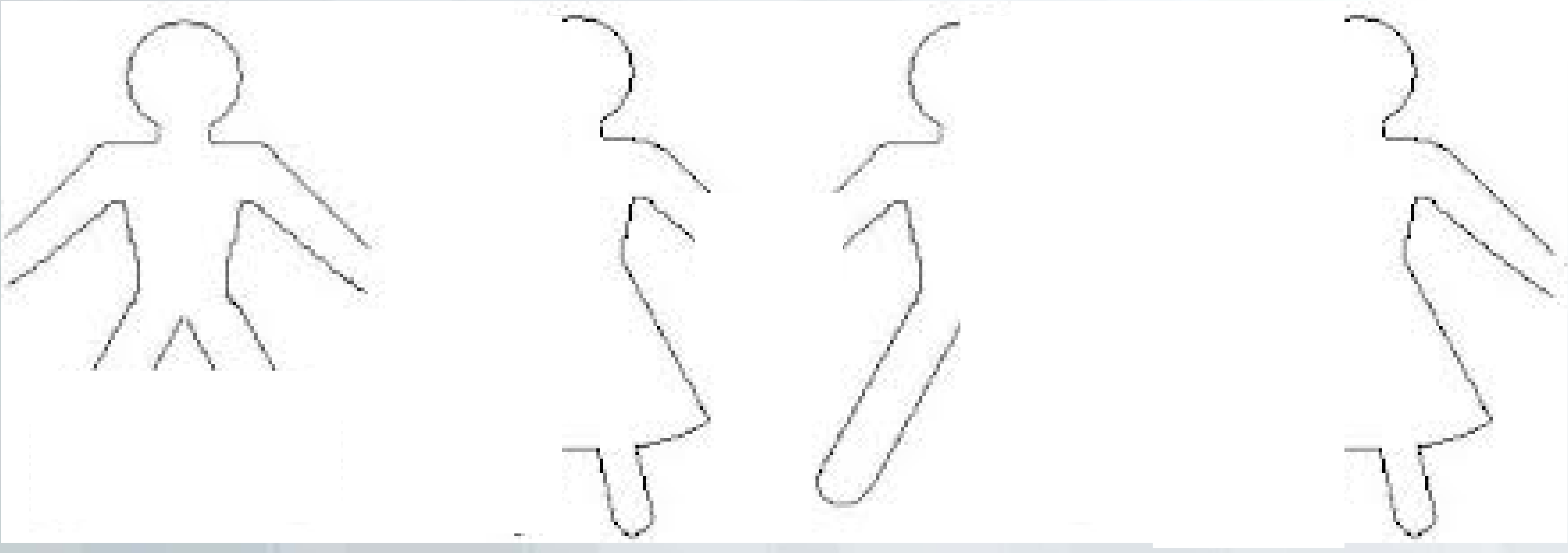
Family – How are you doing? Do you need more support?

Fun – Are interventions enjoyable?

Fitness – If possible..getting a program to help fitness?



Taking shape



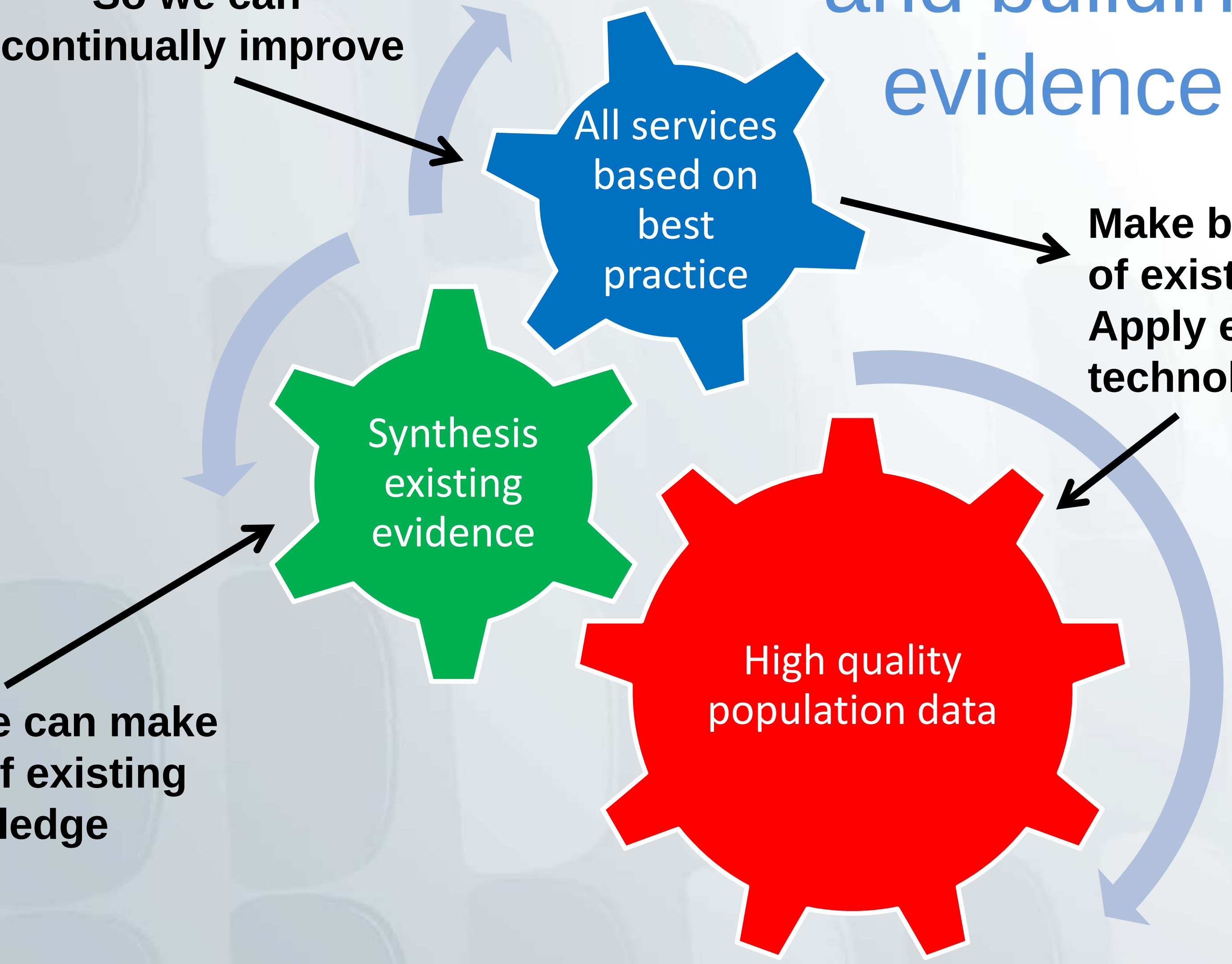
We have the technology

- e records

eHealth

- Tele-care

Underpinned by and building evidence



So we can continually improve

All services based on best practice

Make best use of existing data
Apply emerging technologies

Synthesis existing evidence

So we can make use of existing knowledge

High quality population data

Ensure evidence translation - service to research and back again

Workforce

- Increasing number of professionals with interest in disability
- Need to understand
  - Commonalities between disabilities
  - Areas where specialisation is needed
- Care coordination expertise is crucial

Unlikely that current training & educational models that are discipline or domain specific will be adequate

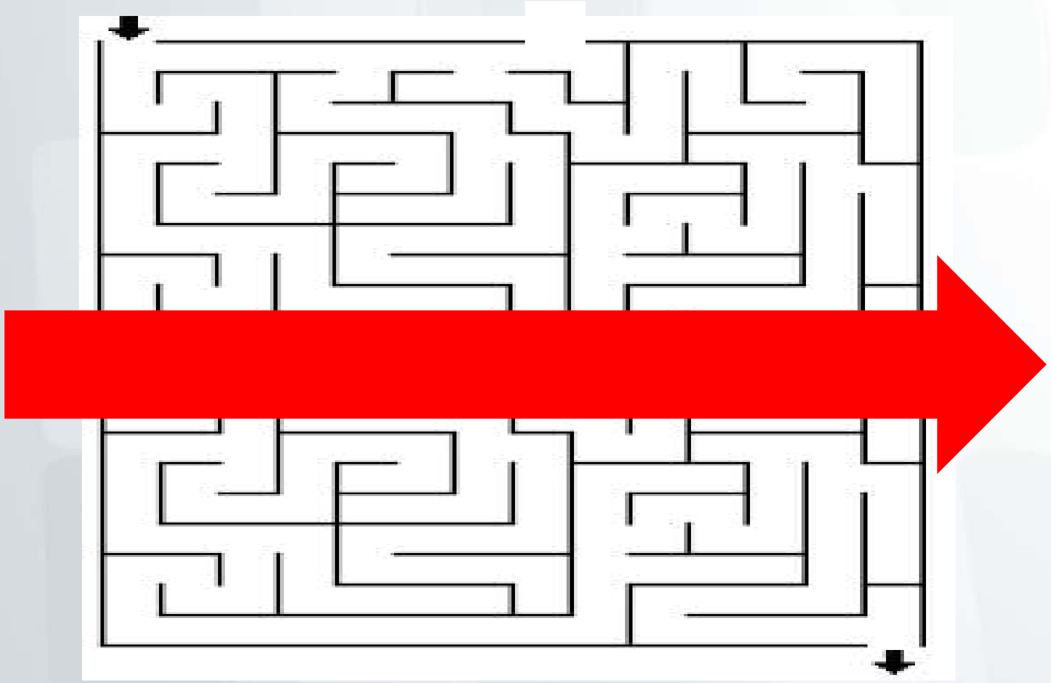
National Disability Insurance Scheme

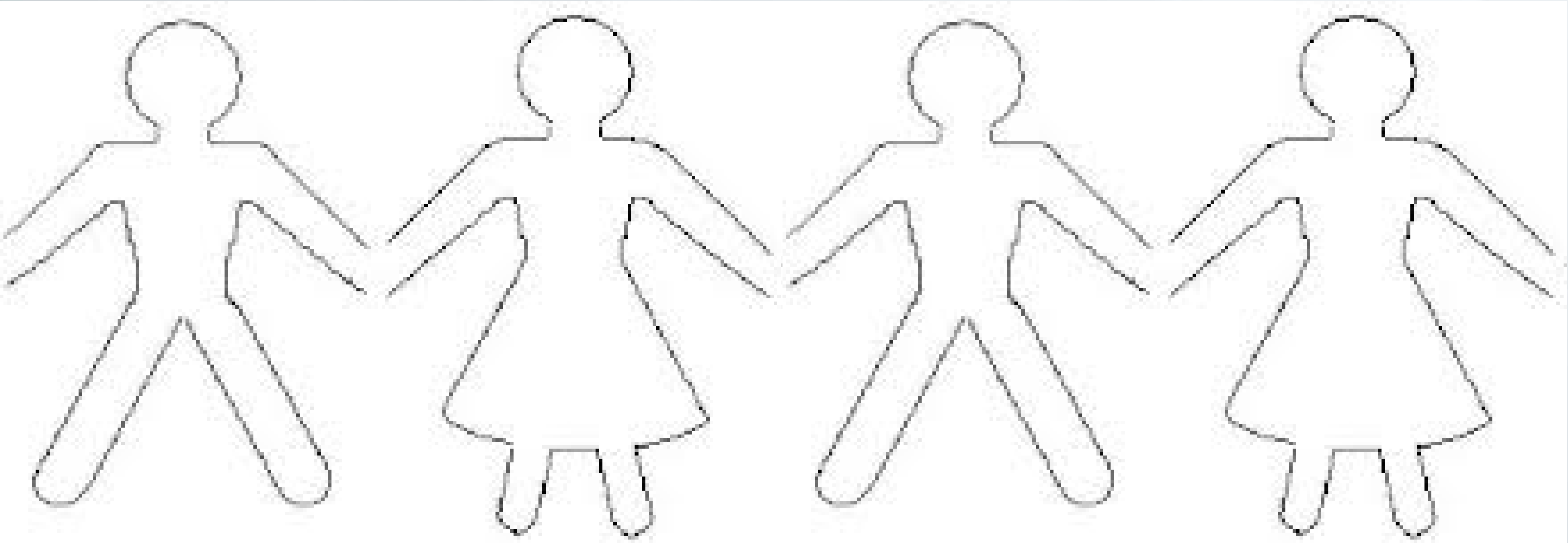
~~disabilitycare~~
Australia

- Insurance model that requires predicted expenditure based on likely outcomes
  - Will need diagnosis and functional assessments
- Being rolled out region by region across Australia

✓ Single entry for services
✓ Registered care providers
✓ Funding for services & products

✓ Comprehensive evaluation
✓ Opportunities for research





Cerebral Palsy

How can we put the ABLE back into childhood disability

The best possible:

- Inclusion
- Participation
- Quality of life for children and their families

Currently some receive good treatment.

For others:

- Diagnosis is made too late
- Families report being poorly informed and supported
- Postural deformities
- Poor nutrition
- Premature death

How can we do better?

The Early Journey

Tom

- Maternal infertility
- Conceived following IVF
- Premature labour at 26 weeks' gestation
- Many neonatal problems including intraventricular haemorrhage and sepsis
- Some irritability and not sitting at 9 months

What does the paediatrician do?

1. Feels uncomfortable about making the diagnosis/talking about high risk
2. Considers that it is not the right time: let’s wait and see until child is a little older
3. Decides to make a referral to paediatric neurologist so he / she could break the news
4. Believes that early diagnosis / therapy makes no difference

What is the average age of diagnosis of cerebral palsy?

19 months

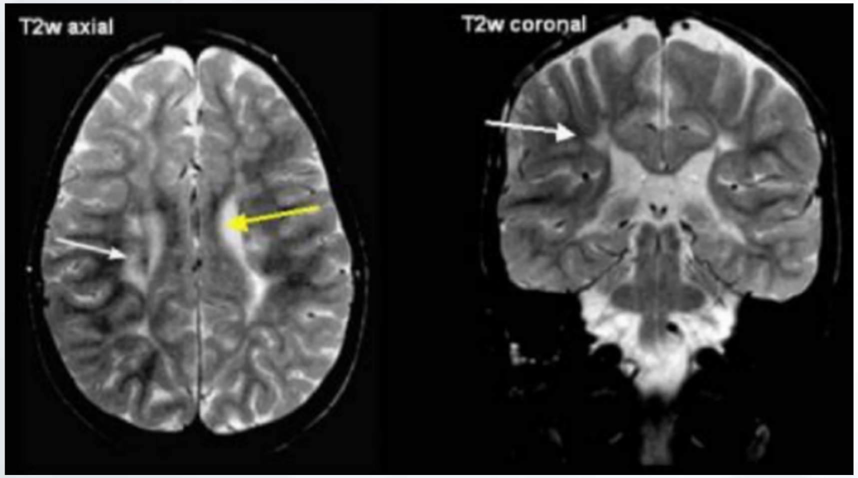
More severe diagnosed earlier

n=1734 | Australian Cerebral Palsy Register [NSW/ACT] (2011)

So can we change this “late diagnosis”?

Early diagnosis can now be made

- General Movements Assessment
  - Good reliability
  - Good validity
- Hammersmith Infant Neurological Examination
  - HINE less than 57 at 3-months 96% predictive of cerebral palsy



2004 – American Academy of Neurology
All children with cerebral palsy of unknown aetiology should undergo neuroimaging, with MRI being the preferred investigation
Will confirm neuropathology in about 80%

Early diagnosis

- For infants less than 5 months and at high risk of cerebral palsy
  - Early detection using a combination of General Movements assessment and MRI at near term age over 95% accurate
- For infants older than 5 months corrected age, and at high risk of cerebral palsy
  - Early detection using a combination of the Hammersmith Infant Neurological Examination and early MRI is over 90% accurate

International Clinical Guideline for Early Detection of High Risk of Cerebral Palsy

COMING SOON

Does early intervention help?

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY SYSTEMATIC REVIEW

Effect of early intervention in infants at very high risk of cerebral palsy: a systematic review

No firm conclusions

Difficult to generalize because of heterogeneity of interventions, especially type, frequency and duration of interventions and also because of limited group sizes

Suggest that early intervention in the first year of life should consist of a combination of:

- Developmental stimulation that includes trial and error
- Learning in a challenging enriched environment
- Supportive of parent-infant interaction

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY SYSTEMATIC REVIEW

Effectiveness of motor interventions in infants with cerebral palsy: a systematic review

<u>Conclusion:</u>

- Studies varied considerably in methodological quality, the intervention approaches and outcome measures used and had small sample sizes

  Recommendation for clinical practice are **<u>weak</u>**

- Common themes for the most successful approaches:
  - Child initiated movement
  - Environmental modification/enrichment
  - Task specific training

MORE RESEARCH TO BE DONE: REACH & GAME STUDIES

Many individuals with cerebral palsy die young

Population-based survey 3507 individuals with CP in Victoria. Mortality rates:

- 3% by the age of 5 years,
- 6% by the age of 10 years,
- 11% by the age of 20 years,
- 17% by the age of 30 years,
- 20% by the age of 40 years (Individuals with CP had an 80% survival rate to the age of 40 years)

NO IMPROVEMENT IN SURVIVAL BETWEEN

THE 1970S AND 2000S

Can we do better?

Management

- Need to search for the best evidence
- Recent systematic review of 64 discreet interventions for CP, only 24% were demonstrated to be effective, 70% had uncertain effects and 6% were demonstrably ineffective

Novak I, McIntyre S, Morgan C, Campbell L, Dark L, Morton N, et al. A systematic review of interventions for children with cerebral palsy: state of the evidence. Developmental Medicine & Child Neurology.55(10):885-910.

Management of health issues and related co-morbidities

All children should have:

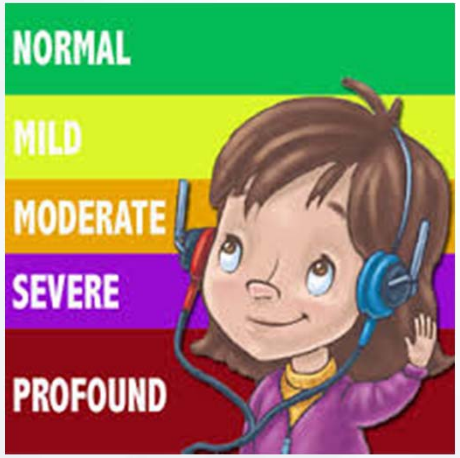
Hearing assessed

Vision assessed

Be immunised

Have regular dental care

Boys should be screened for undescended testes



Management of health issues and related co-morbidities

Epilepsy

- All seizure types are seen
- Some types of epilepsy are a direct consequence of the underlying brain injury and may persist throughout life.
- Other types of epilepsy are not directly related to a child’s cerebral palsy eg benign childhood epilepsy with centrotemporal spikes (Rolandic epilepsy)

Cerebral palsy and Epilepsy

166 children with CP and WMI

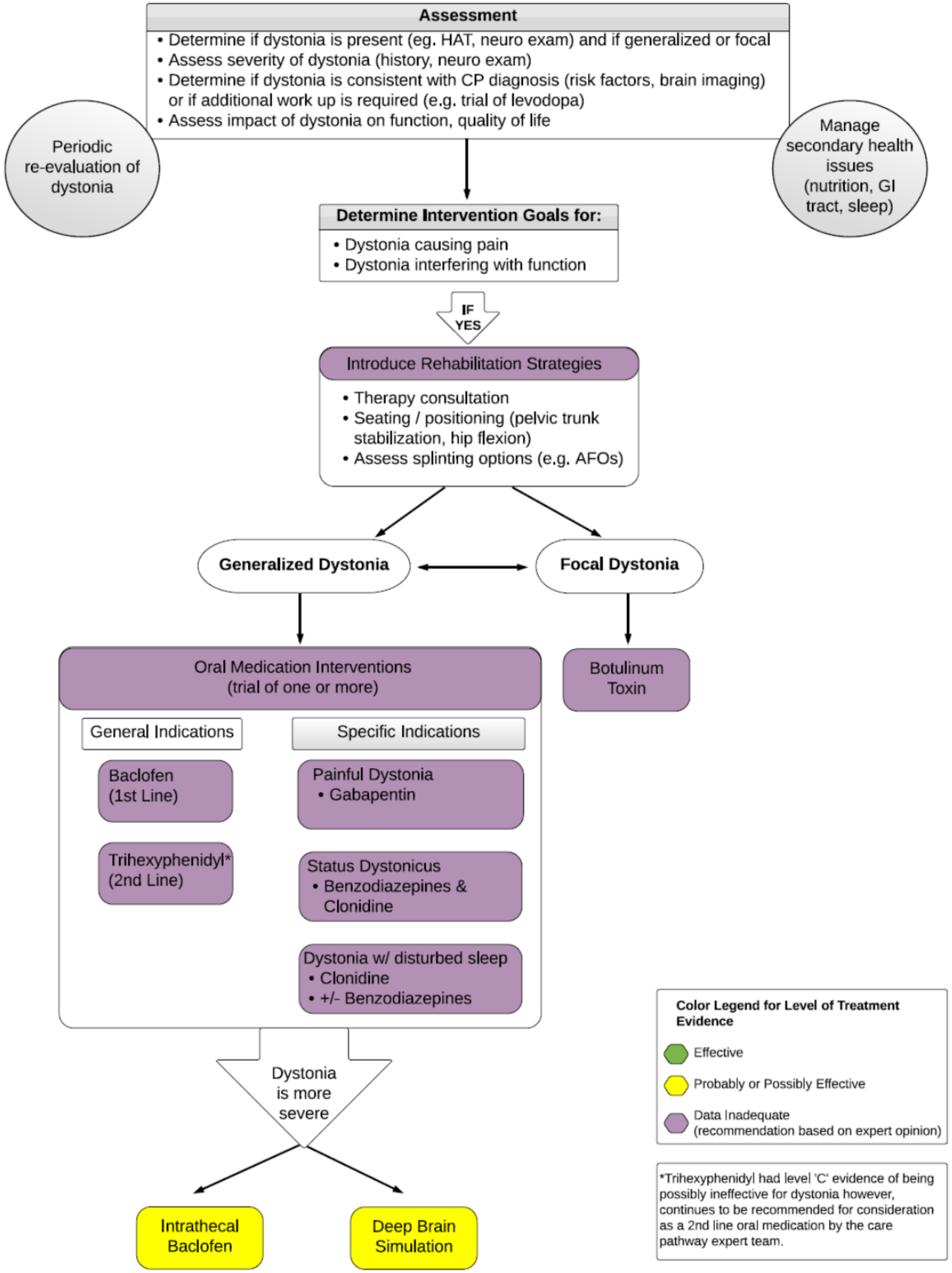
- 41 children (25%) had seizures
  - 30 focal epilepsy typical of childhood epilepsy with centrotemporal spikes
  - 2 idiopathic epilepsy
  - At last follow-up, 80% had not had a seizure for > 2 years
- Favourable outcome in most, important for counselling and drug treatment

63 children with CP and AIS

- 34 children (54%) had seizures, majority were focal seizures suggestive of Rolandic or occipital seizure origin
- Only 15% had active epilepsy 10 years after onset.

Care Pathways - Dystonia

Flow Diagram for an Evidence-Informed Care Pathway for Dystonia in Cerebral Palsy



Assessment
- Determine if dystonia is present (eg. HAT, neuro exam) and if generalized or focal
- Assess severity of dystonia (history, neuro exam)
- Determine if dystonia is consistent with CP diagnosis (risk factors, brain imaging) or if additional work up is required (e.g. trial of levodopa)
- Assess impact of dystonia on function, quality of life

Periodic re-evaluation of dystonia

Manage secondary health issues (nutrition, GI tract, sleep)

Determine Intervention Goals for:
- Dystonia causing pain
- Dystonia interfering with function

IF YES

Introduce Rehabilitation Strategies
- Therapy consultation
- Seating / positioning (pelvic trunk stabilization, hip flexion)
- Assess splinting options (e.g. AFOs)

Generalized Dystonia

Focal Dystonia

Oral Medication Interventions (trial of one or more)

General Indications

Baclofen (1st Line)

Trihexyphenidyl* (2nd Line)

Specific Indications

Painful Dystonia
- Gabapentin

Status Dystonicus
- Benzodiazepines & Clonidine

Dystonia w/ disturbed sleep
- Clonidine
- +/- Benzodiazepines

Botulinum Toxin

Dystonia is more severe

Intrathecal Baclofen

Deep Brain Simulation

Color Legend for Level of Treatment Evidence

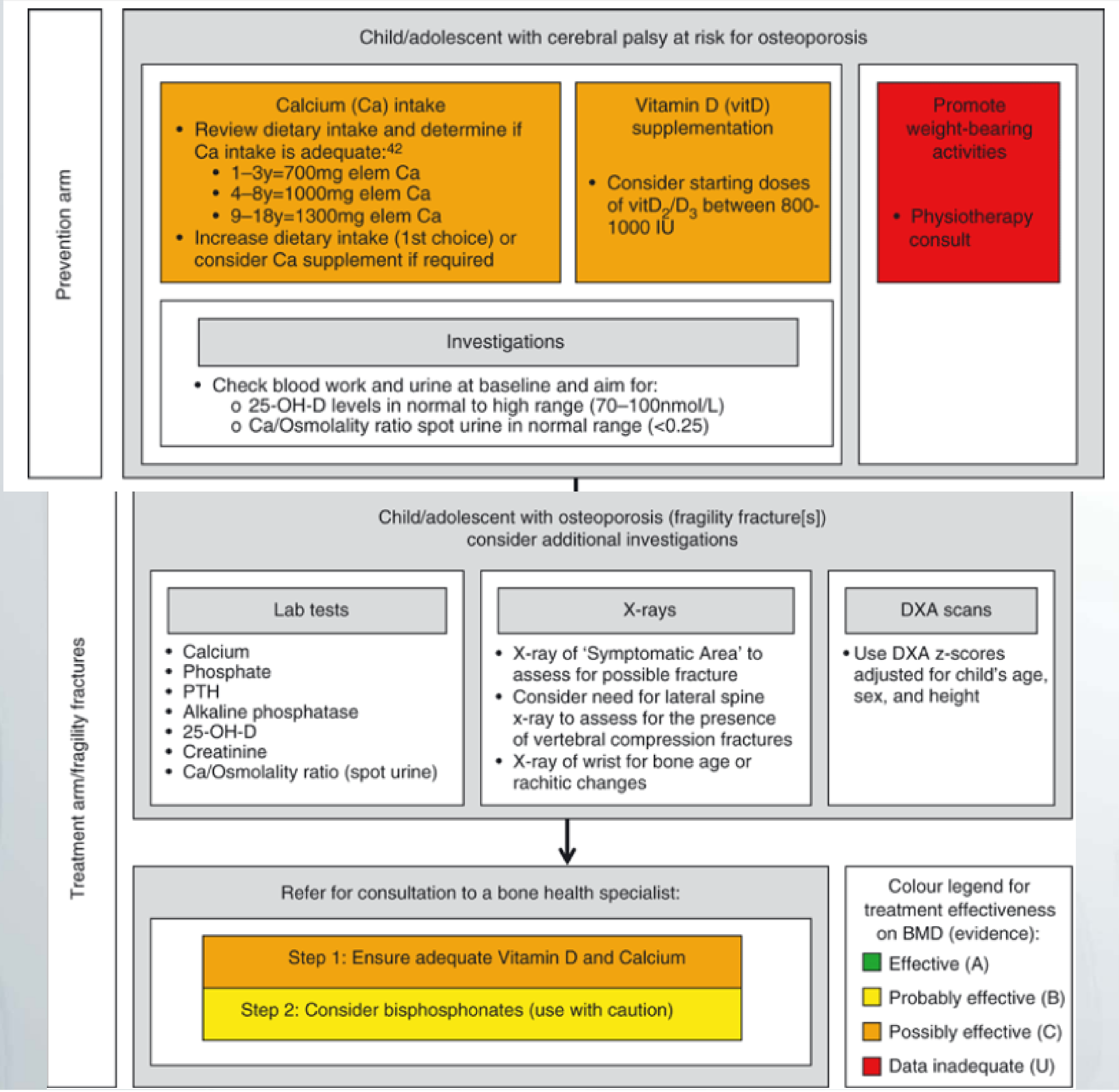
🟩 Effective

🟨 Probably or Possibly Effective

🟪 Data Inadequate (recommendation based on expert opinion)

*Trihexyphenidyl had level 'C' evidence of being possibly ineffective for dystonia however, continues to be recommended for consideration as a 2nd line oral medication by the care pathway expert team.

Clinical Guideline for Osteo-porosis



Child/adolescent with cerebral palsy at risk for osteoporosis

Calcium (Ca) intake

- Review dietary intake and determine if Ca intake is adequate:[42]
  - 1–3y=700mg elem Ca
  - 4–8y=1000mg elem Ca
  - 9–18y=1300mg elem Ca
- Increase dietary intake (1st choice) or consider Ca supplement if required

Vitamin D (vitD) supplementation

- Consider starting doses of vitD$_2$/D$_3$ between 800-1000 IU

Promote weight-bearing activities

- Physiotherapy consult

Investigations

- Check blood work and urine at baseline and aim for:
  - o 25-OH-D levels in normal to high range (70–100nmol/L)
  - o Ca/Osmolality ratio spot urine in normal range (<0.25)

Child/adolescent with osteoporosis (fragility fracture[s]) consider additional investigations

Lab tests

- Calcium
- Phosphate
- PTH
- Alkaline phosphatase
- 25-OH-D
- Creatinine
- Ca/Osmolality ratio (spot urine)

X-rays

- X-ray of 'Symptomatic Area' to assess for possible fracture
- Consider need for lateral spine x-ray to assess for the presence of vertebral compression fractures
- X-ray of wrist for bone age or rachitic changes

DXA scans

- Use DXA z-scores adjusted for child's age, sex, and height

Refer for consultation to a bone health specialist:

Step 1: Ensure adequate Vitamin D and Calcium

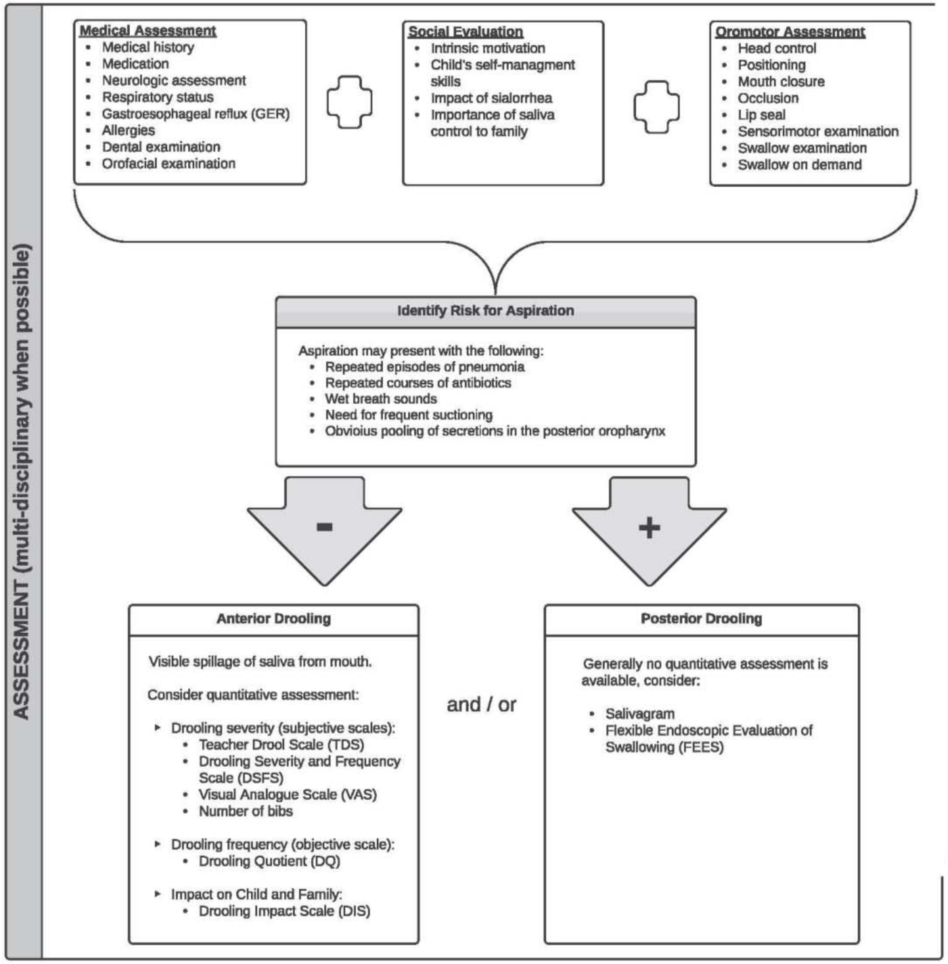
Step 2: Consider bisphosphonates (use with caution)

Colour legend for treatment effectiveness on BMD (evidence):

🟩 Effective (A)
🟨 Probably effective (B)
🟧 Possibly effective (C)
🟥 Data inadequate (U)

Clinical Practice Guideline for Sialorrhea

Flow Diagram for Evidence-Informed Clinical Practice Guideline for Sialorrhea in Children/Youth with Cerebral Palsy



ASSESSMENT (multi-disciplinary when possible)

Medical Assessment
- Medical history
- Medication
- Neurologic assessment
- Respiratory status
- Gastroesophageal reflux (GER)
- Allergies
- Dental examination
- Orofacial examination

+

Social Evaluation
- Intrinsic motivation
- Child's self-managment skills
- Impact of sialorrhea
- Importance of saliva control to family

+

Oromotor Assessment
- Head control
- Positioning
- Mouth closure
- Occlusion
- Lip seal
- Sensorimotor examination
- Swallow examination
- Swallow on demand

Identify Risk for Aspiration

Aspiration may present with the following:
- Repeated episodes of pneumonia
- Repeated courses of antibiotics
- Wet breath sounds
- Need for frequent suctioning
- Obvioius pooling of secretions in the posterior oropharynx

\-

\+

Anterior Drooling

Visible spillage of saliva from mouth.

Consider quantitative assessment:

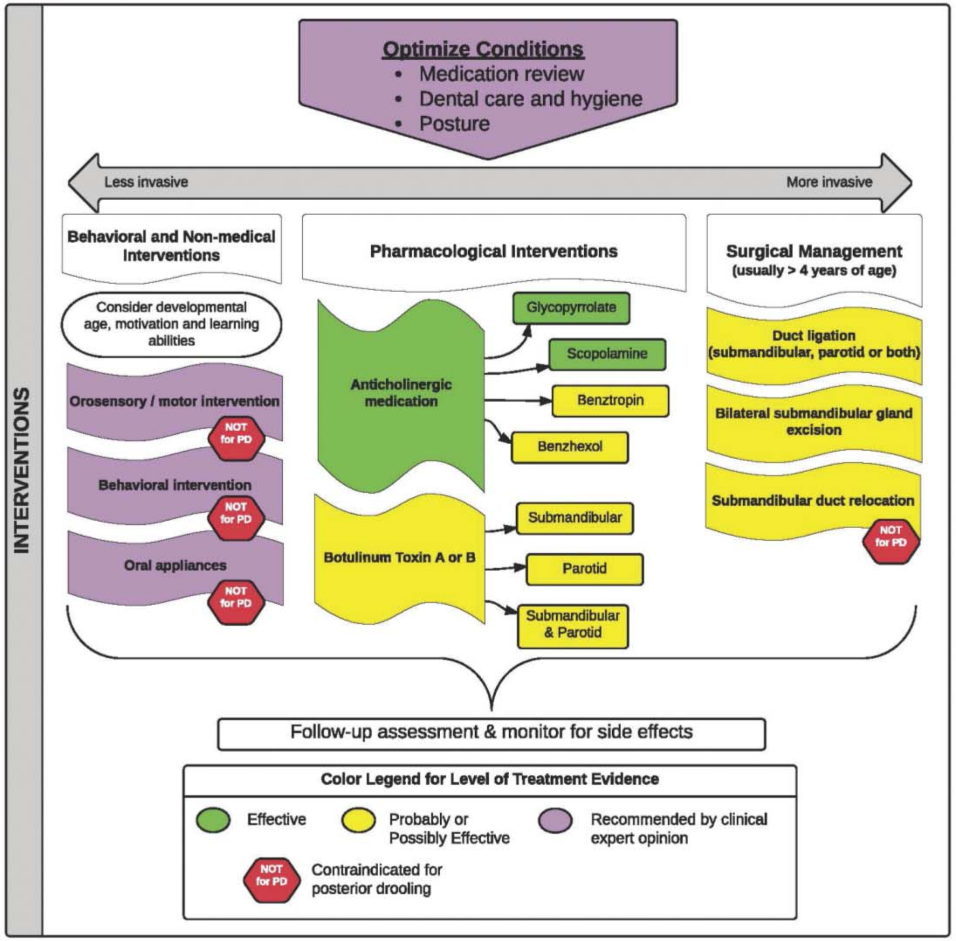
- Drooling severity (subjective scales):
  - Teacher Drool Scale (TDS)
  - Drooling Severity and Frequency Scale (DSFS)
  - Visual Analogue Scale (VAS)
  - Number of bibs
- Drooling frequency (objective scale):
  - Drooling Quotient (DQ)
- Impact on Child and Family:
  - Drooling Impact Scale (DIS)

and / or

Posterior Drooling

Generally no quantitative assessment is available, consider:

- Salivagram
- Flexible Endoscopic Evaluation of Swallowing (FEES)



INTERVENTIONS

Optimize Conditions
- Medication review
- Dental care and hygiene
- Posture

Less invasive — More invasive

Behavioral and Non-medical Interventions

Consider developmental age, motivation and learning abilities

Orosensory / motor intervention — NOT for PD

Behavioral intervention — NOT for PD

Oral appliances — NOT for PD

Pharmacological Interventions

Anticholinergic medication → Glycopyrrolate, Scopolamine, Benztropin, Benzhexol

Botulinum Toxin A or B → Submandibular, Parotid, Submandibular & Parotid

Surgical Management (usually > 4 years of age)

Duct ligation (submandibular, parotid or both)

Bilateral submandibular gland excision

Submandibular duct relocation — NOT for PD

Follow-up assessment & monitor for side effects

Color Legend for Level of Treatment Evidence

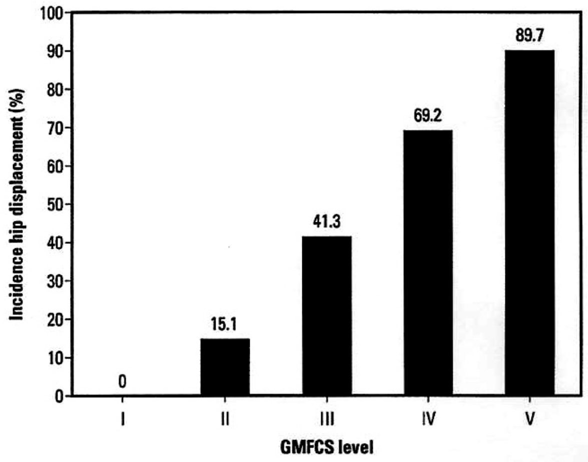
🟢 Effective

🟡 Probably or Possibly Effective

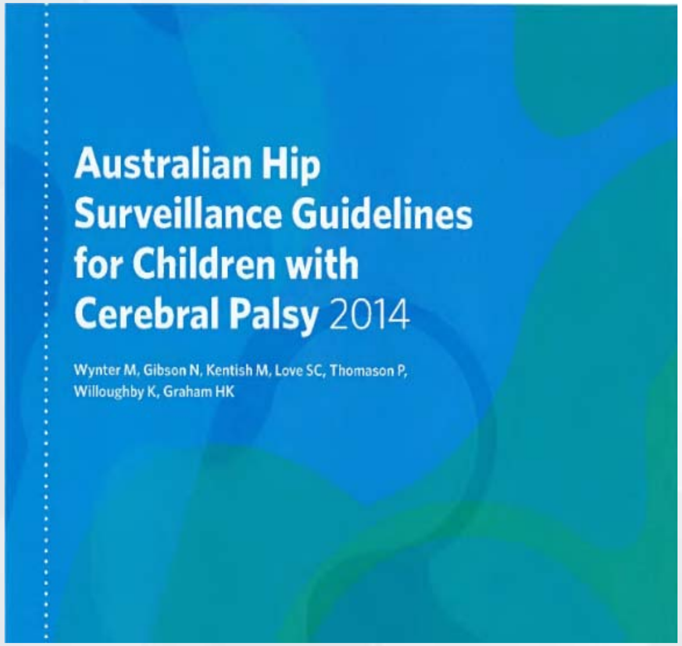
🟣 Recommended by clinical expert opinion

NOT for PD Contraindicated for posterior drooling

Hip Surveillance Guidelines



Incidence of hip displacement (a migration percentage of >30%) according to the Gross Motor Function Classification System (GMFCS) level.



Australian Hip Surveillance Guidelines for Children with Cerebral Palsy 2014

Wynter M, Gibson N, Kentish M, Love SC, Thomason P, Willoughby K, Graham HK

https://ausacpdm.org.au/professionals/hip-surveillance/australian-hip-surveillance-guidelines/

Effective interventions

General principles

- Goal-directed training
- Child-active structured training in self-care tasks
  - eg dressing, designed so task is meaningful for child
- Involve parent education and encourage parent-child interaction

Therapies shown to be effective

- Bimanual training for hemiplegia
  - 30 – 60 hrs of therapy over 6-8 weeks
- Constraint-induced movement therapy for hemiplegia
  - 30 – 60 hrs of therapy over 6-8 weeks
- Strength training

Improved technology

Parental mental health

294 mothers of children with a disability

High rates of mental ill health

- 44% clinically significant depression
- 42% anxiety
- 21.8% suicidality in the previous 12 months

96% of mothers perceived a need for professional support

- only 54% attempted to access this.

Key barriers to accessing support were

- limited time (44.7%)
- not perceiving the mental health problem as serious enough (36.2%).

Two current research studies

Resourcing Key Workers / Early Childhood Intervention Workers to:

- Detect maternal mental health problems
- Support mothers to access referrals

(Dr Elise Davis, University of Melbourne)

Wellbeing for Parents and Carers

A resource for parents and carers who are raising a child, adolescent or young adult with a disability. This resource was developed through interviews with parents who shared their experiences as a carer. Their perspectives are illustrated in the quotes throughout this resource.

What is wellbeing?

Wellbeing is the happiness and satisfaction that we feel about our lives. It often goes up and down depending on what is happening in our life. Good wellbeing can include feeling able to cope with the daily stresses of life, having supportive social relationships, feeling connected to your community and generally enjoying life. It enables us to perform better in family and community life. Wellbeing does not mean that you are free from illness and never experience difficult feelings or situations. The way we achieve wellbeing may be different from person to person – we are all different in how we think and feel.

> “Wellbeing to some people might be having time off and reading a book or being able to go for a bike ride; for somebody else it might be feeling more in control of what's going on with them and their child's life. It might be eating a good diet or getting some help with your marriage”
>
> - Susan, parent of Andrew (aged 8)

The “F words”

Thanks to Peter Rosenbaum and Jan Willem Gorter

Function – What has your child done well over the past few months?

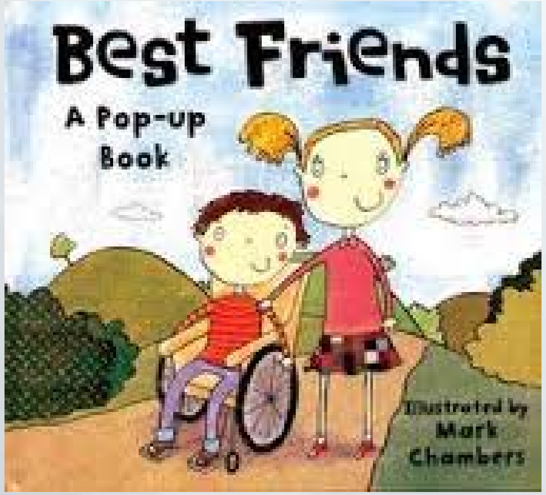
Friends – How is your child getting on with other children?

Family – How are you doing?

Do you need more support?

Fun – Are interventions enjoyable?

Fitness – If possible..getting a program to help fitness?



Putting able back into childhood disability

- Improved evidence
- Use of knowledge that is available
- Greater focus on children within families & their community

TO CREATE A PATHWAY TO A BETTER FUTURE

Put the able back into childhood disability

Disability, Abuse and Neglect

What do we know?

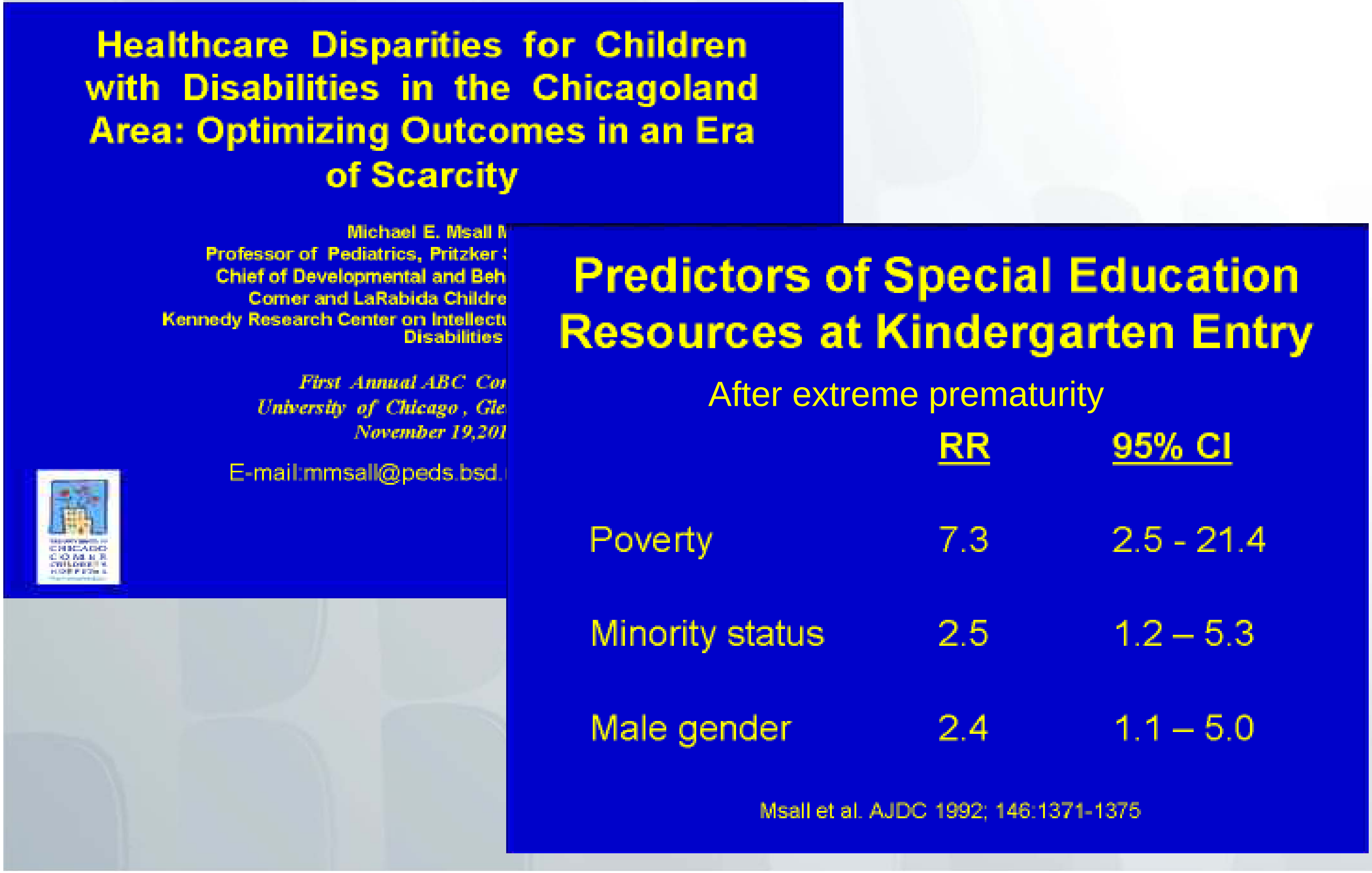
Are children with a disability more likely to live in situations of social disadvantage?

Http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Chapter4002008

“Families with at least one young child with a disability have a variety of different experiences and circumstances but tend to have lower socioeconomic status, labour force participation and income than other families with young children. This may be partly due to the larger size of families with a child with a disability.”

What do we know?

Impact of social disadvantage on disability



Healthcare Disparities for Children with Disabilities in the Chicagoland Area: Optimizing Outcomes in an Era of Scarcity

Michael E. Msall
Professor of Pediatrics, Pritzker
Chief of Developmental and Beh
Comer and LaRabida Childre
Kennedy Research Center on Intellect
Disabilities

First Annual ABC Con
University of Chicago , Gle
November 19,201

E-mail:mmsall@peds.bsd.

Predictors of Special Education Resources at Kindergarten Entry

After extreme prematurity

	RR	**95% CI**
Poverty	7.3	2.5 - 21.4
Minority status	2.5	1.2 – 5.3
Male gender	2.4	1.1 – 5.0

Msall et al. AJDC 1992; 146:1371-1375

What do we know?

Prevalence of abuse & violence

Systematic review and meta-analysis

Jones et al. Lancet 2012;380:899-907

Approximately 2000 children under 18 years

17 studies included in final – heterogeneity and variable quality

- Risk of physical and sexual violence three to four times more likely in children with disabilities. Similar rates for neglect and emotional abuse.
- 25% of children with a disability will experience abuse in their lifetime
- did not include all forms of abuse:
  - bullying
  - experience of war or terrorism
  - witnessing domestic violence

Birth

Girl with spina bifida delivered at term

- Born in district general hospital
- No antenatal diagnosis
- Large thoracic level lesion with hydrocephalus and Chiari malformation
- Early transfer to neonatal intensive care, 70km away from home for treatment

Day 1

- Back closed by neurosurgeon and plastic surgeon. Difficult to close
- VP shunt inserted for severe hydrocephalus

Family history

- Second child to mother
- First child to father
- Mother previously worked as an enrolled nurse at closest tertiary institution (30 km)

- 3 year old female sibling - noted to swear a lot when visiting neonatal ward

- Father verbally abused mother on the neonatal ward

Second month of life

- Day 28 baby developed meningitis and CSF leak
- Shunt removed and externalised
- One month later VP shunt reinserted

While hospitalised

- Episode of physical violence in the care be parent unit
- Mother discloses domestic violence and her wish to leave father to social worker
- Abuse -physical and verbal
  - Threats to burn down family home
  - Abduct mother’s older daughter
  - Murder mother

- Father - regular heavy marijuana use and bipolar disorder

- Mother - long standing depression

Post discharge

- Not referred to child protection
- Sent home with early intervention services and with Strengthening Families
- Voluntary

- Mother refused to allow workers into the home
- Failed to attend multiple hospital appointments
- Marked neglect noted by early intervention workers who reported difficulty engaging mother

Increasing services

- Protective services referral made
- Disability services involved
- Mother refused to see one paediatrician in spina bifida clinic following protective services referral
- Transferred to other paediatrician in clinic
- Local paediatrician engaged
- Close liaison

- Parents separate and then reunite multiple occasions
- Next pregnancy – brother born when aged 2 years

School age

- WPPSI performed IQ - 71
- Commences at local primary school with funding for physical disability

<u>Family</u>

- Mother reports difficulties with her other 2 children
- Son - aggressive, hyperactive, constantly demanding
- Older daughter - behavioural problems and learning difficulties
- Maternal mental health deteriorating

Ongoing complex care needs

Education

- Transferred to specialist school aged 10
- Often failed to attend

Mental Health

- Developed marked anxiety symptoms reported by school

Complex health care needs

Neuropathic bowel and bladder

- Catheterised 4 hourly and manual disimpaction by mother for bowel care

Skin care

- Multiple pressure areas
- Weight gain

Orthopaedic problems

- Hip dislocation from dysplasia
- Fractured femur- aged 8 - admitted under orthopaedic unit and no communication with paediatrician
- Kyphoscoliosis - marked deterioration
- Surgery not possible

Complex health care needs

Respiratory problems

- Developed OSA -oxygen requirement
- Severe central apnoea
- Severe restrictive lung disease from severe kyphoscoliosis
- Tonsillo-adenoidectomy aged 10
- On overnight BiPAP at home
- Significant respiratory compromise with frequent presentations to local hospital

PLAN FOR PALLIATIVE CARE DISCUSSED WITH MOTHER

Admitted aged 11

Physical health

- Respiratory infection and UTI
- Severe breakdown of thoraco-lumbar wound with subcutaneous collection
- Head lice

Family breakdown

- Restraining order against father for violence to mother and children
- Breached multiple times by mother and father
- Father remanded in custody

Age 11

Child mental health

- Mental health assessment
- Diagnosis of anxiety and depression made by psychiatrist

Services

- Palliative care involvement led to huge boost in provision of equipment e.g. new bed with ripple mattress, bathroom modifications, extra support with school attendance, respite in hospice

Family situation

- No co-operation from mother
- Multiple attempts to help mother engage with services
- Child protection finally brought a Protection Application by Notice
- One year later agreement that care would be shared with mother and foster carer
- 6 months later, judge asked by child to allow her to live full time with her foster carers
- Granted

Four years later…

- Supervised access with biological mother once a fortnight
- General health improved especially pressure areas and sleep
- Very severe obstructive lung disease but no longer requiring BiPAP and oxygen
- Recurrent UTIs and respiratory infections continue
- Concerns about her mental health continue
- Foster family reporting
  - “Lazy”
  - “Does it on purpose”
  - “Gets angry over nothing”

TRANSITION TO ADULT CARE COMMENCING

A child with a disability born into a situation with high risk of abuse

- End of life an option?
- Family support
- Parenting

Soon after birth

Early Childhood

- Family support
- Optimise parental mental health
- Ensure education
- Care coordination

- Family support
- Young person’s mental health
- Support for the young person to gain independence

Adolescence

An ABLE approach

- Professionals - optimal communication
  - Amongst all professionals
  - With the family
- Well coordinated care
- Relevant support offered
- Parental mental health as a focus
  - Prior mental health issues
  - Secondary to grief and care burden
- Services that are not silos
- “Whole of government” action not rhetoric

Your thoughts?