

**Making Sense of Emotional and Behavioural  
Disturbance in Children and Adolescents  
with Intellectual Disability:  
Lessons from  
The Training Curriculum Project  
and  
The CHW School-link Project.**

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# Presentation

1. Context
2. Introduction to Training Curriculum Project
3. Key features of the TCP
  1. Quality of life
  2. Family context
  3. Common language of bio developmental psycho social cultural framework
  4. Multidisciplinary developmental skill building vs medical model
  5. Implications for service development
4. CHW School-link  
Needs analysis & Current initiatives
  1. Newsletter and website
  2. Pilot cross agency supervision of group of school counsellors
  3. Pilot of Stepping Stones Parent Training
  4. Modification of EBSST for Mod and Severe ID
5. Conclusions

# 1. The context

## **Studying The Development Of The Mind: A Prerequisite To Understanding Losing One's Mind?**

Development of the mind involves developing capacities of:

- Sensory integration and the identification of self and non self;
- Motor regulation and coordination;
- Arousal modulation and selective attention;
- Communication skills and an internal voice;
- Mood regulation and Self concept
- Emotional recognition and Reciprocal social interaction;
- Theory of mind, Reality testing, Perspective taking & Problem Solving.

The capacity for developing good quality peer attachment relationships is the best measure of youth and future MH as an adult.

The neurobiology of the basis of mental illness suggests there are commonalities between the processes of development of the mind and losing one's mind (Starling & Dossetor, 2009) (Mouridsen & Hauschild, 2008).

# Context

- MH of C&A with ID is a public concern
- 30-50% of C&A with ID have signif MH probs
- MH for C&A with ID is 14% of MH burden (Emerson & Hatton 2007)
- The MH prob and the burden of care affect QOL
- 2-3x greater financial burden of care for care, treatment & education & reduced income capacity
- Over half of carers (59%) experienced a decline in physical health & two-thirds felt that their mental & emotional health was affected with depression, anxiety or stress (Cummins et al 2005)
- Context of no designated mental health service for MH & ID
- No previous textbook covering this area of multidisciplinary expertise?

## 2. Introduction to Training Curriculum Project (TCP)

- 3 years funding from 3<sup>rd</sup> NMHP and ADHC for project manager (**Donna White**) with partnership with Statewide Behaviour Intervention Service ADHC (**Lesley Whatson**)
- Sources of information
  - Literature review
  - What works in tertiary multidisciplinary multi-agency clinic
  - Areas of demand for training from SBIS
  - Stakeholders survey of areas of intervention focused learning
  - Evaluations and 3 month outcomes on workshops
  - Commissioned 35 chapters which were independently reviewed to be published in 6 months
- Have provided 4 2-day workshops to 460 clinicians

### 3. Key features of the TCP

1. Quality of life
2. Family context
3. Common language of bio developmental psycho social cultural framework
4. Multidisciplinary developmental skill building vs medical/psychiatric model
5. Implications for service development

Give you a flavour of the curriculum

# Why have children?

- Easy, fun and rewarding?
- Children are demanding, hard work and stressful
- The more you have the more this is so
- The older they get the more this is so
- Second happiest stage of married life is when they leave home.

# Climbing a Challenge to Quality of Life

- Why climb mount Everest?
- It is a waste of time,
- Takes time money and effort and you have nothing to show for it!
- Because it is there
- For the physical challenge, some hills are more challenging
- For getting to know yourself and your limitations
- For the friendships you come to depend on and value
- To appreciate the journey not the summit
- A sense of challenge & achievement

# What makes a Quality of Life?

- QoL is a subjective and personal perception
- “How satisfied are you with your life as a whole”
  - An adequate standard of living
  - Feeling safe
  - Reasonable health
  - Connected to valued relationships
  - Linked to a community
  - Contributing a worthwhile role
  - A sense of purpose and productivity
  - Having a hope for the future

# What makes a Quality of Life?

- Pretty similar and fairly good for most (75% +/-20)
- Most people find in the face adversity
  - Chronic ill health adapt
  - Being intelligent or being a slow learner
  - Being rich or poor
- Psychiatric disorders are ‘disorders of quality of life’.
- Health interventions demonstrate health-related quality of life
- Internationally accepted concept of health is
  - Not just a concept of an absence of disease but a sense of health and wellbeing in physical, psychological, social and spiritual or cultural dimensions (WHO)

# What makes a Quality of Life?

- For a child or adolescent with intellectual disability or other developmental disorder?
  - for the young person with Autism (with a central disability of difficulty understanding other people's thoughts and feelings and difficulty communicating) **quality of life still** involves a sense of belonging, of friendship, or friendliness or shared activity
  - for the alienated, hostile, neglected young person living in a refuge, family relationships are **still** the most important (NSW Commissioner for Children)
  - For one with a ID developmental achievement is **still** valued eg walking or functional communication

# Children and families with a diffability

- Research of 92 families with teenagers with severe ID
  - Extraordinary families, making the best of adversity
  - Valuing the relationship & celebrating achievements of their teen with ID
- Some exceptional families are able to see these challenges as advantages
  - Increased sense of purpose and focus on caring
  - Expanded social networks community involvement
  - Bringing the family together & valuing intimacy
  - Personal growth & faith and increased tolerance and understanding
- It also involves hardship, persistence and problem solving
- Having a child with ID is an atypical experience with significant differences or challenges for the child and his or her family,
- Yet all should aspire to having a ‘good enough’ quality of life.
- Emphasise “diffability” rather than “disability”
- 32% vs 85% Downs cohort appreciate life with their child

# *How can clinicians contribute to Quality of Life for Child & Family?*

## **Principles:**

- Provide testimony of ways others resolved similar challenges
- Interpret the scientific literature
- Make science relevant and meaningful for families
- Demystify jargon of different professionals
- Aim to speak in a language that is accessible
- Be holistic in considering the developmental, biological, educational, family, social and cultural context of a child
- Be specific about the evidence that support interventions which bring about change
- “Experts in what can go wrong”: Promote skills to improve situations that are likely to go wrong, and even prevent them occurring
- There is literature about how these children and families can get it ‘right’: insight into the adaptive, proactive and preventative components

# The common traps of caring for a child with ID through the family life cycle

1. Failure of adjustment to a different child
  - Attunement and developmental understanding and special parenting skills
2. Failure to share the care of a different child
  - Adapting to the burden of care
3. Problems of psychiatric disorder
  - Seeking special multidisciplinary skills
4. Failure to look after the carer's wellbeing and family relationships

# What are the main challenges for a family with a child with ID?

1. Getting to know your child
2. Sharing the burden of care
3. Managing the system
  - a. Accessing specialist disability services
  - b. Caring for the carer and family
4. Understanding delayed and uneven development

# The main challenges?

## 1. *Getting to know your special child*

- Do children grow up too quick or too slow? dependent on expectation
- Development is slowed and may be atypical:
  - Some families talk about the advantages of having to spend more of life outside of the fast lane with greater focus on caring
- Quality of life is not related to your destination
  - But to appreciating the journey & marking its milestones & achievements
  - A high value on caring for each other and what that teaches you about life and its values
- The first big challenge is getting to know your child and their differences from ‘average’ expectation.
  - Trying to “cure intellectual disability”: Never say never but a “search for the holy grail” frequently has harmful effects on the quality of life of the child, and the family.
- An understanding of early development

# The main challenges?

## *1. Getting to know your special child*

### *Developmental atunement and realistic expectation*

- Parenting response is conditioned to be modified by the genetic nature and temperament of our child
- Intuitive processes are not sufficient
  - Complex medical or dev needs disrupt their relationship with their parent
  - Modifying expectations to match *this* child's needs & their dev journey
  - Allowing for mastery of skills by breaking them down into smaller steps
- Dealing with the new but different
  - Be clear what may be atypical and how to adapt or manage this
  - Opens the door to a community of especially caring people
  - Accepted & loved by parents but by grand parents, extended family, friends and neighbours, who also have to understand the individuality of the child with ID

# The main challenges:

## *2. The burden of caring*

- Infants are highly dependent, for feeding, dressing and toileting
  - More important: attentional & interactive needs & preverbal communication.
- Caring for an child is hard work, and of limited financial value
  - For a child with ID, this may last five to seventy-five years.
- Burden of long-term caring that most distinguishes families with a child with intellectual disability.
- A baby consumes about seven hours a day of individual care
  - For the child with ID, this is long term.
  - More for children with ID & hyperactive, autistic or poor sleep pattern,
- Typically developing child: visiting friends, sleep overs, birthday parties, and can visit others while parents shop/go to GP
  - For a child with ID this involves a special trusted substitute carer

# The main challenges:

## *2. The burden of caring*

- Coping & survival for a mother of child with ID depends on friends or relatives who provide practical help
  - One or two people who occasionally provided help
  - Need to resolve the practical challenges for the burden of care.
  - Emotional support and understanding may be good, but less important
- Respite care is seen as a crucial cornerstone of enabling a QoL
- Over the last 25 years, gradual change from institutional care to making respite more child and family orientated.
  - The provision of in-home family based respite,
  - The funding to support families and friends to provide respite and develop the skills. (Burnside Family Solutions project in Met North, Sydney.)
  - Still need financial support for alternative care from affectional relationships.

## The main challenges:

### ***3. Managing “the system” and how to survive it***

- Systemic thinking:
  - the way that we are all part of a greater whole.
- For a child with ID, the system is divided into 2 parts:
  1. The challenge of making the specialist disability, educational and health & MH services provide adequately for the special needs of a child with ID
  2. The challenges of maintaining wellbeing and life balance for the parents, the other family members, the extended family, friends, social networks

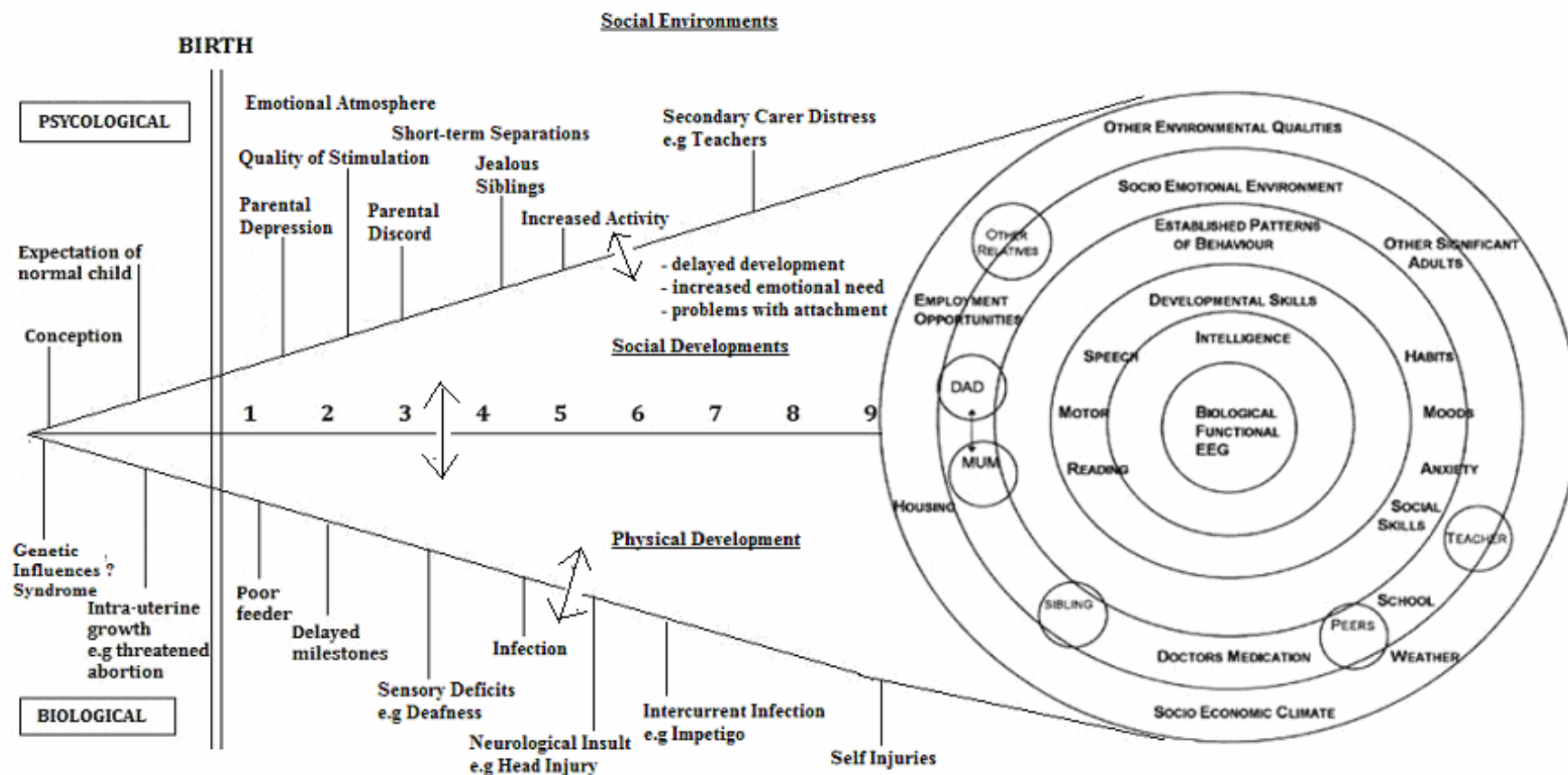
## The main challenges:

### *3. Managing “the system” and how to survive it*

- An infant cannot be considered without a parent (Winnicott).
- Accepting and integrating C&A with ID in our community requires a special valuing of their parents and family.
- Yet the special challenges of accessing necessary services
  - In a cost limiting system,
  - The rotating front door of trainee clinicians
- The skills of advocacy are necessary for every parent of a child with ID need
  - Superlative dimensions of patience, skill, persistence and toughness
  - Considerable skills of discrimination and assertiveness
- Many of these parents, mainly mothers are amongst life heroes

# The bio developmental psycho social cultural multi-aetiological framework for child disorder.

After Brofenbrenner, 1979



# The integration of the psychiatry of ID and child psychiatry

## Psychiatry of Intellectual Disability

**Institution based**

**Biased to biology and genetics**

**Concerned about biological disadvantage**

**Diagnosis based on syndromes recognition**

**Treatment bias to psychopharmacology,  
including segregation & passive eugenics  
communities**

## Child Psychiatry

**Community based**

**Biased to Sociology**

**Concerned about emotional deprivation**

**Diagnosis based on epidemiology**

**Treatment bias to psychotherapies**

**Attributing responsibility to families &**

The social acceptance of difference with biological variation  
Integrating medical sciences with social psychology

## Developmental Neuropsychiatry

**The integration of developmental process in all young people:  
biological underpinnings in a context of family & community  
with expansion of aetiological & therapeutic models**

## **Some common theoretical models and their common context include:**

- Society: welfare, rights, cultural attitudes and socio-economic influences
- Community: environment and social structures
- School: communication and other skill enhancements
- Family: emotional environment and substitute care
- Group: social skills and role learning models
- Solution focused: cognitive behavioural and coping skills models
- Individual Relationship: intra psychic or somatoform emotional models
- Neuropsychiatric processes: neurochemical & psychopharmacological
- Neuropsychology: neuroanatomical function and integrity
- Neurobiological risk & resilience: genetic and neurodevelopmental and molecular biology

## The main challenges:

### *4. Understanding delayed and uneven development*

- **Development** distinguishes a child from an adult
- **Developmental psychopathology** distinguishes child from adult psych dis
- Adults are: mature, autonomous & responsible.
- Adult psychiatric disorders are: disease equivalents that need treatment
- Although adolescents can suffer these psychiatric disorders
  - e.g., schizophrenia, bipolar disorder, depression and PTSD
- Children and adolescents also have an additional range of disorders: emotional, behaviour and neuro-developmental disorders.
- Childhood specific disorders are related to developmental context and competence.
  - The physical and emotional environment esp. of the family
  - The vulnerability of development, temperament & skill competence

# ***“Ontogeny repeats phylogeny”:***

*developmental sequences that occur in evolution & embryology & human development*

- ***The universal principle of development*** (Heinz Werner):
  - *where there is life there is development in a systematic sequence*
- ***Orthogenic principle:***
  - *development progresses from relative globality & lack of differentiation to increasing differentiation, articulation and hierarchic integration.*
  - *both individual and context differentiate, leading to a development-transactional approach. Real development is complex & involves relations constantly changing or transacting with its environment.*
- Skills in a developmental domain occur in sequence.
- Regardless of the cause for delayed acquisition of skills progress follows the same sequence of gaining competence.
  - eg, head control precedes sitting skills followed by standing and walking
  - preverbal noises precede single words followed by short word sequences.
- These sequences are governed by rules of developing mathematical complexity at a level of nerve connectedness

## The main challenges:

# *4. Understanding delayed and uneven development*

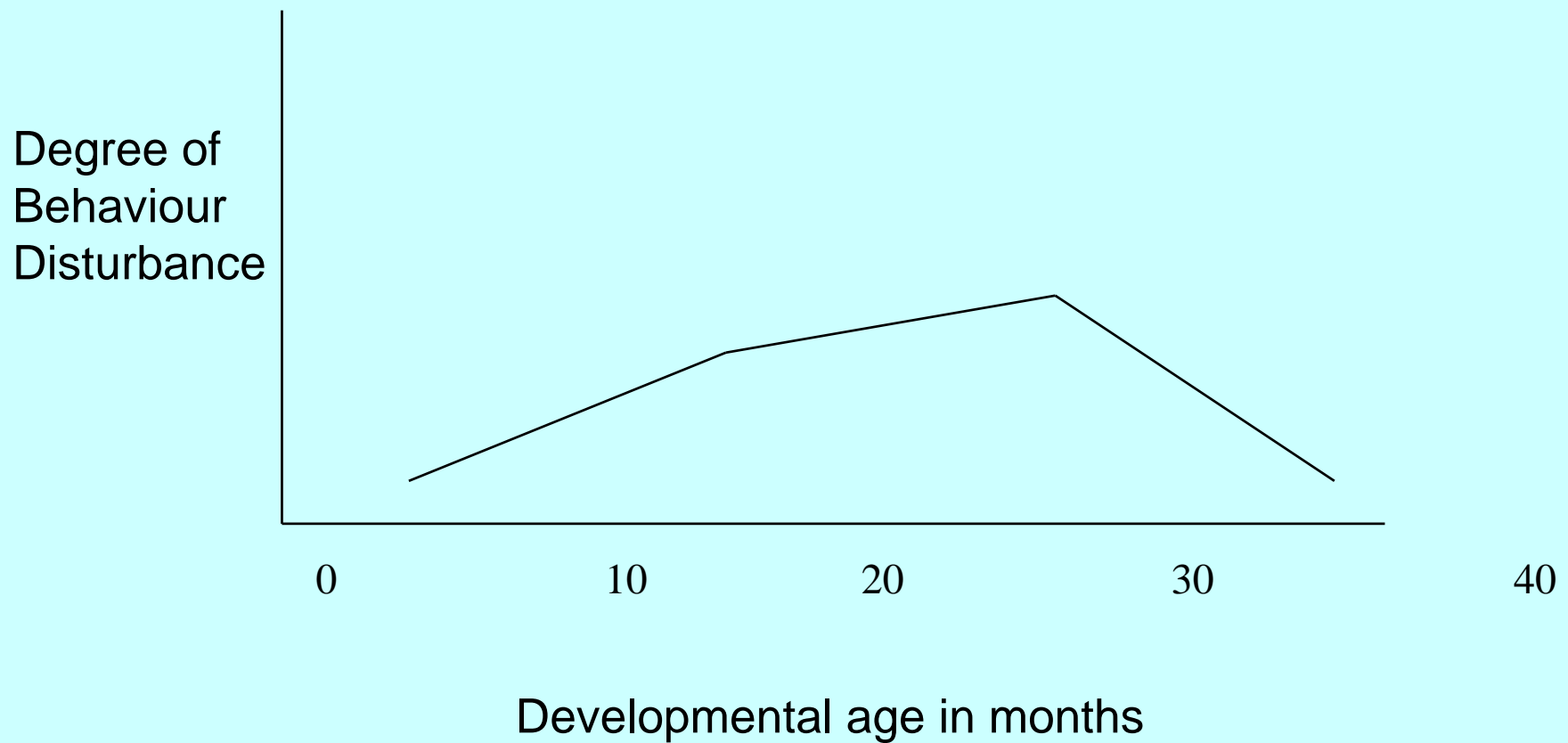
### Assessment of problematic behaviour

#### *Domains of Development*

Handicaps Behaviour Skills Schedule (Wing L)

1. Motor Development, activity and coordination.
  - Motor calmness is prerequisite for concentration
2. Sensory/visuospatial
  - Sensory processing: primary source of physiological arousal before the social dev age of 2.5, the establishment of TOM & internal world.
3. Independence skills: feeding, dressing, toileting
  - Educational and community skill
  - Best clinical measure of IQ before dev educational skills
4. Communication: Expressive / Receptive  
Verbal / Non-verbal/ Symbolic
  - tested functionally by response to commands,
  - the complexity and grammar of commands & an understanding of time
5. Social/Play: Behaviour patterns are more related to developmental than chronological age
  - Gets worse until social age of 2.5-3yrs

# Disturbance vs Developmental age



## The main challenges:

### *4. Understanding delayed and uneven development*

- **Rules of Development:**

- Behaviour should first be considered from a **developmental context**
- If development is delayed, then it is likely to be **unevenly delayed**.
- **If one domain is delayed, then there is an increased expectation of another domain being delayed**

- **Examples**

- If specific language is delayed there is greater risk of ID or probs of social reciprocity (ASD) or ADHD
- If you have coordination disorder then you are more likely to have enuresis
- DCD and ADHD occur in 7%, co-occur in 50%
- If you have delayed development you are more likely to have ADHD
- Autism is more likely in ID (now confirmed by genetic linkage studies)

- **Implication:**

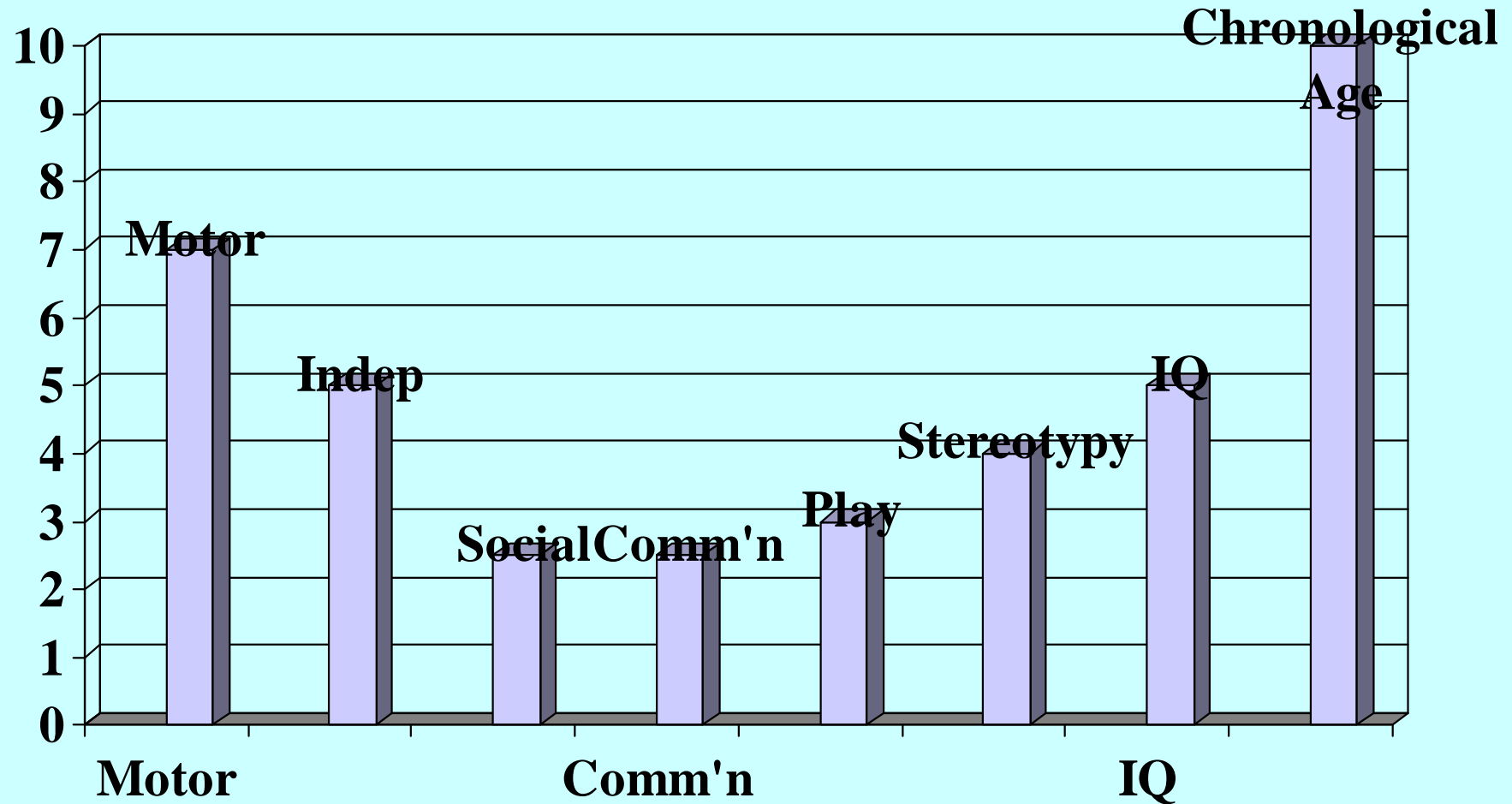
*Developmental processes (and impairments) are genetically linked to each other*

# Autism, Aspergers and ASD:

- 50% of ID have autistic features or delay in social dev
- 80% of presentations of severe beh dist in ID
- Increasing recognition is assoc with conceptual change
- No longer seen as a categorical pure child neuropsychiatric condition with a single causal mechanism
- Better conceptualised as a specific delay in social development:

## **Specific Disorders of Social Development**

# Gringras' Graphic Equaliser Alternative



# Social Responsiveness Scale (SRS)

- 65 item questionnaire of developmental and behavioural items of all different severities; can be filled in by anyone who knows the subject well, without supervision.
- From twin studies, **SRS** has shown the dimensional nature of these features of autism, both in those with autistic disorders and those less severely affected.
- The whole dimension is as genetic as the category of autism.
- Scores (even below the autism threshold) contribute increased variance to the genetic contribution to disturbed beh on CBCL.
- Provides the 1<sup>st</sup> positive means of diagnosing PDD nos.
- Implication: young people presenting with depression, anxiety, disruptive behaviour with mild features of ASD or Disorder of Empathy will have a stronger genetic component to their disturbance, and a worse prognosis.

# Evidence of a developmental framework: Social communication: primary variable for ASD

- Factor analysis of social communication items of ADI-R resulted in a 3 factor solution
  - Symptoms falling into 3 domains:
    - Affective reciprocity (AR) (? 1st year)
    - Joint attention and (? 2nd year)
    - Theory of mind (TOM) (? 3rd year)
- AR was the behavioural propensity to use facial, gestural, vocal and body language in 2 way communication.
- TOM represented social knowledge in the broadest sense.
- The most severely affected autistic children had impairments on all three domains
  - Asp and PDDnos had better affective reciprocity scores than Joint Att, or TOM.
  - The least impaired scores were most impaired in TOM.
  - Shows a developmental progression of Autistic Features

# Stages of Social Development

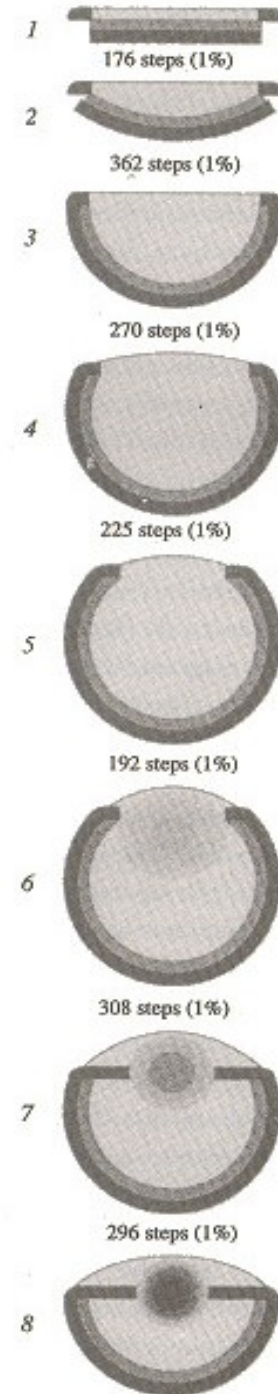
- **0-1yr (Parent oriented)** Development of primary attachment and wariness of strangers. Develop preverbal babble, enjoy rough and tumble, Affective reciprocity
- **1-2 yrs (Adult oriented)** Develop capacity for short lived separations; widen range of adult attachments, develop sense of play and humour with adults, such as Peekaboo. Start to develop joint attention. Respond to gross non-verbal emotional communication
- **2-2.5 yrs (Toddler Independence)** Copy adults, develop pretend and creative play, become away of peer play in parallel. Sensitive to subtle NVC. Shame
- **2.5-.4 yrs (Peer skill development)** Move progressively towards skills of reciprocity with single age related peer; develop skills of sharing and turn-taking. Initially can turn take if in charge or organised. Becoming less ego-centric; popularity comes from organising positive initiatives. Theory of Mind
- **4-8yrs: (Peer Group Association)** Understand reciprocity to maintain friendship and the practical needs a friend fulfils, eg a friend helps you feel happy. Learn to cope with group relations and social organisation by rules. Second order TOM
- **9-13 yrs, (Pre-adolescent)**, Learn to challenge and create group rules. Clear gender split, friendships based on similarity, emotional support, and how they might be viewed by others. Capacity for guilt/sense of object constancy
- **13- (Adolescence):** based on trust and self-disclosure and mutual or admired aspects of personality. Abstract cognitive capacity.

# Nilsson & Pelger's (1994) Computer Generated Theoretical Series, Leading to a Fish Eye.

Shows the mathematical evolution of a 'photon catcher' developing from 3 layers of transparent, light sensitive and light impermeable cells.

Simple mathematic rules determine the shaping of this computer generated eye, which match evolution in the full spectrum of creation's species: light sensitive, direction sensitive, box camera to finally a lens focusing of an image.

From: Climbing Mount Improbable, Richard Dawkins,  
Penguin 1996

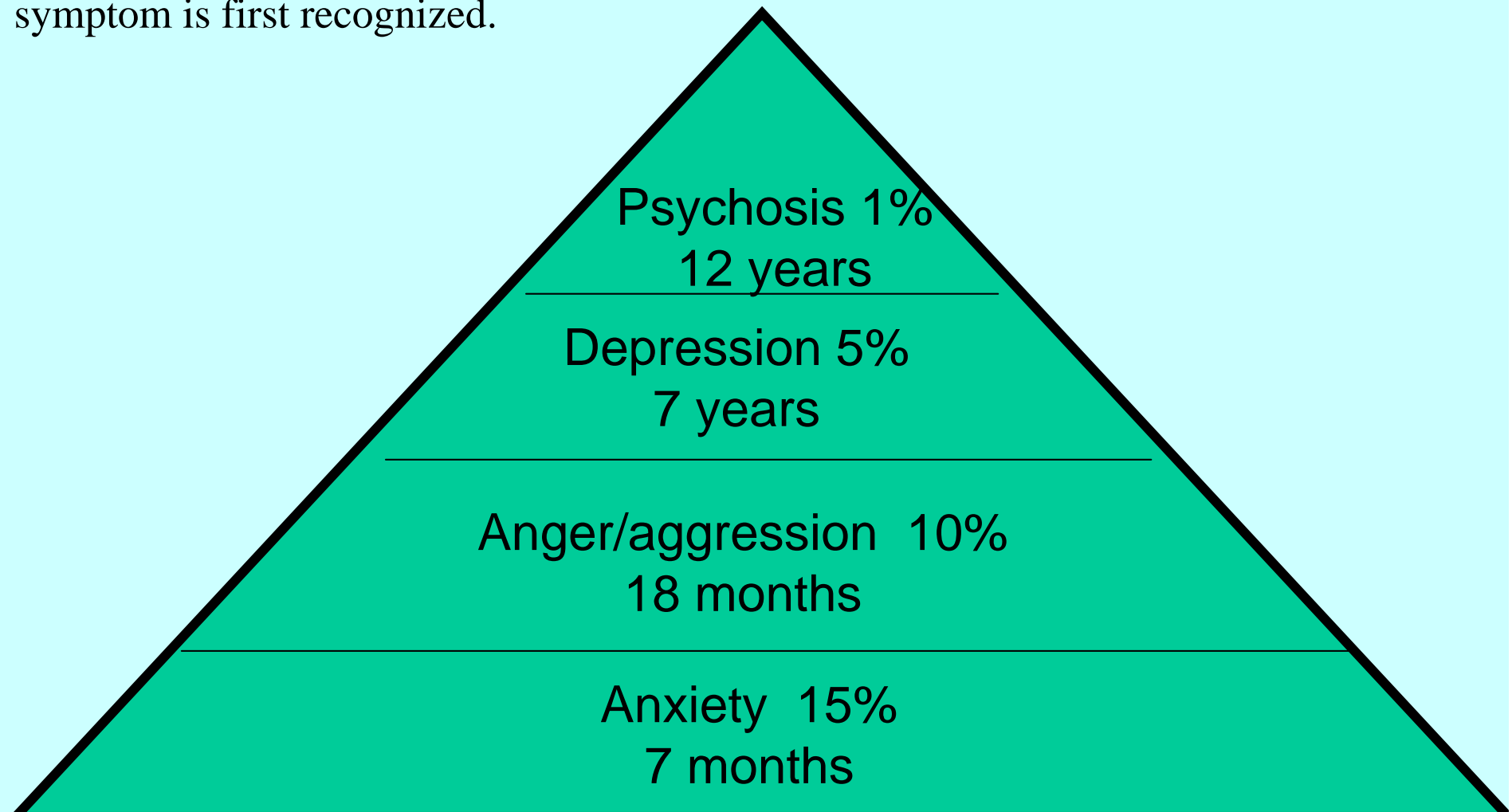


# The 'Photon Catcher' & "Emotion Catcher": Implications for Social Development & Autism

- The evolution of the eye involves progressive functionality and is replicated by a computer program
- **Implications:**
  - Social development arises out of mathematical complexity which can get stuck/delayed;
  - Social dev: due to increasing complexity of networks/mechanisms, no single cause.
  - Developmental Models are helpful & simplify complexity but are difficult to prove
  - Likely to be polygenetic and have multiple causes.
  - Autism is a social developmental age <2 yrs
  - Asperger is a social developmental age <4.5 yrs
  - Studying autism enables us to better understand the development of the consciousness, emotions and the mind
  - Social development and the complexity of emotions are interconnected, and psychopathology are emotions under threat.

# Developmental Hierarchy Of Emotional Disorders

The Hierarchy of Disorders was originally described by Foulds (1976). The hierarchy has parallels in cognitive, language, conceptual and social development. The pyramid illustrates the general frequency of symptoms of psychological/emotional dysphoria & the developmental age at which this symptom is first recognized.



# Implications of Specific Disorders of Social Development (SDSD)

- Social development is the most important domain of development
- A normative view of the biol causes of delays in developing peer relationships
  - helps young people, families and their communities understand and accept
  - specific strengths and weaknesses;
  - increased need for social support and guidance
- Make and need attachments, love and care
  - like one of younger social age
  - difficulties making friends with age related peer
- The importance of social developmental skills and intervention in schools and *special need for protection in peer relations*
- Opens wider the concept of mild SDSDs & social intelligence

# Implications of SDSDs for Treatment

- Infant-like social relating capacity leads to extended dependency on familiar/predictable parents/adults
  - Socially
  - For stimulation and skill building
  - Organisation and predictability
  - Building emotional regulation
  - Enabling community access and participation
- Stepping Stones Triple P Parent Training illustrates how practical and normative approaches can promote a developmentally enabling environment.
  - ie. matching the environment to match their developmental needs, :
    1. Developmental age in cognitive, communication and social understanding for developmental promotion
    2. Chronological age for social norms, age-related content and physiological maturity to enable wider social acceptance
- Developmental framework of SDSDs moves intervention from treatment to developmental appropriateness for learning
- Later use cognitive skills to learn other empathic skills such as emotional recognition & regulation, theory of mind and practical approaches to friendships.

# Disruptive Behaviour Disorders & ADHD

- DBDs are mainly driven by family factors
  - Persistent naughty behaviour is a learned behaviour in response to
  - Inept parental discipline and monitoring.
  - Treatable early by change to improve warmth, rewards, supervision and consistency of contingencies for behaviours
- Also temperamental/genetic vulnerability factors
  - Activity and reactivity levels
  - Induce greater reactivity in the parents
- ADHD is assoc with DBDs in 40-70%
  - Diagnosis of ADHD has predictive validity
  - 60-90% of ADHD is (poly)genetic and related to biological factors of brain development
  - Dimensional not a categorical disorder
  - Stress makes it worse; support & competence improves it
    - e.g., no. of hrs of TV watched by toddlers was related to the risk at 7
  - Early environment: stress abuse deprivation influence brain dev & ADHD
    - The interaction of genes and environment neurotransmitter levels and psychiatric manifestation eg serotonin system

# ADHD in Intellectual Disability

- **In Mild ID** Antshel K, Phillips M, Gordon M, Barkley R, Faraone S. Clinical Psychology Review 2006
  - reliability and predictive validity
  - prevalence of 30%, M=F,
  - possibly greater family factors, depression and social impairment.
  - standard drug Rx is not as effective and more prone to side effects
- **In severe ID**
  - lacks research for reliability and validity,
  - affected by more gen biol factors vs genetics
  - an association with other developmental disorders

# ADHD in Intellectual Disability

- DCD and ADHD occur in 7%, but co-occur in 50%
- ADHD is found in 78% of PDD in clinic pop
- ADHD in 1/2 of teens with ID & autism vs 1/7 with ID but without autism
- Genetic linkage between ID & Autism
- ADHD in behavioural phenotypes
  - SMS 90%, Fragile X 75%, Williams Syndrome 65%, Charge Syndrome 50%, Neurofibromatosis 50%, VCFS 43%, Cornelia de Lange's Syndrome 40%, Soto's Syndrome 38%, Tuberosc Sclerosis 35% and Turners Syndrome 24%.
  - Fetal alcohol syndrome:
    - ADHD 49%, ID in 55%, learning disorders 46%, ODD 41%, anger problems, mood disorders and sleep disorders in 50%
- ADHD in ID suggests a model of developing coherence & efficiency consciousness
- Helpful to identify co-morbid ADHD for ?drug treatment

# Developmentally Supportive Treatments for ADHD

- All children have to learn to concentrate, sit still, and think things through. So what are the developmental processes necessary?
- 1970s: In Autism behavioural intervention works better than talking therapies: eg teaching a child to sit still as a prerequisite for concentration (Rutter & Bartak), precursor of Applied Behaviour Analysis.
- Practical Strategies: Teaching calmness, stillness, sense of time, self monitoring, concentration, organisation and planning .
  - What am I doing now? Am I sitting in the right place?
  - Am I doing what the class is doing? What do I need to work on?
  - What needs to be organised for the next event?
    - 5 minute prompts                      Using timers and visual charts
    - Fading from external prompts (teacher/parent) to self checking

# ADHD in Intellectual Disability

## Evidence of Developmental Sequence

- Hierarchy of Attention:
  - Yr 1: Arousal: Dopa
  - Yr 2: Selective attention: Acetyl choline
  - yr 3: Dual tasking and executive function: Noradrenaline
- Hierarchy of independence and social relating:  
Skills of attention & social/emotional development
  - Yr 1: Attention & social engagement
  - Yr 2: Motor and sensory exploration vs compliance
  - Yr 3: Theory of mind, internal voice and mood regulation

# ADHD in Intellectual Disability

- Attention does have a developmental sequence
- Can also be seen as a developmental disorder (rather than a behaviour disorder)
- Attention and concentration is more important educationally than hyperactivity
- Normally improve with intervening with the internal environment (medication)
- Does improve with parent training
- Multi aetiological contributions to efficiency/coherence of consciousness
- May depend on dev coherence/progress in every domain
  - Attention requires achievement of key dev milestones in motor dev, proprioception, modulation of arousal, receptive and expressive communication skills, sufficient intellect or mental energy, & closely linked is a theory of mind

# Understanding delayed and uneven development

## Assessment of problematic behaviour

Schema for emotions of development [Dosen, A. (2007) JIDR 51(1), 66-74]

1. Social
2. Physical
3. Intellectual
4. Communication
5. Emotion Development

**DIR:** Developmental, individual-difference, relationship-based  
model “Floor time” Stages [Wieder&Greenspan (2003) Autism, 7(4),425-35]

1. Self Regulation & shared attention
2. Engagement and relating
3. Two-way intentional communication
4. Purposeful complex problem solving communication
5. Creating and elaborating symbols
6. Building bridges between symbols (ideas)

# Defns & Semantics of Child Psych in ID

- When is a prob a beh problem & when is it a psychiatric problem?
- A signif psychiatric disorder *is any disturbance of beh or emotions sufficient to cause signif impairment to the child or those caring for them*
- The longitudinal study of young people with ID (Einfeld & Tonge, 1996) indicates
  - 40% have a severe mental health disorder,
  - DBC measures a severity of disturbance, doesn't translate to psych disorders.
- Whether a problem is a Mental Illness, Mental Disorder, a Developmental Disorder or a Challenging Behaviour is
  - Subjective determination
  - Affected by profession & employing agency & different theoretical models
- Mental health services start to prioritise their business to severe MI and emergency services for acute mental disorder
- “Mental health is everyone’s business” suggests
  - All child services have to understand and manage mental health problems.
- Agg is a chronic problem that doesn't improve in psychiatric in-patient units.
- Most conditions are best treated in the community: a shared responsibility between families, neighbourhoods and all government departments.

# Adult MH & ID: Diagnostic Problems

- MI is defined
  - “**a diagnosable illness** that significantly interferes with an individual’s cognitive, emotional, or social abilities.”
- “Generally been recognised” that those with ID have the full spectrum of MI, but usu diagnostic criteria difficult to apply

Methodical approaches are recent

- **DM-ID (2007):** textbook of diagnosis of mental disorders in persons with an ID
  - Developed by an international (American) expert group
  - Reviews of the strength of the evidence supporting each diagnosis and the adaptations of diagnostic criteria for persons with ID
  - **The levels of Cochrane based scientific evidence are generally poor, mainly based on cohort studies and expert opinion.**
  - DSM methods gives people with ID entitlement to MH services
  - Clinical usefulness was evaluated in 2006: a field trial 900 patients, 80 clinicians from 11 countries.
    - The DM-ID was user friendly & more specific than the DSM-IV-TR (text revision 2004).
- **DC-LD (Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation)** (2001, Royal College of Psychiatrists)
  - Provides a “consensus of current practice” for adults with moderate to profound ID leading to ICD10 diagnoses
  - “Sometimes it is not the criteria that need alteration but a different method of eliciting the necessary information”

# Special problems of phenomenology in ID

- Eliciting subjective mental phenomena reliably < 7 years/ IQ <45.
  - Only in the 80s did psychiatry recognise depression in children > 7 yrs.
- Articulating abstract or global concepts eg depressed mood from cognitive and verbal skills.
- Giving answers to please the interviewer
- Intellectual distortion
  - e.g., saying “yes” to “hearing voices”, not understanding the implication of question.
- **Diagnostic overshadowing:** failure to identify co-morbid psych disorder
- Baseline exaggeration or intensification of existing maladaptive behaviour
  - e.g., increase in self injurious behaviour under a time of stress.
  - e.g., anniversary of a loss may be a sufficient pptant that carers may not identify.
  - e.g., change of a teacher or other staff, or a classroom or accommodation or of family visits
- Stress on coping with a lack of cognitive reserve leads to disintegration, disorganisation or psychotic behaviour
- Delusions and hallucinations are frequently very difficult to distinguish from a range of normal developmental phenomena
  - e.g., concrete thinking, pretend friends, stereotypic thinking and imagination, esp in ASD.
- Irritability occ with explosive anger can be mania and depression

Indeed: Families and professionals alike are at risk of diagnosing serious psychiatric disorder where none exists.

Conversely non specialised doctors (GPs) fail to identify mental disorder eg depression

# What Psychiatric Disorders are found in ID?

## a) in USA (Tsiouris et al, 2008).

- Study of **4468 clients**,  $\frac{3}{4}$  in out of home residential settings, found **psych dis in 60%**
- The main DSMIV psychiatric diagnoses in order of frequency:
  - Impulse Disorder 21%
  - Anxiety Disorder 19%
  - Schizophrenia and other psychoses 18%
  - Depression 14%
  - Bipolar Disorder 12%
  - Obsessional Compulsive Disorder 11%
  - Personality Disorder 8%
  - Sleeping Disorder 4%
  - Eating Disorder 3%
  - Tourettes 2%
- No psychiatric diagnosis 40%
- Did not identify any other diagnoses identified in DM-ID eg:
  - Adjustment Disorders
  - Post traumatic Stress Disorders
  - Substance-related disorders
  - Sexual and Gender Identity Disorder
  - Dementia
  - Mental Disorders due to a General Medical Condition, not otherwise classified

# What Psychiatric Disorders are found in ID? a) in USA (Tsiouris et al, 2008).

- ? Other diagnoses are only applied to children :
  - Learning Disorders
  - Motor Skills Disorders
  - Elimination Disorders
  - Pervasive Developmental Disorders
  - ADHD and Disruptive Behaviour Disorders
  - Somatoform and factitious disorders
  - Other Disorders of Infancy, Childhood and Adolescence (Attachment Disorders and Stereotypic movement disorders including Self Injurious Behaviour)
  - Behavioural Phenotype of Genetic Disorders
- Adult psych disorders vs child psych disorders
  - Applied to adolescents and occ children (except personality disorder by defn)
  - Less clear to what extent the child psychiatric disorders apply to adults  
e.g. What is the relationship between ADHD in childhood and Impulse Disorder
  - PDD is a lifelong disorder, yet it is not identified as an adult psychiatric diag.
- ASD is a dimension of impairment not solely a categorical diagnosis,
  - What is the relationship between stereotypic behaviour or thinking & OCD?

# **What Psychiatric Disorders are found in ID? b) in UK/WHO** (Cooper et al, 2007)

- **Epidemiological study in Scotland of 1023 adults > 16yrs with mild, mod or severe ID**
  - The PAS-ADD 10 (The psychiatric assessment schedule for adults with a developmental disability) (Costello et al, 1997).
  - Relies on a key informant to identify and rate symptoms and produces diagnoses using algorithms
  - The PAS-ADD checklist is a screening questionnaire, used with the Mini-PAS-ADD (Moss 2000)
- **Found prevalence rates of Psychiatric Disorder:**
  - Mental ill-health of any type 40.9%
  - Problem Behaviour 22.5%
  - Mental ill-health of any type excluding problem beh 28.3%
  - Mental ill-health of any type excluding ASD 37%

# What Psychiatric Disorders are found in ID? b) in UK/WHO (Cooper et al, 2007)

- **The types of ICD10 Psychiatric Disorder were:**

- Psychotic Disorder 4.4%
- Affective Disorder 6.6%
- Autistic Spectrum Disorder 7.5%
- Anxiety Disorder 3.8%
- Organic Disorder 2.2%
- Pica 2%
- Hyperkinetic Disorder 1.7%
- Personality Disorder 1%
- Alcohol/substance abuse 1%
- Obsessional Compulsive Disorder 0.7%
- Sleep Disorder 0.6%
- Other mental ill-health 1.4%

Compare with USA  
Impulse Disorder 21%  
Anxiety Disorder 19%  
Schiz and other psychoses 18%  
Depression 14%  
Bipolar Disorder 12%  
OCD 11%  
Personality Disorder 8%

# What Psychiatric Disorders are found in ID?

- The rates of diag in the USA and UK are strikingly different
  - A lack of uniformity of diagnostic thinking and processes.
  - Other methodological differences such as sample selection and screening processes.
- The Smiley Scottish prospective study (ie new disorders) (Smiley & Cooper et al, 2007)
  - A **two year incidence** of mental illness of 16.3%, and 12.6%
    - Excluding problem behaviours.
  - Factors related to mental ill-health included:
    - Type of accommodation (out of family care), previous mental ill-health, not having impaired mobility, urinary incontinence, more severe ID, adult abuse, parental divorce in childhood and preceding life events.

# What treatments work in children with ID?

- A literature search of the empirical evidence of effectiveness of intervention in children with ID revealed 2 Cochrane reviews.
  - **Parent training** has the best evidence of being helpful (Diggle, McConachie & Randle, 2003).
  - The Cochrane review of **behavioural intervention** reports short term benefit of behavioural intervention but only some limited evidence of longer term benefit (Hassiotis and Hall, 2008) .

# Parent Training approaches to intervention

- Stepping Stones Triple P: the best empirical evidence for theory & outcome (Roberts et al, 2006)
  - A normalising philosophy & framework
  - Create a safe engaging environment, that facilitates learning of skills and positive beh,
  - Having developmentally realistic expectations; assertive discipline to shape behaviour,
  - Parental emotional adaptation to the (disabled) child,
  - Being a part of the community & taking care of ps' wellbeing.
- Skill growth, independence & self determinism improves prob beh (Nota et al, 2007).
- However parent training approach assumes a complex understanding of beh probs: These include:
  - **Genetic Factors** eg sociability, reactivity and activity levels
  - **Family Environment Factors** eg accidental rewards of undesirable behaviour, escalation traps, emotional messages, ineffective use of punishments, parents beliefs and expectations, parents' relationships and emotions, stress.
  - **Influences outside of the home:** other relationships incl peers, school, media & techn
- The reasons for working on family environment factors are:
  - Most accessible & easiest for parents to influence.
  - 2<sup>ndary</sup> influence on the genetic factors, & makes easier to sort out outside influences
  - Has a long term effect by improving emotional communication & attachments.

# **Framework for Professional Practice for Children and Adolescent with Intellectual Disability**

- **Focus on a child in a family context**
  - adaptation, dev framework, relationship building, community participation
- **Common language to assess and treat emotional/behav disorder in ID**
  - the developmental-bio-psycho-social-cultural model
- **Skill building models for dev maladaptive beh require subspecialty skills**
  - Doctors for bodily health, including vision, hearing, nutrition & fits;
  - Physiotherapy for motor development and coordination;
  - Occupational therapy for proprioception and sensory integration;
  - Speech therapy for receptive, expressive and pragmatic communication;
  - Psychology for the dev of understanding of behaviour, thought, feelings and social interaction;
  - Psychiatry to assess abnormal subjective mental state & Psychopharm
  - Family therapy/cybernetics for how communication & beh shape systems
  - Role of risk management
- **YP with ID need interagency collaboration & service pathways & planned & improved future service development**

# **The Principles for a Service Models for emotional and behaviour disturbance in ID:**

## **What specialist mental health service in ID should we have when there isn't one!**

- Parents have complex explanations for the behaviour in their child,
- Our explanations of mental health problems are limited, complex, and uncertain.
- No single profession or service is sufficient
- Improving our capacity to cure conditions, improve disabling problems, build compensatory skills, minimise handicap and hopefully provide care and humanising support.
- services systems should be designed with a spectrum of responses within a holistic framework:
- Common/milder problems managed with preventative and universal approaches at one end of the range
- With increasing of involvement of different professionals for assessment and intervention for complex severely disabling problems.
- Couched in a humane and community based system of service provision and care.
- A holistic developmental-bio-psycho-social-cultural model that underlies child and adult psychiatry
- The mental health needs of young people with ID necessitates across organisational collaboration
- Service tiers according to need, severity and complexity.

# Tiered Pyramid of Services for C&A with ID & MH problems:

The specialist MH in ID Service for C&A when there is none.

## **Tier 5: Acute short/medium term interventions that inform Tier 4**

Includes: Emergency departments, MH in-patients assessments, other residential behaviour services; and

**Specialist/Tertiary MH in ID clinicians** from mental health & disability services.

## **The Tier 4 Circle: The Final Common Pathway**

Complex case management decision making; 'best endeavour' obligations including decisions about out of family community placements.

## **Tier 3: Multidisciplinary and Multi-agency Collaboration**

**Disability Service:** ADHC behaviour clinician, speech pathologist, OT, other specialist psychology service;

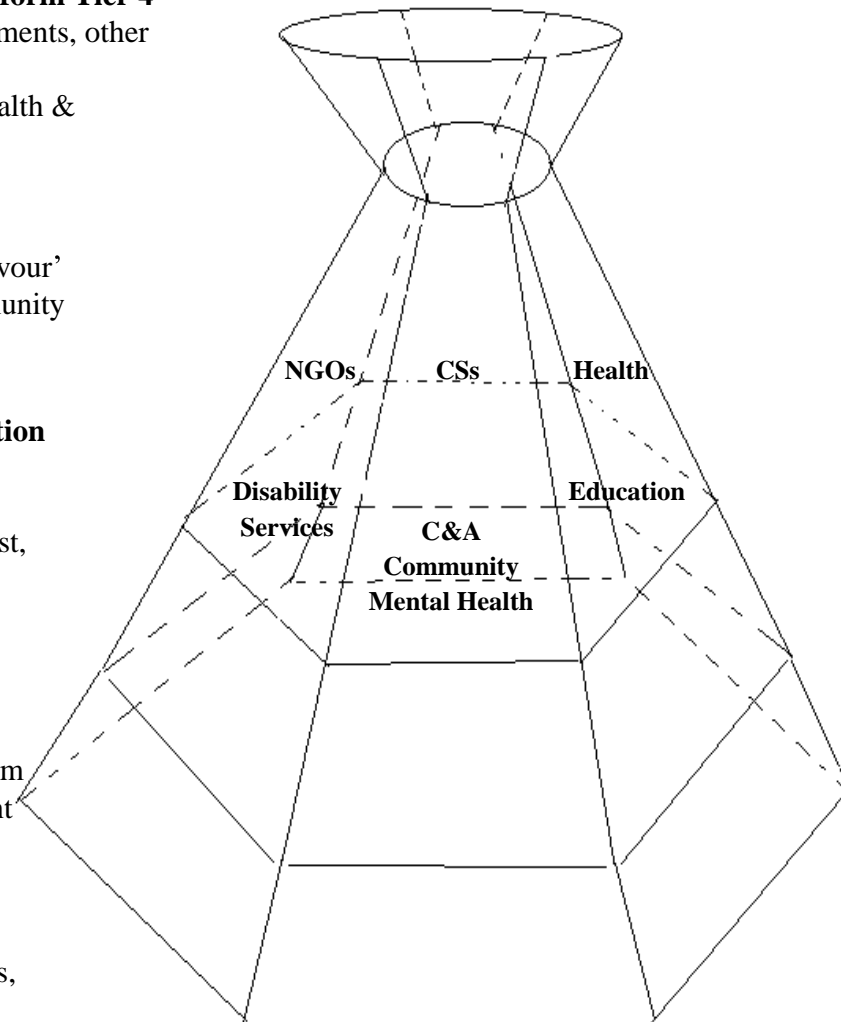
**Health:** GP, paediatrician or neurologist; MH Psychologist, SW, family therapist, psychiatrist; and

**Education:** teacher, aide, school counsellor, principal, behaviour support specialist.

**Tier 2: Community Disability Services providing case management and specialist parent training.** Mainly from ADHC but can be MH or other agency or non-government organisations.

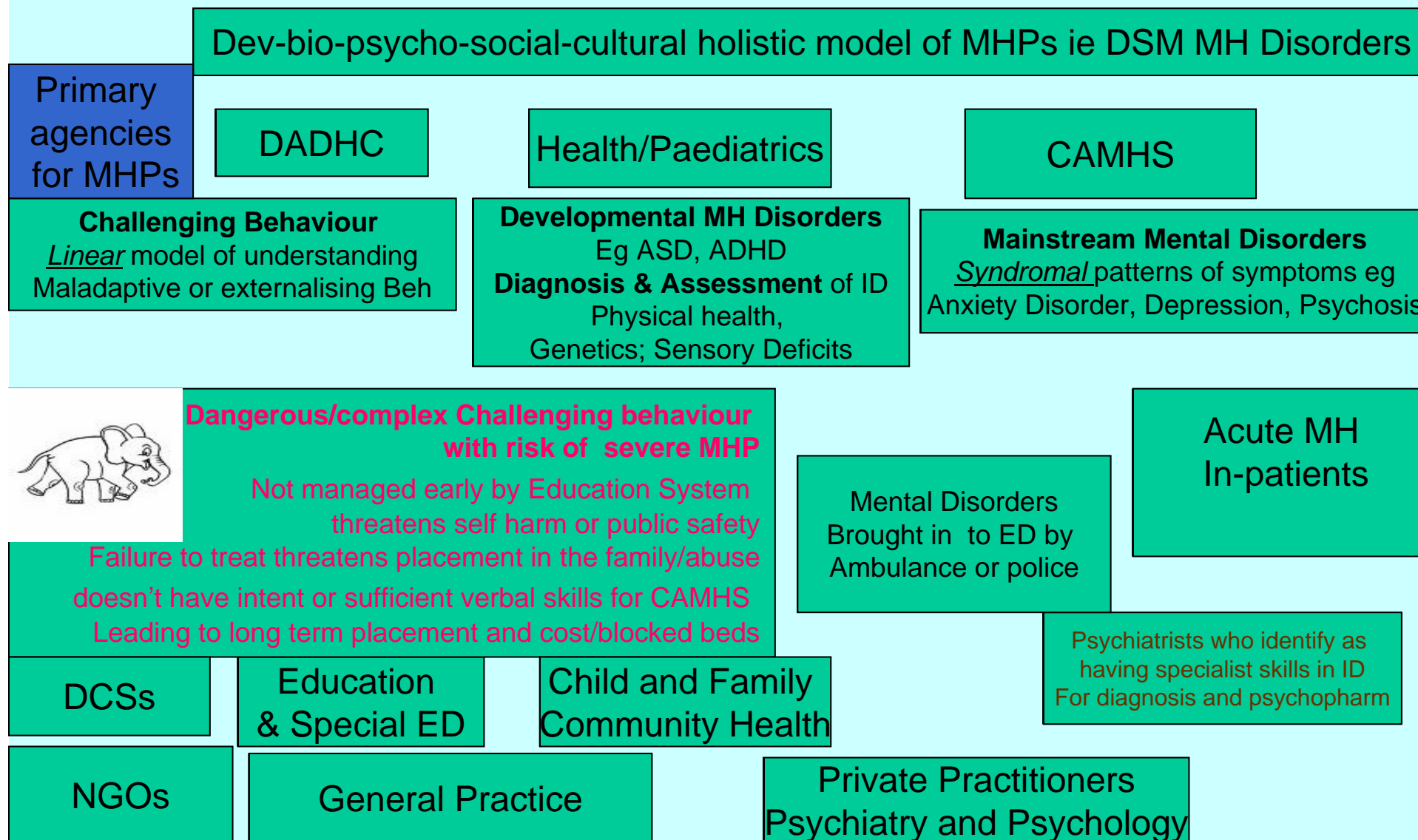
## **Tier 1: Generic Health Provision** for families

Includes: GPs, community nurses, child community teams, Families NSW, Triple P



*3D Model provides for all other human services to be part of the pyramid*

# Understanding the pathways to care



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*"I'm right there in the room, and no one even acknowledges me."*

# CHW School-link Feb 2009

Needs Analysis Survey: of 35/58 School Counsellors of SSPs for ID  
11,000 students in support classes yet

- Major concern for MH problems:
  - identification, adequate time resources; demand for on going training not provided by current school-link (also needed in CAMHS)
- Mainstream prevention and promotion initiatives not appropriate for this setting
- While PPEI is valid, there is little organised PPEI initiatives
- Problems of accessing mental health services: 5% of referrals:
  - inadequate services,
  - lack of expertise,
  - lack of pathway to care
  - Esp for Rural and Remote and CALD

ADHC & Paediatricians are valued more highly

# CHW School-link Outcomes & Aims

4 years funding to continue (4<sup>th</sup> NMHP)

## **Aims:**

- Develop workplan outlining key focus areas
- **Raise awareness** of MH needs of C&A with ID and encourage collaboration
- **Increase identification** of MH Probs
- Develop and clarify **pathways to care**
- Improve **education and support** to DET & MH Staff
- Support initiatives in **PPEI**
- Evaluate impact

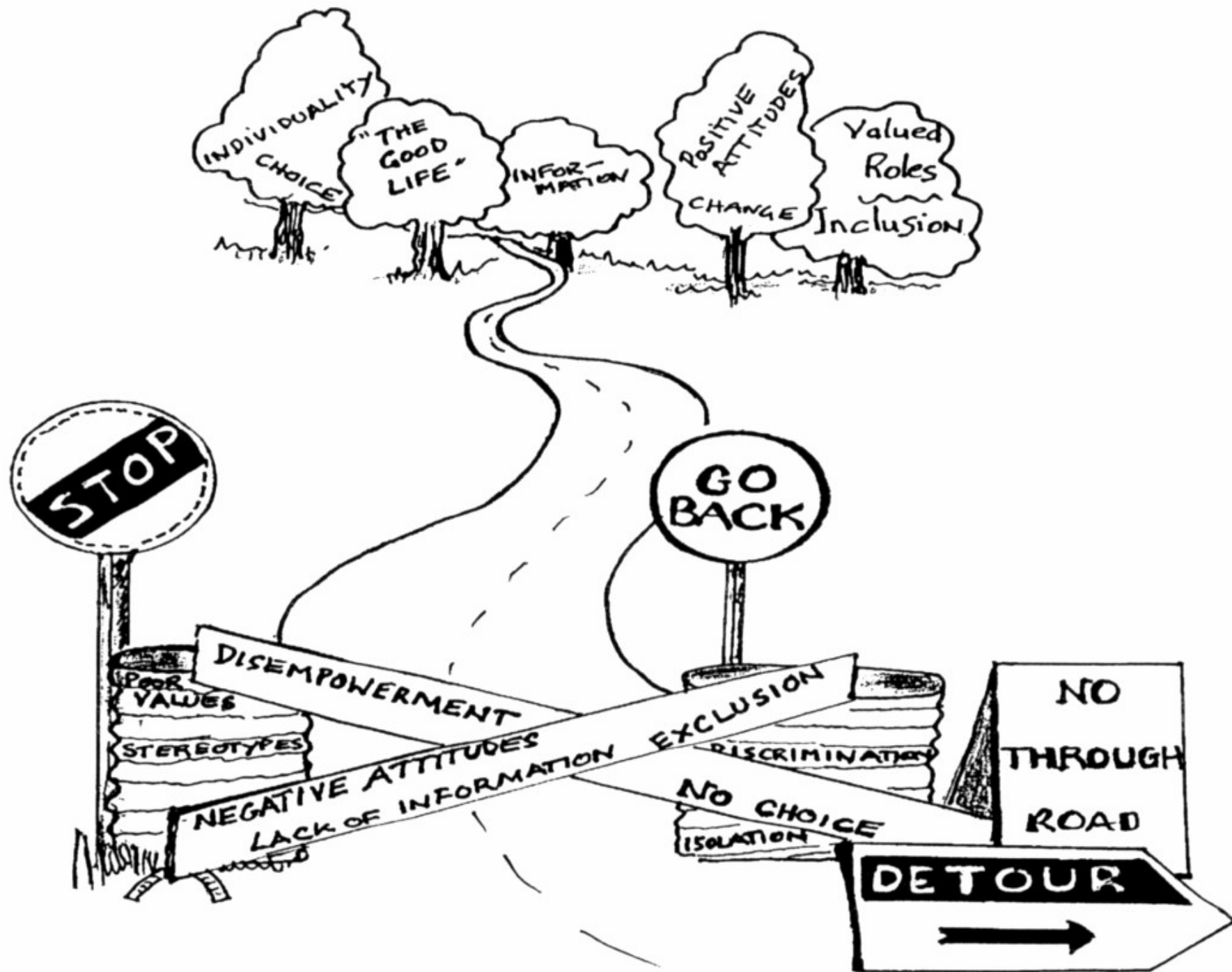
# CHW School-link Projects so far

1. CHW School-link News Letter and website
  - [www.schoolink.chw.edu.au](http://www.schoolink.chw.edu.au)
2. Continue Training Curriculum Project & Book
  - Chapter on Inclusive school settings: KidsMatter& MindMatters, Stop Think Do, Triple P Stepping Stones, PATHS, Social Decision Making/ Social Problem Making Program, Alert Program™, Positive Behaviour for Learning
3. Pilot cross agency and discipline Supervision of School: exploring cases, management, collaboration and pathways to care with 8 School Counsellors & Western Sydney
4. Training and Pilot of Stepping Stone Parent Training in 4 SSPs and evaluate
5. Modification of EBSST for Moderate and Severe ID
6. Planning conference and contributing to others

# Conclusions

- The emotional, behavioural, developmental, and family needs of C&A with ID may be vastly under appreciated
- Yet Health, Mental Health, ADHC and DET are starting to work together
- With a common ground of empiricism and an inter professional educational and learning environment
- The challenge is to interest and influence mainstream practitioners of the importance of promoting the development of the mind not just for children with ID in Special Schools, Satellite Classes or Integrated Classes but for Neurotypical Children

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# *Clinical Expertise And Innovation In Mental Health And Intellectual Disability*

1. Specialist evidence-base parent training skills e.g., Stepping Stones Triple P (Sanders, Mazzucchelli, & Studman, 2003).
2. General health promotion and prevention especially with a focus on other chronic disabilities.
3. School based prevention and early interventions e.g.,
  1. Positive behaviour learning;
  2. Inclusion approaches and practices;
  3. Inclusive communication strategies;
  4. Focus on developing mindfulness of self and others; and
  5. Focus on emotion-based social skills learning
4. The role of exercise and coordination for self esteem, motor/sensory modulation and attention.
5. Sensory profiling and sensory diet interventions for management of arousal levels and motor calmness, relaxation and playfulness e.g., Floortime (Greenspan & Wieder, 1998).
6. Augmentative and alternate communication, especially capitalising on using new electronic devices for socially acceptable forms of visual communication.
7. Problem solving and self monitoring skills.
8. Emotion-based social skills training.
9. Modification of cognitive behaviour skills therapy.
10. Neuro-biological research e.g., based on behavioural phenotypes, new metric and imaging techniques and the effects of medication.







This educational program therefore focuses on developing a common language for understanding the different domains of development and the skills that various disciplines of health science have brought to supporting and promoting development. Establishing a common language has enabled the project team to look at the diverse causes of behaviour and the many perspectives that can be taken when understanding the significance of behaviour. These include,

Medical science for bodily health, including vision, hearing, nutrition and management of seizures;

Physiotherapy for motor development and coordination;

Occupational therapy for proprioception and sensory integration;

Speech pathology for receptive, expressive and pragmatic communication;

Psychology for the development of understanding of thought, feelings and social interaction;

Psychiatry for defining abnormalities of the subjective mental state, and the roles of psychopharmacology; and

Cybernetics or family therapy to look at how communication and behaviour shape systems

## **Section 1: Understanding the Issues and Integrating Scientific Approaches**

**Quality of life** for individuals with Intellectual Disability and Developmental issues

**Empirical approaches, a common language and formulation** for understanding intellectual disability, development, emotions and behaviour.

## **Section 2: The Impact of Disability and Family Well-being**

**Parental Emotional Adaptation** Adjustment, acceptance and hope; Family and cultural issues

**Parental Practical Adaptation: Promoting Healthy Habits and Routines** Sleep, limit setting, skill building, rewards, and stereotypic/ obsessive interests

**Burden of Care** Care needs at different impairment levels and common medical issues

**Models of Respite** Family, friends and respite services

**Maintaining Parental and Family Mental Health and Well-being**

Health, stress, burnout, depression;

Family relationships, siblings and networking.

## **Section 3: Individual Emotional and Behavioural Well-being**

### **1. Interventions to Promote Skill Development**

Physical development, coordination, safety, balance and control.

Sensory diet and activities for calming, concentration and emotional regulation

Communication strategies and symbolic supports for understanding, expression and interaction

Attention, coping strategies and problem solving

Emotional understanding, emotional recognition and social skills.

### **2. Understanding and Managing Mental Health Issues**

At-risk behaviours and related issues i.e. life events, stress, transitions and changes (abuse, attachment and separation experiences)

Mental illness (depression, PTSD & psychosis) versus developmental disorders and psychopharmacology

Modifications of counselling, cognitive-behaviour therapy and other psychological interventions

Adolescence and young adulthood i.e. developmental changes, sexualised behaviours and offending.

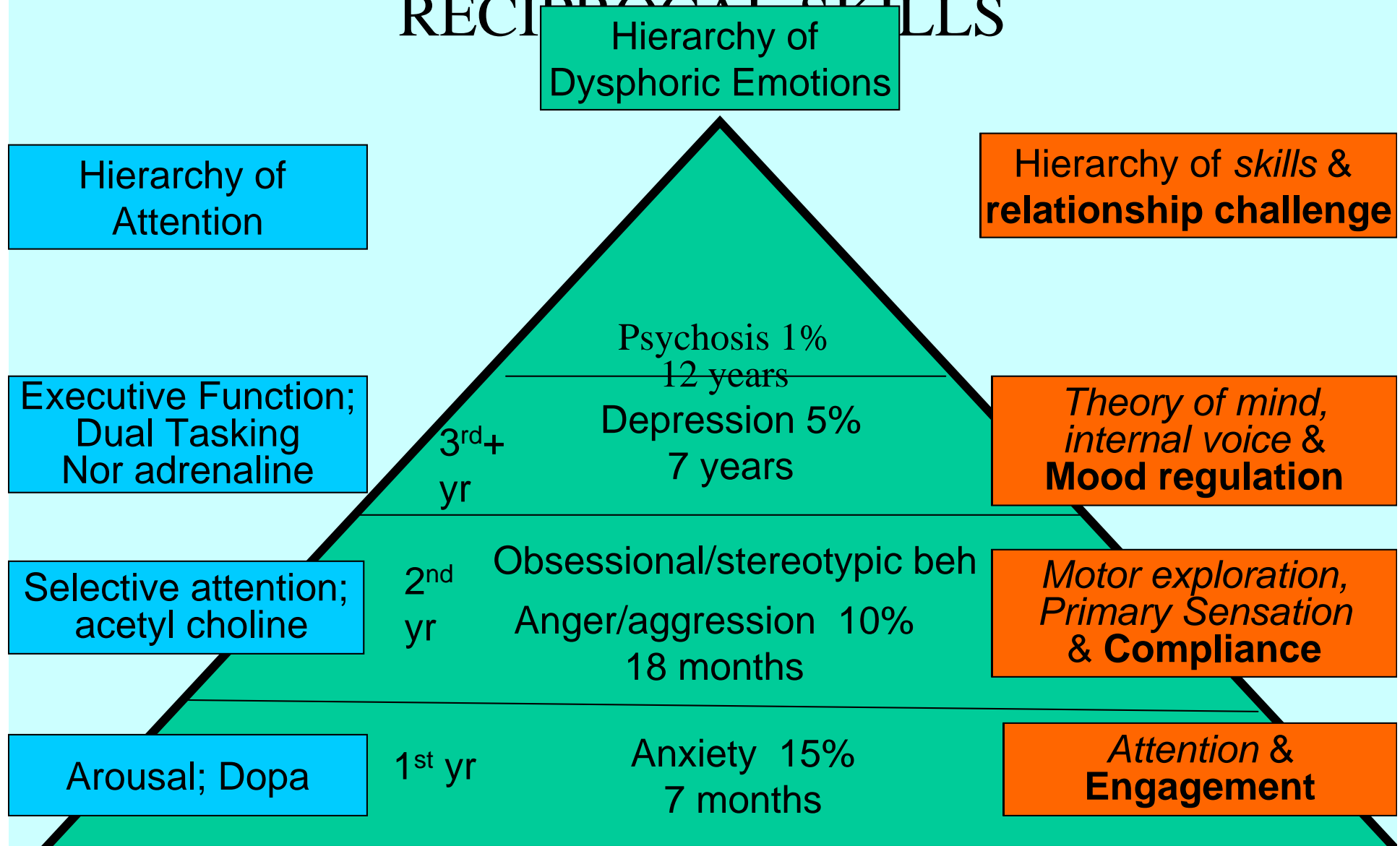
## **Section 4: Integration of Service Systems**

The role of education and community access

**Services:** Expertise, coordination, integration and collaboration

Parents' experiences; Advocacy isn't an option it is a must

# DEVELOPMENTAL HIERARCHY OF EMOTIONS, ATTENTION, INDEPENDENCE AND RECIPROCAL SKILLS



# Conclusion

- Behaviour is predominantly influenced by development
- Dev Neuropsychiatric disorders can be seen as delays of development of competencies & the mind
- Developmental explanation makes behaviour understandable to parents, carers and people with ID
- Infant psychiatry and adult psychiatry of ID:
  - Malice of forethought is not possible below a DA of 6yrs
  - Maladaptive problems before MA of 5 are dependent on environment
  - Problems of int environment (biol dev) need better support from the ext
  - Necessitates multidisciplinary approach to skill building

# Conclusion

- Developmental models are self evident & heuristic
- vs science uses deconstructive models eg pharmacology
- Internal environment is important for medicine & pharmacology
- Models of the development of the mind enable us to look at the special role of external environmental and therefore non medical intervention for beh probs in ID